

Research Article

Validity and Reliability of the Self-Care in MyeloProliferative Neoplasms Inventory (SC-MPNI)

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Received 5 November 2024; Revised 24 February 2025; Accepted 18 September 2025

Academic Editor: Ricardo Santiago Gomez

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Objective: This study aimed to develop and psychometrically test a self-report questionnaire for measuring self-care behaviors in patients with myeloproliferative neoplasms (MPNs): the Self-Care in MyeloProliferative Neoplasms Inventory (SC-MPNI).

Methods: A cross-sectional validation study was conducted in 9 Italian hematology centers from November 2021 to January 2024. Adult patients with myelofibrosis (MF), polycythemia vera (PV), and essential thrombocythemia (ET) were asked to complete a paper-and-pencil questionnaire during their outpatient visit or at home. The SC-MPNI was developed according to the Middle-Range Theory of Self-Care of Chronic Illness. This 30-item questionnaire includes three scales: self-care maintenance, self-care monitoring, and self-care management. The construct validity was tested using confirmatory factor analysis (CFA). The reliability of each scale was evaluated using McDonald's Omega composite reliability.

Results: Overall, 285 patients with MPNs (53% male; mean age = 60 years ± 13) were included. They were diagnosed with MF (43%), PV (29%), or ET (28%). The self-care maintenance scale (13 items and 3 factors: adherence, healthy lifestyle, and prevention) fit well when tested with a three-factor model, and its reliability was 0.87. The self-care monitoring scale (9 items and 2 factors: symptom monitoring and parameter and test monitoring) fit well when tested with a two-factor model, and its reliability was 0.85. The self-care management scale (8 items and 2 factors: provider-directed behaviors and spontaneous behaviors) fit well when tested with a two-factor model, and its reliability was 0.79.

Conclusion: The SC-MPNI is a valid and reliable self-report instrument to measure self-care behaviors in people living with MPNs.

Keywords: adherence; instrument development; myeloproliferative neoplasms; psychometrics; self-care; validity

1. Introduction

Rare cancers, defined by an incidence of less than 6 cases per 100,000 people annually [1–4], account for 24% of new cancer diagnoses overall. Several hematological malignancies are classified as rare cancer, such as BCR::ABL1 negative myeloproliferative neoplasms (MPNs). MPNs include myelofibrosis (MF), polycythemia vera (PV), and essential thrombocythemia (ET) [5]. In patients with MPNs, somatic mutations (*JAK2*, *CALR*, or *MPL*) drive the proliferation of myeloid cells in the bone marrow. MPNs are associated with an increased risk of thrombotic and hemorrhagic events and systemic symptoms that may severely reduce their quality of life [6–9]. Over time, MPN patients may progress to acute myeloid leukemia (AML) [10–12], requiring treatment intensification, including allogeneic hematopoietic stem cell transplantation (allo-HSCT), which is also recommended for some patients with MF [13].

Patients with MPNs can be treated with aspirin, cytoreduction, and/or target therapy based on risk stratification and disease type. The primary treatment goal is to prevent cardiovascular complications in PV/ET patients [14, 15] and improve spleen size and symptoms in MF [16]. Besides fostering treatment adherence, health professionals, especially nurses, play an important role in providing education and self-care support to patients with MPNs [17–19]. In particular, self-care refers to the set of behaviors that patients perform to maintain their physical and emotional well-being despite their illness (self-care maintenance) to monitor symptoms related to their condition and its treatment (self-care monitoring) and to take necessary actions to manage these symptoms and prevent further deterioration of their health (self-care management) [20].

As chronic neoplasms, promoting self-care in MPNs could help prevent and/or early detect both cardiovascular risks (thrombotic and hemorrhagic events) and cancer-related risks (disease progression, second tumors). To improve their overall health, patients with MPNs should be encouraged to follow both general and specific recommendations for daily self-care behaviors. For example, the European Code Against Cancer recommends adopting a healthy lifestyle by modifying dietary habits, avoiding smoking, limiting alcohol intake, increasing physical activity, and maintaining a healthy body weight [21]. Specific recommendations include drinking plenty of water and adopting behaviors that help to reduce the risk of thrombotic events (e.g., avoidance of prolonged immobility and appropriate management of cardiovascular risk factors). Patients should also monitor any symptoms related to their disease or treatment, recognize signs of clinical deterioration, and take necessary action, such as contacting the healthcare provider [20, 22].

Self-care has gained more attention in the nursing community, and several tools have been developed to measure self-care in patients with chronic conditions, such as the Self-Care of Chronic Illness Inventory (SC-CII) [23–26]. However, there has been less emphasis on supporting patients with cancer in managing their illness as

a chronic condition and assessing their self-care behaviors [27, 28]. Researchers have mainly focused on treatment adherence [29–31], managing medications [32], monitoring side effects [29], and alleviating symptoms [33], without capturing a comprehensive understanding of self-care activities. This is crucial because promoting self-care has been linked to a better quality of life [34–37] and reduced mortality rates [38, 39].

