



Communication

Burden in Multiple Sclerosis Caregivers: A Single-Center Experience

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Abstract: **Objective:** To analyze the relation between Zarit and the MSQoL-54 scales in caregivers and patients with multiple sclerosis (MS). **Methods:** Our study included 167 caregivers of 153 patients with MS in a single center, from July 2021 to December 2023. **Results:** Evaluation of the Zarit score revealed a median score of 11 (IQR = 4–21.75). Up to 126 caregivers had a low burden level, while 8 had moderate–severe burden, and 1 caregiver showed a severe burden score. Correlation analysis revealed that the Zarit score significantly correlated positively with the following variables: patient age ($r = 0.25$) and EDSS ($r = 0.40$); and a significant negative correlation was observed with the following variables: Physical Health Composite Score ($r = -0.48$) and Mental Health Composite Score ($r = -0.34$). **Conclusions:** Most caregivers either carry a low burden or none, as well as an inverse correlation between the Zarit and the Physical and Mental Health composite scores of the MSQoL-54 instrument.

Keywords: multiple sclerosis; Zarit; MSQoL-54; quality of life; burnout

1. Introduction

Multiple sclerosis (MS) is considered a primary chronic autoimmune disease that alters the protective covering around nerves in the brain and spinal cord (myelin sheath) due to inflammation [1]. It affects an estimated 2.8 million people worldwide [2]; Europe has the highest incidence, reported as 6.8 per 100,000 persons per year, followed by the USA, with an incidence of 4.8 per 100,000 persons per year; Southeast Asia and Africa have the lowest reported incidence rates, 0.4 per 100,000 persons per year [3]. It is most frequently diagnosed in people between 20 and 40 years of age and mostly develops in women [4].

As a chronic disease, patients with MS present disabilities such as difficulties with vision, muscle coordination, walking, etc., and they eventually require additional assistance with the tasks of everyday life; this is usually provided by caregivers, such as partners or other relatives [5].

Some inherent factors compromise the employment of caregivers such as the duration of caregiving, and the overall health status, age, and gender of the patient [6]. McKenzie T et al. [4] investigated the effect of caregiver stress on their emotional well-being, physical health, and employment, and they reported that over 40% of care partners

(559 of 1288 persons) had missed work in the previous year due to caregiving responsibilities [4]. Occasionally, caregivers develop “caregiver burden”, a sense of overwhelming responsibility, constant worries, uncertainty about the patients’ needs, and a limited social life [7]. Usually, the role of caregiving is unnoticed and taken for granted, although it should be a priority in the public health framework. According to Walton C. [3], since 2013, the prevalence of MS has increased throughout the world; currently, a total of 2.8 million people is estimated to be living with MS worldwide [3] and, at some point, most will need ongoing care or support hence engaging a caregiver’s assistance [8].

The Zarit burden interview was designed in 1980. Initially, this instrument was used to assess the feelings of overburden experienced by the caregivers of patients with dementia, but it is now also applicable to other diseases, including multiple sclerosis [9].

The Multiple Sclerosis Quality of Life (MSQOL-54) scale was constructed based on a review of the literature, and the input of two physicians and a nurse specializing in MS. It is a variant of the SF-36, supplemented with 18 additional items focusing on specific features of MS [10].

2. Materials and Methods

Our study included 167 caregivers of 153 patients with MS at the Centro de Hematología y Medicina Interna Clínica Ruíz, in Puebla, Mexico; between 11 July 2021 and 4 December 2023. Data were collected with face-to-face interviews. Basic demographic information such as sex, age, place of birth, year of diagnosis, MS type (relapsing-remitting [RRMS], secondary progressive [SPMS], primary progressive [PPMS]), disease duration, and years of caregiving was provided by the patients and caregivers. Both parties signed the required informed consent to use their data for research. This study was approved by the internal research ethics committee of Clínica Ruiz (CEI-211123-01).

