

The experience of patients living with multiple myeloma:

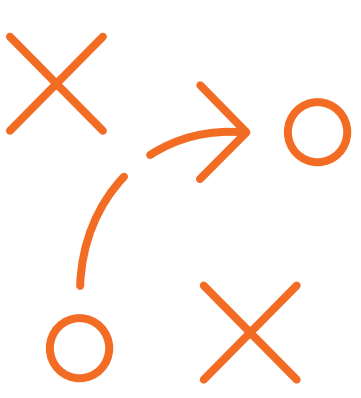
Unmet needs associated with diagnosis, treatment and living with the condition.

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Background

Multiple myeloma (MM) is a haematological malignancy characterised by the uncontrolled proliferation of neoplastic plasma cells within bone marrow (1). It accounts for ~10% of all haematological cancers (2). MM causes high mortality and disability (3) and is associated with the highest symptom burden and lowest health-related quality of life among patients with haematological cancers (4). Patients living with MM and their caregivers face the potential impact of the disease on their physiological, psychosocial and financial well-being (5).



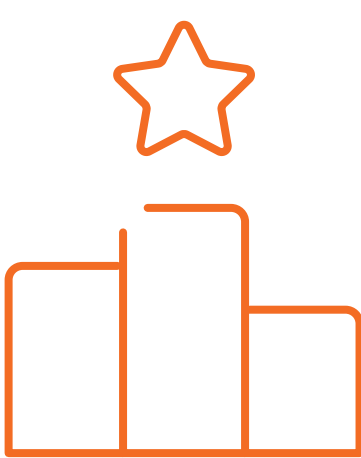
Objectives

This study sought to explore patients' experience of living with newly diagnosed MM (NDMM) during the first two years after diagnosis, to better understand diagnosis and therapeutic pathways from their perspective, focusing on the associated unmet needs at each stage. The study also aimed to identify patient's attitudes towards their condition and their perception of the burden placed on caregivers.



Methods

A 30-minute online survey of actively treated transplant eligible (T-e) and transplant ineligible (T-ie) patients with NDMM from France, Germany, Italy, Russia, Spain, United Kingdom and United States was conducted (June – December 2021). Patients' experiences of diagnosis and treatment initiation, the physical and psychological burden of living with NDMM and the perception of caregiver burden were documented. Responses were assessed on Numerical Rating Scales (NRS); Likert type scales, and the Eastern Cooperative Oncology Group (ECOG) performance status score. Descriptive statistics were calculated for numerical values. Mean percentage of patients selecting each statement or option was calculated for non-numerical responses while open ended questions were analysed qualitatively. Statistical tests used to analyse the observations from the same individuals [(dependent variables); T-tests (mean scores) or Z-tests (distributions)] as well as scores between different sub-groups [(independent variables); T-tests] were conducted at the 95% confidence level. Data was analysed with QPSMR CL 64 2021.2. Informed consent was obtained.

