



Quality of life of elderly people who care for other elderly people with neurological diseases

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Abstract

Objective: to investigate the relationships between the perceived quality of life of elderly people who care for other elderly people with neurological diseases (dementia and strokes) and the gender, age and caregiver burden, diagnosis, functional dependence, and cognitive status of the care recipient. *Method:* 75 caregivers aged over 60 years were interviewed using the Quality of Life Scale (CASP-19) and Zarit Burden Interview. The levels of physical vulnerability of the elderly were identified through the Lawton and Brody questionnaires and the Katz scale and the cognitive assessment of elderly care recipients was assessed with the Clinical Dementia Rating. The data were analyzed by chi-squared test (for comparison of categorical variables), Mann-Whitney and Kruskal-Wallis U tests (for comparison of continuous variables). To study the associations between variables, univariate logistic regression analysis was performed, followed by multivariate logistic regression analysis. *Results:* the age, gender of the caregiver, type of neurological condition, and physical and cognitive functioning of the care recipient did not statistically influence the quality of life of the caregiver. Elderly caregivers with higher levels of burden (≥ 29) were 11.4 times more likely to have a worse quality of life score (CI: 3.16-36.77; $p < 0.001$). *Conclusion:* the quality of life of the elderly caregiver is negatively influenced by the burden involved in caring for another elderly person. Identifying the negative emotional aspects of caregivers that negatively affect their quality of life should be considered a target for intervention by health teams.

Keywords: Quality of Life.
Caregivers. Elderly.

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INTRODUCTION

One characteristic of the epidemiological changes that accompany population aging is the growth of the proportion of elderly persons with chronic-degenerative diseases. Among these diseases are strokes and dementias of various etiologies¹. Diseases that generate significant physical and psychological impairments are also associated with a progressive loss of independence and autonomy, behavioral changes and the need for care of an instrumental, material, social and emotional nature².

The levels of physical and cognitive dependence associated with strokes and dementias range from difficulties in mobility to more complex levels of physical disability, which involve dependence in the performance of activities related to personal care³. These situations have a direct impact on the well-being of family caregivers, who generally perform their role without help or appropriate guidance. Caregivers often become involved in conflicts, anxiety, depression, stress, fears and experience a sense of burden that can have an impact on quality of life⁴.

The World Health Organization⁵ (WHO) defines quality of life as “*the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*”. There are several factors that are related to the perceptions of quality of life of elderly caregivers, including the quality of personal relationships, sociodemographic characteristics such as age and gender, the degree of burden and the abilities to deal with dependent elderly recipients of care⁶.

Population aging has repercussions on two important phenomena. Firstly, there are more people with neurological diseases such as dementias and/or strokes, who exhibit several physical and cognitive functional losses, and secondly, there are more elderly caregivers. The growing number of elderly people can lead to these individuals being burdened by a condition of dual vulnerability due to the burden of care and the aging process. Such situations may influence the psychological, physical and social health of caregivers, affecting their perception of quality of life. The variability of factors that influence quality of life and its subjectivity impose reflections on aging and make it essential understand the factors

that contribute to the well-being of caregivers in each age group^{7,8}.

Those involved in care are constantly exposed to depressive feelings and burden, which increases with the greater dependence of the care recipient and negatively influence the health of caregivers⁹⁻¹¹. Positive and negative feelings, psychological conflicts, grief, fear and insecurity are common throughout the caring experience⁶. Caldeira et al.¹² state that this burden and the physical and cognitive frailty of the caregiver are strongly associated with low caregiver quality of life scores, and that this influences negative perceptions about satisfaction with life.

The psychological resources of caregivers to deal with difficult situations may be inadequate to meet their life needs and the needs of the elderly care recipient, resulting in negative personal perceptions about their quality of life. Engaging in the care of an elderly person often results in the caregiver setting aside their life in favor of assuming responsibility for the life of another, restricting their ability to care for their own health and resulting in negative effects on their quality of life^{13,14}.

