



THE BURDEN OF MYELOMA TREATMENT ROUTES AND LOCATIONS ON PATIENTS AND FAMILIES: INSIGHTS FROM A PAN-EUROPEAN SURVEY

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INTRODUCTION

With increasing numbers of myeloma treatments available and patient survival extending, myeloma patients may undergo multiple treatments over the course of their disease. Treatment specific factors such as the location, mode and frequency of administration, as well as the burden treatment places on the patient and their family, may influence decision-making and quality of life. Understanding myeloma patients' experiences of treatment is critical to enabling patient-centred care.

AIMS

This study aimed to:

1. Generate evidence on how myeloma patients and families feel about how, where and by whom myeloma treatments are administered.
2. Understand the differential impact of myeloma treatment routes and locations on patients and family carers.

METHOD

A pan-European online survey was distributed via a network of myeloma patient organisations in eight languages to gather:

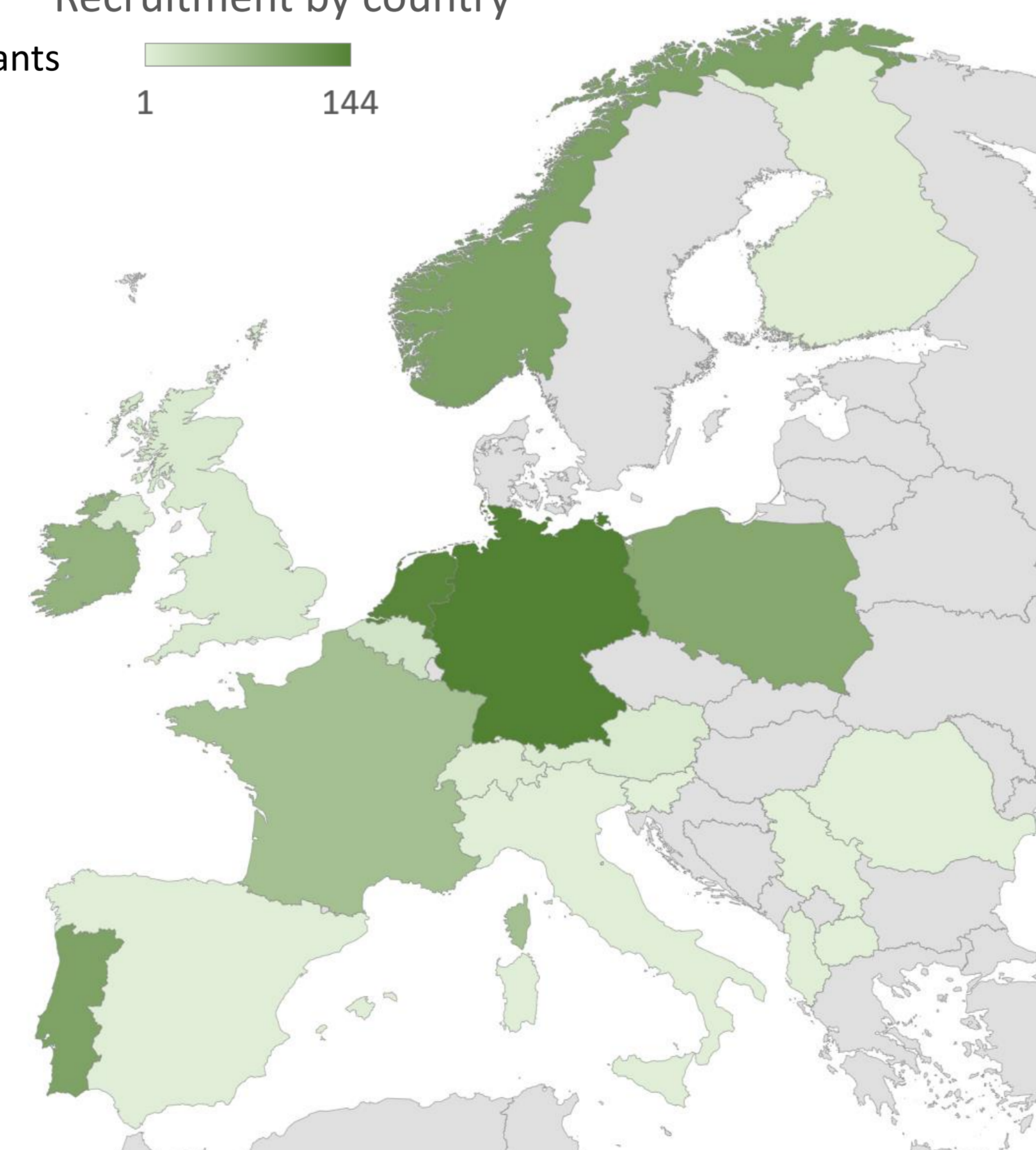
Demographics: including treatment experience, myeloma health state, and socioeconomic factors.

Attitudes to treatment: rated on a Likert scale from 1 (wholly negative) to 10 (wholly positive).

