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Original Articles

1 de 12

Factors associated with the quality of life of elderly caregivers of other elderly persons

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Abstract

Objective: To evaluate the association between the double vulnerability of being elderly and a caregiver and quality of life assessed by *Control, Autonomy, Self-realization and Pleasure* factors (CASP-19*). Method:* 148 elderly caregivers participated in the present study. They were selected for convenience from Brazilian public and private health services – a sample from the study "The Psychological Well-Being of Elderly Persons Caring for Other Elderly Persons in a Family Context". The variables: *caregiver's state of health, care demands, perception of burden, self-rated health, and quality of life* were selected. Descriptive analyses, chi-squared tests, Fisher's exact test, the Kruskal-Wallis test and analysis of multivariate hierarchical logistics were carried out, with the *Stepwise* criteria applied for selection of variables. *Results:* The hierarchical multivariate analyses found that number of symptoms and total burden were significantly associated with a poorer quality of life. Elderly persons with three or more symptoms and those with a high burden level were at a higher risk of poor quality of life. The variables *number of diseases, burden, and self-rated health compared with the past*, were significantly associated with a poorer quality of life. *Conclusion:* It can be concluded that for the elderly caregiver, physical aspects (signs and symptoms, chronic diseases and a perception of health deterioration) combined with burden are the aspects that most influence quality of life.

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INTRODUCTION

Available literature on informal caregivers is wide-ranging, emphasizing the importance of studies of caregivers in the context of population aging[1-3]. However, one consequence of population aging remains little investigated: the growing number of elderly persons who are caregivers of other elderly individuals. This caregiver profile deserves attention, as the elderly are more vulnerable due to their biological frailty and are more prone to the development of chronic diseases[4-6]. Caregivers of the elderly, in turn, are also vulnerable to suffering possible burden from their activities and responsibilities, and to social isolation[7-10]. The elderly caregiver therefore suffers double vulnerability, needing to deal with the requirements of care and their own health needs at the same time.

A meta-analysis performed by Pinquart and Sorensen[11] found that elderly caregivers have worse physical health than their younger counterparts. In considering psychological aspects, the study by Borg and Hallberg[12] of caregivers aged 50-89 years found that life satisfaction declined as age increased. However, Chow and Ho[13] studied caregivers of spouses aged 55 and above and found that elderly caregivers scored significantly lower in emotional and social distress, negative feelings, and depression. Despite this, they presented greater subjective well-being.

In this context, the Control, Autonomy, Self-Realization and Pleasure (CASP-19) scale emerged from the need for an instrument that evaluated quality of life in a form that was theoretically based and specific to the elderly. This instrument consists of four domains: control, autonomy, self-actualization and pleasure. The scale was developed on the basis of Maslow's Basic Needs Theory, which understands that quality of life should be assessed as the degree to which human needs are met[14].

The study by Di Novi et al.[15] which used a sample from the first two phases of the Survey of Health, Ageing and Retirement in Europe (SHARE) study, carried out in 11 European countries, used the CASP-19 scale to compare caregivers and non-caregivers aged 50 and over. The authors divided the sample into three groups (northern Europe, southern Europe and continental Europe), according to public expenditure on long-term care. The results revealed the cultural complexity of informal care, as there were differences between caregivers and non-caregivers in total CASP-19 results and scores for the factors of the scale. These data show that socio-cultural differences influence the perception of the quality of life of caregivers; requiring, therefore, that care is taken when comparing studies from different regions of the world and the adequacy of the instruments and forms of the studies.

Rafnsson et al.[16] analyzed 6,784 participants from the first three phases of the English Longitudinal Study of Aging (ELSA) to prospectively investigate the impact of transitions in informal care on the emotional well-being of the elderly. The results showed that in comparison with non-caregivers, caregivers of spouses or parents had lower CASP-19 scores at baseline and after a follow-up period. Participants who were not caregivers at baseline but who cared for a spouse or their parents two years later, as well as those who continued with the status of caregiver, had deteriorating CASP-19 scores.

In this context, the CASP-19 instrument has been found to be effective in several surveys, some of which[17,18] have suggested working with factors other than those initially proposed. It is important to note that, although the scale has exhibited good internal consistency in several studies, the relationship between the items has demonstrated variability. This seems to be related to the specific characteristics of each population. These specificities need to be better explored for a more detailed understanding of the phenomenon. In a previous study with this sample[19], an association was established between double vulnerability and quality of life assessed by CASP-19.

