

RELATIONSHIP BETWEEN THE EPIDEMIOLOGICAL PROFILE OF CAREGIVERS OF ELDERLY PEOPLE WITH DEMENTIA AND OVERBURDEN OF CARE*

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ABSTRACT: The present study aimed to evaluate the sociodemographic and clinical profile of caregivers and their relationship with overburden of care of elderly people with dementia. Descriptive cross-sectional study, non-probability sample with 94 elderly people suffering with dementia, conducted at a Care Center for Elderly in the state of Rio de Janeiro. Data was collected from February to June 2016, through a questionnaire on sociodemographic aspects and Zarit Inventory. Forty-six (50%) caregivers had moderate overburden, 35 (38%) had little overburden and 11 (12%) moderate/severe overburden; 71 (77%) caregivers took 1 to 5 drugs and 20 (22%) took 6 to 11 drugs. The following trends were observed: individuals with lower income experienced higher levels of overburden; less experienced caregivers had moderate overburden; the greater the overburden of caregivers, the lower the average age of these individuals. Also, overburdened caregivers were in conditions of biological and psychological vulnerability.

DESCRIPTORS: Dementia; Caregivers; Family nursing; Elderly; Vulnerability.

RELAÇÃO DO PERFIL EPIDEMIOLÓGICO DOS CUIDADORES DE IDOSOS COM DEMÊNCIA E A SOBRECARGA DO CUIDADO

RESUMO: Objetivou-se avaliar o perfil sociodemográfico e clínico dos cuidadores e sua relação com a sobrecarga proveniente do cuidado ao idoso com demência. Estudo descritivo transversal, amostra não probabilística com 94 cuidadores de idosos com demência, realizado num Centro de Atenção à Saúde do Idoso no estado do Rio de Janeiro. A coleta de dados ocorreu de fevereiro a junho de 2016, por meio de questionário sociodemográfico e escala de Zarit. Quarenta e seis (50%) cuidadores apresentaram sobrecarga moderada, 35 (38%) pouca sobrecarga e 11 (12%) sobrecarga moderada/severa; 71 (77%) cuidadores usavam de 1 a 5 medicamentos e 20 (22%) 6 a 11 medicamentos. Observou-se as tendências: indivíduos com rendas mais baixas evidenciaram maiores níveis de sobrecarga; cuidadores com menor tempo de experiência possuíam sobrecarga moderada; quanto maior a sobrecarga, menor a média da idade. Verificou-se que a sobrecarga do cuidado coloca o cuidador em condições de vulnerabilidade biológica e psicológica.

DESCRIPTORES: Demência; Cuidadores; Enfermagem familiar; Idosos; Vulnerabilidade.

ASOCIACIÓN ENTRE EL PERFIL EPIDEMIOLÓGICO DE LOS CUIDADORES DE ANCIANOS CON DEMENCIA Y LA SOBRECARGA DEL CUIDADO

RESUMEN: Fue objetivo del estudio evaluar el perfil sociodemográfico y clínico de los cuidadores y su relación con la sobrecarga del cuidado al anciano con demencia. Estudio descriptivo transversal, con muestra probabilística con 94 cuidadores de ancianos con demencia, realizado en un Centro de Atención a la Salud del Anciano en estado de Rio de Janeiro. Los datos fueron obtenidos de febrero a junio de 2016, por medio de cuestionario sociodemográfico y escala de Zarit. Cuarenta y seis (50%) cuidadores presentaron sobrecarga moderada, 35 (38%) poca sobrecarga y 11 (12%) sobrecarga moderada/severa; 71 (77%) cuidadores usaban de 1 a 5 medicamentos e 20 (22%) 6 a 11 medicamentos. Se observaron las siguientes tendencias: individuos con rentas más bajas evidenciaron mayores niveles de sobrecarga; cuidadores con menos tiempo de experiencia tenían sobrecarga moderada; cuanto mayor la sobrecarga, menor la media de edad. Se verificó que la sobrecarga del cuidado pone el cuidador en condiciones de vulnerabilidad biológica y psicológica.

DESCRIPTORES: Demencia; Cuidadores; Enfermería familiar; Ancianos; Vulnerabilidad.