Caregivers completed the Zarit Caregiver Burden interview. This is a questionnaire with 22 items evaluated with Likert-type scoring. It determines the caregiver’s burden by measuring the impact of the patient’s abilities (level of mobility, fatigue, personality change, and cognitive dysfunction) on their own lives (effects on health, privacy, and social life). It is a 5-level scale scored as “0, never” to “4, almost always”. The minimum score is 0 and the maximum score is 88. Scores between 0 and 21 are considered as “no burden–low level”, between 21 and 40 are considered as “mild–moderate”, between 41 and 60 are considered as “moderate–severe”, and between 61 and 88 are considered as “severe” burden perception. The higher the score, the greater the burden.

Patients completed the MSQOL-54, which consists of 54 items distributed in 12 multiple-item scales. It measures the dimensions of quality of life (physical health, limitations due to physical problems, limitations due to emotional problems, pain, emotional well-being, energy, health perception, social function, cognitive function, health concerns, quality of life, sexual function, changes in health, and satisfaction with sexual function).

The Kolmogorov–Smirnov test was used to evaluate the normality of the distribution of the data to be analyzed. The data in our study that did not conform to a normal distribution were presented as medians and interquartile ranges. The Chi-squared and Mann–Whitney U tests were used to compare the data. The correlation of the Zarit Caregiver Burden Scale with other variables was established with Spearman’s test. A p -value < 0.05 was considered significant. Statistical analysis was performed with the SPSS 25 software (version 25.0., IBM Corp., Armonk, NY, USA), and GraphPad Prism 9 (GraphPad Prism version 9 for Windows, GraphPad Software, San Diego, CA, USA, www.graphpad.com accessed on 20 February 2024).

3. Results

The mean age of patients was 44.08 ± 11.41 , and 108 were female and 60 were male. The predominant MS type was RRMS ($n = 99$). A total of 82 caregivers were male and 85 were female. The caregivers and patients were mainly from the Netherlands and the USA. Of the 85 female caregivers, 10 had been unemployed, 6 were retired, and 79 were actively

employed. In contrast, of the 82 male caregivers, 2 were unemployed, 2 were retired, 1 was receiving his pension, and 79 had an occupation. Table 1 shows the main characteristics of patients and caregivers.

Table 1. Caregiver and patient demographics. Expanded Disability Status Scale (EDSS); Interquartile Range (IQR).

Number of Caregivers	167
Male	82
Female	85
Age (mean + SD)	47.95 ± 12.87
Years of caregiving (median, IQR)	3 (IQR = 1.5–11)
Relative	
Yes	138
No	29
Country	
Australia	6
Belgium	1
Bosnia and Herzegovina	1
Brazil	1
Bulgaria	1
Canada	11
Colombia	1
Dominican Republic	1
Egypt	1
England	3
France	4
Germany	2
Holland	2
Hong Kong	1
Ireland	2
Mexico	3
Netherlands	40
New Zealand	2
Norway	7
Scotland	6
Spain	1
UK	20
United States of America	50
Zarit score	
No burden-low level	126
Mild-moderate	33
Moderate-Severe	8
Severe	1
Patients	
RRMS	99
SPMS	27
PPMS	42
EDSS	4, IQR = 2.5–6
Disease duration (years)	6, IQR = 2–12

Evaluation of the caregivers' Zarit results revealed a median score of 11 (IQR = 4–21.75). According to the Zarit score results, 126 caregivers had either a low burden level or none whatsoever, 8 had moderate–severe burden, and only 1 caregiver showed a severe burden score. Results of the MSQoL-54 score were expressed as medians and, overall, reflected

the caregivers' quality of life; the median value was 53.35 (IQR = 36.65–69.18), while the Physical Health composite score was 51.18 (IQR = 37.19–64.38), and the Mental health composite score was 63.26 (IQR = 37.86–73.81). The scores of the subscales of the MSQOL-54 questionnaire are summarized in Figure 1 and grouped according to the Zarit score classification of the caregivers.