The objective of the present study was to evaluate the association between double vulnerability (i.e. of elderly caregivers) and quality of life assessed by the factors of the CASP-19 scale, seeking a better understanding of this relationship through an evaluation of the disassembling of CASP-19 into factors. The model chosen was that developed by

Neri et al.[18], who performed a semantic-cultural validation of the scale for Brazilian adults and elderly persons. In addition, the authors performed factorial analysis and identified two models, with three and two factors, respectively. The proposal of this study was to prioritize the similarity between samples and to use the two factor model (factor 1, evaluating pleasure and autonomy and factor 2, related to autonomy and control with negative connotations), as this is the only study that performed factorial analysis of the instrument with a Brazilian sample.

METHOD

Data were collected from October 2014 to September 2015 and are taken from the study "Psychological Well-Being of Elderly Persons Who Care for Other Elderly Persons in a Family Context" carried out at the Faculty of Medical Sciences of the Universidade Estadual de Campinas, São Paulo, Brazil. The project employed a descriptive cross-sectional design and aimed to analyze the effects of providing care on the physical and mental health of the caregiver, based on the stress and coping model proposed by Pearlin et al.[20]. From this database, sociodemographic variables (age, gender, date of birth, schooling, marital status and paid work), satisfaction with quality of life needs, self-assessment of health, perceived burden, the physical measurements of the caregiver and the degree of physical and cognitive dependence of the elderly recipient of care were selected for the present study.

Sample size was calculated based on the correlations between quality of life and the coping measures investigated in the study. The Pearson correlation coefficient method was used, with Fisher's transformation, considering a level of significance of 1%, a test power of 90%, a null correlation of 0.10 and a minimum correlation of 0.40, resulting in the need to evaluate 140 caregivers.

The sample consisted of 148 people aged 60 years and older who informally cared for other elderly persons with some type of physical or cognitive impairment. They were recruited on a convenience basis in public and private health services in cities in southeastern Brazil, namely Jundiaí (38.5%), Indaiatuba (29.1%), Campinas (18.2%) and Vinhedo (14.2%), all of which are in the state of Sao Paulo.

The exclusion criterion applied was a score below the cut-off point of the Cognitive Abilities Screening Instrument - Short Form (CASI-S) validated for Brazil by Damasceno et al.[21]. The cutoff point for cognitive deficit is 23 for elderly persons aged 60 to 69 years and 20 for elderly persons aged 70 years and over.

Initially, the project was submitted to and approved by the Research Ethics Committee of the Universidade Estadual de Campinas (opinion: 822.364/2014). Participants were then invited to take part in the survey at the health service where the elderly care recipient received treatment. After signing a Free and Informed Consent Form, the research protocol, which lasted approximately one hour, was applied. The interviews were carried out at the health service or at home, when it was not possible for the caregiver to remain at the health service. Conducting interviews at the health service was authorized by the health professionals responsible through a printed document. Seven trained interviewers conducted the interviews at locations and times previously agreed upon with the participants.

The interviews were conducted in two parts. The first contained questions about the socioeconomic variables of the caregiver and their family, the cognition of the elderly care recipient, and the health conditions of the participants. The second part consisted of evaluations of the physical, psychological and social conditions inherent to the provision of care, family functionality, the health conditions and functionality of the care recipient, a subjective evaluation of care burden, subjective well-being, coping, and a self-assessment of health. After the interview the participants were offered a booklet with instructions on how to facilitate communication with the elderly. The instruments used are described in Chart 1.

Descriptive analysis was performed to describe the profile of the sample. Chi-squared and Fisher's exact tests were used to compare the categorical variables. The Kruskal-Wallis test was performed to

compare the numerical variables between the three groups. After this test was applied, Dunn's post-hoc multiple comparisons test was used to identify the differences in the pairs. To analyze the association between the independent variables and quality of life, multivariate hierarchical logistic regression analysis was used, with a Stepwise variable selection criterion. The level of significance was 5%.

Chart 1. Variables of interest and instruments used in study. Campinas, São Paulo, 2015.

