

Quality of Life, Social Support and Religiosity of Brazilian Patients Diagnosed with Multiple Myeloma by a Public Institution

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Abstract

Purpose: To assess the quality of life, social and religious indicators of patients diagnosed with multiple myeloma (MM) and correlate them with sociodemographic and clinical characteristics.

Methods: Cross-sectional study, with all outpatients diagnosed with MM (N: 23), in a 12-month period, in a public hospital in the city of São Paulo, Brazil. Data collection instruments: sociodemographic and clinical assessment; European Organization for Research and Treatment of Cancer Quality of Life Questionnaire; Social Support Scale of Medical Outcomes Study; Instrument Religiosity Index from Duke University.

Results: The quality of life was worst rated for physical (44.1; 95%CI 32.0–56.0) and role performance (41.3; 95%CI 24.0–58.6) and best rated for cognitive function (69.6; 95%CI 58.4–80.8). The emotional support was higher in affective domains (91; 95%CI 85.1–96.9) and in material domains (90.9; 95%CI 84.0–97). The intrinsic religiosity dimension obtained a high score (9.74; 95%CI 8.6–10.9). The older patients showed worse quality of life in emotional function (p=0.003) due to financial difficulties (p=0.009). Individuals from lower economic classes (C2 and D) reported worse quality of life in cognitive function (p=0.04). Men showed higher total emotional support scores (p=0.02), while women showed worse quality of life due to financial difficulties (p=0.04). Married patients reported greater total emotional support (p<0.001).

Conclusion: The quality of life was worse among older patients, the ones with lower purchasing power and women. The social support and the religiosity index were high, in general.

Keywords: Quality of life, Social Support, Spirituality, Religion, Multiple Myeloma, Medical Oncology

Introduction

Multiple myeloma (MM) accounts for approximately 1.4% of malignant neoplasms in general and is the second most common hematologic malignancy. The incidence of MM increases with age, in black and male individuals, and in people with family history. The increased incidence is due to the higher life expectancy of the population in developed and developing countries, such as Brazil. At diagnosis, about 37% of the patients are 75 years or older, 26% are between 65 and 74 years old and only 37% are under 65 years of age [1,2] type:"article-journal";volume:"125"},uris":["http://www.mendeley.com/documents/?uuid=eee4f2da-db96-4d6b-b297-965f0edaddbc"]},{id:"ITEM-2","itemData":{"DOI":"10.3322/caac.21551","ISSN":"00079235","abstract":"Each year, the American Cancer Society estimates the numbers of new cancer cases and deaths that will occur in the United States and compiles the most recent data on cancer incidence, mortality, and survival. Incidence data, available through 2015, were collected by the Surveillance, Epidemiology, and End Results Program; the National Program of Cancer Registries; and the North American Association of Central Cancer Registries. Mor-

tality data, available through 2016, were collected by the National Center for Health Statistics. In 2019, 1,762,450 new cancer cases and 606,880 cancer deaths are projected to occur in the United States. Over the past decade of data, the cancer incidence rate (2006-2015).

MM is still an incurable cancer; however, early diagnosis and treatment with contemporary therapeutic resources increased the patient's overall survival. In poor and developing countries, there seems to have been an increase in MM mortality, such as that occurred in Brazil in the last 20 years (1996–2015). Socioeconomic differences and inadequate health systems are listed among the causes, including infrastructure failures, resources scarcity, barriers to new drugs and treatments, and few qualified professionals [3].

The importance of scientific investments in MM, both in basic and applied research, is justified by the complex symptomatology patient presents and by the low complete response rate with conventional antineoplastic chemotherapy regimens (CT), for more than 3 years, with disease-free survival only achieved in treatment centers of excellence that provide proteasome inhibitors, immunomodulatory drugs and monoclonal antibodies associated with the hematopoietic stem cell transplantation (HSCT). Currently, patient's eligibility for the HSCT procedure (age, performance status and comorbidities) is the most significant perspective of complete therapeutic response and survival rate greater than one decade [4].

The healthcare process for patients with MM is challenging. The patient is usually older, polysymptomatic, with comorbidities and associated polypharmacy. The treatment of MM is essentially an outpatient care, and the CT regimen is oral, in most cases, in daily and intermittent use. Therefore, it is important to implement therapeutic plans that can provide comprehensive care, with adequate signs and symptoms control, early diagnosis of oncological emergencies, such as: febrile neutropenia, spinal cord compression, hypercalcemia; and early introduction of palliative care to improve quality of life (QoL) and promote survival.

