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Patients' and caregivers' understanding of Multiple Myeloma: A scoping review

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Keywords: multiple myeloma, patient , caregiver , understanding, perception , caregiver understanding of multiple myeloma, understanding of multiple myeloma patient, understanding of multiple myeloma, multiple myeloma patient, multiple myeloma, myeloma patient, myeloma diagnosis, perception of myeloma diagnosis, myeloma, complex haematological malignancy with advanced medical terminology, complex haematological malignancy, group of haematological malignancy, haematological malignancy, prognosis, caregiver understanding, regarding diagnosis

Abstract

Objective: The objective of this scoping review is to synthesise the existing literature on the knowledge and understanding of multiple myeloma patients and their informal caregivers regarding diagnosis, prognosis, and treatment options.

Introduction: Knowledge plays a critical role in various aspects of disease management and overall health. Multiple myeloma is a complex haematological malignancy with advanced medical terminology and a variety of treatment options which can be overwhelming for both patients and caregivers. Understanding your disease greatly impacts informed decision-making and health outcomes, however, there is a notable lack of literature examining the degree of understanding that myeloma patients and their family possess. This review will synthesise existing data on patient and caregiver understanding of multiple myeloma.

Inclusion criteria: The review will consider studies reporting on multiple myeloma or a group of haematological malignancies, where myeloma is a subgroup of the population. The concept involves patients or their informal caregivers' understanding, knowledge, or perception of myeloma diagnosis, prognosis or treatment. The context can be within any primary, secondary or tertiary setting.

Methods: The search strategy will aim to locate both published and unpublished studies using the databases MEDLINE, CINAHL, and APA PsycINFO, as well as grey literature. Only studies published in English will be eligible for inclusion, and the review will adhere to the JBI methodology. Two reviewers will independently screen and extract data, with any discrepancies resolved through discussion. The findings will be combined in a narrative synthesise utilising tabulation and thematic analysis.

Background

1 Each year in the UK approximately 5,900 people are diagnosed with multiple myeloma (MM) and thanks to continuous advancements in treatment, life expectancy of myeloma patients has substantially improved (1). Current research shows that patients and their families struggle with understanding the uncertainty associated with having an incurable but treatable condition (2). NHS England's National Cancer Patient Experience Survey consistently reports that haematological patients lack complete understanding of their diagnosis. The 2021 data showed that only 63% of MM patients fully understood their diagnosis (3). There is little published evidence on patients' and their families' understanding of multiple myeloma. The aim of this scoping review is to understand if current literature addresses understanding and perception of myeloma and if future research in this area could benefit patient wellbeing.

Review Objective

2 To review the literature that has explored the knowledge and understanding of diagnosis, prognosis and treatment of multiple myeloma patients and their informal caregivers.

Review Question(s)

3 1. What do patients with myeloma and their informal caregivers understand about their diagnosis, prognosis and treatment?
2. What factors influence patient/caregiver understanding of myeloma?

Methods

4 **Design**
This is a scoping review. We will follow the Joanna Briggs Institute (JBI) method for Scoping Reviews, paired with the PRISMA extension for Scoping Reviews (PRISMA-ScR) (4).

Search results will be collated in Endnote and screening will be managed via the web-based tool, Rayyan. Duplicate references will be removed in Rayyan prior to screening and search dates will be recorded to enable updates as and when required.

Search Strategy
The search strategy will aim to locate both published and unpublished studies. Backwards and forwards citation searches will be conducted on included papers.

All search strategies will be run in the following databases: the terms will be modified as appropriate for each database:
- MEDLINE (via OVID)
- CINAHL (via EBSCO)
- PsycINFO (via EBSCO)

Sources of unpublished studies/ grey literature to be searched include:
- Cancer charities
- TRIP Medical Database
- ProQuest Dissertations and Theses Global

Evidence selection
The first screen of included databases will review the title and abstract of all records from the search. Both qualitative and quantitative papers will be assessed by two reviewers (RH/VS). Reviewers will assess each study independently, using the inclusion criteria described above. Disagreements will be resolved through discussion, and records only excluded if both reviewers agree to this. Following title and abstract review, the same methods will be used to assess the full text of retrieved papers for inclusion. Reasons for exclusion of sources of evidence at full text that do not meet the inclusion criteria will be recorded and reported in the scoping review. The reference lists of all included studies will also be screened for potentially relevant articles that meet inclusion criteria. The same inclusion / exclusion criteria will be applied to grey literature hits. The results of the search and the study inclusion process will be reported in full in the final scoping review and presented in a PRISMA flow diagram (4).

Data extraction and synthesis
A data extraction tool developed in Microsoft Excel, will be piloted on the first three papers before utilised for all included papers. Summary data for each included paper will be extracted by one reviewer into a standardised data extraction table, including: authors, year of publication, participants' characteristics (i.e., age etc.), study characteristics (i.e. study design), methodology, analysis, findings and conclusions.
For qualitative studies, details of the methods of each study with quotes, themes, and concepts pertinent to our research question will be extracted (RH). The findings of each qualitative paper will be coded and
then grouped together into broad themes through discussion (RH/VS). The qualitative and quantitative data will then be brought together in a narrative synthesis using tabulation and thematic analysis.

