



Clinical and functional vulnerability of elderly caregivers of older adults with Alzheimer's

Vulnerabilidade clínica e funcional de idosos cuidadores de idosos com doença de Alzheimer

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Objective: to evaluate the clinical and functional vulnerability of elderly caregivers of older adults with Alzheimer's disease. **Methods:** it was a cross-sectional study with elderly caregivers registered in an Alzheimer's Patient Care Association. A sociodemographic questionnaire and the Clinical-Functional Vulnerability Index-20 were used for data collection, which were analyzed using R statistical software, Spearman's correlation, and Somers' D. **Results:** 31 elderly caregivers participated, mostly women, aged between 60 and 74 years, married, with low schooling, and taking care of the spouse. A greater risk of vulnerability related to self-perceived health, cognition and mood was identified. Functionality in daily activities, communication, mobility, and multiple comorbidities was preserved. **Conclusion:** most elderly caregivers were at risk of frail, which did not stop them from providing care for the relative with Alzheimer's. Professionals and institutions should work to prevent the functional decline of these elderly caregivers.

Descriptors: Geriatric Nursing; Nursing Care; Health of the Elderly; Alzheimer Disease; Vulnerability Analysis.

Objetivo: avaliar a vulnerabilidade clínica e funcional de idosos cuidadores de idosos com Alzheimer. **Métodos:** estudo transversal, realizado com idosos cuidadores, cadastrados em Associação de Assistência a Doente de Alzheimer. Utilizou-se de questionário sociodemográfico e do Índice de Vulnerabilidade Clínico-Funcional-20 itens, para coleta de dados, os quais foram analisados por meio do software R, utilizando-se de porcentagem, correlação de Spearman e D de Somer. **Resultados:** participaram 31 idosos cuidadores, maioria mulheres, com idades entre 60 e 74 anos, casadas, baixa escolaridade e que prestavam cuidado ao cônjuge. Identificou-se maior risco de vulnerabilidade relacionada à autopercepção de saúde, cognição e humor. Funcionalidade preservada nas funções executivas, comunicação, mobilidade e comorbidades múltiplas. **Conclusão:** a maioria dos idosos cuidadores apresentou risco de fragilização, porém realizam o cuidado ao familiar com Alzheimer. Profissionais e instituições devem atuar na prevenção do declínio funcional desses cuidadores idosos.

Descritores: Enfermagem Geriátrica; Cuidados de Enfermagem; Saúde do Idoso; Doença de Alzheimer; Análise de Vulnerabilidade.

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Introduction

Population aging has become a challenge for the health demands of older adults due to the high rates of chronic diseases and their complications⁽¹⁾. Dementias stand out in this scenario with a higher prevalence of Alzheimer's disease. The estimated risk of a person developing this disease after 65 years of age is approximately 10.5%. It causes progressive and incapacitating cognitive and functional decline, requiring supervision and continuous care as the disease evolves. The care of this population is often provided by elderly people⁽²⁾. Despite functional losses inevitable to old age, according to lifestyle and culture, they can present stability, physical, cognitive and emotional competence, thus maintaining the working capacity⁽³⁾.

Family members are the main caregivers of older adults with Alzheimer's, also recognized as the cornerstone, without which the formal care system would collapse⁽⁴⁾. Caring for a person with Alzheimer's is considered one of the most arduous tasks, affecting the psychological and physical health of the caregiver, who may experience high levels of stress, depression, physical and emotional exhaustion⁽⁵⁾. This situation can be aggravated when it comes to elderly caregivers, with a risk for functional disability, a condition that combined with the changes in aging predispose the advancement of vulnerability, in biological, socioeconomic and psychosocial aspects, marked by the loss of functionality⁽²⁾.

