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A Cross-sectional Study of Patients and Physicians on the Impact of Myeloproliferative Neoplasms on Patient Health: The Landmark Survey From Taiwan

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Abstract

Patients with myeloproliferative neoplasm (MPN), including myelofibrosis, polycythemia vera, and essential thrombocythemia, experience a pronounced symptom burden. This study aimed to collect information from physicians and patients in Taiwan to explore their perceptions regarding MPN, treatment goals, and satisfaction with disease management. A cross-sectional, online survey was conducted among patients and physicians from September 2018 to November 2018 in Taiwan as a subset of the expansion of the Landmark survey. Overall, 50 patients with MPN and 30 physicians participated in this study. The symptom burden was low, with the mean number of symptoms experienced being 1.8. The most frequent symptom per physicians' perception was fatigue, whereas it is not the most common symptom from MPN patients' perspective. Blood count was the key indicator to determine treatment success from patients' view, whereas presence of a new symptom was the key indicator from physicians' perspective. Concordant with previous studies, our study revealed a lack of alignment between physician and patient perceptions relating to treatment goals and disease management. Nevertheless, the physical, emotional, work/activities and financial impacts on patients were minimal in Taiwan.

Keywords

myeloproliferative neoplasm, myelofibrosis, quality of life, symptom burden, work productivity

Introduction

Myeloproliferative neoplasms (MPNs) are a group of hematopoietic stem cell disorders, of which polycythemia vera (PV), essential thrombocythemia (ET), and primary myelofibrosis (MF) are collectively called "Philadelphia-negative classical MPN" (1,2). Per a systematic review, the incidence of classic MPN across countries was 2.58 per 100,000 population (3). In Taiwan, an incidence of 256 cases was reported in the year 2012, with an average annual percentage increase of 7.5% and the number of new cases reaching 473 in 2017 per the Taiwan Cancer Registry (4,5). Patients with MPN have burdensome symptoms, including fatigue, early satiety, night sweats and itching, which compromise their general well-being and quality of life (QoL) (6–8).

Several studies have reported that a significant proportion of patients with MPN (40%–55%) seek a caregiver's support, and 31%–36% of employed patients experience an overall work impairment (9–12). Hence, alleviation of symptoms and control of disease progression remain the major treatment goals for patients and physicians (8). Nonetheless, treating MPN is challenging because there are no uniform treatment plans for each of the main subgroups of the disease. Meanwhile, drug accessibility is another consideration. Hydroxyurea and interferon-alpha have been the standard of care for PV and ET (13,14). Phlebotomy is widely practiced in patients with PV. Ropeg interferon has been recently approved for PV in certain countries (15,16). Allogeneic stem cell transplantation is the only curable approach for MF, if the patient is eligible (17,18). For intermediate or high-risk MF, and PV resistant or intolerant to hydroxyurea,

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ruxolitinib, an oral Janus kinase (JAK) 1/JAK 2 inhibitor, is the approved ttherapy (19,20).

To improve the clinical outcomes and treatment satisfaction, greater participation of patients in decision-making is required (21). However, little is known about the understanding of patients with MPN regarding their disease and its impact on their lives. The MPN Landmark surveys are cross-sectional surveys of patients and their treating physicians to get insights on health and productivity of patients with MPN from the United States (US), Canada, United Kingdom (UK), Australia, Germany, Italy, and Japan (8,12). Previous studies have suggested differences in the QoL and overall symptom burden among countries, indicating the need to assess the understanding of physicians and patients regarding MPNs and identify the unmet needs in other geographic areas. Therefore, the Landmark survey was extended to six more countries – China, Turkey, South Korea, Saudi Arabia, Russia, and Taiwan (22,23). Here, we report the responses received from patients with MPN and their physicians from Taiwan.

Methods

Study Design

An online survey of patients with MPN and their treating physicians was conducted from September 2018 to November 2018 in Taiwan. Eligible physicians were contacted through local fieldwork partners. Physicians recruited their patients with MPN after routine consultations and invited them to participate.

