Resilience of family caregivers of elderly with Alzheimer

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ABSTRACT

Resilience is the capacity that people have to cope positively with adversities. A cross-sectional, quantitative study, that aimed to assess factors associated with the resilience of family caregivers of elderly with Alzheimer's disease. Sixty-six caregivers composed the sample, who were accompanied in a neurology ambulatory. Most caregivers presented moderate resilience. Linear regression showed that some factors interfered with caregivers' resilience, being those: overload, the increment of days dedicated to caregiving, the level of kinship daughter-in-law/son-in-law or spouse, and practice of other activities besides caregiving. The findings can be useful in care-related areas, once we identified variables interfering in resilience, and those can be worked and improved to benefit the caregiver and the patient.

Descriptors: Resilience, Psychological; Alzheimer Disease; Caregivers; Dementia; Family.

INTRODUCTION

Dementia is a frequent health problem, and it significantly results in socioeconomic costs. Prevalence estimates in the largest part of the work vary between 5% to 7%, reaching 85% in Latin America[1].

Cognitive or behavioral symptoms (neuropsychiatric symptoms) characterizes dementia, and it interferes with work and with other activities of daily living. They represent a decline of a previous functionality level that is not explained by a delirium or severe psychiatric disorders[2].

There are many types of dementia; the one caused by Alzheimer's disease (AD) is the most prevalent, affecting 50 to 60% of cases, being one of the leading causes of disability in adult life[3]. Considering the exposed, the caregiver role appears at the measure that daily difficulties of a new reality emerge; requiring decision making and the incorporation of activities that becomes of their full responsibility.

To practice and to keep caring for a family member with a chronic disease, especially one that is

progressive and neurodegenerative as the AD, is something that requires caregiver's good physical and mental health, once the demands request a growing rhythm of attention and care, as the disease stages accelerate.

The caregiver is the person who conducts or helps the person with limitation to perform basic and instrumental daily activities (from personal hygiene to family financial management) at the private domestic environment, aiming to preserve the patient's autonomy and independence[4].

The task of caring for a family member with dementia is recognized as associated with physical and emotional issues for the caregiver[5]. The stress from a caregiving routine results from the lack of caregiving support, lack of knowledge about dementia stages and, the lack of prepare for caregiving.

With the intention to alleviate the physical and emotional overload, family caregivers need to develop a positive attitude that can help them support a load of negative and harmful factors that affect their health caused by the caregiving process. To develop higher resilience levels could benefit the caregiver as well as the person receiving care.

As a capacity of every human being to adapt using internal and external resources, resilience is understood as the maintenance of a development process, regardless of its difficult conditions, being something systematic, dynamic and complex, resulting from the interaction between the individuals and the environment[6].

When focusing on resilience as a human capacity, one of the possibilities to re-direct health care emerges from recognizing strengths and from developing strategies to build existing skills, once resilience connotes inner strength, competence, optimism, flexibility, and ability to deal with the adversity effectively[7]. Thus, to know factors capable of influencing the maintenance process of resilience can help nurses to instrumentalize, train and form their team, so the team can strengthen potentialities, to promote and to stimulate new ways to cope with difficulties, overall of those individuals who present moderate to low resilience.

The objective of this study was to assess factors associated with the resilience of family caregivers for elderly with Alzheimer's disease.

MATERIAL AND METHODS

We conducted a cross-sectional, descriptive, correlational and quantitative study.

It was held at the Ambulatory of Cognitive and Behavioral Neurology from UFSCar (ANEU), based on the Municipal Center of Specialties (CEME), in the city of São Carlos – SP, during May and December of 2014. The ANEU is a specialized medical, neurological ambulatory, that attends people with cognitive and behavioral disorders associated with neurological and non-neurological diseases, noting dementias.

We included in the study family caregivers who daily interacted and cared for elderly, preferably living in the same house; who were caregiving for one year or more, older than 18 years, from both genders, and of any educational level.

Family caregivers of elderly diagnosed with AD composed the sample, who were accompanied in the Neurological Ambulatory from UFSCar (ANEU). We identified dementia phases through the scale Clinical Dementia Rating (CDR). Sixty-six subjects composed the sample, distributed by disease stage. AD group – 66 family caregivers, distributed in three subgroups according to the dementia stage:

a) Subgroup mild AD – 25 caregivers, elderly at mild phase dementia.

b) Subgroup moderate AD – 22 caregivers, elderly at moderate phase dementia.

c) Subgroup advanced AD – 19 caregivers, elderly at advanced phase dementia.

After the approval of the Ethics Committee in Research with Human Beings from the Universidade Federal de São Carlos – UFSCar, Protocol nº 489.795, that requested authorization for data collection to the coordinators of the Centers of Medical Specialties (CEME). The caregivers who met the inclusion criteria were invited to participate in the study, and they signed the Free and Informed Consent Term.