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● INTRODUCTION

The latest census revealed decline in the rate of population growth and increase in the number of elderly, which now account for about 11% of the population. Increase in the life expectancy of the population led to a significant increase in age-related chronic degenerative diseases, including the different forms of dementia, with emphasis to Alzheimer's disease (AD), the most common form⁽¹⁾.

Thus, aging can be defined as the gradual decrease in functional capacity soon after sexual maturity. Forgetfulness is a common complaint among older individuals. This age-related memory loss that commonly affects the elderly must be investigated to distinguish between normal and pathological memory problems⁽²⁾.

The increase in the life expectancy of the population is accompanied by a significant increase in the cases of dementia. Dementia is a chronic and progressive syndrome caused by various brain deficits that affect memory, the ability to think, behavior and the ability to perform daily routine activities. In 2010, it was estimated that 35.6 million people were diagnosed with dementia. Every year 7.7 million new cases are identified, which means that every four seconds, somewhere in the world, a new case of dementia is detected⁽³⁾.

Elderly with cognitive impairment caused by dementia need a caregiver to help them perform their daily activities. Caregivers monitor the routine of these elderly, being attentive to all the manifestations of the disease to ensure the integrity of the patients. Therefore, these professionals are exposed to possible behavioral changes of the elderly, and must be prepared to handle this situation to avoid damage to their health and the health of the elderly⁽⁴⁾.

The care provided to elderly with dementia has many different implications in the lives of caregivers. These individuals have sleep disturbances, emotional problems, depression, mood swings that affect their physical, emotional, psychological and social aspects. The progressive dependency of elderly with dementia impairs the health of caregivers⁽⁵⁾.

Thus, this disorder is a two-way street, where dementia has an impact on the quality of life of the caregiver and the quality of life of the caregiver can impact the care delivered to the elderly. Therefore, both the caregiver and the elderly need specialized care focused on their needs.

Understanding this situation is necessary to plan the care targeted to the needs of this audience, to ensure a good quality of life to caregivers and hence improve the quality of care. Therefore, the present study aimed to describe the sociodemographic and clinical profile of caregivers and assess its relationship with overburden of caregivers who care for elderly with dementia.

● METHOD

Cross-sectional descriptive cross-sectional study that uses a quantitative method. The study site was the Care Center for the Elderly and their Caregivers (CASIC), geriatric outpatient care unit of Universidade Federal Fluminense, in Niterói, Rio de Janeiro. Data collection took place from February to June 2016 during nursing consultations.

The study used non-probability sample and included 92 participants. The inclusion criteria were: informal caregiver of elderly individuals with dementia that attended the CASIC; caregiver responsible for most care provided to the elderly patient for at least six months. The exclusion criteria were lack of practical experience as caregiver of elderly individuals with dementia; communication disorder that impairs the application of the tests and missing three consecutive consultations without prior justification.

The protocol adopted for data collection with caregivers of elderly people with dementia used structured interviews conducted during nursing consultation.

Two instruments were used in data collection: the socio-demographic questionnaire especially designed for the study to identify the profile of caregivers of elderly with dementia through clinical

and sociodemographic variables, and the Zarit inventory to measure overburden of care.

The Zarit Burden Interview (ZBI) is one of the most widely used instruments for measuring overburden of caregivers of elderly patients with dementia. The scale was validated in 2002 in a study conducted at Hospital das Clínicas of the School of Medicine, of the University of São Paulo (IPQ-HCFMUSP) and the Integrated Center for Mental Health of Santa Casa de Misericórdia, also in São Paulo⁽⁶⁾.

This inventory has 22 questions and the answers are never (0 points), rarely (1 point), sometimes (2 points), often (3 points) and always (4 points). The total score ranges from 0 - 88 points. The higher the score, the greater the overburden.

The level of overburden experienced by the caregiver is classified according to the following scores: <21 = little overburden; between 21 and 40 = moderate overburden; from 41 to 60 = severe to moderate overburden and between 61-88 = severe overburden⁽⁷⁾.

Data analysis involved the construction of an electronic spreadsheet with Excel® software using double data entry and validation procedure to compare the entries. Following validation and interpretation, the data was described through charts and tables. Kolmogorov-Smirnov test was used to analyze data normality, since the sample consists of more than 50 participants. The referred test is used to determine the correct choice of the subsequent tests of data association. Normal distribution means that random events follow a predictable pattern. On the other hand, non-normality shows that some of the variables that describe an event follow a non-predictable pattern due to reasons inherent to the phenomenon.