Patients and physicians were provided a link and instructions to complete the survey which took approximately 25–30 min to complete and could be attempted only once. The survey materials were translated into Chinese and verified by accredited agencies. Both sets of participants were allocated survey numbers to ensure anonymity.

Selection Criteria

This survey included patients aged ≥18 years with a confirmed diagnosis of MF, PV, or ET and residing in Taiwan. Patients participating in clinical trials were excluded.

Physicians specializing in hematology, oncology, or hemato-oncology with active MPN cases in the preceding 12 months and a caseload of MF ≥2, PV ≥4, and ET ≥4 were included; provided they had qualified more than a year ago but not more than 55 years ago. However, physicians with overall practice of ≤25% hematology cases were excluded.

Survey Objectives

The objectives of the survey were to assess patients' and physicians' understanding of MPN and their unmet needs at the time of diagnosis; compare patients' and physicians' perceptions regarding symptoms and treatment options; determine patients' self-awareness of symptoms, functionality, and the

Table 1. Demographic Characteristics of Patients.

Characteristics	MF (n = 16)	PV (n = 14)	ET (n = 20)	Total MPN (n = 50)
Age (years), mean (SD)	63.4 (9.4)	50.1 (13.0)	61.2 (14.4)	58.8 (13.5)
Age at diagnosis (years), mean (SD)	54.8 (9.1)	41.1 (13.0)	50.0 (15.7)	49.0 (14.0)
Years since diagnosis, mean (SD)	8.6 (6.1)	9.0 (8.1)	11.2 (8.6)	9.8 (7.7)
Female, n (%)	8 (50)	11 (79)	12 (60)	31 (62)
Symptom burden, n (%)				
None	9 (56.2)	9 (64.3)	8 (40)	26 (52)
Low	4 (25.0)	3 (21.4)	7 (35)	14 (28)
Moderate	2 (12.5)	2 (14.3)	4 (20)	8 (16)
High	1 (6.3)	0	1 (5)	2 (4)
Total duration of symptoms before diagnosis, n (%)				
< 6 months	4 (25)	7 (50)	10 (50)	21 (42)
6 months to 1 year	8 (50)	3 (21)	7 (35)	18 (36)
1–2 years	0	3 (21)	1 (5)	4 (8)
> 2 years	4 (25)	1 (7)	2 (10)	7 (14)
Current health status, n (%)				
Very good	4 (25)	2 (14)	5 (25)	11 (22)
Good	10 (63)	9 (64)	8 (40)	27 (54)
Fair	1 (6)	3 (21)	6 (30)	10 (20)
Poor	1 (6)	0 (0)	1 (5)	2 (4)
Employed, n (%)	3 (18.8)	8 (57.1)	7 (35)	18 (36)
Full time	2 (66.7)	6 (75)	4 (57.1)	12 (66.7)
Part time	0	2 (25)	2 (28.6)	4 (22.2)
Self-employed	1 (33.3)	0	1 (14.3)	2 (11.1)

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

need for early treatment intervention. In addition, the survey aimed to identify the physical, emotional and economic burden of the disease on patients.

Survey Variables

The physician survey covered the following areas: physician demographics and caseload, patient disease burden, patient management and treatment decisions, and physician perceptions.

The patient survey included the following variables: patients' awareness and perception of symptoms, impact of the disease on patients' daily living and caregivers, work productivity and associated activity impairment, disease history and treatment, patients' satisfaction, and disease information availability (to the patient).

Data Analysis

The analysis was primarily descriptive – numerical variables were presented as mean (standard deviation [SD]), and categorical variables as the total number of responses and corresponding percentages. The analysis was conducted using Stata statistical software version 16.0 or later (StataCorp LLC). Respondents with missing values for a particular variable were excluded from all analyses where that variable was used; however, they were included in other analyses.

