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Parallel Journeys, Similar Challenges, and Different Reasons: Navigating Life Challenges in Multiple Myeloma from the Perspectives of Patients and Caregivers

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Research Article

Keywords: Multiple myeloma, quality of life, survivorship, dyad study, caregiver's needs, caregiving burden, communication

Posted Date: October 12th, 2025

DOI: https://doi.org/10.21203/rs.3.rs-7467643/v1

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Additional Declarations: No competing interests reported.

Abstract

Background

With advances in multiple myeloma (MM) treatment and increased patient survival rates, supportive care for patients and caregivers has become increasingly important. This study aimed to identify life challenges and gaps faced by MM patients and their caregivers.

Methods

We conducted a mixed-methods study. Qualitative interviews and quantitative surveys were conducted with MM patients (aged > 18) and their caregivers at a university-affiliated cancer center in Seoul, Korea, from October 2021 to March 2022. Semi-structured in-depth interviews were conducted with each patient and caregiver separately. Quality of life (QOL) and cancer-related distress were assessed using the Distress Thermometer (DT) and the WHOQOL Brief Version.

Results

Of total, 41 patients and 38 caregivers (21 spouses and 17 adult children) participated in the study. Patients and spousal caregivers had similar DT scores (mean, 4.2 and 3.9; SD, 2.5 and 2.8). Due to the relapsing and recurring nature of the disease, patients encountered various challenges in their daily lives, including reduced physical and psychological function, diminished spiritual well-being, and strained family and social relationships. Primary caregivers reported facing almost identical challenges. However, although both patients and caregivers experienced similar difficulties, the underlying reasons for these challenges differed. For patients, the major causes were directly related to cancer and their declining health. In contrast, the caregivers' challenges were primarily rooted in the burden of caring for the patient and managing the needs of the family.

Conclusion

While MM patients and their caregivers experience similar challenges, the underlying reasons differ significantly. Patients primarily face the physical and emotional burden of the disease, whereas caregivers deal with the demands of caregiving and financial stress. Tailored support systems that foster mutual understanding and address the specific needs of both patients and caregivers are essential for improving overall well-being throughout the MM journey.

Trial registration: N/A

BACKGROUND

Multiple myeloma (MM) is an incurable systemic hematologic malignancy that most patients experience in a relapsing/remitting manner (1, 2). The mean age at diagnosis is between 65 and 70 years, and the combination of MM and age-related physical decline exacerbates patients' physical health, contributing

to diminished health-related quality of life (HRQOL) (3). MM patients often experience various disease and treatment-related symptoms such as bone pain, neuropathy, and fatigue, which are associated with a decline in their role functioning (4–6). In addition to these physical challenges, many patients experience psychological distress owing to uncertainty about the future, concerns about death, feelings of hopelessness, and social isolation (4, 7).

Similarly, caregivers of MM patients encounter poor HRQOL and high levels of psychological distress, primarily owing to the heavy caregiving burden, constant worry about loved ones, and uncertainty about the future (8, 9). Following diagnosis, caregivers often undergo significant life changes as they prioritize patient care, often at the expense of their own well-being (10, 11). They frequently report losing personal time and privacy and feeling the dual burden of providing care while managing their own psychological distress, which leads to unmet physical and psychosocial needs (10, 11).

With advances in MM treatment and increased patient survival rates, supportive care for patients and caregivers has become increasingly important. However, there is limited evidence to guide the development of supportive interventions that consider the perspectives of both groups. Furthermore, the reasons for differences in HRQOL and unmet needs between the two groups remain poorly understood. This study aimed to identify life challenges and gaps faced by MM patients and their caregivers, specifically exploring lifestyle, physical, psychological, family relationship, and spiritual aspects of health.