The measure of central tendency used for all non-normal data was the median, since the measure of dispersion was the interquartile range. On the other hand, for age and time spent as caregiver, which had normal distribution, mean and standard deviation were used.

One-way ANOVA and Kruskal-Wallis tests were used. Analysis of Variance or ANOVA is an effective collection of statistical models developed by Fisher. According to this model, the variance observed in the values is decomposed into several components. In its simplest form, data is analyzed in a completely randomized design or ANOVA, using one criterion of classification (ANOVA one way). Normal data distribution is necessary to obtain valid results⁽⁸⁾.

Traditional ANOVA is not recommended for data that is not normally distributed, Kruskal-Wallis test that compares measures of central tendency of data can be used in these cases⁽⁸⁾.

To measure the strength of association in ANOVA the statistical software G* Power 3.1.3 was used. To check the size of the association effect between the variables with non-normal distribution, Cramer's V test was used.

The study was approved by the Research Ethics Committee of Hospital Universitário Antônio Pedro (HUAP), under statement no 1.220.297.

● RESULTS

Table 1 shows the sociodemographic profile of the sample, with emphasis to variable gender, with 57 (62%) women, aged between 48 and 57 years, and the marital status of most of them was married: 48 (52.17%).

Table 1 – Sociodemographic data of the sample. Niterói, RJ, Brazil, 2016 (continues)

Variable	Categories	f (n)	fr (%)
Gender	Female	57	62
	Male	35	38

Age (years)	18 to 27	2	2
	28 to 37	1	1
	38 to 47	8	8.7
	48 to 57	30	32.6
	58 to 67	29	32
	68 to 77	13	14
	78 to 87	8	8,7
	88 to 97	1	1
Schooling (years)	0 to 9	26	29
	10 to 19	63	68
	19 to 20	3	3
Marital status	Married	48	52.17
	Widowed	6	6.52
	Separated/Divorced	17	18.47
	Single	12	13.04
	Other type of familial bond	9	9.8
Income	R\$800,00 to R\$3.000,00	39	42
	R\$3.001,00 to R\$6.000,00	29	32
	R\$6.000,00 to R\$12.000,00	14	15
	R\$12.001,00 to R\$24.000,00	9	10
	R\$24.000,00 to R\$34.000,00	1	1
Degree of kinship to the elderly	Spouse	48	52
	Son/daughter	6	6.5
	Daughter-in-law/Son-in-law	17	18.5
	Brother/sister	13	13
	Others	9	10
Works	Yes	36	39
	No	56	61

Other percentages (Table 2) were identified: hypercholesterolemia was detected in five (5.4%) participants; two (2.2%) participants reported the following health problems: Parkinson's syndrome, herpes Zoster, thyroid nodules, gastritis, depression and fibromyalgia. Less frequent diseases observed in at least one 1%) participant were anxiety disorder, ischemia, labyrinthitis, Alzheimer's disease, prostatitis, renal calculus and Obsessive Compulsive Disorder. It should be stressed that regarding the variable diseases, Table 2 highlights the frequency in which these conditions were detected in the study population, and one caregiver could be affected by various pathologies.

Table 2 – Clinical data of the sample. Niterói, RJ, Brazil, 2016 (continues)

Variable	Categories	f (n)	fr (%)
Diseases	Systemic Arterial Hypertension	43	46.7
	Arthrosis	39	42.4
	Spinal problems	36	39.1
	Diabetes Mellitus	14	15.2
	Cardiopathy	12	13
	Osteoporosis	11	12
	Hypothyroidism	10	10.8
	Vitamin deficiency	8	8.6
	Others	24	25.6

Use of medications (number of medications per day)	Does not take any medication	1	1
	1 to 5	71	77
	6 to 11	20	22

Table 3 shows the descriptive analysis of the variables related to care to the elderly. Regarding the time spent in the caregiving role, in months, it varied significantly. The minimum time spent in this activity was six months, and for periods greater than six months, six-month intervals were used to facilitate the presentation.