Results

Demographics

Overall, 30 physicians participated in the survey, of whom 93% were oncologists or hemato-oncologists, and 7% were hematologists. Over the preceding year, each physician had cared for a mean of 3.4 patients with MF, 9.6 with PV, and 12.0 with ET. A greater proportion of physicians worked at university/teaching hospitals (63%) or regional/community hospitals (27%), and only 10% were associated with private hospitals.

The survey included 50 patients with MPN (MF, n = 16; PV, n = 14; ET, n = 20) with a mean (SD) age of 58.8 (13.5) years. Majority of the patients (78%) were diagnosed within 1 year of experiencing symptoms (Table 1).

Diagnosis and Assessment

Physician and patient agreement was noticed regarding symptom assessment, with 48% of patients reporting that physicians proactively asked them about symptoms. More than half of the physicians (57%) indicated that only some or very few patients could relate their symptoms to MPN. Despite that, 57% of physicians discussed only the most bothersome symptoms that might occur and 20% of physicians explained the comprehensive list of symptoms to their patients. As few as 8% of patients reported that their treating physicians explained the list of symptoms in detail.

Two-thirds of the physicians assessed symptom presence and severity at every visit; only 10% of physicians asked their patients to fill out a symptom checklist, and one-third of physicians evaluated symptom severity using validated assessment forms.

International prognostic scoring system (IPSS, 42%) and dynamic IPSS (DIPSS, 25%) were the assessment tools preferred by physicians. Although 80% of physicians used prognostic risk categories for classifying their patients, none of the patients were aware of their risk score.

Notably, presence of a new symptom followed by blood counts were the key determinants of disease progression from a physician's perspective. For patients, treatment success was mainly defined by improvements in blood counts or laboratory results, physicians' feedback, and symptomatic relief.

Symptomology and Disease Burden

Almost all physicians acknowledged being comfortable assessing the symptoms of a patient with MPN. A disconnect was noticed when fatigue was reported as one of the most prevalent symptoms according to physicians (67% in MF, 60% in ET). However, none of the patients with MF and only 15% of patients with ET reported fatigue as a common disease symptom (Figure 1). The average number of symptoms ever experienced by patients was 1.8 for all three MPN types. The symptom burden was higher in patients with MF (2.4) than in those with ET or PV. The most common symptoms reported by patients across all MPN subtypes were dizziness or vertigo (18%), headache (12%), numbness in the hands and feet (12%), and itching (12%). On querying the symptom severity during the preceding 12 months, with '10' being the worst score and '0' the best score, patients reported redness, throbbing, or burning in the hands and feet (8.5); difficulty sleeping (8.0); night sweats (7.7); fatigue or tiredness (7.3); and shortness of breath (7.0) as severe symptoms.

Although 97% of physicians strongly or somewhat believed that even mild-to-moderate symptoms can negatively impact the QoL, only 20% of patients agreed that their symptoms could reduce their QoL. Most patients did not notice any interference from the symptoms on their daily activities and family or social life. Many patients (>75%) did not experience any impact on general or emotional feelings, such as anxiety about their health condition, depression, irritability, or change in appetite, among other feelings.

Treatment and Goals

Physicians preferred to wait and watch 20%–40% of patients with MPN before commencing treatment. Ruxolitinib remained the most prescribed treatment for MF (92%),