Therefore, there is a need for a new comprehensive tool that measures self-care in patients with cancer across three key dimensions: maintenance, monitoring, and management [40, 41]. The current study introduces a novel instrument designed for both research and clinical purposes, focusing on various disease-specific self-care aspects in patients with persistent hematological neoplasms, specifically MPNs. This tool would assist health professionals in identifying self-care deficits and guide education interventions to support patients in adopting healthy lifestyles. Thus, this study aims to develop and psychometrically test a self-report questionnaire for measuring self-care behaviors in patients with MPNs: the Self-Care in MyeloProliferative Neoplasms Inventory (SC-MPNI).

2. Methods

2.1. Design. A cross-sectional validation study was conducted in 9 Italian hematology centers from November 2021 to January 2024. The Italian Association of MPN Patients (AIPAMM) promoted the SELF-CARE_AIPAMM study. The process of data collection was initiated after the SC-MPNI development and content validation phases, which were performed according to the COSMIN methodology [42]. In accordance with the guidelines of the European Statistical System [43, 44], the overall study comprises six steps: (1) conceptualization, (2) item development, (3) face validity, (4) content validity, (5) prefield test, and (6) data collection. Phase 1 consisted of steps 1 through 5, while Phase 2 only included step 6.

2.2. Phase 1: Development of the Questionnaire

2.2.1. Conceptualization. For the purpose of this study, self-care in MPN patients was defined as “the actions taken by MPN patients to promote their health, maintain the physiological stability of the disease, recognize and manage symptoms, and adopt behaviors to prevent oncological and cardiovascular risks” [20, 22, 45, 46].

2.2.2. Item Development. The items were developed using the Middle-Range Theory of Self-Care of Chronic Illness, which consists of three scales: self-care maintenance, self-care monitoring, and self-care management [20, 22, 27]. A group of patient advocates, hematologists, nurses, and researchers developed a list of recommended behaviors for MPN patients based on their clinical experience and evidence from the literature. To ensure the list was patient-centered, they also considered feedback from two focus

groups with patients. They grouped the recommended behaviors into dimensions for each scale of self-care, allowing for a comprehensive understanding of the different aspects of self-care [27]. At least three items were developed for each dimension. The initial version of the SC-MPNI consisted of 35 items. A scale of frequency was chosen for the response format of each item of the self-care maintenance and self-care monitoring, while a scale of likelihood was adopted for each item of the self-care management. The items were developed in both Italian and English languages, ensuring equivalence.

2.2.3. Face Validity. To ensure item generation and verify relevance, comprehensiveness, and comprehensibility, we conducted individual interviews with hematologists and patient advocates. The team worked diligently to ensure that each item was expressed in simple syntax and familiar word. They carefully revised each item in an iterative process to guarantee relevance and that responders could easily connect with them. By making these adjustments, we ensured that our responders could better understand and engage with the content. Also, the instructions of the instrument were discussed and revised.

2.2.4. Content Validity. To ensure that the SC-MPNI accurately measures the concept of interest, a total of 35 items were evaluated by 27 experts for their content validity. These experts, comprising 19 Italian and 8 English speakers (12 hematologists, 9 nurse researchers, 1 psychologist, and 5 patient advocates), rated the selected items on their relevance using a 4-point ordinal scale. The scale ranged from 1 (*not relevant*) to 4 (*highly relevant*). We calculated the content validity index (CVI) for each item (I-CVI) and the overall scale (S-CVI) [47]. We decided to remove 5 items because of poor I-CVI (< 0.78). The S-CVI of the 30-item version was 0.93.

2.2.5. Prefield Test. The researcher administered the SC-MPNI to five patients through cognitive interviews using the think-aloud technique to ensure that responders understood each item as intended [48]. During cognitive interviews, patients read each item aloud and then explained its meaning. Minimal revisions were made based on patient feedback to improve understanding.

2.3. Phase 2: Validation Study

2.3.1. Ethics. Ethical approval was obtained first from the Valpadana Ethics Committee (Prot. No. 33866), as Ospedale Maggiore ASST of Crema was the coordination center, and then from the ethics committee of each participating center, including Bologna—Area Vasta Emilia Centro (Prot. No. 218/2023), Florence—Area Vasta Centro (Prot. No. 21313_oss), Milano Area 2 (Prot. No. 337_2022), Varese—Insubria (Prot. No. 280_97/2022), Rome—Gemelli (Prot. No. 25373/22), Palermo 1 (Prot. No. 04/2022), Catania 2 (Prot. No. 271/2022), Fondazione I.R.C.C.S. Policlinico

S. Matteo (Prot. No. 20714). Potential participants were given comprehensive information in both written and verbal forms about the study's objectives, procedures, and data collection. Participants were informed that their involvement in the research was voluntary and that they could withdraw their consent at any time. Participants were assured that their identities would remain anonymous, and their data would be securely stored and treated confidentially. Patients who agreed to participate provided written consent.