The present study aimed to investigate the relationships between the perceptions of quality of life of elderly caregivers of elderly people with neurological diseases (dementia and strokes) and gender, age and caregiver burden, as well as the diagnosis, functional dependence and cognitive status of the care recipient.

METHODS

The present study integrated the database of the study entitled “*The psychological well-being of elderly people who take care of other elderly people in a family context*”, which had a convenience sample of 148 participants indicated by professionals linked to public and private services aimed at the elderly, such as elderly care clinics, home care and medical services.

These caregivers met the following inclusion criteria: age 60 or older, had been a caregiver for at least six months, and agree to participate in the survey. Caregivers who scored below the cutoff point of the Cognitive Abilities Screening Instrument -

Short Form (CASI-S) were excluded¹⁵. These cutoff points were 23 for elderly persons aged 60 to 69 years, and 20 for those aged 70 or older.

The Proc Power procedure of the SAS program (Statistical Analysis System) version 9.2 for Windows was used for the planning of the sample size required to analyze the correlation between the scores of the scales used in the database. The Pearson's correlation coefficient method with Fisher's transformation was applied, with a significance level of 5%, a test power of 80%, and a zero correlation of 0.00, giving a sample size of at least 46 caregivers. For a null correlation greater than 0.10, or closer to the minimum correlation of 0.40, the sample would be 78 caregivers. For a 90% test power, significance level of 1% and zero correlation of 0.10, the suggested sample would be 145 elderly family caregivers, the number reached in the database¹⁶.

Of the sample of 148 caregivers, 50% cared for elderly persons with some type of dementia or stroke, 21% reported that their care recipients were immobile or had a physical disability, and 29% reported that the elderly had a chronic somatic illness. This information was obtained through an open question that aimed to identify the main medical diagnosis of each elderly care recipient. For the present study, 45 elderly people who cared for other elderly people with dementia and 30 elderly people who cared for elderly people with strokes were chosen from the above-mentioned base sample.

Trained interviewers collected data from the elderly who were recruited from households (62.7%), at private medical practices (25.3%) and in the Geriatric outpatient clinic of a University Hospital (12%) in the Greater Campinas Region. The mean duration of the interviews was 57 (+ 13.1) minutes.

Data collection took place from October 2014 to July 2015, following approval from the Research Ethics Committee of the Universidade Estadual de Campinas on 6/10/2014 (C.A.A.E. 35868514.8.0000.5404). The subjects confirmed their agreement to participate by signing a Free and Informed Consent Form. The present study complied with Resolution n° 196/96 on the Rights and Regulatory Guidelines on Research Involving Human Beings.

The variables of interest selected for the present study were: the gender, age, burden and perceived quality of life of elderly caregivers, and the type of illness (dementia or stroke) and levels of physical and cognitive dependence of the elderly care recipients.

The Zarit et al.¹⁷ Burden Interview was used. This consists of 22 items with five points each (from 0 = never to 4 = always), which assess the caregiver's opinion about how much physical, psychological and social burden is involved in the care they provide^{9,18}. The instrument generates a total score ranging from 0 to 88. The cutoff point for separating the caregivers with the lowest and highest burden is 8. The higher the score the greater the total perceived burden. In the present study the distribution of the total scores of participants was divided into terciles: 0 to 20 (low burden), 21-28 (moderate burden) and ≥ 29 (high burden). The three factors described by Bianchi⁷ were also considered: factor 1 (role-related stress) composed of 10 items, factor 2 (intrapsychic stress) with 7 items and 3 factors (presence or absence of competencies and expectations related to care) with 5 items. These factors were identified by means of exploratory factorial analysis achieved following orthogonal varimax rotation and the commonality of the items of the Zarit Burden Interview Scale.⁷

To investigate the quality of life as perceived by the caregiver, the CASP-19 scale was used for individuals aged 55 years and over. This acronym designates control, autonomy, self-realization and pleasure, and is based on Maslow's basic human needs theory¹⁹. It has 19 items in Likert format (never = 0, occasionally = 1, almost always = 2 and always = 3), with a total score ranging from 0 to 57²⁰. The scale has undergone semantic-cultural validation and validation of its construct, which is based on a structure composed of two factors, the first of which brings together items from the self-realization and pleasure domains and the second which includes items from the control and autonomy domains generated by confirmatory factorial analyzes^{20,21}.