The QoL assessment of patients with MM can predict the impact of the disease and treatment from a multidimensional perspective, important for the integral care planning, considering different domains, such as physical aspects, daily activities, social performance, emotional aspects and religiosity. The cancer diagnosis significantly interferes in the QoL of patients and caregivers, mainly in the physical and emotional aspects, considering the stigmatized culture of the disease. In addition, in the case of MM, there are functional limitations arising from the disease and the death risk due to the recurrences and worsening of the clinical condition [5].

Adding to the importance of the QoL assessment, the social support identification perceived by cancer patients and their religiosity level as contributors to the social resources promotion and the educational actions that are capable of clarifying and strengthening individuals to obtain support, comfort and consolation, enabling the recognition that, although life may present itself limited or non-socially productive, renewal is possible [6].

In view of the complex diagnostic and therapeutic condition of patients with MM, this investigation is justified by the importance of obtaining data on QoL, social support and religiosity as substrates in the patients' profile construction, with the goal of meeting their diverse demands and better assist these patients in the first months of treatment and preparing them for invasive procedures or for the chronic course of the disease, in order to conquer and maintain balance in the physical, emotional, social and religious dimensions.

The objectives were to measure the indicators of QoL, social support and religiosity, and correlate the results with the sociodemographic and clinical characteristics of MM patients in the first year of diagnosis.

Methods

Ethical aspects

This study met the ethical recommendations and obtained approval by the Ethics and Research Committee of the Universidade Federal de São Paulo – UNIFESP; CAAE 59724016.4.0000.5505 (CEP No.: 1257/2016).

Study design, period and location

This is a cross-sectional, analytical, quantitative study conducted from September 2016 to September 2017, with all patients admitted to the Hospital São Paulo Specialty Outpatient Clinic, Universidade Federal de São Paulo, São Paulo, Brazil.

Population, inclusion and exclusion criteria

The sample consisted of all patients admitted to the service in the established period, being considered eligible: patients diagnosed with MM attested in medical records, admitted to an outpatient basis, and aged 18 years or older. The exclusion criteria were patients with cognitive impairment or with some psychiatric disorder attested in medical records.

Study protocol

Instruments

Four instruments were used, the first for sociodemographic and clinical characterization. This instrument identified: age, sex, marital status, education, economic class (Brazil Economic Classification Criteria, 2016) [7], year of diagnosis, cancer type, disease clinical staging and treatment performed. The data available in electronic medical records were used to fill out the clinical information. Following three instruments, EORTC-QLQ-C30, MOS-SSS, and DUREL, all authorized for use: a) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ-C30): validated in Brazil composed of 30 items, distributed in the following subscales: functional (physical, role in society, cognitive, emotional and social), symptomatic (fatigue, pain, nausea and vomiting) and general health, followed by individualized issues of symptoms frequently reported by cancer patients. The scores range from 0 to 100. In the functional and global health status scales, higher scores are related to better QoL; however, for symptoms scales, higher scores correspond to worse QoL. b) The Medical Outcomes Study Social Support Scale (MOS-SSS): translated and adapted into Portuguese, composed of 19 socio-problematic questions. For the standardized scores calculation of each of the five dimensions of social support, points are assigned to each response option, which ranged from 1 (never) to 5 (always). The scores are obtained by each dimension sum of total points and divided by the maximum possible score in the same dimension. c) An Index of Religiosity Instrument of Duke University (DUREL), also validated, composed of 5 questions about organizational (formal/institutional), non-organizational (adopted by the individual) and intrinsic (motivation for religiosity) religiosity [8].

Data collection procedures

The instruments were applied to patients by the researchers of this study, who assisted them in reading and interpretation of items, without interfering with the interviewees' choice. The moments chosen for the patient's approach and questionnaires answers were in the pre or post medical appointment, according to the patient's convenience. Once the participation was allowed, the patient answered the questionnaires following the sequence: sociodemographic and clinical, EORTC QLQ-C30, MOS-SSS and DUREL, with a total duration of 20 to 30 minutes.

Statistical analysis

Descriptive statistics were used for the sample characterization that analyzed frequency, mean and standard deviation of the studied variables, in addition to the parametric statistical tests and graphic analysis: T-Student test, Pearson Correlation, Confidence Interval (CI) for mean and P-value, with significance level of 0.05 (5%) and 95% statistical confidence. The software used for statistical analyses was SPSS V20, Minitab 16 and Excel Office 2010.

Results

In total, 23 patients participated in the study, with a median age of 59.0 (SD: 8.6); predominance of male patients (60.9%), married (73.9%), with 2 or more children (78.2%), 1 to 8 years of education (52.2%) unemployed and or retired (91.3%). There was a prevalence of C and D economic classes (78.1%). Regarding habits, 17.4% reported being smokers and 8.7% alcoholics. From the clinical perspective, 56.5% of the patients had comorbidities, predominantly isolated hypertension (n=7, 53.56%) or combined with other diseases (n=3, 23.07%); 82.61% of them were diagnosed at stages equal to or greater than IIIA, and 65.23% with daily medication intake (Table 1).