Functionality is defined as the ability of people to adjust to adversities in daily life, including acting in society, even if they present some social, physical or mental restriction⁽⁶⁾. Thus, based on the premise that to develop care safely and effectively, the elderly caregiver needs to present preserved functionality, frequent assessments of health conditions can guide team decision making and prevent negative outcomes. In this context, this study used the following question: How is the health of elderly caregivers of older adults with Alzheimer's?

Among the methods to evaluate the function-

nal capacity of older adults, the Clinical-Functional Vulnerability Index-20 (IVCF-20) stands out, a multifunctional vulnerability assessment instrument for simple and quick application for Brazilian elderly, which enables immediate identification of the functional situation of older adults⁽⁷⁾. Currently, there is little information on the clinical and functional status of older adults who take on the role of caregivers of Alzheimer's patients. In the recent literature, two studies were identified, one focusing on overload and the other, on the knowledge level of caregivers about the disease⁽⁸⁻⁹⁾. Thus, this study aimed to evaluate the clinical and functional vulnerability of elderly caregivers of older adults with Alzheimer's.

Methods

It was a cross-sectional study carried out with elderly caregivers of older adults with Alzheimer's disease registered in the Association of Studies, Research and Support for Alzheimer's Patients, from a municipality in the interior of the State of Paraná, Brazil, a nongovernmental organization founded in 2012 to provide guidance and monitor actions in the Social and Health area, with home care, in order to prevent the occurrence of vulnerability and social risk situations⁽¹⁰⁾. Data collection took place in February and March 2016, at the home of the selected elderly. The inclusion criteria comprised: people aged 60 years and older, being the primary caregiver of the older adult with Alzheimer's, of both genders, not presenting incapacitating dysfunctions to answer the instruments.

The institution followed 63 older adults and their caregivers. When applying the inclusion criteria, 18 were not elderly and 14 were caregivers of older adults who had died, thus resulting in a study population of 31 elderly caregivers. For data collection, a questionnaire was designed by the authors and subjectively validated by the team of the Association of Studies, Research and Support for Alzheimer's Patients for socio-demographic characterization (gen-

der, age, marital status, occupation, color, religion, use of the Family Health Strategy, kinship, and difficulties in care).

To evaluate the vulnerability of the participants, the IVCF-20 was applied, which was validated in Brazil in 2016, including multidimensional aspects of the health condition of older adults, composed of 20 questions, with specific scores distributed in eight sections that make up 40 points. In most questions, the "no" answer equals a zero score. The higher the value obtained, the greater the risk of clinical-functional vulnerability. The frailty markers that make up the sections are: age, health self-perception, functional disabilities, cognition, mood, mobility (reach, graspingness, and pincer grip, aerobic/muscular capacity, gait, and sphincteric incontinence), communication, and multiple comorbidities. From these markers they can be classified as: robust older adults (from 0 to 6 points); older adults at risk of frail (7 to 14 points); and frail older adults (≥ 15 points)⁽⁷⁾.

Data were entered, organized and tabulated in spreadsheet in Microsoft Excel, and then analyzed with the aid of R statistical software. Absolute values and percentages were used to describe the results. In the association between the score with age, schooling and caregiver time, Spearman's correlation coefficient, appropriate for ordinal scale, was applied. To evaluate the association between the IVCF-20 score with gender, occupation, marital status, use of the Family Health Strategy, and kinship, Somer's D was applied, suitable for dichotomous variables. The analyzes used the significance level of 5%.

Research Ethics Committee of the State University of the Central West approved the research under protocol n^o 1,777,066 and Certificate of Presentation for Ethical Appreciation n^o 60789816,0,0000,0106.

Results

Results of this study indicated the caregivers' profile, consisting of 26 (83.8%) females, 25 (80.6%) aged 60-74 years, 26 (83.8%) married, and 15 (48.3%) with basic education, as presented in Table 1.

