

# Differences in Treatment Goals and Perception of Symptom Burden Between Patients With Myeloproliferative Neoplasms (MPNs) and Hematologists/Oncologists in the United States: Findings From the MPN Landmark Survey

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**BACKGROUND:** This analysis of the myeloproliferative neoplasm (MPN) Landmark survey evaluated gaps between patient perceptions of their disease management and physician self-reported practices. **METHODS:** The survey included 813 patient respondents who had MPNs (myelofibrosis [MF], polycythemia vera [PV], or essential thrombocythemia [ET]) and 457 hematologist/oncologist respondents who treated patients with these conditions. **RESULTS:** Greater proportions of physician respondents reported using prognostic risk classifications (MF, 83%; PV, 59%; ET, 77%) compared with patient recollections (MF, 54%; PV, 17%; ET, 31%). Most physician respondents reported that their typical symptom assessments included asking patients about the most important symptoms or a full list of symptoms, whereas many patient respondents reported less specific assessments (eg, they were asked how they were feeling). Many patient respondents did not recognize common symptoms as MPN-related. For example, approximately one-half or more did not believe difficulty sleeping resulted from their MPN (MF, 49%; PV, 64%; ET, 76%). Physician respondents underestimated the proportion of patients who had symptomatic PV or ET at diagnosis compared with patient respondents. There was discordance regarding treatment goals: among patient respondents with MF or PV, “slow/delay progression of condition” was the most important treatment goal, whereas physician respondents reported “symptom improvement” and “prevention of vascular/thrombotic events,” respectively. Finally, more than one-third of patient respondents were not “very satisfied” with their physician’s overall management/communication. **CONCLUSIONS:** The care and satisfaction of patients with MPN may be improved with increased patient education and improved patient-physician communication. *Cancer* 2017;123:449-58. © 2016 The Authors. *Cancer* published by Wiley Periodicals, Inc. on behalf of *American Cancer Society*. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made

**KEYWORDS:** communication, essential thrombocythemia, health care surveys, myeloproliferative disorder, patients, physicians, polycythemia vera, primary myelofibrosis, questionnaires.

## INTRODUCTION

Discordance between patient and physician perceptions of disease burden has been identified in various hematology and oncology disease settings and may affect patient outcomes. A recent systematic review of patient and physician perceptions in oncology settings revealed that physicians often underestimate symptom prevalence and severity,<sup>1</sup> which may delay or hinder the alleviation of symptoms. When considering patients with prostate cancer, 1 study indicated that physicians underestimated pain severity,<sup>2</sup> which could compromise the ability to achieve improvements in quality of life (QoL). Those investigators also reported that physician estimates regarding the effects of breast cancer on patient QoL, social functioning, and role functioning differed from patient perceptions.<sup>2</sup> In a third study, physicians overestimated the burden of common treatment options for myelodysplastic syndrome compared with patient perceptions. Consequently,

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Additional supporting information may be found in the online version of this article

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physicians may have recommended treatment discontinuation because of inaccurate perceptions about treatment effectiveness in their patients.<sup>3</sup>

Patients with Philadelphia chromosome-negative myeloproliferative neoplasms (MPNs), including myelofibrosis (MF), polycythemia vera (PV), and essential thrombocythemia (ET), have increased mortality rates<sup>4</sup> and experience notable symptoms that negatively affect QoL.<sup>5</sup> However, limited data are available concerning patient and physician perceptions about MPN symptomatology and treatment goals. Attempts to better understand these perceptions may lead to optimized patient care and, ultimately, better patient outcomes.

The MPN Landmark survey was the first large observational study to evaluate patient and physician perceptions about MPNs among contemporary populations in the United States. The first report from the MPN Landmark survey summarized patient-reported effects of MPNs on overall health and productivity, but it did not evaluate physician or patient respondent data concerning treatment goals or satisfaction and did not make direct comparisons between physician and patient respondent perceptions.<sup>6</sup> The objective of this second analysis of MPN Landmark survey data was to identify gaps between patient respondent perceptions about their disease management and physician respondent self-reported practices regarding MPN-related prognostic risk assessment, symptom burden, treatment goals and expectations, and treatment satisfaction.

## MATERIALS AND METHODS

### *Study Population*

Patients who were previously diagnosed with MF, PV, or ET in the United States were eligible to participate in the survey. Patient respondents were recruited through physician offices, advocacy groups, and the media, as previously described.<sup>6</sup> The study received approval from an internal institutional review board at ICF International (Fairfax, Va), which assisted in conducting the MPN Landmark survey. All respondents provided informed consent.

A national sample of physicians in direct patient care who specialized in hematology or oncology was drawn as a national probability sample of these specialties from the American Medical Association and American Osteopathic Association databases and was contacted by mail, e-mail, and fax. Those who met practice eligibility requirements for the study were asked to participate in the MPN Landmark survey. Eligible physician respondents were those who actively practiced in hematology or oncology settings

in the United States and had managed the care of  $\geq 2$  patients with MF,  $\geq 5$  patients with PV, or  $\geq 5$  patients with ET within the 12 months before the survey. Physician respondents received modest remuneration for their participation; patient respondents did not receive remuneration. The method of patient and physician respondent recruitment was not revealed to the investigators, and the survey did not collect the method of respondent recruitment.

