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Posted Date: 12 February 2024

doi: 10.20944/preprints202402.0694.v1

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Caregivers' burden experience: a comparison between Parkinson's Disease, Multiple System Atrophy and Amyotrophic Lateral Sclerosis

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Abstract: Background: Caregiving for individuals with neurological disease involves providing physical, emotional, and social support, which can be a challenging and stressful experience. This study aims to compare the caregivers' burden, including the impact on mental and physical health, social support, and quality of life, in different neurodegenerative disorders. **Methods:**Fifty-five primary caregivers (F=41;mean age=53.07±12.29) of patients with Parkinson's Disease (PD=26), Multiple System Atrophy (MSA=16), and Amyotrophic Lateral Sclerosis (ALS=13), took part in the study. Standardized screening scales for the quality of life (EQ-5D/EQ-VAS and PQoL), levels of the caregiving burden (CBI and FSQ), and the assessment of the anxiety-depressive axis (HADS) were administered. **Results:** The mean CBI score was higher for caregivers of MSA patients (28.81±21.90) and ALS (25.15±16.23) than for caregivers of PD patients (16.08±10.34; p=0.036). Critical burden (cut-off>36) was present in the caregivers of MSA (31.3%), ALS (23.1%), and PD (19.2%) patients. Caregivers of patients with ALS had a worse perception of quality of life (EQ-5D total score) than caregivers of patients with MSA and PD (p<0.001). Caregivers of PD patients showed higher levels of anxiety (p=.000) and depression (p=.000) than the other two groups. Caregivers of PD and ALS patients showed a higher score in urgent requests for psychological support (U), as compared with caregivers of MSA patients (p<0.001). **Conclusions:** Caregiving for individuals with neurodegenerative diseases can be a challenging and stressful experience that negatively impacts the well-being of caregivers. Interventions such as psychoeducation, support groups, and respite care are needed to reduce caregivers' burden and improve well-being.

Keywords: caregivers' burden; quality of life; neurological diseases; Parkinson's disease; multiple system atrophy; amyotrophic lateral sclerosis

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1. Introduction

The term caregiver defines the person who cares for someone who is in a state of need and does not have complete autonomy.

Caregiver burden refers to a particular response to the chronic stress perceived by caregivers due to their caring actions towards ill family members. [1]. Caregiver burden is one of the most serious problems for family caregivers assisting a family member with progressive chronic disease. Evidence [2–5] shows that family caregivers of patients with mental illness, Parkinson's disease (PD), dementia, and terminal cancer experience a significant burden in providing care for them.

The burden of caregiving causes the caregiver to delay his or her own needs and leads to negative experiences, such as reduced interpersonal relationships and impaired physical health, which subsequently affect the caregiver's level of well-being and may result in emotional changes such as stress [6–8]. The fulfillment of one's basic needs and a good level of Quality of Life (QoL) are two of the most important factors determining the well-being of carers, both in protecting their health and in providing care for their family carers. Carers with a good level of well-being can provide better care for their patients and better cope with adverse conditions that may occur [9].

Perceived caregiver burden not only affects the caregiver's well-being but also causes stress in carrying out his or her caring role [10,11]. Caregiver burden is closely related to the way caregivers mentally process the care they provide [12–14].

Neurological disorders affect the QoL not only of patients but also of caregivers due to the physical and psychological discomfort and deficiencies they cause [15,16].

Gallop et al. [17] conducted a study among informal caregivers of persons with PD, multiple systemic atrophy (MSA), pure autonomic failure, or Lewy body dementia. Caregivers of patients (n= 60) with neurogenic Orthostatic Hypotension (nOH) reported a higher burden in all outcomes than those without nOH (n= 60). Furthermore, it was found that pharmacological treatment for nOH was the variable most associated with a significant improvement in caregiver health-related QoL ($p < 0.05$).

A study of 11 primary caregivers of family members with MSA [18] found that caregiving burden and anxiety were correlated. Qualitative sub-themes of the caregiving theme included not only patient safety and caregiver health but also the rapid progression of the disease, which generates frustration and disorientation in caregivers.