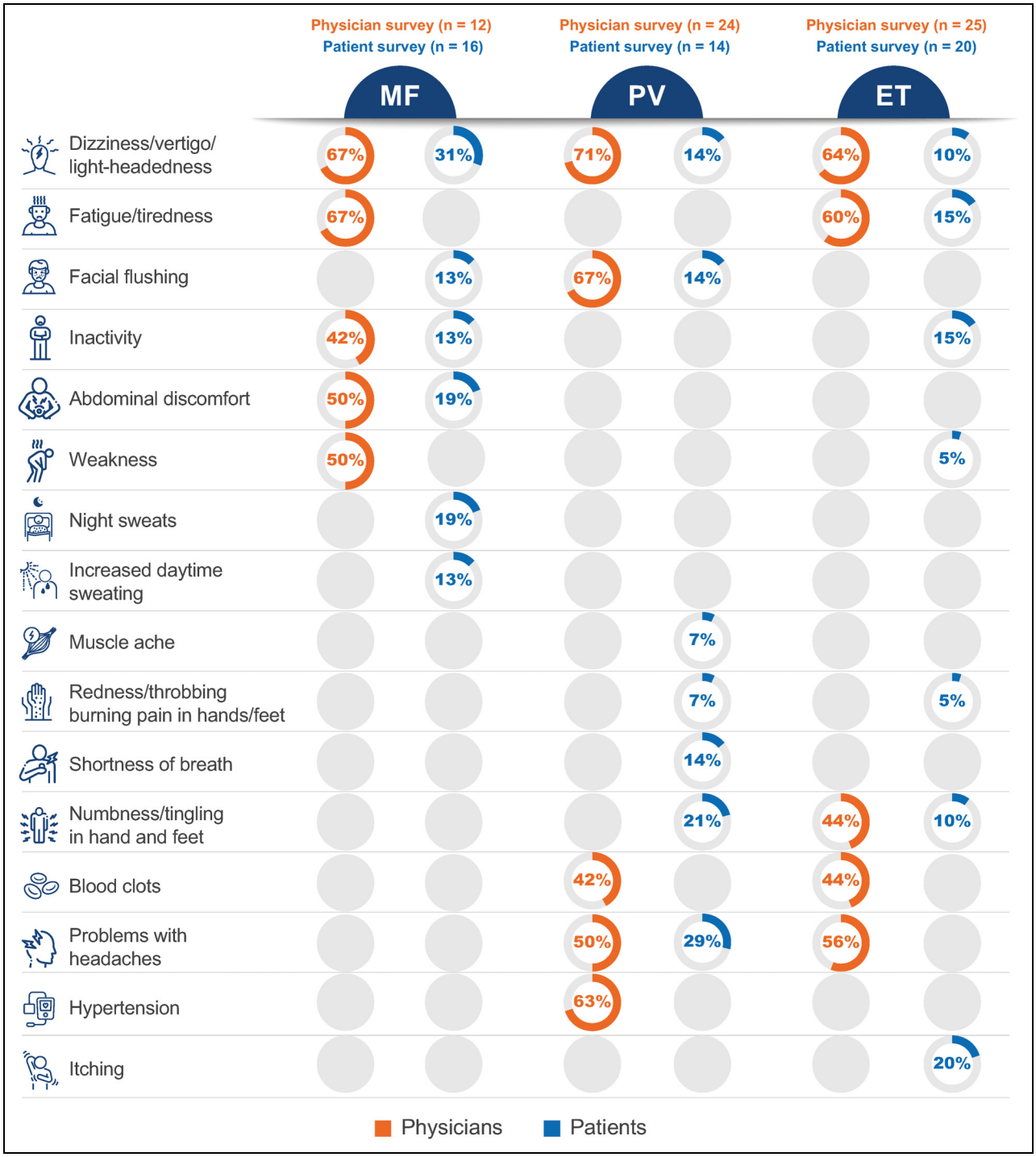

Figure 1. Most common symptoms across MPN subtypes per physicians and patients.

followed by hydroxyurea (75%) and aspirin (67%); the latter two drugs were the treatment choices for PV and ET as well. More than 70% of physicians continued to prescribe phlebotomies for patients with PV, and even though half of the physicians considered it bothersome for patients, none of the patients considered it as a burden on their QoL.

The treatment goals differed between physicians and patients – physicians aimed for better QoL and symptom improvement, whereas 90% of patients considered healthy blood counts as the treatment goal other than cure. Two-thirds of the physicians treating patients with MF targeted for reduction in spleen size, though it was not listed as an indicator for disease progression from a physician's perspective. However, none of the patients were concerned about their spleen size (Figure 2).

