

# Relationship between functional dependence of elderly people with dementia and overload of informal caregivers

Relação entre a dependência funcional de idosos portadores de demência e a sobrecarga de cuidadores informais  
Relación entre la dependencia funcional de los ancianos con demencia y la carga de los cuidadores informales

## RESUMO

Objetivo: Identificar fatores associados a sobrecarga de cuidadores de idosos com demência. Método: Estudo descritivo de natureza quantitativa, composto por 50 cuidadores e 50 idosos atendidos na Policlínica da Região Oeste, no período de agosto a dezembro de 2019. As escalas utilizadas para avaliação da sobrecarga foram: questionário sociodemográfico, QASCI e Escala de Zarit. Para a avaliação da dependência do idoso: Pfeffer e Escala de Katz. A análise estatística foi realizada no software Statistical Package for the Social Sciences (SPSS) versão 20.0 e análise descritiva feita com os testes de Kruskal-Wallis e Qui-quadrado. Resultado: Dos 50 cuidadores entrevistados, 26% apresentaram sobrecarga leve, 42% moderada e 32% grave. Já os idosos, 8% apresentavam independência, 32% dependência parcial e 60% dependência total. Conclusão: Observou-se que a sobrecarga dos cuidadores se relaciona de forma significativa com o tempo dedicado ao cuidado e com o nível de dependência do idoso.

**DESCRIÇÕES:** Idoso; Demência; Cuidadores.

## ABSTRACT

Objective: To identify factors associated with burden of caregivers of elderly people with dementia. Method: A descriptive study of quantitative nature, composed of 50 caregivers and 50 elderly assisted at the Western Region Polyclinic, in the period from August to December 2019. The scales used to assess the burden were: sociodemographic questionnaire, QASCI and Zarit Scale. For the assessment of the dependence of the elderly: Pfeffer and Katz Scale. The statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) software version 20.0 and descriptive analysis was made with Kruskal-Wallis and Chi-square tests. Result: From the 50 caregivers interviewed, 26% presented light burden, 42% moderate and 32% severe. As for the elderly, 8% were independent, 32% were partially dependent and 60% were totally dependent. Conclusion: It was observed that the caregivers' burden is significantly related to the time dedicated to the care and to the level of dependence of the elderly.

**DESCRIPTORS:** Aged; Dementia; Caregivers.

## RESUMEN

Objetivo: Identificar los factores asociados a la carga de los cuidadores de personas mayores con demencia. Método: Estudio descriptivo de carácter cuantitativo, compuesto por 50 cuidadores y 50 ancianos atendidos en la Policlínica da Região Oeste, en el período de agosto a diciembre de 2019. Las escalas utilizadas para evaluar la carga fueron: cuestionario sociodemográfico, QASCI y Escala de Zarit. Para la evaluación de la dependencia de los ancianos: Escala de Pfeffer y Katz. El análisis estadístico se realizó con el programa Statistical Package for the Social Sciences (SPSS) versión 20.0 y el análisis descriptivo se realizó con las pruebas de Kruskal-Wallis y Chi-cuadrado. Resultados: De los 50 cuidadores entrevistados, el 26% presentaba una sobrecarga ligera, el 42% moderada y el 32% grave. En cuanto a los ancianos, el 8% eran independientes, el 32% parcialmente dependientes y el 60% totalmente dependientes. Conclusión: Se observó que la carga de los cuidadores está significativamente relacionada con el tiempo dedicado al cuidado y con el nivel de dependencia de los ancianos.

**DESCRIPTORES:** Anciano; Demencia; Cuidadores.

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**INTRODUCTION**

According to data from the Brazilian Institute of Geography and Statistics, in 2000, individuals over 60 years of age represented more than eight million and, according to the last Demographic Census, in 2010, it exceeded twenty million. <sup>(1)</sup> It is expected that in 2050, there will be approximately 58.4 million elderly people, representing 26.7% of the Brazilian population. <sup>(2)</sup> It is observed that the number of elderly people and life expectancy has increased over the years and this demographic change has brought the prevalence of non-communicable chronic degenerative diseases, including dementia.

