

# Family functionality regarding the elderly with cognitive impairments: the caretaker's perception\*

FUNCIONALIDADE FAMILIAR DE IDOSOS COM ALTERAÇÕES COGNITIVAS: A PERCEÇÃO DO CUIDADOR

FUNCIONALIDAD FAMILIAR DE ANCIANOS CON ALTERACIONES COGNITIVAS: LA PERCEPCIÓN DEL CUIDADOR

Ariene Angelini dos Santos<sup>1</sup>, Sofia Cristina Iost Pavarini<sup>2</sup>

## ABSTRACT

The objectives of this study were to characterize the caregivers of elderly individuals with cognitive impairment living in different contexts of social vulnerability, and assess the family functionality of the elderly as perceived by the caregivers. Family functionality was evaluated using the Family APGAR instrument, assessed during home interviews with 72 caretakers. All the ethical aspects were observed. Spearman's correlation and the Mann-Whitney test were used, with 5% significance level ( $p < 0.05$ ). Results show that 82% of caregivers reported a good family functionality, 14% reported moderate family dysfunction, and 4% reported high family dysfunction. A statistically significant correlation was found between Family APGAR and the number of people living in the house ( $p = 0.048$ ). Further studies could verify the relationship between family functionality and the caretaker's overload in the context of elderly persons with dementia.

## DESCRIPTORS

Aged  
Dementia  
Social vulnerability  
Caregivers  
Family relations  
Geriatric nursing

## RESUMO

Este trabalho objetivou caracterizar os cuidadores de idosos com alterações cognitivas morando em diferentes contextos de vulnerabilidade social, e avaliar a funcionalidade familiar desses idosos segundo a percepção dos cuidadores. A funcionalidade familiar foi avaliada utilizando o instrumento APGAR de família, durante entrevistas domiciliares com 72 cuidadores de idosos. Todos os cuidados éticos foram observados. Foi utilizada a correlação de Spearman e o teste de Mann-Whitney, com nível de significância de 5% ( $p < 0,05$ ). Os resultados mostram que 82% dos cuidadores relatam boa funcionalidade familiar; 14%, moderada disfunção familiar; e 4%, elevada disfunção familiar. Houve correlação estatisticamente significativa entre o APGAR de Família e o número de pessoas que residem na casa ( $p = 0,048$ ). Investigações futuras poderiam verificar a relação entre funcionalidade familiar e sobrecarga do cuidador no contexto de idosos com demência.

## DESCRITORES

Idoso  
Demência  
Vulnerabilidade social  
Cuidadores  
Relações familiares  
Enfermagem geriátrica

## RESUMEN

Se objetivó caracterizar a los cuidadores de ancianos con alteraciones cognitivas viviendo bajo diferentes contextos de vulnerabilidad social y evaluar la funcionalidad familiar de tales ancianos según la percepción de los cuidadores. La funcionalidad familiar fue evaluada utilizando el instrumento APGAR de familia, durante entrevistas domiciliarias con 72 cuidadores de ancianos. Todos los cuidados éticos fueron observados. Se utilizó la correlación de Spearman y el test de Mann-Whitney, con nivel de significatividad de 5% ( $p < 0,05$ ). Los resultados muestran que el 82% de los cuidadores refieren buena funcionalidad familiar, el 14% moderada disfunción familiar y el 4% elevada disfunción familiar. Existió correlación estadísticamente significativa entre el APGAR de Familia y el número de personas residentes en el domicilio ( $p = 0,048$ ). Investigaciones futuras podrían verificar la relación entre funcionalidad familiar y sobrecarga del cuidador en el contexto de ancianos afectados por demencia.

## DESCRIPTORES

Anciano  
Demencia  
Vulnerabilidad social  
Cuidadores  
Relaciones familiares  
Enfermería geriátrica

\* Taken from the thesis "Idosos com alterações cognitivas: um estudo sobre a funcionalidade familiar em contexto de pobreza", Graduate Nursing Program, Universidade Federal de São Carlos, 2009. <sup>1</sup> RN. M.Sc. in Nursing, Universidade Federal de São Carlos. Member of the Research group Health and Aging and the Research Group Health and Family – CNPq. São Carlos, SP, Brazil. [arieneangelini@yahoo.com.br](mailto:arieneangelini@yahoo.com.br) <sup>2</sup> RN. Ph.D. in Education, Universidade Estadual de Campinas. Associate Professor, Nursing Department, Universidade Federal de São Carlos. Deputy Coordinator, Program for the Elderly, Teaching Health Unit. Coordinator of the Project Care Technology for Elderly Patients with Cognitive Impairments (FINEP). Leader of the CNPq Research Group Health and Aging. Member of the Research Group Health and Family. São Carlos, SP, Brazil. [sofia@ufscar.br](mailto:sofia@ufscar.br)