### *Survey Instrument*

Questionnaires specific to the MF, PV, and ET settings were created for patient and physician respondents (6 surveys total) and were conducted in English only. Some patient survey questions related to MPN symptoms and QoL were adapted from the MPN Symptom Assessment Form (MPN-SAF)<sup>7</sup> and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30,<sup>8</sup> which are validated survey instruments. However, the MPN Landmark survey instruments were not validated. The questionnaires, which respondents completed online, included 59 to 65 multiple-choice questions (respondent/disease dependent) and required 20 to 25 minutes to complete. The surveys included a core set of questions that required responses before submission. Partially completed interviews were excluded from all analyses. A summary of the physician survey is included in the online version of this article (see online supporting information), and a summary of the patient survey was described in a previous publication.<sup>6</sup> The current report includes data from respondents about: 1) demographics, 2) MPN prognostic risk assessment, 3) MPN symptom burden, 4) MPN treatment goals and expectations, and 5) MPN treatment satisfaction. Descriptive statistics were used for all analyses.

## RESULTS

### *Respondent Demographics*

#### **Patient respondents**

Patient respondent demographics (MF,  $n = 207$ ; PV,  $n = 380$ ; ET,  $n = 226$ ) from the MPN Landmark survey have been reported previously<sup>6</sup> and are briefly summarized in Table 1<sup>6,9-11</sup> and Supporting Table 1 (see online supporting information).

#### **Physician respondents**

Overall, 457 physicians who practiced in a hematology and/or oncology specialty completed an MPN subtype-specific version of the survey (MF,  $n = 156$ ; PV,  $n = 250$ ; ET,  $n = 51$ ) (Table 2). Physician respondents had graduated from medical school a mean of 20 or 21 years before the

**TABLE 1.** Characteristics of Patient Respondents With Myeloproliferative Neoplasms<sup>a</sup>

Characteristic	No. of Respondents (%)		
	MF, n = 207	PV, n = 380	ET, n = 226
Age: Median [range], y	66 [28-90]	64 [25-94]	62 [23-87]
Women	112 (54)	237 (62)	163 (72)
Race <sup>b</sup>			
White	203 (98)	371 (98)	221 (98)
Black	2 (1)	3 (1)	2 (1)
Asian	1 (<1)	4 (1)	2 (1)
Unknown	1 (<1)	2 (1)	1 (<1)
Disease duration since diagnosis: Median [range], y	4 [0-36]	7 [0-61]	7 [0-36]
Calculated prognostic risk score <sup>c</sup>			
Low	13 (6)	49 (13)	76 (34)
Intermediate-1	47 (23)	119 (31)	126 (56)
Intermediate-2	84 (41)	57 (15)	NA <sup>d</sup>
High	63 (30)	155 (41)	24 (11)

Abbreviations: ET, essential thrombocythemia; MF, myelofibrosis; NA, not applicable; PV, polycythemia vera.

<sup>a</sup>Adapted from Mesa R, Miller CB, Thyne M, et al. Myeloproliferative neoplasms (MPNs) have a significant impact on patients' overall health and productivity: the MPN Landmark survey. *BMC Cancer*. 2016;16:167.<sup>6</sup>

<sup>b</sup>Patient respondents were allowed to give multiple answers regarding race; this table shows only the first answer given by each patient respondent.

<sup>c</sup>Prognostic risk scores were categorized as low, intermediate (1 or 2), or high and were determined using published scoring systems for MF (the Dynamic International Prognostic Scoring System: Passamonti F, Cervantes F, Vannuchi AM, et al. A dynamic prognostic model to predict survival in primary myelofibrosis: a study by the IWG-MRT [International Working Group for Myeloproliferative Neoplasms Research and Treatment]. *Blood*. 2010;115:1703-1708<sup>9</sup>, PV (modified from Tefferi A, Rumi E, Finazzi G, et al. Survival and prognosis among 1545 patients with contemporary polycythemia vera: an international study. *Leukemia*. 2013;27:1874-1881<sup>10</sup>, and ET (International Prognostic Score for Essential Thrombocythemia: Passamonti F, Thiele J, Girodon F, et al. A prognostic model to predict survival in 867 World Health Organization-defined essential thrombocythemia at diagnosis: a study by the International Working Group on Myelofibrosis Research and Treatment. *Blood*. 2012;120:1197-1201<sup>11</sup>).

<sup>d</sup>Patient respondents with ET could receive prognostic risk scores of low, intermediate, or high; intermediate scores were not divided into intermediate-1 and intermediate-2.

survey, depending on which MPN subtype-specific survey they completed, and most reported treating patients in a single-specialty group or an academic hospital. On average, physicians reported treating between 11 and 20 patients with MF, PV, or ET at the time of the survey.

