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The double vulnerability of elderly caregivers: multimorbidity and perceived burden and their associations with frailty

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Abstract

Objective: To identify if multimorbidity and burden are associated with a greater likelihood of frailty in elderly caregivers of other elderly persons within the family context. *Method:* 148 elderly caregivers caring for other elderly persons [M=69.7 (±7.0) years old] were recruited using a criterion of convenience in public and private health services in the city of Campinas and surrounding areas. Information was gathered about socio-demographic context, context of care, physical health, care burden using the Zarit Burden Scale, and frailty, measured by subjective evaluation. Four groups of vulnerability were created based on the presence or absence of multimorbidities and high or low burden, in order to verify which group was most strongly associated with frailty. Data were analyzed using descriptive analysis, measurements of association and multivariate hierarchical logistic regression. *Results:* The prevalence of multimorbidity was 55.4%. The Zarit Burden Scale presented a median of 23 out of a total of 88 points. Of the sample, 35.1% were frail, 46.0% intermediate, and 18.9% robust. Elderly caregivers with multimorbidity and high burden had a greater probability of frailty (OR=3.6; CI 1.55-8.36), followed by those with multimorbidity and low burden (OR=2.8; CI 1.13-6.79). *Conclusion:* The sensation of burden among caregivers was reduced; those with double vulnerability were most prevalent among the four groups and had the greatest association with the occurrence of frailty; multimorbidity was associated with frailty. If combined with perceived burden, however, the *odds ratios* of the elderly caregivers being frail increased.

Keywords: Caregivers. Frail Elderly. Health of the Elderly.

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INTRODUCTION

Becoming the caregiver of a dependent elderly person represents a stressful event at any age. Care comprises the characteristics of a chronic stress experience as it generates physical and psychological stress over long periods of time; is accompanied by high levels of unpredictability and lack of control of the situation; has the ability to create secondary stress in various domains of life, such as work and family relationships; and often requires high levels of surveillance[1]. Becoming a caregiver in old age, or even aging while providing care, may mean facing challenges linked to stressors, as coping with daily care requires various types of resources, which may be scarce or insufficient in old age, hindering appropriate adaptive responses.

Elderly caregivers usually take care of someone of their own age group, which predisposes them to cope with the increasing dependence of the individual receiving care and often requires them to invest a great deal of physical effort into tasks that are strenuous for a body that is also in the process of aging, increasing the risk of becoming ill[2]. In caregivers of spouses who age while performing this role, the risk of illness can also occur due to a shared life course, reflected in health habits and other similar life circumstances that may pose risks, such as social and financial disadvantages or access to opportunities and services[3].

Literature diverges as to the burden and benefits of the task of caring and its repercussions for health. Two studies clearly demonstrate this contrast. The first is the longitudinal Study with data from the Caregiver-Study of Osteoporotic Fractures, which found a lower mortality rate among elderly caregivers than among the non-caring elderly. This finding supports the "Healthy Caregiver" hypothesis, which suggests that being a caregiver in old age reflects better physical and functional conditions, inherent in those selected to perform the role of caregiver[4,5].

In contrast, a second study demonstrated through biochemical evidence that the state of exhaustion caused by care may result in marked coagulation. To reach this conclusion, Swiss researchers investigated spouses aged 55 and over who were caregivers of patients with dementia, as well as non-caregivers, and observed that the blood tests of caregivers showed higher levels of the procoagulant molecule D-Dimer. These elevated levels were related to the role of caregiver, not age, as is the case with IL-6, which makes caregivers more susceptible to the development of cardiovascular diseases than non-caregivers[6].

Another risk is the increased chance of becoming frail. French researchers[7] argue that older people who care for other elderly persons are often at risk of succumbing to frailty, due to the ability of chronic stress to result in physical and emotional exhaustion for which the physiological reserves of an aging person are insufficient.

