ISSN: 2755-9351

Journal of Alzheimer's Disease & Reports

SCIENTIFIC Research and Community

Research Article

Open Access

Quality of Life of the Caregivers of Patients with Neurodegenerative Disorders, Miami Dade County, Florida

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ABSTRACT

Background: Neurodegenerative disorders, such as Parkinson's disease, dementia, and Alzheimer's disease, impact caregivers, influencing their quality of life and mental well-being. Understanding these perceptions is crucial for developing targeted support systems.

Purpose: This descriptive study aimed to explore caregivers' experiences with specific neurodegenerative disorders in Miami-Dade County, focusing on psychological distress, coping strategies, and socio-emotional context.

Methods: Employing a cross-sectional descriptive survey design, formal and informal caregivers above 18 years old, providing care for patients diagnosed with Alzheimer's Disease, Parkinson's Disease, or dementia, and residing in Miami-Dade County were included. Data collection involved self-reported measures on caregiving characteristics, patients' emotional status, caregiver well-being, and overall health perception. Statistical analysis was accomplished with the IBM-SPSS version 29 (2022) statistical software package.

Results: This study presents preliminary findings from a diverse caregiver sample, predominantly female (79%), with varied educational backgrounds. Caregivers reported emotional exhaustion, insomnia, and fatigue. Psychological symptoms showed nuanced associations with educational levels. Detailed demographics reveal marital status (52% married), caregiver types (95% informal), and relationships to care receivers (48% daughters). Frequency and percentage breakdowns are provided for caregiver burdens, patient emotional status, and health assessments, emphasizing the need for targeted support interventions.

Conclusion: This study contributes to knowing caregivers' experiences in specific neurodegenerative disorders, emphasizing the need for tailored interventions. While preliminary, these findings highlight the potential impact of educational background on caregiver well-being. Further research and targeted support programs are crucial to improving the overall quality of life for caregivers and patients facing these challenging conditions.

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Received: December 31, 2025; **Accepted:** January 06, 2026; **Published:** January 14, 2026

Keywords: Caregivers, Neurodegenerative Disorders, Quality of Life, Mental Well-Being, Socio-Emotional Context, Alzheimer's Disease, Parkinson's Disease, Dementia

Introduction

Since the past century, brain impairment has been considered a family matter because it involves the patient and the entire family unit at diverse levels stated that brain impairment might trigger an extensive range of neuropsychological and psycho-behavioral sequelae, which demand an intricate and long-lasting rehabilitative process and continuous support by at least one informal caregiver [1].

Caregivers might have an active role in the rehabilitation progression; similarly, it is frequently perceived in clinical practice that the negative impact of inappropriate caregiving methods on the patient, in several cases, obstructs the neurorehabilitation team. However, Özdilek expressed that providing support from family members and living with neurocognitive patients is a substantial burden on primary caregivers. Primary caregivers might be involved in circumstances that increase psychological distress because of the chronically harmful patients' social, psychological, and financial demands [2]. Correspondingly, psychological anguish is theoretically defined as an uncomfortable, emotional state experienced by a person in reaction to a particular stressor or demand that results in either impermanent or permanent harm to the individual.

Background

Akila and Agnes emphasized the significance of caregivers' quality of life and health, highlighting the effectiveness of inclusive health care approaches in addressing caregivers' coping procedures and problem-solving tactics to reduce distress. These coping tactics empower caregivers to confidently care for both themselves and their companions [3].

Gilhooly identified caregiver characteristics as potential risk factors for physical and psychological stress in individuals with neurocognitive disorders. While psychological benefits for caregivers are common, adverse outcomes may result from denial, wishful thinking, and evasion of coping strategies [4]. Psychoeducational and psychosocial interventions were recommended to support caregivers and older adults with neurocognitive disorders. Excessive caregiver burden was associated with unstable emotions, potentially damaging the patient-caregiver relationship and diminishing the caregiver's quality of life [5].

Bakof observed a rise in mental health issues among caregivers, especially those caring for older individuals with dementia. Social isolation, emotional fatigue, and psychological distress were linked to reduced quality of life and a decrease in the caregivers' social network. The study confirmed that caregivers of the elderly face daily demanding circumstances that could induce depression symptoms [6]. Higher academic levels were inversely correlated with stress and depression symptoms, suggesting that education might mitigate the negative impact on caregivers' quality of life.