The level of physical impairment of the elderly care recipients was assessed from the Lawton and Brody questionnaire (1969), in a version by Brito, Nunes and Yuaso and by the Katz (1963) scale validated for Brazil by Lino et al.²², which investigated the help that each elderly person needed

to perform Basic Activities of Daily Living (BADL) and Instrumental Activities of Daily Living (IADL). Both have three response options: no help, partial help, or total help. The partial and total help options were included in one possibility – with help. The items of the two scales to which the answer was with help were counted and added together. The distribution was divided into terciles (1 to 8, 9 to 12 and 13 activities of daily living impaired).

The level of cognitive impairment of the elderly care recipients was assessed by the Clinical Dementia Rating – CDR²³. This instrument assesses the degree of impairment of cognitive functions in people with suspected dementia. It is divided into six categories: memory, orientation, judgment & problem solving, community affairs, home & hobbies and personal care. Scores can range from 0 (no dementia) to 3 (severe dementia), with intermediate points 0.5 (uncertain or delayed diagnosis), 1 (mild dementia) and 2 (moderate dementia). The memory domain carries the most weight in the scoring²⁴.

The distributions of the caregiver scores on the quality of life and burden scales were submitted to the Kolmogorov-Smirnov test for the evaluation of normality. As the distributions were not normal,

non-parametric tests (Chi-square and Fisher's Exact, Mann-Whitney and Kruskal-Wallis) were chosen to compare the two groups of caregivers according to the variables of interest. Fisher's Chi-square and Exact Tests were used to make comparisons between the nominal variables and the Mann-Whitney U-Test was used to compare the ordinal variables. To study the associations between the total score and the two factors of the perceived quality of life scale and the independent variables, univariate logistic regression analysis was performed, followed by multivariate logistic regression analysis. The significance level adopted for the statistical tests was 95%, or $p < 0.05$. The data were analyzed using the SAS System for Windows (Statistical Analysis System) software, version 9.2. for Windows²⁵.

RESULTS

Of the 75 caregivers, the majority were female (81.3%). The mean age was 69.8 (+7) years. There were no statistically significant differences between the caregivers of elderly people with dementia and caregivers of the elderly with strokes (Group A and Group B, respectively) in relation to the variables studied (Table 1).

Table 1. Frequencies of gender, age, burden and quality of life of the total sample of caregivers of elderly people with neurological diseases, Campinas, São Paulo, 2016.

Variable	Condition	n (total)	Group A*	Group B**	p-value
			n (%)	n (%)	
Gender	Men	14	10 (22.2)	4 (13.3)	0.333
	Women	61	35 (77.8)	26 (86.7)	
Age	60-64	23	11 (24.5)	12 (40.0)	0.339
	65-69	33	21 (46.7)	12 (40.0)	
	75 and +	19	13 (29.8)	6 (20.0)	
Burden	≤20	23	14 (31.1)	9 (30.0)	0.556
	21 to 28	27	18 (40.0)	9 (30.0)	
	≥29	25	13 (29.9)	12 (40.0)	
Role-related stress (Factor 1 of the burden scale)	≤ 9	25	15 (36.6)	10 (33.4)	0.056
	10 to 15	23	17 (33.0)	6 (20.0)	
	≥16	23	9 (41.0)	14 (46.6)	
Intrapsychic stress (Factor 2 of the burden scale)	≤1	27	17 (38.6)	10 (33.3)	0.692
	2 to 4	24	15 (34.2)	9 (30.0)	
	≥5	23	12 (27.3)	11 (36.7)	