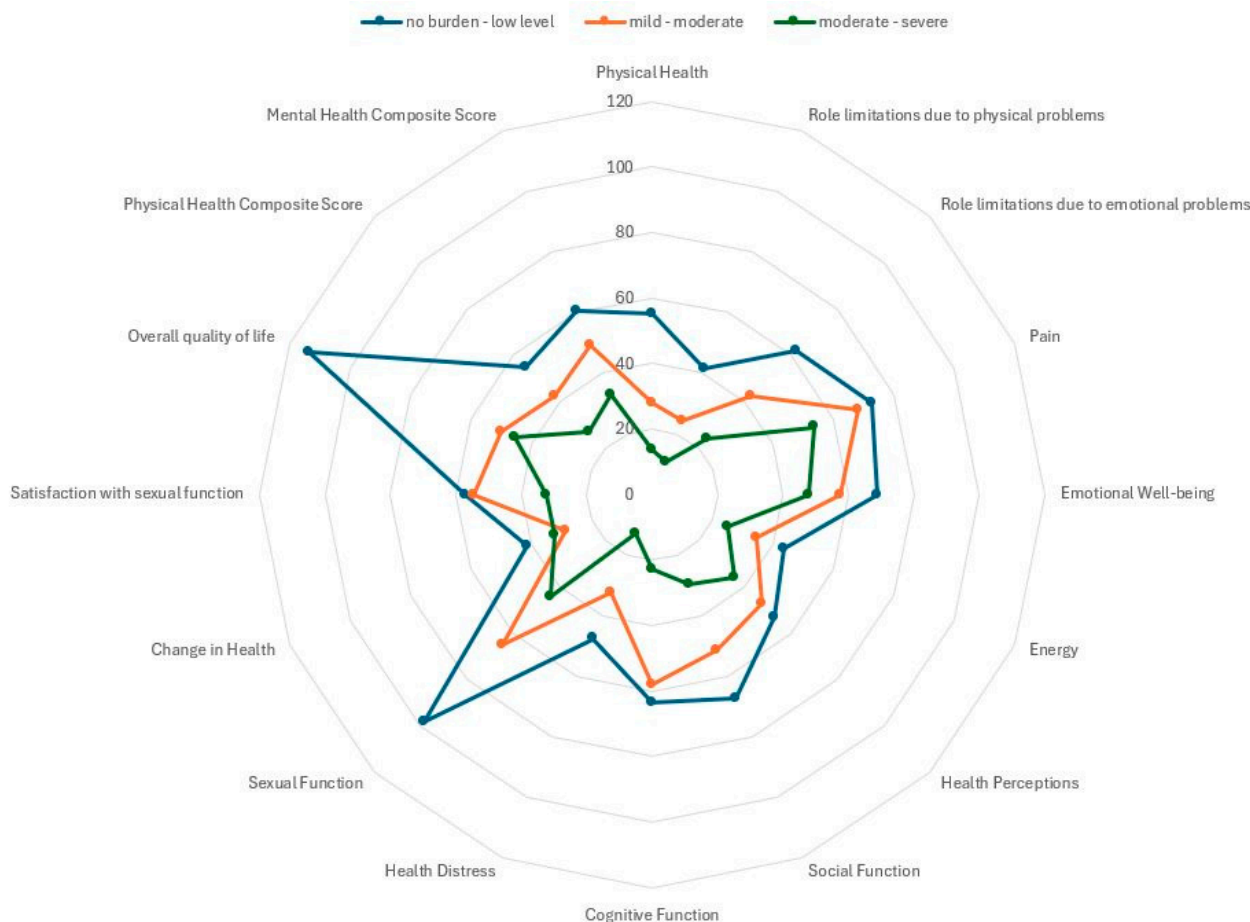


Figure 1. Relationship between Zarit score and MSQOL-54.

Correlation analysis revealed that the Zarit score significantly correlated positively with the following variables: patient age ($r = 0.25$, $p = 0.001$) and EDSS ($r = 0.40$, $p \leq 0.05$). A significant negative correlation was observed with the following variables: Physical Health Composite Score ($r = -0.48$, $p \leq 0.05$) and Mental Health Composite Score ($r = -0.34$, $p \leq 0.05$). A correlation matrix of all the analyzed variables is shown in Figure 2.