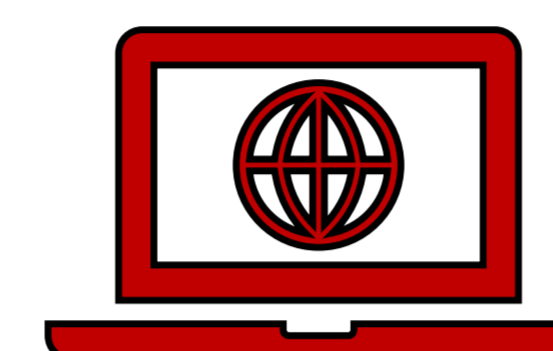
Treatment burden: frequency, effort, precautions, emotional, daily activity, family life, and financial were rated on a scale of 0 (no burden) to 10 (considerable burden) for each domain.

Total burden: for each treatment type was summed across all burden domains with a maximum possible score of 80 for patients, and 70 for family carers. Independent-samples median tests were conducted to compare patients' and carers' responses.

Recruitment by country
Number of participants 1 144



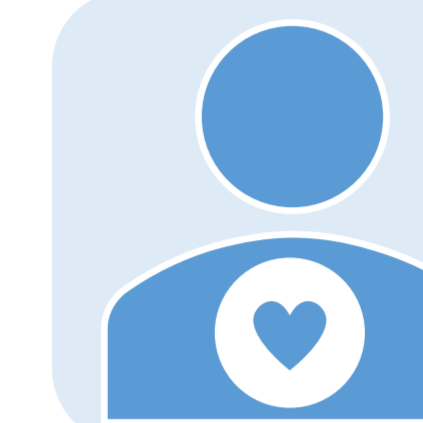
RESULTS



1070 responses
22 countries



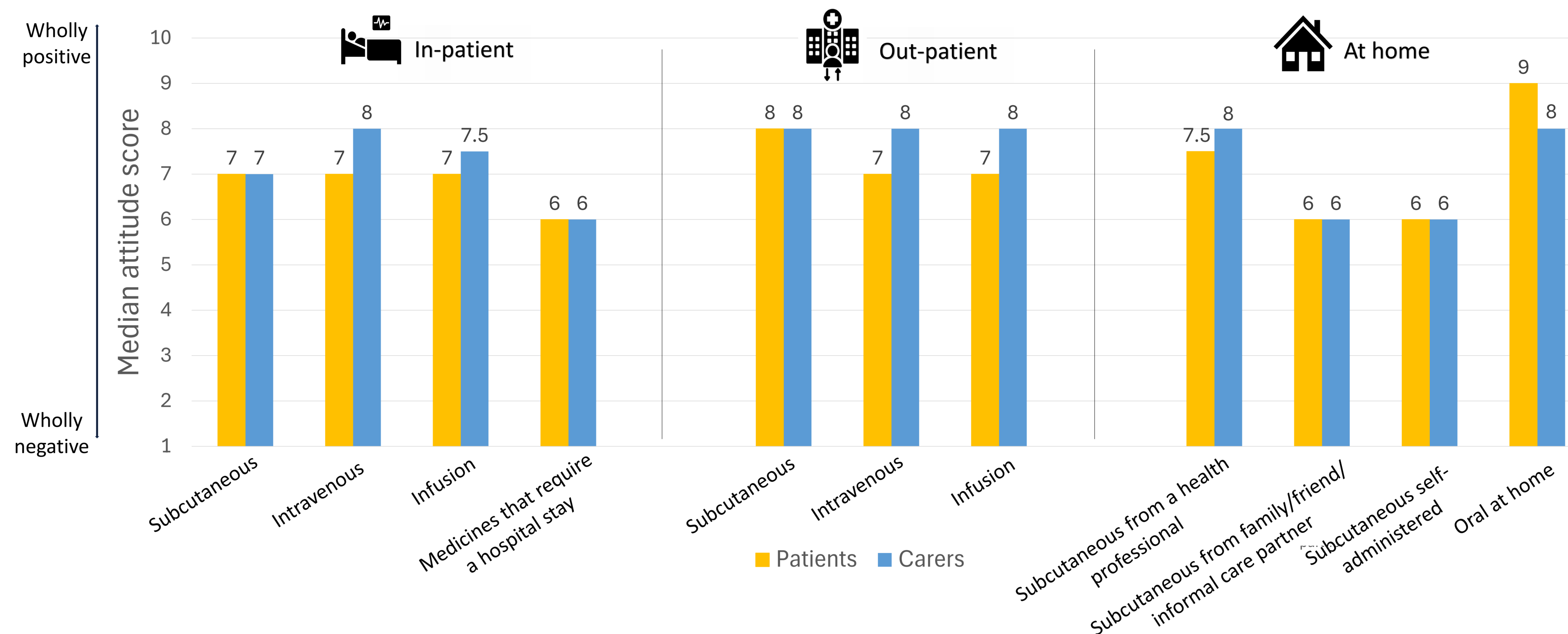
901 patients
53% female
Mean age: 62 years
Age range: 32-88