Tulek et al. [19] conducted a descriptive study of 108 amyotrophic lateral sclerosis (ALS) patients and their informal caregivers which showed that the caregiving burden was related not only to the patient's gender and functional status but also to several caregiving factors such as the relationship with the patient, gender, health status, time spent on care and living in the same house with a limited environment. In addition, the burden was associated with the caregiver's quality of life, social support, anxiety, and depression.

The present study aimed to analyze the factors influencing caregiver burden, which may be related to both caregiver characteristics and disease features in different neurological disorders. Specifically, three different groups of primary caregivers of patients with PD, MSA, and ALS were examined and compared.

2. Materials and Methods

2.1. Procedure

The present study was conducted on caregivers consecutively recruited from the outpatient clinics of the "San Giovanni di Dio e Ruggi d'Aragona" Salerno University Hospital (Southern Italy). The study was approved by the local Ethics Committee, "Asl Napoli3" (number 130/2021).

Participants came to the Hospital as caregivers of outclinic patients with PD, MSA, and ALS, diagnosed according to the respective criteria [20–22], and were recruited at the end of the routine follow-up visit. First, the researchers briefly explained the purpose of the study and asked for informed consent for participation in the experimental protocol and data collection. Data collection was based on standardized screening scales for the quality of life (QoL), levels of the caregiving burden, and the assessment of the anxiety-depressive axis. Demographic and clinical data concerning the patient and his/her illness and the personal data of the caregivers were noted. Disease severity was assessed using the Hoehn and Yahr scale [23] and the Unified Parkinson's Disease Rating Scale (UPDRS III) [24] for PD; by mean values of the Unified Multiple System Atrophy Rating Scale (UMSARS I-II) [25] for MSA; using the Revised Amyotrophic Lateral Sclerosis Functional Rating Scale (ALS-FRS-R) [26] for ALS.

All the methods were carried out by relevant Institutional guidelines and regulations.

2.2. Assessment

Screening tests used are:

1. EuroQol - EQ-5D [27] to assess the caregiver's health status through 5 questionnaire dimensions: mobility, personal care, habitual activities, pain/discomfort, and anxiety/depression. From the five dimensions of EQ-5D, a synthetic index is derived with a maximum score of 1 indicating

the best health status, while the higher the scores of the individual questions, the more severe or frequent the problems are. The EQ-5D questionnaire also includes a visual analogue scale (VAS) with which the carer expresses his or her perceived overall health level using a value ranging from 0 (worst imaginable health state) to 100 (best imaginable health state).

2. PQoL Carer [28] consisting of 26 items, was used to assess the HR-QoL perceived by caregivers. A cut-off>62 was proposed to identify caregivers with a severe burden and a severe level of anxiety/depression. Overall life satisfaction (LF) was assessed on a scale from 0 (extremely dissatisfied) to 100 (extremely satisfied).
3. Hospital Anxiety and Depression Scale - HADS [29] is used to assess levels of anxiety and depression; includes 14 questions with 4 possible answers corresponding to a score from 0 to 3. This results in two subscales, one for anxiety (HADS-A) and one for depression (HADS-D), constituting two independent measures. In both cases the cutoff>=8 (about generalized anxiety disorder and major depression episodes respectively). The HADS is divided into four grades: normal (0-7), mild (8-10), moderate (11-15), and severe (16-21).
4. Caregiver Burden Inventory - CBI [30] is a caregiver burden assessment instrument consisting of 24 questions and divided into 5 sections to assess different stress factors: time-dependent burden or objective burden (T/dep-B) describing the burden associated with the restriction of time for the caregiver; developmental burden (Dev-B) understood as the caregiver's perception of feeling cut off from the expectations and opportunities of their peers; physical burden (Phys-B) describing feelings of chronic fatigue and somatic health problems; social burden (Soc-B) describing the perception of role conflict; emotional burden (Emot-B) describing feelings towards the patient, which may be induced by unpredictable and unusual behavior. In the adult population, a cut-off score >36 is conventionally used to indicate the presence of burden.
5. Family Strain Questionnaire Short Form - FSQ-SF [31] to identify the level of stress and strain experienced by the caregiver in caring for his/her relative. It consists of 30 dichotomous ("yes" or "no") questions in order of severity and grouped into 4 areas of increasing psychological risk: OK, R (recommended), SR (strongly recommended), and U (urgent).