Hlabangana and Hearn reported lower quality-of-life scores among caregivers compared to non-caregivers in the general population of the United Kingdom. A culture of self-compassion in partner caregivers after the diagnosis of neurocognitive disorders was proposed to reduce the risk of mental health-related conditions and enhance their quality of life. Respite aids for informal carers were also suggested to improve self-compassion [7]. The provision of effective caregiver assistance services is crucial to maintaining caregivers' quality of life by offering support and permitting time away from extensive caregiving responsibilities [8].

Rationale

The motivation for this study stems from identified limitations and critical gaps in existing research, particularly highlighted by Bussè and Wells et al. The study by Wells et al. lacked clarity regarding emotional control, underscoring the pressing need to address these deficiencies in current research. The identified limitations in previous studies pose a threat to internal validity and the accurate interpretation of results, emphasizing the imperative for a methodologically robust approach in the current study [9,10].

Moreover, these limitations have created gaps in understanding caregivers' emotional experiences, necessitating a more rigorous and comprehensive research effort in this domain. To bridge these gaps and address the limitations, the current study aimed to implement a methodological approach. By doing so, it aspired to contribute to the understanding of emotional factors in caregivers of individuals with neurodegenerative disorders. The detailed investigation of the perception of quality of life and its impact on caregivers is crucial for providing valuable insights that can inform support strategies and interventions for this vulnerable population.

Significance

Caring for patients with neurodegenerative disorders might lead to diminished quality of life, a deterioration in psychological health, and increased depression, stress, and anxiety among caregivers. Further, the negative emotional effects of caregiving might be key to dysfunctional coping [11]. Additionally, health care providers should evaluate aspects, such as burdens or depressive symptoms associated with the caregiving role, often to prevent negative health outcomes in patients with neurocognitive disorders and their caregivers stated that the psychological distress that happens among caregivers might have deleterious effects on them, mainly if primary caregivers are isolated and fully accountable for the care of their loved ones.

Although the importance of self-care is highlighted, caregivers frequently come into the role of caregiving as essential; they have yet to gain any previous knowledge of skill care. Also, they might take the "learn-as-you-go" tactic, which might result in them feeling more pressure. Being the sole care provider often entails numerous responsibilities, including aspects such as parenting, career, and household chores. As alluded to above, sharing data and recommendations to services such as national societies or associations might provide caregivers with valuable skills.

For the reasons explored above, it is imperative to work towards easing the burdens experienced by caregivers that may eventually lead to the deleterious outcomes that the caregiver's situation might cause. However, one of the first steps towards easing caregiver burden and improving their quality of life and overall well-being is assessing the current state of burden in caregivers. Therefore, the purpose of this cross-sectional, descriptive, survey study was to explore perceptions of quality of life among caregivers of patients with neurodegenerative disorders such as Parkinson's Disease, Dementia, and Alzheimer's Disease in Miami Dade County.

Methods

Research Design

A descriptive cross-sectional survey design was piloted by surveying primary formal or informal caregivers of the older population diagnosed with neurodegenerative disorders to determine the perception of their quality of life in Miami-Dade County.

Study Participants or Source of Data

The recruitment plan was based on the accessibility to caregivers of patients with Alzheimer's disease, Parkinson's disease, and dementia. The population is related to mental health facilities that support this type of population with one of the three neurocognitive disorders. Consequently, a survey was offered to caregivers willing to participate and fill out the survey.

Sampling Methodology

This study was a descriptive cross-sectional study in which the sampling strategy was a non-probability method, which involves selecting study participants based on their accessibility and proximity to the research. Therefore, the best possible method was a convenience sample because the researcher decided who was enrolled in a study. The main advantages of convenience sampling were that it was efficient, low-priced, and simple for the application [12].

Study Measures

Data were collected via survey from formal or informal caregivers of three types of neurodegenerative disorders such as Parkinson's disease, Alzheimer's disease, and dementia. The survey was used to define respondents' perceptions of their quality of life.

Data Collection

The study survey was sent through email to prospective participants, who received an email invitation letter along with an electronic link to the survey instrument. Participants were instructed to acknowledge their participation and submit private and anonymous information. Survey outcomes were subsequently opened by the lead investigator without any personal identifiers. Information submitted to the principal investigator was stored on a password-protected cloud drive.

Data Analysis

Statistical analysis was conducted using the IBM-SPSS version 29 (2022) statistical software package. Demographic and general survey information were analyzed using descriptive statistics to provide measures of central tendency and variance. These descriptive statistics were used to summarize study findings.