Dementia are chronic and progressive neurodegenerative diseases that have

different causes, compromising memory, behavior, independence and autonomy. Throughout its evolution, the elderly may present neuropsychiatric disorders, such as euphoria, agitation, irritability, depression, apathy, delirium, hallucination and changes in sleep or appetite. <sup>(2)(3)</sup> Dementia symptoms can influence, compromise and prevent the performance of Activities of Daily Living (ADL) considered fundamental in maintaining functional capacity. <sup>(4)</sup> As the disease progresses, the presence of a caregiver becomes indispensable, as the autonomy and independence of the elderly are reduced. <sup>(5)</sup>

It can be distinguished between formal when the activity is carried out by a professional and informal who provides unpaid care, represented mainly by family

members, who may also be friends or neighbors. <sup>(6)</sup> Elderly people with dementia require complex care and for a longer period, so many caregivers feel overwhelmed and emotionally stressed. <sup>(7)</sup> Taking care of someone requires effort, patience, dedication, information, physical strength and demand for emotional balance, as the role of care changes the routine, in addition to having to reconcile with occupations already established before this new responsibility. The burden on caregivers of people with dementia occurs due to a set of physical, psychological, emotional, social and financial factors as a result of lack of information and training. <sup>(8)</sup>

When care is provided for full or prolonged time, it can generate greater overload, as the non-division of the service is

a factor that can affect the physical and mental well-being of the caregiver.<sup>(9)</sup> Dementia impacts the health of those who care, and the care provided will influence the quality of life of the elderly, therefore, the binomial lacks specialized attention focused on their individual needs. In view of the above, this study has as its main objective the identification of factors that are associated with the burden of caregivers of elderly people with dementia.

## METHOD

This is a descriptive study of a quantitative nature, carried out at the Polyclinic of the Western Health Region of the Federal District, from August to December 2019. The sample consisted of 50 informal caregivers and 50 elderly people with dementia, the inclusion criteria for caregivers were: being at least 18 years old, being primarily responsible for the care of the elderly and signing the Free and Informed Consent Term and for the elderly were: age 60 years or older, having some form of dementia and being assisted by the Polyclinic team. The exclusion criterion was for those who expressed a desire to interrupt their participation in the study.

The instruments used were: Sociodemographic Questionnaire, Zarit Scale, Informal Caregiver Burden Assessment Questionnaire (QASCI - Questionário de Avaliação da Sobrecarga do Cuidador Informal), by Pfeffer and Katz. The socio-demographic questionnaire was intended to assess the socioeconomic and demographic reality in which caregivers and the elderly find themselves, in addition to verifying the caregiver's profile. To verify the burden of informal caregivers, the reduced Zarit scale was used, presenting 7 items that assess caregiver burden, each item is scored on a scale from 1 to 5, as follows: never = 1, almost never = 2, sometimes = 3, often = 4 and almost always = 5. The total score is calculated by adding up all the items, ranging from 1 to 35. Up to 14 points indicates mild overload, from 15 to 21 points moderate and above 22 points is severe.<sup>(10)</sup>

Caregivers who had moderate to severe scores answered the QASCI to assess physical, emotional and social burden. There are 32 items that integrate 7 dimensions: involvement in personal life (11 items); satisfaction with the role and with the family member (5 items); reactions to requirements (5 items); emotional overload (4 items); family support (2 items); financial burden (2 items) and perception of effectiveness and control mechanisms (3 items). The rating ranges from 1 to 5: never/never = 1, rarely = 2, sometimes = 3, almost always = 4 and always = 5. After adding up all the items, the highest values correspond to situations with greater burden.<sup>(11) (12)</sup> The Pfeffer scale verifies the cognitive decline of the elderly through a questionnaire with 11 questions regarding the ability to perform certain functions, such as, for example, whether they are able to manage their own money or take care of their own medications.<sup>(13)</sup> The score can range from 0 to 33 points, and scores equal to or greater than five can characterize the elderly as dependent.<sup>(14)</sup> To identify the elderly's dependence, the Katz scale was also used, which assesses functional independence in carrying out daily activities. 6 functions are assessed (bathing, dressing,

toileting, transferring, continence and feeding). The score ranges from 0 to 6, with less than 2 being classified as total dependence; from 3 to 5 partial dependence; and score 6 is independent.<sup>(15) (16)</sup>

Statistical analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 20.0 software. For descriptive analysis, the Kruskal-Wallis and Chi-square tests were used to relate the variables and the caregiver burden indicator.