For the data collection, we used the following instruments: a caregiver characterization questionnaire: developed by the researchers, which allowed access to personal information, life habits, and caregiving characteristics; Brazilian Criteria for Economic Classification (CCEB): an instrument used to estimate the purchasing power of families and urban people. Resilience Scale (RS): one of the few tools used to assess levels of positive psychosocial adaptation considering the significant life events[8]. The scores range from 25 to 175 points. Scores between 25 to 120 indicate low resilience, from 125 to 145 indicate moderately low to moderate resilience and scores higher than 145 indicate moderately high to high resilience. Zarit Burden Interview Scale: assessed aspects related to the caregiver health, and the Beck Depression Inventory: an instrument used to track depression symptoms, all translated and validated to the Brazilian culture. The primary study variables were: caregiver resilience level, gender, marital status, education, age, caregiving time and level of kinship.

We conducted descriptive analyses for the statistical data treatment. We used the Bonferroni t-test to compare means between groups, Spearman correlations to verify the association between resilience and other variables and, a multiple linear regression to identify factors that interfered in the resilience of groups. We adopted a significance level of 5% and a confidence interval of 95% for this study.

The sample was part of an ambulatory individual consideration, and it is not possible to generalize the results, thus, they should be limited only to the studied population.

RESULTS

Tables 1 and 2 represent the sociodemographic data from the 66 family caregivers who composed the sample.

About the scoring in the resilience scale, most caregivers (80.3%) presented moderate resilience. Only two (4.2%) had resilience classified as high and, 11 caregivers (23%) presented low resilience.

Table 1: Percentage of elderly per gender in each classification level of the Alzheimer's disease (AD), with variable measures of dispersion and position for Age and Education per AD classification and considering the general population. São Carlos, SP, Brazil, 2014.

		Mild AD	Moderate AD	Advanced AD	General AD
Gender	Female	12	12	16	40
	Male	13	10	3	26
Age	Mean	55.1	56.3	56.7	56
	Standard Deviation	12.7	15	12.8	13.3
	Minimum	37	23	35	23
	Maximum	80	85	88	88
Education	Mean	6.9	7.9	9.4	8
	Standard Deviation	3.6	3.3	4.8	3.9
	Minimum	3	3	3	3
	Maximum	14	15	18	18

Table 2: Absolute and relative frequencies of the variable levels Marital Status, Economic Class, and Level of kinship per level of AD and the general population. São Carlos, SP, Brazil, 2014.

		Mild AD		Moderate AD		Advanced AD		General AD	
		n	%	n	%	n	%	n	%
Marital status	Married/Stable Relationship	18	72%	19	86%	13	68%	50	76%
	Divorced/Separated	3	12%	3	14%	5	26%	11	17%
	Widowed	2	8%	0	0%	1	5%	3	5%
	Single	2	8%	0	0%	0	0%	2	3%
Economic class	A2	3	12%	0	0%	0	0%	3	5%
	B1	1	4%	2	9%	2	11%	4	6%
	B2	4	16%	4	18%	4	21%	3	5%
	C1	10	40%	10	45%	10	53%	5	8%
	C2	4	16%	5	23%	5	26%	4	6%
	D	3	12%	1	5%	1	5%	0	0%
Level of kinship	Son/Daughter	14	56%	10	45%	10	53%	34	52%
	Brother/Sister	1	4%	0	0%	2	11%	3	5%
	Nephew/Niece	0	0%	0	0%	3	16%	3	5%
	Son-/Daugther-in-law	1	4%	2	9%	0	0%	3	5%
	Spouse	8	32%	8	36%	4	21%	20	30%
	Other	1	4%	2	9%	0	0%	3	5%

According to the multiple linear regression analysis (Table 3), some factors were associated with the increment of resilience, within them: the overload; the days per week that the caregiver spends with the elderly; the level of kinship: when the caregiver is the daughter-/son-in-law or spouse in comparison to when the caregiver is the patient's son/daughter; the fact that they consider their physical health as good in relation to those who consider it great; and, when they perform other activities besides caregiving.

Table 3: Distribution of resilience levels of caregivers of elderly with Alzheimer's disease (AD), according to the Resilience Scale[8]. São Carlos, SP, Brazil, 2014.

	High		Moderate		Low	
	n	%	n	%	n	%
Mild AD	0	0.0	21	84.0	4	16.0
Moderate AD	1	4.5	17	77.3	4	18.2
Advanced AD	1	5.3	15	79.0	3	15.7
General ADl	2	3.0	53	80.3	11	16.7

Other factors were associated with the decrease of caregivers' resilience levels. Those were: self-perceiving their mental health as average in comparison with caregivers who considered it significant, depression, with the increase of depression, resilience levels decreased; and the economic class, resilience decreased when the caregiver pertained to class A2 in comparison with caregivers from classes B1 and C1.

