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Profile and degree of dependency of the elderly and overload of their caregivers*

Perfil e grau de dependência de idosos e sobrecarga de seus cuidadores

Perfil y grado de dependencia de personas de la tercera edad y sobrecarga de sus cuidadores

Helena Meika Uesugui[1], Diego Santos Fagundes[2], Diana Lucia Moura Pinho[3]

ABSTRACT

Objective: To analyze the profile and degree of dependency of elderly users of a home care center, as well as the profile and burden their caregivers. **Methods:** Exploratory and descriptive study with a sample consisting of 31 elderly and 31 caregivers. Data collection was conducted through interviews at home, using a semi-structured questionnaire containing sociodemographic variables. To assess the degree of dependency of the elderly, the Katz Index and Lawton Scale were used, and the burden of caregivers was measured using the Zarit Burden Interview Scale. **Results:** A high percentage of elderly patients were identified with total dependence for basic and instrumental activities of daily living, with a statistically significant variable in relation to caregiver burden and perception of their health status. **Conclusion:** The analysis of variables can contribute to the design of intervention proposals based on the real needs of the group studied.
Keywords: Health of the elderly; Home nursing; Health promotion

RESUMO

Objetivo: Analisar o perfil e o grau de dependência de idosos usuários de um Centro de Internação Domiciliar, bem como o perfil e a sobrecarga em seus cuidadores. **Métodos**: Estudo exploratório e descritivo composto por amostra de 31 idosos e 31 cuidadores. A coleta de dados foi realizada por meio de entrevista no domicílio, com aplicação de questionário semiestruturado, contendo variáveis sóciodemográficas. Para avaliação do grau de dependência dos idosos, foram utilizados o *Índice de Katz* e *Escala de Lawton* e a sobrecarga dos cuidadores foi mensurada com base na *Escala Zarit Burden Interview*. **Resultados**: Foi revelado percentual elevado de idosos com dependência total para atividades básicas e instrumentais da vida diária, sendo a variável estatisticamente significativa em relação à sobrecarga dos cuidadores e a percepção sobre seu estado de saúde. **Conclusão:** A análise das variáveis estudadas pode contribuir para o delineamento de propostas de intervenção baseada nas reais necessidades do grupo estudado.
Descritores: Saúde do idoso; Assistência domiciliar; Promoção da saúde

RESUMEN

Objetivo: Analizar el perfil y el grado de dependencia de personas de la tercera edad usuarios de un Centro de Internamiento Domiciliario, así como el perfil y la sobrecarga en sus cuidadores. **Métodos**: Estudio exploratorio y descriptivo compuesto por una muestra de 31 personas de la tercera edad y 31 cuidadores. La recolección de datos se realizó por medio de entrevista en el domicilio, con aplicación de un cuestionario semiestructurado, conteniendo variables sociodemográficas. Para la evaluación del grado de dependencia de las personas de la tercera edad, fueron utilizados el *Índice de Katz y la Escala de Lawton* y la sobrecarga de los cuidadores fue mensurada con base en la *Escala Zarit Burden Interview*. **Resultados**: Fue revelado un porcentaje elevado de personas de la tercera edad con dependencia total para actividades básicas e instrumentales de la vida diaria, siendo la variable estadísticamente significativa en relación a la sobrecarga de los cuidadores y la percepción sobre su estado de salud. **Conclusión:** El análisis de las variables estudiadas puede contribuir en el delineamiento de propuestas de intervención basada en las reales necesidades del grupo estudiado.
Descriptores: Salud del anciano; Atención domiciliaria de salud; Promoción de la salud

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INTRODUCTION

Population ageing is a current phenomenon that occurs worldwide. In Brazil, in 2025, there will be about 34 million elderly individuals, representing 15% of the total population[1]. Factors such as reduction in births and child mortality, technological advances, and increase in life expectancy contributed to the change of the age pyramid.

In Brazil, the exponential growth of the elderly population is followed by an increase in chronic-degenerative diseases, increasing the morbidity rates, and leading to new demands, such as the use of hospital beds for a longer period and the increase in the costs of hospital stay for the Unified Health System (SUS)[2].