to be continued

Continuation of Table 1

Variable	Condition	n (total)	Group A*	Group B**	p-value
			n (%)	n (%)	
Presence or absence of competencies and expectations related to care. (Factor 3 of the burden scale)	≤3	27	14 (34.1)	13 (43.3)	0.642
	4 a 9	22	14 (34.1)	8 (26.6)	
	≥10	24	15 (31.8)	9(30.0)	
Perceived quality of life	≤38	25	15 (35.0)	10 (33.2)	0.382
	39 a 46	24	12 (27.3)	12 (40.0)	
	≥47	26	18 (40.0)	8 (26.8)	
Sense of self-realization and pleasure (Factor 1 of perceived quality of life scale)	≤22	27	16 (37.2)	11 (36.6)	0.375
	23 a 26	21	10 (23.3)	11 (36.6)	
	≥27	25	17 (39.5)	8 (26.8)	
Sense of control and autonomy (Factor 2 of perceived quality of life scale)	≤9	20	12 (27.2)	8 (27.5)	0.765
	10 a 12	27	15 (34.0)	12 (41.3)	
	≥13	26	17 (38.8)	9 (31.2)	

*Group A= Caregivers of elderly persons with dementia; **Group B= Caregivers of elderly persons who had suffered a stroke.

The independent variable with the most robust association with low quality of life score was the burden perceived by the caregivers. Caregivers with a higher total score in burden (≥ 29) had a greater chance of low quality of life scores than those with moderate and low burden scores (OR= 11.43; CI= 3.46 – 37.76). Caregivers with high scores for items that represent role-related stress (Factor 1 of the burden scale) had a higher chance of low quality of life scores. Caregivers who scored on the 2nd tercile of factor 3 of the perceived burden scale (presence or

absence of competencies and expectations related to care) were 3.2 times more likely to have low perceived quality of life scores than those who scored in the third tercile and the reference value, according to univariate logistic regression analysis (Table 2).

Higher scores in total burden, role-related stress, intrapsychic stress and the presence or absence of skills and expectations connected to care resulted in greater chances of an outcome of self-realization and pleasure of the elderly caregivers (Factor 1 of CASP-19) (Table 3).

Table 2. Univariate logistic regression analysis for low scores in the quality of life scale of elderly caregivers of other elderly persons with neurological diseases, Campinas, São Paulo, 2016.

Variable	Categories	p-value	O.R*	CI 95% O.R**
Gender	Male (ref.)***	---	1.00	---
	Female	0.283	1.81	0.61 – 5.36
Age	60-64 years (ref.)	---	1.00	---
	65-74 years	0.233	1.83	0.68 – 4.91
	≥75 years	0.491	1.48	0.48 – 4.56
Diagnosis of Recipient of Care	Dementia (ref.)	---	1.00	---
	Stroke	0.496	1.34	0.57 – 3.15
Number of partially or totally impaired BADL and IADL**** of care recipients	1-8 (ref.)	---	1.00	---
	9-12	0.570	0.69	0.19 – 2.47
	13	0.903	1.06	0.42 – 2.68
Care recipient score in the measure of impairment of cognitive function	0-0.5 (ref.)	---	1.00	---
	1-2	0.319	1.85	0.55 – 6.17
	3	0.484	1.47	0.50 – 4.34

Continuation of Table 2

Variable	Categories	p-value	O.R.*	CI 95% O.R.**
Caregiver score in total perceived burden	≤20 (ref.)	---	1.00	---
	21-28	0.056	2.87	0.97 – 8.47
	≥29	<0.001	11.43	3.46 – 37.76
Caregiver score in role-related stress (factor 1 of burden scale)	≤9 (ref.)	---	1.00	---
	10-15	0.0100	4.33	1.43 – 13.15
	≥16	<0.001	7.89	2.48 – 25.06
Caregiver score in intrapsychic stress (factor 2 of burden scale)	≤1 (ref.)	--	1.00	---
	2-4	0.336	1.65	0.60 – 4.58
	≥5	0.090	2.46	0.87 – 7.00
Caregiver score in presence or absence of competences and expectations related to care (factor 3 of burden scale)	≤3 (ref.)	---	1.00	---
	4-9	0.030	3.28	1.12 – 9.58
	≥10	0.070	2.61	0.93 – 7.36

*Odds Ratio = Relative risk for worse quality of life; **Confidence interval of 95% relative risk; ***Reference level; **** Basic Activities of Daily Living - BADL and Instrumental Activities of Daily Living – IADL.