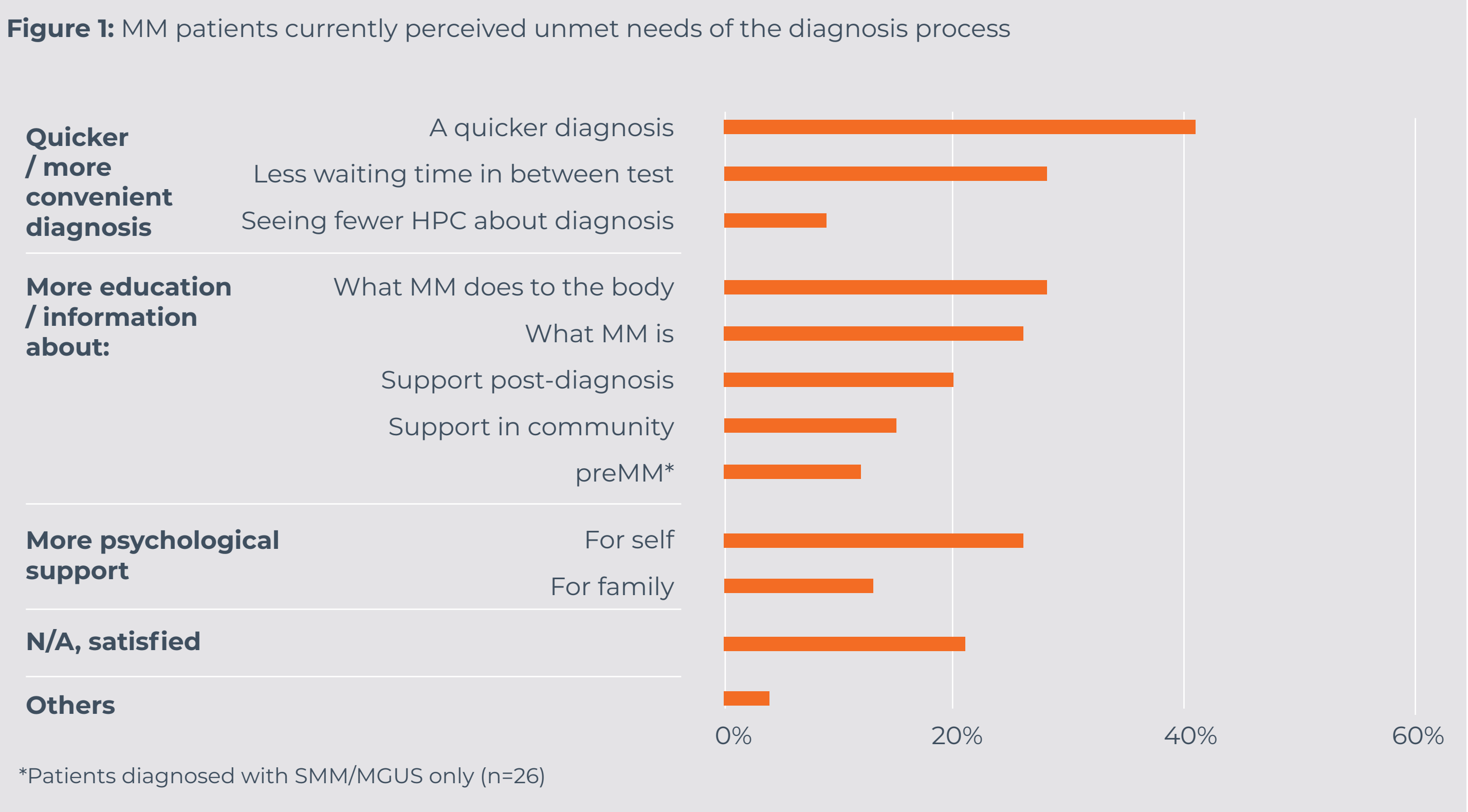


Results

94 patients with NDMM [15 months (mean), 12 months (median) post-diagnosis; 60%, T-e; 40%, T-ie; age 59.9 years (mean)] completed the survey. At diagnosis, 95% were psychologically distressed; 39% felt in the worst mental health state possible (NRS); 86% were physically impacted (mainly due to pain, reported by 55%); 35% were unable to work or undertake light activities (ECOG). Length of time since MM diagnosis varied between 4 and 24 months. A mean of 7.4 (range: 0 – 35) and 5.1 (range: 0 – 18) consultations for those who were / were not diagnosed with a MM precursor respectively, were needed before reaching the diagnosis.