Characteristics	Frequency
Age (years)	
Mean	60.2
Median	59.0
Minimum - Maximum	37-73
Sex - n (%)	
Female	9 (39.13)
Male	14 (60.86)
Marital status - n (%)	
Single	1 (4.35)
Married	17 (73.91)
Divorced	2 (8.70)
Widow/widower	2 (8.70)
Free union	1 (4.35)
Coexistence - n (%)	
Lives alone	1 (4.34)
Accompanied	22 (95.65)
Occupation - n (%)	
Unemployed and/or retired	21 (91.30)
Employed	2 (8.69)
Children - n (%)	
No children	1 (4.34)
1 child	4 (17.39)
2 children	7 (30.43)
3 children	4 (17.39)
4 or more children	7 (30.43)
Education level - n (%)	
0 years of study	1 (4.34)
1 to 8 years of study	12 (52.17)
9 to 12 years of study	8 (34.78)
>13 years of study	2 (8.69)
Religion - n (%)	
Catholic	13 (56.52)
Evangelical	4 (17.39)
Adventist	2 (8.69)
Christian	1 (4.35)
Jehovah's witness	1 (4.35)
Spiritist	1 (4.35)
Atheist	1 (4.35)
Economic class - n (%)	

B2	5 (21.74)
C1	13 (56.52)
C2	3 (13.04)
D	2 (8.70)
Smoking - n (%)	
Non-smoker	10 (43.48)
Former smoker	9 (39.13)
Smoker	4 (17.39)
Alcoholism - n (%)	
No	21 (91.30)
Yes	2 (8.70)
Staging - n (%)	
IIIA/ISS 1	1 (4.5)
IIIA/ISS 2	4 (17.39)
IIIA/ISS 3	4 (17.39)
IIIB/ISS 3	10 (43.48)
IIA/ISS 1	1 (4.35)
IIA/ISS 2	2 (8.70)
IB/ISS 2	1 (4.35)
Comorbidities - n (%)	
Yes	13 (56.52)
No	10 (43.48)
HTN	7 (53.85)
HTN + Renal insufficiency	2 (15.38)
HTN + DM + Epilepsy + Labyrinthitis	1 (7.69)
DM + Cardiac disease	1 (7.69)
Obstructive Chronic Pulmonary Disease	1 (7.69)
Hypothyroidism	1 (7.69)
Quantity of medicines per day - n (%)	
None	8 (34.78)
Up to 2	10 (43.48)
3 to 4	2 (8.70)
5 to 6	1 (4.35)
>7	2 (8.70)

Table 1: Sociodemographic and clinical characteristics of patients diagnosed with MM (n=23), São Paulo (Brazil), 2019.

When assessing the mean QoL scores obtained in the various categories, the QoL index was lower for the role performance domains (41.3; 95%CI 24.0–58.6) and physical function (44.1; 95%CI 32.0–56.0). The cognitive function was the best rated domain (69.6; 95%CI 58.4–80.8). The symptoms that were worst rated about QoL were fatigue (60.4; 95%CI 47.6–73.2) and pain (42.8; 95%CI 27.5–58.1). Financial difficulty (50.7%; 95%CI 32.9–68.5) was also pointed out as an important intervening factor in QoL. The least reported symptom was diarrhea (2.9; 95%CI). The overall status was 60.1 (95%CI 50.3–69.8) (Table 2).

The social support was recognized as the highest in the affective (91; 95%CI 85.1–96.9) and material domains (90.9; 95%CI 84.0–97.8). The total social support score was also high (87.5; 95%CI 81.3–93.7) (Table 2).