This study strictly followed resolution 510/2016, being approved by the Ethics Committee in Research with Human Beings of the Fundação de Ensino e Pesquisa em Ciências da Saúde through opinion 4,153,081. All participants signed the free and informed consent form and, in case of vulnerability, the legal guardian.

## RESULTS

Of the 84% of caregivers, the average age is 53 years. The care time was divided into full and partial, being evaluated subjectively for those caregivers who gave up leisure, work, studies and other activities to dedicate themselves only to caring for the elderly. Generally, this caregiver works 24

Table 1. Characterization of the sample population, Polyclinic of the Western Health Region of the Federal District.

Characteristics of informal caregivers	%
Gender	
Female	84
Kinship with the elderly	
Son or daughter	66
Wives	16
Employment status	
Employed	30
Unemployed	46
Pensioner or Retired	24
Education	
Higher education	28
High School	48
5th to 8th grade	16

Source: authors data, 2019

hours a day, as the elderly person is totally dependent. Some caregivers reported that they stopped going to the market or the bakery, as the elderly could not and could not be alone.

Part-time, on the other hand, was also evaluated subjectively, and the caregiver usually had a formal job, and received help from other family members. Most of the time, the elderly person was partially dependent or independent, so he was not fully dependent on his caregiver. Therefore, 78% of caregivers were fully dedicated to the elderly.

88% of caregivers lived in their own home and located in an urban area with an average of approximately 3 people. Among the elderly who receive care, the average age was 82 years, with 70% being female. With regard to changes in the level of caregiver burden, 26% had mild burden, 42% moderate and 32% severe. In view of this, the result of all the questions contained in the scale is shown in Table 2.

Regarding the QASCI (Table 3), there was a predominance of the items “No/Never” and “Always”. Due to the complexity of the questionnaire, it was used for caregivers who presented moderate and severe burden, with a total of 37 caregivers, out of the 50 interviewees.

Na aplicação da escala de Pfeiffer para as atividades obteve-se uma média de  $27,30 \pm 8,10$  pontos.

No que diz respeito à escala de Katz, 60% recebem ajuda para lavar mais de uma parte do corpo, ou não toma banho sozinho; 62% necessitam de ajuda para pegar as roupas ou vestir-se; 38% não vai ao banheiro ou equivalente para eliminação fisiológica; 50% deitam-se e levantam-se com ajuda; 40% necessitam de ajuda para manter o controle da micção e evacuação; e 42% alimentam-se sozinho.

As escalas acima foram utilizadas para avaliação da capacidade funcional do idoso no qual vai ser determinada a dependência ou independência dele. As conclusões dos testes para relacionar as variáveis e os indicadores de sobrecarga são com base no valor de p usando a faixa de corte tradicional de 5%, assim, há uma relação significante

**Table 2 - Percentage of responses of caregivers participating in the Zarit Scale, Polyclinic of the Western Health Region of the Federal District.**

ZARIT items	Never	Almost never	Sometimes	Frequently	Often
	%	%	%	%	%
1. Do you feel that, because of the time you spend with your family member, you no longer have enough time for yourself?	18	2	32	4	44
2. Do you feel stressed/distressed by having to take care of your family member and at the same time being responsible for other tasks?	26	4	46	8	16
3. Do you feel that your current situation affects your relationship with friends or other family members in a negative way?	48	4	24	8	16
4. Do you feel exhausted when you have to be with your family member?	32	12	26	6	24
5. Do you feel that your health has been affected by having to take care of your sick family member?	42	4	32	4	18
6. Do you feel that you have lost control of your life since your family member's illness started?	66	4	14	8	8
7. Overall, do you feel very overwhelmed by having to take care of your family member?	24	2	32	6	36

Source: authors data, 2019

**Table 3 - Percentage of QASCI responses of the 37 participating caregivers, Polyclinic of the Western Health Region of the Federal District.**

