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Factors associated with quality of life in caregivers of patients with multiple myeloma

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Abstract

Background/Aim: Advances in the therapeutic treatment of multiple myeloma have continuously led to better prognoses. However, longer lives for patients include complications due to both potential comorbidities and the possible severe side effects of specific treatments. These issues make caring for such patients exhausting. In this study, we investigated the most important factors that negatively affect the quality of life (QoL) of non-professional caregivers of patients with multiple myeloma (MM).
Methods: This study was a cross-sectional study conducted between March 2023 and August 2023. The caregivers of 144 patients with MM were assessed for inclusion/exclusion. The demographics of caregivers, their familial relation to the patient, and their socioeconomic status (education, both marital and financial status, and occupations) were recorded. Additionally, data from MM patients were retrieved: (1) clinical and demographic data, (2) light and heavy chain types, (3) disease stage, (4) lytic lesions, and (5) treatment(s). The Caregiver Quality of Life Index-Cancer (CQOLC) questionnaire contains four sub-scores and a total score and was administered to all caregivers who volunteered to participate.
Results: A total of 73 patients and their caregivers were included in the study. For patients, their mean age was 65.7 (11.4) years, 52% were female, and the mean value of the disease duration was 30.5 (16.0–66.5) months. For caregivers, their mean age was 47.2 (12.8) years, and 63% were females. Multivariable linear regression revealed that higher (>40 years) caregiver age was independently associated with a higher CQOLC Burden and Positive adaptation score. Being a female caregiver was independently associated with a higher CQOLC Disruptiveness score. Having university-level or higher education status was independently associated with a lower CQOLC Financial Concerns score. In terms of the overall score, we found that higher (>40 years) caregiver age and the gender of the caregiver (female) appear to be factors that are independently associated with higher CQOLC total scores, whereas being a second-degree relative to the patient independently lowered the total score.
Conclusion: Among caregivers of MM patients, those who were older, female, and/or the first-degree relative of the patient (versus second-degree) with having lower education (versus university or higher) resulted in an improved caregiver QoL. The gender bias among caregivers is also a novel finding.

Keywords: multiple myeloma, caregiver, quality of life, female, high age, educational level, relatives

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Ethics Committee Approval
Ethical approval was obtained from University of Health Sciences, İstanbul Prof. Dr. Cemil Taşcıoğlu City Hospital Ethics Committee, Date: 9 March 2023, No: 60.
All procedures in this study involving human participants were performed in accordance with the 1964 Helsinki Declaration and its later amendments.

Conflict of Interest
No conflict of interest was declared by the authors.

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Introduction

Multiple myeloma (MM) is the second most common hematologic malignancy with an incidence that has steadily increased over the past ten years [1]. MM is marked by abnormal clonal plasma cells in the bone marrow that potentially lead to destructive bone lesions, kidney damage, and cytopenia [2]. Despite therapeutic advances leading to better patient prognoses, MM is ultimately a fatal disease [3,4]. MM causes long-term complications, and its treatment can cause severe side effects. Most MM patients suffer from debilitating conditions, including fatigue, bone pain, frequent infections, renal failure, and peripheral neuropathy, all of which reduce health-related quality of life (QoL) for the patients [1,4,5]. Moreover, considering that MM is often diagnosed in older adults, patient comorbidities may cause worsening of MM-related morbidities (1, 3, 5). A growing number of studies have demonstrated the severe impact of MM on QoL, leading to dependency on caregivers [1,6,7] and necessitating long-term care.

Long-term care for MM patients is sometimes provided by professional caregivers, patient's relatives, or rarely, other acquaintances. Due to the long-term nature of MM treatment, patients and caregivers often devote a significant portion of their time to managing the disease, which can affect their QoL and psychological well-being [8,9]. Regrettably, the QoL and the experiences of caregivers caring for MM individuals are largely unknown [7]. Improving the QoL of caregivers must be an important aspect of healthcare policies since an efficient and compassionate performance will improve the QoL of both the patient and caregiver. The ability to process the demands of caregiving can contribute to better prognosis and therapeutic success. Hence, pinpointing the factors impacting caregivers' QoL and addressing these issues can help alleviate the adverse effects of MM on both caregivers and patients. Nevertheless, research is scarce on this topic [7,10,11], and we do not have enough data to draw definitive conclusions about issues affecting either population.

The Caregiver Quality of Life Index-Cancer (CQOLC) questionnaire, a self-administered rating scale, was developed by Weitzner et al. in 1999 to evaluate the QoL of caregivers with cancer [12]. In this study, we aimed to report the QoL of non-professional caregivers of MM patients in our population and to identify the most important factors that may have an impact on QoL based on CQOLC questionnaire.