## INTRODUCTION

Nowadays, Brazil is going through a demographic transition moment, due to the progressive growth of the elderly population. At the same time, the epidemiology of diseases has changed from infectious conditions to chronic-degenerative and non-transmissible diseases<sup>(1-2)</sup>.

Among non-transmissible chronic conditions, dementia can be mentioned. It is known today that the prevalence of dementia increases in more advanced age groups<sup>(3)</sup>. This greater prevalence of dementia in more advanced age groups is a source of concern, as elderly people with dementia can be considered vulnerable<sup>(4)</sup>.

Vulnerability is a multidimensional construct, understood as a process of being at risk of altered health conditions, resulting from inadequate economic, social, psychological, family, cognitive or physical resources<sup>(5)</sup>. Elderly people in poverty contexts seem to be highly vulnerable to stressors, increasing their exposure to health problems.

Thus, the chronic situation of health problems, in combination with greater life expectancy, can compromise the elderly people's functional condition and autonomy, thus making them dependent on a caregiver<sup>(6)</sup>.

In Brazil, care delivery to dependent elderly people traditionally happens in the family context. The family is acknowledged as the primary support sources and the female figure is elected as the agent of this care<sup>(7)</sup>.

Families have gone through some transformations in recent times. Their structure was expanded and has become nuclear today, with rearrangements to see to the needs of older and dependent members in this new context<sup>(8)</sup>. Family functioning needs to be assessed, as it is not certain that this new family is prepared to assume the caregiver task<sup>(9)</sup>.

Family functioning can be assessed with the help of an instrument called the Family Apgar, which G. Smilkstein developed in 1978, and which has been translated, adapted and validated for the Brazilian culture<sup>(10)</sup>. The instrument consists of five questions to measure family members' satisfaction with five components that are considered basic in any family unit and functioning: adaptation, companionship, development, affectivity and problem-solving ability<sup>(11)</sup>.

Research on the use of the APGAR involving relatives and caregivers to elderly people remains scarce. A study developed in São Paulo is highlighted, in which APGAR results were compared between independent

Brazilian elderly people and their caregivers. The results showed that the APGAR was capable of verifying the impact of dependence on the family dynamics. Family APGAR scores were higher in the independent elderly group, followed by the dependent elderly group and, finally, by the caregiver group. Lower family APGAR scores in the dependent elderly and caregiver groups showed that, in their compliance with their functions, family functioning as a family unit is more compromised in these groups when compared with the scores obtained in the independent elderly group<sup>(11)</sup>.

In a Colombian study, subjects were 35 functionally dependent elderly community dwellers in the city of Buenaventura and their caregivers. The results showed that most caregivers were female (91%), with a mean age of 49.4 years, education ranging around five years (60%), and daughter as the predominant degree of family relationship with the elderly (57%). A significant correlation was found between the caregiver burden and the Family APGAR, with overburdened caregivers assessing their family as dysfunctional<sup>(12)</sup>.

A gap is found in knowledge production about elderly caregivers with cognitive alterations and in different social vulnerability contexts. Thus, the aim in this study was to characterize caregivers to elderly people with cognitive alterations living in different social vulnerability contexts and to assess the family functioning of these elderly people as the caregivers perceive it.

## METHOD

This descriptive and cross-sectional study was based on the premises of quantitative research. It was developed in São

Carlos, a city in the interior of São Paulo State. According to the 2010 Census, there were 221,950 inhabitants in São Carlos, 12.92% of whom were 60 years of age or older. In 2007, twelve Family Health teams were active in the city, which offered care to approximately 4,700 elderly people, corresponding to 8.7% of all people registered of all ages.

In this research, the São Paulo Social Vulnerability Index (IPVS) was considered. The IPVS ranks the São Paulo State census sectors according to the social vulnerability levels its residents are subject to, ranging from one (no vulnerability) to six (very high vulnerability). The IPVS score from the Family Health Unit – FHU where the elderly person was registered was taken into account.