Table 1 – Distribution of frequencies and results of correlation tests between the Clinical-Functional Vulnerability Index-20 and the socioeconomic and demographic variables of elderly caregivers of older adults with Alzheimer's

Variables	n %	Correlation	
		Coefficient	p-value
Age (years)		0.121 [†]	0.518
60-74	25 (80.6)		
75-84	2 (6.4)		
85-94	4 (12.9)		
Gender		-0.392*	0.178
Female	26 (83.8)		
Male	5 (16.1)		
Occupation		-0.509*	0.111
Retired	12 (38.7)		
Housewife	15 (48.3)		
Other	4 (12.9)		
Marital status		-0.169*	0.572
Married	26 (83.8)		
Single	5 (16.1)		
Education		-0.303 [†]	0.097
Illiterate	11 (35)		
Basic education	15 (48.3)		
High school	4 (12.9)		
Higher education	1 (3.2)		
Assisted by the Family Health Strategy		0.139*	0.647
Do not know	5 (16.1)		
Acknowledges	26 (83.8)		
Caregiver time (years)		0.216 [†]	0.244
1-4	13 (41.9)		
5-9	10 (32.2)		
10-14	6 (19.3)		
>15	2 (6.4)		
Kinship		-0.070*	0.761
Spouse	19 (61.2)		
Children	8 (25.8)		
Sibling	3 (9.6)		
Caregiver	1 (3.3)		

*Somer's D; [†] Spearman's correlation coefficient

Predominantly, women have been the caregivers of older adults with Alzheimer's, retired or housewives. There is a correlation tendency between the vulnerability index and the educational level of the

caregivers, revealing that caregivers with low level of education tended to present worse results, indicating a higher vulnerability. Additionally, the vulnerability index score increases with the time the caregiver performs the role.

Table 2 presents the results of the main difficulties reported by elderly caregivers of Alzheimer’s patients when performing this role. Hygiene care of older adults with Alzheimer’s (74.1%) and agitation and aggression (41.9%) were the main difficulties pointed out by elderly caregivers. Only 10.0% of the participants stated that they did not have difficulties performing the care.

Table 2 – Frequency distribution of variables related to the difficulties of elderly caregivers of older adults with Alzheimer’s

Difficulties	n (%)
None	3 (10.0)
Hygiene care	23 (74.1)
Agitation/aggression/irritation	13 (41.9)
Feeding	7 (22.5)
Insomnia	5 (16.1)
Get up/get out of bed	2 (6.4)
Locomotion	2 (6.4)
Escapes	2 (6.4)
Communication	1 (3.2)
Medication	1 (3.2)
Dressing	1 (3.2)

It was identified that the Clinical and Functional Vulnerability Index ranged from 2 to 27 points, with a mean and median of 12.8 and 12 points, respectively. Regarding dispersion, a standard deviation of 7.22 points was obtained, with a coefficient of variation of 56.39%, thus indicating a high dispersion of the data around the average (Table 3).

Data demonstrate that the elderly caregivers participating in the study obtained low scores in most variables: age, 25 (80.6); excellent or good health self-perception, 16 (51.6%); activities of daily living, 21 (67.7%) and 30 (96.7%), ability for instrumental and

basic activities of daily living, respectively. As for mobility, 31 (100.0%) were able to raise the arms above shoulder level, 29 (93.5%) were able to hold small objects, 23 (74.1%) did not present unintentional weight loss, and 22 (68%) had five or less comorbidities. They scored high on the variables related to mood, dismay and sadness, 17 (54.8%), and involuntary loss of urine or feces, 14 (45.1%) (Table 3).

