

Associations between gender, disease features and symptom burden in patients with myeloproliferative neoplasms: an analysis by the MPN QOL International Working Group

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Appendix 1: MPN-SAF PRO Development and Validation

The MPN-SAF included existing questions from the Myelofibrosis Symptom Assessment Form (MF-SAF; fatigue, early satiety, abdominal pain, abdominal discomfort, inactivity, cough, night sweats, pruritus, bone pain, fever, weight loss and quality of life) and was expanded to include 'problems with concentration', 'difficulty sleeping', 'numbness/tingling', 'depression or sad mood' and 'problems with sexual desire or function'. All questions were scored on a scale from 0 (as good as it can be/absent) to 10 (as bad as it can be/worst-imaginable). The survey was drafted in English format and translated into other languages via an established Patient Reported Outcome translation method. Translation for each language involved three independent survey translations created by translators fluid in both English and the respective language requiring translation. A fourth translator then compares the three translator manuscripts to develop a consensus translation.

Upon completion of the survey, patients were recruited from academic, government-funded and private practice international medical centers. Patients were requested to self-complete the MPN-SAF during an office visit. Patients were also provided the opportunities to include additional symptoms omitted from the survey via open-ended questions.

Physicians who were blinded to patient responses were required to rank patient symptoms on the same 0-10 scale as well as document patient disease status including laboratory data, treatment history and prognostic scores. Anova F tests or 2-sample t tests were used to assess continuous variables whereas χ^2 tests were used to compare categorical variables. The relationships between variables was assessed using Pearson correlations. Patient scores between language groups were adjusted by disease type using general linear models and intraclass correlation coefficient (ICC) was analyzed on the basis of a 2-way ANOVA model.