Notably, nurses were involved the most in providing care and counseling to patients. On an average, patients visited their respective doctors 7.7 times in the last 12 months.

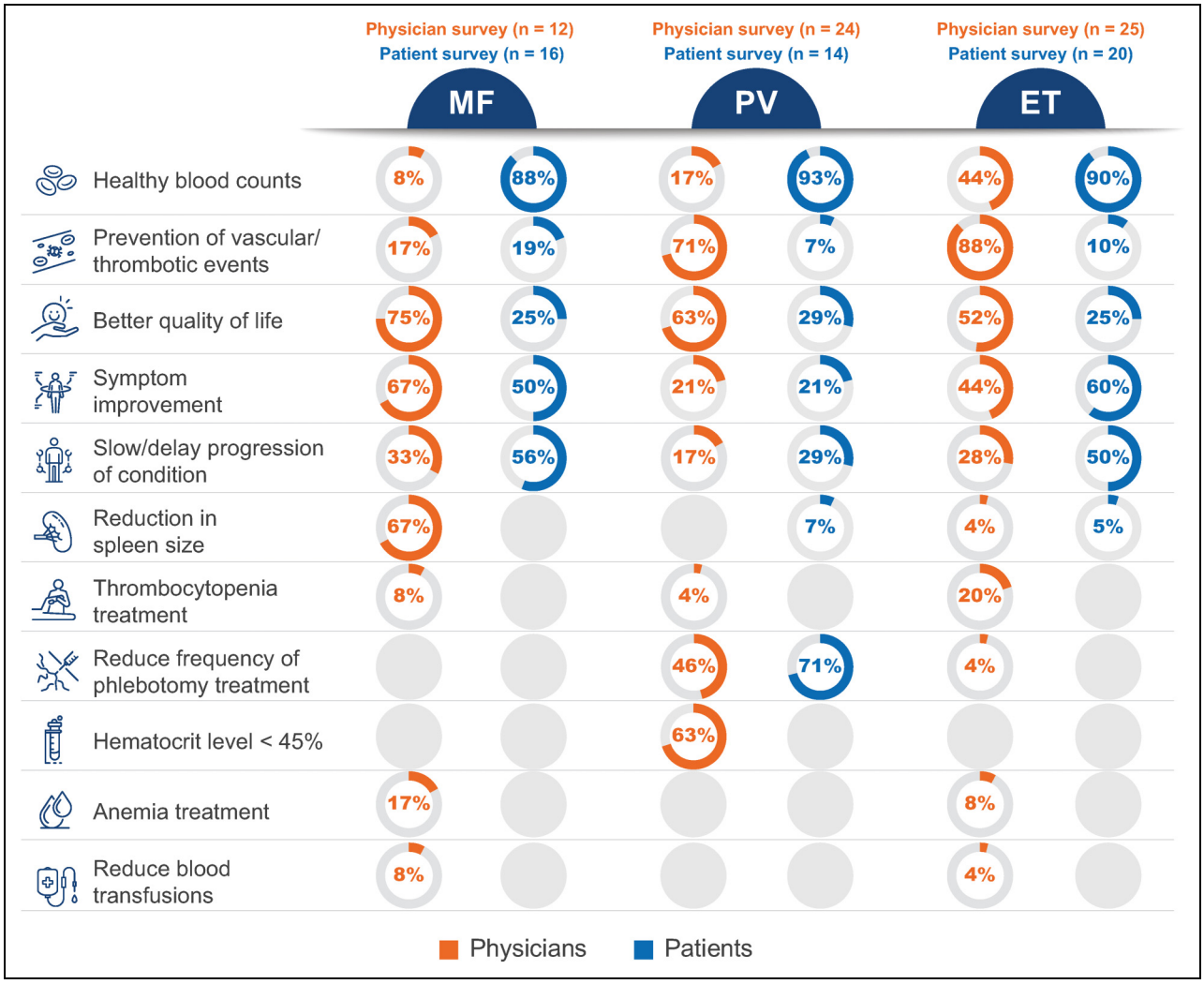

Figure 2. Treatment goals of physicians and patients for each MPN subtype.