METHODS

Study design and participant recruitment

We conducted a mixed-methods study to record the experiences of MM patients and their caregivers. Our goal was to recruit 40 patient-caregiver pairs. Qualitative interviews and quantitative surveys were conducted at a university-affiliated cancer center in Seoul, Korea, from October 2021 to March 2022. Patients were eligible if they were 1) aged > 18 years; 2) diagnosed with MM; and 3) able to read, write, and speak Korean. Patients with serious psychiatric disorders were excluded. As older patients or patients with disease recurrence might have different experiences, we used a stratified sample based on age (<70 vs. ≥70) and disease status (newly diagnosed vs. relapse/refractory). Primary caregivers, as designated by the patients, were invited to participate once the patient consented. The same inclusion and exclusion criteria were applied to the caregivers. Physicians introduced the study to both the patients and caregivers during outpatient visits. If patients attended outpatient appointments without their caregivers, trained researchers contacted the caregivers via telephone with the patient's consent. Informed consent was obtained from all the participants (IRB approval: SMC 2021-05-145). Patients and caregivers could choose the interview method either face-to-face or via telephone.

Data collection and measurement

To collect qualitative data, we developed a semi-structured interview guide with open-ended questions, based on a thorough literature review. This review identified several barriers and unmet needs related to physical, psychosocial, and spiritual well-being in both MM patients and their caregivers. The interview guide included questions addressing 1) the experience of living with MM after diagnosis, 2) changes in life (physical, psychosocial, and spiritual) following diagnosis, and 3) difficulties, challenges, and unmet needs related to MM. Each interview lasted between 60 and 90 min and was conducted in a single session by two trained interviewers with backgrounds in behavioral science and oncology nursing. To maintain consistency, all interviews began with a common question, "Can you describe your experience with MM and your general health status after diagnosis?" Patient and caregiver interviews were conducted separately to ensure openness and honesty.

In addition to qualitative interviews, we conducted a quantitative survey to support the qualitative findings. The survey assessed quality of life (QOL) and cancer-related distress using the National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) version 1.0 and the World Health Organization Quality of Life: Brief Version (WHOQOL-BREF). The NCCN DT consists of a single item that rates the level of distress on an 11-point scale, ranging from 0 (no distress) to 10 (extreme distress) (12, 13). The WHOQOL-BREF measures QOL across four domains: physical health (seven items), psychological health (six items), social relationships (three items), and environmental health (eight items). Domain scores are calculated by averaging the items within each domain, and raw scores are transformed into a range of 0–100. Higher scores indicate better QOL, whereas scores below 60 are considered indicative of poor QOL (14).

Data analysis

The interviews were audio-recorded and transcribed verbatim. Five researchers, including the interviewers, read and analyzed the transcripts. For the qualitative data analysis, we employed thematic analysis, a method used to systematically identify, organize, and provide insights into the patterns of meaning and themes across a dataset (15). We followed six thematic analysis steps: familiarizing with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final report. After individual familiarization with the data through repeated reading, the researchers independently performed the initial coding and categorization of the themes. A final group discussion was conducted to ensure trustworthiness and consistency of the analysis.

For the quantitative survey, we performed a descriptive analysis of sociodemographic and clinical data. Comparisons between groups were performed using the chi-square test and analysis of variance. Given the small sample size, p-values were calculated using the Fisher's exact test. All analyses were conducted with R (version 4.1.2; R Foundation for Statistical Computing, Vienna, Austria), and p-values < 0.05 were considered significant.

RESULTS

Characteristics of participants and quantitative survey

Among the 80 participants, 41 were patients and 39 were caregivers (21 spouses, 17 adult children, and one parent caregiver). Parent caregivers were excluded from qualitative and quantitative analysis because of their small sample size. The median age of patients was 69 years (IQR: 57.0–73.0); spousal caregivers were 66 years (IQR: 52.0–69.0), and adult child caregivers were 46 years (IQR: 43.3–49.8, Table 1). Notably, 71.2% of the child caregivers did not live with the patients and primarily focused on financial support. One out of three patients had already retired or was on sick leave (36.5%). Most spousal caregivers were homemakers (42.9%), while most adult child caregivers were employed (76.5%).

Patients reported poor overall QOL than caregivers, although adult child caregivers scored lower on the psychological health and environmental domains as the patients (mean, 69.6 and 65.0, 67.1 and 63.7, respectively) (Tables 2 and Figure 2). Patients and spousal caregivers had similar DT scores (mean, 4.2 and 3.9; SD, 2.5 and 2.8, respectively; Table 2).

