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RESEARCH

Perfil de cuidadores familiares de idosos no domicílio

Profile of family caregivers of elderly at home

Perfil de los cuidadores familiares de personas mayores en el domicilio

Karla Ferraz dos Anjos [1] , Rita Narriman Silva de Oliveira Boery [2] , Rafael Pereira [3] , Vanessa Cruz Santos [4] , Eduardo Nagib Boery [5] , Cezar Augusto Casotti [6]

ABSTRACT

Objective: To investigate the sociodemographic profile of family caregivers of elderly at home and the level of overload resulted by care activity. **Method:** A descriptive cross-sectional study, conducted with 29 family caregivers of elderly individuals enrolled in a Family Health Strategy. There were collected data on functional independence, demographic data and level of caregiver overload. A study approved by the Research Ethics Committee, under Opinion No. 128,580/2012. **Results:** It was found that 79% of the elderly had functional dependence. The profile of caregivers showed that the majority are women, married, with advanced age, level of education and low income. It was also found that the time devoted to the care is long, justifying the overload observed, mainly in caregivers of dependent elderly. **Conclusion:** The results point out the need for more social support and health care to family caregivers, which could contribute to reducing the overload related to caring. **Descriptors:** Caretakers, Family, Elderly, Social Support.

RESUMO

Objetivo: Investigar o perfil sociodemográfico de cuidadores familiares de idosos que residem no domicílio e o nível de sobrecarga imposta pela atividade de cuidado. **Método:** Estudo transversal e descritivo, realizado com 29 cuidadores familiares de idosos, cadastrados em uma Estratégia Saúde da Família. Foram coletados dados referentes à independência funcional dos idosos, sociodemográficos e nível de sobrecarga do cuidador. Estudo aprovado pelo Comitê de Ética em Pesquisa, sob Parecer nº 128.580/2012. **Resultados:** Constatou-se que 79% dos idosos cuidados apresentavam dependência funcional. O perfil dos cuidadores evidenciou que em sua maioria são mulheres, casadas, com idade avançada, grau de escolaridade e renda baixa. O tempo dedicado ao cuidado é longo, justificando a sobrecarga observada, principalmente nos cuidadores de idosos dependentes. **Conclusão:** Evidenciou-se necessidade de maior suporte social e de saúde aos cuidadores familiares, o que poderia contribuir na redução da sobrecarga relacionada ao cuidar. **Descritores:** Cuidadores, Família, Idoso, Apoio Social.

RESUMEN

Objetivo: Investigar el perfil sociodemográfico de los cuidadores familiares de personas mayores que residen en domicilio y el nivel de sobrecarga impuesta por la actividad asistencial. **Método:** Estudio descriptivo y transversal, realizado con 29 cuidadores familiares de adultos mayores inscritos en Estrategia Salud de Familia. Se recogieron datos sobre independencia funcional de los idosos, datos sociodemográficos y nivel de sobrecarga del cuidador. Estudio aprobado por el Comité de Ética de Investigación, bajo la opinión Nº 128.580/2012. **Resultados:** Se encontró que el 79% de los ancianos cuidados tenían dependencia funcional. El perfil de los cuidadores mostró que la mayoría son mujeres casadas, con edad avanzada, nivel de educación y bajos ingresos. También se encontró que el tiempo dedicado a la atención es longo, lo que justifica sobrecarga observada, sobre todo los cuidadores de personas mayores dependientes. **Conclusión:** Demostró la necesidad de mayor apoyo social y de salud a los cuidadores familiares, lo que podría contribuir a reducir la sobrecarga relacionada al cuidado. **Descriptores:** Cuidadores, Familia, Mayores, El Apoyo Social.