Finally, two open-ended questions were added as follows:

1. *“Could you please tell me about your experience, what you experience, what you feel in caring for your family member at home?”*
2. *“Has the experience of caring for your family member ever made you think about the risk of the disease on your person?”*

A qualitative, thematic content analysis was performed on this content, which was transcribed.

2.3. Data analysis

Quantitative analysis: ANOVA was performed for the analysis of the mean and standard deviation (M±*SD*) of the variables under study. A comparison of the mean of the scores obtained on the screening scales among the subgroups of the caregivers’ sample according to specific variables was performed by chi-square value. Pearson’s bivariate correlation analysis was performed with patients’ and caregivers’ features with p= 0.01/0.05 significance values.

The statistical software IBM SPSS v.23 (Armonk, NY: IBM Corp; 2015) was used.

Qualitative analysis: the whole corpus (8237 words) of the narrative was analyzed through an automatic procedure for content analysis (Predecessors and Successors), performed by T-Lab Plus 2022 software [32]. This procedure made it possible to map the main dimensions of meanings underlying the content set. The method is based on the general assumption that meanings are formed in terms of lexical variability [33].

Transition probabilities (Markov chains) were calculated and outputs concerning the target words were generated.

3. Results

3.1. Participants

Fifty-five primary caregivers took part in the study (Female= 41; mean age= 53.07±12.29). Regarding the degree of relationship with the patient, 58.2% were the spouse, 38.2% were the son/daughter and 3.2% were "other".

The total sample had an average education level of 12.31±4.26 and 50.9% were employed in manual work, 40% in intellectual work, and 9.1% were retired. 74.5% of patients lived with their caregiver and the total sample reported an average daily employment for caregiving of 12.78±9.33 (expressed in hours).

Caregivers were divided into groups according to the specific diagnosis of the patients, specifically caregivers of patients with Parkinson's Disease (PD; n= 26), Multiple System Atrophy (MSA; n= 16), and Amyotrophic Lateral Sclerosis (ALS; n= 13). All characteristics of the caregiver groups are shown in Table 1. No difference was found in demographic and clinical features among caregivers' groups.

Table 1. Demographic and clinical features of the caregivers (CG) groups.

		PD caregivers (n= 26)	**MSA caregivers (n= 16)**	**ALS caregivers (n= 13)**	***p***
Sex	Male	7	4	3	.967
	Female	19	12	10	
Age (y)	-	57.04±10.64	49.63±11.73	49.38±14.41	.075
Degree of kinship	Spouse	16	9	7	.747
	Son/Daughter	10	6	5	
	Other	-	1	1	
Cohabitation	Yes	20	11	10	.819
	No	6	5	3	
Scholarship (y)	-	13.23±4.46	11.50±4.19	11.46±3.82	.321
Job position	Manual labor	13	9	6	.658
	Intellectual work	10	7	5	
	Retired	3	0	2	
Time of caregiving (h)	-	12.85±10.78	14.47±9.11	10.69±6.07	.574

Clinical characteristics of the patients according to diagnosis are shown in Table 2.

Age and disease duration were higher in PD patients as compared with MSA and ALS patients (p=0.002; p=0.001).

Table 2. Clinical characteristics of the patients (P) groups.

		PD patients (n= 26)	**MSA patients (n= 16)**	**ALS patients (n= 13)**	***P***
Sex	Male	19	10	8	.685
	Female	7	6	5	
Age (y)	-	72.27±10.54	61.94±6.37	64.38±9.92	.002

Disease duration (y)	-	7.62±4.75	4.25±2.17	3.31±2.28	.001
Ambulatory patients	Yes No	26 0	14 2	13 0	.000
Disease severity	Hoehn-Yahr	2. 69±0.54	-	-	-
	UPDRS III	28.46±11.35	-	-	-
	UMSARS I	-	23.06±5.50	-	-
	UMSARS II	-	26.56±7.49	-	-
	ALS-FRS-R	-	-	26.45±7.63	-

3.2. *Quality of Life*

Regarding the QoL index, caregivers of ALS patients are those who perceived their condition worst, with an average EQ-VAS score significantly lower than PD and MSA caregivers ($p<0.001$). Specifically, on the subscales of mobility, self-care, usual activities, and anxiety depression, the caregivers of patients with ALS showed significantly worse scores than PD and MSA caregivers (see Table 3).