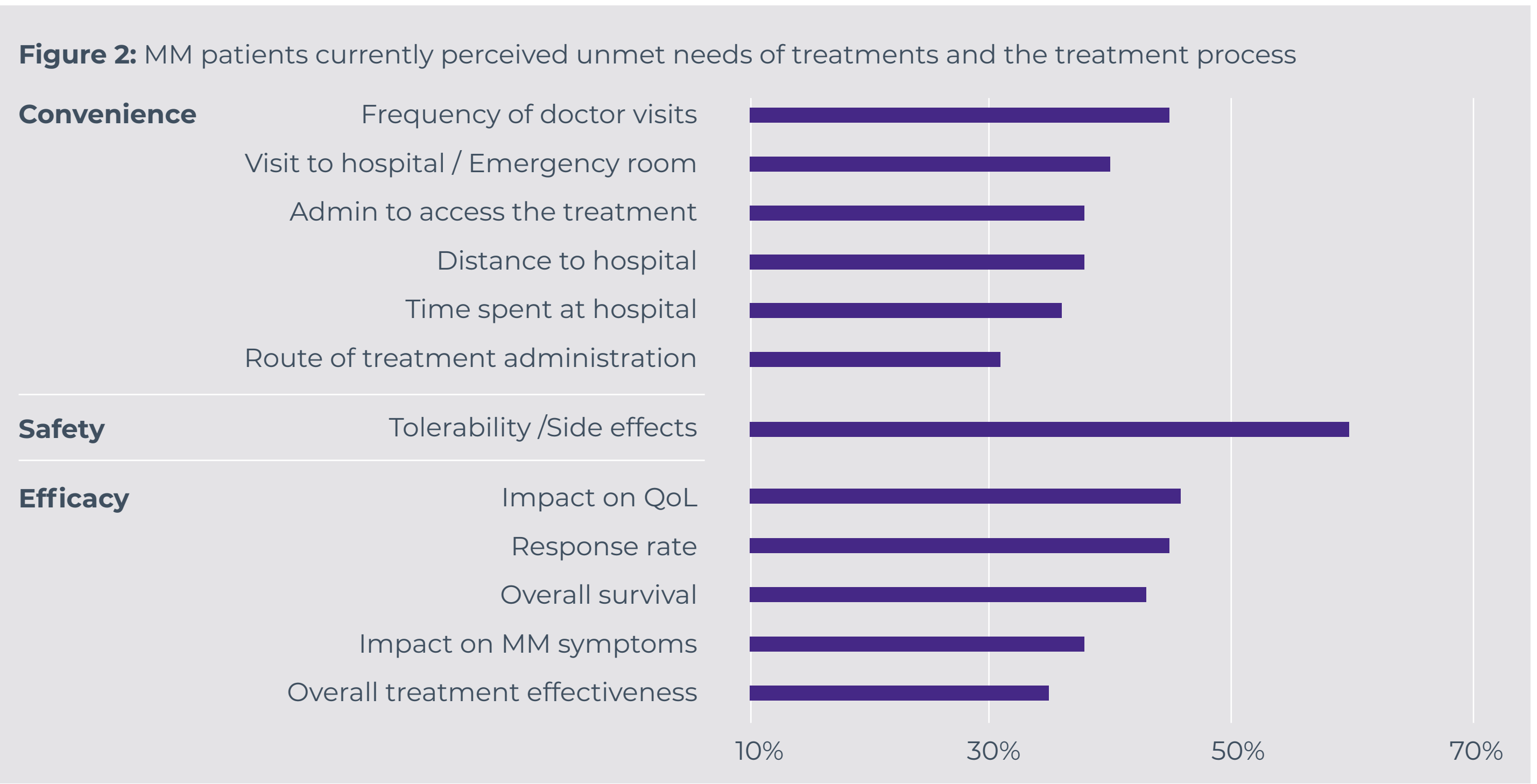
Unmet needs associated with diagnosis

A quicker diagnosis, shorter waiting time in-between tests, education on MM and its impact on the body, and psychological support were identified as key unmet needs at this stage (Fig. 1). At treatment initiation, 60% of patients felt involved in decision making, though only 43% were involved as much as they wanted and 20% were dissatisfied with the process. 26% felt overwhelmed by the different regimens.



Unmet needs associated with treatment

Once on treatment, 72% of patients still felt some form of psychological distress; including 49% who worried about the future and 13% who described their mental health as the worst it could be (NRS). Despite this ongoing psychological burden, 55% of patients had not accessed psychological support and 31% had never discussed it with a physician. 89% of patients were physically impaired; 26% were unable to work or undertake light activities (ECOG). 86% of patients on treatment reported at least one treatment unmet need (i.e., 60% reported tolerability issues, and 46%, reported quality of life impact; Figure 2).



89% of patients with NDMM received support from family, 75% of whom received this support daily. The support provided was predominantly emotional but also included practical factors such as housework, meal preparation and financial assistance. 55% of patients with NDMM felt their caregiver was highly impacted (NRS) by their caring role. Caregivers commonly reported experiencing worry about the future, limited social life and psychological distress; however, only 23% of families accessed psychological support.

Conclusions

Patients with NDMM and their caregivers are highly emotionally burdened by the disease. Whilst emotional burden improves after treatment initiation, physical burden and disruption to normal life persists even when patients are established on treatment. Quicker diagnosis, more tolerable treatment regimens, education and information on treatments and outcomes, quality of life improvement, and easily accessible psychological and social support for patients and caregivers are key unmet needs.

References
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