Brief Report

A Brief Report on the Caregiver Burden: Exploring the Risk and Psychological Factors in Caregivers of Patients with Parkinson's Disease

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A Brief Report on the Caregiver Burden: Exploring the Risk and Psychological Factors in Caregivers of Patients with Parkinson's Disease

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Abstract: Background: Parkinson's disease (PD) is a neurodegenerative disorder that affects both patients and their caregivers, particularly parents who often become informal caregivers. Caring for someone with PD is linked to increased psychiatric morbidity and persistent anxiety-depressive distress. **Methods:** This study investigates the burden on caregivers of PD patients using multidimensional scales and identifies the personological and environmental factors contributing to this burden. **Results:** 20.6% of participants reported a severe burden according to the Caregiver Burden Inventory (CBI), while 13.8% had a moderate to severe burden according to the Zarit Caregiver Burden Inventory (ZBI). The Family Strain Questionnaire Short Form (FSQ-SF) highlighted a minority of caregivers needing psychological support, with some cases requiring urgent attention, particularly in stress-related symptoms (SR) and urgent support (U). The Depression Anxiety Stress Scales Short Version (DASS-21) results showed a higher prevalence of stress-related symptoms compared to anxiety and depression. Retired caregivers reported higher ZBI scores and lower life satisfaction levels compared to working caregivers. Additionally, years of schooling negatively correlated with the ZBI score. T-test analysis indicated that caregivers of patients with cognitive impairment were at greater risk compared to caregivers of patients without cognitive impairment. **Conclusions:** The results underscore the need for early recognition of risky situations and adequate support for caregivers.

Keywords: caregiver burden; parkinson's disease; quality of life; psychiatric morbidity; anxiety-depressive distress

1. Introduction

Parkinson's disease (PD) is a chronic and progressive neurodegenerative disorder that primarily affects the motor system. It is characterized by symptoms such as tremors, rigidity, and bradykinesia. However, it is important to recognize that the impact of PD extends beyond the physical symptoms experienced by patients. Caregivers, particularly relatives who often take on the role of informal caregivers, play a crucial role in supporting and caring for individuals with PD [1].

Caring for a person with PD can be emotionally and physically demanding, placing significant strain on caregivers. The loss of autonomy and the need for continuous care undoubtedly have a profound impact on the quality of life of caregivers. The burden experienced by caregivers can manifest in various ways, encompassing objective burden, psychological burden, physical burden, social burden, and emotional burden [2]. Objective burden refers to the physical demands of caregiving, such as assisting with daily activities, managing medications, and attending medical appointments. Psychological burden encompasses the emotional strain and distress experienced by caregivers, including feelings of anxiety, depression, and frustration. Physical burden refers to the impact of caregiving on the physical health of caregivers, which can lead to fatigue, sleep disturbances, and other health issues. Social burden is the strain on social relationships, as caregiving

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responsibilities may limit social interactions and activities. Lastly, emotional burden encompasses the complex emotions experienced by caregivers, such as guilt, sadness, and grief [3].

The burden experienced by caregivers of individuals with PD can have a significant impact on their mental well-being. Studies have shown that caregivers of patients with PD are at an increased risk of psychiatric morbidity, including persistent anxiety and depressive distress [4]. The constant demands of caregiving, coupled with the progressive nature of PD, can lead to chronic stress and emotional exhaustion among caregivers.

The study aims to capture the various dimensions of caregiver burden and identify the factors that contribute to this burden. By examining both personological and environmental factors, the study seeks to shed light on the specific challenges caregivers face in patients with PD. Factors such as the caregiver's age, gender, education level, employment status, and relationship with the patient will be explored. Additionally, the study will investigate environmental factors, including the availability of social support, access to healthcare resources, and the presence of cognitive impairment in the patient.

2. Materials and Methods

The study was conducted at the Neurology Department of the A.O.U. "San Giovanni di Dio and Ruggi D'Aragona" of Salerno between September 2020 and May 2021.

