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Real-world experiences of family carers supporting people with myeloma

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MPE Myeloma Patients Europe

INTRODUCTION

The course of myeloma is often complex, typically involving several lines of treatment and alternating phases of remission and relapse[1]. Throughout this, friends and family can provide essential emotional, practical and logistical help[2]. The impact of myeloma can be cumulative over time and negatively impact emotional wellbeing and quality of life for caregivers[3]. Despite their crucial role, caregivers' own needs often remain overlooked in research and in support service provision[4]. There is an important gap in understanding and addressing the full impact of myeloma and treatments on carers.

AIM

This research aimed to generate evidence on the experiences of family carers supporting people with myeloma across Europe. A further aim was to examine the differential impact of myeloma administration types on carers.

METHOD

A pan-European online survey was distributed through Myeloma Patients Europe's (MPE) network of patient organisations. Eligible participants were over 18 and currently supporting someone diagnosed with myeloma who had received (or was currently receiving) at least one treatment.

The survey was available in eight languages and included items related to demographics, quality of life, types of support and the impact of myeloma treatment administration types.

Participants rated their own health and quality of life on a scale of 1(very poor) to 7 (excellent). The impact of treatments on the carer was rated across the domains frequency, effort, precautions, emotional, daily activity, family life and financial. Impact was rated on a scale of 0 (no impact) to 10 (considerable impact).

Online survey
Pan-European
8 languages

RESULTS

169 family carers

14 countries

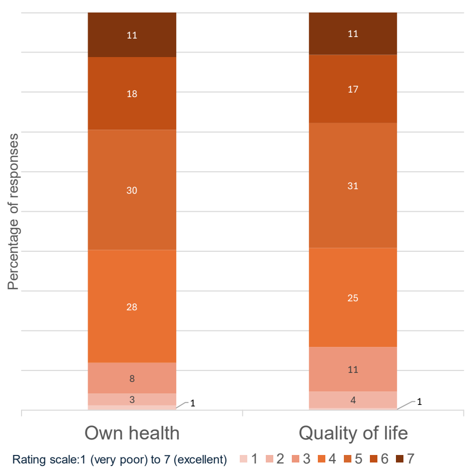
79% carers were women

76% had to adjust own work commitments

5 most common types of support provided

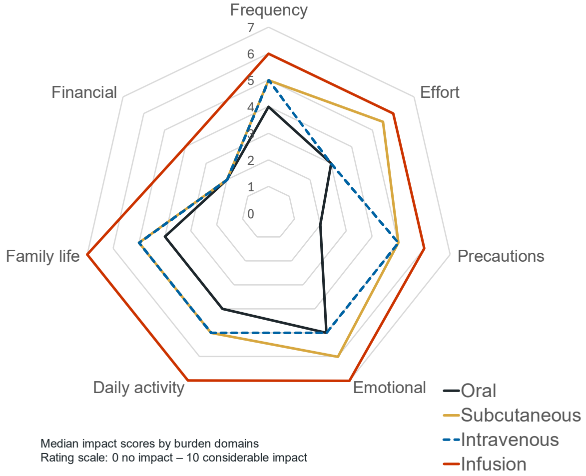
1. **Emotional support** with myeloma (talking and listening)
2. **Getting information** about their illness and treatments
3. Coming with them to **appointments**
4. Doing what I can to maintain the **quality of life** of my relative/friend
5. Helping them to manage their **symptoms and side-effects**

Health and quality of life ratings



The greatest proportion of ratings were around the **mid-point** of the scale; **58%** and **56%** rated **4 or 5** for health and quality of life respectively.

Impact of treatment administration types



Median impact scores by burden domains
Rating scale: 0 no impact – 10 considerable impact

The greatest impact overall was reported for **infusion** treatments and the least impact for **oral**. Across all treatment types, **emotional well-being** saw the highest rated impact.

CONCLUSIONS

Family carers play an extensive multi-dimensional role in myeloma care. Carers re-adjust their lives to ensure patients are supported, impacting their daily life, emotional health, work commitments and family life.

Many carers rated their own health and quality of life at the mid-point on the scale suggesting that they are experiencing strain.

Myeloma treatments were consistently reported to affect the emotional well-being, daily activity and family life of carers. With new advances in developing treatments, and a shift to at-home care, our findings show the need to further understand carer roles and their specific needs across different stages of the myeloma care pathway.

These findings point to the need for improved recognition, resources and systemic support tailored to the needs of people supporting someone with myeloma.

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