2.3.2. Participants. The study recruited outpatient participants diagnosed with MPNs from the 9 hematology centers across Italy, including 5 in the north, 2 in the center, and 2 in the south. The goal was to enroll around 310 patients, comprising approximately 103 patients diagnosed with ET, 103 patients diagnosed with PV, and 103 patients diagnosed with either overt MF or prefibrotic MF. MPN patients were eligible if they were 18 or older, fluent in Italian, and without cognitive or perceptual impairments that could limit their survey completion.

2.3.3. Instruments. In order to measure self-care, we used a questionnaire that we specifically developed for this purpose: the 30-item version of the SC-MPNI. This includes three scales: self-care maintenance, self-care monitoring, and self-care management. Self-care maintenance is assessed by items that measure adherence (e.g., taking medications as prescribed), healthy lifestyle (e.g., eating a healthy balanced diet), prevention (e.g., abstaining from smoking), mental health habits (e.g., lowering physical and/or emotional stress), and information seeking (e.g., learning more about the disease and medications). Items about self-care monitoring include tests and visits (e.g., getting blood tests as prescribed), monitoring symptoms (e.g., monitoring for the onset of new symptoms), and monitoring clinical parameters (e.g., checking the weight). Items about self-care management include both provider-directed behaviors (e.g., contacting the healthcare provider) and spontaneous behaviors (e.g., implementing home remedies). Each item of the self-care maintenance and self-care monitoring is rated on a 6-point Likert scale of frequency from 1 (*never*) to 6 (*always*), while each item of the self-care management is rated on a scale of likelihood ranging from 1 (*not likely*) to 6 (*extremely likely*). Scores range from 0 to 100, standardized mathematically.

To verify convergent validity with the SC-MPNI, the Self-Care Self-Efficacy Scale (SCSES) was used [49]. This is a valid and reliable self-report tool used to measure self-efficacy in self-care behaviors for patients with chronic illnesses. It was designed as a single-domain scale comprising 10 items to measure self-efficacy in self-care maintenance, self-care monitoring, and self-care management. For example, it assesses the confidence of patients in monitoring their condition regularly. Each of the SCSES items starts with the phrase "How confident are you that you can . . ." Each item is rated on a 5-point Likert scale, ranging from 1 (*not at*

all confident) to 5 (*very confident*). Scores range from 0 to 100, standardized mathematically. Higher scores indicate higher levels of self-efficacy. Participants' sociodemographic and clinical information were also gathered.

2.3.4. Data Collection. Patients were enrolled from 9 Italian hematology centers from November 2021 to January 2024 during outpatient visits. Each center was required to enroll 30 patients with MPNs. The hematologists approached eligible patients during their outpatient visits and invited them to participate in the research study by completing a self-report questionnaire on paper. Additionally, about 60 patients were contacted directly by volunteers from AIPAMM, who provided them with a questionnaire on paper either in person or by mail.

2.3.5. Data Analysis. Descriptive statistics were computed for sociodemographic and clinical factors. The statistical analysis included only data from patients who completed the SC-MPNI or had at most 10% missing data. For each item of the SC-MPNI, we calculated the mean, standard deviation (SD), skewness, and kurtosis to assess the distribution's normality. In order to evaluate the dimensionality of the SC-MPNI, we utilized a confirmatory approach, considering it the most suitable analysis method due to the theory-based nature of the instruments. In particular, we conducted a separate confirmatory factor analysis (CFA) for each of the three scales. We tested a multidimensional model based on the Middle-Range Theory of Self-Care of Chronic Illness [20, 25] and its adaptation to the cancer context [27], in accordance with item development. The Kaiser–Meyer–Olkin (KMO) index of sampling adequacy and Bartlett's test of sphericity were used to preliminarily investigate data factorability. Due to the non-normal item distribution, CFA was performed using the robust maximum likelihood (MLr) estimator [50]. We tested a second-order model to account for a strong correlation among dimensions. The following fit indices were considered to evaluate the model fit: comparative fit index (CFI; values ≥ 0.90 indicate a good fit), Tucker and Lewis Index (TLI; values ≥ 0.90 indicate a good fit), root mean square error of approximation (RMSEA; values ≤ 0.08 indicate a good fit), and standardized root mean square residual (SRMR; values ≤ 0.08 indicate a good fit) [51–53]. The chi-square (χ^2) test was also computed. We estimated that a sample size of at least 200 individuals would be adequate for an effective CFA [54].

The reliability of the SC-MPNI was evaluated by assessing the internal consistency of each scale using McDonald's Omega (ω) composite reliability, which is a more appropriate indicator of reliability for multidimensional scales [55, 56]. A value of > 0.70 is considered adequate. Each of the three scales is separately scored and standardized from 0 to 100, with higher values indicating better self-care. Pearson's correlation coefficients were used to evaluate the construct (convergent) validity of the SC-MPNI with respect to the SCSES, as we expected significant positive correlations. Correlations with values ranging from 0.10 to 0.29 are considered weak, those from

0.30 to 0.49 are moderate, and values equal to or greater than 0.50 are strong [57]. Statistical analyses were performed using SPSS 22.0 (IBM Corp. Armonk, NY, USA) and Mplus 7.1 (Muthén and Muthén, Los Angeles, CA, USA).