Qualitative interview

Lifestyle challenges

Both patients and caregivers faced significant lifestyle changes after diagnosis. They reduced their physical activities, participated in fewer social events, and altered their life priorities and future plans. Patients commonly experience reduced activities owing to fear of physical harm, particularly bone fractures, as advised by their physicians. Many patients reported being overly cautious, which limited their physical and social interactions. Moreover, some patients experienced heightened sensitivity and lower self-esteem, often avoiding social activities to conceal their cancer diagnosis.

Similarly, caregivers, especially spouses, experienced lifestyle changes primarily because their caregiving responsibilities left little time for personal or social activities. Some caregivers expressed a loss of motivation, while others avoided social settings because of the stress of discussing the patient's condition.

"I've become more introverted since my MM diagnosis. I try to be careful and avoid activities that might cause fractures." (P17, 43 years old, female, RRMM)
"I stopped meeting friends because I didn't want to explain my husband's cancer diagnosis." (C12, 69 years, female, spouse)

The diagnosis led to a profound re-evaluation of life priorities for both groups. Patients struggled with the loss of their pre-diagnosis lifestyle as career aspirations and family roles became secondary to prioritizing their health. Similarly, caregivers, particularly spouses and adult children, experienced a drastic shift in focus. Spouses who had been looking forward to family well-being and retirement, and adult children advancing in their careers suddenly faced the demanding responsibility of caregiving. This shift often meant altering or relinquishing personal and family plans. The uncertainty surrounding a patient's health adds an additional layer of anxiety, making it difficult for caregivers to plan for the future and forcing them to prioritize caregiving.

"I had to quit my studies after my husband's diagnosis because I didn't know when he'll need me again." (C07, 55 years old, female, spouse).

"Before my mom's diagnosis, my career was my top priority. Now, I care for her full-time." (C09, 49 years old, female, adult child)

Physical challenges

Although patients reported worse physical health than caregivers in the quantitative survey, both groups experienced significant physical challenges following the MM diagnosis (Table 2, Figure 1). Patients attributed their physical struggles to disease- and treatment-related symptoms such as bone and joint pain, decreased appetite, nausea, diarrhea, and numbness or tingling. Many patients also limited physical activity because of the fear of injury, particularly fractures, during outdoor activities.

Caregivers reported physical challenges stemming from the burden of caregiving. Most focused on the patient's recovery at the expense of their own health, leading to physical decline. Caregivers with pre-existing medical conditions often reported worsened physical well-being after taking on caregiving duties.

"I've had serious numbness and tingling in my feet and hands and have been on painkillers for years." (P08, 57 years, female, RRMM)

"I used to go to physiotherapy for my back pain, but after my father's diagnosis, I couldn't find the time. If I don't care for him, no one will." (C30, 46 years, female, NDMM, adult child)

Psychological challenges

Both patients and caregivers experienced psychological problems, including worry, anxiety, fear of cancer recurrence (FCR), depression, and loneliness. Patients reported heightened anxiety and depression when physical symptoms such as fatigue and decreased appetite emerged, fearing these as signs of cancer relapse. The nature of MM, with its potential for relapse, makes it difficult for patients to dismiss concerns about death, further intensifying their distress.

Caregivers also faced psychological challenges, largely driven by the uncertainty of caregiving responsibilities. Spousal caregivers, especially homemakers, encountered financial strain when patients took sick leave, thereby reducing household income. Adult children, who are often responsible for covering medical costs such as transportation and medication, also faced financial burdens, along with anxiety and FCR.

"When I feel tired, I fear it's a sign of recurrence. I try not to think about cancer, but it is always on my mind." (P15, 78 years, F, RRMM)"

"My dad doesn't know how much I spend monthly on his hospital visits. It's about $400–$500.". (C31, 49 years, F, NDMM, adult children)"

Both groups experienced increased loneliness and depression owing to reduced social activity. Patients tended to avoid social situations because of the fear of harm, which deepened their isolation. Caregivers, particularly those with limited personal time, felt isolated as their social networks diminished. This loneliness was not only a byproduct of physical limitations or caregiving responsibilities but also a profound emotional consequence of their altered lifestyles.

