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RESEARCH

Vulnerability of caregivers of the elderly with dementia: a cross-sectional descriptive study

A vulnerabilidade dos cuidadores de idosos com demência: estudo descritivo transversal

Vulnerabilidad de los cuidadores de ancianos con demencia: estudio descriptivo transversal

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ABSTRACT

Objective: to evaluate the sociodemographic and clinical profile of the caregivers and its relation with the overburden from the care of the elderly with dementia. **Method:** a cross-sectional descriptive study; the sample was non-probabilistic, developed with caregivers of elderly people with dementia. The field of investigation was the Health Care Center of the Elderly and their Caregivers (CASIC), in the city of Niterói, Rio de Janeiro, Brazil. Data collection took place from February to June 2016, with the following instruments: a sociodemographic questionnaire and Zarit scale. **Results:** fifty percent of the caregivers presented moderate overburden; 38% presented little overburden; and 12% moderate/severe overburden. It was observed that the median of weekly care hours increases as the overburden increases. Caregivers with moderate to severe overburden, in the majority, do not share care. **Conclusion:** it is clear that the overburden of care places the caregiver in conditions of biological and psychological vulnerability.

Descriptors: Dementia; Caregivers; Family Nursing; Elderly; Nursing.

RESUMO

Objetivo: avaliar o perfil sociodemográfico e clínico dos cuidadores e sua relação com a sobrecarga proveniente do cuidado ao idoso com demência. **Método:** estudo descritivo transversal, a amostra foi do tipo não probabilística, desenvolvida com os cuidadores de idosos com demência. O campo de investigação foi o Centro de Atenção à Saúde do Idoso e seus Cuidadores (CASIC), Niterói, Rio de Janeiro, Brasil. A coleta de dados ocorreu de fevereiro a junho de 2016, com os seguintes instrumentos: questionário sociodemográfico e escala de Zarit. **Resultados:** 50% dos cuidadores apresentaram sobrecarga moderada, 38% apresentaram pouca sobrecarga e 12%, sobrecarga moderada/severa. Observou-se que a mediana das horas de cuidados semanais aumenta conforme a sobrecarga aumenta. Cuidadores com sobrecarga de moderada a severa, em caráter majoritário, não dividem o cuidado. **Conclusão:** Dessa forma, fica claro que a sobrecarga do cuidado coloca o cuidador em condições de vulnerabilidade biológica e psicológica.

Descritores: Demência; Cuidadores; Enfermagem Familiar; Idoso; Enfermagem.

RESUMEN

Objetivo: evaluar el perfil sociodemográfico y clínico de los cuidadores y su relación con la sobrecarga derivada del cuidado al anciano con demencia. **Método**: estudio descriptivo transversal. Muestra tipo no probabilística, integrada por cuidadores de ancianos con demencia. Investigación desarrollada en el Centro de Atención a la Salud del Anciano y sus Cuidadores (CASIC), Niterói, Rio de Janeiro, Brasil. Datos recolectados de febrero a junio de 2016, utilizándose los siguientes instrumentos: cuestionario sociodemográfico y escala de Zarit. **Resultados**: 50% de los cuidadores presentaron poca sobrecarga, 12% sobrecarga moderada/severa. Se observó que la mediana de horas de cuidado semanal aumenta toda vez que la sobrecarga aumenta. Los cuidadores con sobrecarga de moderada a severa, de manera mayoritaria, no comparten el cuidado. **Conclusión**: de esta forma, queda claro que la sobrecarga del cuidado expone al cuidador a condiciones de vulnerabilidad biológica y psicológica.

Descriptores: Demencia; Cuidadores; Enfermería de la Familia; Anciano; Enfermería.