Table 3 – Variables related to care. Niterói, RJ, Brazil, 2016

Variable	Intervals	f (n)	fr (%)
Hours per week spent in care	0 to 12	4	4
	13 to 24	7	8
	25 to 36	12	13
	37 to 48	8	9
	49 to 60	13	14
	61 to 72	9	10
	73 to 84	22	24
	85 to 96	2	2
	97 to 108	5	5.5
	109 to 120	5	5.5
	121 to 132	0	0
	133 to 144	0	0
	145 to 156	1	1
	157 to 168	4	4
Time spent in the caregiving role in months	6	4	4
	7 to 12	4	4
	13 to 18	3	3
	19 to 24	2	2
	25 to 30	0	0
	31 to 36	8	9
	37 to 42	0	0
	43 to 48	5	5.5
	49 to 54	0	0
	55 to 60	11	12
	61 to 66	0	0
	67 to 72	0	0
	73 to 78	0	0
	79 to 84	9	10
	85 to 90	1	1
	91 to 96	8	9
	97 to 102	0	0
	103 to 108	3	3
≥ 109	30	33	

Still on care-related variables, another aspect identified was sharing the care of elderly with another family member. It was found that 88% (n = 81) of the caregivers shared care with another family member and 12% (n = 11) provided comprehensive care without any help from another caregiver.

Table 4 shows the normality test of the study population. All data presented a non-normal distribution, except for variable age with $p = 0.169$.

Table 4 - Kolmogorov-Smirnov normality test. Niterói, RJ, Brazil, 2016

	Kolmogorov-Smirnov		
	Statistics	DF	Sig.
Age	0,082	92	0,169
Takes drugs	0,246	92	0
Hours per week spent in care	0,135	92	0
Time spent in the caregiving role	0,123	92	0,002
Shares caregiving with another caregiver	0,504	92	0
Income	0,195	92	0

Regarding the use of the Zarit burden inventory, 50% (n=46) of the caregivers showed moderate overburden, 38% (n=35) showed little overburden and 12% (n=11) had moderate/severe overburden.

Regarding age, ANOVA was used to check the possible association between age and the results of the Zarit Inventory. No statistically significant difference was found between these variables, $p=0.402$. The level of significance adopted was $p\leq 0.05$.

Despite the lack of a statistically significant difference ($p\leq 0.05$), when the means of caregivers with little, moderate and moderate/severe overburden are considered, analysis of the strength of association shows that the data have a moderate tendency to the following result: the higher the overburden, the lower the average age of the caregivers. Individuals with little overburden had an average age of 61.17, those with moderate overburden had an average age of 59.74 old and those with moderate/severe overburden had an average age of 55.36.

Regarding the time spent in the caregiving role, one-way ANOVA obtained $p=0.091$, indicating that there was no significant difference between the results of the Zarit burden inventory and this variable. The level of significance used was $p\leq 0.05$. The strength of association of these variables was 0.508, and regarding the means of the individuals with little (mean: 97.34, standard deviation: 62.5), moderate (mean: 75.17, standard deviation: 48.3) and moderate to severe overburden (mean: 106.36, standard deviation: 44.9), it was found that the caregivers with moderate overburden had the lowest average time spent in the caregiving role and the caregivers subjected to moderate to severe overburden had the highest average of time spent in the caregiving role. Therefore, less experienced caregivers were subjected to moderate overburden of care.

Regarding income, when related to the Zarit burden inventory, Kruskal-Wallis test did not show a statistically significant difference between data, with $p=0.224$. However, the median income of the participants with little overburden was R\$5.000,00, and the interquartile range was R\$4.612,00. The explanation for this value is the fact that three participants were outside the parameters expected in this group.

The median income of the individuals with moderate overburden was R\$2.994 and the interquartile range was R\$4.777, 00; the median income of caregivers with moderate to severe overburden was R\$ 2.200,00 and the interquartile range was R\$3.190,00. Cramer's V test showed strong association between these variables, with a strength of 0.835 for the fact that individuals with lower incomes were subjected to higher levels of overburden of care.

Data heterogeneity may explain the fact the non-statistically significant difference in variable analysis.

● DISCUSSION

Regarding gender, 62% (n = 57) of the participants were female. In a patriarchal society, as it is the case of Brazil, women traditionally play caregiving roles, as mothers and housewives, which is consistent with the literature⁽⁹⁾.