Materials and methods

Setting and ethical statement

This cross-sectional study was conducted at the Hematology Department of Prof. Dr. Cemil Taşcıoğlu City Hospital in Istanbul, Turkey. The study procedure was thoroughly explained to all participants, and written informed consent was obtained from both caregivers and patients before inclusion in the study. The study was designed with due consideration for ethical principles, adhered to the Declaration of Helsinki and its subsequent amendments, and received approval from the Ethics Committee of Prof. Dr. Cemil Taşcıoğlu City Hospital (Date: 9 March 2023, No: 60).

Study population

The study assessed the principal caregivers of 144 MM patients who were diagnosed between January 2008 and July 2021 and who were not receiving professional care and regularly presenting for follow-up at our hospital. Caregivers eligible for inclusion were defined as those who had been providing care to the patient from the time of the diagnosis until the questionnaire was administered. Using the method, we were able to avoid uncoupling of patient–caregiver data and prevent biased outcomes at both ends of the spectrum (long-term and recent caregivers). We are aware that this approach introduces a secondary concern, namely that the challenges faced by caregivers working for 15+ years would not resemble those providing caregiving for only two years. Exclusion criteria included caregivers below the age of 18, individuals unwilling to participate, caregivers whose patients had passed away, those with known psychiatric or cognitive disorders, individuals with a known history of cancer diagnosis, individuals who were not the primary caregivers, and/or professional caregivers.

Data collection

Patient data

MM was diagnosed according to current international guidelines [13-15]. The following data of the patients about demographical features, diagnosis, and follow-up were obtained from the hospital computer database and patient files. Patients' ages, genders, and comorbidity information, duration of the disease, light and heavy chain types at the first diagnosis, highest disease stages detected at the diagnosis or during the follow-ups, whether lytic lesions developed at the time of diagnosis or during follow-up, and treatment information including whether they received radiotherapy, whether autologous stem cell transplantation was applied, the type of treatment (primary or advanced), and treatment response (progression, stable disease, partial response, very good partial response, or complete response) were collected. The patients were categorized into two age groups: (1) those aged 60 years or younger and (2) those older than 60 years. To calculate the disease duration (in months), we considered the period from the initial diagnosis to the time of questionnaire completion. Based on disease duration, patients were further divided into two groups: (1) those with a disease duration of 60 months or less and (2) those with a duration exceeding 60 months. Additionally, we classified patients receiving three lines of therapy or fewer as undergoing primary treatment, while those receiving four or more lines of therapy were categorized as undergoing advanced treatment [7].

Caregiver data

Between March and August 2023, the relatives of the patients with MM received phone calls, were informed about the study, and then asked whether the patients received/did not receive professional care. During the initial follow-up examination, face-to-face interviews were conducted with the primary caregivers of the patients. These caregivers were generally family members and expressed their willingness to participate in the study. Information collected during these interviews included caregivers' ages, genders, relationship degrees with the patient, marital status (single, married, widowed), educational backgrounds (literate, primary school, secondary school, high school, university, postgraduate), employment statuses (unemployed, employed), and income levels (equal or below minimum wage, above minimum wage). Caregivers were categorized into two age groups: (1) those aged 40 years or younger and (2) those older than 40 years. Caregivers who were children, spouses, or siblings of the patient were classified as first-degree relatives, while other relatives serving as caregivers were designated as second-degree relatives.

The Turkish version of the CQOLC (CQOLC-T) questionnaire [16] was administered to all non-professional caregivers. CQOLC measures the effect of caring for cancer patients on the quality of the caregiver's life. The original CQOLC is designed to assess how caregiving for cancer patients impacts the caregiver's quality of life. It encompasses four functional sub-dimensions: (1) physical, (2) emotional, (3) family, and (3) social for a total of 35 items. These items cover various aspects with 10 related to burden, seven related to disruptiveness, seven related to positive adaptation, three related to financial concerns, and eight related to additional factors, such as sleeplessness, satisfaction with sexual functions, daily focus, mental strain, being informed about the disease, protection of the patient, management of the patient's pain, and family interest in caregiving [12]. Each item was rated on a 5-point Likert-type scale: (1) 0 (not at all), (2) 1 (a little bit), (3) 2 (somewhat), (4) 3 (quite a bit), and (5) 4 (very much). CQOLC subscale scores were determined by summing the scores of the items in the subscales. Total CQOLC scores were determined based on the sum of 35 items. The scores of items with negative expressions were reversed in which 0 is converted to 4, 1 to 3, 3 to 1, and 4 to 0. The total CQOLC scale score could range from 0 to 140 with a higher score indicating a better QoL [12].