### **Patient-Physician Comparisons: MPN Prognostic Risk Assessment**

Most physician respondents self-reported that they classified their patients according to prognostic risk categories (MF, 83%; PV, 59%; ET, 77%). In contrast, notably smaller proportions of patient respondents reported that their diagnosing physician had stratified their MPN with a prognostic risk score (MF, 54%; PV, 17%; ET, 31%).

### **Patient-Physician Comparisons: MPN Symptom Burden**

Patient respondent perceptions of physician management differed from the management practices reported by physician respondents regarding symptom assessment and related communications (Table 3). Compared with patient respondents, larger proportions of physician respondents reported that their typical management practices included asking patients about their most important MPN-related symptoms during symptom assessment and referring to a full list of symptoms when discussing potential symptoms

and disease progression. In contrast, patient recollections of physician visits suggest that physicians were less specific (eg, they were most likely to simply ask how patient respondents were feeling during symptom assessment). Approximately 5% to 15% of patient respondents in each MPN group reported that their physician was uninterested or did not ask about symptoms.

Patient respondents who reported experiencing known MPN-related symptoms often did not recognize a connection between the symptom and their MPN (Fig. 1). Historically, difficulty sleeping is 1 of the most frequent symptoms experienced by patients with MPNs<sup>12</sup>; however, some patient respondents in the MPN Landmark survey who reported difficulty sleeping did not think that their difficulty sleeping was related to their MPN (MF, 49%; PV, 64%; ET, 76%). In contrast, many physician respondents (MF, 53%; PV, 34%; ET, 25%) reported that "all" or "almost all" of their patients recognized their symptoms as MPN-related. A considerable proportion of patient respondents reported experiencing symptoms at the time of diagnosis (MF, 81%; PV, 89%; ET, 84%). However, physician respondent recall of newly diagnosed patients with symptoms was markedly lower for PV and ET: 50% who treated patients with PV estimated that  $\leq 40\%$  of their patients had no symptoms, and

**TABLE 2.** Characteristics of Physician Respondents Who Treat Patients With Myeloproliferative Neoplasms

Characteristic	No. of Respondents (%)		
	MF, n = 156	PV, n = 250	ET, n = 51
Time since graduation from medical school: Mean ± SD, y	21 ± 11	21 ± 12	20 ± 12
Primary specialty			
Hematology/oncology	142 (91)	221 (88)	46 (90)
Oncology	10 (6)	18 (7)	3 (6)
Hematology	4 (3)	11 (4)	2 (4)
Practice setting			
Single-specialty group	66 (42)	101 (40)	22 (43)
Academic hospital, outpatient clinic	46 (29)	75 (30)	17 (33)
Community hospital, outpatient clinic	18 (12)	27 (11)	3 (6)
Multispecialty group/HMO	14 (9)	26 (10)	8 (16)
Solo practice	8 (5)	13 (5)	1 (2)
Academic hospital, inpatient	1 (1)	3 (1)	0 (0)
Other	3 (2)	5 (2)	0 (0)
No. of patients with an MPN reportedly under the care of each physician at the time of survey: Mean ± SD	11 ± 16	17 ± 16	20 ± 19

Abbreviations: ET, essential thrombocythemia; HMO, health maintenance organization; MF, myelofibrosis; MPN, myeloproliferative neoplasm; PV, polycythemia vera; SD, standard deviation.

**TABLE 3.** Patient and Physician Respondent Perspectives on Communication About Myeloproliferative Neoplasm Symptoms

Variable	No. of Respondents (%)					
	MF Respondents		PV Respondents		ET Respondents	
	Patients, n = 207	Physicians, n = 156	Patients, n = 380	Physicians, n = 250	Patients, n = 226	Physicians, n = 51
Physician symptom assessment <sup>a</sup>						
Proactively asks how patient is feeling	105 (51)	55 (35)	197 (52)	86 (34)	99 (44)	12 (24)
Waits for patient to mention symptoms	44 (21)	8 (5)	76 (20)	22 (9)	40 (18)	6 (12)
Asks about patient's most important symptoms	41 (20)	86 (55)	57 (15)	127 (51)	40 (18)	28 (55)
Physician uninterested or does not ask about symptoms	10 (5)	NA	35 (9)	NA	33 (15)	NA
Fills out a symptom list/review each symptom	7 (3)	6 (4)	15 (4)	15 (6)	14 (6)	4 (8)
Other	NA	1 (1)	NA	0 (0)	NA	1 (2)
Physician communication of potential symptoms and disease progression <sup>b</sup>						
Only discusses current symptoms	89 (43)	NA	161 (42)	NA	116 (51)	NA
Asks about a full and comprehensive list of symptoms	73 (35)	81 (52)	127 (33)	134 (54)	51 (23)	33 (65)
Outlines most likely symptoms	19 (9)	43 (28)	27 (7)	69 (28)	18 (8)	10 (20)
Outlines the most bothersome symptoms	13 (6)	30 (19)	34 (9)	43 (17)	22 (10)	8 (16)
Does not discuss symptoms	0 (0)	NA	5 (1)	NA	4 (2)	NA
Other	13 (6)	2 (1)	26 (7)	4 (2)	15 (7)	0 (0)

Abbreviations: ET essential thrombocythemia; MF, myelofibrosis; NA, not applicable; PV, polycythemia vera.

