



Parallel Journeys, Similar Challenges, and Different Reasons:

Navigating Life Challenges in Multiple Myeloma from the Perspectives of Patients and Caregivers

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Introduction

Both MM patients and caregivers experience physical challenges, psychological distress, and social isolation. However, there is limited evidence to develop supportive interventions that consider the perspectives of both groups. **Objective**

To identify life challenges and gaps faced by MM patients and their caregivers.

Methods

- Study design: A mixed-methods study
- Participants: 40 pairs of adult MM patients and their primary caregiver
 - Recruited from a university-affiliated cancer center in Seoul, Korea from October 2021 to March 2022.
- Measurement: Semi-structured in-depth interview guide, The Distress Thermometer (DT) and the WHOQOL Brief Version
- Statistical analysis: thematic analysis

Spiritual

Uncertainty

Changing life goals

Hopelessness

Family-relationship

Feeling guilty to family

Challenges in MM patients and caregivers Different reasons by patients and caregivers Fear of Cancer Recurrence Decreased physical strength Lack of information about MM Negative perception about cancer patients Caregiver Endless caregiving Anxiety due to the possibility of patient's recurrence Lack of their personal time Financial burden Underestimate caregiving demand Patients' self-confidence about their health/situation Having stress and reminding death or negative experience of MM Feeling drifting apart from family role due to MM Conflict with family members Caregiver Avoiding communication about MM Misunderstanding/unrealistic expectation on patients Caregivers' confidence about patient's condition/situation Complaints about the burden of caregiving alone Financial burden Avoiding argument that might cause emotional distress to patients Lack of care to other family members

Results

Characteristics of participants and QOL

	Patients N = 41	caregiver N = 21	caregiver N = 17
Age, median (IQR)	69.0 (57.0–73.0)	66.0 (52.0–69.0)	48.5 (43.3–49.8)
Sex, male	25 (61.0)	7 (33.3)	10 (58.8)
Current job	Retired/sick leaving (36.5%)	Homemaker (42.9%)	Employed (76.5%)

Characteristics	Spousal Patients caregiver		Adult child caregiver p-value	
	N = 41	N = 21	N = 17	
WHOQOL-BREF, mean (SD)				
Physical health	60.7 (11.2)	78.4 (12.8)	74.6 (10.1)	< 0.001
Psychological health	65.0 (10.8)	73.3 (12.3)	69.6 (8.3)	0.017
Social relationships	63.4 (8.2)	70.5 (10.5)	71.4 (7.7)	0.001
Environment	63.7 (8.8)	72.9 (13.0)	67.1 (10.1)	0.006
Distress thermometer mean (SD)	42 (25)	3 9 (2 8)	3 1 (2 5)	0.314

Discussion

Both patients and their caregivers encountered various challenges in their daily lives, with different reasons for those challenges.

Recognizing these different perspectives is crucial for developing effective interventions.

Tailored support systems that address the specific needs of both patients and caregivers are essential for improving overall well-being throughout the MM journey.

References

- Cormican, O. and M. Dowling, Living with relapsed myeloma: Sy mptoms and self-care strategies. J Clin Nurs, 2018. 27(7-8): p. 1
- Johnsen, A.T., et al., Health related quality of life in a nationally re presentative sample of haematological patients. Eur J Haematol, 2009. 83(2): p. 139-48.
- Wang, B., et al., How adult children experience and cope with the ir parents' diagnosis of multiple myeloma: A qualitative exploratio n. Eur J Oncol Nurs, 2024. 70: p. 102604.
- Mazanec, S.R., et al., A family-centered intervention for the transi tion to living with multiple myeloma as a chronic illness: A pilot st udy. Appl Nurs Res, 2017. 35: p. 86-89.