Validation of the Turkish scale was done by Bektas et al. [16] and Ozer et al. [17]. As a result of this validity study, items 4, 10, 12, 16, 22, 23, 27, 28, 34, and 35 were removed from the scale based on the factor analysis.

The CQOLC-T has the same four sub-dimensions as the original scale (burden represents psychological distress based on 10 items), disruptiveness (represents disruption in daily life based on six items), positive adaptation (represents caregiving responsibility based on six items), and financial concerns (three items). Again, each item (n=25) was scored using a 5-point Likert scale to reach a total score range of 0 to 100 points.

Outcomes

The primary outcome of the study was to investigate patient- and caregiver-related factors that affect the total CQOLC-T score and its four subscale scores.

Statistical analysis

The statistical procedures were performed using SPSS. To assess the normality of data, the Shapiro–Wilk test was used. Descriptive statistics encompassed mean and standard deviation (SD) for normally distributed continuous variables, while non-normally distributed variables were expressed as median (1^{st}–3^{rd} quartiles), and categorical variables were presented as frequencies (percentages). Comparative analyses for normally distributed variables were performed using the Student's t-test, whereas the Mann–Whitney U test was used for non-normally distributed variables. To identify the factors independently associated with CQOLC-T scores, multivariable linear regression was applied by incorporating the stepwise selection method. Variables that exhibited statistical significance based on the outcomes of between group analyses were included as predictors in the regression analysis. The significance threshold was set at *P*-values <0.05, indicating statistical significance.

Table 1: Summary of patients' and caregivers' characteristics and index scores

Age, patients	**65.68 (11.38)**
≤60	24 (32.88%)
>60	49 (67.12%)
Sex, patients	
Male	35 (47.95%)
Female	38 (52.05%)
Duration of disease, months	30.5 (16.0 - 66.5)
≤60	53 (72.60%)
>60	20 (27.40%)
Type, heavy chain	
IgG	47 (70.15%)
IgA	20 (29.85%)
Type, light chain	
Kappa	46 (63.89%)
Lambda	26 (36.11%)
Stage	
Stage I	11 (15.28%)
Stage II	13 (18.06%)
Stage III	48 (66.67%)
Lytic lesions	44 (60.27%)
Radiotherapy	14 (19.18%)
Autologous stem cell transplantation	30 (41.10%)
Treatment	
Primary	55 (75.34%)
Advanced	18 (24.66%)
Response to treatment	
Progression	4 (5.48%)
Stable disease	12 (16.44%)
Partial response	18 (24.66%)
Very good partial response	21 (28.77%)
Complete response	18 (24.66%)
Comorbidity, patients	35 (47.95%)
Diabetes mellitus	6 (8.22%)
Hypertension	15 (20.55%)
Heart diseases	7 (9.59%)
Respiratory diseases	5 (6.85%)
Renal diseases	10 (13.70%)
Other malignancies	3 (4.11%)
Others	9 (12.33%)
Age, caregivers	47.19 (12.76
≤40	19 (26.03%)
>40	54 (73.97%)
Sex, caregivers	
Male	27 (36.99%)
Female	46 (63.01%)
Relationship of caregivers	
First degree	62 (84.93%)
Second degree	11 (15.07%)
Marital status, caregivers	
Single	14 (19.18%)
Married	58 (79.45%)
Widow	1 (1.37%)
Education status, caregivers	
Literate	1 (1.37%)
Primary school	27 (36.99%)
Secondary school	6 (8.22%)
High school	24 (32.88%)
University	13 (17.81%)
Postgraduate	2 (2.74%)
Working status, caregivers	
Not working	40 (54.79%)
Working	33 (45.21%)
Income, caregivers	
Equal or below minimum wage	35 (47.95%)
Above minimum wage	38 (52.05%)
Caregiver Quality of Life Index-Cancer scores	
Burden	24 (17 - 28)
Disruptiveness	9.56 (5.93)
Positive adaptation	8.36 (5.53)
Financial concerns	3 (1 - 6)
Total	43.49 (21.26)

Data are given as mean (standard deviation) or median (1st quartile - 3rd quartile) for continuous variables according to normality of distribution and as frequency (percentage) for categorical variables. IgA: Immunoglobulin A, IgG: Immunoglobulin G

Results

A total of 73 patients and their caregivers were included study. All data are summarized in Table 1. The mean age of the patients was 65.68 (11.38) years, and 38 (52.05% of the) patients