3. Results

3.1. Participants' Characteristics. Overall, 300 adult patients with MPNs were enrolled at 9 hematology centers across Italy. Out of them, 285 (95%) completed the SC-MPNI, and their data were included in the statistical analysis (Table 1). Most of the participants were male ($n = 151$, 53.0%) with a mean age of 60.0 (SD = 13.4 and range = 22.8–87.4). Most of the participants had a partner ($n = 199$, 70.3%), about a quarter ($n = 75$, 26.4%) had achieved a university education level, and half of them ($n = 139$, 49.8%) were employed.

All participants had been diagnosed with MPN: MF in 42.8% ($n = 120$), PV in 27.9% ($n = 78$), and ET in 29.3% ($n = 82$) (Table 1). The median time since diagnosis was 5.9 years (IQR = 3.0–11.6). The most frequent driver mutation was *JAK2* ($n = 195$, 68.4%). Approximately 43.1% ($n = 113$) of the participants were receiving hydroxyurea, and 85.8% ($n = 235$) were undergoing antiplatelet/anticoagulant treatment.

3.2. Item Descriptive Statistics and CFA. Descriptive statistics, including mean, SD, skewness, and kurtosis for each item of the SC-MPNI, are presented in Table 2. Several items ($n = 22$) exhibited non-normal distribution, indicated by skewness and kurtosis values exceeding |1|. The factor analysis was appropriate for the data because the Bartlett test of sphericity was significant ($p < 0.001$) and the KMO was 0.83.

To assess the dimensionality of the self-care maintenance scale, we conducted a CFA to test a three-factor model. Specifically, the "Adherence" factor consisted of items #1, #2, and #3; the "Healthy lifestyle" factor consisted of items #4, #5, #6, #7, #12, and #13; and the "Prevention" factor consisted of items #8, #9, #10, and #11. All factor loadings were found to be significant and higher than 0.30. In addition, we specified in the model the covariance between the residuals for item #8, "Abstain from smoking," and item #9, "Limit alcohol consumption," as well as between the residuals for item #7, "Do physical activity for at least half an hour a day," and item #13, "Perform activities that improve your mental and physical well-being," due to their similar meaning and modification indices. The correlation between the three factors was greater than 0.40, and thereby we specified a second-order factor (self-care maintenance), with factor loadings greater than 0.60 (Figure 1). The CFA we conducted yielded satisfactory fit indices: χ^2 ($df = 60$) = 135.32, $p < 0.001$; CFI = 0.90; TLI = 0.87; RMSEA = 0.066 (90% CI = 0.052–0.081) $p = 0.036$; and SRMR = 0.062.

To assess the dimensionality of the self-care monitoring scale, we conducted a CFA to test a two-factor model. Specifically, the "Symptom monitoring" factor included items #16, #17, #18, #19, and #20; and the "Parameter and

TABLE 1: Participants' sociodemographic and clinical characteristics ($n = 285$).

		n	%
Sex ($n = 285$)	Male	151	53.0
	Female	134	47.0
Age ($n = 285$)	< 45 years	37	13.0
	45–64 years	135	47.4
	≥ 65 years	113	39.6
Marital status ($n = 283$)	Single	37	13.1
	Partnered	199	70.3
	Divorced	31	11.0
	Widowed	16	5.7
Education ($n = 284$)	≤ Secondary school	72	25.4
	High school	137	48.2
	University	75	26.4
Employment ($n = 279$)	Full-time	117	41.9
	Part-time	22	7.9
	Retired	106	38.0
	None	34	12.2
Diagnosis ($n = 280$)	Overt-MF	83	29.6
	Pre-MF	37	13.2
	PV	78	27.9
	ET	82	29.3
Time since diagnosis ($n = 260$)	< 3 years	66	25.4
	3–9 years	116	44.6
	≥ 10 years	78	30.0
Driver mutation ($n = 285$)	JAK2	195	68.4
	CALR	31	10.9
	MPL	1	0.4
	Triple negative	11	3.9
	Unknown	47	16.5
Cytoreductive therapy ($n = 262$)	Hydroxyurea	113	43.1
	Interferon	14	5.3
	JAK inhibitor	51	19.5
	Anagrelide	5	1.9
	None	79	30.2
Anticoagulant treatment ($n = 274$)	Aspirin	188	68.6
	Other	47	17.2
	None	39	14.2

Abbreviations: ET = essential thrombocythemia, IQR = interquartile range, MF = myelofibrosis, PV = polycythemia vera.

test monitoring” factor included items #14, #15, #21, and #22. All factor loadings were significant and higher than 0.30. In addition, we specified in the model the covariance between the residuals for item #16, “Monitor for worsening of disease-related symptoms,” and item #17, “Monitor for the onset of new symptoms,” and between the residuals for item #21, “Check your weight,” and item #22, “Check any measurement your healthcare providers recommend,” as well as between the residuals for item #14, “Get blood tests as prescribed by your hematologist,” and item #15, “Do the instrumental examinations as prescribed or recommended by your hematologist,” due to their similar meaning and modification indices. The correlation between the two factors was 0.90, and thereby we specified a second-order factor (self-care monitoring), with factor loadings greater than 0.50 (Figure 2). The CFA we conducted yielded satisfactory fit indices: χ^2 ($df = 22$) = 50.52, $p < 0.001$; CFI = 0.95; TLI = 0.92;

RMSEA = 0.067 (90% CI = 0.043–0.092) $p = 0.11$; and SRMR = 0.037.