The term frailty is used in gerontological literature to refer to a syndrome involving energy reduction, neuroendocrine dysregulation and decline of immune function, resulting in the reduction of physiological reserves and the ability of the individual to adapt adequately to stressful conditions[8]. According to the definition and proposition of Fried et al.[9], such syndrome is identified in the elderly population through the manifestation of a specific phenotype composed of unintentional weight loss, reduced gait speed, a decrease in grip strength, fatigue, and lower levels of physical activity. Although they are distinct phenomena, frailty and comorbidity are often associated and conducive to negative outcomes such as disability and mortality. The identification of frailty usually occurs through objective measures of physical performance plus the self-reporting of fatigue. The self-evaluation of the elderly of their own performance has also been proven to be a valid way of tracking elderly persons in a process of frailty in larger populations[8].

Elderly caregivers of older people have been studied as part of the wider group of caregivers[10], and there are no specific descriptors for such individuals in the search databases. This hinders a greater understanding of the needs and repercussions of exercising the caregiver activity in parallel with the deterioration involved in aging itself. The present study therefore sought to identify whether multimorbidity and burden are associated with a greater likelihood of frailty in elderly persons who care for other elderly individuals in a family context.

METHOD

This is a cross-sectional, descriptive and analytical study based on data from a larger study entitled "The Psychological Well-Being of Elderly Persons Who Care for Other Elderly People in A Family Context", developed by researchers linked to the Postgraduate Program in Gerontology of the Universidade Estadual de Campinas, São Paulo, Brazil.

Data collection was carried out from October 2014 to July 2015, following the approval of the Research Ethics Committee of the Universidade Estadual de Campinas (Protocol No. 35868514.8.0000.5404). Subjects were recruited on a convenience basis in health services of the public and private network of the cities of Campinas, Indaiatuba, Jundiaí and Vinhedo, located in the state of São Paulo, Brazil. After the participants signed a Free and Informed Consent Form, the interviews were carried out at the health service units or at the caregivers' homes, by trained researchers, in a single session with an average duration of 60 minutes. At the end, the participants and their families received an information manual to optimize communication with the elderly.

The inclusion criteria were 60 years and over, have cared for a sick elderly relative with some degree of dependency for six months or more, and agree to participate in the survey. Caregivers who scored below the cut-off score established by the Cognitive Trace instrument CASI-S[11], the abbreviated version of the Cognitive Abilities Screening Instrument - Short Form, validated for Brazil, were excluded.

For the present study, sociodemographic data, data related to the context of care, health variables, and data on burden and frailty were extracted from the original study. The cognition of the elderly person receiving care was evaluated based on the reports of the caregiver using the Clinical Dementia Rating (CDR)[12] instrument, which investigates memory, orientation, judgment or problem solving, community relations, leisure and personal care. The attributable scores for both the individual items and the overall scale score are 0 (absent), 0.5 (questionable), 1 (mild), 2 (moderate), and 3 (severe). Adapted versions of the scales used to assess performance in the six Basic Activities of Daily Living (BADL) of Katz et al.[13] and the seven Instrumental Activities of Daily Living (IADL) of the Lawton and Brody Scale[14] were applied to evaluate the intensity of the care provided by the caregivers. The intensity of care was identified from the number of activities in the scales in which the individual declared themselves to be the main source of helping with or completing the activity, with the possibilities ranging from 0 to 13 activities, for which categories of low, medium intensity or high were applied, based on the distribution of the sample in terciles.

From the self-reported diseases it was possible to identify whether there was the presence or absence of multimorbidity (considered in this study as the presence of two or more chronic diseases) for each caregiver.

Caregiver burden was evaluated by the Zarit Burden Scale[15], which consists of 22 items with responses ranging from 0 (never) to 4 (always). This instrument generates a total score ranging from 0 to 88 and reflects the level of caregiver burden in the domains discomfort with health, personal and social life, financial situation, emotional well-being and interpersonal relationships. The total score of the interviewee was classified as low or high burden from the median score of the total study sample.

From the presence or absence of multimorbidity and low or high burden, four groups of vulnerability were created in order to verify which was most strongly associated with frailty. The groups of vulnerability generated were: Group 1 (without multimorbidity and low burden), Group 2 (without multimorbidity and high burden), Group 3 (with multimorbidity and low burden), Group 4 (with multimorbidity and high burden).