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INTRODUCTION

The word *dementia* originates from the Latin word *demens* (*de* – deprivation; *mens* –intelligence). It is a set of signs and symptoms, commonly presented in a chronic and progressive way, in which the degradation of cognitive function occurs—that is, the ability to organize thinking—outside of the normal expected with aging. With advancing age, the prevalence of cases of dementia increases progressively. Data for Latin America shows that dementia affects 1.3% of the population aged 60-64 years; between 65 and 69 years, 2.6% of cases are observed; regarding the age range from 70 to 74 years, 4.5%; from 75 to 79 years, the value almost doubles, and reaches 8.4% of the elderly; from 80 to 84 years, 15.5%; from 85 to 89 years old, 28.6% of cases and, finally, in those older than 90 years, this percentage reaches 63.9% of cases. Overall, estimates show that dementias reach approximately 5.0% to 8.0% of the population over the age of 60(1).

This reality shows that the elderly population and their families need more comprehensive health policies, considering the significant increase in dementia. Demographic estimates indicate that by 2020 there will be about 29.8 million people aged 60 or older, and approximately 4.7 million individuals over the age of 80(2). In the present context, the focus should be not only on the children, young, and adult population; it is necessary to look at the emerging elderly population and to improve public health programs for the elderly(3).

Because dementia is a very common syndrome in the elderly population, knowledge of the main types, and their most common repercussions in the elderly, is relevant to nursing care and guidance. Because it affects memory and cognitive functions, this neurodegenerative disease implies the need to include a caregiver to help the elderly.

The caregiver is present in the routine of the elderly individual in a dementia process, witnessing all of the manifestations of dementia, and with the responsibility of looking after the physical integrity of the person. Thus, the caregiver is exposed to the behavioral changes that can be presented by the elderly person, and should have the appropriate management of their actions to conduct a certain circumstance, in order to avoid damage to the elderly person's health.

Sometimes the demand for care is intense. Research shows that the caregiver becomes stressed due to care, and may present overburden related to this care. This overburden can have implications for their physical and mental health(4-5).

In a qualitative study conducted at the Health Care Center of the Elderly and their Caregivers (CASIC)(6) with caregivers of elderly people with dementia, the possible nursing diagnoses for this public were raised. Twelve nursing diagnoses were identified: stress overburden; tension/stress overburden; caregiver role tension; relocation stress syndrome; social isolation; dysfunctional family process; anxiety; social interaction impairment; risk-prone health behavior; ineffective family control of the therapeutic regimen; inefficient performance of the role; fatigue; and poor knowledge(6).

Care for the elderly with dementia causes innumerable and different repercussions in caregivers' lives, with fatigue, and physical and emotional weakening being highlighted(7-9). Therefore, the nursing team's guidelines aim to clarify doubts and make care less painful through the understanding of factors involved in the development of dementia, suggesting strategies that improve caregivers' and the elderly's quality of life(10).

It should be emphasized that when care is given for an extended period of time, it can lead to a greater overburden(11-12). Non-division of care, too, has proved to be a factor that can lead to impairment to the caregiver's quality of life(12).

From this perspective, dementia becomes a two-way path that impacts the caregivers' quality of life, and their quality of life can influence the delivery of care. Therefore, both the caregiver and the elderly need specialized attention focused on their needs.

This is a relevant study because it allows the identification of the levels of care overburden with elderly people with dementia, and its association with factors related to care. There is a lack of studies that relate the overburden of care to the aspects associated with its accomplishment. This kind of research contributes to the evidence of vulnerability of caregivers. From the results of the study, the planning of the care can be done, directed to the needs of this public. The maintenance of the caregiver quality of life brings benefits to the caregiver himself, and also acts in the improvement of the quality of care provided.

Based on the above, the present study has the objective of evaluating the sociodemographic and clinical profile of caregivers and its relation with the overburden from care of the elderly with dementia.

METHOD

Ethical aspects

The study follows Resolution 466 of December 12, 2012, of the National Health Council/Ministry of Health which, through its legal powers, establishes guidelines and norms that regulate research involving human beings. The research was approved by the Research Ethics Committee of Hospital Universitário Antônio Pedro (HUAP).

Study design, setting and period

This was a cross-sectional, descriptive study with a quantitative approach. The study site was the Health Care Center of the Elderly and their Caregivers (CASIC), a geriatric outpatient clinic for elder care at the Fluminense Federal University, located in the city of Niterói, Rio de Janeiro. This unit is considered a reference in the city to attend elderly people with dementia and their caregivers. About 120 caregivers of the elderly are attended to in this care center. Data collection took place through nursing consultation from February to June, 2016.