To assess the dimensionality of the self-care management scale, we conducted a CFA to test a two-factor model. Specifically, the “Provider-directed behaviors” factor included items #23, #24, and #25; and the “Spontaneous behaviors” factor included items #26, #27, #28, #29, and #30. All factor loadings were significant and higher than 0.30. The correlation between the two factors was 0.55, and thereby we specified a second-order factor (self-care monitoring), with factor loadings greater than 0.60 (Figure 3). The CFA we conducted yielded satisfactory fit indices: χ^2 ($df = 19$) = 28.95, $p = 0.07$; CFI = 0.96; TLI = 0.94; RMSEA = 0.043 (90% CI = 0.000–0.073) $p = 0.62$; and SRMR = 0.043.

3.3. Reliability, Scoring, and Construct Validity. Internal consistency, as measured using the Omega composite reliability, was good for the self-care maintenance scale ($\omega = 0.87$), the self-care monitoring scale ($\omega = 0.85$), and the self-care management scale ($\omega = 0.79$). The self-care monitoring scale had the highest score ($M = 83.92$ and $SD = 15.60$), while the self-care management scale had the lowest score ($M = 64.49$ and $SD = 16.74$), mainly because of the low score for spontaneous behaviors ($M = 52.13$ and $SD = 21.05$) (Table 3). Using Pearson's correlations, significant positive correlations were found between the SCSES ($M = 77.35$ and $SD = 15.50$) and each SC-MPNI scale, demonstrating construct validity (Table 3).

4. Discussion

This study showed that the SC-MPNI is a valid and reliable self-report instrument for assessing self-care behaviors in people with MPNs. The items were created based on the Middle-Range Theory of Self-Care of Chronic Illness [20, 22, 27], which underscores the significance of three key components: self-care maintenance, self-care monitoring, and self-care management. Specifically, the SC-MPNI allows clinicians and researchers to assess the extent to which MPN patients engage in daily healthy behaviors, including adherence to treatment, maintaining a healthy lifestyle, and taking preventive measures. It also assesses how frequently patients effectively self-assess disease-related symptoms and monitor health parameters. Additionally, it measures how likely patients are to seek advice from healthcare professionals and take proactive measures if their condition worsens. By measuring these behaviors, nurses and other health professionals can identify any self-care deficits and address them by implementing targeted educational interventions [34, 35, 58, 59].

In particular, the self-care maintenance scale consists of three dimensions: Adherence, Healthy lifestyle, and Prevention, which is one dimension more than the self-care maintenance scale of the SC-CII, the instruments developed by Riegel for chronic conditions [25]. The “Healthy lifestyle” dimension is similar to “Health promoting behavior” and encompasses general behaviors that both healthy and nonhealthy individuals should engage in to maintain good

TABLE 2: Statistics for the 30 items of the SC-MPNI and their factor loadings at EFA ($n = 285$).

Items	Mean	SD	Skewness	Kurtosis	Factors loading
Self-care maintenance: how often do you do the following activities					
1 Follow the recommendations of healthcare providers.	5.50	0.91	-2.60	8.35	0.69
2 Take medications as prescribed.	5.75	0.65	-3.96	21.05	0.79
3 Attend all scheduled clinical appointments.	5.86	0.55	-5.94	43.85	0.76
4 Get enough sleep to feel rested.	4.63	1.22	-0.62	-0.40	0.60
5 Eat a healthy balanced diet.	4.52	1.17	-0.84	0.55	0.62
6 Drink at least 1 and a half liters of water a day.	4.59	1.37	-0.68	-0.66	0.54
7 Do physical activity for at least half an hour a day.	3.84	1.60	-0.22	-1.05	0.57
8 Abstain from smoking.	5.33	1.53	-2.12	2.86	0.35
9 Limit alcohol consumption.	5.24	1.15	-1.78	3.18	0.32
10 Maintain good oral hygiene.	5.62	0.75	-2.53	8.12	0.55
11 Behave in a way that reduces the risk of thrombosis and/or bleeding.	5.13	1.08	-1.35	1.68	0.63
12 Lower physical and/or emotional stress.	4.01	1.28	-0.26	-0.52	0.64
13 Perform activities that improve your mental and physical well-being.	3.08	1.72	0.25	-1.24	0.40
Self-care monitoring: how often do you do the following activities					
14 Get blood tests as prescribed by your hematologist.	5.83	0.59	-4.62	25.95	0.42
15 Do the instrumental examinations as prescribed or recommended by your hematologist.	5.74	0.80	-4.10	18.64	0.37
16 Monitor for worsening of disease-related symptoms.	5.22	1.25	-1.83	-2.86	0.75
17 Monitor for the onset of new symptoms.	5.30	1.15	-1.98	3.67	0.83
18 Monitor for side effects of the medications you take.	5.33	1.17	-2.15	4.42	0.71
19 Monitor whether you tire more than usual doing normal activities.	5.15	1.19	-1.53	1.96	0.79
20 Monitor your emotional state.	4.73	1.35	-0.98	0.18	0.72
21 Check your weight.	4.75	1.38	-1.01	0.19	0.45
22 Check any measurement you healthcare providers recommend.	4.72	1.40	-0.99	0.04	0.47
Self-care management: when you have symptoms, how likely are you to ...					
23 Take prescribed medications to reduce symptoms.	5.29	1.23	-2.08	3.91	0.52
24 Contact your healthcare provider immediately to ask what to do.	4.85	1.41	-1.16	0.32	0.75
25 Accurately report symptoms to your healthcare providers during visits to get a comprehensive response.	5.47	0.89	-1.97	4.22	0.52
26 Ask for psychological support to overcome emotional problems.	2.78	1.60	0.62	-0.76	0.56
27 Implement home remedies that help you reduce symptoms.	3.82	1.73	-0.32	-1.21	0.54
28 Slow down your activity level.	4.07	1.38	-0.36	-0.67	0.39
29 Use physical and mental practices to improve symptoms.	3.13	1.74	0.32	-1.23	0.66
30 Change what you eat and drink to avoid symptoms.	4.31	1.39	-0.61	-0.27	0.53