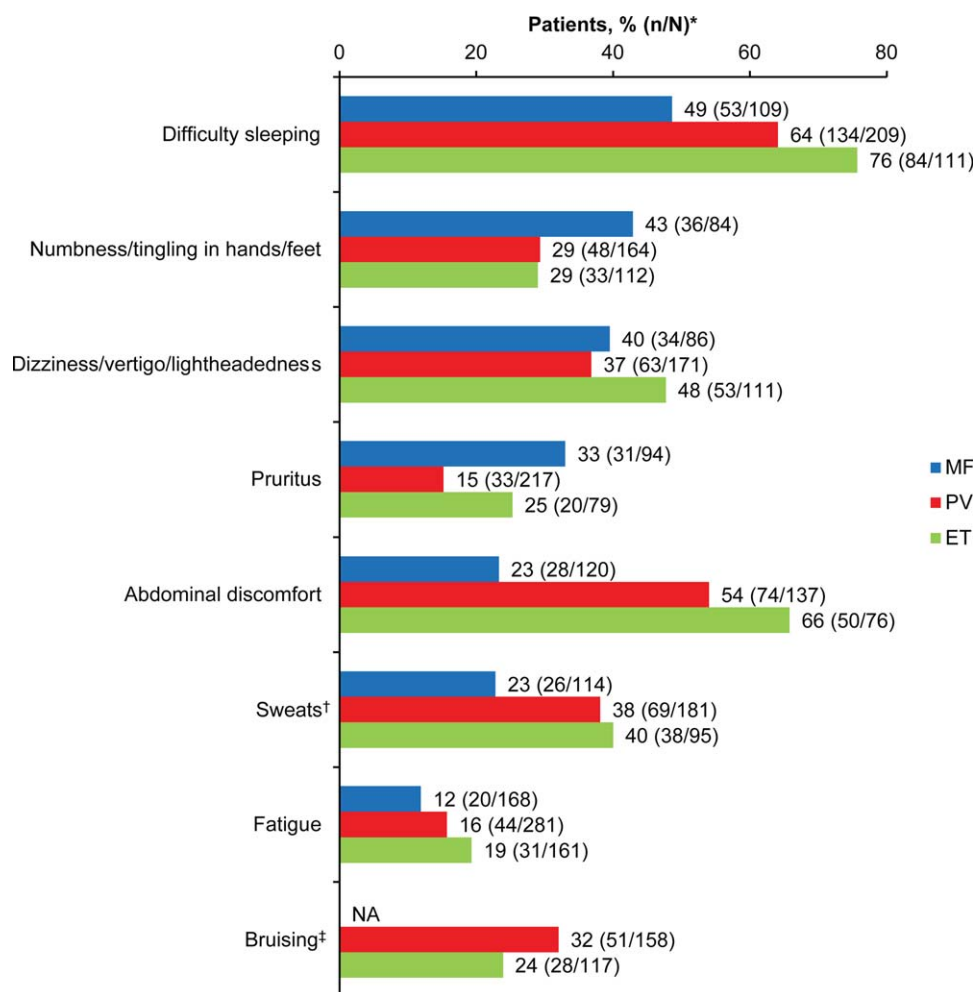
<sup>a</sup>The question was worded to patient respondents as follows: "How does the doctor you see most often for your diagnosis assess any symptoms you may be experiencing?" The question was worded to physician respondents as follows: "During an average patient visit, how do you assess patients' symptoms?"

<sup>b</sup>The question was worded to patient respondents as follows: "How did your doctor explain the potential symptoms you may experience and overall progression of the disease?" The question was worded to physician respondents as follows: "During an average patient visit, how do you discuss the symptoms that the patient might experience?"

50% who treated patients with ET estimated that  $\leq 50\%$  had no symptoms (Fig. 2).

Although the majority of patient respondents reported reductions in their QoL because of MPN-related symptoms (Supporting Table 2; see online supporting information),<sup>6</sup> many physician respondents (MF, 28%; PV, 46%; ET, 47%) were "somewhat" or "strongly" in agree-

ment that patient QoL was not significantly affected unless splenomegaly was severe. However, most physician respondents believed that MPNs were associated with functional impairments, which is consistent with patient respondent perceptions (Supporting Table 2; see online supporting information). Physician respondents reported that most patients felt anxious about their MPN (MF,



**Figure 1.** The proportions of patient respondents who did not recognize common symptoms as being related to their myeloproliferative neoplasm (MPN) are illustrated. Bars indicate the percentages and numbers of patient respondents who did not select each symptom in response to the question, “Which of these symptoms do you believe are the result of your MPN?” Data are from all respondents who reported experiencing each symptom (excluding those who had missing data). The 5 most frequently reported symptoms for each MPN are included. N indicates the number of patients who reported experiencing each symptom, and n indicates the number of patients who did not believe that the symptom was a result of their MPN (asterisk). Patients who had myelofibrosis (MF) and essential thrombocythemia (ET) had night sweats, and patients who had polycythemia vera (PV) had day or night sweats (dagger). Bruising was not included as an option on the MF survey (double dagger). NA indicates not applicable.