First, a survey was made of Family Health Units in the city and each census sector was identified with its respective IPVS. The census sector of the FHU was located through the address and, with the help of the

Families have gone through some transformations in recent times. Their structure was expanded and has become nuclear (...) Family functioning needs to be assessed, as it is not certain that this new family is prepared to assume the caregiver task.

Brazilian Institute of Geography and Statistics (IBGE) unit in the city, data were checked. Next, the IPVS map was consulted to check the score attributed to that census sector.

Units with IPVS score 1, i.e. without social vulnerability, and units without an IPVS score at the time of data collection did not participate in this study. The units inserted in different social vulnerability contexts were included, ranging from IPVS 2 to 6 (Very Low to Very High Vulnerability)<sup>(9)</sup>.

Next, elderly people with cognitive impairments were identified in a database of the Research Group Health and Aging – UFSCar - CNPq and confirmation was obtained from the Family Health team to update the data. To screen the elderly with cognitive impairments, the Mini Mental State Examination (MMSE) was reapplied, an instrument that has been translated, adapted and validated<sup>(13)</sup>. Elderly people with results below the cut-off score for education level were considered cognitively impaired. The following cut-off points were used: 18 points illiterate, 21 points between one and three years of education, 24 points between four and seven years of education and 26 points eight years of education or more. Caregivers were selected based on the elderly patients<sup>(14)</sup>.

The database included 1578 registered elderly patients and cognitive conditions were assessed in a sample of 755 elderly. In this database, 195 patients were identified with MMSE scores below the cut-off point. A sample of 88 elderly, defined based on statistical criteria, represented the cognitively impaired elderly registered at the six Family Health Units of interest. Seventy-two of them had a caregiver who participated in data collection<sup>(15)</sup>.

Hence, 72 primary caregivers of elderly people with cognitive impairments served as the research subjects, coming from regions with different social vulnerability scores (M=63; H=9). The inclusion criteria were: being the main caregiver as referred by the elderly; living in a region with IPVS higher than one; signing the Informed Consent Term. All ethical care for research involving human beings was observed and respected, in compliance with Resolution 196/96. Approval for the project was obtained on June 06<sup>th</sup> 2008 from the Research Ethics Committee at the University where the research was accomplished (Opinion 253/ 2008).

Data collection started after participants had read and signed the Informed Consent Term.

Previously scheduled individual and home interviews were held at the homes of 72 caregivers to cognitively impaired elderly patients. Data were collected between July and December 2008. Data collection involved a structured interview, using the Family APGAR

to measure family functionality and a previously elaborated instrument with data like gender, age, marital status, education, referred morbidity, income, co-residency with the elderly, type of relation with the elderly, existence of help to take care of the elderly and family relation with the elderly.

For data analysis, Spearman's correlation and the Mann-Whitney test were used, with significance set at 5% ( $p < 0.05$ ).

## RESULTS

Seventy-two caregivers were interviewed. Fifty percent of them ( $n=36$ , with 32 women and four men) come from low and medium social vulnerability regions and 50.0% ( $n=36$ , with 31 women and five men) to regions of high and very high social vulnerability. For each elderly, the primary caregiver was considered as indicated by the elderly him/herself.

Table 1 shows the sociodemographic characteristics of the people serving as caregivers to the cognitively impaired elderly patients in this study.

The caregivers to the elderly patients who participated in this research are predominantly women (87.5%), elderly (63.9%), between 41 and 60 years of age (38.9%), with a mean age of 50.0 years (standard deviation = 17.7; median= 51.0 years) and, in most cases, live with the elderly (76.4%).

As for the caregivers' education, the majority had not finished primary education (43.0%).

Concerning income, 75.0% of the caregivers affirm that they do not have a paid job and 36.1% reported no income. Some caregivers do not have a paid job, but gain an income ( $n=28$ , 38.8%). This income results from a pension or informal activities like sewing and making snacks for sale.

When the caregivers were questioned about the reasons why they take care of these elderly patients, 50.0% affirm that they take care because they want to and 41.7% because they are the only person available for this task.