"I feel weaker than before the diagnosis, so I avoid crowded places." (P04, F, patient, 60 years, RRMM)"

"I used to be very social, but since my mom's diagnosis, I've cut back on activities. It's hard not to feel isolated." (C15, 53 years, F, RRMM, adult children)"

Family-relationship challenges

Following the diagnosis, both patients and caregivers encountered challenges in family relationships, including conflict, reluctance to discuss the diagnosis, and feelings of guilt. Patients felt misunderstood by caregivers who assumed that they had returned to normal life despite ongoing struggles with the effects of cancer and FCR. They stressed the need for ongoing support from their families. Patients often believed that only others with MM could truly understand their situation.

""My family thinks I've returned to normal, but they don't understand the emotional toll. I cried a lot behind their backs." (P20, F, patient, 48 years, RRMM)"

""After the diagnosis, my husband and I started drifting apart. He used to help a lot, but things have changed."(P08, F, patient, 57 years, RRMM)"

Caregivers felt that they had a better grasp of the patient's condition because of their continuous support, but this often led to frustration when their efforts went unrecognized. Spousal caregivers, in particular, reported feeling undervalued, which sparked conflict. Over time, some caregivers expressed resentment regarding their responsibilities.

"I take care of him 24/7 because I'm the only one who can." (C13, 51 years, F, RRMM)

"I did everything for her, but now I'm frustrated because she isn't trying to get back to normal. I'm done." (C08, 56 years, M, RRMM, spouse)

Conflicts also arose with other family members over the uneven burden of caregiving, particularly among the adult children. These tensions strained family communication.

"My siblings thank me for caring for Dad, but I feel burdened. Is this all my responsibility?" (C31, 49 years, F, NDMM, adult children)"

Patients and caregivers both tended to avoid conversations about MM, fearing that it would cause distress or lead to conflict. Spousal caregivers occasionally attempted to initiate discussions about

symptom management, but the patients often reacted sensitively, leading to further withdrawal.

“My partner and I don’t talk about cancer because we don’t want to worry about relapse or dying." (P03, 68 years, M, RRMM)”

"I don’t even want to talk about cancer. My son gave me a book about it, but I was too scared to read it." (P37, 70 years, M, NDMM)”

Physical challenges after a diagnosis also caused patients, particularly primary earners, to feel detached from their family roles. Caregivers, especially young children, felt guilty about the impact of caregiving on other family members.

"I wish I wasn’t sick so my wife could go out and enjoy life with me." (P14, 69 years, M, RRMM)”

"I feel guilty that my priorities shifted from my kids to my husband." (C33, 42 years, F, NDMM, spouse)”

Spiritual challenges

Both patients and caregivers faced spiritual challenges marked by uncertainty, changing life goals, and feelings of hopelessness. A common sentiment was, "I cannot be sure of my future, and I cannot plan for it." Patients often expressed hopelessness owing to FCR and a decline in physical strength. Many patients felt uncertain about managing their long-term symptoms and emotional distress, attributing their struggles to a lack of information about MM. The combination of weakened physical health and the threat of recurrence reinforced their identity as cancer patients, deepening their frustration.

Caregivers, particularly spouses, experienced similar spiritual challenges, grappling with the uncertainty of when their caregiving roles might end. The incurable and relapsing nature of MM fueled anxiety about the future, prompting a reevaluation of life goals. The relentless demands of caregiving, coupled with financial strain, also led to feelings of hopelessness, as caregivers were forced to adjust or abandon their original life plans.

"The hardest part is not being able to dream or plan for the future." (P17, 43 years, M, RRMM)”

DISCUSSION

In this study, we conducted dyadic interviews with MM patients and their primary caregivers to explore the challenges and difficulties faced during survivorship. Due to the relapsing and recurring nature of the disease, patients encountered various challenges in their daily lives, including reduced physical and psychological function, diminished spiritual well-being, and strained family and social relationships. Primary caregivers reported facing almost identical challenges. However, although both patients and caregivers experienced similar difficulties, the underlying reasons for these challenges differed. For patients, the major causes were directly related to the cancer and their declining health. In contrast, the

caregivers' challenges were primarily rooted in the burden of caring for the patient and managing the needs of the family.