Table 3. Mean±SD of EQ-5D and PQoL index for Quality of Life.

	PD caregivers (n= 26)	**MSA caregivers (n= 16)**	**ALS caregivers (n= 13)**	***p***
EQ-5D Total score	6.96±1.99	6.94±1.34	15.62±4.01	.000
EQ-5D (Mobility)	1.35±0.79	1.13±0.34	3.62±1.19	.000
EQ-5D (Self-care)	1	1	3.77±1.01	.000
EQ-5D (Usual activities)	1.12±0.32	1	3.85±0.68	.000
EQ-5D (Pain/Discomfort)	1.81±0.74	1.81±0.65	2.08±1.18	.613
EQ-5D (Anxiety/Depression)	1.69±0.83	2±0.63	2.31±1.03	.097
EQ-VAS	75.38±15.29	82.06±19.42	36.15±21.42	.000
PQoL	26.27±17.05	34.19±15.51	33±22.13	.317
PQoL - LF	72.31±15.44	70.63±24.41	60.38±31.52	.294

3.3. *Caregivers burden*

The mean CBI score was higher for caregivers of patients with MSA (28.81±21.90) and ALS (25.15±16.23) than for caregivers of patients with PD (16.08±10.34; p=0.036). Also, the analysis of the subscales concerning objective burden (T/dep-B; p= 0.15), developmental burden (Dev-B; p= 0.32), physical burden (Phys-B; p= .605), social burden (Soc-B; p= .322) showed that the caregivers of ALS and MSA patients had higher scores than caregivers of PD patients (see Table 4). In contrast, in the Emot-B subscale (p= .155), caregivers of MSA patients had high mean values (2.94±4.28) compared to PD (1.69±1.73) and ALS (1.08±1.11).

Critical burden (patients with scores >36) was found in 31.3% of the caregivers of MSA patients, 23.1% of the caregivers of ALS patients, and 19.2% of the caregivers of PD patients (p= .685).

Table 4. Mean±SD of CBI index and subscales.

	PD caregivers (n= 26)	**MSA caregivers (n= 16)**	**ALS caregivers (n= 13)**	***p***
CBI – T/dep-B	5.81±5.85	10.75±6.38	10.54±5.59	.015
CBI – Dev-B	2.85±3.19	6.56±6.13	5.46±4.57	.032
CBI – Phys-B	3.54±3.06	4.69±4.43	4.46±4.66	.605
CBI – Soc-B	2.19±2.77	3.88±5.36	3.62±3.45	.322
CBI – Emot-B	1.69±1.73	2.94±4.28	1.08±1.11	.155
CBI TOTAL SCORE	16.08±10.34	28.81±21.90	25.15±16.23	.036

3.4. Anxiety-depression axis and family strain

The caregivers of PD patients showed higher levels of anxiety (*p*= .000) and depression (*p*= .000) than the other two groups (Table 4).

Regarding the urgency of psychological support, caregivers of patients with PD and ALS patients showed a higher score in urgent requests for psychological support (U), as compared with caregivers of MSA patients (*p*<0.001).

Table 4. Mean±SD of HADS index for anxiety (A) and depression (D) and FSQ – AREA U subscale.

	PD caregivers (n= 26)	**MSA caregivers (n= 16)**	**ALS caregivers (n= 13)**	***p***
HADS – A	22.50±1.67	12.88±1.78	6.46±3.90	.000
HADS – D	17.38±2.56	7.19±1.94	6.46±2.87	.000
FSQ – AREA U (urgent)	15.92±1.46	3.69±2.77	15.23±2.04	.000

3.5. Correlations with clinical features

Considering caregivers of PD patients, a significant correlation emerged between the variable "cohabitation" and EQ-VAS (*r*= .409; *p*= .038). Life satisfaction (LF) was related to CBI (*r*= -.555; *p*= .003).