However, this profile is changing. Previous studies found that more than 70% of caregivers were women. This was also demonstrated in other scientific investigations⁽⁹⁻¹⁰⁾ that reported percentages between 70.6% and 87.6%. Therefore, the fact that 38% (n=35) of the sample was composed of men revealed that these individuals are more involved in care and the primary caregivers of elderly.

Regarding age, 64.6% of the participants are in the 48-57 age range and 58-67 age range. A significant percentage of caregivers were over 60 years of age, as follows (58 to 67 years (32%); 68 to 77 (14%); 78 to 87 (8.7%) and 88 to 97 (1%), accounting for more than 50% of the sample.

The present study found that many older people are playing the role of caregivers to elderly relatives with dementia. This finding corroborates data from other studies that also reported that more than 40% of the sample consisted of caregivers over 60 years of age⁽¹¹⁾. Or else, in addition to checking the needs of the caregivers, the health professionals must consider the specificities of their age ranges.

Concerning education, 71 % of the participants had completed more than 10 years of schooling. This finding is not consistent with those obtained in other studies⁽¹¹⁻¹²⁾ where most caregivers had completed only primary school.

The level of education of caregivers and the elderly patients is essential to the nursing team, since the content of the educational measures to be handed to those individuals must be accessible to them⁽¹²⁾.

Regarding the marital status, most individuals were married, 52.17%. This data is consistent with data obtained in other similar studies with caregivers. Some studies^(11,13) obtained percentages between 50.7% and 78.3% of married individuals.

Regarding monthly income, most caregivers earned R\$800,00 to R\$3.000,00 (42%) and R\$3.001,00 to R\$6.000,00 (32%). A study⁽⁹⁾ found that the average family income was approximately R\$630 reais, which is far below the average income found in the present study.

As for the degree of kinship to the elderly, 52% (n=48) of the caregivers were spouses; 6.5% (n=6) were sons/daughters; daughters-in-law or sons-in-law 18.3% (n=17) and brothers/sisters 13% (n=13), in addition to other type of family bond. The fact that more than 50% of the population was composed of spouses corroborates the results of previous studies that found that family are often the primary caregivers of elderly with dementia. Women are often primary caregivers, being responsible for providing most of the day-to-day needs of the elderly for a long period of time⁽¹⁴⁾.

However, the findings related to daughters-in-law and sons-in-law contrast with data obtained on other studies. Sons/daughters are usually the primary or secondary caregivers. This situation was identified in other studies^(13,15).

Regarding the occupation of the family caregivers, it was also found that 61% (n=56) of them did not work outside and 39% (n=36) worked outside. Some authors reported that it is hard for these family caregivers to work outside the house, since elderly with dementia require permanent supervision. When there is no support from a secondary caregiver, full-time primary caregivers are compelled to quit their jobs to devote themselves exclusively to the care of elderly with dementia. This decision may cause psychological problems⁽⁹⁾.

The health problems faced by family caregivers are worrying, since these individuals responsible for providing care are most of the time alone at home with the elderly. The most common diseases detected in these caregivers were: hypertension (HBP) 46.7%, arthrosis 42.4%, spinal problems 39.1%, Diabetes Mellitus 15,2%, cardiopathy 13%, osteoporosis 12%, hypothyroidism 10,8%, and vitamin deficiency 8.6%. The diseases that affect caregivers are a major challenge for health professionals. It should be stressed that some family caregivers are already old and, thus, will need help from others to

carry out their care activities properly⁽¹¹⁾.

A cross-sectional observational study conducted in Brasília found that systemic arterial hypertension (SAH) was the most common disease in caregivers. According to the authors, this finding was expected, since many individuals were over 60 years of age. The SAH is a chronic disease expected to occur for this age group. Another relevant aspect was the complaint of pain, and the most frequent complaints involved back pain⁽⁹⁾. This finding is consistent with the results of the present study.

Complaints for bodily pain were identified in another study⁽¹⁵⁾ as the most prevalent problem in caregivers. There was also a tendency for worse self-perception of physical health among caregivers of patients with Alzheimer's disease compared to other types of dementia.

It should be stressed that 1% of the sample did not use any medication, while 77% of them took 1 to 5 drugs and 22% took 6 to 11 drugs. Polypharmacy is associated with increased risk and severity of adverse drug reactions, drug interactions, cumulative toxicity, medication errors, in addition to reducing adherence to treatment and increasing morbidity and mortality⁽¹⁶⁾.