Note: Range 1–6; SD = standard deviation. The self-care maintenance scale includes the following factors: adherence, healthy lifestyle, and prevention. The self-care monitoring scale includes the following factors: symptom monitoring and parameter and test monitoring. The self-care management scale includes the following factors: provider-directed behaviors and spontaneous behaviors.

health. These behaviors include getting enough sleep, eating well, drinking enough water, doing physical activity, lowering stress, and improving overall well-being. It is worth noting that staying well hydrated by drinking plenty of water is highly recommended for patients with MPNs who experience symptoms related to thickened blood and circulation (e.g., tingling). Our findings indicate that patients with MPNs may require greater support to identify and participate in activities that enhance their mental and physical well-being, including sports. People with cancer may feel limited in their ability to be physically active, but engaging in exercise is one of the most effective evidence-based non-pharmacological interventions. It can help increase physical capacity [60], combat fatigue [61], reduce cardiovascular risk [62], protect against infections [63], limit cognitive decline [64], and even lower the risk of developing second cancer [65, 66].

The self-care maintenance scale includes dimensions such as Adherence and Prevention, commonly

recommended for people living with or at risk of developing a disease, like illness-related behavior [25]. On the one hand, adherence to treatment and recommendations is widely recognized as the most important task for patients with cancer [31, 67–69]. On the other hand, it is crucial to engage in preventive behaviors when living with a chronic disease such as MPNs. These patients specifically need to reduce both cardiovascular and cancer-related risks, with inflammation serving as a common pathway [70, 71]. Therefore, it is more crucial for patients with MPNs to avoid unhealthy habits such as smoking and excessive alcohol consumption, compared to healthy individuals. Smoking, for instance, has been associated with higher risks of cardiovascular disease and cancer [60, 72–75], as it can exacerbate oxidative stress and chronic inflammation.

The self-care monitoring scale has two dimensions: symptom monitoring and parameter and test monitoring; this is one dimension more than the SC-CII [25]. The distinction between monitoring symptoms and monitoring

