Patient Understanding of Multiple Myeloma

Findings of an Online Survey of Patient Perspectives on Communication, Information and Support

PUMMaCE
Patient Understanding of Multiple Myeloma and Communication Experiences

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AIM To explore patient understanding and experiences of communication, information and support in Multiple Myeloma.

INTRODUCTION

- Multiple myeloma (MM) is a complex haematological malignancy requiring specialised and evolving treatment, making effective communication essential for informed decision-making and patient-centred care[1].
- Patients' understanding and management of MM is influenced by the information provided by healthcare professionals (HCPs) and how this information is communicated.

METHODS

- UK-wide online survey (Jan-Apr 2025) of adults living with MM.
- Co-developed with HCPs and patient representatives to identify examples of gaps in communication or information that was challenging to discuss or understand.
- Explored understanding, experiences and gaps in communication and information (six sections with both fixed-choice and free-text response formats).
- Shared with myeloma charities, support groups, via social media and by word of mouth.
- Quantitative and qualitative data analysed using descriptive statistics and thematic analysis respectively.

RESULTS [2,3]

N = 138 UK Patients

Patient experiences reveal important gaps in understanding, but also clear opportunities to improve communication and support.

75% had never heard of MM prior to their diagnosis (104/138)

46.6% had discussed prognosis (56/120)

75% of prognosis discussions were initiated by patients (42/56)

Only 3.6% received a recording of the consultation (5/138)

84.8% satisfied with treatment and management discussions (117/138)

80.4% had access to a specialist nurse (111/138)

1. Demographics: 138/151 (91%) people completed the survey (81 female, age ranges between 31 – 90)

2. Symptoms before diagnosis:

Most frequent symptoms

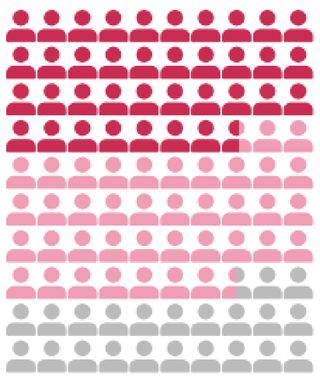
bone pain (46%)

tiredness (44%)

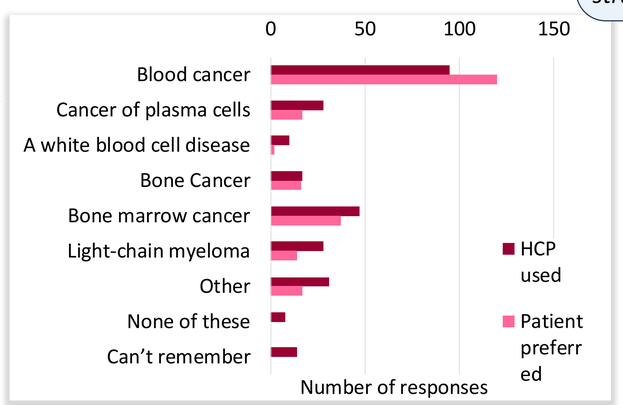
dark pink = 3 or more (37%)

light pink = 1 or 2 (40%)

grey = no symptoms (22%)



3.Terms to describe multiple myeloma: graph shows the phrase the patient said the health professional used and patients' preference.



Gaps in understanding myeloma

Diagnosis

- 49.3% (n=68) felt well-informed about MM and its treatment since diagnosis.
- 51.4% (n=71) were confused about the diagnostic terms such as *paraproteins or light chains*.

Prognosis

- Some acknowledged that questions about prognosis were difficult to answer, but there was the desire to know in order to make informed decisions about the future.

"Timescales and prognosis are something that is still uncertain and even after two stem cell transplants and ongoing maintenance, there are no time scales for when you're going to die. I struggle with this at times" (male, 51-60y)

HCP Interactions

"I have found my haematology consultant and the clinical navigator to be very reassuring when I have voiced concerns. I have felt listened to by them" (female, 51-60y)

Examples of positive and negative free-text quotes

+ "Being easy to contact"
+ "Listening"
+ "Being clear and honest"
+ "Responding to emails and phone calls"

- "Using multiple terms for things such as autograft for autologous stem cell transplant and plasma cell neoplasm for cancer cells is confusing"
- "Saying 'myeloma is the good cancer, if I was going to choose one it's what I would choose as there are lots of treatment options.' It downplays what you are going through"

Key themes from free-text responses

Helpful Communication

- Clear and honest explanations
- Time to ask questions
- The use of lay language

"Explaining the disease in simple terms and drawing diagrams." Female, Age 61-70

Unhelpful Communication

- Multiple terms
- A lack of facts
- Not answering questions directly

"Using multiple terms such as plasma cell neoplasm for cancer cells was a bit confusing.'" Female, Age 51-60

Barriers to Understanding

- Use of complex terminology
- Unexplained clinical results

"Sent me letters with information in that I had no context for e.g. your bone marrow is 70% myeloma, your light chains are 2300." Male, Age 31-40

CONCLUSIONS

- Patients identified persistent communication challenges surrounding diagnosis, prognosis and complex treatment information.
- Complex language used routinely by HCPs can contribute to distress and misunderstandings.
- Opportunities were identified to enhance communication throughout the patient journey.
- Findings will inform the development of educational resources to support more effective communication between patients, their families and HCPs.

REFERENCES

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