The study used several standardized screening scales to assess caregiver burden and psychological factors. These scales included:

a) Caregiver Burden Inventory (CBI) [5]: A questionnaire consisting of 24 items that allow for the identification of five sub-categories of burden (objective, psychological, physical, social, and emotional).

b) Depression Anxiety Stress Scales Short Version (DASS-21) [6]: A questionnaire consisting of 21 items that assess three distinct but interrelated areas: depression, anxiety, and stress.

c) Family Strain Questionnaire Short Form (FSQ-SF) [7]: A questionnaire comprising 30 items grouped into areas of increasing psychological risk.

d) Zarit Caregiver Burden Inventory (ZBI) [8]: A questionnaire consisting of 22 items that assess personal stress and pressure related to the caregiver's role.

e) Life Satisfaction: A single item that aims to evaluate the degree of life satisfaction using a Likert scale.

3. Results

3.1. Participants' Characteristics

A total of 29 caregivers (69% female) participated in the study, with a mean age of 55.14 years (SD= 9.85). Table 1 shows all the characteristics of the caregivers group.

Regarding the type of relationship between caregivers and patients, the data are divided into three groups: 'son/daughter', 'spouse', and 'other'. The largest percentage of cases (58.6%) falls into the category 'spouse', followed by 'son' with 27.6% of cases and 'other' with 13.8%. Cumulatively, the categories 'spouse' and 'son' cover 86.2% of cases. This breakdown suggests a varied distribution of relationships, with spouses being the most common, followed by sons and then other relationships. Most caregivers, amounting to 79.3% of the dataset, fall into the category "YES" to the variable "cohabitation". In contrast, "NO" accounts for fewer cases (20.7%).

The distribution of percentages among the different occupational categories is segmented into three main groups: 'Manual work', 'Intellectual work', and 'Retirement'. The category 'Manual work' accounts for most cases, with 37.9% of the data, followed closely by the category 'Intellectual work' with 31%. The 'Retirement' category also holds a significant share, accounting for 31% of the cases. Overall, the 'Manual Work' and 'Intellectual Work' categories account for 69% of the dataset, with the 'Retirement' category making up the remaining 31.0%. The sample shows an average level of schooling of 11.69 years (SD= 3.87).

Table 1. Participants' characteristics.

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Sex	Degree of kinship	Cohabitation	Job position	Cognitive impairment of the patient/carer
Male (31%)	Spouse (58.6%)	Yes (79.3%)	Manual work (37.9%)	Present (17.2%)
Female (69%)	Son/Daughter (27.6%)	No (20.7%)	Intellectual work (31%)	Absent (82.8%)
	Other (13.8%)		Retired (31%)	

3.2. Dimension of the Burden

The mean score of the Caregiver Burden Inventory (CBI) was 26.31 (SD= 22.43). The majority of caregivers (58.6%) experience a low burden, while a smaller proportion faces mild (20.7%) or moderate (17.2%) burdens. Only a few caregivers (3.4%) report a severe burden. We also found an increase in total CBI scores for caregivers of patients with cognitive impairment (36.40, SD= 18.796) compared to caregivers of patients without cognitive impairment (24.21, SD= 22.895).

Regarding the Zarit Caregiver Burden Inventory (ZBI), most caregivers (51.7%) experience little or no burden, while 34.5% have a mild to moderate burden. Only a small proportion of caregivers (6.9% each) report a moderate to severe or severe burden.

The results of the Depression Anxiety Stress Scales Short Version (DASS-21) showed a higher prevalence of stress-related symptoms (M = 10.90, SD = 10.712) compared to anxiety (M = 7.52, SD = 10.752) and depression (M = 8, SD = 10.876).

The Family Strain Questionnaire Short Form (FSQ-SF) shows a minority of caregivers in need of psychological support: the sample presents different averages for the extent of support required: 2,97 (SD= 1,991) for recommended support (R); 2,83 (SD= 2,465) for strongly recommended support (SR) and 2,79 (SD= 2,637) for urgent support (U). Table 2 shows the frequency indices of the tests administered.