Table 2: Analysis results of Caregiver Quality of Life Index scores with regard to patients' and caregivers' characteristics

	Burden	***P*-value**	**Disruptiveness**	***P*-value**	**Positive adaptation**	***P*-value**	**Financial concerns**	***P*-value**	**Total**	***P*-value**
Age, patients										
≤60	21 (12 - 27.5)	0.290	8.04 (6.44)	0.126	6.33 (4.57)	**0.028**	4 (0 - 6.5)	0.868	38.04 (22.03)	0.126
>60	25 (17 - 29)		10.31 (5.58)		9.35 (5.73)		3 (1 - 6)		46.16 (20.58)	
Sex, patients										
Male	24 (16 - 29)	0.916	10.17 (6.26)	0.403	8.63 (5.91)	0.689	4 (1 - 7)	0.772	44.71 (22.55)	0.641
Female	24.5 (17 - 28)		9.00 (5.64)		8.11 (5.23)		3 (1 - 6)		42.37 (20.25)	
Duration of disease, months										
≤60	23 (15 - 27)	0.136	9.21 (6.07)	0.410	7.85 (5.65)	0.205	3 (0 - 6)	0.399	41.53 (21.76)	0.201
>60	26 (20 - 31.5)		10.50 (5.58)		9.70 (5.09)		4 (2 - 6)		48.70 (19.46)	
Type, heavy chain										
IgG	24 (17 - 28)	0.337	10.17 (6.52)	0.129	8.51 (5.40)	0.441	4 (1 - 7)	0.196	45.68 (20.84)	0.138
IgA	24 (7.5 - 26.5)		7.70 (4.57)		7.35 (6.05)		2.5 (0 - 5)		37.15 (22.38)	
Type, light chain										
Kappa	24 (14 - 29)	0.902	9.93 (6.63)	0.485	8.17 (6.03)	0.770	3 (0 - 6)	0.632	43.35 (23.91)	0.924
Lambda	24 (20 - 28)		9.00 (4.60)		8.58 (4.73)		4 (1 - 6)		43.81 (16.51)	
Stage										
Stage I & II	21 (14.5 - 28)	0.437	7.83 (5.43)	0.086	6.92 (5.17)	0.128	3.5 (0 - 5)	0.281	38.54 (18.98)	0.169
Stage III	24.5 (17 - 28.5)		10.40 (6.10)		9.04 (5.68)		3.5 (1 - 7)		45.94 (22.31)	
Lytic lesions										
No	22 (15 - 27)	0.584	8.03 (5.36)	0.074	7.59 (5.17)	0.338	3 (1 - 5)	0.366	39.79 (18.84)	0.230
Yes	24 (17 - 28.5)		10.57 (6.13)		8.86 (5.77)		3.5 (1 - 7)		45.93 (22.60)	
Radiotherapy										
No	25 (15 - 28)	0.950	9.22 (5.65)	0.316	8.17 (5.49)	0.558	4 (1 - 7)	0.358	42.95 (21.13)	0.657
Yes	21.5 (17 - 30)		11.00 (7.04)		9.14 (5.87)		2.5 (0 - 6)		45.79 (22.49)	
Autologous stem cell transplantation										
No	25 (17 - 29)	0.174	10.19 (5.43)	0.285	9.42 (5.44)	**0.049**	3 (0 - 7)	0.905	46.49 (20.78)	0.151
Yes	20.5 (14 - 28)		8.67 (6.57)		6.83 (5.40)		3.5 (1 - 6)		39.20 (21.56)	
Treatment										
Primary	25 (17 - 29)	0.305	9.84 (5.66)	0.493	8.38 (4.99)	0.955	3 (1 - 6)	0.732	44.38 (19.93)	0.536
Advanced	20.5 (14 - 27)		8.72 (6.80)		8.28 (7.10)		3.5 (1 - 6)		40.78 (25.36)	
Response to treatment										
PD & SD & PR	21.5 (13 - 27)	0.155	9.53 (6.42)	0.966	8.59 (6.13)	0.740	5 (1 - 7)	0.124	42.06 (24.80)	0.594
VGPR & CR	24 (17 - 29)		9.59 (5.55)		8.15 (5.03)		2 (1 - 4)		44.74 (17.87)	
Comorbidity, patients										
No	21.5 (14 - 28)	0.304	8.55 (6.20)	0.131	7.21 (4.96)	0.065	2.5 (0 - 6)	0.263	39.95 (20.71)	0.139
Yes	25 (17 - 29)		10.66 (5.50)		9.60 (5.92)		4 (1 - 7)		47.34 (21.48)	
Caregivers										
Age										
≤40	17 (7 - 25)	**0.002**	6.89 (5.76)	**0.022**	5.21 (5.29)	**0.003**	3 (0 - 6)	0.612	31.42 (22.15)	**0.003**
>40	25 (20 - 29)		10.50 (5.75)		9.46 (5.23)		3.5 (1 - 6)		47.74 (19.42)	
Sex										
Male	21 (13 - 26)	**0.009**	6.81 (4.98)	**0.002**	7.00 (5.37)	0.109	3 (1 - 5)	0.333	35.30 (18.84)	**0.011**
Female	25 (17 - 30)		11.17 (5.90)		9.15 (5.53)		3.5 (1 - 7)		48.30 (21.32)	
Relationship										
First degree	24 (17 - 29)	0.097	10.10 (5.63)	0.067	8.82 (5.38)	0.087	4 (1 - 6)	**0.022**	45.92 (19.11)	**0.020**
Second degree	17 (2 - 26)		6.55 (6.95)		5.73 (5.92)		0 (0 - 2)		29.82 (28.04)	
Marital status										
Not married	17 (10 - 25)	**0.010**	7.07 (5.99)	0.067	6.47 (6.55)	0.139	4 (1 - 7)	0.420	34.20 (23.11)	0.057
Married	25 (19 - 29)		10.21 (5.79)		8.84 (5.19)		3 (1 - 6)		45.90 (20.28)	
Education status										
High school or below	24.5 (19 - 29)	**0.009**	10.34 (5.96)	**0.025**	9.21 (5.26)	**0.009**	4 (1 - 7)	**0.044**	47.09 (20.29)	**0.004**
University or above	17 (2 - 25)		6.53 (4.87)		5.07 (5.50)		1 (0 - 4)		29.60 (19.71)	
Working status										
Not working	25.5 (20 - 29)	**0.019**	11.03 (6.21)	**0.019**	9.38 (5.44)	0.083	4 (1 - 7)	0.204	48.90 (20.48)	**0.016**
Working	21 (13 - 26)		7.79 (5.12)		7.12 (5.48)		3 (0 - 6)		36.94 (20.63)	
Income										
Equal or below minimum wage	26 (21 - 30)	**0.008**	11.11 (6.43)	**0.031**	9.69 (5.76)	**0.048**	4 (0 - 8)	0.190	49.57 (23.21)	**0.018**
Above minimum wage	21 (15 - 26)		8.13 (5.11)		7.13 (5.09)		3 (1 - 5)		37.89 (17.82)	