In the group of caregivers with MSA patients, the score of caregiver's burden (CBI) was related to the disease severity as assessed by UMSARS I (*r*= .561; *p*=.024) and UMSARS II (*r*= .519; *p*= .039) and FSQ – AREA U (*r*= .512; *p*= .043). Levels of depression (HADS-D) correlated with FSQ – AREA U (*r*=.564; *p*=.023).

Life satisfaction (LF) of the group of caregivers of ALS patients was significantly related to the anxiety index (HADS-A) (*r*= -.775; *p*= .002). Depression (HADS - D) was related to LF (*r*= -.604; *p*= .029) and CBI score (*r*= .779; *p*= .002). Caregivers' burden score (CBI score) correlated with EQ-VAS (*r*= -.739; *p*= .004). The ALS-FSR-R disease severity index correlated with the QoL index (EQ-5D; r= -.672; *p*= .024).

A linear regression model performed on the total sample showed that a diagnosis of PD was a predictor of a better QoL and higher scores on HADS-A (*p*= 0.000) and HADS-D (*p*= 0.000).

3.6. Qualitative analysis

Tables 5 and 6 show the lists of predecessors and successors associated with the words most recurrent in the narratives showing a high statistical probability (p= 0.1).

The second column of both tables shows the most recurrent words (headwords) and reflects the profile of the sufferers (autonomous, need, illness, medicine, lonely, tiredness for predecessors; years, attention, medicine, manage, think, worry, hope, tiredness and visit for successors). The first column refers to the terms preceding (see Table 5) or succeeding (see Table 6) the headwords in the second column.

Table 5. List of predecessors associated with the words most recurrent in the narratives.

Predecessors	Headwords	Prob. (p)
AUTONOMOUS	HELPING	0.1
AUTONOMOUS	CARING	0.1
NEED	HELPING	0.1
NEED	CARING	0.1
DISEASE	HELPING	0.1
DISEASE	PROBLEMS	0.1
DRUGS	PROBLEMS	0.1
ALONE	DAUGHTER	0.1
SICKNESS	HELPING	0.1

Table 6. List of successors associated with the words most recurrent in the narratives.

Successors	Headwords	Prob. (p)
HELPING	NEED	0.1
YEARS	DAUGHTER	0.1
ATTENTION	NEED	0.1
DRUG	WORRY	0.1
MANAGE	HELPING	0.1
THINK	PROBLEMS	0.1
WORRY	NEED	0.1
RESOLVE	WORRY	0.1
HOPE	PROBLEMS	0.1
SICKNESS	PROBLEMS	0.1
VISIT	DAUGHTER	0.1

4. Discussion

Caregiver burden refers to the physical and emotional strain experienced by individuals who provide care to loved ones with chronic illnesses, disabilities, or age-related conditions. It is a complex issue that can have a significant impact on the well-being of caregivers. In this study, we analyzed several vulnerability factors that increase the risk of caregiver burden and the quality of life. Regarding the presence of critical burden (cut-off >36) in the total sample, it emerges that a higher percentage is present in the caregivers with MSA patients (31.3%), with ALS (23.1%), and PD (19.2%) (p= .685).

Caring for a loved one can result in increased physical demands, leading to exhaustion and a decline in the caregiver's health. Several studies have highlighted the adverse effects on caregivers' physical well-being. For instance, a study by Schulz et al. [34] found that caregivers of individuals with dementia had higher rates of chronic conditions and poorer overall health compared to non-caregivers. Our results found that caregivers of patients with ALS have a higher average score on the EQ-5D “mobility” subscale (3.62±1.19) and that in general caregivers of patients with PD

(75.38±15.29) and ALS (36.15±21.42) have a worse perception of quality of life (EQ-5D total score) than caregivers of patients with MSA (82.06±19.42). Providing care to a loved one can lead to increased stress, anxiety, and depression among caregivers. They may experience emotional strain due to witnessing the decline in their loved one's health or struggling to manage their caregiving responsibilities. A systematic review by Pinquart and Sörensen [35] examined the relationship between caregiving and depression, showing that caregivers are at higher risk of experiencing depressive symptoms compared to non-caregivers. In our research sample, a moderate to severe level of anxiety and depression emerged especially in caregivers of patients with PD (HADS-A= 22.50±1.67; HADS-D= 17.38±2.56) ed MSA (HADS-A= 12.88±1.78).