In order to measure frailty, the subjective criteria of the frailty syndrome validated by Nunes et al.[8] was used. This is composed of five dichotomous questions directly related to the components of the frailty phenotype measured by Fried et al.[9] Caregivers were categorized as frail when they had three or more components, pre-frail when presenting one or two components and robust when they did not have any of the components.

The Statistical Analysis System version 9.2 was used for statistical analyzes. The Chi-squared and Fisher's exact tests were used to compare the categorical variables. The Kruskal-Wallis test was used to compare the variables with three or more categories, and Dunn's post-hoc multiple comparisons test was used to find where the difference, if there was one, resided. To study the factors associated with the presence of frailty, univariate and multivariate hierarchical logistic regression analysis was used, applying a Stepwise criterion of variable selection. The level of significance adopted for the statistical tests was 5%, or $p<0.05$.

RESULTS

Table 1 shows the sociodemographic characteristics and the context of care. There was a predominance of female caregivers (77.0%). Age ranged from 60 to 86 years, with a mean of 69.73 (+7.0) years.

In terms of the context of care, the age of the individual receiving care ranged from 60 to 104 years. Most caregivers took care of their spouses (62.0%). Of the recipients of care, 55.4% had cognitive impairment (mild, moderate or severe) and 77.0% had six or seven impaired IADL. Approximately one third of the caregivers (33.1%) were the main source of support for all 13 activities investigated.

Table 2 shows the distribution of the presence of multimorbidity, perceived burden, the vulnerability groups and the frailty of the caregivers. The average amount of illness per caregiver was 1.86 (+1.4). The most prevalent diseases were systemic hypertension (58.8%), arthritis (34.4%), diabetes (23.6%), osteoporosis (20.9%), heart disease (15.5%) and depression (14.2%). Multimorbidity was present in 55.4% of the individuals and frailty in 35.1%, with the group classified as pre-frail being the most prevalent (45.9%). The Zarit Burden Scale had a mean of 26.1 (+13.5) points and a median of 23 points, which was used to divide the sample between those with a low level (<23 points) and a high level of burden (>23 points).

In this way, 48,6% caregivers presented low burden while 51.3% had high burden. The group with concomitant presence of multimorbidity and a high level of perceived burden, or in other words, those with double vulnerability, was the prevalent in the sample (32.4%).

Table 1. Frequencies, means and standard deviations of the sample in relation to sociodemographic variables and the context of care (N=148). Campinas, São Paulo, 2015.

Variable	n (%)	Mean (±sd*)	Minimum-Maximum
Gender			
Male	34 (23.0)	-	-
Female	114 (77.0)	-	-
Age (years)		69.7 (7.0)	60-86
60-70	85 (57.5)	-	-
≥71	63 (42.5)	-	-
Marital status			
Married	118 (80.3)	-	-
Single	14 (9.5)	-	-
Widowed	9 (6.1)	-	-
Divorced	6 (4.1)	-	-
Schooling (years)		5.61 (4.2)	0-19
0-4	87 (60.0)	-	-
≥5	58 (40.0)	-	-

to be continued

Continuation of Table 1

Variable	n (%)	Mean (±sd*)	Minimum-Maximum
Income (minimum salary)**		4.01 (3.6)	1.0-27.6
0-3	71 (51.4)	-	-
3.1-5	41 (29.7)	-	-
≥5.1	26 (18.8)	-	-
Age of care recipient		81.2 (9.8)	60-104
60-69	20 (13.5)		-
70-79	43 (29.0)		-
≥80	85 (57.4)		
Relationship with caregiver			
Spouse	92 (62.2)	-	-
Parent	41 (27.7)	-	-
Father/Mother in law	5 (3.4)	-	-
Brother	3 (2.0)	-	-
Uncle	3 (2.0)	-	-
Son	4 (2.7)	-	-
Duration of care (years)		4.56 (4.0)	0.5-20
<2	41 (28.5)	-	-
2.0-4.9	52 (36.1)	-	-
≥5	51 (35.4)	-	-
CDR Classification***			-
Absent / questionable	66 (44.6)	-	-
Mild / moderate	36 (24.3)	-	-
Serious	46 (31.1)	-	-
Dependence in IADL †			-
0-2	10 (6.8)	-	-
3-5	24 (16.2)	-	-
6-7	114 (77.0)	-	-
Dependence in BADL††			-
0-1	63 (42.6)	-	-
2-4	23 (15.5)	-	-
5-6	62 (41.9)	-	-
Intensity of care		9.0 (3.8)	0-13
0-6 activities	38 (25.7)	-	-
7-12 activities	61 (41.2)	-	-
13 activities	49 (33.1)	-	-