Almost half of the patients ever changed their treating doctors, primarily because of dissatisfaction with care (48%), referral (30%), or unknown reasons (22%).

Work and Activity Impairment

None of the patients missed work in the last 7 days or availed sick leave in the past month. Almost all patient respondents (96%) managed without any caregiver support. Only two patients required occasional help from their children for 1.5 h in the past 7 days, mainly for assistance with transportation and healthcare.

Most MPN treatment cost was covered by the National Health Insurance in Taiwan, with patients spending an average of US$10.9 out of their pockets on prescription drugs. Hence, most patients (94%) experienced no financial hardships because of their condition.

Only 10% of the patients were aware of patient support groups, of whom only 20% were members of any such group and 75% of them did not find these groups valuable.

Patient and Physician Perceptions

Almost all the physicians and patients agreed on satisfaction with symptom management. A fair agreement was noted between physicians and patients regarding treatment goals (77%), and more than 80% of patients considered and preferred their respective doctors as the primary treatment decision-maker. More than 95% of patients and physicians were satisfied with their mutual communication regarding MPN and its treatment.

Among patient respondents, 98% felt that their physicians preferred to discuss blood counts over symptoms, whereas only 53% of physicians agreed to this response (Figure 3). Furthermore, 68% of patients responded that they were uncertain of how best to describe their symptoms. This fact was confirmed by 84% of physicians, and approximately