Population or sample: inclusion and exclusion criteria

The exclusion criteria were: not having practical experience as a caregiver of elderly people with dementia; presence of a communication disturbance that made it difficult to carry out the tests; or three consecutive consultations with no prior justification. Inclusion criteria were: to be an informal caregiver of elderly people with dementia; to attend CASIC; to be the primary caregiver for at least six months.

The place where the research was carried out had the medical records of 120 caregivers. However, when contact was established, it was observed that nine elderly people who were registered with their caregivers had died, thus leaving a population of 111. Then, after applying the inclusion and exclusion criteria, 94 participants were selected in the study. The sample was called non-probabilistic. However, two caregivers were excluded due to lack of consultations. The consultations were carried out by spontaneous demand. All informal caregivers who attended the study site and who met the established criteria participated in the study, totaling 92.

Study protocol

The protocol adopted for data collection with caregivers of elderly people with dementia was a structured interview conducted during the nursing consultation.

To collect data, two instruments were included: the sociodemographic questionnaire created for the research, with the objective of identifying the profile of the caregiver of elderly people with dementia through clinical and sociodemographic variables; and the Zarit scale to measure the overburden from care(13).

Analysis of results and statistics

Result analysis involved the construction of a spreadsheet in Excel® software, where data were organized and tabulated by double typing, and then checking and comparison of the digits were performed.

After data confirmation and interpretation, the data were described in the form of graphs and tables. The variables Zarit, Income, Age, Drug use, Caregiver Time, Hours of Care, and Shared Care were imported from the statistical software Statistical Package for the Social Sciences (SPSS®) for Windows, version 21, where the statistical analyses were performed. For all tests, the significance level $p \leq 0.05$ was adopted.

To analyze data normality, the Kolmogorov-Smirnov test was applied, because the sample has more than 50 participants.

The central tendency measure used for all data, with non-normal distribution was at the median and the dispersion, the interquartile range, except for Age and Time as a caregiver, because these data presented normal distribution and, therefore, were represented in a descriptive way by mean and standard deviation.

The tests used were: Kruskal-Wallis and Chi-square.

As the data present a non-normal distribution, the Kruskal-Wallis test was used, because its purpose is to compare the measure of central tendency of the data.

Chi-square was used for the nominal variables, with the purpose of analyzing the association between the qualitative variables.

RESULTS

Table 1 provides the sociodemographic descriptive analysis of the sample by means of the simple absolute frequency (f) and the relative frequency (fr), equivalent to the percentage, and Table 2 illustrates the result of the Zarit scale.

Table1 – Sociodemographic data of the sample, Niterói, Rio de Janeiro, Brazil, 2016

Variable	f^1 (n)	fr^2 (%)
Gender		
Female	57	62
Male	35	38
Age (years)		
18 to 27	02	02
28 to 37	01	01
38 to 47	08	8.7
48 to 57	30	32.6
58 to 67	29	32
68 to 77	13	14
78 to 87	08	8.7
88 to 97	01	01
Educational level (years)		
0 to 9	26	29
10 to 19	63	68
19 to 20	03	03
Marital Status		
Married	48	52.17
Widowed	06	6.52
Separated/Divorced	17	18.47
Single	12	13.04
Other relation	09	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$6,001.00 to R$12,000.00	14	15
R$12,001.00 to R$24,000.00	09	10
R$24,001.00 to R$34,000.00	01	01
Relatedness		
Spouse	48	52
Son/Daughter	6	6.5
Daughter/Son-in-law	17	18.5
Brother/Sister	13	13
Other relative	09	10
Work		
Yes	36	39
No	56	61

Note: f^1 = simple absolute frequency; fr^2 = relative frequency

Table 2 – Overburden from elderly care, Niterói, Rio de Janeiro, Brazil, 2016

Zarit Scale		
	f[1] (n)	fr[2] (%)
Overburden Level		
Low overburden	35	38
Moderate overburden	46	50
Moderate/severe overburden	11	12
∑	92	100

Note: f[1] = simple absolute frequency; fr[2] = relative frequency

Tables 3 and 4 present Zarit scale data associated with the other variables obtained through the application of the following statistical tests: Kruskal-Wallis in Table 3 and Chi-square in Table 4.