Table 4: Analysis of the linear regression having as outcomes the level of resilience and the explanation variables of caregivers for elderly with Alzheimer's disease. São Carlos, SP, Brazil, 2014.

		Estimate	T Statistics	p-value
	Overload	0.3	3.2	0
Variables	**Depression**	-0.5	-2.2	0.03
	Age	-0.7	-1.9	0.07
Time spent caring for elderly	**Hours per day**	-0.3	-1.8	0.08
	Days per week	5.6	3.1	0
	B1	-11.3	-2.9	0
	B2	-3.7	-1	0.28
Economic classification (A2)	**C1**	-12.8	-3.3	0
	C2	-8	-1.8	0.07
	D	-18	-2.6	0.01
	Brother	6.5	1.1	0.07
	Nephew	4.7	1	0.2
Level of kinship	**Daughter-/Son-in-law**	46.7	4.7	0.32
	Spouses	8.3	2	0
	Other	11.3	2.3	0.05
	Good	10.7	2.4	0.02
Health state	**Moderate**	5.1	0.9	0.37
	Bad	-0.2	0	0.98
Performs other activities	**Yes**	4.4	2.2	0.03

DISCUSSION

Most identified studies agreed with the female gender of caregivers[9-10] and culturally related it as caring being primarily a female activity, and when facing fragility situations in the family structure or the presence of a disease, care is absorbed by women[11]. However, there is a growing participation of the male gender helping with care[12], which justifies the 52% of men in the mild AD subgroup in our study.

About caregivers' age which the mean was 56 years, we found similar results in national studies[12-13], and in some international studies, where the mean age was 69[14] until 91 years[15]. These differences reinforce the fact that in developed countries, life expectancy is higher than in developing countries, justifying the higher mean age of caregivers when compared to the average of caregivers from national studies.

A national study conducted with family caregivers for elderly with AD[9] also scored a mean of eight to 11 years of education. However, another study carried out in Faro (Portugal) with 110 informal caregivers for dependent elderly pointed in their results that most caregivers (67.3%) had four years or less of education[16], characterizing a low education profile. People with lower educational levels can be more susceptible to the caregiver role, once society requires higher levels of education for the formal job market[12]. Thus, it is comprehensible that family members with less time of education are more dedicated to domestic tasks and

caregiving for dependent family members.

Regarding the marital status of caregivers, most are in the married category or, in a stable relationship, corroborating with the national and international scientific literature, which bring in their results that most studied samples also were married or in a stable relationship[12-13].

Referring to the resilience level presented by caregivers verified by the RS; our study pointed that in the general AD group (80.3%) and also in its subgroups, most caregivers had moderate resilience. It is important to note that only two caregivers had high resilience scores. The human being can adapt to diverse situations, however, to care for a person with a chronic disease, overall a degenerative one as AD could reflect in its resilience level.

We found a similar result in an international study[17] where authors assessed the resilience of 53 caregivers of elderly with Alzheimer's disease. In its findings, higher resilience scores were also significantly correlated with the overload, with the levels of neuroticism and extroversion, self-efficacy and self-esteem, and less use of coping strategies focused on emotions.

Through the multiple linear regression analysis, we identified that some variables interfere in the outcome at the resilience level of caregivers, for the increase and decrease of these levels. In the present study, the level of kinship propitiated resilience increase when dealing with spouses, daughter- or son-in-law and others, opposed to the decrease when dealing with sons/daughters of the elderly with AD. Results from another study pointed that children and spouses presented median and high level of resilience when compared to siblings and in-laws[9]. The present study agrees with the data from these same authors, that also bring that a good perception of physical health was associated with a high level of resilience. The authors still highlight that the elderly with AD in its family and social context had more resilient capacity because this person keeps mental and physical balance, favoring the caring task.

Caregivers who had other activities in addition to caregiving had a significant increase in their resilience when compared to those that did not. About that, another study pointed to the need for caregivers to develop extra activities, and, they observed that caregivers who participate in community events, support groups and those with social support, coped better with their role[10]. It calls out attention to the importance of support from other caregiver's family members, even if this occurs in short moments, as informal visits. Still, it is relevant that when the health team is assisting the person with AD, they should also insert the caregiver in the plan of care, resolving possible doubts about the disease, thus, contributing to the decrease in anxiety and searching for strategies to alleviate their stress.

Higher levels of resilience relate to lower rates of depression and better physical health, and the social support has been a moderator factor for resilience, as a variety of types of support seem to alleviate the physical and mental overload caused by stress[18].

In the present study, all caregivers were non-paid family members and, besides, they had emotional load because they are part of the family, staying in permanent exposition to the patient's demands.