Longevity and chronic degenerative diseases are considered the main causes for the increase in the number of elderly with disabling diseases that can get worse as they get older. When they develop disabilities and lose independence, there is involvement of their autonomy and the tasks they can no longer perform are then carried out by another person who has the role of caregiver[3].

The caregiver can be categorized according to the nature of the bound with the elderly using the difference between formal and informal care as a reference. Formal care is the care provided by professionals and informal care is that provided by relatives, friends, and neighbors, among other people[4].

Our study focused on informal care, carried out by informal caregivers. These caregivers are classified into primary caregivers, considered as the person who has all or the main responsibility for care to the elderly, and the secondary caregiver, the person who helps with the complementary activities, such as purchases and finance[4].

In Brazil, about 40% of the people 65 or over depend on some sort of help to perform at least one task, and the support is predominantly provided by relatives[1].

The National Health Policy for the Elderly in the country adopts as a structuring axis fostering healthy ageing through strategies that aim to maintain the functional capacity of elderly and their caregivers. To prioritize actions that can provide support to the dependent elderly and their informal caregiver to meet their emerging needs is a challenge to the current health system[5].

The caregiver is considered an individual that absorbs different levels of anxiety in the process of care to elderly individuals due to some characteristics such as the change in their social roles and the adjustment to the condition of caregiver that demands dedication, patience and abnegation. Thus, follow-up and support provided by the health service can contribute to minimize the difficulties demanded by the care provided to the dependent elderly[6].

A greater challenge than prolonging life is maintaining the functional capacity, preserving the autonomy and the functionality both of the elderly and their caregivers[7].

Investigations regarding ageing have been little explored in the North Region, especially in the State of Rondônia, where we cannot find a reference approaching the context of elderly and their caregivers. Thus, the present study aimed to assess the level of dependency of the elderly that used a Center of Home Care and the burden on caregivers generated by the activities of providing care to the elderly.

METHODS

Exploratory and descriptive study carried out in a Home Care Center (HCC), in the city of Ariquemes – RO, connected to the Municipal Health Secretariat that provides care services to the population of elderly enrolled, and provides guidance to caregivers. HCC has been chosen as a reference to carry out the study because it is a service that cares for an expressive number of dependent elderly who need follow up and care provided by a caregiver.

The inclusion criteria adopted for the elderly were: to be 60 or over, to live in the urban perimeter, and to agree to take part in the study. For caregivers, they were: to perform the role of main caregiver for at least a month and to agree to take part in the study. Caregivers have been selected based on the record of the elderly included in the sample.

The first stage to define the sample was performed through a query in the records of HCC, totaling 367 elderly individuals. Next, with a visit to their homes, the records provided by the HCC were checked and updated.

Of the total of 367 initially selected elderly individuals, 102 (27.8%) were not found in the home, 67(18.3%) had passed away, 42(11.5%) changed homes, 38(10.4%) were referred for care through the Family Health Strategy – ESF. Thus, 118 elderly (32%) were seen by the HCC (Table 1).

Table 1 – Current record situation of the elderly seen by the Home Care Center - 2008

Situation	n.º	%
Family Health Strategy	38	10.4
Moved	42	11.5
Deaths	67	18.3
Not found at home	102	27.8
Care performed by the HCC	118	32.0
Total	367	100.0

Source: Home Care Center – Ariquemes, 2008

After the group of elderly had been defined, a new home visit was carried out with an interval of 60 days

between the first and the second visit. In this last stage, applying a semi-structured questionnaire, we have collected sociodemographic data from the elderly and their caregivers that agreed to take part in the study and the final sample of the study participants was defined.

Of the 118 elderly individuals, 27 (22.8%) did not agree to take part in the study, 16 (13.5%) died, 10 (8.4%) changed home and their whereabouts was unknown, 2 (1.6%) were excluded because they did not have a caregiver, and 1 was referred to the ESF, totaling 58 elderly individuals (31 non-institutionalized and 27 institutionalized) and 36 caregivers (31 informal and 5 formal).