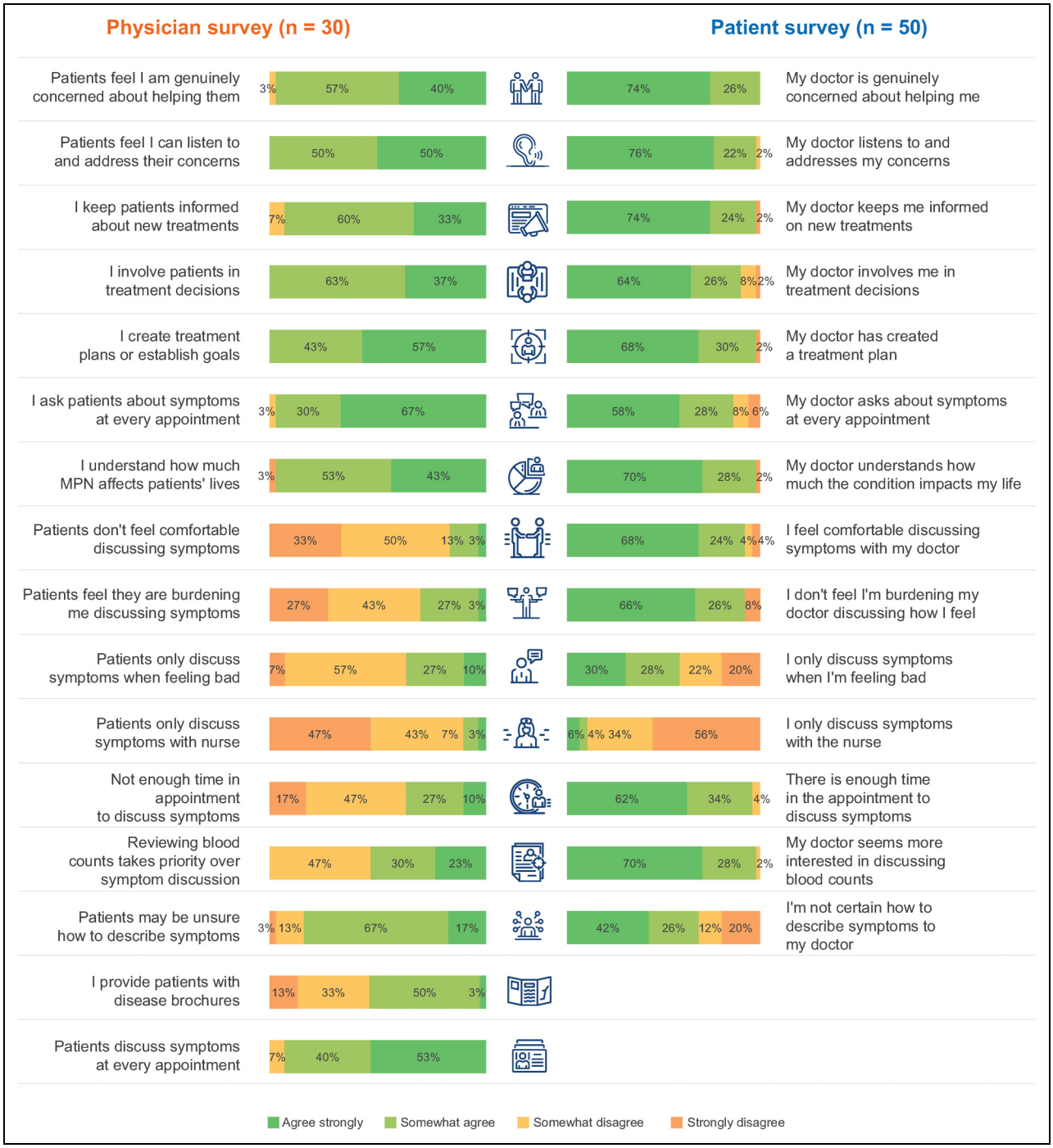

Figure 3. Physicians' and patients' perceptions of disease management.

53% of physicians provided patients with disease brochures (Figure 3).

Discussion

This was the first comprehensive survey of patients with MPN and their treating physicians from Taiwan. The MPN Landmark survey has been previously conducted in the US (US-Landmark) (8), Canada, UK, Australia, Germany, Italy, and Japan (International Landmark) (12). This report is a subset of the expansion of the MPN Landmark survey conducted in China, Turkey, South Korea, Saudi Arabia, Russia, and Taiwan.

The MPN symptom burden seemed to be low in Taiwan study, with patients experiencing an average of 2 symptoms compared with the overall average 6 symptoms for entire study population (24). Especially for fatigue, it is the most common symptom according to other survey; however, very few Taiwan patients reported fatigue as most common symptom. As per previous research, there is a great variation

for cancer-related fatigue (CRF), ranging from 50%–90% due to lack of definition and diagnostic criteria (25). In previous Taiwan local data, CRF varied with different diagnostic criteria, higher with ICD-10 than BFI-T (26). This lack of standardized symptom assessment could address the discrepancy observed in our study.

Our study identified a huge gap with regard to patients recognizing their symptoms, relating it to the disease, and describing it to their treating physicians. In this survey, only 16% of physicians provided information on MPN to their patients, and 57% of physicians believed that at least few of their patients could relate their symptoms to MPN. On the contrary, 68% of patients responded that they were uncertain of how best to describe their symptoms. This difference could be because of physicians' overestimation of their patients' ability to recognize disease-related symptoms. This disparity could partly explain the low symptom burden reported by patients. Because patients were unable to recognize that their symptoms were being caused by MPN, they likely underreported the frequency or severity and the impact of MPN symptoms on QoL. One possible solution could be through proactive use of validated and standardized symptom assessment scales at diagnosis and over the course of treatment. Moreover, biomarker-based evaluation methods may be employed for accurate quantification of symptom severity rather than solely relying on subjective assessment.