Variables of interest	Instruments
Socioeconomic conditions of caregiver	Questions related to the characteristics of the caregiver: age, gender, date of birth, schooling, marital status and whether they perform paid work. The items in this block were tested in the Fibra Study [22].
Physical health of caregiver	Evaluated by a list of self-reported diseases, based on the question: *Has a doctor ever told you that you have the following diseases*? A list of signs and symptoms that have occurred in the last 12 months. The list of signs and symptoms was based on that used in the SABE Study[23] and replicated in the Fibra Study[22]. The measure of frailty validated by Nunes et al.[24] was also used, according to the criteria of Fried et al.[25]. This consists of five questions about weight loss, reduced strength, reduced physical activity, walking speed and fatigue. These measures are answered in a dichotomous manner.
Self-assessment of health	Contains a five-point question on how the participant evaluates their overall health, another on how they evaluate health care, a three-point question on how they evaluate their health compared to a year ago, and one on how they evaluate their health compared to other people of the same age. Suggested by Bowling[26] and tested in the Fibra Study[22].
Characteristics of elderly care recipient	Age, main health problem, if caregiver resides with the elderly care recipient, if caregiver is the main and/or sole person responsible for them.
Degree of dependence of elderly care recipient in IADLs and BADLs *	Brazilian version of the Lawton and Brody scale[27,28]: evaluates telephone use, transportation, shopping, preparing food, performing household chores, using medication and handling money. The respondent states whether, for each of the actions, they are independent, need help or are totally independent. Katz et al.[29] scale validated for the Brazilian population by Lino et al.[30]. Evaluates the following activities: bathing, dressing, using the toilet, transference, continence and food. The caregiver indicates if the patient needs partial or total help or does not need help for each of these activities
Cognitive dependence of elderly care recipient	Clinical Dementia Rating (CDR): assesses cognitive impairment through six categories: memory, orientation, judgment or problem solving, community relations, home or leisure activities, and personal care. Each category is classified according to the degree of impairment (no change, questionable, mild, moderate and severe). This evaluation is performed through an interview with a person close to the patient.
Satisfaction in quality of life needs	Composed of 19 items answered through a four point Likert type scale (CASP-19)[14].
Caregiver burden	An instrument consisting of 22 questions, with answers given through a five-point scale. It was developed by Zarit et al.[31] and translated and validated for the Brazilian population by Scazufca[32] ($\alpha=0.87$). The study by Bianchi[33] carried out a factorial analysis of the scale and found three factors. Factor 1 is the domain related to the perception of stresses attached to the role, Factor 2 is the domain of perception of intrapsychic tensions, Factor 3 can be interpreted as the domain related to the presence or absence of competence and negative expectations related to care.

* IADLs: instrumental activities of daily living; BADLs: basic activities of daily living.

RESULTS

The participants were aged between 60 and 86 years old, with a mean age of 69.8 (±7.1) years. The majority were women (77%) and had between 0 and 4 years of schooling (87%), while 51% were the sole caregiver. Regarding the care recipient, 62% were spouses, 28% offspring and 10% other family members, and the mean age was 81 (±9.8) years.

Tables 1 and 2 show the results of the comparisons of the categorical and numerical variables between the terciles of the quality of life factor scores and the results of the hierarchical logistic regression analysis for worsening in quality of life factor 1 and quality of life factor 2. There was a significant difference between the terciles of the quality of life factor 1 score and the number of symptoms (a greater frequency of three or more symptoms in caregivers with worse quality of life), frailty (greater frequency of frail caregivers in those with worse quality of life), Zarit burden scale total and factor scores (greater frequency of greater degree of burden in those with worse quality of life), and subjective evaluation of current health and health compared with the past (greater frequency of worse subjective assessment of current health and health compared with the past in caregivers with worse quality of life).

There was also a significant difference between the terciles of the quality of life factor 2 score based on gender (greater frequency of women in caregivers with worse quality of life), number of diseases (greater frequency of three or more diseases in caregivers with worse quality of life), Zarit burden scale total and factor scores (greater frequency of greater degree of burden in caregivers with worse quality of life), and subjective health assessment (greater frequency of regular health with worse quality of life).

Table 1. Comparison between the frequencies of Casp-19/factor 1 and results of univariate logistic regression analysis for worse quality of life/factor 1, physical health, dependence of recipient of care, burden and self-assessment of health (N=148). Campinas, São Paulo, 2015.