In the present study, the group of non-institutionalized elderly individuals and their respective informal caregivers has been considered. Thus, the final sample was formed by 31 informal elderly individuals.

Sample error for the group of non-institutionalized elderly was carried out through the estimate of the population proportion of elderly in the North Region of Brazil (6.8%), using as a reference the data provided by the Brazilian Institute of Geography and Statistics. The level of reliability adopted was 95% (1.96) of certainty with a maximum sample error of 8.88% for the elderly individuals[8].

The elderly profile corresponded to the analysis of the variables age group, gender, schooling, marital status, individual income and practice of exercise.

In the analysis of the elderly level of dependence, the Katz Index and the Lawton Scale have been used. The two instruments are complementary.

Katz Index is used to know the dependence level regarding basic activities of daily living[7-9], from a score that ranges from "A" to "G", where "A" represents the level of total independence to all activities, and "G", maximum dependence to all of them.

The Lawton Scale is used to know the level of dependence in the instrumental activities of daily living regarding the participation of individuals in the social context; it is formed by nine questions. Each question has three options: the first indicates independence; the second partial dependence, and the third total dependence. After the levels of dependence and independence are defined, the analysis is carried out in three levels, "no help", "with partial help" and "cannot do it" and to calculate the overall score they are scored as 3, 2 and 1 points respectively, with a maximum score of 27. The higher the score, the higher the level of independence[7].

To assess the profile of caregivers, the variables assessed were age group, gender, marital status, individual income, perception on their health status, kinship with the elderly, living with the elderly, having help for care, and time (hours/day and years) dedicated to care.

The burden attributed to caregivers because of the

activities related to care for the elderly were measured using the Zarit Burden Interview Scale (ZBI), that assess the impact of care in the social, and emotional dimensions, and in the physical and financial well being of caregivers. This instrument is formed by 22 items and the perception of caregivers is recorded in a scale (never=0, rarely=1, sometimes=2, frequently=3 or always=4) with a score that ranges from 0 to 4 points. The burden is defined by the sum of these scores. Thus, the higher the score, the higher the overburden attributed to caregivers[10].

Once the profile of non-institutionalized elderly individuals and their caregivers was identified, the means of the ZBI Scale were compared with the categories of the variables regarding the profile of elderly individuals, doing the same for the categories of the variables referring to caregivers' profile.

The means of the ZBI Scale were compared using Kruskal-Wallis and Mann-Whitney tests.

Data obtained were tabulated in spreadsheets and were grouped according to the arrangement already adopted in its collection using software Br Office Calc. Differences were considered statistically significant when p<0.05. For the statistical analysis, the BioEstat 5.0 program was used.

The research project was approved by the Research Ethics Committee at Faculdade São Lucas de Porto Velho – RO (AP/CEP/156/2007). All participants gave their written consent, according to the Resolution CNS no 196/96.

RESULTS

Elderly profile
Mean age was 77.6 years (SD= 8.9 years), male gender (46.9%), female (53.1%), incomplete elementary education (56.2 %), illiterate (43.7%), married (46.8%), income of up to 1 minimum wage (87.5%) and did not practice exercises (93.7%).

Caregiver profile
Mean age was 47.7 years (SD= 15.37 years), female gender (96.6%), schooling level corresponding to complete elementary education (66.6%), married (63.3%), income up to 1 minimum wage (70.0%), perception on their health status considered as "satisfactory" (63.3%), kinship with the elderly: daughter/son or spouse (83.3%), lives with the elderly (86.6%), has help to provide care (73.3%) and the time care has been provided is up to 3 years (46.6%).