Both patients and caregivers had substantially changed lives and experienced similar challenges due to the MM diagnosis. We found that both groups encountered issues related to decreased physical function, physical symptoms, psychological distress, financial toxicity, and social relationships. These challenges are likely linked to the nature of MM, which requires ongoing treatment, frequent relapses, and the management of both immediate and long-term side effects (16). The mean age of MM patients is approximately 65 years, and they often require long-term care, which heavily involves caregivers (17). Caregivers, particularly spouses, may face equal or greater physical and psychological challenges as they provide direct care and emotional support while also managing their own well-being (9). This is especially true for spousal caregivers who typically live with patients and often contend with their own health issues. In our study, the mean patient age was 66 years, and 55% of the caregivers were spouses, many of whom had limited physical function due to comorbidities.

In our study, both groups had to reduce their physical activity and had worse physical function after diagnosis. According to the previous studies, MM patients had fatigue, injuries, pain, coexisting health conditions, and decline in physical functioning due to age, which are barriers to physical activity (18). Similarly, most patients in our study avoided physical activity because of fatigue and concerns about potential injuries, which further contributed to poor physical function. Caregivers, on the other hand, reduced their physical activities because of their caregiving responsibilities. Many caregivers reported having little time or energy for themselves due to the burden of caregiving. This is particularly true for primary family caregivers, who devote most of their time to caring for patients (19). Spousal caregivers, especially those of an older age who live with the patient and provide 24/7 care, faced greater challenges in maintaining physical activity (20). While some interventions exist to improve physical activity in MM patients (21), there is a lack of interventions focused on caregivers. Developing programs that encourage caregivers to prioritize their health, along with guidelines for managing daily life and physical activity for both patients and caregivers, is essential.

Our findings revealed that cancer patients and their caregivers receive less social support, largely because of limited social activities following diagnosis. This reduction in social engagement is accompanied by cancer stigma, which further exacerbates isolation and is contrary to the social support needed. Specifically, MM patients are more likely to become housebound and avoid socializing, primarily owing to fear of physical harm and the stigma associated with cancer (22). Similarly, our patients reported refraining from social activities because of the fear of physical harm, reduced self-esteem, and diminished motivation. Notably, cancer stigma has emerged as a significant barrier to social interaction among these patients, contributing to poor self-esteem, anxiety, depression, and a lack of social support (23).

The demanding nature of caregiving responsibilities leaves caregivers with little time for personal activities, including social engagement, which is vital for their emotional and psychological health (24–

26). Beyond the physical and emotional tolls, caregivers also experience cancer-related stigma, which further exacerbates their isolation (26). Our caregivers often refrained from participating in social activities to avoid conversations about the patient's MM diagnosis. Despite these challenges, interventions aimed at reducing the negative attitudes and stereotypes associated with MM are limited. Additionally, there is a significant lack of information on the social support available to both MM patients and their caregivers (27). It is essential to develop and provide comprehensive information and social support programs for both patients and caregivers to reduce the stigma associated with MM and encourage them to reconnect with others and their communities, as they did before the diagnosis.

In our study, both the patients and caregivers encountered significant challenges in their family relationships following the MM diagnosis. Although both groups shared similar experiences, the underlying reasons differed. Patients, coping with the physical and emotional toll of MM, often felt isolated within their families (28) believing that only others with the same diagnosis could truly understand their struggles, particularly regarding FCR. This perceived lack of understanding led them to withdraw from family interactions, avoid discussions about their condition, and feel guilty over the burden they placed on their loved ones (29, 30). This sense of being misunderstood further deepened their isolation.

Conversely, caregivers saw their role as essential and believed that their continuous support provided them with a deeper understanding of the patient's condition. However, their efforts often went unrecognized, leading to frustration. Spousal caregivers, who typically bore the heaviest caregiving burden, reported more frequent conflicts due to intense emotional and physical strain (7). Adult child caregivers faced additional challenges in balancing caregiving with other responsibilities, including financial pressures that were often hidden from the patient (31).

These differing perspectives highlight the complex dynamics of post-diagnosis family relationships and emphasize the need for interventions that address both the emotional and practical challenges faced by patients and caregivers. Improving communication and mutual understanding could help alleviate the relational and financial tensions that arise in the context of MM.