Results

Demographic and Background Characteristics

The caregiver sample was predominantly female (79%), with fewer males (21%). A substantial portion of participants reported being married (52%), while others identified as single (29%), cohabitating (12%), or divorced/separated (7%). Educational backgrounds varied, with 29% having some college, 24% holding an associate's degree, 21% graduating high school, and 12% possessing a bachelor's degree. In terms of caregiver type, the majority (95%) were informal caregivers, with the remaining 5% being formal caregivers (Table 1). Regarding the relationship to the care receiver, 48% were daughters, 24% were wives, 12% were sons, and approximately 7% were husbands. Participants represented diverse socioeconomic statuses, with 33% earning between $30,000 and $39,999 annually, 21% reporting incomes between $20,000 and $29,999, 19% between $40,000 and $49,999, and 14% earning less than $19,999 per year. Twelve percent of respondents had an annual income exceeding $50,000 (Table 1).

Occupationally, 38% of caregivers had part-time jobs, 31% worked full-time, and an additional 31% did not work. Emotional burden was prevalent among caregivers (71%), followed by physical burden (24%), while 5% reported experiencing social burden. The detailed breakdown of these demographic and caregiver characteristics are summarized in the accompanying table for clarity and reference (Table 1).

Table 1: Demographics and Background Characteristics

Participant Gender		
	Frequency	Percent
Female	33	78.60
Male	9	21.40
Marital Status		
	Frequency	Percent
Married	22	52.40
Single	12	28.60
Cohabitation	5	11.90
Divorced/separated	3	7.10
Caregiver Education		
	Frequency	Percent
Some college	12	28.60
Associates degree	10	23.80
High school graduate or GED	9	21.40
Bachelor's degree	5	11.90
Elementary school	3	7.10
Some graduate school	3	710.00
Caregiver Type		
	Frequency	Percent
No formal	40	95.2
Formal	2	4.8
Caregiver Relationship		
	Frequency	Percent
	20	47.6
	10	23.8
	5	11.9
	4	9.5
	3	7.1
Type of Burden		
	Frequency	Percent
Emotional burden	30	71.4
Physical burden	10	23.8
Demographics and background characteristics cont.		
Social burden	2	4.8
Type of Work		
	Frequency	Percent
Part-time	16	38.1
Full-time	13	31
No work	13	31
Socioeconomic Status		
	Frequency	Percent
<$19,999	6	14.3
$20,000-29,999	9	21.4
$30,000-39,999	14	33.3
$40,000-49,999	8	19
$50,000-59,999	5	11.9

Caregiving Characteristics and Patient Emotional Status

Caregivers participating in the study reported providing care at home. Thirty-one percent of the sample mentioned spending 3 to 4 days per week on caregiving, while another 31% expressed dedicating 4 to 5 days per week. Approximately 17% of the sample provided care for 2 to 3 days per week, and around 21% of caregivers were engaged in caregiving for all 7 days of the week. Concerning the emotional status of patients, a significant proportion of the sample (45%) had depression symptoms, while the remaining 55% did not exhibit any signs of depression. There was no missing data regarding patient depression. Patients experiencing sleep difficulties constituted a substantial portion of the sample (57%) compared to those without sleeping problems (57%) (Table 2).

Table 2: Caregiving Characteristics and Patient Emotional Status

Caregiving Activity Pay		
	Frequency	Percent
No	39	92.9
Yes	3	7.1
Days Caregiving		
	Frequency	Percent
4 to 5	13	31
7	13	31
2 to 3	9	21.4
	7	16.7

Patient Depressed		
	Frequency	Percent
No	23	54.8
Yes	19	45.2
Patient's Sleep		
	Frequency	Percent
Regular	24	57.1
Irregular	18	42.9
Caregiver Exhaustion		
	Frequency	Percent
Yes	31	73.8
No	11	26.2
Experience Insomnia		
	Frequency	Percent
No	23	54.8
Yes	19	45.2
Experience Sadness		
	Frequency	Percent
Yes	37	88.1
No	5	11.9
Experience Irritability		
	Frequency	Percent
No	31	73.8
Yes	11	26.2
Experience Fatigue		
	Frequency	Percent
Yes	31	73.8
Caregiving Characteristics and Patient Emotional Status cont.	11	26.2
No	11	26.2

Among the participating caregivers, 74% of the sample had experienced emotional exhaustion, while 26% did not feel emotionally exhausted by caregiving. Additionally, 45% of the sample had experienced insomnia during the nights, while 55% of the caregivers reported no difficulty sleeping. However, 74% of the sample had experienced fatigue, with 26% of caregivers not experiencing it. Approximately 8% of the sample had experienced sadness, and 26% of caregivers had experienced irritability due to caregiving (Table 2).