* sd=standard deviation; **Brazilian minimum wage of R$788.00 in the period of data collection; ***CDR= Clinical Dementia Rating; †IADL= Instrumental Activities of Daily Living; ††BADL= Basic Activities of Daily Living.

Table 2. Distribution of multimorbidity, frailty, burden and the groups of vulnerability in the sample of elderly caregivers. Campinas, São Paulo, 2015.

Variable	n (%)	Mean (±sd*)
Multimorbidity		
Yes	82 (55.4)	-
No	66 (44.6)	-
Components of frailty		-
Weight loss	41 (27.7)	-
Loss of grip strength	79 (53.4)	-
Low level of physical activity	63 (42.5)	-
Reduction of gait speed	80 (54.0)	-
Fatigue/exhaustion	32 (21.8)	-
Level of frailty		
Robust	28 (19.0)	-
Pre-frail	68 (46.0)	-
Frail	52 (35.0)	-
Perceived burden		26.1 (13.5)
Low (<23points)	72 (48.6)	-
High (≥23points)	76 (51.3)	-
Vulnerability groups		
1 (without multimorbidity and low burden)	38 (25.7)	-
2 (without multimorbidity and high burden)	28 (18.9)	-
3 (with multimorbidity and low burden)	34 (22.9)	-
4 (with multimorbidity and high burden)	48 (32.4)	-

* sd=standard-deviation.

The profile of the individuals who composed each of the vulnerability groups is shown in Table 3, along with the statistically significant variables. Male subjects, with a high level of schooling, without the loss of grip strength, with no reduction in gait speed, who did not suffer fatigue, and who were robust were concentrated in the groups without multimorbidity.

Table 3. Distribution of the number and proportion of elderly persons among the four groups of vulnerability according to the significant sociodemographic variables, context of care and frailty. Campinas, São Paulo, 2015.

Variable	Group 1 n (%)	Group 2 n (%)	Group 3 n (%)	Group 4 n (%)	*p*-value*
Gender					
Male	12 (31.6)	11 (39.3)	6 (17.7)	5 (10.4)	0.014
Female	26 (68.4)	17 (60.7)	28 (82.3)	42 (89.6)	
Schooling (years)					
0-4	18 (47.4)	12 (44.5)	25 (78.1)	32 (66.7)	0.015
> 5	20 (52.6)	15 (55.5)	7 (21.9)	16 (33.3)	
Loss of grip strength					
Yes	13 (34.2)	12 (42.9)	21 (61.8)	33 (68.7)	0.006
No	25 (65.8)	16 (57.1)	13 (38.2)	15 (31.3)	
Reduced gait speed					
Yes	13 (34.2)	14 (50.0)	20 (58.8)	33 (68.7)	0.014
No	25 (65.8)	14 (50.0)	14 (41.2)	15 (31.3)	
Fatigue / exhaustion					
Yes	3 (8.1)	3 (10.7)	10 (29.4)	16 (33.3)	0.012
No	34 (91.9)	25 (89.3)	24 (70.6)	32 (66.7)	
Levels of frailty					
Robust	12 (31.6)	8 (28.6)	5 (14.7)	3 (6.3)	0.040
Pre-frail	18 (47.4)	11 (39.3)	16 (47.1)	23 (47.9)	
Frail	8 (21.0)	9 (32.1)	13 (38.2)	22 (45.8)	

*Probability of significance by chi-squared test.

The association between the study variables and profiles of frailty were also evaluated. It was found that the most prevalent subjects at the pre-frail and frail levels (in the process of becoming frail) had lower levels of education, declared themselves to be spouses of the care recipients, suffered from multimorbidity, and were in vulnerability groups 3 and 4.