Level of dependence of the elderly for the basic functions – Katz Index (ADL)
The elderly individuals were between two extremes

Table 2 – Characteristics of the elderly studied, according to the mean of the Zarit Burden Interview (ZBI) scores.

n=31

Characteristics	(%)	Mean	Standard - Deviation	CI 95%		P Value
Age group						
From 60 to 70 years	15.63	26.20	5.54	19.32	33.08	
From 70 to 80 years	43.75	23.36	10.07	17.55	29.17	0.831*
From 80 to 90 years	31.25	23.50	13.97	13.51	33.49	
From 90 to 100 years	9.38	23.33	10.02	-1.55	48.22	
Gender						
Male	46.88	24.80	12.09	18.10	31.50	0.526**
Female	53.13	23.00	9.21	18.26	27.74	
Schooling						
Illiterate	43.75	21.71	6.66	17.87	25.56	0.338**
Incomplete Elementary Education	56.25	25.50	12.70	19.19	31.81	
Marital Status						
Married	46.88	23.87	12.48	16.95	30.78	
Separated	3.13	16.00	-	-	-	0.948*
Divorced	3.13	11.00	-	-	-	
Widow(er)	46.88	24.20	9.34	19.03	29.37	
Individual						
1 MW	87.50	23.75	10.50	19.68	27.82	0.934**
2 MW	12.50	24.50	12.29	4.95	44.05	
Physical Activity						
Yes	6.25	18.50	2.12	-0.56	37.56	0.403**
No	93.75	24.20	10.77	20.18	28.22	

*Kruskal-Wallis Test, **Mann-Whitney Test

in the classification of the Katz Index, represented on one side by score A (24.2%) – independent for all activities and on the other side by score G (42.4%) – total dependence. Score B (6.1%) independent for activities but one; score E (9.1%) independent for all activities but bathing, dressing, and toileting, and another one; score F (15.2%) independent for all activities but bathing, dressing, toileting, transferring, and another one. None of the elderly was classified in scores C and D independent for all activities but bathing and another one, and independent for all activities but bathing, dressing and another one, respectively.

Level of dependence of elderly for Lawton instrumental activities of daily living – (IADL)

As for the dependence for the IADL, a mean of 12.38 was obtained by the Lawton Scale (SD= 4.80), based on the questions related to instrumental activities.

Burden level on caregivers and variables connected with the elderly

In the comparison between the means of ZBI scores and the categories of the variables related to the elderly, statistically significant differences have not been found (Table 2).

Level of burden on caregivers (*ZBI*) and variables related to caregivers

The means of the ZBI scores compared to the categories of the variables related to caregivers presented statistically significant difference for the variable "perception of the health status" (Table 3).

DISCUSSION

Elderly Profile

The profile of the elderly individuals regarding gender followed the trends of similar studies where most of the elderly population was formed by women[7,10-14]. As for schooling, most elderly had complete elementary school; this was similar to what was found by other studies[10-11,15-17].

The income of up to 1 MW corresponded to 87.5% of the elderly, indicating a difficulty to maintain their basic needs. A similar result has been found by a study carried out in the city of Ribeirão Preto-SP[17].

Caregiver profile

The results show some characteristics of the caregiver profile similar to what was found in the literature, where elderly are mostly cared for by women, daughters or wives[3,10,18].

Schooling and income presented results that followed the trend observed by other studies where more than 50% of the caregivers had finished elementary school and the maximum income was 1 MW, which may suggest a close correlation between schooling and income[18].

Table 3 - Characteristics of the caregivers studied, according to the mean of the Zarit Burden Interview (ZBI) scores.