Caregivers may face social isolation as their caregiving responsibilities limit their ability to participate in social activities and maintain relationships. This isolation can contribute to feelings of loneliness and a lack of support. A study by Navaie-Waliser et al. [36] found that caregivers reported decreased social activities and interactions due to their caregiving responsibilities.

The level of caregiver burden may vary between different neurodegenerative diseases. In our study, we considered PD, ALS, and MSA and although each of these diseases presents unique challenges and characteristics, there are some general differences in the caregiver burden associated with each disease.

Regarding PD, some clinical factors that may influence caregiver burden are: a) the severity of symptoms, patients with more severe symptoms may require a higher level of care and support from caregivers; b) associated complications, some patients with PD may develop complications such as dyskinesias (involuntary movements), dystonia or motor fluctuations. These complications may require more intensive management and adaptation of care by caregivers. c) non-motor symptoms, such as depression, anxiety, sleep disturbances, and cognitive problems. The management of these symptoms may require additional caregiver commitment. In our study, caregivers of patients with PD show critical levels of anxiety (HADS-A= 22.50±1.67) and depression (12.88±1.78) compared to other groups of caregivers. A study by Liu et al. [37] suggests that caregivers of patients with neurodegenerative disease and dementia should receive more support than is currently available as levels of stress, anxiety, and depression impair QoL. Furthermore, the difficulty of these caregivers to seek help from both first (family) and second (friends) type relational networks has been verified [38].

Caregivers of patients with MSA have a higher caregiver burden score (CBI TOTAL SCORE= 28.81±21.90) than those of patients with PD and ALS. Indeed, the severity and progression of disease in MSA are major in MSA than PD and patients with more severe symptoms and rapid progression may require a more intensive and continuous level of care. The management of these dysfunctions may affect the caregivers' burden. In the study conducted by Langford et al. [39], mild-to-moderate caregiver burden and anxiety were found in caregivers of patients with MSA, as the rapid progression of the disease-oriented caregivers increased their workload. The higher caregiver burden in MSA than in ALS is more difficult to explain, probably because both are severe and rapidly progressive diseases.

Caregivers of patients with ALS are those who require the most urgent psycho-physical support. We may speculate that the rapid progression of muscle weakness, respiratory and nutritional complications, together with communication problems importantly affect the caregivers' burden. An urgent need for psychological support also emerged in caregivers of PD patients, possibly due to the longer disease duration and consequent longer commitment as caregivers for this group of patients.

The descriptive cross-sectional study of Thomas et al. [40] conducted with 30 ALS patients and their caregivers (men = 19; women = 11) showed that function and quality of life were negatively correlated with caregiver burden. Caregiver burden was negatively associated with 'negative emotional state' and 'patient interaction with family and environment', subdomains of the ALSQOL scale.

Caregiver well-being is defined as the fulfillment of basic needs, such as getting enough sleep and nutrition, and the maintenance of life activities, such as doing housework or participating in social activities.

As Maslow suggested [41,42], physical needs are basic and are at the lower level of the hierarchy of needs. In the case of caregivers, the satisfaction of the most basic needs is interrupted by the patient's illness. Therefore, the satisfaction of basic needs becomes more important for the caregiver. In this context, it is important to support the carer so that he/she can satisfy his/her basic needs and maintain his/her life activities when providing care to the patient for whom he/she has assumed responsibility. Attempts to determine and improve the well-being of caregivers can be considered a protective shield to reduce the negative effects of life, such as stress, on an individual and to prevent the development of diseases.

Various interventions and support systems can help reduce caregiver burden. These include respite care, support groups, counseling services, and caregiver training programs. A review by Gaugler et al. [43] and other more recent studies [44–46] evaluated the effectiveness of interventions aimed at reducing caregiver burden and found that multicomponent interventions were most effective.