Table 3. Univariate logistic regression analysis for low sense of self-realization and pleasure scores in the quality of life of elderly caregivers of other elderly people with neurological diseases. Campinas, São Paulo, 2016.

Variables	Categories	p-valor	O.R.*	CI95% O.R.**
Gender of caregiver	Male (ref.)***	---	1.00	---
	Female	0.209	2.11	0.66 – 6.76
Age of caregiver	60-64 years (ref.)	---	1.00	---
	65-74 years	0.160	2.06	0.75 – 5.63
	≥75 years	0.725	1.22	0.40 – 3.76
Diagnosis of Recipient of Care	Dementia (ref.)	---	1.00	---
	Stroke	0.555	1.30	0.55 – 3.06
Number of partially or totally impaired BADL and IADL**** of care recipients	1-8 (ref.)	---	1.00	---
	9-12	0.687	0.77	0.21 – 2.76
	13	0.967	1.02	0.40 – 2.63
Care recipient score in the measure of impairment of cognitive function	0-0.5 (ref.)	---	1.00	---
	1-2	0.574	1.42	0.42 – 4.82
	3	0.731	1.21	0.40 – 3.67
Caregiver score in total perceived burden	≤20 (ref.)	---	1.00	---
	21-28	0.052	2.97	0.99 – 8.93
	≥29	<0.001	10.12	3.06 – 33.48
Caregiver score in role-related stress (factor 1 of burden scale)	≤9 (ref.)	---	1.00	---
	12-15	0.072	2.68	0.92 – 7.86
	≥16	0.003	5.35	1.74 – 16.40
Caregiver score in intrapsychic stress (factor 2 of burden scale)	≤1 (ref.)	---	1.00	---
	2-4	0.638	1.28	0.46 – 3.53
	≥5	0.009	4.36	1.44 – 13.18
Caregiver score in presence or absence of competences and expectations related to care (factor 3 of burden scale)	≤3 (ref.)	---	1.00	---
	4-9	0.148	2.22	0.76 – 6.53
	≥10	0.019	3.59	1.23 – 10.43

Odds Ratio = Relative risk for worse quality of life; **Confidence interval of 95% relative risk; *Reference level; **** Basic Activities of Daily Living - BADL and Instrumental Activities of Daily Living – IADL.

Caregivers with higher total perceived burden scores and those with the highest levels of burden assessed by factor 1 (role-related stress) were 6.93 and

8.45 times more likely, respectively, to have low sense of control and autonomy scores than those that had moderate and low burden scores, as shown in table 4.

Table 4. Univariate logistic regression analysis for low sense of control and autonomy scores in the quality of life of elderly caregivers of other elderly persons with neurological diseases. Campinas, Brazil, 2015-2016.

Variables	Categories	<i>p-value</i>	O.R.*	CI 95% O.R.**
Gender of caregiver	Male (ref.)***	---	1.00	---
	Female	0.212	2.06	0.66 – 6.41
Age of caregiver	60-64 years (ref.)	---	1.00	---
	65-74 years	0.513	0.72	0.26 – 1.94
	≥75 years	0.685	1.23	0.41 – 3.86
Diagnosis of Recipient of Care	Dementia (ref.)	---	1.00	---
	Stroke	0.663	1.21	0.51 – 2.88
Number of partially or totally impaired BADL and IADL**** of care recipients	1-8 (ref.)	---	1.00	---
	9-12	0.582	1.43	0.40 – 5.09
	13	0.752	0.86	0.34 – 2.20
Care recipient score in the measure of impairment of cognitive function	0-0.5 (ref.)	---	1.00	---
	1-2	0.834	1.14	0.34 – 3.76
	3	0.702	0.81	0.27 – 2.40
Caregiver score in total perceived burden	≤20 (ref.)	---	1.00	---
	21-28	0.173	2.12	0.72 – 6.21
	≥29	0.001	6.93	2.18 – 22.01
Caregiver score in role-related stress (factor 1 of burden scale)	≤9 (ref.)	---	1.00	---
	10-15	<0.001	8.45	2.60 – 27.53
	≥16	<0.001	8.45	2.57 – 27.84
Caregiver score in intrapsychic stress (factor 2 of burden scale)	≤1 (ref.)	---	1.00	---
	2-4	0.369	1.60	0.58 – 4.44
	≥5	0.215	1.94	0.68 – 5.55
Caregiver score in presence or absence of competences and expectations related to care (factor 3 of burden scale)	≤3 (ref.)	---	1.00	---
	4-9	0.246	1.87	0.65 – 5.41
	≥10	0.425	1.52	0.54 – 4.27