Quality of life	Mean	Standard Deviation	95%CI	Min	Max
FUNCTIONAL DOMAINS					
General health	60.1	24.0	50.3 - 69.8	0.0	100.0
Physical function	44.1	29.3	32.0 - 56.0	0.0	100.0
Role functioning	41.3	42.3	24.0 - 58.6	0.0	100.0
Emotional function	54.0	33.3	40.4 - 67.6	0.0	100.0
Cognitive function	69.6	27.4	58.4 - 80.8	0.0	100.0
Social function	57.2	37.9	41.7 - 72.7	0.0	100.0
SYMPTOM DOMAINS					
Fatigue	60.4	31.4	47.6 - 73.2	0.0	100.0
Nausea and vomiting	11.6	19.1	3.8 - 19.4	0.0	66.7
Pain	42.8	37.5	27.5 - 58.1	0.0	100.0
Dyspnea	21.7	31.2	9.0 - 37.4	0.0	100.0
Insomnia	29.0	35.3	14.6 - 43.4	0.0	100.0
Loss of appetite	17.4	36.1	2.7 - 32.1	0.0	100.0
Constipation	24.6	37.9	9.1 - 40.1	0.0	100.0
Diarrhea	2.9	13.9	0.0 - 8.6	0.0	66.7
Financial difficulty	50.7	43.7	32.9 - 68.5	0.0	100.0
EMOTIONAL SUPPORT					
Material	90.9	17.0	84.0 - 97.8	30.0	100.0
Affective	91.0	14.4	85.1 - 96.9	46.7	100.0
Emotional	85.0	19.2	77.2 - 92.8	40.0	100.0
Information	85.0	20.7	76.6 - 93.4	40.0	100.0
Positive social interaction	85.4	20.8	76.9 - 93.9	40.0	100.0
Total	87.5	15.1	81.3 - 93.7	54.3	100.0
RELIGIOSITY					
Organizational religiosity	2.57	1.88	1.80 - 3.34	0.00	5.00
Non-organizational religiosity	3.48	1.59	2.83 - 4.13	0.00	5.00
Intrinsic religiosity	9.74	2.82	8.59 - 10.89	0.00	12.00

Table 2: The scores on Quality of Life, Emotional Support and Religiosity among patients diagnosed with MM (n=23), São Paulo (Brazil), 2019
Caption: 95%CI: 95% Confidence Interval.

Regarding the mean scores for religiosity scale (Table 2), it is observed that the intrinsic religiosity dimension obtained a high value (9.74; 95%CI 8.6–10.9), close to the maximum one. The organizational and non-organizational religiosity scores obtained moderate values.

By correlating the sociodemographic and clinical characteristics with the results of the instruments, statistically significant results were found, as shown in Table 3. Age was positively correlated with emotional support and negatively correlated with some QoL dimensions. Older patients recognize greater emotional support, overall (p = 0.001), in positive social interactions (p = 0.001), because they feel welcomed (p = 0.001) and because they receive helpful information (p = 0.002). However, the higher the age, the worse the QoL in the emotional function was perceived (p = 0.003), as well as financial difficulties (p = 0.009).

The economic class was positively related to religiosity and emotional support and negatively with the QoL (Table 3). Thus, the patients from higher economic classes perceived more intensely non-organizational (p = 0.04) and intrinsic (p = 0.03) religiosity; as well as the support of affective (p = 0.006), emotional (p = 0.005), in positive social interactions (p=0.005) and for having received aid information (p = 0.002) domains. On the other hand, the patients of lower economic classes perceived worse QoL in cognitive function (p=0.04) and due to symptoms, such as nausea and vomiting (p < 0.001), loss of appetite (p = 0.02), and diarrhea (p = 0.02).

	Age	P value	Economic class	P value	Schooling level	P value	N. children	P value
RELIGIOSITY								
Organizational religiosity	-0.130	0.554	0.146	0.505	-0.117	0.594	-0.190	0.385
Non-organizational religiosity	0.403	0.057	0.436	0.037	0.262	0.227	-0.165	0.453
Intrinsic religiosity	0.220	0.314	0.466	0.025	0.116	0.597	-0.370	0.083
EMOTIONAL SUPPORT								
Material	0.330	0.124	0.274	0.206	0.185	0.399	0.220	0.314
Affective	0.410	0.052	0.552	0.006	0.464	0.026	-0.137	0.534
Emotional	0.647	0.001	0.566	0.005	0.263	0.225	-0.115	0.601
Information	0.618	0.002	0.622	0.002	0.345	0.107	-0.138	0.529
Positive social interaction	0.625	0.001	0.570	0.005	0.342	0.110	-0.010	0.963
Total	0.659	0.001	0.638	0.001	0.386	0.069	-0.047	0.832
QUALITY OF LIFE – FUNCTIONAL DOMAINS								
General health	0.164	0.456	0.021	0.926	0.086	0.695	0.143	0.515
Physical function	-0.035	0.875	-0.210	0.337	-0.076	0.732	0.027	0.903
Role functioning	-0.184	0.400	-0.062	0.777	-0.055	0.803	-0.091	0.679
Emotional function	-0.587	0.003	-0.375	0.078	-0.114	0.604	-0.207	0.342
Cognitive function	-0.278	0.198	-0.436	0.038	-0.478	0.021	0.147	0.502
Social function	-0.360	-0.091	-0.044	0.842	0.339	0.114	-0.180	0.411
QUALITY OF LIFE – FUNCTIONAL DOMAINS								
Fatigue	-0.227	0.298	-0.135	0.538	0.036	0.871	-0.058	0.794
Nausea and vomiting	-0.235	0.281	-0.683	<0.001	-0.474	0.022	0.267	0.218
Pain	-0.274	0.205	0.003	0.989	-0.168	0.443	-0.124	0.573
Dyspnea	-0.200	0.360	-0.327	0.128	0.015	0.947	-0.094	0.669
Insomnia	-0.251	0.249	-0.013	0.952	-0.332	0.121	0.012	0.958
Loss of appetite	-0.033	0.881	-0.493	0.017	-0.349	0.103	0.314	0.144
Constipation	0.252	0.246	0.023	0.919	0.026	0.9070	-0.001	0.996
Diarrhea	-0.115	0.600	0.492	0.017	-0.198	0.364	0.146	0.505
Financial difficulty	-0.534	0.009	-0.326	0.130	-0.137	0.534	-0.217	0.321

