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Myeloma patients' attitudes and perceived burden towards treatment routes and locations: insights from a European survey

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INTRODUCTION

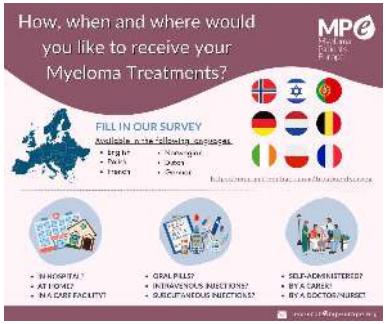
A diagnosis of myeloma has a big impact on patients' physical and emotional health[1]. Treatments for myeloma bring additional burden and impact on daily, family and work life[2]. Europe has seen a broad shift of resources from acute and in-hospital treatment to care in the community[3]. However, the evidence for how myeloma patients feel about, and the burden experienced from different routes and locations of treatment is limited.

AIM

To understand myeloma patients' attitudes and experiences of treatment routes, locations and treatment-burden and identify predictors of treatment burden.

METHOD

A pan-European survey was distributed via Myeloma Patients Europe's network[4] of patient organisations. The survey was available online in eight languages. Mann-Whitney U tests compared patients' attitudes by modality experience. Multiple linear regressions were conducted to predict burden of treatment type using working status (working or not working), living status (living alone or with someone), rurality and age.



RESULTS

Patient attitudes

Oral treatments at home

Median rating **9/10**

Subcutaneous treatments

Median rating with outpatient delivery **8/10**

Median rating in-hospital or at home by health professionals **7.5/10**

Median rating in-hospital or at home by self or family carer **6/10**

Patients with **experience** of specific treatment routes and locations had significantly different attitudes than those without.

Oral at home attitudes were more positive in patients with experience.

Conversely, attitudes towards **infusion** were less positive in patients with experience.

No differences for subcutaneous or intravenous treatment by prior experience

Responses

- 901 patients
- 22 European countries

At-home attitudes

Self/family administered

Health professional administered

Less positive attitudes

More positive attitudes

Predictors of burden

Age + 65

Working

Subcutaneous

Intravenous

Infusion

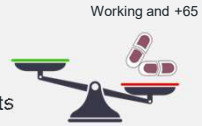
Oral

Burden

Greatest burden was reported from intravenous treatment (median 25.5/80). Least burdensome was reported from oral (median 14/80).

The hardest part of all treatments was reported to be how they affected **daily activities** and **daily life,** followed by the **emotional** burden and the burden on **family life**.

Multiple linear regression revealed that **oral** treatment burden was higher for patients who were **working** and patients **older** than 65 years old.



Patients **older** than 65 had significantly higher burden from **subcutaneous** and **infusion** treatments.

CONCLUSIONS

This research provides insights into myeloma patients' attitudes towards, and the burden experienced from different treatment modalities. Having evidence directly from patients on their perspectives on treatments is critical for efforts to improve patient-centred care and quality of life. Patients' attitudes towards at-home treatments suggests that there is some uncertainty felt towards self-administration and family-carer assisted administration. Undertaking at-home administration of myeloma treatments may create some worry and uncertainty and may not be the best option for every patient. Education and support for both patients and their families are needed to ensure patients feel comfortable and confident with at-home treatment.

These results show that burden of treatments is higher for patients who are 65 and older. With age comes the increasing risk of comorbidity and frailty, and greater susceptibility to some treatment-related toxicities and adverse events[5], which can add additional burden to patients and families. Treating clinicians need to appreciate that older patients may well have different treatment priorities, preferences and needs.

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