According to the patients with RRMS, correlation analysis revealed that the Zarit score significantly correlated positively with the following variable: EDSS ($r = 0.38$, $p \leq 0.05$). A significant negative correlation was observed with the following variables: Physical Health Composite Score ($r = -0.45$, $p \leq 0.05$) and Mental Health Composite Score ($r = -0.32$, $p \leq 0.05$). A correlation matrix of all the analyzed variables is shown in Figure 3.

On the other hand, as per the patients with PPMS, correlation analysis revealed that the Zarit score significantly correlated positively with the following variables: patient age ($r = 0.31$, $p = 0.04$), and EDSS ($r = 0.34$, $p \leq 0.05$). A significant negative correlation was observed with the following variables: Physical Health Composite Score ($r = -0.53$, $p \leq 0.05$) and Mental Health Composite Score ($r = -0.44$, $p \leq 0.05$). A correlation matrix of all the analyzed variables is shown in Figure 4.

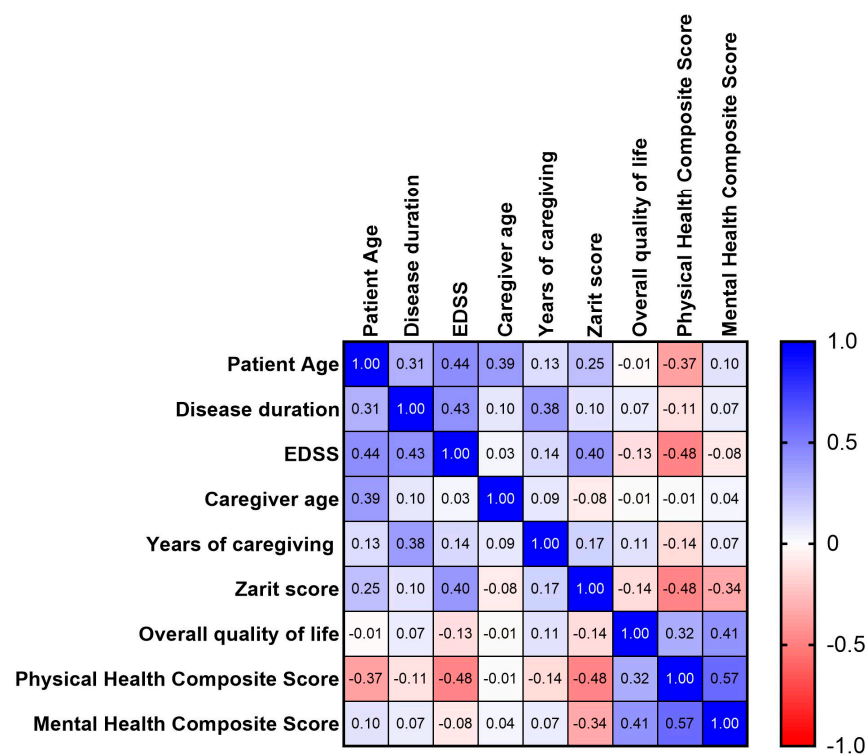


Figure 2. Correlation matrix of the main evaluated variables.