Data are given as mean (standard deviation) or median (1st quartile - 3rd quartile) for continuous variables according to normality of distribution and as frequency (percentage) for categorical variables. IgA: Immunoglobulin A, IgG: Immunoglobulin G

were female. The median disease duration was 30.5 (16.0–66.5) months with <60 months in 72.60% (n=53). The mean age of caregivers was 47.19 (12.76) years, and 46 (63.01%) were females. Fifty-four (73.97%) of the caregivers were older than 40 years, while 19 (26.03%) were 40 years or younger. According to the CQOLC-T survey, the median Burden score was 24 (17–28), Disruptiveness was 9.56 (5.93), Positive adaptation was 8.36 (5.53), Financial concerns 3 (1–6), while the total CQOLC-T score was 43.49 (21.26) points.

Univariate analysis of the relationship between CQOLC-T scores and other variables is presented in Table 2. Accordingly, for patient-related data, age greater than 60 years (*P*=0.028) and not undergoing autologous stem cell transplantation (*P*=0.049) were associated with higher Positive adaptation scores. For caregivers, age greater than 40 years was associated with higher Burden (*P*=0.002), Disruptiveness (*P*=0.022), Positive adaptation (*P*=0.003), and total scores (*P*=0.003). Being a female caregiver was associated with higher Burden (0.009), Disruptiveness (*P*=0.002), and Total score (*P*=0.011). Being a first-degree relative of the patient was significantly associated with higher Financial concerns (*P*=0.022) and total scores (*P*=0.020). Married couples (caregiver/patient) translated to higher Burden scores (*P*=0.010). Caregivers who had received university-level or higher education had significantly lower Burden (*P*=0.009), Disruptiveness (*P*=0.025), Positive adaptation (*P*=0.009), Financial concerns (*P*=0.044), and total scores (*P*=0.004). Being an employed caregiver was associated with lower Burden (*P*=0.019), Disruptiveness (*P*=0.019), and total score (*P*=0.016). Having an income exceeding minimum wage was associated with lower Burden (*P*=0.008), Disruptiveness (*P*=0.031), Positive adaptation (*P*=0.048), and total scores (*P*=0.018).