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INTRODUCTION

Currently, Brazil is considered a young country, but in the process of population aging. Every year, approximately 650 thousands new elderly are incorporated into the Brazilian population, which leads to increased incidence of chronic diseases and functional limitations. In less than 40 years we have a scenario of mortality itself a young population to a framework of complex and burdensome illnesses, typical of old age, characterized by multiple chronic diseases, that last for years,[1] thus requiring permanent care by family caregiver.[2]

Concurrent with the increase in the number of seniors who experience a process of chronic and disabling disease, there is increased physical dependence and thus the need for caregivers who are mostly relatives of these poor elderly.[3] The assistance offered by LDCs such as Brazil, makes the family is the main core of social support for elderly dependents.[3-4]

Nevertheless, Brazilian laws to protect the elderly as the National Health Policy for Older Persons and the Elderly claim that it is the duty of the family, but also the obligation of the community, society and the State to assist the elderly, ensuring the participation in the community, defending the dignity and well-being, guaranteeing them the right to life.[5-6] It is clear that the above laws mainly particular relationship to the family's obligation to take care of the elderly, which is realized in daily practice.

In this context, the growing concern about the caregiver that sometimes is not prepared for this practice, which may cause deleterious processes in care of the elderly. [7] Therefore, the integral promotion of health and support to family caregivers,[2] also known as informal caregivers,[8] represent new challenges to the health system of Brazil.[2]

Taking care of an elderly family member can mean feelings often ambiguous by the caregiver, being influenced by the recognition, duty, obligation, gratuity, compensation feelings accumulated during the course of life of the elderly with the caregiver.[9-10] Thus, it is evident that these family caregivers need social support, which in addition to assist them in the care process can instruct them in the ways of realization of this practice in order to avoid overload and negative effects on their biopsychosocial dimensions.

In this perspective, this study is relevant because from the profile of family caregivers of the elderly will be possible to identify the demands of these individuals so that health professionals establish health actions that can contribute to the prevention of injuries from the process caring for an elderly relative.

Given the above, this study aimed to investigate the sociodemographic profile of family caregivers of elderly residing in the household and the level of overhead activity this matter carefully.

METHOD

A transversal and descriptive study, conducted with family caregivers of elderly enrolled in a Family Health Strategy (FHS) in Jequié, located in the State of Bahia, northeastern Brazil.

The ESF, field of study, has two teams, 12 micro areas and 607 seniors registered. The study sample consisted of all family caregivers of elderly enrolled in the health unit, totaling 29, of these 23 were caring for elderly dependent and independent six, according to the criteria of the scale of Basic Activities of Daily Living (ADL) of Katz.[11] The independent elderly were included by stating caregivers have to help them in other daily activities. The inclusion criteria were: to be the primary caregiver of the elderly, live with it and have aged 18 years old.

The data collection was held at home, with date and time scheduled, during the month of January 2012. Initially it was utilized as instrument the Scale of Katz[11] to evaluate the independence Elderly functional in the performance of AVD. This evaluates the independence in performance of six everyday functions (bath, dressing up, go to the bathroom, transfer, continence and feeding) classifying the elderly as independents or dependents for a, twice, three four, five or in all functions; then applied the demographic questionnaire and the *Zarit Burden Interview* [12] to assess caregiver burden on the provision of daily care. This instrument consists of 22 items each of which are scored from 0 to 4 according to the intensity of an affirmative answer. The total score varies 0 to 88, so as to a higher the score indicate a greater overloading. For their analysis was used scores proposed for the study,[13] namely: $\leq$21 no overload of 21-40 overload moderate, in the range of 41-60 overload moderate to severe, $\geq$ 61 burden severe.

Statistical analysis was performed on the Statistical Package for Social Science (SPSS) version 18.0, opting to make a descriptive analysis using mean and standard deviation (SD) of sociodemographic variables and the level of overhead obtained from caregivers.

This study submitted to and approved by the Ethics Committee in Research of the State University of Southwest Bahia, campus Jequie, Bahia, under the Protocol and 128.580/2012 CAAE: 08643612.6.0000.0055.

RESULTS AND DISCUSSION

We surveyed 29 caregivers of the elderly, of which 79,3% were caring for dependent elderly and 20,7% independent.