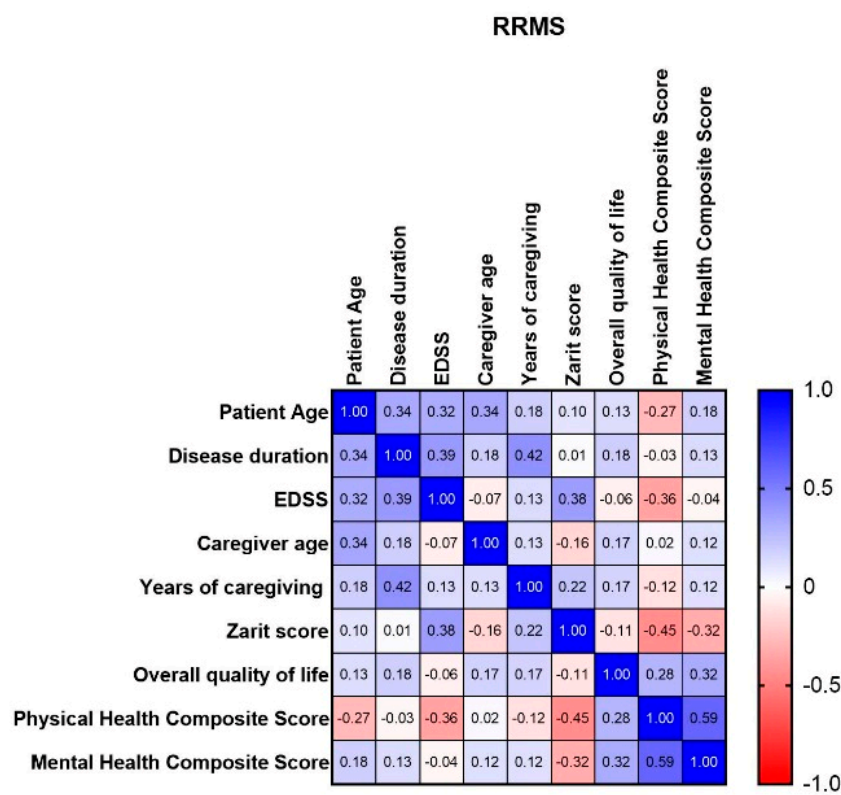


Figure 3. Correlation matrix of the main evaluated variables (patients with RRMS).

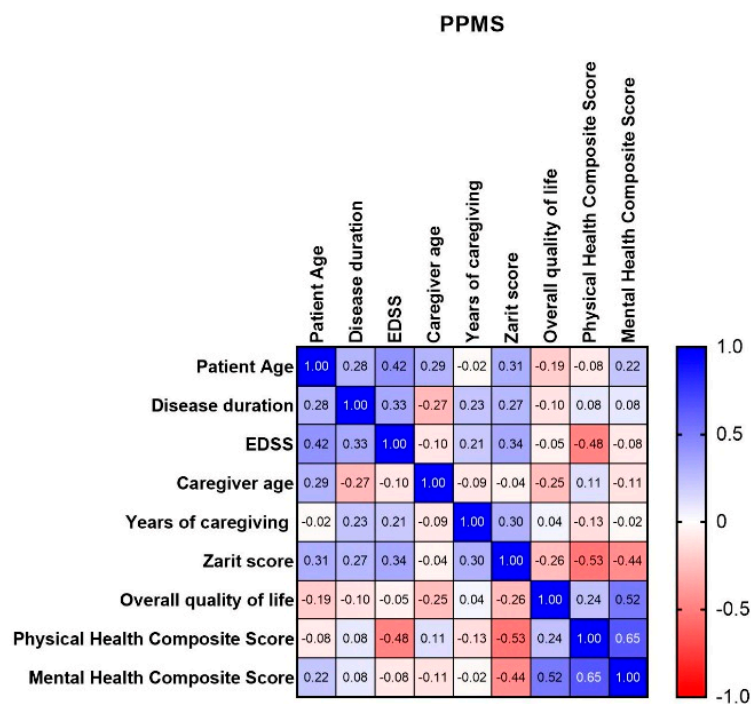


Figure 4. Correlation matrix of the main evaluated variables (patients with PPMS).

Regarding the patients with SPMS, correlation analysis revealed that the Zarit score significantly correlated positively with the following variable: EDSS ($r = 0.36, p \leq 0.05$). A significant negative correlation was observed with the following variable: Physical Health Composite Score ($r = -0.46, p \leq 0.05$). A correlation matrix of all the analyzed variables is shown in Figure 5.