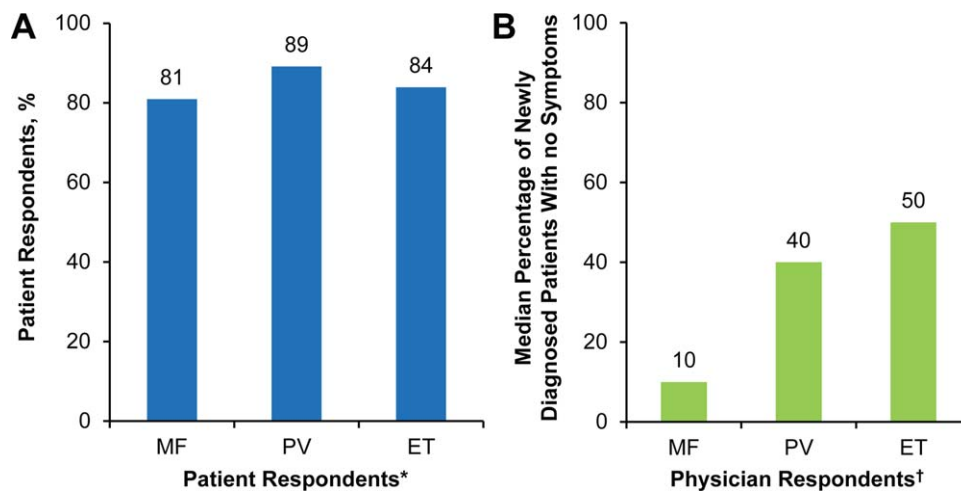
99%; PV, 100%; ET, 98%), had difficulty focusing (MF, 97%; PV, 96%; ET, 90%), and avoided social interactions (MF, 92%; PV, 83%; ET, 84%) and that MPNs interfered with daily activities (MF, 99%; PV, 96%; ET, 92%), family/social life (MF, 99%; PV, 92%; ET, 88%), and sex life (MF, 98%; PV, 96%; ET, 90%).

#### **Patient-Physician Comparisons: MPN Treatment Goals and Expectations**

The perceptions of patient and physician respondents about treatment needs and goals were generally not well aligned. Among patient respondents, “slow/delay progres-

sion of condition” was the most important treatment goal in the MF and PV settings; in contrast, physician respondents reported “symptom improvement” and “prevention of vascular/thrombotic events” as the most important treatment goals for MF and PV, respectively (Fig. 3). Many patient and physician respondents agreed that “prevention of vascular/thrombotic events” was the most important treatment goal for ET (patient respondents, 35%; physician respondents, 57%); however, there remained notable discordance in the ET setting about other treatment goals.

In the MF and PV settings, patient respondents (MF, 47%; PV, 33%) and physician respondents



**Figure 2.** Myeloproliferative neoplasm-related symptoms at diagnosis are illustrated among (A) patient and (B) physician respondents. The question to patient respondents (asterisk) was, “Which of these symptoms were you experiencing at the time of diagnosis?” The analysis included the percentages of patient respondents who did not answer “none.” The question to physician respondents (dagger) was, “Out of 100%, what proportion of all newly diagnosed patients do you estimate have no symptoms?” The analysis included the median value provided by physician respondents for the proportion of newly diagnosed patients with symptoms. ET indicates essential thrombocythemia; MF, myelofibrosis; PV, polycythemia vera.

(MF, 65%; PV, 31%) identified fatigue as the single symptom that patients would most like to resolve. Fatigue was also chosen as the most important symptom or complication by patient respondents (33%) and by a notable proportion of physician respondents (22%) in the ET setting; however, the largest subgroup of physician respondents (29%) reported stroke as the single most important to resolve.

Discordance between patient and physician respondents concerning treatment needs and plans could limit patient compliance with prescribed treatment and, in turn, clinical and QoL outcomes and patient satisfaction. More than 75% of physician respondents in each group reported that patients “sometimes” or “often” did not wish to comply with physicians’ primary treatment recommendation (MF, 77%; PV, 84%; ET, 78%). Reasons for lack of patient compliance are unclear. However, some patient respondents did not believe that their physician had a treatment plan (MF, 30%; PV, 27%; ET, 35%) or believed that their physician was not providing updates regarding new treatments (MF, 29%; PV, 37%; ET, 41%).