Table 3: Correlation between demographic variables, religiosity, emotional support and quality of life, São Paulo (Brazil), 2019.

Finally, schooling was positively correlated with affective support and negatively correlated with cognitive function and nausea/vomiting symptoms of QoL (Table 3). Therefore, the patients with higher education perceived more strongly affective support ($p = 0.03$), and worse QoL due to the decline of cognitive functions ($p = 0.02$) and presence of nausea/vomiting symptoms ($p = 0.02$).

Table 4 shows the religiosity scores, emotional support and QoL, according to sex. Men reported a higher perception of total emotional support ($p = 0.02$), because they felt more emotionally welcomed ($p = 0.01$) and because they received aid information ($p = 0.04$). Women perceived their QoL as worse due to symptoms such as nausea/vomiting ($p < 0.001$) and due to financial difficulties ($p = 0.04$).

	Mean		95%CI		P value
	Female	Male	Female	Male	
	N = 9	N = 14	N = 9	N = 14	
Religiosity					
Organizational religiosity	50.0	38.1	28.9-71.1	21.9-54.3	0.386
Non-organizational religiosity	59.3	57.1	43.8-74.8	41.9-72.3	0.857
Intrinsic religiosity	61.5	67.1	44.5-78.5	60.3-73.9	0.493
Emotional support					
Material	83.9	95.4	68.8-99.0	90.1-100.0	0.115
Affective	85.9	94.3	74.5-97.3	88.2-100.0	0.181
Emotional	72.8	92.9	59.4-86.2	85.6-100.0	0.011
Information	73.9	92.1	58.1-89.7	84.3-99.9	0.035
Positive social interaction	77.2	90.7	58-86.4	80.7-100.0	0.131
Total	78.7	93.1	68.6-88.8	86.7-99.5	0.022
Quality of Life - functional domains					
General health	62.0	58.9	45.4-78.6	46.4-71.4	0.768
Physical function	34.8	50.0	14.7-54.9	35.4-64.6	0.234
Role functioning	33.3	46.4	6.1-60.5	23.6-69.2	0.481
Emotional function	48.1	57.7	23.2-73.0	41.6-73.8	0,514
Cognitive function	59.3	76.2	39.6-79	63.5-88.9	0.152
Social function	55.6	58.3	33.8-77.4	36.4-80.2	0.869
Quality of Life - functional domains					
Fatigue	74.1	51.6	53.9-94.3	36.2-67.0	0.094
Nausea and vomiting	27.8	1.2	13.4-42.2	0.0-3.5	<0.001
Pain	53.7	35.7	32.1-75.3	14.9-56.5	0.272
Dyspnea	29.6	16.7	6.6-52.6	1.8-31.6	0.342
Insomnia	44.4	19.0	20.1-68.7	2.6-35.4	0.092
Loss of appetite	33.3	7.1	4.5-62.1	0.0-21.1	0.089
Constipation	37.0	16.7	7.3-66.7	0.3-33.1	0.216
Diarrhea	7.4	0.0	0.0-21.9	-x-	0.220
Financial difficulty	74.1	35.7	50.3-97.9	13.5-57.9	0.036

Table 4: Religiosity scores, emotional support and quality of life, according to sex, São Paulo (Brazil), 2019.

By associating the religiosity scores, emotional support and QoL, we also identified statistically significant differences (Table 5). Married patients declared greater intrinsic religiosity ($p = 0.02$), reported noting greater total emotional ($p < 0.001$), affective ($p = 0.01$) and welcoming emotional ($p = 0.02$) support, due to positive social interactions ($p = 0.02$) and for having received aid information ($p < 0.001$). In addition, married patients declared better QoL in emotional ($p = 0.004$) and cognitive functions ($p = 0.004$). On the other hand, unmarried patients perceived their QoL as worse in nausea/vomiting ($p = 0.002$), dyspnea ($p = 0.006$) and loss of appetite (0.007) symptoms and due to financial difficulties ($p = 0.009$).