The elderly caregivers were mostly women (89,7%), brown colored (51,7%) with stable (51,7%), age over 61 years (34,5%). Caregivers lived in the same household as the

dependent elderly, cohabiting with an average of 3,3 persons (SD ± 1,19) in the house. Also in relation to caregivers, most were children (as) or daughter (son) of the elderly (55,1%) and the mean age was 52,9 years (SD ± 16). The sociodemographic characteristics of caregivers are described in Table 1.

Table 1 - Sociodemographic characteristics of family caregivers of elderly of Jequié, Bahia, Brazil, 2013.

Characteristics	n=(29)	%
Gender		
Female	26	89,7
Male	3	10,3
Race/color		
White	9	31
Brown	15	51,7
Black	5	17,2
Age (years)		
20 – 30	3	10,3
31 – 40	3	10,3
41 – 50	5	17,2
51 – 60	8	27,6
61 – 70	6	20,7
71 or older	4	13,8
Marital status		
Married	10	34,5
Consensual union	5	17,2
Single	9	31
Divorced/separated	3	10,3
Widower	2	6,9
Kinship with the elderly		
Spouse	6	20,7
Son/daughter	11	37,9
Brother/sister	3	10,3
Grandson/granddaughter	4	13,8
Daughter-in-law	5	17,2
Cohabitation		
1 to 2 people	8	27,6
From 3 to 4 people	14	55,2
From 5 to 6 people	5	17,2

Living longer is relevant in that it adds quality to the additional years of life,[1] that involves the ability to live independently. Conversely, some people need help to perform ADLs, which can include everything a little help as monitoring of displacement, or even a significant degree and continuous help as to perform personal hygiene. In general, those who live to an old age may end up needing help to perform ADLs as a family.[8]

The profile of caregivers here confirms data from other studies, which show, in general, that most caregivers are female[10,14-18] and married.[10,18-19] It must [15] mainly because

that the caregiving role is seen as natural for women as it is inscribed in the social role of mother. Caregiving for elderly relatives is more of the roles that women assume in the domestic sphere. However, recent studies have pointed [10,14,16,18,20-21] the increased participation of male caregivers.

An interesting fact reported in the literature[14-15] is that in many situations the average age of caregivers, usually close to or the same as the elderly, or are elderly independent youth caring for the elderly dependent. In this context, our results corroborate other studies, since [10,14,16,18,20-22] also identified an average age of caregivers over 50 years old. This could be explained, at least in part, to be, in many cases, the caregiver spouse.[22]

By reviewing previous studies,[7,9-10] it was found that the question of color/race has not been explored so assiduously. Study[19] found that a higher percentage of caregivers reported skin color white, which can be related to southeastern Brazil, where conducted the survey. In contrast, the results of this study found that the group of caregivers was composed mostly of mixed race, this finding may be related to greater mixing characteristic of the Northeast region, where the present study was developed.

Regarding the variable education and profession of caregivers, it was found that 37,9% had low education, being illiterate or only elementary education. Among caregivers 82,8% were unemployed and 83,3% reported having worked outside the home. In relation to individual income, 44,5% earned below the poverty level and 34,5% had no income. The average income of the caregiver was R$ 583,45 (SD ± 645,95), as shown in Table 2.

Table 2 – Socioeconomic characteristics of family caregivers of elderly in Jequié, Bahia, Brazil, 2013.

Characteristics	n=(29)	%
Schooling		
Illiterate	1	3,4
Fundamental incomplete	10	34,5
Fundamental complete	3	10,3
Secondary incomplete	2	6,9
Secondary complete	9	31
Superior complete	2	6,9
Superior incomplete	2	6,9
Current professional situation		
With another gainful activity	5	17,2
No gainful activity	24	82,8
Professional status before care		
Had worked out	20	83,3
Never worked	4	16,7
Individual income in minimum wage* (SM)		
No income	10	34,5
Until 1 SM	13	44,5
Until 2 SM	3	10,3
More than 2 SM	3	10,3

* Minimum wage (SM) de R($) 620,00.