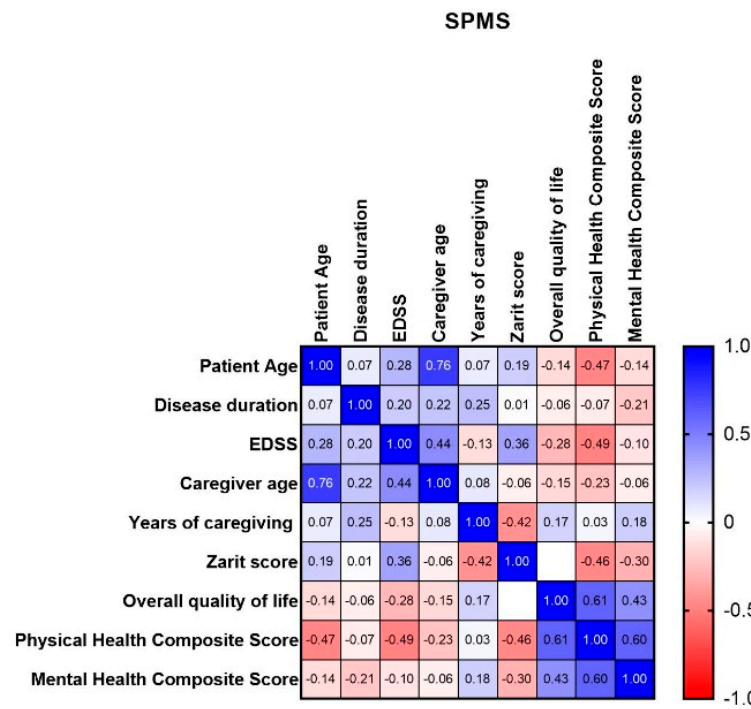


Figure 5. Correlation matrix of the main evaluated variables (patients with SPMS).

4. Discussion and Conclusions

This study analyzed the relationship between the Zarit and the MSQol-54 scores. We found that most caregivers had either a low burden level or none and detected an inverse correlation between the Zarit score and the Physical and Mental Health composite scores obtained with the patients' MSQol-54 screening.

Caregivers who are related to the MS patient are at a considerable risk of developing "care burden" [11,12] since they must cope with the disease and its prognosis [8]. The Zarit Caregiver Burden Interview is used to evaluate the burden and its consequences on the caregivers. In 2023, a study was conducted by Vega E. et al. who identified a relationship between the caregivers' quality of life and an overload among the caregivers of patients with complications resulting from type 2 diabetes mellitus; they used the Short-Form Health Survey (SF-36) and the Zarit scale. They detected an inverse correlation between the caregivers' burden and their quality-of-life dimensions, where if one decreases, the other increases [13]. We evaluated the MSQOL-54, a similar instrument to the SF-36 but it includes 18 more questions. Our results showed that the greater the caregiver's age, the more changes were found in the Zarit questionnaire. Again, the greater the patient's EDSS, the higher the caregiver's Zarit score. Most of the caregivers in our cohort were relatives of the patients.

High caregiver anxiety and low economic status predict a higher burden score [14]. We observed that 21 caregivers had financial problems, of which 7 were men and 14 were women. In our cohort, the number of caregiving males and females was similar. Another study reported that caregivers are usually females, and the authors suggested that this could result from the historic fact that caregiving has traditionally been a woman's assigned responsibility, while men rarely assume this role [15]. Our results did not show a significant difference between the male and female caregivers. Buchanan et al. reported that male caregivers had greater odds of developing high-burden stigmata than women [16]. In a study of 219 caregivers in which 53.4% were male, Algahtani H et al. reported that 57.1% had little or no burden, 30.1% had a mild to moderate burden, 10.5% had a moderate to severe burden, and 2.3% had severe burden [17].

The burden of caregivers of MS patients should be routinely evaluated. Centers that treat and manage patients with MS should also provide self-management programs to all caregivers, as well as social and spiritual support [18].

The main limitation of this study is that it is a single-center study. For this reason, the data correspond to the patients who underwent autologous hematopoietic stem cell transplantation at the Clínica Ruiz. Furthermore, the proportion of MS subtypes was not equal, since the diagnosis of RRMS predominated with 99 patients, followed by PPMS with 42 and, finally, PMSCS with 27 patients.

However, the strength is that the study was not limited to analyzing patients from a single origin; the patients included are from different countries and even different continents and, in most cases, the primary caregivers are family members.

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Data Availability Statement: The data that support the findings of this study are available on request from the corresponding author.

Conflicts of Interest: All authors declare that they have no conflicts of interest.

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