Concerning the physical health of the caregivers, which included physical illness and injuries, around 62% of the sample expressed they did not experience any illness and/or injuries. However, 38% of the caregivers were not sure how many days in the past 30 days their physical health was not good. In regard to mental health, 50% of the caregivers were not sure about how many days in the past 30 days their mental health was not good (Table 3).

Table 3: Physical and Mental Health Assessment of Caregivers: Responses on Illness, Injuries, and Mental Well-Being

Physical Health Past 30 Days		
	Frequency	Percent
None	26	61.9
Don't know/Not sure	16	38.1
Mental Health Past 30 Days		
	Frequency	Percent
None	21	50
Don't know/Not sure	21	50
Poor Physical or Mental Health Activities		
	Frequency	Percent
	22	52.4
	20	47.6

Caregiver Impairments and Health Conditions Activity Limitations and Support Needs

As shown in Table 4, 81% of the sample did not experience impairment problems that limited the caregiving activity; however, around 55% of the caregivers expressed they were not sure if they had a major impairment health problem that limited their activities. Fourteen percent of the sample developed hypertension, 7% experienced back or neck problems, and around 14% of the caregivers had experienced symptoms of diabetes, heart problems, or rheumatism. The caregivers expressed that they did not need any help from other persons with their personal care such as eating, bathing, dressing, or getting around the house. However, around 12% of the caregivers stated they needed help with their routine.

Table 4: Caregiver Impairments and Health Conditions: Activity Limitations and Support Needs

Limited Activities Impairment Problem		
	Frequency	Percent
0	34	81
1	8	19
Major Impairment Health Problem		
	Frequency	Percent
Don't know/Not sure	23	54.8
Hypertension/high blood pressure	6	14.3
Other impairment/ problem	3	7.1
Back or neck problem	3	7.1
Arthritis/rheumatism	2	4.8
Diabetes	2	4.8
Heart problem	2	4.8
Depression/anxiety/ emotional problem	1	2.4
Help with Routine		
	Frequency	Percent
No	37	88.1
Yes	5	11.9

Caregiver Well-Being and Emotional Experiences: Responses on Pain, Depression, Anxiety, Rest, and Overall, Health

Forty percent of the caregivers were not sure how many days they experienced any pain during the past 30 days. Approximately 67% of the sample was not sure how many days in the past month they experienced depression. Moreover, 83% of the caregivers were not sure or did not know how many days in the past month they felt worried, tense, or anxious. Additionally, caregivers who were not sure or did not know how many days in the past month they could not get enough rest comprised a greater proportion of the sample (76%), and 24% of the sample expressed they did NOT get enough resting the past 30 days. Lastly, 76% of the sample was not sure of how many days in the past month they felt very healthy as well as full of energy (Table 5).

Table 5: Caregiver Well-Being and Emotional Experiences: Responses on Pain, Depression, Anxiety, Rest, and Overall, Health

How Many Days in Pain		
	Frequency	Percent
None	25	59.5
Don't know/Not sure	17	40.5
Felt Sad Blue Depressed		
	Frequency	Percent
Don't know/Not sure	28	66.7
None	14	33.3
Felt Worried Tense Anxious		
	Frequency	Percent
2	35	83.3
1	7	16.7
Not Get Enough Rest		
	Frequency	Percent
Don't know/Not sure	32	76.2
None	10	23.8
Felt Very Healthy		
	Frequency	Percent
Don't know/Not sure	32	76.2
	6	14.3
None	4	9.5

Caregiver Time Allocation and Well-Being

Insights into Caregiving Hours, Hobbies, Social Activities, and General Health Perception

As shown in Table 6, 33% of the caregivers spent 6-8 hours of caregiving without any type of job. However, around 17% of the sample spent 2 to 4 hours caregiving after a part-time job. Similarly, 10% of the sample spent between 4 to 6 hours caregiving after a full-time job, and around 29% spent 2 to 4 hours after a fulltime job. Additionally, 31% of the sample have a fulltime job apart from the caregiving activity, while 38% of the caregivers have a part-time job plus the caregiving activity and 31% of the sample do not have a job.

Concerning time spent in hobbies, around 60% of the sample spent 2 hours per week on hobbies. 26% of the caregivers spent 4 hours in hobbies. 12% of the sample spent one day of the weekend on hobbies, and 2% of the sample spent all the weekend in hobbies. In regard to the spent in social activities, those caregivers who spent 2 hours comprised a greater proportion of the sample (40.5%) compared to the caregivers that could spend 4 hours on social activities (28.6%) and those caregivers who could spend one day of the weekend in social activities (Table 6). Finally, 45% of the sample expressed they have good health in general, 19% of the sample experienced very good health in general, 29% of the sample experienced a fair health perception in general, and 2% of the sample reported excellent health status overall (Table 6).