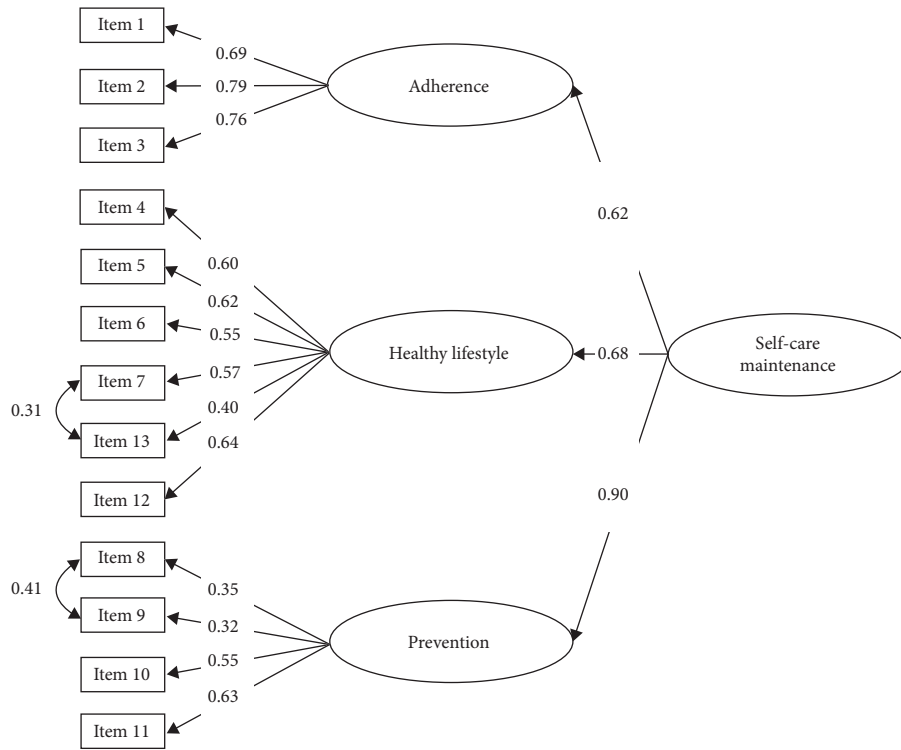


FIGURE 1: Confirmatory factor analysis model of the self-care maintenance scale.

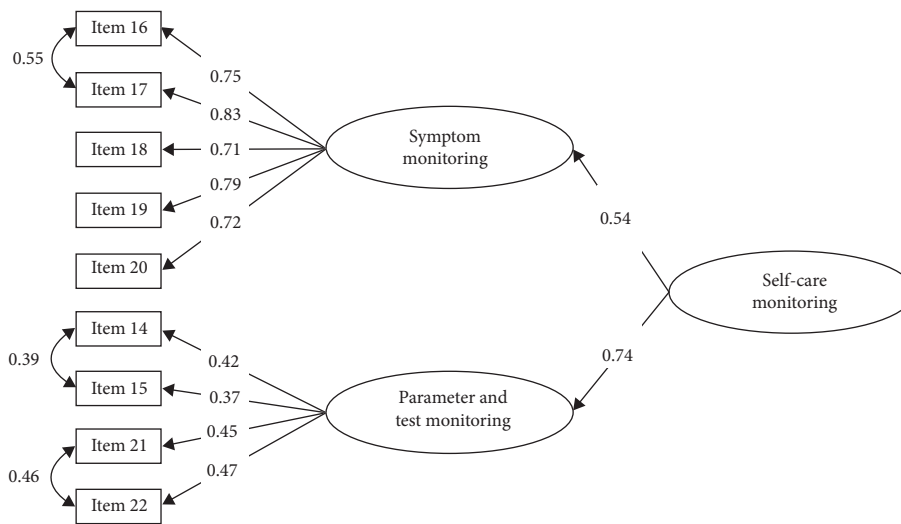


FIGURE 2: Confirmatory factor analysis model of the self-care monitoring scale.

parameters was created to emphasize the importance of tracking symptoms over time for patients with MPNs. It is worth noting that in the context of cancer, self-care is often seen as symptom management [45, 76, 77], since symptoms such as pain and fatigue are major concerns for patients dealing with cancer. In individuals with MPNs, monitoring symptom onset and severity is essential not only for effective symptom management but also for detecting medication toxicities (e.g., gastrointestinal disorders and skin abnormalities) and MPN progression (e.g., night sweating) [78]. In addition, disease monitoring involves regular blood tests to

track blood counts, monitoring weight to identify any unintended weight loss, doing instrumental examinations such as abdominal ultrasound to measure spleen size, and checking other measurements recommended by healthcare providers, with the latter behavior scoring the lowest. In order to encourage patients to become more involved in monitoring these measurements, health professionals should offer precise guidance on which parameter to monitor, how often to monitor them, and how to do so, even if they believe it falls under the responsibility of other specialists (e.g., blood pressure monitoring).

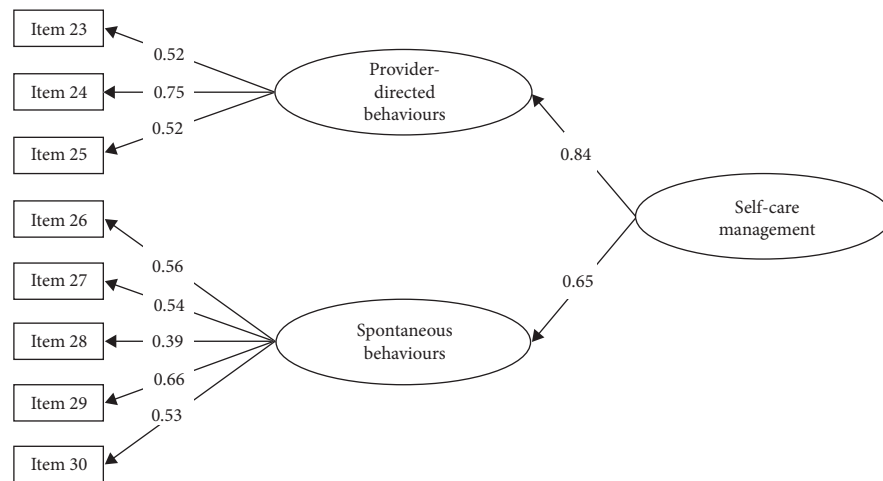


FIGURE 3: Confirmatory factor analysis model of the self-care management scale.

TABLE 3: Scores of the SC-MPNI and correlations with SCSES ($n = 281$).