Table 3 – Distribution of Frailty Markers of elderly caregivers of older adults with Alzheimer’s according to the Clinical-Functional Vulnerability Index-20

Variables regarding the Clinical-Functional Vulnerability Index-20	n (%)
Age	
60-74	25 (80.6)
75-85	3 (9.6)
> 85	3 (9.6)
Self-perception of health	
Excellent, very good, or good	16 (51.6)
Regular or bad self-perception of health	15 (48.3)
Activities of daily living	
Disability in at least one instrumental activities of daily living	11 (35.4)
Stopped bathing alone for physical condition – basic activities of daily living	1 (3.2)
Cognition	
A relative or friend mentioned forgetfulness of the patient	19 (61.2)
Worsening of forgetfulness in the last months	17 (58)
Mood	
Dismay, sadness, or hopelessness	17 (54.8)
Loss of interest or pleasure in previously enjoyable activities	17 (54.8)
Mobility	
Inability to raise the arm above shoulder level	-
Inability to hold small objects	2 (6.4)
Unintentional weight loss or BMI < 22 kg/m ² or calf circumference <31 cm or time during the gait speed test for 4 m > 5 s	8 (25.8)
Walking difficulties	10 (32.2)
Two or more falls in the last year	7 (22.5)
Involuntary loss of urine or feces at some point	14 (45.1)
Communication	
Vision problems that may prevent the performance of some daily activity	11 (35.4)
Hearing problems that may prevent the performance of some daily activity	8 (25.8)
Multiple comorbidities	
Five or more chronic diseases or daily use of five or more different drugs or hospitalization in the last six months	9 (29.0)

Considering that the total IVCF-20 score was 40 and the study participants scored between 2 and 27, with a mean and median of 12.8 and 12, respectively, 13 (41.9%) elderly caregivers are in the category of at risk of frail; 10 (32.2%) frail; and only 8 (25.8%) were robust.

Discussion

It is worthy highlighting that the cross-sectional nature of the research and the reduced sample led to limitations to the study, nevertheless, they did not prevent the development of the research. Furthermore, it presents important information about clinical and functional vulnerability of elderly caregivers of older adults with Alzheimer's, strengthening the knowledge on the subject and instrumentalizing nursing professionals for actions that can improve care for elderly caregivers.

The study evaluated the clinical and functional condition of elderly caregivers of older adults with Alzheimer's from a multifunctional perspective. Data demonstrate that most elderly caregivers belong to the category of at risk of frail: independent for all activities of daily living, but present predictive conditions of adverse outcomes⁽⁷⁾. These results corroborate another study of vulnerability assessment, in which most of the elderly also presented this condition⁽¹¹⁾.

Demographic characteristics of the studied population indicate similarity in gender, age, marital status, education level, and occupation⁽¹²⁾. They corroborate an earlier and larger scale study, differing only in years of study. In the United States of America, a representative sample of elderly informal caregivers revealed that 82.0% of the caregivers had higher education⁽¹³⁾. In the Brazilian scenario, it is common to find informal caregivers with an average of four years of study. Low level of education was also verified in a study with elderly caregivers in Mexico, 71.4% had basic education⁽¹⁴⁾. The level of education of the caregiver influences the quality of care, the higher the

level of education, the better the understanding and learning, demonstrating the importance of education in this context of care⁽⁸⁾.

The spouse as the primary caregiver of Alzheimer's patients is a fact pointed out by other studies and in different realities^(8,13). Among the main reasons that contribute to this family decision there are socioeconomic and cultural factors⁽¹⁴⁾. It is observed that the cultural matter permeates the way of coping with the possible difficulties encountered in caring. One example is the fact of being a woman, prepared for this role from very early on, and performing it with compromise, while the man is expected to work to provide support for the family⁽¹³⁾. Like the findings of the present study, another study showed that they performed technical activities, from maintaining medication control, wound care, hygiene and comfort, 52.3% performed more than two medical/nursing actions⁽¹⁵⁾.

In the development of care actions performed by elderly caregivers of older adults with Alzheimer's, corroborating the findings, it is noteworthy that people with dementia may exhibit verbal or physical aggressive behaviors at the time of bathing or dressing, usually related to refusal⁽¹⁶⁾. Nonetheless, it is an indispensable action, since it mainly provides comfort, stimulates circulation, prevents skin lesions, and promotes a sense of well-being for the elderly⁽¹⁶⁾. Carrying out these activities requires a certain amount of caregiver hygiene, mobility and strength, but even with a certain degree of difficulty, they manage to perform their role. This finding was confirmed by another study carried out with elderly caregivers from an urban and rural region of Campinas-SP, Brazil, in which most of the elderly were at risk of frail⁽¹⁷⁾.