	Mean		95%CI		P value
	Married	Not married	Married	Not married	
	N = 17	N = 06	N = 17	N = 06	
Organizational religiosity	45.1	36.1	32.0-58.2	28.3-43.9	0.558
Non-organizational religiosity	63.7	41.7	48.7-78.7	25.2-58.2	0.079
Intrinsic religiosity	70.2	50.0	48.2-92.2	28.2-71.8	0.020
Material	93.5	83.3	84.9-100.0	73.9-92.7	0.213
Affective	95.3	78.9	90.2-100.0	64.8-93.0	0.013
Emotional	92.6	63.3	85.5-99.7	53.5-73.1	<0.001
Information	93.5	60.8	86.9-100.0	46.4-75.2	<0.001
Positive social interaction	92.9	64.2	85.1-100.0	50.0-78.4	0.002
Total	93.6	70.1	88.4-98.8	60.9-79.3	<0.001
General health	61.3	56.9	48.2-74.4	49.1-64.7	0.713
Physical function	47.8	33.3	32.8-62.8	16.8-49.8	0.309
Role functioning	46.1	27.8	24.1-68.1	6.0-49.6	0.375
Emotional function	65.2	22.2	51.2-79.2	4.5-39.9	0.004
Cognitive function	76.5	50.0	64.9-88.1	27.7-72.3	0.038
Social function	63.7	38.9	45.3-82.1	14.1-63.7	0.173
Fatigue	54.2	77.8	38.8-69.5	59.2-96.4	0.116
Nausea and vomiting	4.9	30.6	0.2-9.6	9.2-52.0	0.002
Pain	39.2	52.8	20.0-58.4	29.8-75.8	0.459
Dyspnea	11.8	50.0	0.0-24.3	27.7-72.3	0.006
Insomnia	23.5	44.4	6.0-41.0	22.6-66.2	0.219
Loss of appetite	5.9	50.0	0.0-17.4	13.2-86.8	0.007
Constipation	23.5	27.8	6.0-41.0	0.0-63.3	0.819
Diarrhea	0.0	11.1	-x-	0.0-32.9	0.093
Financial difficulty	37.3	88.9	17.2-57.4	75.1-100.0	0.009

Table 5: Religiosity scores, emotional support and quality of life, according to marital status, São Paulo (Brazil), 2019.

Caption: 95%CI: 95% confidence interval; -x-: impossible to calculate

Other associations were performed with the variables smoking, time of diagnosis, type of religion (Catholic versus non-Catholic) and retirement, not presented in the tables. Smoking was associated with religiosity and non-smokers reported a higher perception of organizational religiosity ($p = 0.02$). Regarding the time elapsed since diagnosis, patients diagnosed up to three months reported worse QoL scores for constipation symptoms ($p = 0.01$). Regarding the religion type, there was only association with organizational religiosity ($p = 0.007$), indicating that Catholic patients reported a greater perception in the dimension of religiosity scale. In addition, the organizational religiosity perception was higher among non-retired patients ($p = 0.05$), while there was a report of greater material support among retirees ($p = 0.02$).

There was no association between the religiosity scales, emotional support and QoL with the presence of comorbidities and use of medications.

Discussion

The median age of respondents was lower than the usual seen in the literature, indicating that older MM patients, in our country, might not be adequately diagnosed and end up dying before because of disease complications. The highest incidence in men follows the world statistics [1]. The wide age gap (range from 37 to 73 years) is related to the number of children, marital condition, comorbidities prevalence, low schooling (52.1% with up to 8 years of studies) and smoking habit (56.4% among smokers and former smokers).

Brazilian education, as in other developing countries, is still low in general and one study indicates that it is usually accompanied by low health literacy, greatly compromising the proper necessary care conduction for the disease control and health promotion [9] patients with limited health literacy often struggle with this. The expectation of patients' engagement in health care decisions by their healthcare providers likely increases the burden that cancer patients are already experiencing following a life-changing diagnosis. Involving patients with cancer in medical decision-making requires them to have an adequate understanding their disease and treatment options. Limited health literacy poses a barrier to patient engagement in their own care, contributing to health disparities and poorer cancer outcomes. Aim: Our primary objective was to determine levels of health literacy among patients with cancer and the extent of its association with patient preference for care. We also sought to identify sociodemographic and clinical characteristics associated with limited cancer health literacy. Methods: As part of a larger prospective cohort study, $N = 345$ adult cancer patients attending a large, university-affiliated outpatient oncology clinic were recruited using consecutive sampling. Face to face interviews were conducted using questionnaires. Instruments used included the 30-item Cancer Health Literacy Test (CHLT-30). The tobacco control in Brazil has completed 22 years since the first restrictions for consumption in public places and demonstrated a favorable impact on the decrease (55%) in the number of smokers. However, 17.5% of the population still uses tobacco products, which corresponds to 25 million people, confirming the need for the maintenance of continuous anti-smoking campaigns, including patients already diagnosed with cancer [10].