Furthermore, some differences emerged between the three groups of caregivers taken into consideration in the present study. The correlational analysis showed that the level of life satisfaction of the caregivers of PD patients correlated negatively with the caregiver’s burden index, whereas the perception of the QoL correlated with the variable “cohabitation”, which would suggest that living together with these patients would alleviate concern about the management and care of the disease because it would allow greater control. No correlation was found in this group between burden and disease features.

On the other hand, in the group of caregivers of MSA patients, the caregiver burden score was directly related to UMSARS I and UMSARS II, assessing disease-related impairment in activities of daily living and motor examination, respectively. This suggests that, as the patient's symptoms increase, so does the stress burden associated with care. Furthermore, both the caregiver burden and levels of depression are correlated with the urgent need for psychological support in this caregiver group.

Life satisfaction (LF) of the ALS patient-caregiver group correlated negatively with anxiety and depression scores. Furthermore, the caregiver burden score (CBI) was positively related to levels of depression (r= .779; p= .002) and negatively related to the perceived QoL (EQ-VAS; r= -.739; p= .004). Greater disease severity index correlated with a lower QoL, showing that also in this group the worsening of the disease negatively affected the caregivers' QoL.

These findings indicate that many factors relating to the different diseases and their management negatively influence both the caregivers' QoL and the onset of anxious-depressive symptoms.

From the qualitative analysis of the caregivers' narratives, it is evident that the most recurrent lemmas relate to the caregivers' concern about the problems of their family member being cared for, the daily routine of the illness related to pharmacotherapy, the constant request for help, and the fatigue of caring for such serious patients. It is undoubtedly the overload of care that generates the burden which we found to be means of quantitative scales. In both tables we found the related term “daughter”, and this is again in line with our quantitative data, which recognize a greater care overload for women, especially daughters of patients (CBI score: F= 22.24±17.04 vs. M= 21±15.64; p= .811).

5. Conclusions

In this study, the caregiver burden of caregivers of family members with neurological disorders was investigated and it was concluded that the level of well-being is worse, and the level of stress is higher in caregivers who perceive the caregiver burden to be high. The assessment of these variables in caregivers can be considered a factor in maintaining the health of both caregivers and individuals in need of care. In this context, it can be argued that if caregiver well-being is to be preserved, it is important to plan interventions that reduce the perceived caregiver burden for caregivers of patients with neurological disorders, which inevitably require someone to assume the role of caregiver. Interventions such as psychoeducation, support groups, and respite care have been shown to reduce the burden and improve the well-being of caregivers. Psychoeducation programs that provide caregivers with information about the disease and its management have been shown to improve the caregiver's knowledge and confidence, reduce distress, and improve the quality of life. Support groups provide a platform for caregivers to share their experiences and receive emotional support from other caregivers. Respite care, which involves temporary relief from caregiving responsibilities, has been shown to reduce caregiver burden and improve well-being.

6. Limitations and prospects

This study shows several methodological limitations. In the first place, the failure to collect further variables characterizing the sample, such as socio-economic status (SES), did not allow for further investigation of the correlation of the factors with burden.

Furthermore, no age differences could be detected. According to a primary prevention perspective and in continuity with further future developments in this area of investigation, it would be useful to hypothesize a protocol for assessing the emotional-cognitive states of caregivers, to monitor any influence of environmental and context variables that may undermine adaptive coping strategies. Furthermore, the usefulness of this monitoring would allow the creation of an intervention action through focus groups of sharing, empowerment, and personal well-being.

Author Contributions: Conceptualization, L.C., C.R., Gi.Sa., and Gi.St.; methodology, L.C., E.T., F.P., C.R, Gi.Sa., and Gi.St.; formal analysis, L.C.; data curation E.T., F.P., L.C., C.R, Gi.Sa., and Gi.St.; writing—original draft preparation, L.C., C.R, Gi.Sa., and Gi.St.; writing—review and editing, Gi.Sa. and C.R.; visualization, P. B, A. T, M.T.P. and M.M. All authors have read and agreed to the published version of the manuscript.

Consent to Participate: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: The datasets used during the current study are available from the corresponding author upon reasonable request.

Conflicts of Interest: The authors declare no competing interests.

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