Variable	n	Categories	Comparison between Casp-19 frequencies				Univariate regression analysis values		
			≤22 %	23-27 %	≥28 %	p-value	p-value	O.R.*	CI 95% O.R.*
Gender	143	Male	15.56	24.53	26.67	0.402**			
		Female	84.44	75.47	73.33				
Age	143	60-64	31.11	18.27	40	0.123**			
		65-74	46.67	54.72	31.11				
		≥75	22.22	26.42	28.89				
Number of diseases	143	0 (ref.)	20	15.09	28.89	0.357**	---	1.00	---
		1-2	40	52.83	44.44		0.510	1.31	0.59–2.90
		≥3	40	32.08	26.67		0.143	1.89	0.81–4.42
Number of symptoms	143	0 (ref.)	15.56	15.09	33.33ᵃ	0.006**	---	1.00	---
		1-2	37.78	60.38ᵃ	48.89		0.195	1.70	0.76–3.78
		≥3	46.67ᵃ	24.53	17.78		**0.002**	4.31	1.75–10.62
Level of frailty	143	Robust (ref.)	8.89	24.53ᵃ	20ᵃ	0.015**	---	1.00	---
		Pre-frail	35.56	49.06ᵃ	53.33ᵃ		0.754	1.14	0.49–2.65
		Frail	55.56ᵃ	26.42	26.67		**0.019**	2.91	1.20–7.09
Physical functionality of care recipient (dependence in IADLs and BADLs)	143	0-6 (ref.)	15.56	30.19	31.11	0.377**	---	1.00	---
		7-12	44.44	37.74	42.22		0.233	1.59	0.74–3.41
		13	40	32.08	26.67		0.077	2.06	0.92–4.60
Cognitive Functionality (CDR) of care recipient	143	0-0.5 (ref.)	31.11	49.06	53.33	0.253**	---	1.00	---
		1-2	28.89	20.75	22.22		0.146	1.77	0.82–3.83
		3	40	30.19	24.44		**0.045**	2.07	1.02–4.22
Total Burden	143	≤19 (ref.)	13.33	37.74	46.67ᵃ	0.001**	---	1.00	---
		20-27	26.67	39.62ᵃ	28.89		0.301	1.51	0.69–3.30
		≥28	60ᵃ	22.64	24.44		**0.003**	3.09	1.46–6.54
Factor 1 burden	137	≤9 (ref.)	17.78	47.92ᵃ	43.18ᵃ	0.011**	---	1.00	---
		10-15	28.89	22.92	31.82ᵃ		0.510	1.31	0.59–2.90
		≥16	53.33ᵃ	29.17	25		0.143	1.89	0.81–4.42

to be continued

Continuation of Table 1

Variable	n	Categories	Comparison between Casp-19 frequencies				Univariate regression analysis values		
			≤22 %	23-27 %	≥28 %	p-value	p-value	O.R.*	CI 95% O.R.*
Factor 2 burden	142	≤1 (ref.)	22.22	36.54	48.89	0.057**	---	1.00	---
		2-3	24.44	28.85	24.44		0.167	1.74	0.79–3.82
		≥4	53.33	34.62	26.67		**0.003**	2.98	1.44–6.18
Factor 3 burden	140	≤3 (ref.)	28.89	43.14	40.91	0.321**	---	1.00	---
		4-7	20	23.53	27.27		1.000	1.00	0.45–2.23
		≥8	51.11	33.33	31.82		0.087	1.85	0.91–3.74
Subjective health assessment	143	Good/Excellent (ref.)	33.33	50.94[a]	64.44[a]	0.017***	---	1.00	---
		Fair	57.78[a]	41.51	35.56		**0.009**	2.33	1.24–4.41
		Poor/Very poor	8.89[a]	7.55	0		**0.034**	4.71	1.13–19.70
Subjective health assessment compared to past	143	Better (ref.)	8.89	16.98[a]	17.78[a]	0.024**	---	1.00	---
		Same	33.33	54.72[a]	53.33[a]		0.776	1.14	0.46–2.83
		Worse	57.78[a]	28.30	28.89		**0.030**	2.85	1.10–7.34
Subjective assessment of health compared to others	135	Better (ref.)	54.76	54.72	75	0.274***	---	1.00	---
		Same	30.95	33.96	17.50		0.121	1.76	0.86–3.61
		Worse	14.29	11.32	7.50		0.191	1.98	0.71–5.54

*OR = odds ratio for worse quality of life; (n=45 with ≤22, n=53 with 23-27 and n=45 with ≥28). CI 95% OR = 95% confidence interval for odds ratio. Ref.: reference level. Proportional hazards model; **Chi-squared test; ***Fisher exact test; [a]Statistically significant difference.