Regarding the illness condition, the majority patients were in stages IIIA or B and ISS 3, which evidences delay in the disease recognition, resulting in proportionally larger tumor mass and worse QoL. Bone involvement and anemia has shown to compromise the QoL of these patients since the diagnosis [11] and patients typically present with bone marrow infiltration of clonal plasma cells and monoclonal protein in the serum and/or urine. The diagnosis of multiple myeloma is made when clear end-organ damage attributable to the plasma cell proliferative disorder or when findings that suggest a high likelihood of their development are present. Distinguishing symptomatic multiple myeloma that requires treatment from the precursor stages of monoclonal gammopathy of undetermined significance and smouldering multiple myeloma is important, as observation is the standard for those conditions. Much progress has been made over the past decade in the understanding of disease biology and individualized treatment approaches. Several new classes of drugs, such as proteasome inhibitors and immunomodulatory drugs, have joined the traditional armamentarium (corticosteroids, alkylating agents and anthracyclines).

In relation to the QoL, some scores have high variability (CV greater than 50%), demonstrating the heterogeneity of the sample. However, although few studies jointly assess several illness aspects of patients diagnosed with onco-hematological diseases, especially MM, the results found were similar [12,13].

The domains of physical function and role performance obtained poor levels, with averages ranging from 54.81 to 41.18. The drop in the perception of the health related QoL in the physical function domain and, consequently, in the role performance, is justified by the late MM diagnoses, and thus polysymptomatic patients in the first 12 months of diagnosis. Invariably the patients present sequelae related to kidney complications and bone lesions, the latter being responsible for pain conditions with chronicity characteristics [11] and patients typically present with bone marrow infiltration of clonal plasma cells and monoclonal protein in the serum and/or urine. The diagnosis of multiple myeloma is made when clear end-organ damage attributable to the plasma cell proliferative disorder or when findings that suggest a high likelihood of their development are present. Distinguishing symptomatic multiple myeloma that requires treatment from the precursor stages of monoclonal gammopathy of undetermined significance and smouldering multiple myeloma is important, as observation is the standard for those conditions. Much progress has been made over the past decade in the understanding of disease biology and individualized treatment approaches. Several new classes of drugs, such as proteasome inhibitors and immunomodulatory drugs, have joined the traditional armamentarium (corticosteroids, alkylating agents and anthracyclines).

Among all functions, the emotional one was the most impaired. From the diagnosis suspicion to its confirmation, the cancer patient suffers emotionally, and fear is one of the main feelings, even when they have cure prospects and access to treatments. There are moments of sadness, anxiety and hopelessness manifestations. In addition, the way the disease interferes with the patients' daily activities, with routine changes, dependence on other people to perform simple tasks, along with the disease symptoms, such as pain, insomnia and fatigue, corroborate the perspective of changes in life objectives and, consequently, emotional responses [14,15]. Psychological science and evidence-based practice are making important contributions to addressing the pressing needs of cancer survivors. Research is demonstrating that adults diagnosed with cancer evidence generally positive psychosocial adjustment over time; however, a subset is at risk for compromised psychological and physical health stemming from long-term or late effects of cancer and its treatment. In this article, we characterize survivorship after medical treatment completion during the periods of reentry, early survivorship, and long-term survivorship. We describe the major psychosocial and physical sequelae facing adults during those periods, highlight promising posttreatment psychosocial and behavioral interventions, and offer recommendations for future research and evidence-based practice.

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By relating emotional state to social habits, we observed that some patients remained smokers and alcoholics despite the MM diagnosis. The association of tobacco, alcohol and antineoplastic therapies is a worrisome factor for the patient's safety and failure to the therapeutic regimen, since it can potentiate falls and accidents risks, incite psychic instabilities and lead to disease aggravation.

There are still more than a billion active tobacco users in the world, and it is estimated that, by 2020, smoking-related cancers will cause the death of approximately 650 Americans every day and of 7,800 people per day worldwide. The tobacco products sold in various parts of the world vary significantly in nicotine levels and carcinogens amount, these being around 70 in cigarettes. Brazil was able to reduce the number of smokers in the population through policies to restrict smoking, however, there was no effective control over the quality of the consumed tobacco products by the remaining group [16,17].

From this perspective, it is important to highlight the fundamental role of the health professional, in relation to a comprehensive assessment regarding the use, abuse or dependence, together with the referral to educational programs that play an important role in tobacco cessation as well as in cessation of alcohol consumption which maintains high consumption rates in all Brazilian regions [18].