169 family carers
79% female
Mean age: 52 years
Age range: 21-79

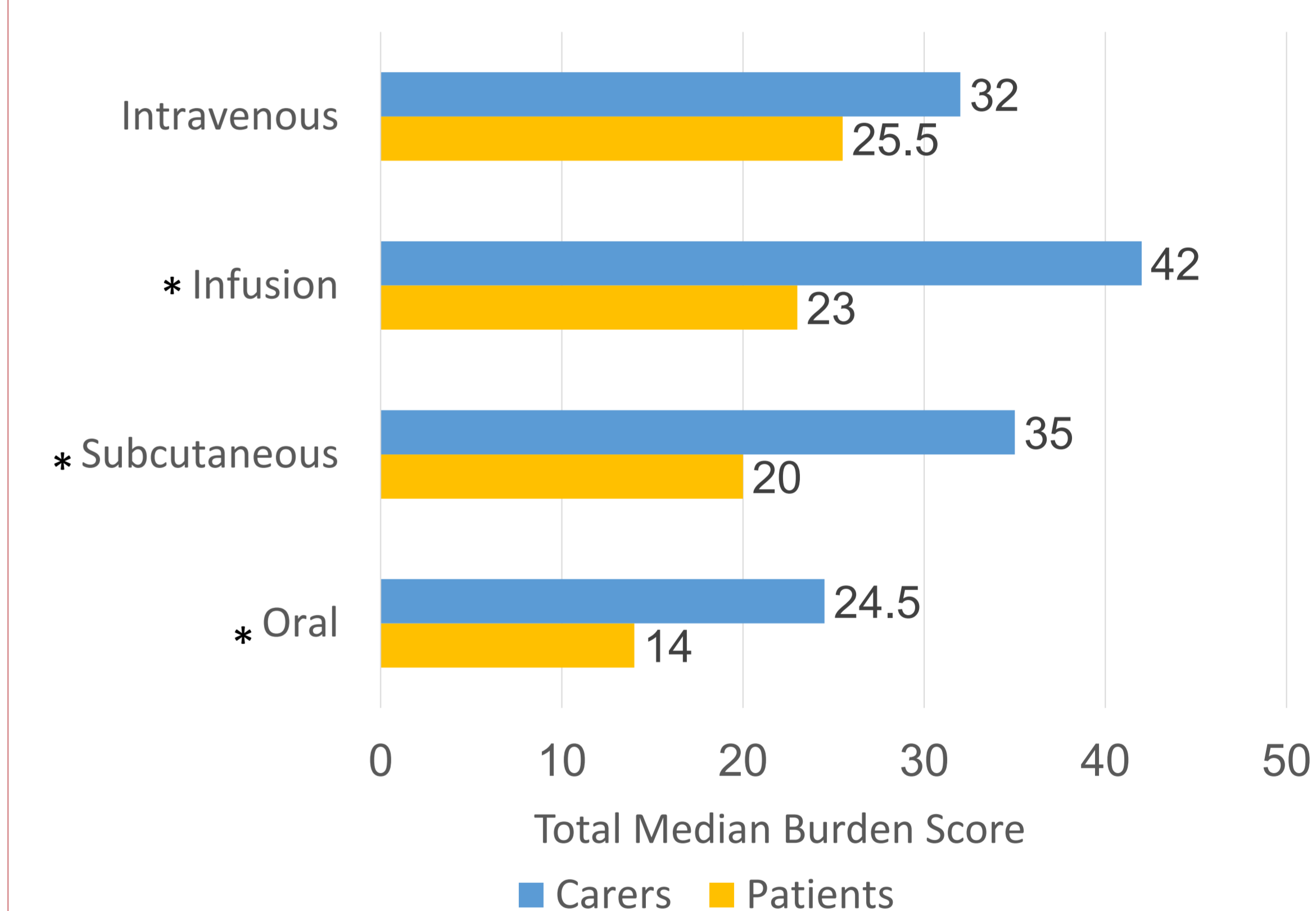
Attitudes to treatment types and locations

Attitudes to modes of administration were not significantly different for patients and family carers.



Treatment Burden

Family carers rated the burden significantly * higher than patients for oral (p.001 to p=0.14), subcutaneous (p<.001) and infusion (p<.001 to p=.006) treatments.



CONCLUSIONS

The results highlight the importance of considering both patient and family perspectives in treatment planning and support services. Healthcare providers should be aware of the impact of treatments beyond clinical efficacy, on patients' daily living, emotional well-being and quality of life. At-home treatments need to be carefully supported to ensure patients, and their families, are coping comfortably and lessen their daily burden. The administration of therapy a patient endures during their disease can have a profound effect on family members and there is a lack of dedicated, ongoing support for them. Discussions between myeloma patients, families and their health care teams should include information about treatment mode and location and prioritise patients' and families' needs to support shared decision-making.

ACKNOWLEDGEMENTS

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