Table 2. Comparison between Casp-19/factor 2 and results of univariate logistic regression analysis for worse quality of life/factor 2, physical health, dependence of recipient of care, burden and self-assessment of health (N=148). Campinas, São Paulo, 2015.

Variable	n	Categories	Comparison between Casp-19 frequencies				Univariate regression analysis values		
			≤9 %	10-12 %	≥13 %	p-Value	O.R.*	p-value	CI 95% O.R.*
Gender	144	Male	12.50	33.33a	18.87	0.046**			
		Female	87.50a	66.67	81.13a				
Age	144	60-64	30	25.49	33.96	0.082**			
		65-74	40	49.02	43.40				
		≥75	30	25.49	22.64				
Number of diseases	144	0 (ref.)	7.50	21.57	32.08a	0.005**	1.00	---	---
		1-2	40	50.98a	47.17		2.14	0.070	0.94–4.86
		≥3	52.50a	27.45	20.75		5.01	<0.001	2.05–12.26
Number of symptoms	144	0 (ref.)	12.50	23.53	24.53	0.081**	1.00	---	---
		1-2	42.50	56.86	50.94		1.34	0.473	0.61–2.96
		≥3	45	19.61	24.53		2.48	0.044	1.03–6.00
Level of frailty	144	Robust (ref.)	7.50	19.61	26.42	0.086**	1.00	---	---
		Pre-frail	42.50	50.98	43.40		2.08	0.093	0.89–4.89
		Frail	50	29.41	30.19		3.10	0.013	1.27–7.58
Physical functionality of care recipient (dependence in IADLs and BADLs)	144	0-6 (ref.)	17.50	27.45	30.19	0.492**	1.00	---	---
		7-12	47.50	45.10	33.96		1.80	0.130	0.84–3.87
		13	35	27.45	35.85		1.34	0.470	0.60–2.99
Cognitive Functionality (CDR) of care recipient	144	0-0.5 (ref.)	37.50	47.06	47.17	0.872**	1.00	---	---
		1-2	30	23.53	22.64		1.43	0.357	0.67–3.03
		3	32.50	29.41	30.19		1.22	0.588	0.60–2.47
Total Burden	144	≤19 (ref.)	12.50	31.37a	52.83a	<0.001**	1.00	---	---
		20-27	35	27.45	33.96		2.58	0.017	1.19–5.59
		≥28	52.50a	41.18	13.21		6.25	<0.001	2.82–13.84
Factor 1 burden	137	≤9 (ref.)	12.82	37.50a	54 a	<0.001**	1.00	---	---
		10-15	35.90a	22.92	28		2.86	0.010	1.28–6.36
		≥16	51.28a	39.58	18		4.88	<0.001	2.24–10.64

to be continued

Continuation of Table 2

Variable	n	Categories	Comparison between Casp-19 frequencies				Univariate regression analysis values		
			≤9 %	10-12 %	≥13 %	p-Value	p-value	O.R.*	CI 95% O.R.*
Factor 2 burden	143	≤1 (ref.)	27.50	23.53	53.85a	**<0.001****	---	1.00	---
		2-3	15	39.22a	25		0.222	1.63	0.74–3.57
		≥4	57.50a	37.25	21.15		**<0.001**	4.13	1.96–8.72
Factor 3 burden	141	≤3 (ref.)	35	37.50	43.40	0.850**	---	1.00	---
		4-7	25	20.83	24.53		0.688	1.18	0.53–2.61
		≥8	40	41.67	32.08		0.347	1.40	0.70 – 2.81
Subjective health assessment	144	Good/Very good (ref.)	25	60.78a	58.49a	**<0.001****	---	1.00	---
		Fair	60a	37.25	39.62		**0.017**	2.17	1.15–4.09
		Poor/Very poor	15a	1.96	1.89		**0.003**	11.87	2.32–60.68
Subjective health assessment compared to past	144	Better (ref.)	12.50	11.76	20.75	0.045**	---	1.00	---
		Same	37.50	47.06a	58.49a		0.761	1.15	0.47–2.83
		Worse	50a	41.18a	20.75a		**0.025**	2.94	1.14–7.54
Subjective assessment of health compared to others	135	Better (ref.)	47.22	62.50	70.59	0.125***	---	1.00	---
		Same	33.33	27.08	25.49		0.192	1.61	0.79–3.27
		Worse	19.44	10.42	3.92		**0.013**	3.96	1.33–11.75

