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UNMET NEEDS RELATED TO EXPERIENCES OF MYELOMA PATIENTS AND THEIR CAREGIVERS AND POTENTIAL SOLUTIONS: A SYSTEMIC LITERATURE REVIEW

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INTRODUCTION

The phrase “unmet need” has not yet been comprehensively explored in terms of patient and caregiver experience for multiple myeloma (MM). This systematic review addresses this gap by highlighting unmet needs and proposed solutions related to experiences of MM patients and their caregivers and provides direction for future research.

METHOD

- We followed the PRISMA guidelines to search PubMed, Embase, and ClinicalTrials.gov using the relevant keywords and MeSH terms related to MM and “unmet” needs without restrictions.
- They were further manually screened to select the studies reporting unmet needs related to patient and caregiver experience to develop a timeline and to identify the article types and the solutions proposed.

CONCLUSIONS

- Our study identified diverse unmet needs and potential solutions related to experiences of MM patients and caregivers largely focusing on the need for holistic care. The dynamic nature of these needs should be considered while addressing gaps with future research.

RESULTS

- 72/1214 article included (46% abstracts and 54% manuscripts).
- The use of the term “unmet” increased through the years [2001-2009 (1%), 2010-2017 (38%), and 2018-2024 (61%)].
- 53% cross-sectional, 15% retrospective, and 14% prospective (including two phase II trials) studies.
- 88% reported on patient experience; 12% additionally included caregiver experiences.
- The Majority (54%) reported supportive/holistic care and quality of life of MM patients including disease education, symptom management, psychological, and financial/social support as the unmet needs.
- Palliative/end of life care (6%) and addressing cachexia (2%), fatigue (2%), and frailty (3%) were among others.
- Distinct needs reported after 2018 were supportive care during the COVID-19 pandemic (4%), patient/caregiver quality of life/wellbeing peri-ASCT (4%) and digital/eE-health (4%).
- The Most common solution suggested was long-term/individualized supportive care services to address the holistic needs (23%).
- Other solutions proposed by individual studies included: developing a short form of Survivor Unmet Needs Survey scale, early introduction of palliative care, NT-proBNP to assess frailty, Falls Risk Questionnaire to assess fall risk, comprehensive geriatric assessment, patient education utilizing social media, digital life coaching, E-health to target unmet needs, etc.