Multiple linear regression analysis (stepwise selection) revealed that high (>40 years) caregiver age (*P*=0.001) was independently associated with a high CQOLC-T Burden score. Other variables in the analysis, including caregiver sex (*P*=0.056), caregiver marital status (*P*=0.526), caregiver education status (*P*=0.105), caregiver working status (*P*=0.106), and caregiver income (*P*=0.126) were found to be non-significant (Table 3). A female caregiver (*P*=0.002) was independently associated with a higher CQOLC-T Disruptiveness score. Other variables in the analysis included caregiver age (*P*=0.066), caregiver education status (*P*=0.156), caregiver working status (*P*=0.188), and caregiver income (*P*=0.153), all of which were found to be non-significant (Table 4). High (>40 years) caregiver age (*P*=0.003) was independently associated with a higher CQOLC-T Positive adaptation score. Other variables included in the analysis were patient age (*P*=0.075), autologous stem cell transplantation (*P*=0.064), caregiver education status (*P*=0.096), and caregiver income (*P*=0.130) were found to be insignificant (Table 5). Having a university-level or higher education (caregiver; *P*=0.036) was independently associated with a lower CQOLC-T Financial concerns score. The other variable included in the analysis, namely, the family relationship of the caregiver to the patient (*P*=0.122), was found to be non-significant (Table 6). Finally, high (>40 years) caregiver age (*P*=0.008) and being a female caregiver (*P*=0.026) were independently associated with higher CQOLC-T Total score, while being a second-degree relative of the patient (*P*=0.012) was independently associated with a lower CQOLC-T Total score. Other variables in the analysis, including caregiver education status (*P*=0.276), caregiver working status (*P*=0.258), and caregiver income (*P*=0.143), were found to be non-significant (Table 7, Figure 1).

Table 3: Significant factors independently associated with Caregiver Quality of Life Index Burden score, multivariable linear regression analysis

	Unstandardized β	**Standard error**	**Standardized β**	***P*-value**	**95% Confidence interval for β**	
(Constant)	15.579	2.063		<0.001	11.465	19.693
Age, caregivers (>40)	8.273	2.399	0.379	**0.001**	3.489	13.057

R^2=0.143, F=11.891, *P*=0.001

Table 4: Significant factors independently associated with Caregiver Quality of Life Index Disruptiveness score, multivariable linear regression analysis

	Unstandardized β	**Standard error**	**Standardized β**	***P*-value**	**95% Confidence interval for β**	
(Constant)	2.456	2.299		0.289	-2.128	7.040
Sex, caregivers (Female)	4.359	1.352	0.357	**0.002**	1.663	7.055

R^2=0.128, F=10.392, *P*=0.002

Table 5: Significant factors independently associated with Caregiver Quality of Life Index Positive adaptation score, multivariable linear regression analysis

	Unstandardized β	**Standard error**	**Standardized β**	***P*-value**	**95% Confidence interval for β**	
(Constant)	5.211	1.202		<0.001	2.813	7.608
Age, caregivers (>40)	4.252	1.398	0.340	**0.003**	1.465	7.040

R^2=0.115, F=9.251, *P*=0.003

Table 6: Significant factors independently associated with Caregiver Quality of Life Index Financial concerns score, multivariable linear regression analysis

	Unstandardized B	**Standard error**	**Standardized β**	***P*-value**	**95% Confidence interval for β**	
(Constant)	6.421	1.258		<0.001	3.912	8.930
Education status, caregivers (University or above)	-2.110	0.990	-0.245	**0.036**	-4.084	-0.137

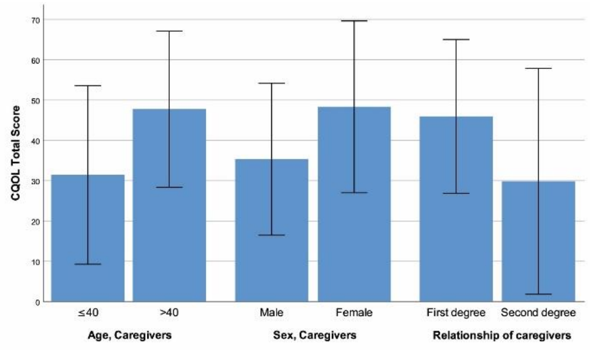
R2=0.060, F=4.547, *P*=0.036

Table 7: Significant factors independently associated with Caregiver Quality of Life Index Total score, multivariable linear regression analysis