Odds Ratio = Relative risk for worse quality of life; **Confidence interval of 95% relative risk; *Reference level; **** Basic Activities of Daily Living - BADL and Instrumental Activities of Daily Living - IADL.

Four blocks of variables were considered in hierarchical multivariate logistic regression analysis, the dependent variable of which was total quality of life perceived by the caregivers. In block 1 gender and age of caregivers were included; in block 2, the neurological diseases of the elderly; in block 3, the levels of physical and cognitive impairment of the elderly care recipients and; in block 4, the

measures of perceived burden (total and in each of the three factors).

Based on the results of the hierarchical multivariate analysis, with the Stepwise criterion of variable selection, only the total score of the perceived burden scale was associated with a low total score on the perceived quality of life scale. The

elderly people with high total burden (≥ 29 points) were 10.8 times more likely to perceive lower levels of quality of life. (CI: 3.16 - 36.77, $p < 0.001$).

DISCUSSION

The present study characterizes the profile of caregivers of the elderly in terms of gender, age, burden and perceived quality of life, in situations where the caregiver is also elderly. In addition, it describes the characteristics of the care recipients in terms of levels of physical and cognitive dependence and what influences these variables in the perception of quality of life of the elderly caregiver.

The predominance of elderly women in the study sample was similar to the findings of other studies^{6, 26}. This corroborates the importance of the role of women in the task of caring, as within the family context women most frequently become caregivers²⁶. However, being female did not influence the chance of perceiving a worse quality of life⁷. This finding is in contrast to the study by Lopes and Cachioni⁶ which revealed that women involved in caring perceive more negatives than positives in the act of caring, in comparison with male caregivers.

It was also observed that being elderly is not related to a worse perception of quality of life. Lopes and Cachioni⁶ affirm that the elderly have a more active and participative position in relation to care, a result of the psychologically positive vision that the elderly construct throughout life, which helps them to understand the negative situations of the daily act of caring⁶. There is disagreement among literature on this subject, however. In the study by Guerra et al.²⁷ which evaluated caregivers from different age groups, it was found that, in a statistically significant manner, caregivers aged ≥ 50 years are more likely to perceive a lower quality of life than younger caregivers. The authors justify these results by the conditions of frailty in aging, where the elderly caregivers present functional losses and a decline in their overall health.

The high or low levels of functionality in the elderly affected by the neurological diseases in question, namely strokes and dementia, did not exhibit significant differences in terms of association with perception of quality of life. Bianchi et al.⁷

state that the elderly assume the care of other elderly people despite the psychological discomforts and physical demands of such care as they have an understanding of the difficult circumstances of life and are possibly less psychologically affected by the health situations of the elderly people in question. However, Thober, Creutzberg and Viegas³ affirm that high levels of dependence among care recipients can impact the well-being of family caregivers, who generally perform their role without support or adequate guidance, adding to the negative effects on the health of caregivers²³. Some studies^{28, 29} have shown that both strokes and dementia are diseases that negatively affect the quality of life of caregivers.