Fashion similar to previous studies [10,14,17,23] found that caregivers had lower education, which close [23] relationship with low-income households. In terms of social class,[17] the majority of caregivers were classified as class D, ie classified as living conditions in economically disadvantaged.

Our results indicate that several caregivers were asked to give up work or reduce exercising the journey to caring for the elderly, especially when it requires constant dedication, which has been observed in samples of family caregivers residing in different locations with social reality.[10] A significant proportion of caregivers reported having other activities besides labor care, being one of the most prevalent of domestic, corroborating other studies. [14,18]

We asked the informants (ie, caregivers interviewed) if were trained or participated in some way to be related to the caregiver or care to assist them in developing the care for the elderly, and unanimously reported that there.

Of the caregivers, 41,3% perform the function of caring for six or more years, 86,2% spent a workload daily between 18 and 24 hours, with a mean of 21,4 hours (SD ± 5,06). Among the caregivers, 51,7% received help to take care of the elderly, with 27,5% of children and/or maid (Table 3).

Table 3 – characteristics of family caregivers of elderly according to the time of the caregiver and support received from Jequié, Bahia, Brazil, 2013.

Characteristics	**n=(29)**	**%**
Caregiver time in years		
Until 1 year	2	6,9
1 to 2 years	7	24,1
3 to 5 years	8	27,6
6 to 10 years	8	27,6
11 to 15 years	3	10,3
37 years	1	3,4
Hours daily devoted to care		
8 – 12	4	13,8
12 – 24	25	86,2
Gets help to take care of the elderly		
Yes	15	51,7
No	14	48,3
From who gets help		
Son/daughter	5	17,2
Domestic worker	3	10,3
Grandaughter	2	6,9
Other*	5	17,2

* Regarding domestic and sister; niece; mother and brother; brother-in-law and neighbor.

A high percentage of caregivers devotes several hours daily to elderly care, changing your routine life,[14] averaging 18 or more hours per day, reaching in some cases be full time. It is noteworthy that several of care between two and 12 hours daily.[10,14,18,20] In referring to

the time engaged in this activity, the majority of caregivers develop this activity for a period between three and six years[10,16]

As for the support received for performing caregiving activities, most caregivers reported receiving no support or interim activity with other people, which corroborates other authors.[18] worth noting that social support is one of the variables involved in quality life of the binomial family caregiver-dependent person. Furthermore, it becomes strategy to preserve the health of the caregiver providing social support.[16]

The high daily workload in elderly care, coupled with the long period of time in which this function is exercised may predispose the caregiver risk of illness, especially those who are caregivers ones who take full responsibility.[10]

Regarding health of caregivers, 86,2% reported some health problem and 51,7% were using any medication. In Table 4, it is possible to verify the relationship of these diseases, the most prevalent: varicose veins (58,6%), back problems (55,2%) and hypertension (55,2%).

Table 4 - Distribution of diseases mentioned by family caregivers of elderly in Jequié, Bahia, Brazil, 2013.

Diseases	Caregivers of independent seniors		Caregivers of dependent elderly		Total	
	n=(29)	%	n=(29)	%	n=(29)	%
Arterial hypertension	1	3,4	8	27,6	9	31
Digestive problems	1	3,4	3	10,4	4	13,8
Back problems	3	10,3	13	44,9	16	55,2
Diabetes mellitus	1	3,4	1	3,4	2	6,8
Heart Diseases	-	-	3	10,3	3	10,3
Respiratory problems	-	-	6	20,7	6	20,7
Osteoporosis	-	-	3	10,3	3	10,3
Arthrosis	1	3,4	1	3,4	2	6,8
Circulatory problems (varicose veins)	3	10,3	14	48,3	17	58,6
Other*	1	3,4	8	27,6	9	31

* Refers to Neurogenic bladder, bursitis, esophageal hernia, hyperthyroidism, prostate, tendinopathy, sciatic nerve inflammation, wall and hernia cholelithiasis.