Some studies reveal⁽⁹⁻¹⁰⁾ the large use of medications by family caregivers, and these medications are often purchased without a prescription for controlling pain and insomnia.

In the study population, most family caregivers devoted long time (73 to 84 hours per week) to care, which is equivalent to approximately 10 to 12 hours per day. Even when the primary caregiver is supported by another person, his/her concern with the daily care activities persists. Some caregivers are unable to fully disconnect themselves from care even when they are not directly responsible for providing such care

The impact of overburden of care on the lives of caregivers is obvious: due to the very time-consuming demands of care, these individuals tend to neglect their quality of life⁽¹⁶⁾. This fact may impact the care delivered to the elderly. The healthcare team must be always attentive to the psychobiological needs of the elderly, their living conditions and health to promote the care of the elderly and their caregivers⁽¹⁷⁾.

The impact of overburden on the lives of caregivers are obvious: Due to the great demand of time required for the care, the caregiver while neglecting the quality of life⁽¹⁶⁾. This fact may influence care for the elderly. The health team must be attentive to the needs of psychobiological, conditions v round of elderly health, to promote the care of both⁽¹⁷⁾.

Regarding the sharing of care activities, basic descriptive statistics demonstrates that the caregivers who did not share their care activities with another person, had a level of overburden higher than 80%. This finding is consistent with the literature⁽¹¹⁾. Sharing care with a secondary caregiver may contribute do reduce overburden.

Overburden of caregivers is common. Their tasks are generally performed by one person, the primary caregiver. This individual serves as a liaison between the elderly patient, the family and the healthcare team.

These caregivers become responsible for several care activities that include hygiene, food, home supervision and monitoring of health services, administration of drug therapy, support to physical exercises, among others. This full-time involvement in care activities may contribute to overburden⁽¹⁰⁾.

Also, the lowest mean of the variable time performing the role of caregiver was detected among caregivers with moderate overburden and the highest one was found in caregivers with moderate to severe overburden. A study⁽¹¹⁾ conducted in 2012 found that caregivers with more than 24 months of experience considered their activities stressful. They also reported worsening of their emotional status, as well as fatigue. Another aspect that deserves attention is related to the proximity to death in old age, which may distress the caregivers.

The contributions of this study concern the findings about the vulnerability of caregivers and highlight the need for actions targeted to the prevention and promotion of the health of this population. In view of the aforementioned, this study demonstrated that the number of hours spent by caregivers in care and sharing care are key aspects that should be discussed and planned with health professionals to prevent overburden of care.

One limitation of this study concerns the size of the sample, as it was conducted in only one center of care to elderly individuals and caregivers that involve a specific multidisciplinary healthcare team composed of nurses, psychologists, pharmacists, physicians and occupational therapists. Thus, these finds depict a particular scenario that may diverge from other scenarios, not allowing the generalization of the results obtained.

Moreover, the caregivers did not attend their subsequent appointments on a timely basis, which made the contact with the participants difficult. The population that composed the sample was very heterogeneous, which may also have been a limitation.

● CONCLUSIONS

The dependency of elderly with dementia and the overburden of care lead to biological and psychological vulnerability of the caregivers. The percentage of caregivers identified with alarming levels of overburden was high.

Understanding the vulnerability of these caregivers is the first step in the construction of care prescriptions that cover the needs of this population.

The advanced age of caregivers should be considered a warning factor, as these individuals are at greater biological vulnerability.

In addition, the history of previous diseases of caregivers of elderly with dementia should be known to avoid the worsening of the symptoms of any preexisting pathology and prevent, the onset of others. On the other hand, the availability of other persons to help primary caregivers in the delivery of care is necessary to ensure a good quality of life to these individuals.

Furthermore, the data obtained call attention to the inestimable value of the Care Centers for the Elderly and their Caregivers. These units contribute to the management of care and provide a support network for the elderly and their caregivers.

It is proposed that the nursing staff pay close attention to the health status of the caregivers of elders with dementia and consider the impact of this activity on their lives. Therefore, it is necessary to identify the aggravating and mitigating factors to develop the appropriate interventions.

Further studies that use the same methodology of the present study are needed, which also include comparison between the results obtained for formal and informal caregivers, to identify any possible differences. Therefore, longitudinal studies with caregivers are recommended to obtain an effective control of unmeasured variables.

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