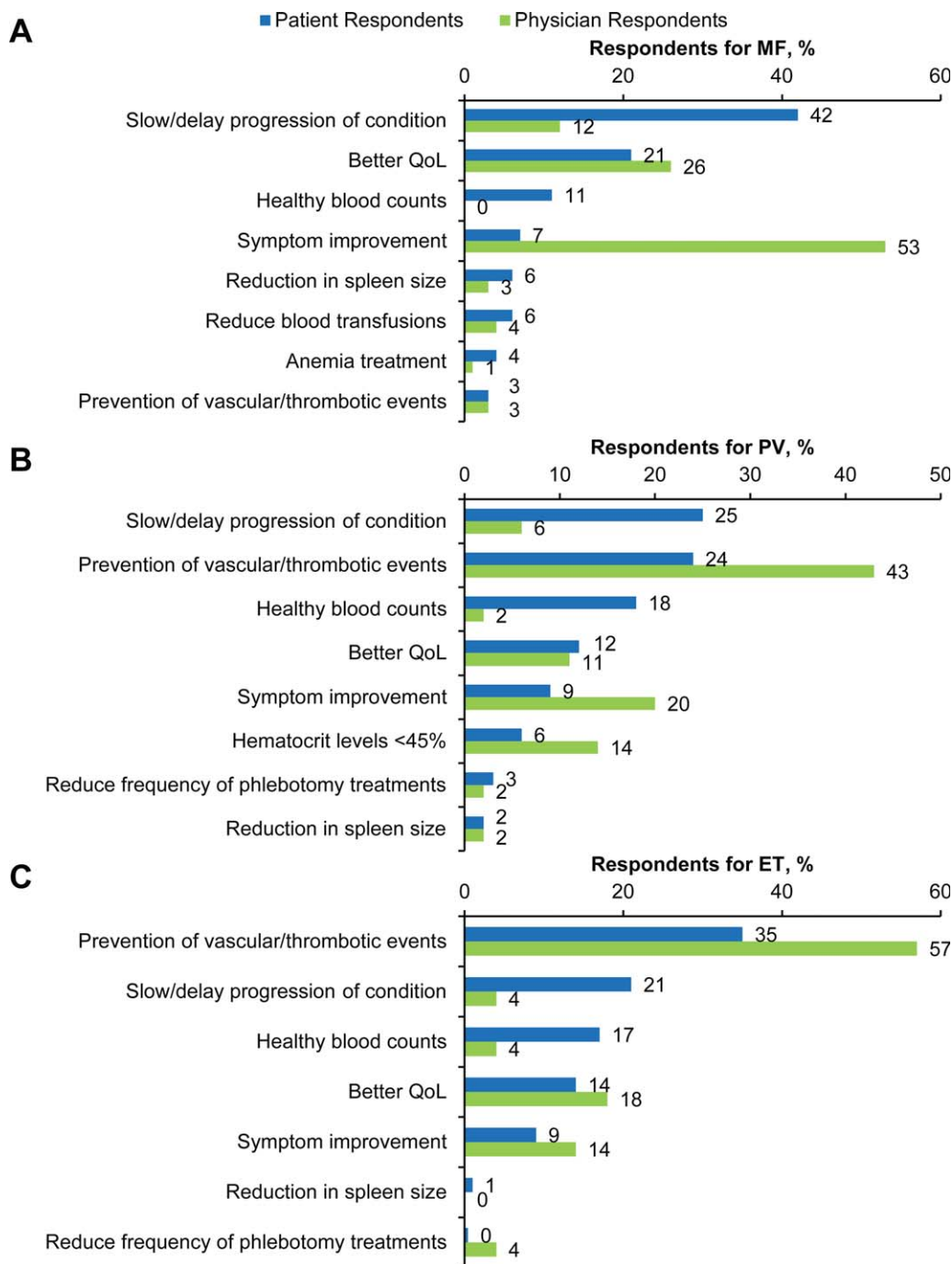
#### **Patient Respondent MPN Treatment Satisfaction**

Subgroups of patient respondents were dissatisfied with the care they received from their physician. More than one-third of patient respondents were not “very” satisfied with their physician’s overall management of their disease, and an additional subgroup was “somewhat” or “very” dissatisfied (MF, 8%; PV, 10%; ET, 12%) (Fig. 4A). Similarly, more than one-third of patient respondents

were not “very” satisfied with their physician’s communication about their disease, and an additional subgroup was “somewhat” or “very” dissatisfied (MF, 9%; PV, 13%; ET, 16%) (Fig. 4B). Among patients who had researched their condition (MF, 97%; PV, 96%; ET, 97%), the majority of patient respondents included the Internet among the most helpful sources of information about their diagnosis (MF, 90%; PV, 87%; ET, 89%), with a minority including their physician’s office (MF, 26%; PV, 21%; ET, 20%). Approximately one-half of all patient respondents reported that they had changed their MPN physician (MF, 47%; PV, 46%; ET, 56%); the most frequently reported reason for the change was dissatisfaction with prior care received (MF, 40%; PV, 37%; ET, 33%).