Both patients and caregivers in our study experienced conflict, communication avoidance, and feelings of guilt within the family. Caregivers, often family members such as spouses or adult children, reported a higher burden, likely because of their central role in providing direct care and emotional support. As noted in previous research, family-engaged caregivers tend to have a deep understanding of the patient's condition, which they attribute to continuous involvement and support (19, 32, 33). However, this close involvement can also lead to increased conflict and misunderstandings between patients and caregivers (8). Most existing studies on relationship problems have mainly focused on spousal caregivers, consistently showing that MM patients and their partners experience significant conflict and feelings of guilt towards each other (26, 34). Conversely, our study found that adult child caregivers faced similar challenges. This highlights the importance of developing family-relationship interventions that support both MM patients and all types of family caregivers.

Limitation

This study had several limitations. First, the sample size was relatively small; however, the mixed-methods approach, which combined in-depth qualitative interviews with quantitative data, helped address this limitation by offering a more comprehensive understanding of the challenges faced by MM patients and their caregivers. This study was conducted at a single university-affiliated cancer center in Seoul, Korea, and cultural or regional factors may limit the generalizability of the results to other populations. Second, although the cross-sectional design captured the experiences of patients and caregivers at a single point in time, this approach may not fully reflect the dynamic and evolving nature of the challenges faced throughout the disease trajectory. Longitudinal studies could offer more comprehensive insights into how these challenges and their impacts on family relationships change over time. While the mixed-methods approach allowed for a deeper exploration of patient-caregiver dynamics, the reliance on self-reported data introduces the possibility of response bias. Participants may have underreported or exaggerated certain challenges due to social desirability or recall bias. Additionally, the study focused primarily on spousal and adult child caregivers, potentially overlooking the experiences of other family members or friends who also play significant caregiving roles. Including a more diverse range of caregivers in future studies could provide a broader understanding of caregiving dynamics within families.

IMPLICATION AND CONCLUSION

In conclusion, this study demonstrated that while MM patients and their caregivers experience similar challenges, the underlying reasons differ significantly. Patients primarily face the physical and emotional burden of the disease, whereas caregivers deal with the demands of caregiving and financial stress. Recognizing these different perspectives is crucial for developing effective interventions. Tailored support systems that foster mutual understanding and address the specific needs of both patients and caregivers are essential for improving overall well-being throughout the MM journey.

Declarations

Ethical approval and consent to participate

This study adhered to the Declaration of Helsinki and was approved by the Institutional Review Board of Samsung Medical Center (SMC). All informed consent was obtained from all the participants (IRB approval: SMC 2021-05-145)

Consent for publication

Not applicable

Availability of data and materials

All data generated or analysed during this study are included in this published article

Competing interests

YoungJu Park is current employees of Janssen Korea LTd. Remaining authors have declared that they have no conflicts of interest to disclose.

Funding

This work was supported by the Janssen Korea Ltd [grant numbers: 68284528MMY4008].

Authors' Contributions

All authors contributed to the concept and design of this study. SK, YP, NK, JP and GB contributed to data analysis and interpretation. SK was a major contributor in statistical analysis and writing the manuscript. All authors read and approved of the final manuscript.

Acknowledgements

There is nothing to declare.

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Tables

Table 1. Characteristics of patient and caregiver dyads (N = 79)

Characteristics	Patients	Caregiver		P-value
		Spouse	Adult child	
	N = 41	N = 21	N = 17	
Age, *median (IQR)*	69.0 (57.0–73.0)	66.0 (52.0–69.0)	48.5 (43.3–49.8)	
Sex				0.103
Male	25 (61.0)	7 (33.3)	10 (58.8)	
Female	16 (39.0)	14 (66.7)	7 (41.2)	
Living with patient, *yes*	—	20 (95.2)	5 (27.8)	
Comorbidities, *yes*	32 (78.0)	—	—	
Recurrence or Refractory, *yes*	21 (51.2)	11 (52.3)	8 (47.1)	0.814
Marital status, *married*	36 (87.8)	21 (100.0)	15 (88.2)	**0.016**
Education				0.091
High school graduate or less	23 (56.1)	7 (33.3)	4 (23.5)	
College or University graduate	18 (43.9)	14 (66.7)	13 (76.5)	
Current Job				**0.023**
Unemployed	5 (12.2)	1 (4.8)	1 (5.9)	
Employed or self-employed	8 (19.5)	8 (38.1)	13 (76.5)	
Homemaker	13 (31.7)	9 (42.9)	2 (11.8)	
Retired/sick leaving	15 (36.5)	3 (14.3)	1 (5.9)	
Monthly household income ($), *mean (SD)*	3320.7 (2750.8)	3660.19 (1990.94)	4980.82 (2810.33)	0.090
Residence area				0.226
Seoul and metropolitan	22 (53.7)	11 (52.4)	13 (76.5)	
Rural	19 (46.3)	10 (47.6)	4 (23.5)	