	Unstandardized β	**Standard error**	**Standardized β**	***P*-value**	**95% Confidence interval for β**	
(Constant)	34.236	10.791		0.002	12.709	55.764
Age, caregivers (>40)	13.913	5.133	0.289	**0.008**	3.673	24.154
Sex, caregivers (Female)	10.641	4.665	0.243	**0.026**	1.335	19.948
Relationship of caregivers with patient (Second degree)	-15.975	6.179	-0.271	**0.012**	-28.301	-3.649

R2=0.244, F=7.431, *P*<0.001

Figure 1: Caregiver Quality of Life Index-Cancer Total score, mean and standard deviation, with regard to caregiver age, sex, and familial relationship with patient



Discussion

Cancer is the leading cause of mortality and morbidity in the world [18], and as found with other chronic diseases, cancer has many sequelae and greatly limits self-sufficiency. Patients often require support from other people, usually from their close relatives. These individuals are known as informal or non-professional caregivers. The role of these caregivers is key to providing help and support to such cancer patients, but these caregivers can experience a significant burden on many levels, which can affect their QoL [19]. Due to the challenging characteristics of MM and the palliative approach to treatment, MM has evolved into a chronic disease for numerous patients [1], particularly in relation to the extended life expectancy achieved through improved management [20]. Many patients are living with significant side effects and disabilities and require assistance from caregivers and equipment [20]. MM diagnosis and treatment affects not only the patient but also their relatives, particularly since these relatives are the people who assume the caregiver role [10]. In a pilot study employing the CQOLC scale, the great majority of caregivers reported experiencing heightened levels of stress, possibly in relation to their concerns regarding the health of their loved ones while concurrently witnessing their relative's deterioration [20]. The anxiety experienced by caregivers of MM patients (which originates from concerns about their loved ones), uncertainties regarding patient survival and QoL, and the necessity for frequent visits spanning several years of MM treatment, may contribute to their caregiver-related burden and distress [7,21]. Decreased caregiver QoL may impact the quality of care they provide to MM patients in their care [22]. This decrease is a major concern for both the patient and the caregiver since improving QoL is in fact one of the most important aspects of MM treatment [23].

The study aimed to identify key factors influencing the QoL of caregivers for MM patients. Findings indicate that caregivers over 40 years of age experienced less psychological distress and demonstrated better caregiving capabilities. A minor sex bias was apparent among caregivers with most caregivers being women. Although our data indicate that female caregivers experience fewer disruptions in their daily lives, this reduction in disruptions is likely to be associated with other factors, including employment, education, social functioning, and interpretation of gender roles. Those caregivers with university-level educations or higher expressed more financial concerns. Moreover, caregivers over 40 years of age, females, and first-degree relatives were associated with higher total QoL scores as independent predictors. The results provided by the limited number of studies on caregivers of MM patients are described. In the multivariate analysis of one study, age, gender, and education status of caregivers and treatment modality of patients with MM were not associated with caregiver QoL or psychological distress. In unadjusted analyses, only older caregiver ages were associated with better caregiver QoL but not with psychological distress [7]. In another study, no correlations were found between assessing unmet needs, caregiver age, patient age, caregiving daily care, caregiving duration, and caregiver QoL [10]. Simoneau et al. suggested that distress did not differ according to caregiver gender, but younger caregivers showed higher distress than older ones [11]. Some studies have shown that the deterioration in the QoL of caregivers of MM patients decreases over time [7,24]. Conversely, research on caregivers of cancer patients in general is notably more abundant. An example from China highlights the significance of caregiver QoL, indicating that it is markedly influenced by the quality of the partner relationship, the presence of chronic illnesses in the caregiver, the patient's daily activities ($r=-0.21$), the duration of cancer ($r=-0.11$), the total number of caregivers ($r=0.21$), and the overall caregiving duration ($r=-0.27$). Notably, the quality of the partner relationship with the patient exerted the most substantial influence on caregiver QoL. However, no noteworthy associations were observed between caregiver age, gender, educational attainment, and QoL in that particular study [25]. The spousal relationship has been documented as a critical parameter affecting QoL of caregivers in other studies [26-28]. Low income, being married, living in rural areas, and other sociodemographic characteristics have also been shown to impact caregiver QoL in other countries [29]. Many studies have shown that family caregivers of advanced cancer patients or allogeneic transplant patients during the peri-transplant period exhibit higher levels of anxiety, depression, and stress [11,24,30].