Table 3 – Use of drugs per day and hours of care per week regarding Zarit scale, Niterói, Rio de Janeiro, Brazil, 2016

Variables	Kruskal-Wallis Statistical Test					
	Zarit			Statistical Tests		
	Low	Moderate	Moderate to Severe	Kruskal-Wallis	V of Cramer	
					Value[1]	*p* value
Use of drugs	2±2	2±2	3±6	0.523	0.351	0.417
Hours of care per week	56±56	70±56	84±28	0.167	0.423	0.970

Note: Value[1] = Value of the V of Cramer coefficient; Median ± Interquartile Amplitude

Table 4 – Shares or does not share care related to the result of the Zarit scale, Niterói, Rio de Janeiro, Brazil, 2016

	Chi - square				
	Observed	Expected	Residues	Cramer's V	
	n	n		Value[1]	*p* value
Yes	81	46.0	35.0		
No	11	46.0	-35.0	0.287	0.552
∑	92				

Note: Value[1] = Cramer's V coefficient value

The most frequent diseases in the study population were: systemic arterial hypertension (46.7%); arthrosis (42.4%); spinal problems (39.1%); diabetes mellitus (15.2); cardiomyopathy (13%); osteoporosis (12%); hypothyroidism (10.8%); and vitamin deficiency (8.6%).

The following percentages were identified in the item Other Types: hypercholesterolemia represented 5.4% of the sample. In addition, 2.2% of study participants reported the following health problems: Parkinson's; herpes zoster; thyroid nodules; gastritis; depression; and fibromyalgia. The most frequent diseases (1%) reported in the research were: anxiety disorder; ischemia; labyrinthitis; Alzheimer's disease; prostatitis; renal calculus; and obsessive compulsive disorder.

It is worth mentioning that in the variable diseases, the frequency with which they appeared in the studied population is described, and it is possible that the same caregiver has several pathologies. Only 12% of the study participants did not present any type of disease, and 88% had one or more diseases.

As for the use of some type of daily medicine, 1% did not use any medication, 77% used one to five medicines, and 22% would take six to 11 medications.

Regarding the frequency of dedicated hours per week at 12-hour intervals, it was observed that 24% of caregivers dedicate from 73 to 84 hours per week, 14% from 49 to 60 hours, 13% from 25 to 36 hours, 10%, 61 to 72 hours, 9%, 37 to 48 hours, 8%, 13 to 24 hours, 5.5%, 97 to 108 hours, as well as from 109 to 120 hours; 4% of study participants between 0 and 12, and 157 and 168 hours spent per week; 2% dedicate from 85 to 96 hours, and 1% of them spend from 145 to 156 hours per week giving care.

Concerning the variables related to care, another aspect identified was sharing the care of the elderly individual with another person. Among caregivers, 88% shared care with another family member, and 12% performed full care without any kind of help.

The Zarit scale assesses the burden from elderly care. The results of the scale generate a numeric value that later falls into one of the following categories: low overburden; moderate overburden; moderate/severe overburden; and severe overburden. In the sample, 50% of the caregivers presented moderate overburden, 38%, little overburden, and 12% moderate/severe overburden.

At the beginning, to analyze data normality, the Kolmogorov-Smirnov test was performed, because it is a sample with more than 50 individuals. All data presented a non-normal distribution.

The measures of central tendency and dispersion of the adopted variables were: median and interquartile range; values were: drug use, 2 and 3; hours of care per week, 70 and 48; sharing of care, 1 and 0.

When analyzing, through the Kruskal-Wallis test, the relationship between the results of the Zarit scale and the amount of medication used by the caregivers, there was no statistically significant difference among data, $p = 0.523$.

Despite this, the value of Cramer's V indicated a moderate tendency for the following fact: the caregivers who take a greater number of medications presented higher overburden.