Significant correlations were found between specific variables and mean test scores. Retired caregivers reported higher ZBI scores (p = 0.423) and lower levels of life satisfaction (p = -0.460) compared to working caregivers. Moreover, years of schooling showed a negative linear correlation with the ZBI score (p = -0.491).

Table 2. Burden level frequencies.

CBI	ZBI	DASS-21	FSQ-SF
Low burden (58.6%)	Little or no burden (51.7%)	Stress M= 10.90, SD= 10.712	Recommended (R) M= 2.97, SD= 1.991
Mild burden (20.7%)	Mild to moderate burden (34.5%)	Anxiety M= 7.52, SD= 10.752	Strongly Recommended (SR) M= 2.83, SD= 2.465
Moderate burden (17.2%)	Moderate to severe burden (6.9%)	Depression M= 8, SD= 10.876	Urgent (U) M= 2.79, SD= 2.637
Severe burden (3.4%)	Severe burden (6.9%)		

4. Discussion

The results of this study highlight the significant burden experienced by caregivers of patients with Parkinson's disease and the need for early recognition of risky situations and the provision of adequate support. The multidimensional scales used in the study allowed for a comprehensive assessment of caregiver burden, including objective, psychological, physical, social, and emotional dimensions.

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The Family Strain Questionnaire Short Form (FSQ-SF) highlighted a minority of caregivers who needed psychological support, with some cases requiring urgent attention. The Depression Anxiety Stress Scales Short Version (DASS-21) results showed a prevalence of stress-related symptoms compared to anxiety and depression.

Significant correlations were found between specific variables and mean test scores. Retired caregivers reported higher Zarit Caregiver Burden Inventory (ZBI) scores and lower life satisfaction levels compared to working caregivers. Years of schooling showed a negative linear correlation with ZBI scores. Additionally, caregivers of patients with cognitive impairment were found to be at a greater risk compared to caregivers of patients without cognitive impairment.

The results indicate that a significant proportion of caregivers experience severe burdens, which can have detrimental effects on their mental and physical well-being. The prevalence of stress-related symptoms suggests the need for interventions targeting stress reduction and emotional support for caregivers.

Retired caregivers and those with lower levels of education were found to be at a higher risk of experiencing burden and lower life satisfaction. This highlights the importance of considering socio-economic factors in providing support and interventions for caregivers [1].

Caregivers of patients with cognitive impairment were also found to be at greater risk, emphasizing the need for tailored interventions to address the specific challenges faced by this subgroup of caregivers. A systematic review and meta-analysis revealed that the severity of cognitive impairment in care recipients is associated with increased caregiver burden. The study found that caregivers of patients with dementia or severe cognitive decline often experience significant psychological symptoms, such as anxiety and depression, due to the intense demands of caregiving and the progressive nature of cognitive disorders [9].

5. Conclusions

In conclusion, caregiving for patients with Parkinson's disease is associated with a significant burden on caregivers, impacting their quality of life and mental well-being.

Understanding the factors that contribute to caregiver burden is crucial to providing appropriate support and interventions [10]. By identifying the specific challenges faced by caregivers of patients with PD, healthcare professionals can develop targeted interventions and support programs to alleviate the burden and improve the overall well-being of caregivers. It is through this comprehensive understanding and targeted support that we can truly make a difference in the lives of caregivers and enhance the quality of care provided to individuals with PD.

Further research is needed to develop targeted interventions that address the specific needs of caregivers and improve their overall well-being.

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Institutional Review Board Statement: The study was conducted with caregivers recruited consecutively from the outpatient clinics of the “San Giovanni di Dio e Ruggi d’Aragona” Salerno University Hospital in Southern Italy. Approval for the study was obtained from the local Ethics Committee, "Asl Napoli3" (number 130/2021).

Informed Consent Statement: 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 conflicts of interest.

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