The need for help in performing ADL usually culminates in aid of one or some members of his own family of the elderly.[8] However, the act of caring for the elderly within their complexity, the caregiver generates different feelings such as fatigue, wear, joy and satisfaction. These feelings must be understood as part of the relationship between carer and the person cared for, having to also assess the presence of stressors among those involved, given that, can encourage risk of caregiver's own illness.[2]

Caring for the elderly requires physical demands and/or psychic for caregivers, which is detrimental to their health, as evidenced by their illness due to the overhead that this action imposes.[24] Similarly to other studies, the caregivers in our sample who had health

problems,[14] as arterial hypertension, other cardiovascular problems, musculoskeletal problems and mental health.[10]

When analyzing the data workload of caregivers of elderly independent verified that 10,3% have moderate levels of burden, while among caregivers of dependent elderly, 41,4% had moderate to severe overload. (Table 5).

Table 5 - Distribution of levels of overload of family caregivers of elderly in Jequié, Bahia, Brazil. 2013.

Levels of overload *	Caregivers of independent elderly n=(6)	%	Caregivers of dependent elderly n=(23)	%	Total n=(29)	%
The absence of overload (< to 21)	2	33	-	-	2	6,9
Moderate overload (21 a 40)	3	50	6	26	9	31
Moderate to severe overload (41 to 60)	1	17	12	52	13	44,9
Severe Overload (≥ 61)	-	-	5	22	5	17,2

* Scores was used in the study. [13]

Although it is also a reality that generates questions, the elderly caregiver is an individual present in the Brazilian health care setting. The condition of being caregiver denotes workload, usually linked to situations of family conflict and lack of information necessary to the performance of care.[2] The degree of burden among caregivers has been studied,[18,20] and observed a prevalence of moderate overload.

Our results corroborate previous findings,[18,20] since the majority of participants reported moderate to severe overhead, followed by moderate overhead, thus showing wear objective and subjective caregiver in relation to the care of the elderly.

Living with people those have some sort of chronic disabling disease shows up a situation that imposes several times, over the life of family caregivers, thereby reducing their chances of interaction with other people in the social network and makes it difficult to maintain their quality of life. Overloading can occur in everyday situations due to lack of support from family or even by the impositions of care dependent elderly.[21]

It is reported in the literature [17,25] the notorious lack of training among caregivers. The findings of this study converge with these studies, as unanimously, no caregiver was trained or participated in a course to help them to develop activities related to caring for the elderly.

In this context, support groups and guidance to caregivers become fundamental to the quality of life for these patients and should be encouraged as a primary prevention of morbidities related to caring.[18]

Caring for an elder is always a mission that involves a lot of experiences and feelings, which requires delicate management.[22] The profile of the caregiver is in a stand-alone network and generally disintegrated health services, in need of guidance and support from health professionals. Therefore, it is of paramount importance to expansion of actions

that have the caregiver as main subject, that this activity be recognized and invested in appropriate practices, bringing benefits to those who care and who care.[7]

CONCLUSION

The findings of this study showed the profile of family caregivers of elderly residents in a city in the interior of Bahia are mostly women, older age, low education level and income, and performing care for a long time and, in most of the time in full.

It was noted association of caregiver burden with the functional independence of the elderly, since levels of caregiver burden of dependent elderly were higher.

From the results, we can identify the profile of family caregivers of a city in the interior of Bahia does not differ much from family caregivers from other regions of Brazil (eg, Southeast), or even the European, indicating that the act to care for a family member has limitations and challenges inherent in the function itself, regardless of regional or cultural aspects. Additionally, it should be considered as necessary to implement policies aimed at greater social support for health professionals working in primary caregivers, since from this it will be possible to identify factors that affect negatively the biopsychosocial conditions of these individuals, thus being able to plan actions for health promotion and prevention.

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