	Mean	SD	SCSES (r)
Self-care maintenance scale	77.08	12.49	0.297
Adherence	94.06	11.81	0.220
Healthy lifestyle	62.28	18.66	0.266
Prevention	86.53	15.81	0.181
Self-care monitoring scale	83.92	15.60	0.378
Symptom monitoring	82.88	20.06	0.334
Parameter and test monitoring	85.27	14.91	0.326
Self-care management scale	64.49	16.74	0.397
Provider-directed behaviors	84.09	17.87	0.381
Spontaneous behaviors	52.13	21.05	0.307

Note: All scores are standardized 0–100. All correlations are significant at $p < 0.005$.

Abbreviations: SCSES = Self-Care Self-Efficacy Scale, SD = standard deviation.

The self-care management scale consists of two dimensions: provider-directed behaviors and spontaneous behaviors, similar to the SC-CII [25]. Patients with MPNs should consult health professionals as soon as possible when managing disease exacerbations or report the problem at the next visit, depending on the severity of their clinical condition. Afterward, they should follow the necessary actions recommended by the health professionals, such as taking specific medications. Therefore, health professionals should educate patients to promptly recognize the urgency of the situation in order to take appropriate action [35]. Moreover, patients who are empowered can take independent actions when they experience symptoms or notice changes in their clinical condition, often drawing on previous experiences (e.g., changing what they eat or drink). Support from peer groups and patient associations can enable patients to share their experiences and discover what strategies work best for them. For example, individuals with PV may find it helpful to apply talcum powder to alleviate itching after a shower. Health professionals should assess the level of evidence for each supportive care practice by inquiring

about the self-care practices patients employ to manage symptoms [79]. It is important to note that some of these practices, such as using certain supplements, could be hazardous. Interestingly, our findings indicate that seeking psychological support was the least common self-care management behaviors, and it was perceived as spontaneous rather than directed by providers in this sample. This suggests that patients may seek psychological support from friends or private health professionals on their own rather than being referred to a public psychologist by a doctor or through a formal screening process. To improve the mental health of patients with cancer, health professionals, including oncology nurses, should assess their psychosocial needs early and direct them to the appropriate support service [80].

Overall, the findings from this study have important implications for clinical practice from a multiprofessional perspective. By providing a valid and reliable tool to measure the extent to which patients with MPNs engage in self-care behaviors, we enable clinicians to identify self-care deficits during outpatient visits in a standardized way. By doing so, they will quickly recognize patients at higher risk of nonadherence and self-neglect and provide evidence-based information to address these issues. Moreover, health professionals, especially nurses, could implement targeted education interventions, such as motivational interviewing, to support patients in managing their disease and adopting healthy lifestyles. The SC-MPNI can also serve as an outcome measure in research studies aimed at evaluating the effectiveness of multicomponent educational interventions. By promoting self-care, patients may experience improved quality of life [34–37], better health status that helps them be fit for HSCT, fewer disease complications, lower emergency department visits, and a reduced risk of mortality [38, 39]. Although our study was conducted within the context of Italian patients with MPNs, similar self-care needs are likely present in the MPN community worldwide. Finally, the SC-MPNI can provide a basis for developing other cancer-specific tools to assess self-care in targeted populations.

5. Limitations

The results of this study should be considered in light of a few limitations. First, our sample consisted of patients with PV, ET, and MF. While these conditions are all classified as MPNs, they have specific features that may result in different patient symptoms and needs (e.g., low hemoglobin levels in MF and high in PV). Second, further testing is required to evaluate the test–retest reliability and responsiveness of the SC-MPNI, as well as its correlations with other variables. Additionally, although the items of the SC-MPNI were developed in both Italian and English, the English version has not undergone psychometric testing. Therefore, its validity should be assessed in a large group of English-speaking patients with MPNs. Finally, the SC-MPNI could be translated into different languages and tested in various countries to examine its cross-cultural validity.

6. Conclusions

Self-care is crucial for MPN patients as they need to consistently manage their condition and reduce the risk of cardiovascular and cancer-related issues. The results of this study show that the SC-MPNI is a valid and reliable self-report instrument for measuring self-care behaviors in individuals with MPNs. This inventory was specifically designed for MPN patients to comprehensively assess self-care activities, including self-care maintenance, self-care monitoring, and self-care management. Advancing research and education in this area will empower patients and enhance their quality of life.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Disclosure

All authors agree to be accountable for the content and conclusions of the article.

Conflicts of Interest

The authors declare no conflicts of interest.

Author Contributions

Valentina Biagioli: conceptualization, methodology, formal analysis, investigation, project administration, visualization, and writing—original draft. Alessandro Inzoli, Antonella Barone, and Giovanni Barosi: conceptualization, methodology, resources, supervision, project administration, and writing—review and editing. Alessandra Iurlo, Paola Guglielmelli, Francesca Palandri, Barbara Mora, Stefana Impera, Silvia Betti, Marco Santoro, and Vittorio Rosti: investigation, resources, and writing—review and editing.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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