Qualitative data: A data extraction form will be developed, using Excel to record the following:
- Study characteristics: author, year, location, population
- Research aim
- Methodology (e.g. interviews, focus groups)

- Themes related to understanding and perception of myeloma
- Quotations or narrative descriptions that reflect perceptions of myeloma or understanding of diagnosis/prognosis/treatment options

Quantitative data: A standardised data extraction form will be developed, using Excel to record the following:

- Study characteristics: author, year, location, population size
- Study design (e.g., cross-sectional, cohort)
- Outcome measures related to perception/understanding of prognosis or treatment
- Statistical measures (e.g., means, percentages, standard deviations, confidence intervals, p-values) relating to perception of myeloma).

Data presentation

Summary Tables: Data will be presented in a table and grouped into thematic categories based on study characteristics such as participants, methodology, and data collection technique.

Graphs and Charts: quantitative findings may be illustrated using bar charts, pie charts, or forest plots, such as the proportion of participants reporting satisfactory understanding of their diagnosis.

Narrative Summary: Data will be interpreted to identify commonalities and differences in themes across all selected studies, with findings being represented in a descriptive and narrative format - quotations may also be included to support thematic findings.

Inclusion/Exclusion Criteria

5

- **Participants:** patients and informal caregivers
- **Concept 1:** Multiple Myeloma
- **Concept 2:** Diagnosis
- **Concept 3:** Prognosis
- **Concept 4:** Treatment
- **Concept 5:** Patient outcomes (e.g. understanding, knowledge, and informational needs)
- **Context:** Primary, secondary, or tertiary care
- Limit to adults and English language

	A	B
	Inclusion Criteria	**Specification**

	A	B
	Population	Multiple Myeloma adult patients - both transplant-eligible and transplant-ineligible Family and/or friends of a multiple myeloma patient Caregiver of a multiple myeloma patient
	Context	Primary, secondary, or tertiary care
	Outcomes	Multiple Myeloma patients and informal caregivers' knowledge and understanding of diagnosis, prognosis and treatment at various stages and timepoints of care.
	Study design	Qualitative and Quantitative studies (no restriction on study design) Primary data
	Date	No date restriction
	Language	English language
	Exclusion criteria	Studies in relation to other cancers Studies addressing monoclonal gammopathy of undetermined significance, smouldering multiple myeloma, or primary amyloid light chain amyloidosis Studies including non-adult participants (under 18) Studies where participants are solely healthcare professionals Studies reporting secondary data, letters, editorials, or conference abstracts Studies which do not report participant understanding of diagnosis, prognosis or treatment

Table 1. Inclusion/Exclusion criteria

*Studies reporting on haematological malignancies with myeloma as a subgroup of the population, will be considered.

Protocol references

(1) *Myeloma - an introduction*, *Myeloma UK*. Available at: https://www.myeloma.org.uk/library/myeloma-an-introduction/ (Accessed: 25 September 2024).
(2) Howell, D.A. et al. 'Incurable but treatable: Understanding, uncertainty and impact in chronic blood cancers—a qualitative study from the UK's Haematological Malignancy Research Network', PLOS ONE, 2022; 17(2). doi:10.1371/journal.pone.0263672
(3) NHS England *2021 survey results*, *National Cancer Patient Experience Survey*. Available at: https://www.ncpes.co.uk/2021-survey-results/ (Accessed: 25 September 2024).
(4) Peters MDJ, Godfrey C, McInerney P, Munn Z, Tricco AC, Khalil, H. Scoping Reviews (2020). Aromataris E, Lockwood C, Porritt K, Pilla B, Jordan Z, editors. JBI Manual for Evidence Synthesis. JBI; 2024. Available from: https://synthesismanual.jbi.global. https://doi.org/10.46658/JBIMES-24-09

Appendices: Search strategy
Supplementary file 1: Search strategy developed for MEDLINE (OVID) and adjusted for other databases

	A
	exp *Multiple Myeloma/
	Myeloma.mp.
	or/1-2
	exp *Patients/
	patient*.mp.
	exp *Caregivers/
	caregiver*.mp.
	(''family member'' or ''member of family'').mp.
	partner.mp.
	friend.mp.
	carer*.mp.

	A
	or/4-11
	exp *Diagnosis/
	pathway.mp.
	Refer*.mp.
	Detect*.mp.
	Symptom*.mp.
	exp *Prognosis/
	relapsing-remitting.mp.
	Relaps*.mp.
	Remitting.mp.
	Remission.mp.
	exp *therapeutics/
	''side effect''.mp.
	or/13-24
	exp *Comprehension/
	Understand*.mp.
	Comprehen*.mp.
	Interpret*.mp.

	A
	Insight.mp.
	Familiar*.mp.
	View*.mp.
	Perception.mp.
	Aware*.mp.
	Perspective.mp.
	Concern.mp.
	Knowledge.mp.
	''Information* need''.mp.
	''Patient information''.mp.
	or/26-39
	3 and 12 and 25 and 40
	limit 41 to english language

* produced 2754 returns

Supplementary file 2: Grey literature sources with search terms

	A	B
	Source	**Search terms applied**
	ProQuest	Myeloma AND Understanding

	A	B
	TRIP medical	Myeloma AND patient knowledge
	Mednar	Myeloma AND patient understanding
	Open access theses and dissertations	Myeloma AND patient knowledge
	Myeloma UK	Patient understanding of Myeloma
	Blood Cancer UK	Myeloma and patient understanding
	UK Myeloma Society	Myeloma and patient understanding
	CRUK	Myeloma and patient understanding
	Macmillan	Myeloma and patient understanding

*First 100 hits per source were screened