Unmet needs reported in the published articles	No.	Solutions reported in the published articles to address the unmet needs
2001-2009 (Total 1)		
Information on disease progression to patients	1	Knowing the patient's information strategy to communicate with patients (Hoff et al.)
2010-2017 (Total 27)		
Supportive needs and QoL including information about disease, complex care, care co-ordination, holistic care, emotional/practical/educational support, mental health treatment and education	18	Long-term supportive care services (Molassiotis et al.); Individualized supportive care (Hulin et al.); Holistic care (Ware et al.) Addition of a specialist nurse/other health professional to improve patients' transition to living with MM (Monterosso et al.) Assistance with accessing relevant financial support and services such as online and telephone peer support programs (Hall et al.) Addressing psychological distress and unmet supportive care needs experienced during treatment to improve QoL (Oberoi et al.) Separate studies of the experiences of people with the different hematological cancer subtypes (Oberoi et al.) Survivorship care plans for good information provision (Oerlemans et al.); Specialist care coordination to navigate treatment (King et al.) Special service team to address complex care needs (Hayes et al.) Sheffield Profile for Assessment and Referral for Care(SPARC) questionnaire (Boland et al.) Using holistic needs assessment (HNA) to identify concerns and needs (Hewlett et al.) Use of antidepressants in patients with depression to improve outcomes (Chung et al.)
Understanding of Palliative and End of Life care	1	Further research to promote understanding of end-of-life care (Howell et al.)
Measures for unmet needs	1	Developing a short form of Survivor Unmet Needs Survey (SUNS) scale (Campbell et al.)
Fatigue	1	Asking ‘Were you tired’ as a screening tool to identify patients experiencing an unmet need concerning fatigue (Madsen et al.)
Frailty assessment	2	NT-proBNP as a biomarker for newly diagnosed MM patients to assess frailty (Milani et al.) Falls Risk Questionnaire (FRQ) to assess fall risk (Wildes et al.)
Unmet needs of Patient & caregiver experience around MM diagnosis	1	Accurate evaluation of the emotional and practical difficulties of patients and caregivers (Ferretti et al.)
Unspecified unmet needs of patients in general	3	The MM Steering Committee (MYSC) to address those unmet needs (Gertz et al.) Psychiatric intervention in the multidimensional approach (Goncalves et al.)
2018-2024 (Total 41)		
Supportive needs and QoL including disease education/informational, symptom management, emotional, psychological, financial support, lifestyle intervention and social situation	13	Cilta-cel to improve patients’ health related QoL (Weisel et al.); Social media for patient-centric education and support programs (Lin et al.) Utilizing a screening tool & integrating Palliative Care & Psychology into VA oncology (Martin et al.) Flexible, person-centered approaches and nurse led care to comprehensive survivorship care (Monterosso et al.) Psychosocial Providers & payment reform advocates (Doherty et al.); Mobile application for symptom tracking and management (Leblanc et al.) Supporting emotional needs tailored for older and younger caregivers (Pereira et al.) Addressing emotional needs and psychological morbidity to promote QoL (Pereira et al.) Further research and tailored intervention to address uncertainty in illness (Langmuir et al.); Lifestyle change support (Kerschner et al.)
Supportive care in low & middle income countries	1	More studies in to assess the unmet needs in low and middle income countries (Raghavan et al.)
Supportive care: a urban/rural care access perspective	1	Systemic strategies for assisting support persons via financial assistance & travel subsidies in rural areas (Lynagh et al.)
Supportive care needs in geriatric patients	1	Comprehensive geriatric assessment (CGA) (Handforth et al.)
Unmet psychosocial & informational needs, supportive care during COVID pandemic	3	Patient-reported surveys via online portal, like HealthTree to assess the patient community and result in hypothesis-generating research questions to enhance patient outcomes (Sweeney et al.)
Cachexia	1	Providing clinical attention to cachexia (Vagnildhaug et al.)
Wellbeing during the acute peri-ASCT period	1	Digital life coaching (DLC) to improve patient experience after ASCT in MM (Banerjee et al.)
Healthcare services post ASCT for patients and caregivers	2	Educational resources & innovative therapies to reduce the disease burden of MM and enhance the QoL of patients and caregivers (Hansen et al., Hansen et al.)
End of life & palliative care	2	A modified palliative care model: palliative care is introduced from the diagnosis, provided alongside care of curative/life-prolonging intent, and subsequently leads to death & bereavement care/cure & survivorship care (Cheng et al.) Further studies including qualitative studies & prospective trials to optimize & integrate palliative care utilization, identify best time frames for palliative care utilization, & address disparities in care (Mohyuddin et al.)
Patient knowledge/perception of palliative care	1	Educate patients about palliative care to overcome barriers to palliative utilization in HSCT (El-Jawahri et al.)
Treatment accessibility for RRMM patients in UK	1	The Early Access to Medicines Scheme (EAMS) to provide early access of new therapies in RRMM (Fermahan et al.)
Digital Health	2	Application of digital health (Jagannath et al., Banerjee et al.)
Pain management following biopsy	1	Histone post-translational modifications as potential therapeutic targets for pain management (Torres-Perez et al.)
Rehabilitation needs	1	Considering patients' ability to use coping strategies when screening for rehabilitation needs (Sonsby et al.)
Caregiver burden, psychological distress, information needs, QoL, supportive needs for carer	5	Frequent monitoring of psychosocial well-being & signposting to holistic support (Sheridan et al.) Further research on treatment, caregiver burden, and handling appointments (Lyall et al.) Early supportive relationships between carers & health care (Cormicon et al.) Interventions to satisfy supportive care needs, to reduce caregiving burden, and to strengthen social support ties (Lv et al.)
Unspecified unmet needs of patients in general	5	E-health to target unmet needs and improving the quality of their care and life (Botto et al.) Short-Form Survivor Unmet Needs Survey (SF-SUNS) (Pereira et al.); Using smartphones to address unmet needs (Guttierez et al.) Intervention programs addressing information & emotional needs, raising awareness and (Pereira et al.)