Another reason for the low symptom burden noted in our study could be because of selection bias. We excluded the patients who were participating in any clinical trial so that we do not come across any unexpected symptom due to the study intervention. Such patients could be more representative of the disease and accompanying symptoms and their severity. Additionally, all patients were recruited by their treating physicians in this study subset. Though, we had matched patient physician cohort by this approach, selection bias could not be avoided. In the International Landmark study, 57% of patients were recruited by patient organizations and these patients reported higher symptom burden than those recruited by physicians (12). In Taiwan, only 10% of patients with MPN were aware of patient support groups, of whom 20% were involved as members and 75% did not find them valuable. Nevertheless, such groups enrich patient knowledge about treatment options and set realistic expectations regarding health outcome, thereby improving the decision-making process, as well as patient participation and satisfaction.

Furthermore, nurses and other healthcare professionals involved in the care of patients with MPNs are uniquely positioned to help ameliorate the functional and societal burden faced by patients by providing valuable information and facilitating access to the available support services (27). In Taiwan, nurses were the healthcare professionals most involved in the care and counseling of patients. Therefore, to improve patients' care, there is a pressing need to educate patients on MPN and its symptoms by nurses, physicians, or patient support groups.

Ruxolitinib remains the most prescribed treatment for MF in Taiwan. Since October 2016, ruxolitinib has been covered by the National Health Insurance for intermediate- or high-risk patients with MF with symptomatic splenomegaly and/or other symptoms and not eligible for stem cell transplantation. Even though symptom assessment is recommended for correct dosing of the drug (20) and for applying insurance by these patients (28), none of the patient respondents with MF were asked to fill out a symptom checklist and review each symptom. Moreover, only 13% of patients with MF reported that their treating physicians explained to them the full and comprehensive list of symptoms. In addition, the treatment goals differed between patients and physicians, more prominently for MF. Notably, physicians prioritized QoL, reduction in spleen size, and symptom improvement, whereas patients focused on healthy blood counts and delayed progression. This could be due to limited knowledge of patients wherein blood count seemed to be the topmost indicator of treatment success or failure for them. Focused communication on treatment goals and holistic management practices could improve patients' understanding of their disease and treatment expectations.

There was a notable discordance between patients' and physicians' perspectives, not only regarding the presence and impact of MPN symptoms but also on how often these are discussed during clinical visits. In Taiwan, patients with MPNs visited their respective doctors on an average of 8 times in the last 12 months compared with 10 times in the expansion of the Landmark study (22). None of the patients in Taiwan and one-third in the overall study were aware that their physicians classified them per the risk scores (22).

There are a few limitations because of having only descriptive data. Because it was an online survey, a minimum level of education was required, and this criterion could have caused a selection bias. Hence, the survey respondents might not be representative of the overall population of patients with MPN. In addition, patients and physicians who agreed to participate may have characteristics and perceptions different from those who did not participate. The patient-level data on pain and symptoms were based on self-report, and thus, might be subject to recall bias and human error.

Notwithstanding these limitations, this was one of the feasible methods for assessing such rare conditions in a nationally distributed general population. The study indicated that the impact of MPN on patients varied with geographic location. In the Taiwan MPN setting, the Landmark survey reported a relatively low symptom burden, negligible economic burden, and minimal impairment in work and activity, without much need for caregiver support.

Conclusions

This survey observed a gap in patients' understanding of their MPN symptoms. Therefore, patients should be encouraged to participate in patient support groups, which could improve

their awareness of the disease and knowledge of symptoms. Moreover, the survey highlighted the need to standardize symptom assessment for improving patient care. Although the survey reported patient satisfaction in disease management, a patient–physician discordance regarding treatment goals was observed. However, this study observed no significant impact of the disease on patients' productivity and general well-being, and patients are more likely to receive a higher quality of care and treatment satisfaction through shared decision-making.

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Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Cheng-Shyong Chang reports receiving honoraria from AbbVie, Celgene, Janssen, MSD, Novartis, Roche, and Takeda.Chieh-Wen Chen was an employee of Novartis at the time of the study and manuscript writing.I-Ju Chiang, Fan-Chen Ku, Yee-Ming Lee, and Asif Siddiqui are paid employees of Novartis.

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