Table 4 shows the results of the univariate and multivariate hierarchical logistic regression analysis to identify the odds ratios for frailty. The variables that make up blocks 1, 2 and 3 represent, respectively, the sociodemographic characteristics, the care context and the vulnerability groups. It was observed in both the univariate and multivariate analyzes that only vulnerability groups 3 and 4 had a statistically significant probability of frailty. Elderly caregivers with greater chances of frailty were: those with multimorbidity and low burden (2.8 times greater risk), and those with multimorbidity and high burden (3.6 times greater risk).

Table 4. Results of univariate and multivariate logistic regression analysis for frailty (N=148). Campinas, São Paulo, 2015.

	Variable	Univariate logistical regression		Multivariate hierarchical logistical regression	
		OR* (CI95%)**	*p*-value	OR* (CI95%)**	*p*-value
Block 1	Gender				
	Male (ref.)***	1.00 (-)	-	-	-
	Female	1.20 (0.59-2.47)	0.612	-	-
	Age				
	60-70 years (ref.)	1.00 (-)	-	-	-
	≥71 years	0.90 (0.49-1.65)	0.726	-	-
Block 2	Duration of care (years)				
	<2 (ref.)	1.00 (-)	-	-	-
	2-4.9	1.11 (0.51-2.40)	0.790	-	-
	≥5	0.89 (0.41-1.92)	0.756	-	-
	Dependence in IADL † and BADL††				
	0-6 (ref.)	1.00 (-)	-	-	-
	7-12	1.10 (0.52-2.36)	0.798	-	-
	13	1.74 (0.78- 3.87)	0.176	-	-
	CDR Classification†††				
	0-0.5 (ref.)	1.00 (-)	-	-	-
	1-2	1.39 (0.65-2.99)	0.398	-	-
	3	1.87 (0.91-3.81)	0.088	-	-
Block 3	Vulnerability groups				
	1 (ref.)	1.00 (-)	-	1.00 (-)	-
	2	1.47 (0.59-3.71)	0.410	1.48 (0.59-3.73)	0.406
	3	2.50 (1.03-6.06)	0.043	2.76 (1.13-6.79)	0.027
	4	3.74 (1.63-8.59)	0.002	3.60 (1.55-8.36)	0.003

*OR=Odds Ratio for frailty (n=28 robust. n=68 pre-frail and n=52 frail); **CI95%= Confidence interval 95%; ***ref= reference value; †IADL= Instrumental Activities of Daily Living; ††BADL= Basic Activities of Daily Living; †††CDR= Clinical Dementia Rating.

DISCUSSION

The present study represents an advance in that it provides data relating to elderly persons who care for other elderly persons in a family context. Although much literature exists on the perceived burden of caregivers, few studies have investigated the characteristics of this role when the caregivers of the elderly are elderly themselves. The present study was based on the theory that the condition of double vulnerability could be associated with a greater chance of the occurrence of frailty, a hypothesis confirmed by the results.

Like other studies[16-19] of elderly caregivers, the sample consisted predominantly of female subjects, who most frequently cared for a spouse or surviving parent. The feminization of care remains a reality, despite the increasing numbers of male caregivers. While elderly women face greater challenges in adapting declining health conditions to the tasks of caring, elderly men are faced with the challenges of being a caregiver, a role which involves skills rarely acquired during the lives of this cohort, for the first time. It is believed that care for spouses will become increasingly important given tendencies such as increased life expectancy, reduced support

relationships in old age, reduced parent-child cohabiting, the increased participation of women in the workforce outside the home, a reduction in the number of children, and the improvement of male health[20-22].