QASCI Items	No/ Never	Rarely	Sometimes	Very often	Always
	%	%	%	%	%
1. Do you feel like running away from the situation you are in?	62,2	8,1	13,5	0	16,0
2. Do you consider that taking care of your family member is psychologically difficult?	29,7	0	29,7	5,4	35,1
3. Do you feel tired and exhausted from taking care of your relative?	10,8	2,7	45,9	5,4	35,1
4. Do you conflict with yourself for taking care of your family member?	51,4	5,4	21,6	0	21,6
5. Do you think your health status has worsened because you are taking care of your relative?	43,20	2,70	21,6	8,1	24,3
6. Has taking care of your family member required a lot of physical effort?	21,6	8,1	13,5	8,1	48,6

que se encontra na tabela 4.

Table 4 shows the crossing between the time of care and the caregiver's burden and the p-value associated with the chi-square test. By the value of p, it can be said that there is a significant association between the variables, that is, the time of care interferes with the overload to which he is exposed.

Table 5 shows the cross between the Pfeiffer scale and caregiver burden and the associated p-value of the chi-square test. Considering that the value is close to being less than 5%, there would be a significant association between the variables.

## DISCUSSION

It was observed that 84% of the caregivers interviewed were female, evidencing the role of women as caregivers in Brazilian culture. It is common for women to take care of themselves even though they have another job, which leads to reduced free time and implications for social life.<sup>(11) (17)</sup> Man's participation in care is usually secondary and attributed to financial issues that require physical effort.<sup>(16) (18)</sup> The fact that most caregivers are children can be explained by the retribution of care obtained in the past, which is a determining factor for the caregiver to fully dedicate himself to the elderly throughout the course of the disease.<sup>(19)</sup> As the results show, most caregivers were unemployed and the time spent with the elderly was full, and many reported giving up care for themselves to take care of the other, thus obtaining some degree of overload.

Most caregivers reported that care interfered with their personal life and emotional overload, but on the other hand, there was family support, satisfaction with the role and with the family member, and the perception of effectiveness and control mechanisms were positive. Although the entire family is affected by the disease, it is the main caregiver who provides physical, emotional and even financial assistance.

Most caregivers reported that care interfered with their personal life and emotional overload, but on the other hand, there

7. Sente que perdeu o controle da sua vida desde que o seu familiar adoeceu?	62,2	0	18,9	0	18,9
8. Have the plans you had made for this stage of life changed as a result of taking care of your family member?	27,0	2,7	13,5	5,4	51,4
9. Do you think that you dedicate too much time to caring for your relative and that the time is not enough for you?	27,0	10,8	13,5	5,4	43,2
10. Do you feel that life has played a trick on you?	48,6	2,7	27,0	5,4	16,2
11. Is it difficult to plan for the future, given that your family member's needs cannot be foreseen?	18,9	5,4	18,9	8,1	48,6
12. Does taking care of your relative make you feel trapped?	27,0	10,8	29,7	2,7	29,7
13. Do you avoid inviting friends over because of your family member's problems?	73,0	0	10,8	0	16,2
14. Has your social life been affected by taking care of your family member?	40,5	2,7	13,5	5,4	37,8
15. Do you feel lonely and isolated because you are taking care of your relative?	62,2	2,7	16,2	2,7	16,2
16. Have you felt financial difficulties because you are taking care of your family member?	40,5	2,7	29,7	0	27,0
17. Do you feel that your economic future is uncertain, as you are taking care of your family member?	43,2	5,4	18,9	5,4	27,0
18. Have you ever felt offended and angry with your relative's behavior?	40,5	2,7	27	8,1	21,6
19. Have you ever felt embarrassed by your relative's behavior?	54,1	5,4	16,2	2,7	21,6
20. Do you feel that your relative asks too much for unnecessary situations?	40,5	8,1	16,2	5,4	29,7
21. Do you feel manipulated by your family member?	73,0	5,4	21,6	0	0
22. Do you feel that you do not have as much privacy as you would like, because you are taking care of your family member?	59,5	5,4	16,2	0	18,9
23. Are you able to do most of the things you need to, despite the time you spend caring for your family member?	16,2	0	24,3	13,5	45,9
24. Do you feel able to continue taking care of your family member for much longer?	8,1	5,4	10,8	8,1	67,6