The caregiver burden can limit all aspects of a caregiver’s life, causing anxiety, insecurity, and isolation. These can lead to the loss of social support systems, which can increase the risk of stress and fatigue [31]. Caregivers of MM patients are at risk of higher workload and lower QoL than caregivers of patients with other oncological diseases [32]. Moreover, patients with MM and their caregivers are more likely to suffer from financial problems, including treatment and care costs [22]. In fact, many caregivers are reported to have lost their jobs due to time constraints [24,33]. Metin et al. [22] showed that lower levels of the financial well-being of caregivers of patients with MM negatively affects their QoL, and vice versa. Carreño and colleagues [34] noted that the economic burden of caregivers is not only related to medical services but also to a lack of labor productivity and even job loss. They also reported that this financial burden was linked to higher levels of anxiety and distress experienced by caregivers.

The present findings and literature results demonstrate that older caregivers experience less reduction in overall QoL; however, several other studies did not find a link between age and QoL [7,10,25]. In addition, in contrast to most previous studies [7,11,35], our study also found that female sex, less education, and first-degree relationships were associated with better QoL. In several studies, it was suggested that being a spouse is associated with reduced QoL. It was stated that if the caregiver is a spouse, the reason for the lower QoL may be related to the fact that spouses are less likely to receive help from other people than other non-spouse caregivers. Spouses are the most vulnerable group, and they tend to provide the most comprehensive care [25,36]. The deviation from previous findings concerning first-degree relatives might be attributed to cultural disparities. Additionally, second-degree relatives might be less willing to provide care, while first-degree relatives more readily accept this responsibility. An intriguing discovery in our study was the absence of a significant correlation between QoL results and factors, such as cancer stage, treatment features, and disease duration, all of which are highly peculiar findings in the light of earlier research [11,24,25,30]. This difference may be because our study excluded patients in which the primary caregiver had changed during the study period, thus skewing the population toward younger patients with shorter disease durations. Therefore, the lack of relationships shown for these parameters must be interpreted based on this information.

Caregiving creates physical, emotional, social, and financial problems that burden caregivers and lead to a reduction in their QoL [19,37]. The need for interventions to improve caregiver QoL, reduce their psychological distress, and cultivate adaptive coping strategies that may help improve the shared experience over the MM disease course exists [38]. Unfortunately, supportive care interventions that address the psychological needs of caregivers of patients with MM are lacking [7]. Studies aimed at enhancing the QoL of caregivers have emphasized the significance of social support systems, access to support networks [39,40], implementation of coping strategies [41,42], improvements in economic status [43], training [43,44], exercising practices [19], breathing exercises [19], and counseling sessions [19]. A cross-sectional descriptive study reported that moral support was the most predictive domain for QoL in caregivers of cancer patients followed by practical support and information [44]. These effects have been proven in prior studies. For instance, in a study utilizing a different scale (Quality of Life in Life-Threatening Illness - Family Carer Version), the QoL of family caregivers of patients with advanced cancer was measured before and after multicomponent intervention (Pranayama, yoga relaxation, counseling, and education). Significant improvements were reported in post-intervention test scores [45]. The presented study aimed to highlight potentially correctable factors that may be associated with the QoL of caregivers who care for MM patients. In summary, we can say that caregivers who are younger, male, non-first-degree relatives, and those with higher education levels present a higher risk of lower QoL.

Limitations

The cross-sectional design does not allow for causal relationships, while the exclusive use of self-report measures limits reliability and may have introduced recall bias. The fact that it is a single-center study with a small number of participants might limit the generalizability; however, we employed strict inclusion/exclusion criteria to ensure that the patients and their caregivers were matched in the study. Although limitations from the point of generalizability are present, we believe the results accurately represent the characteristics of our target group.

Laboratory results of patients were not assessed, and we deemed such tests unnecessary for the present hypothesis. Detailed measures that can evaluate the psychiatric conditions of caregivers such as anxiety and depression were not examined. The chronic diseases of caregivers [25] and activities of daily living [25] could have had a threshold effect on QoL-related findings and scores; however, these parameters could not be examined. Finally, it is quite possible that cultural and traditional factors also have an impact on caregiver QoL. Therefore, interpretations of our results should always consider the gender aspect and sociocultural characteristics of the target society.

Conclusion

Our study shows that the caregivers of patients with MM may experience different levels of their QoL. Caregivers who were older, female, first-degree relatives of the patient (versus second-degree), and those with lower education levels (versus university or higher education) had higher QoL. These correlations are evidently caused by multidimensional and multifaceted effects that apply differently to each of the independent factors identified in this study. However, the results suggest that the age, gender, familial relation, and education levels of caregivers should be considered by healthcare professionals to prevent caregiver burnout and adverse mental outcomes. This consideration can make a significant contribution to the QoL of not only caregivers but also the MM patients to whom they are providing essential care.

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