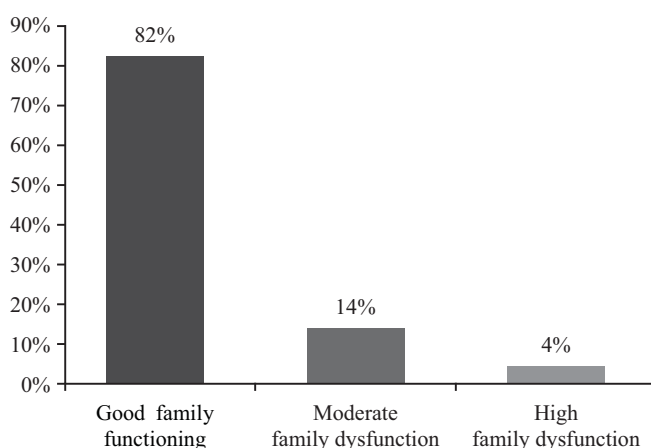
Approximately 65.0% of caregivers had no disease at the time of data collection, 29.2% report arterial hypertension, 4.2% diabetes, 4.2% osteoporosis, 1.4% arthritis/arthritis.

As for help received to take care of the elderly, 51.4% of the caregivers affirm they get no help with care delivery.

Concerning the family functioning according to the elderly, 82% affirm good family functioning, 14% moderate and 4% high levels of dysfunction (Figure 1).

**Table 1** – Characteristics of caregivers to elderly patients with cognitive impairment – São Carlos, SP, 2011

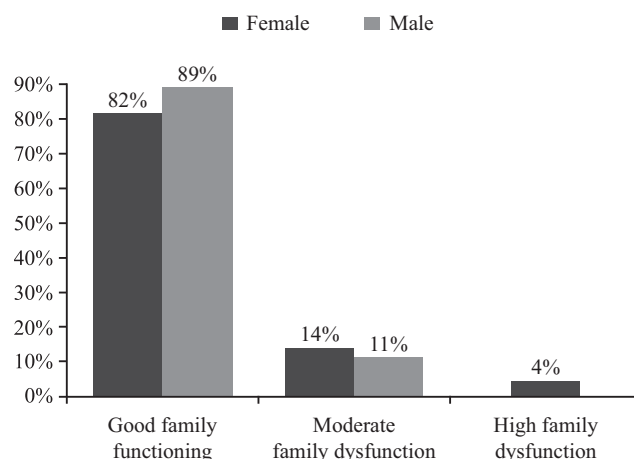
Characteristics		N	%
Gender	Female	63	87.5
	Male	9	12.5
Marital status	Single	16	22.2
	Married	46	63.9
	Separated	6	8.3
	Widowed	4	5.6
Co-residency with the elderly	Yes	55	76.4
	No	17	23.6
Age	40 years or older	22	30.5
	41 to 60 years	28	38.9
	61 to 70 years	12	16.7
	70 years or older	10	13.9
Education	Illiterate	10	13.9
	Adult alphabetization	1	1.4
	Unfinished primary	31	43.0
	Finished primary	14	19.4
	Unfinished secondary	1	1.4
	Finished secondary	12	16.7
	Unfinished higher	1	1.4
	Finished higher	2	2.8
Paid job	Yes	18	25.0
	No	54	75.0
Income	Yes	46	63.9
	No	26	36.1
Reason for care	Intimate relation	14	19.4
	Desire	36	50.0
	Degree of family relation	19	26.4
	Only person available	30	41.7
	Geographical proximity	6	8.3
Referred disease or condition	None	47	65.3
	Arterial hypertension	21	29.2
	Diabetes	3	4.2
	Alcoholism	1	1.4
	Osteoporosis	3	4.2
	Arthritis	1	1.4
Help with care	Yes	35	48.6
	No	37	51.4



**Figure 1** – Distribution of family functioning according to caregivers to elderly patients – São Carlos, SP, 2011

A statistically significant correlation was found between the Family APGAR and the number of people living in the house ( $p=0.048$ ).

With regard to gender, 89% of male caregivers affirm good family functioning and 11% moderate family dysfunction. Concerning female caregivers, 80% present good family functioning, 15% moderate family dysfunction and 5% high family dysfunction (Figure 2).