Table 6: Caregiver Time Allocation and Well-Being: Insights into Caregiving Hours, Hobbies, Social Activities, and General Health Perception

Time Spent Caregiving		
	Frequency	Percent
2 to 4 hours per day	2	4.8
4 to 6 hours per day	14	33.3
6 to 8 hours per day	3	7.1
After a part-time job, 2 to 4 hours	7	16.7
After a part-time job, 4 to 6 hours	4	9.5
After a full-time job, 2 to 4 hours	12	28.6
Time Spent Hobbies		
	Frequency	Percent
2 hours per week	25	59.5
4 hours per week	11	26.2
One day of the weekend	5	11.9
All the weekend	1	2.4
Time Spent Social Activities		
	Frequency	Percent
2 hours per week	17	40.5
4 hours per week	12	28.6
6 hours per week	1	2.4
One day of the weekend	12	28.6
Health in General		
	Frequency	Percent
Poor	2	4.8
Fair	12	28.6
Good	19	45.2
Very good	8	19
Excellent	1	2.4
Type of Work		

Caregiver Time Allocation and Well-being: Insights into Caregiving Hours, Hobbies, Social Activities, and General Health Perception cont.

	Frequency	Percent
Full time	13	31
Part-time	16	38.1
No work	13	31

Discussion

Caregivers' experiences with individuals with neurodegenerative disorders, encompassing Parkinson's disease, dementia, and Alzheimer's disease in Miami-Dade County were discovered in this small, cross-sectional survey study. This discussion aims to provide an in-depth exploration of the major findings, their interpretative dimensions in alignment with the research question, a comparison with analogous studies, the theoretical and practical applications extrapolated from the findings, an examination of the study's limitations, and recommendations for future research.

Interpretation

Central to the current study's inquiry was the observation of caregivers' perceptions of their quality of life. The current study's findings, congruent with Bussè et al, showed heightened levels of anxiety, depression, and sleep disturbances among caregivers of individuals with neurodegenerative disorders.

As delineated by Bakof higher education was linked with the prevalence of stress and depression among caregivers. The association between the educational background of caregivers and the manifestation of psychological symptoms introduce a distinctive dimension, shedding light on the interplay between individual characteristics, educational attainment, and the caregiving experience

Comparison with Similar Studies

Consistent with Bakof et al. and Özdilek et al. the current study's outcomes underscored the relevance of the caregiving struggle. Conversely, a review of existing literature, especially research by Bussè et al. and Wells et al. revealed certain methodological limitations as the absence of a control group and potential caregiver influence over emotional behavior. Wells et al.'s research underscored the need for methodological robustness in future studies.

Theoretical and Practical Implications

The study's rationale enhanced our understanding of caregivers' emotional well-being. By spotlighting the moderating role of education in psychological distress, the study contributed to the refinement of existing theoretical frameworks Bakof et al. guiding caregiving research. The study emphasized the importance of targeted interventions and support programs, particularly for caregivers with more modest educational backgrounds. By integrating educational components into caregiver support initiatives, such as workshops on stress management or online resources offering practical caregiving tips, coping mechanisms were fortified, contributing to enhanced overall well-being. Some examples of educational components included providing accessible educational materials, organizing webinars on relevant topics, or offering support groups tailored to the specific needs of caregivers with varying educational levels. Health care providers and policymakers should assimilate these insights when devising programs aimed at enhancing caregiver quality of life

Limitations

This study was not devoid of limitations. The reliance on self-reported measures introduced potential response bias, urging caution in interpreting findings. The cross-sectional design, though insightful, hindered causal relationship establishment. Future studies could leverage longitudinal designs for a better understanding of caregiver experiences.

Another limitation pertained to the geographical focus on caregivers in Miami Dade County, potentially limiting the generalizability of findings. Culturally sensitive considerations were imperative for improved and complete comprehension, necessitating future research to encompass diverse cultural and geographical contexts [13-17].

Recommendations for Future Research

Given the identified limitations, future research endeavors should consider adopting mixed methods approaches for a holistic understanding of caregiver experiences. Longitudinal investigations could have temporal dynamics characterizing caregiver well-being, allowing for a more comprehensive grasp of their journey. Furthermore, an exploration of cultural divergences in caregiving experiences would elevate the cultural competency of support programs. Comparative studies across diverse regions might have unveiled distinctive challenges and coping mechanisms specific to certain demographic cohorts, further enhancing the tailored nature of support initiatives.

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