Agitated and aggressive behaviors reflect the level of neurological impairment of Alzheimer's disease. These factors, along with others, were reported as difficulties by the caregivers, agents that can increase the overload. Study conducted with people with various forms of dementia indicated that irritability,

agitation and disinhibition are frequent symptoms in Alzheimer's, the greater the functional decline and cognitive performance, the greater the difficulty in communicating, thus causing irritability. Caregiver overload is also related to the fact that the tasks are usually assumed by a single person as the primary caregiver, who often is responsible not only for the care but also for household chores⁽¹⁸⁾.

Regarding self-perceived health, an important indicator of mortality, the worse perception of health status indicates a higher risk of death compared to those reporting excellent health. Even though most of them present this feature of preserved functionality, one cannot ignore the number of those who considered their health poor, putting them in the category at risk of frail⁽¹²⁾. Similarly, study performed with a population of older adults in Rio Grande do Sul, Brazil, in which 61.3% of the respondents considered their health good or very good, indicated a lower functional decline⁽¹⁹⁾. However, there was also a considerable number of negative health perceptions. Negative self-perception may be associated with factors such as age, gender, hypertension, financial resources, schooling, visual deficit, urinary incontinence, hearing deficit, and history of falls⁽²⁰⁾.

The functional capacity of older adults includes the ability to perform physical and mental tasks. Cognitive decline translates into mild slowness of mental abilities that evolves with advancing age. Study that evaluated the memory of older adults in the city of São Paulo, Brazil, reveals that the low cognitive performance is related to the low level of schooling, converging with the findings of this study⁽¹⁷⁾. Among the factors that influence the adaptation of the cognitive aging process are personality, negative emotional state and intellectual level. New experiences represent an important factor for the maintenance of cognitive capacity⁽¹⁹⁾.

The mood affects the health condition of older adults, demonstrating the degree of risk of developing depression. The feeling of hopelessness and/or disin-

terest in performing pleasurable activities were also mentioned as a problem in other studies⁽¹⁹⁻²⁰⁾. This variable is related to mental functions, such as sensory perception, level of consciousness and thought, as well as the necessary support for social participation or performance of the elderly. Depressive mood is one of the conditions that put older adults at risk of frail, as well as involuntary loss of urine and feces⁽¹²⁾.

Involuntary loss of urine and feces is an important indicator of risk of vulnerability. Inability to control urination and evacuation was also identified in study developed in Bagé-RS, Brazil, in which it presented a high prevalence of inability⁽²⁰⁾. This is a significant fact, since the embarrassment caused by urinary incontinence can lead to social isolation, changes in self-image and self-esteem, and sexuality, which may compromise the performance of daily life activities. Spontaneous incontinence alone does not constitute a degree of dependence, since it is a function rather than an activity, which must be identified and treated.

Conclusion

Elderly caregivers of older adults with Alzheimer's are independent for daily life activities but present some predictors of negative outcomes marked by increased risk of functional decline, mild cognitive impairment, negative health self-perception, and urinary incontinence. Although they manage to perform care, they are at risk of frail, a situation that puts professionals and institutions on alert for the health of these caregivers, since they must act to prevent the functional decline of these elderly.

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Collaborations

Barbosa MEM contributed to the design, data analysis, drafting of the article, and critical review of intellectual content. Bertelli EVM contributed to the design, data collection and analysis, and drafting of the article. Scolari GAS and Bortolanza MCZ contributed to the drafting of the article and relevant critical review of intellectual content. Higarashi IH and Carreira L contributed to the drafting of the article and final approval of the version to be published.

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