In this sense, the family caregiver needs guidance about how to proceed in daily situations. Thus,

whenever possible, they should receive periodic visitations from health professionals intended to resolve doubts about the disease, to learn about neuropsychiatric symptoms coming from more advanced phases of the disease, so when informed, they can be better prepared for caring, as well as, to alleviate their anxiety about the unknown. Thus, they will be less likely to be worn out about the care; they will be able to have a better quality of life and consequently, preserving their mental health.

CONCLUSION

This study allowed us to conclude that family caregivers of elderly with AD present moderate resilience and, determined variables influences this individual coping capacity. These variables can contribute to the increase this ability, as well as, to act in its reduction.

The lack of publications of quantitative studies addressing the resilience theme is a gap identified in this research that deserves attention, considering that in Brazil, we verify a tendency of prevalence studies addressing this topic more subjectively. This fact impeded us to compare results with other national studies in some aspects.

Care-related fields could use our findings, and once the variables interfering in resilience are identified, these can be worked and improved to benefit the caregiver and the patient.

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REFERENCES

1. Prince M, Bryce R, Albanese E, Wimo A, Ribeiro W, Ferri CP. The global prevalence of dementia: a systematic review and metaanalysis. Alzheimer's & dementia: Alzheimers Dement. 2013;9(1):63-75e2.
2. McKhann, GM. at al. The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. Alzheimers Dement. 2011;7(3):263-9.
3. Alzheimer´s Disease International. World Alzheimer Report 2009.[acesso em: 21 maio2013]. Disponível em: https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf.
4. Moreira, M. D.; Caldas, C. P. A importância do cuidador no contexto da saúde do idoso. Escola Anna Nery Revista de Enfermagem, Rio de Janeiro, v. 11, n. 3, p. 520-525, set. 2007.
5. Valente, L. et al. Autopercepção de saúde em cuidadores familiares e o tipo de demência: resultados preliminares de uma amostra ambulatorial. Revista Brasileira de Neurologia. 2013; 49(1): 13-19.
6. Reppold CT, Mayer JC, Almeida, LS, Hutz CS. Avaliação da resiliência: controvérsia em torno do uso das escalas. Psicol Reflex Crit. 2012;25(2):248-255.
7. Wagnild, GM, Young, HM. A Review of the Resilience Scale. Journal of Nursing Measurement, 2009; 17(2): 5-14.
8. Wagnild GM, Young HM. Development and psychometric evaluation of resilience scale. Journal of nursing measurement. 1993;1(2):165-178.
9. Gaioli CCLO, Furegato ARF, Santos JLF. Perfil de cuidadores de idosos com doença de Alzheimer associado à

resiliência. Texto Contexto Enferm. 2012; 21(1):150-157.

10. Lopes SRA, Massineli CJ. Perfil e nível de resiliência dos cuidadores informais de idosos com Alzheimer. Aletheia. 2013; 40: 134-145.

11. Valente L,Truzzi A, Souza WF, Alves GS, Sudo FK,Alves CEO, et al. Autopercepção de saúde em cuidadores familiares e o tipo de demência: resultados preliminares de uma amostra ambulatorial. Rev Bras Neurol. 2013;49(1):13-9.

12. Gratão ACM, Vendrúscolo TRP, Talmelli LFS, Figueiredo LC, Santos JLF, Rodrigues RAP. Sobrecarga e desconforto emocional em cuidadores de idosos. Texto Contexto Enferm. 2012;21(2):304-312.

13. Bagne BM, Gasparino RC. Qualidade de vida do cuidador do portador de Doença de Alzheimer. Revista Enfermagem UERJ. 2014; 22(2): 258-263.

14. Haley W, Bergman EJ, Roth DL, McVie T, Gaugler JE, Mittelman MS. Long-Term Effects of Bereavement and Caregiver Intervention on Dementia Caregiver Depressive Symptoms. Gerontologist. 2008;48(6):732–740.

15. Lavretsky H, Siddarth P, Irwin MR. Improving depression and enhancing resilience in family dementia caregivers: a pilot randomized placebo-controlled trial of escitalopram. Am J GeriatrPsychiatry 2010 Feb; 18 (2): 154-64.

16. Rocha BMP, Pacheco JEP. Idoso em situação de dependência: estresse e *coping* do cuidador informal. Acta Paul Enferm. 2013; 26(1):50-6.

17. Fernández-Lansac V. Crespo-López M, Cáceres R, Rodríguez-Poyo M. Resiliencia en cuidadores de personas con demencia: estudio preliminar. Rev Esp Geriatr Gerontol.2012;47(3):102-9.

18. Dias R. Santos RL, Sousa MF, Nogueira MM, Torres B, Belfort T, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. Trends Psychiatry Psychother. 2015;20(10):1-8.