* OR = Odds ratio for worse quality of life; (n=40 with ≤9, n=51 with 10-12 and n=53 with ≥13). 95% CI OR = 95% confidence interval for odds ratio. Ref.: reference level. Proportional hazards model; **Chi-squared test; ***Fisher exact test; aStatistically significant difference.

In the hierarchical multivariate analyzes, the number of symptoms and total burden were significantly associated with poorer quality of life in the factor 1 score. The elderly persons with the highest risk of a worse quality of life were those with three or more symptoms (3.0 times greater risk), and a high degree of burden (5.9 times greater risk). The variables *number of diseases*, *burden factor 2* and *subjective assessment of health compared with the past* were significantly associated with a worse quality of life in the factor 2 score. The elderly with the highest risk of a worse quality of life were those with three or more diseases (5.0 times greater risk), those with a high degree of factor 2 burden (6.0 times greater risk), and a worse assessment of health compared with the past (4.9 times greater risk).

DISCUSSION

Despite its different dimensions, burden was the most significant variable in determining quality of life. For factor 1, total burden remained in the model. For factor 2, only burden-factor 2 remained in the final model.

Factor 1 is more related to issues of pleasure and self-realization, or how one perceives one's life. This association was expected because, although perceived burden was associated with objective issues related to care, such as the degree of dependence of the care recipient and hours dedicated to care[34,35], it was also related to the variables *quality of life* and *well-being of the caregiver*[36,37].

Factor 2 is more closely related to control and autonomy, especially in relation to external factors. Contador et al.[38] evaluated the burden of informal caregivers of patients with dementia and verified that aspects related to control (self-efficacy and contingency) most explained burden. In this study, only factor 2 burden, which concerns intrapsychic tensions, remained in the final model.

Regarding caregiver health, having more signs and symptoms of disease was associated with a worse factor 1 quality of life, while chronic diseases were associated with factor 2 quality of life. Although signs and symptoms are directly related to physical health, studies have shown that the manifestation of symptoms does not occur in the same way for all subjects. The perception of symptoms is related to attention to internal states, mood, cognition and environment[39].

Thus, exhibiting more signs and symptoms of disease and perceiving greater burden was associated with lower quality of life in the pleasure and self-realization dimension; and the presence of more chronic diseases, perception of declining health and more intrapsychic stresses related to care were associated with lower quality of life in the control and autonomy dimension.

In general, the health of the caregiver (signs and symptoms, chronic diseases and perception of poor health) and perceived burden were the aspects most associated with quality of life. However, the degree of physical and cognitive dependence of the care recipient did not prove very important for this association. These data suggest that for the elderly caregiver, their health and how they perceive the burden of care influence quality of life more than the dependencies of the elderly care recipient.

Although it provides advances in our theoretical knowledge of elderly persons who care for other elderly persons, the present study has limitations. As it did not use a representative sample, the results cannot be extended to the entire population of elderly caregivers in Brazil.

CONCLUSION

When the two factors are considered it can be concluded that, for elderly caregivers, aspects of physical health (signs and symptoms, chronic diseases and perception of worsening of health), together with burden, most influence the quality of life of this type of caregiver.

The objective conditions of care (degree of physical and cognitive dependence of the care recipient) did not appear to be relevant to the caregiver's quality of life, contrary to the findings of other studies. Perhaps because of their age, the health of the caregiver is more important than the dependence of the care recipient.

Further studies on the elderly who informally care for other elderly persons are recommended. It is important to carry out research that tests interventions with this specific population, in order to propose improvements to the quality of life of these caregivers.

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