was family support, satisfaction with the role and with the family member, and the perception of effectiveness and control mechanisms were positive. Although the entire family is affected by the disease, it is the main caregiver who provides physical, emotional and even financial assistance.<sup>(11)</sup> This research showed that the main factors associated with the level of caregiver burden are the degree of dependence of the elderly and the time devoted to care. The elderly, when dependent, are totally vulnerable and need support to carry out their basic and instrumental daily activities, so the caregiver needs to have a longer period of care and the time available to himself becomes insufficient. In view of this, it can be said that the division of care, when present, offers better quality of support to the elderly, as it reduces the negative effects of stress on caregivers.<sup>(11) (18)</sup> It was identified that 24% of respondents attended only elementary school, which is a problematic factor, since schooling is an indicator of vulnerability and must be taken into account, because it contributes to the limitation of social and economic ascension, in addition, it compromises caregivers for the assimilation of information and the ability to deal with tasks.<sup>(20)</sup>

25. Do you think you have the knowledge and experience to take care of your family member?	10,8	8,1	18,9	8,1	54,1
26. Does the family (who do not live with you) recognize the work you have in taking care of your relative?	18,9	5,4	21,6	5,4	48,6
27. Do you feel supported by your family members?	24,3	8,1	16,2	2,7	48,6
28. Do you feel good about taking care of your relative?	0	0	5,4	0	94,6
29. Does your family member show gratitude for what you are doing for them?	10,8	2,7	16,2	8,1	62,2
30. Are you satisfied when your family member shows appreciation for small things?	8,1	0	2,7	0	89,2
31. Do you feel closer to your family member because you are taking care of them?	8,1	0	5,4	2,7	83,8
32. Has taking care of your family member been increasing your self-esteem, making you feel like a special person, with more value?	21,6	0	18,9	0	59,5

Source: authors data, 2019

This reality demonstrates the need for nursing actions that improve the life of this informal caregiver through educational practices, training and guiding them on

the performance of care. In this follow-up, identifications and interventions to eradicate, avoid or reverse the burden should be proposed, and it is necessary that the care

Table 4: Relationship between the time used in care and the caregiver’s burden based on the Zarit scale, Polyclinic of the Western Health Region of the Federal District

	Severe	%	Light	%	Moderated	%	Total	%	P
Full	14	28	7	14	19	38	40	80	0.02
Partial	1	2	6	12	3	6	10	20	
Total	15	30	13	26	22	44	50	100	

Source: authors data, 2019  
The p value refers to the comparison between time dedicated to care and the degree of burden.

Table 5: Relationship between the dependence of the elderly and the level of burden of the caregiver, participants in the research at the Polyclinic of the Western Health Region of the Federal District.

	Severe	%	Light	%	Moderated	%	Total	%	p
Independent	0	0	2	4	0	0	2	4	0.052
Dependent	15	30	11	22	22	44	48	96	
Total	15	30	13	26	22	44	50	100	

Source: authors data, 2019  
The p value refers to the comparison between time dedicated to care and the degree of burden.

teams become familiar with the living conditions of the elderly and the caregiver.<sup>(20)</sup> Caregivers with a moderate to severe burden, 74%, can be monitored in Psychosocial Care Centers (CAPS), which are daily mental health care services, replacing the psychiatric hospital. CAPS has a multidisciplinary team and the activities developed in the space are diversified, offering group or individual care, therapeutic workshops, physical and recreational activities.<sup>(21)</sup> Thus, the caregiver will feel more welcomed and supported in the face of the difficulties presented by him.

There were some limitations of the study, due to the fact that it was carried out in only one unit and many absences of caregivers and elderly people during consultations.

## CONCLUSION

The study reveals that the elderly need a longer time of differentiated care, according to their level of dependence. Thus, the caregiver's level of burden is totally related to the time he or she dedicates to care. The data from this study prove that caring for

an elderly person with dementia has direct implications for the caregiver. Therefore, it is essential to identify the caregiver as a subject who also needs health actions. The existence of educational, psychological and social support services is essential to reduce the consequences arising from the act of caring. The importance of the Unified Health System in keeping up with the current aging profile of the Brazilian population is highlighted, bringing with it strategies and public policies that address assistance to informal caregivers of the elderly.

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