The median use of drugs in people with low overburden was 2 and the interquartile range 2; with moderate overburden, the median was 2 and the interquartile range also 2; and with moderate to severe overburden, the median was 3; however, the interquartile range was 6.

Under the variable Hours of Care, it is observed that when related to the Zarit scale by means of the Kruskal-Wallis test, there is no statistically significant difference between the data, $p = 0.167$.

However, in this case, the value of Cramer's V also indicates a moderate trend toward the fact that the values of the central tendency measure of weekly care hours increase as the overburden increases.

Median weekly care hours, when there is little overburden, is 56, and the interquartile range 56; moderate overburden, median 70, and interquartile range 56; moderate to severe overburden, median 84 and interquartile range 28, that is, the greater the overburden the greater the median of hours spent with care.

When comparing the Zarit scale and the dichotomous variable shares care (1 = yes and 2 = no) by means of the Chi-square statistical test, it is observed that there was no statistically significant difference, $p = 552$. Cramer's V test was performed as an indicator of Chi-square test power and resulted in $p = 0.552$, indicating the power of the Chi-square test.

The expected absolute frequency for the response was not equal to 46, but the one found was 11. The sample has a negative residue for the response "no" of 35.

It is also possible to consider, through the value of Cramer's V, that the population reveals a moderate tendency toward the fact that the participants with higher levels of overburden do not share care.

Simple descriptive statistical analysis reveals that, in relation to the individuals who divided care, 40.74% reported low overburden, 50.62% moderate overburden, and 8.64% moderate to severe overburden. Regarding those who did not share care, it was evidenced that 18.18% had little overburden, 45.45% moderate overburden, and 36.36% moderate to severe.

DISCUSSION

It is evident that 62% of the population interviewed, the majority of the sample, presented more worrying levels of overburden. The literature confirms(4,8-9,14) that the findings in this research are also present in other realities with a higher percentage of overburden(14).

A descriptive and cross-sectional epidemiological survey(15), which aimed to estimate the prevalence of overburden among caregivers of dependent elderly people in the city of João Pessoa, Paraíba, identified that 84.6% of the caregivers included in the study were under a state of moderate or moderate-to-severe overburden. The caregivers' tension increases when they perceive themselves to be overwhelmed; thus, their performance is impaired, which generates a picture of unbalanced care, usually accompanied by deficits in the care of the elderly(15).

Overburden, in addition to being related to the elderly individual's dependence, may be related to the lack of discernment of the caregiver as to the need for total, maximum, or only minimum supervision during care. In some cases, the subject receiving care has the physical and cognitive capability to perform a certain activity, but lack of knowledge, fear, and the feeling that they are neglecting care lead the caregiver not to delegate the task(16).

In this context, the differentiated approach of health professionals to caregivers is essential. Understanding the physical, social, and emotional barriers involved in caring is relevant to provide higher quality of life and lower burden on caregivers, thus improving care provided to caregivers(17).

Health interventions aim to protect individuals and populations from health risk and vulnerability situations. In the case of caregivers, vulnerability assumes different forms and dimensions. From the perspective of overburden, a psychological vulnerability is evident, because it depends on how the individuals' psyche was constituted by their affective and imaginative experiences(18). Spiritual vulnerability is strongly related to psychological vulnerability, because the current culture provides few symbolic resources of meaning to collaborate with coping with challenges and in the transcendence of the limits placed by the current reality(18).

Zarit's scale, used to assess overburden, explores the caregivers' perception of how care impacts their lives, seeks to identify the extent to which care experience interferes with the qualitative management of one's personal life. Therefore, high levels of overburden demonstrate the psychological vulnerability of these individuals.

Related to drug use and the Zarit score, Cramer's V test indicated a moderate trend toward the fact that caregivers taking more medications had greater overburden.

Research has shown that the high use of medications by caregivers is a common practice, and these drugs are often used without medical prescription for pain relief and resolution of problems with insomnia(8).