The low mean and median values of perceived burden found in the sample are notable in comparison with studies of younger caregivers[23,24]. Low to moderate burden in elderly caregivers is not uncommon in literature. This finding corroborates the results of an Irish population study[25] which, when applying the same instrument as the present study, found lower scores in a group of caregivers aged 65 years or over (31.3 points) than in groups aged 46-64 years (34.3 points) and those younger than 46 years (33.2 points). There are three major justifications for the low perceived burden found. The first is the simple fact of being old. It is possible that evaluations of stressful events are less intense among the elderly, thanks to the presence of adaptive coping strategies, although such individuals are more affected by the physical burden of care[26,27]. The second cause is reduced competition between the demands of work and the demands of care, a conflict which is often found in young and middle-aged caregivers. The third is that burden may be attenuated by the predominance of female caregivers of spouses in this sample, individuals for whom the task of caring is considered socially normative[28]. The role is often confused with the tasks of marriage among the elderly, such as preparing and serving meals to a husband on a daily basis[29].

The prevalence of self-reported diseases found in the present study meant that the morbidity profile was similar to that found in other studies in Brazil[30]. This contradicts the "Healthy Caregiver" hypothesis as a general rule for elderly caregivers, although it may be applicable to the 25% of the sample without multimorbidity and a low level of burden.

The proportional distribution of the frailty profiles in the sample is similar to most other studies on the subject, including those on community-dwelling elderly persons and convenience samples, and studies using both objective and subjective measures[9]. The pre-frail profile was the most frequent. There was also a large percentage of frail caregivers, a finding from which two explanatory hypotheses can be derived. One is due to the fact that such elderly persons perform the special role of caregiver. Another hypothesis relates to the instrument used to calculate frailty, which, because of its subjective nature, opens up greater possibilities for complaints related to the performance of the role, such as physical problems and discomfort, including a perception of slowness, fatigue, weight loss, strength and less involvement in physical activities. Literature has found that the elderly tend to complain of psychological discomfort through physical and functional references[31]. The components that refer to deterioration in physical performance were the most reported. This may be due to the physical burden of providing care in an aged body, considering the high intensity of the care found here, or the ease with which these deficits are perceived in the task of caring, as it is a self-reported instrument[8].

The elderly were evenly distributed among the four groups of vulnerability, indicating the heterogeneity of this condition. It is worthy of note, however, that group 4, representing multimorbidity and high burden, was the most prevalent of the groups. This supports double vulnerability as a recurrent factor among elderly caregivers.

Regression analysis revealed that the chances of being frail in groups 3 and 4 were significant, as the two groups represented the presence of multimorbidity. A greater chance of being frail was observed in the group with the greatest perceived burden (group 4). It can therefore be understood that multimorbidity plays a primary role in the association with frailty in elderly caregivers. When added to the condition of burden, the chances of suffering from the syndrome increase.

Due to these findings, it can be inferred that the double vulnerability of elderly caregivers increases the chance of the negative outcomes for the frailty syndrome described in literature, such as falls, hospitalization, institutionalization and death[9,32], which will only be confirmed in a longitudinal follow-up study.

The fact that the other variables in the study did not remain in the regression model is believed to be due to the explanatory power of the multimorbidity variable, which is associated with disadvantageous conditions of caring such as the female gender, advanced age and duration of care, variables which are intrinsic to multimorbidity.

Among the limitations of the study are the use of a convenience-based sample, which limits the generalization of the findings, and the non-functional evaluation of the elderly caregivers. However, the study represents an advance by warning of the need to observe a specific group of caregivers, which tends to increase in coming decades. The challenge facing the health system and its professionals is to support the daily practices of such caregivers. There is therefore a need for more caregiver care programs that provide, as well as guidelines on care, assistance with the maintenance and promotion of the physical and mental health condition of caregivers.

CONCLUSION

The results indicate the need to consider the needs of elderly caregivers, a specific group of caregivers that is likely to increase in the coming decades. In view of the behavior of this sample, it can be concluded that: (1) the burden of caring was attenuated in elderly caregivers; (2) for a significant group there is an overlap between variables of vulnerability associated with aging and care; (3) multimorbidity was associated with frailty, and if combined with perceived burden the chances of the elderly caregiver being frail are greater.

We have therefore identified a need for future research to monitor the transition in levels of frailty over the duration of care and to explore further the behavior and needs of these groups. There is also a need for further training and preparation in the social and health care network, so that the physical and psychological demands of these caregivers can be identified.

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