#### **DISCUSSION**

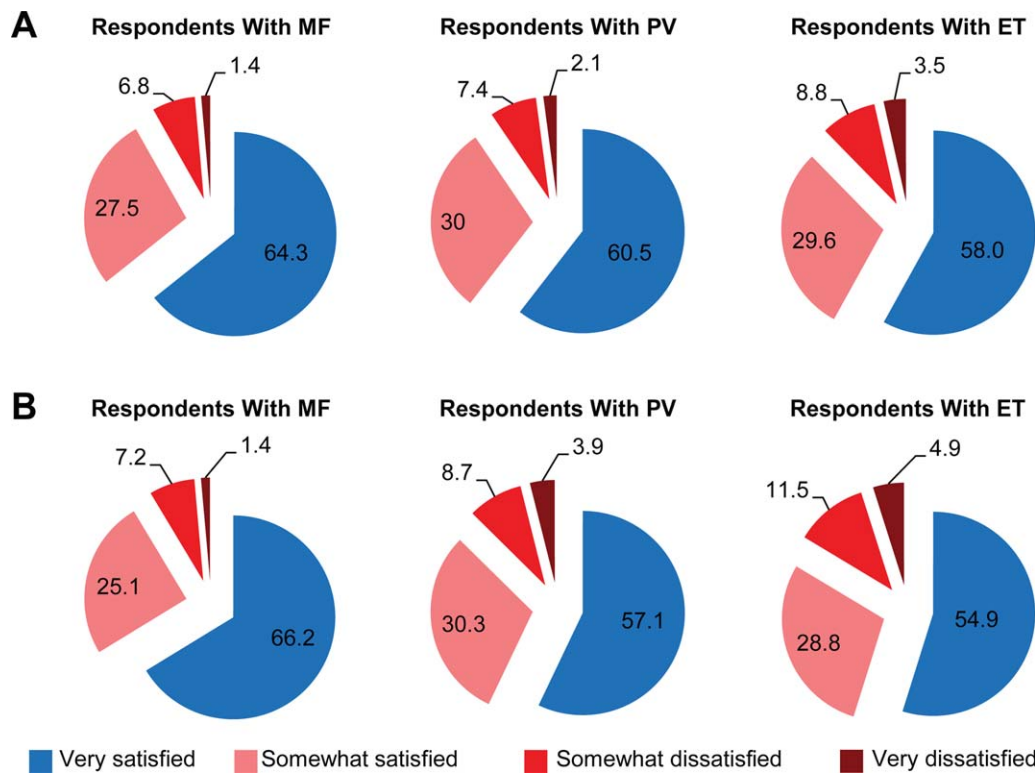
Although several analyses in recent years have evaluated MPN-related symptoms and effects on QoL,<sup>6,7,13-15</sup> to our knowledge, this is the first study in the MPN setting to evaluate discordance in communication and perceptions between patients and physicians. This analysis of MPN Landmark survey data identified several gaps between the perceptions of patient respondents with MPNs and the self-reported practices of physician respondents who treat patients with MPNs. Most physician respondents reported that their standard practices included classifying patients by prognostic risk, including patients with PV and ET, which are disease settings that do not have



**Figure 3.** Charts illustrate the most important myeloproliferative neoplasm treatment goals from patient-physician respondent comparisons in (A) the myelofibrosis (MF), (B) polycythemia vera (PV), and (C) essential thrombocythemia (ET) settings. The question for patient and physician respondents was, “Other than a cure for diagnosis, what is your most important treatment goal for therapy?” QoL indicates quality of life.

widely accepted prognostic risk scoring instruments.<sup>10,11</sup> This was discordant with patient respondents, most of whom did not recall receiving a prognostic risk score. In the PV and ET settings, physician respondents underre-

ported the proportion of patients who experienced symptoms at diagnosis compared with patient respondents. Furthermore, most patient respondents reported that MPN-related symptoms negatively affected their QoL,



**Figure 4.** Patient respondent satisfaction with (A) physician management and (B) physician communication is illustrated. ET indicates essential thrombocythemia; MF, myelofibrosis; PV, polycythemia vera.

yet many physician respondents did not believe that patient QoL was reduced in the absence of splenomegaly. It is challenging to put these data into context, because splenomegaly rates were not captured by the MPN Landmark survey. However, the splenomegaly associated symptoms of abdominal discomfort and early satiety occurred in 53% and 37% of patients with MF, respectively; in 35% and 22% of those with PV, respectively; and in 31% and 21% of those with ET.<sup>6</sup> Taken together, these gaps in perception suggest a need for greater physician appreciation for the importance of MPN-related symptoms from the perspective of patients. In addition, the median time since diagnosis (MF, 4 years; PV and ET, 7 years) was relatively recent for many patient respondents, suggesting that there may be a particular need for addressing this issue among patients in the early stage of their disease.

Research in non-MPN disease settings suggests that patient satisfaction may be improved with patient-centric communication styles, which have been associated with improvements in adherence, satisfaction, and overall health in the primary care setting.<sup>16</sup> A meta-analysis that included patients and physicians from primary care and specialty practice settings reported a significant correla-

tion between physician communication skill and patient adherence.<sup>17</sup> However, further research is necessary to determine whether these findings are applicable to MPN settings.