n=31

Characteristics	(%)	Mean	Standard Deviation	CI 95%		*p* value
Age group						
From 20 to 35 years	20.00	27.333	7.033	19.952	34.714	
From 35 to 50 years	46.67	25.071	11.146	18.636	31.507	0.808*
From 50 to 65 years	20.00	23.833	11.923	11.321	36.346	
From 65 to 80 years	13.33	19.500	13.026	-1.227	40.227	
Gender						
Male	3.33	27.000	-	-	-	0.839**
Female	96.67	24.448	10.742	20.362	28.534	
Schooling						
Complete and Incomplete Elementary School	66.67	24.350	10.101	19.623	29.077	
Complete and Incomplete High School	16.67	22.800	6.380	14.879	30.721	0.831*
Complete and Incomplete University	16.67	27.000	16.508	6.503	47.497	
Marital Status						
Single	36.67	23.818	10.815	16.553	31.084	0.675**
Married	63.33	24.947	10.695	19.792	30.102	
Individual Income						
Below 1 MW	70.00	24.667	9.871	20.174	29.160	0.287**
Above 1 MW	30.00	24.222	12.686	14.471	33.974	
Perception on their health status						
Satisfactory	36.67	30.273	10.706	23.080	37.465	0.018**
Unsatisfactory	63.33	21.211	9.187	16.783	25.683	
Kinship with the elderly						
Son/daughter/spouse	83.33	24.520	11.237	19.882	29.158	0.897**
Other	16.67	24.600	7.197	15.663	33.537	
Lived with the elderly						
Yes	86.67	25.538	10.730	21.204	29.873	0.137**
No	13.33	18.000	7.348	6.307	29.693	
Help with care						
Yes	73.33	25.864	10.895	21.033	30.694	0.292**
No	26.67	20.875	9.250	13.142	28.608	
Hours/day dedicated to the elderly						
Up to 8 hours	23.33	21.714	8.712	13.657	29.772	
From 8 to 10 hours	13.33	31.750	5.909	22.347	41.153	0.165*
Above 10 hours	63.33	24.053	11.569	18.477	29.628	
Number of years dedicated to care						
Up to 3 years	46.67	26.929	12.958	19.447	34.410	
From 3 to 5 years	33.33	21.900	8.698	15.678	28.122	0.622*
Above 5 years	20.00	23.333	6.563	16.446	30.220	

*Kruskal-Wallis Test, ** Mann-Whitney Test

To provide care to another person involves providing for the basic needs such as food, performance of physical activities, and for the specific needs such as purchase of medication. Therefore, limited financial resources can be a stress to caregivers.

The perception of the health status of caregivers shows that the worse the health condition the greater the burden. Other studies show the same perspective[15].

A study carried out with patients and their informal caregivers in a school-hospital of the city of São Paulo also showed statistical significance between ZBI scores regarding the variable "referred physical health", which may suggest a physical and emotional stress because of the continuous care provided to the elderly[16].

Other studies mention that the fact that caregivers lived with the elderly is a burden factor and may be related to the constant exposure to care demands as well as the need for caregivers to perform other activities in addition to the care provided[3,18]. Although this study did not show statistically significant difference regarding this variable, the p-value found was close to the significant value (p= 0.137), which may be attributed to a heterogeneous sample with a high standard-deviation.

Association between the level of elderly dependence to perform ADL and IADL and the increase in workload attributed to caregivers has been observed in the present study. In a study carried out in the University Hospital at Universidade Federal da Paraíba, the author mentions the association between elderly dependence to perform tasks that require greater physical effort with a high level of tension to caregivers[18].

Level of dependence

None of the elderly was classified in scores C "independent for all activities but bathing and another one" and D "independent for all activities but bathing, dressing and another one", with a concentration in the percentage distribution of elderly in the two extreme

sides of the scale, with predominance of score G "total dependence", followed by score A "independent for all activities". It is worth mentioning that all classification scores converging to a greater dependence ("E" and "F") can indicate a global trend for a more severe dependence. In this sense, the Katz Index can be considered a predictive instrument to be used to plan care needs for the elderly.

Between Katz Index and Lawton Scale there was an association between the data, that is, the higher the dependence for ADL, the greater the dependence to IADL, reinforcing the importance of the use of the two instruments complementarily to assess the level of dependence of the elderly.

CONCLUSION

To analyze the profile of elderly and their caregivers, as well as the level of dependence of the elderly and the burden

on their caregivers can contribute to design intervention proposals based on the actual needs of the group studied.

The outcomes found in the present study suggest representative values with a high level of total dependence of the elderly. On the other hand, they also present an important percentage of independent elderly which indicates the need for programs that consider the inclusion of measures that can contribute to risk reduction, greater functionality and maintenance of the autonomy, both of the elderly and of their caregivers.

The values found regarding caregivers' burden show the need to offer support to the care provided at home to reduce the burden related to the activities connected with care and to give them access to knowledge.

Similar studies should be carried out to increase the number of studies involving human ageing in our region and to contribute as a parameter to reinforce the analysis of the results discussed in our study since the sample studied can be a limitation to this investigation.

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