The data from the present study revealed that the perception of quality of life is strongly associated with caregiver burden. There are multiple factors that contribute to different perceptions of burden and denote poor perceptions of quality of life^{30, 31}. These include the occupational and financial impact and the loss of support caused by the disease, and difficulties arising from the lack of knowledge on how to deal with the symptoms of the disease. Costa et al.³² affirm that changes in the lives of caregivers lead to a strong tendency towards neglecting one's own health, which contributes to the process of burden and, consequently, to a poor quality of life.

The higher levels of intrapsychic stress and expectations related to care demonstrated in this study were strongly associated with a declining perception of quality of life in the domain of self-realization and pleasure. Some studies³³ have already shown that when there is stress, burden, mental fatigue, there is, therefore, impairment to the perception of quality of life, also explained by the exhausting routine of managing daily activities, which often detract from feelings of pleasure.

On the other hand, intrapsychic stress, which combines feelings of anger, indecision about care and shame, did not have a statistically significant relationship with the perception of a worse quality of life and a worse sense of control and autonomy. According to Paulo and Pires³⁴ there is a tendency to neglect or minimize the problems that arise in situations of stress or tension, characteristics of the act of caring. In addition, because they are elderly caregivers, they tend to have a more enjoyable and

normative view about life. Additionally, a greater sense of personal control leads to more intense feelings of satisfaction, and thus psychic stress affects quality of life less.⁷

The presence or absence of competencies and expectations related to care, that is, the perception that one should be taking better care of the elderly care recipient, had a significant relationship with a worse overall quality of life. Literature⁹ shows that if an elderly care recipient requires support beyond the expectations of the caregiver, it can lead to situations of stress or crisis, a fact that translates into perceptions of a lack of control over life with negative emotions about the quality of life of the caregiver. In addition, even those with a high sense of self-esteem can suffer negative influences from caring and feel sad and lacking in enthusiasm²⁷. The perception that one should be doing more or taking better care of someone is constantly related to an expectation of self-efficacy that can circumstantially influence quality of life.¹² The difficulties experienced by caring for a highly dependent elderly person usually lead caregivers to relinquish their social relationships, resulting in negative effects on their sense of personal realization²⁷.

One limitation of the present study is the relatively small sample size which may have contributed to the statistical inferences. The data refer only to caregivers of patients with dementia or a stroke. Caring for the elderly with other diseases such as Parkinson's or multiple sclerosis may reveal different perceptions on the quality of life of the elderly caregiver. Furthermore, because it is a cross-sectional study, no conclusions can be drawn about causality. A longitudinal study may provide more accurate information about the situations that influence the quality of life of the elderly caregiver. Despite this, the data presented represent a step forward in understanding issues that encompass care in the lives of elderly caregivers.

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CONCLUSION

The data revealed by the present study demonstrate that the perception of quality of life of elderly people who care for other elderly people with neurological diseases (dementia and strokes) is not negatively influenced by gender, age, diagnosis, and the functional dependence or cognitive status of the elderly care recipient, despite the critical events of aging. However, these same data reveal that perceived burden negatively influences the quality of life of the caregiver. This indicates the importance of increasing our knowledge of the circumstances that cause burden among elderly caregivers, so that the awareness of such individuals about the emotional situations they are experiencing can be raised and they can seek help in the appropriate health services.

In contributions to the field of study it is important to highlight that the present study contemplates a better understanding of the perception of quality of life of elderly caregivers, as a large part of related studies involve young individuals. Identifying the emotional and instrumental needs of elderly people that care for other elderly individuals is essential, as due to population aging this group is increasingly present in Brazil and throughout the world. Therefore, developing and applying new strategies of support and physical and psychological assistance for the elderly and primarily those who suffer from a daily burden of care is an emerging Geriatric and Gerontological practice.

It is therefore important to encourage health professionals to consciously reflect upon the difficulties that elderly caregivers face in their daily lives. Experience and knowledge about elderly caregivers is crucial to a proactive attitude towards the various difficulties experienced by this population segment. It is important that health professionals improve their recognition of elderly caregivers who feel emotionally and physically burdened.

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