This analysis of MPN Landmark survey data provides a basis for further strategies to close the gaps in perception between patients with MPNs and their managing physicians in an effort to optimize patient care and satisfaction. First, improved patient education may better prepare patients to communicate key aspects of their disease and manage treatment expectations. Many patient respondents in the MPN Landmark survey did not recognize a connection between common MPN symptoms and their MPN diagnosis. MPN-related symptoms have been associated with reduced QoL,<sup>7,18</sup> suggesting that there is an opportunity to improve QoL in patients who may be living with symptoms they do not realize are related to MPN. In addition to educating patients on MPN symptoms, physicians should proactively assess symptoms with early and regular use of formal patient-reported outcome instruments (eg, MF Symptom Assessment Form,<sup>19</sup> MPN-SAF,<sup>7</sup> European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire-Core



30<sup>8</sup> to accurately capture symptom severity and guide treatment decisions.

Second, many patient respondents reported slowing disease progression as their primary treatment goal, although it has not been demonstrated that current treatment options delay MPN progression or cure MPNs. In some instances, improved patient education is needed to manage expectations and to help patients set achievable goals. In agreement with studies of non-MPN patient populations, clearer and more thorough physician communication may improve satisfaction among patients with MPNs. Many patient respondents from the MPN Landmark survey did not recall their physician discussing their full disease burden, rather focusing on select symptoms or, in some patients, no symptoms.

Finally, limited availability and access to effective treatment options that provide durable, clinically relevant improvements in QoL may also be a contributor to the observed discrepancies between patients and physicians. Among patients with chronic lymphocytic leukemia, the increased effectiveness of new treatment options<sup>20</sup> is expected to correspond with improvements in health-related QoL.<sup>21</sup> It is likely that the use of more effective treatments in the MPN setting could yield similar improvements and enhance the alignment of patients and physicians with regard to MPN symptomatology and treatment goals.

Limitations of this analysis stem primarily from the nature of the study. First, because patient responses were based on their recollection and awareness of their MPN management details, some differences may be the result of patient error rather than a true disconnect with physicians. Second, responses were not matched between physicians and the specific patients under their care, which limits how these data can be compared and interpreted. Third, the low MPN prevalence rates in the general population required nonprobability sampling methods for patient respondents, which may have limited how representative the MPN Landmark survey patient respondent population was of all US patients with MPNs. For example, patient respondents were primarily white and female and had a high level of advanced education; however, it remains unclear whether these characteristics are representative. The physician respondent population was recruited based on a probability sample. However, there may have been a self-selection bias regarding which physicians chose to participate that may have influenced the sample sizes for each MPN. Although physician respondents primarily practiced in single-specialty groups or outpatient clinics in academic hospitals, with relatively few from communi-

ty hospitals, multispecialty groups, health maintenance organizations, or individual practices, this distribution of practice settings may be representative.

### Conclusions

This analysis of MPN Landmark survey data suggests that patient and physician respondents often view the assessment of MPN prognosis, disease burden, and treatment goals differently, with physician respondents overestimating the ability of patients to recognize symptoms as MPN-related. Taken together, these findings suggest that there is room for improved patient education in the MPN setting. In particular, improved patient-physician communication regarding treatment goals and enhanced patient access to effective treatment options may improve patient outcomes and overall treatment satisfaction.

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### CONFLICT OF INTEREST DISCLOSURES

Ruben A. Mesa served as a consultant for Novartis and received research funding from Incyte Corporation, CTI BioPharma, Gilead, Genentech, Promedior, NS Pharma, and Pfizer. Carole B. Miller served on speakers bureaus and received honoraria and research funding from Incyte Corporation. Maureen Thyne served on speakers bureaus for Incyte Corporation. James Mangan received research funding from Novartis and served on an advisory committee for Incyte Corporation. Salman Fazal served on speakers bureaus, served as a consultant, and received research funding and honoraria from Incyte Corporation and Gilead. Xiaomei Ma served as a consultant for Incyte Corporation. Wendy Wilson received honoraria from Incyte Corporation. Dilan C. Paranagama, David G. Dubinski, Ahmad Naim, and Shreekanth Parasuraman are employees and stockholders of Incyte Corporation. John Boyle is an employee and stockholder of ICF International. John O. Mascarenhas received research funding paid to his institution from Incyte Corporation, Roche, Promedior, CTI BioPharma, Kalobios, and Novartis. Sara Goldberger has no competing interests to disclose.

### AUTHOR CONTRIBUTIONS

Ruben A. Mesa, Carole B. Miller, Maureen Thyne, Sara Goldberger, Salman Fazal, John Boyle, and John O. Mascarenhas participated in designing and coordinating the study, drafting the article, and approved the final article for submission. James Mangan participated in analyzing data, reviewing and revising the article, and approved the final article for submission. Xiaomei Ma participated in designing and coordinating the study, reviewing and revising the

article, and approved the final article for submission. Wendy Wilson participated in designing the research plan, reviewing and revising the article, and approved the final article for submission. Dilan C. Paranagama, Ahmad Naim, and Shreekant Parasuraman participated in analyzing data from the study and reviewed and approved the final article for submission. David G. Dubinski participated in developing the study, analyzing data from the study, drafting the article, and approved the final article for submission.

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