Table 2. Comparison of WHOQOL-BREF and Distress Thermometer (NCCN DT) scores between patients and caregivers (N = 79)

Characteristics	Patients	Spousal 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)*	4.2 (2.5)	3.9 (2.8)	3.1 (2.5)	0.314

Figures

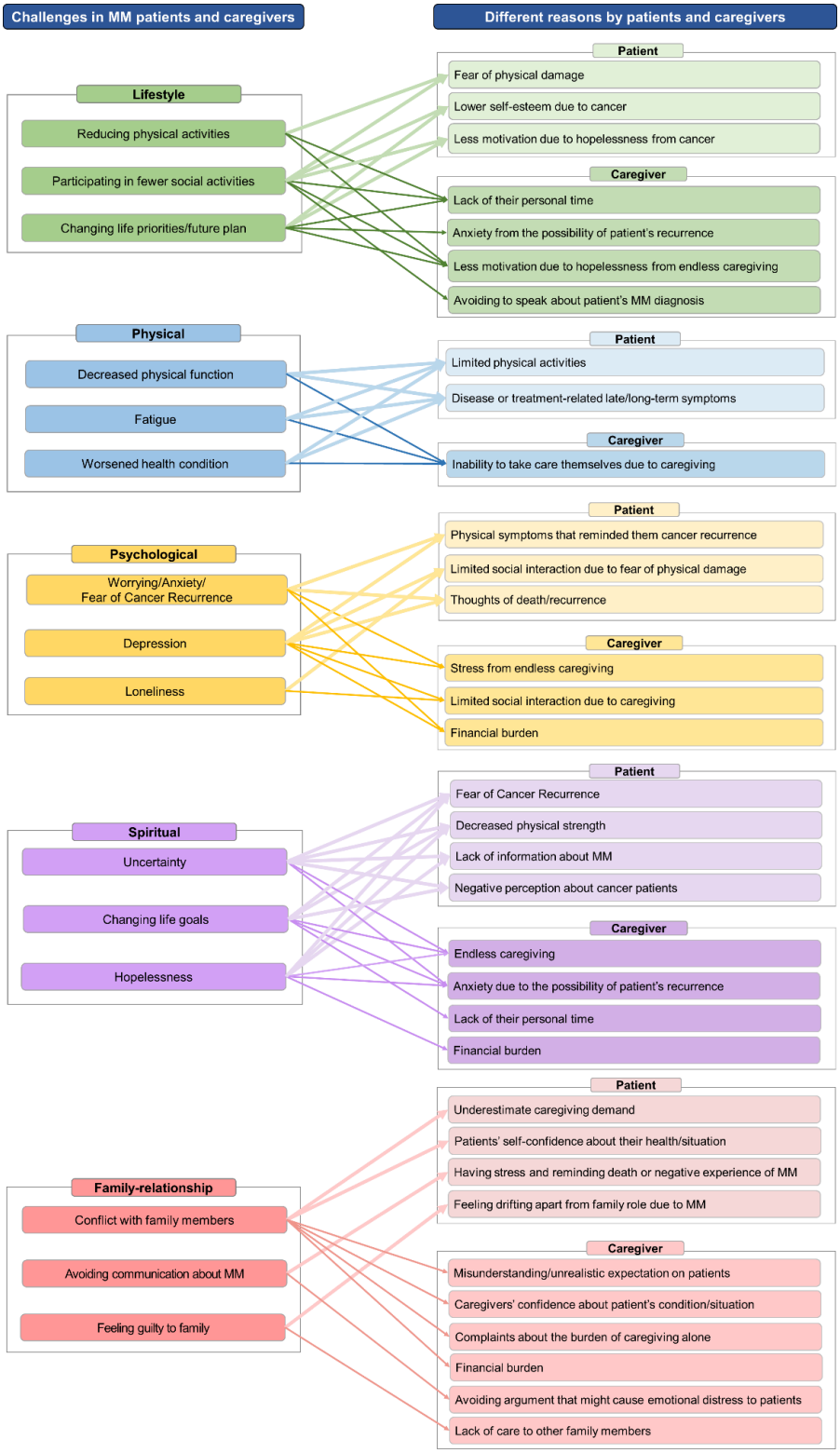


Figure 1

Similar challenges, different reasons for patients and caregivers (N = 79)

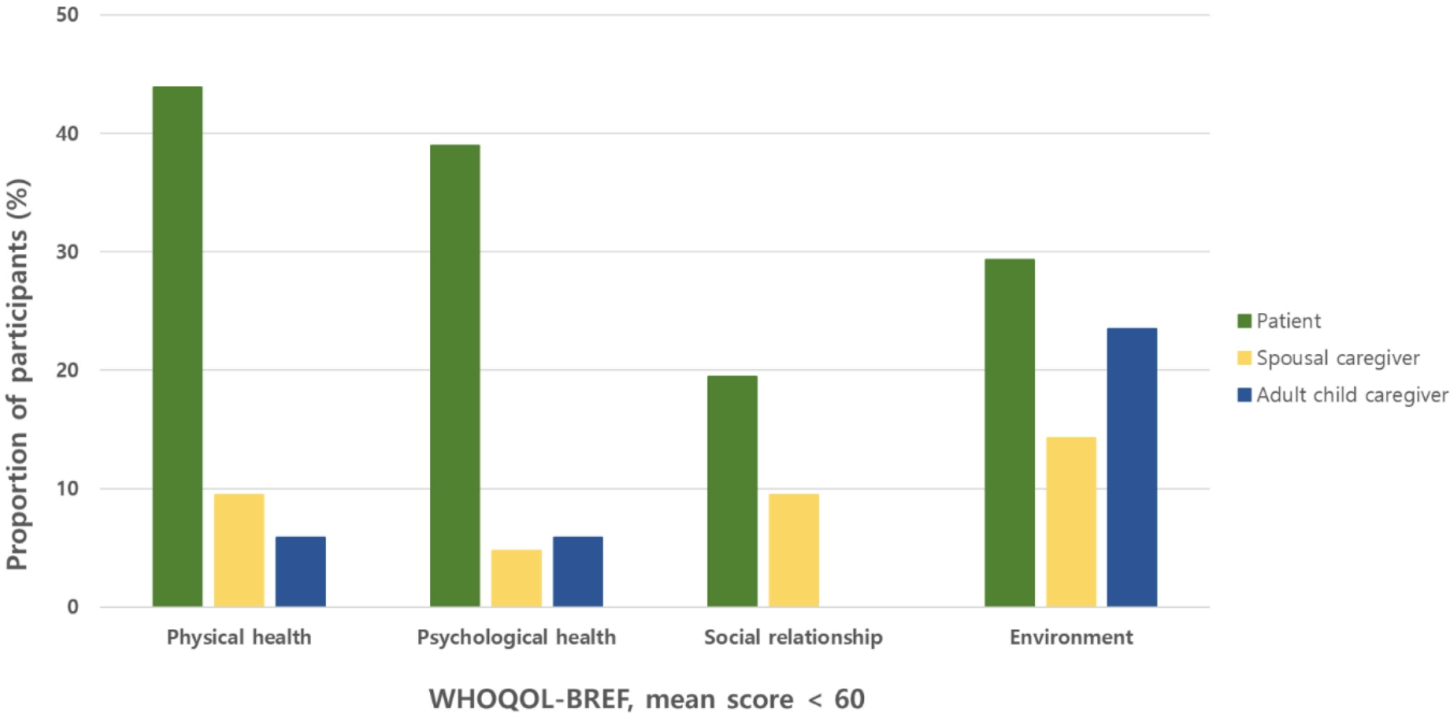


Figure 2

Proportion of problem groups among patients and caregivers based on WHOQOL-BREF scores (N = 79)