The polypharmacy used by caregivers is related to the increased risk and severity of adverse reactions to medications, to precipitant drug interactions, to causing cumulative toxicity and medication errors, as well as reducing treatment compliance, and increasing morbidity and mortality(19).

When comparing the results regarding hours spent with the care and the level of overburden identified, a moderate tendency is also observed between the association of higher overburden with higher rates of hours spent with care.

The range of hours made available with the most frequent care was high, from 73 to 84 hours per week, about 10 to 12 hours per day. Although the caregiver has a second caregiver, he continues to occupy his thinking with the performance of daily tasks with the elderly person. Some caregivers cannot completely disassociate themselves from care, although they are not directly responsible for it.

The repercussions on the life of the caregiver are evident; the demand for time required for care means that the life of the caregiver does not receive the necessary attention(19). This is also due to the intense involvement with the patient's life, thus neglecting leisure, social, family, and affective life, which causes quality of life impairment. One of the biggest risks for caregivers is getting sick from the burden of care. This population is less likely to be involved in health promotion and prevention measures(9).

Therefore, it is clear, through data analysis, that the caregiver has a biological vulnerability. It is successively unbalanced by biologically destructive elements, necessitating self-poiesis and self-organization(17).

From this perspective, some authors(20) affirm that, as a strategy for coping and relief from the burden of care, caregivers need to keep their external interests, dedicating time for themselves, occupying their minds with other activities.

Coping strategies focusing on emotion suggest the protection of Alzheimer's patients caregivers from developing the highest levels of anxiety(20).

Regarding the sharing of care, a moderate trend is observed in the fact that caregivers who do not share care have a higher level of overburden. This finding is in agreement with what is observed in the literature(21). Care sharing with a secondary caregiver contributes to lesser overburden.

It is common to observe cases of caregivers' overburden. The tasks performed by them tend to be taken by a single person, who is called the primary caregiver. Therefore, the link between the elderly, the family, and the health team is centered on this individual. They assume care actions, and are responsible for their care, including hygiene, food, home supervision, health services, conduction of medication therapy, support in the practice of physical exercises, among others that arise due to the dependence and health needs of the elderly with dementia. This fact implies the total involvement of the caregiver's routine, which may contribute to overburden(22).

Further research reveals that when caregivers dedicate themselves to care full-time, in most cases they reside in the same home as the patient and therefore do not have a predetermined time to perform the function, thereby dedicating the whole day to care. This fact increases the probability of intense overburden, since it is a continuous and arduous care delivery(8).

The impact of caring for people with dementia and the need for increased caregiver support, education, and training interventions is evident. The lack of compensatory benefits for the caregiver and limited access to health programs should be a concern of political managers (23).

Considering that this research was carried out in a given center of attention to the elderly and their caregivers, where there are several visits involving a multidisciplinary team of nurses, psychologists, pharmacists, physicians, and occupational therapy, it is worth mentioning that the findings show a particular reality that may diverge from other scenarios and subjects, preventing the generalization of results.

Study limitation

It is possible to mention that, due to the delay of return of the caregivers to the subsequent consultations, patient attraction was performed by means of connection to the possible participants, requesting the attendance at the sector.

Contributions to the health area

The contributions of the research come from the findings about the caregivers' vulnerability, and highlight the need for actions aimed at prevention and health promotion in this population. Thus, the study demonstrated that the hours of care spent by caregivers, as well as care sharing, are points that should be discussed and planned with the health professional, in order to avoid cases of overburden.

CONCLUSION

These research findings reveal that the dependence of the elderly with dementia and care overburden place the caregiver in conditions of biological and psychological vulnerability.

Understanding caregiver vulnerability is the first step to build prescriptions of care that address the needs of this population. By understanding the theme, it becomes clear that when professionals have an elderly person with dementia as a patient, they should think about prescriptions of care and guidelines also directed at the caregivers involved.

It is proposed that nursing should turn their attention to the health of caregivers of elderly people with dementia and consider the consequences of this work and the impact on their lives. First, it is necessary to identify the aggravating and attenuating factors, and then to design adequate intervention strategies.

Finally, longitudinal studies with caregivers, in order to obtain control of the variables, are recommended.

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