On the symptom scale, fatigue obtained a higher prevalence. Fatigue is a frequent symptom in cancer patients and, in MM, may be aggravated if the patient also has anemia that affects more than 2/3 of MM cases at the diagnosis, resulting from the disease and its complications, such as renal failure, infiltration of neoplastic cells in the bone marrow, suppressive and nephrotoxic chemotherapy effect, radiotherapy, hemolysis, vitamin B12 or folic acid deficiencies.

Another study that assessed the social support of cancer patients through MOS-SSS also indicated similar results - "always" was the option with the highest response percentage in all domains. Recovering data on socio-demographic characterization, the majority of the patients investigated do not live alone, and some live with their own family, spouse and children. Family support is very important, considering the extensive physical, psycho-emotional and clinical symptomatology of MM patients.

Family plays a relevant role in drug adherence, general well-being and, consequently, improvement in the patients QoL in several studies. The diagnosis of cancer has a negative impact on patients and their family's life due to huge suffering, social and financial repercussions. So it is necessary to aim for family-centered care, so that its coping mechanisms are strengthened, providing clarifications and conferring autonomy within their existence conditions, since the family sphere and its ways of living vary according to the cultural standards and needs of each family group [5].

All domains of social support scale obtained high scores, revealing that patients perceive and use the support network that surrounds them; however, with a relative impact on social and emotional functions (scores between 50 and 60), on the QoL scale. Considering the several challenges, from physical and psychological symptomatology to socioeconomic negative impact, patients and family members should receive strong social support, with well-defined public policies and assistance by health professionals prepared for multidimensional assessment and able to undertake effective actions that favor patient's QoL and well-being [19].

Patients' religiosity was high in this study, especially the intrinsic one. This data are reiterated by other studies that have shown spirituality/religiosity as an important distress reducer that may influence better emotional response and resilience, physical comfort and better therapeutic response of cancer patients [20,21].

Although there has been a change in the exclusive focus on physical symptoms and in the treatment of cancer patients to a holistic view in past decades, in which the patient should be considered as their psychosocial and spiritual needs, health professionals still maintain an incongruous attitude because they do not include in the patient's care an objective assessment on the level of religiosity/spirituality nor favorable interventions thereof. To advance, there is a need to convert scientific evidence on this subject into educational and care projects capable of potentiating the patients' spirituality/religiosity into QoL [21,22].

From the vulnerable groups' perspective, the data reiterate studies that showed worse QoL for women, older adults and the most impoverished. Women demonstrated worse QoL and social support than men, evidencing the male protection culture in the illness process, especially in the condition of married people who, for both sex, was a variable associated with lower intensity of symptoms and greater emotional support. Thus, the need for a broad sociodemographic and psychosocial characteristics assessment of patients affected by cancer is reaffirmed, as well as the adoption of measures to support and provide social aid [23,24] but there is a paucity of research on potential processes underlying this vulnerability. The present cross-sectional study examined whether specific cancer-related problems were associated with the odds of relationship breakup following diagnosis and whether these relationships differed between male and female cancer survivors. Methods: A national cross-sectional quality of life study assessed self-reported cancer-related problems and relationship change among survivors who were either 2, 6, or 10 years post-diagnosis (n = 6099).

The limitation of this study lies in the small sample number, although all patients admitted to the study institution were included.

Conclusion

Data showed that MM patients are vulnerable under socioeconomic and clinical aspects, have a high religiosity rate, compromised QoL mainly in the physical function and role performance domains, although they have high score in social support. Older patients showed worse QoL in emotional function due to financial difficulties. The individuals from lower economic classes (C2 and D) reported worse QoL in cognitive function. However, those in the higher economic classes (B2 and C1) reported higher organizational and intrinsic religiosity, and greater emotional support in affective, emotional, and positive social interactions, and for having received helpful information. Men reported higher total emotional support score, while women reported worse QoL due to financial difficulties. Married patients reported greater total emotional support.

Considering that patients were within 12 months of MM diagnosis, the data revealed demands for care that need to undergo planned interventions, based on strengthening care actions, ability to participate in decision-making processes (self-management), strengthening social and family relationships and tendency to respected and stimulated spirituality/religiosity. Implications for practice: The data should support a multidimensional care plan for the MM patients, including their families, seeking comprehensive care.

Authors' Contributions

LAS and EBD designed the study. LAS, VTM, MMB and EBD acquired and analyzed the data. MMB and TOT developed the analyses. LAS, EBD, WMB and MMB interpreted the data. EBD and WMB critically revised the manuscript for important intellectual content. All authors approved the final manuscript.

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Conflict of Interest

The authors declare no conflicts of interest.

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