**Figure 2** – Percentage distribution of family functioning of caregivers to elderly patients according to gender – São Carlos, SP, 2011

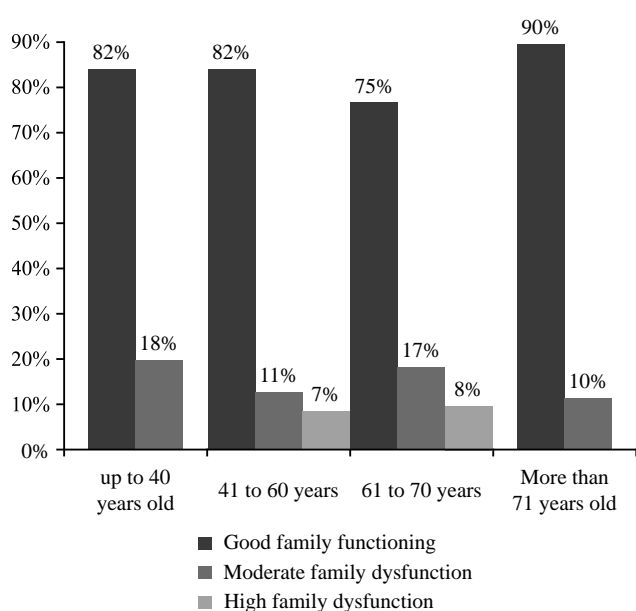
The Mann-Whitney test was used to compare the Family APGAR score between male and female caregivers, showing no significant differences between the presented scores ( $p=0.718$ ).

In terms of age range, good family functioning is observed in 82% of caregivers aged up to 40 years, in 82% of caregivers aged between 41 and 60 years, in 75% of caregivers between 61 and 70 years of age and in 90% of caregivers aged 71 years or older (Figure 3).

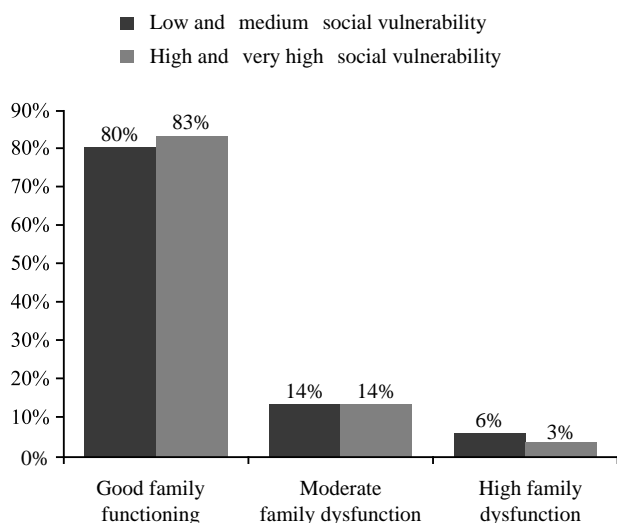
The assessment of the correlation level between the Family APGAR score and the elderly caregivers' age, using Spearman's correlation coefficient, showed that the correlations were not significant (correlation coefficient = 0.19 and  $p = 0.876$ ).

When considering regions of social vulnerability, 83% of caregivers to elderly patients living in poverty contexts show good family functioning, 14% moderate family dysfunction and 3% high family dysfunction. As for the caregivers to elderly patients living in low and medium social vulnerability conditions, 80% reveal good family functioning, 14% moderate family dysfunction and 6% high family dysfunction (Figure 4).

According to the Mann-Whitney test, no significant difference was found between the high and very high social vulnerability and the low and medium social vulnerability groups with regard to the Family APGAR score ( $p>0.05$ ).



**Figure 3** – Percentage distribution of family functioning of caregivers to elderly patients according to age range – São Carlos, SP, 2011



**Figure 4** – Percentage distribution of family functioning of caregivers to elderly patients according to social vulnerability regions – São Carlos, SP, 2011

## DISCUSSION

Caregivers were predominantly female, married, adult, with low education levels and, in most cases, lived with the elderly. Various studies were found in literature to support these findings<sup>(2,7,15-17)</sup>.

This fact reflects a Brazilian cultural pattern in which the primary caregiver’s role is still seen as a female function, especially linked to the elderly’s wife or daughter. In some cases, the elderly receive care from secondary caregivers to perform their instrumental activities of daily

living. In that case, a significant percentage of men (40%) play this role<sup>(18)</sup>.

Most caregivers had not finished primary education. Low education levels can act as a barrier in the health education process. When caregivers’ knowledge is limited, health professionals need to use a wide range of resources and dynamics to reach the desired objectives. Low education levels can interfere in care delivery to the elderly, lowering care quality. Then, professionals need to enhance their attention to caregivers, in order to teach them to prevent possible mistakes<sup>(19)</sup>.

In this research, most caregivers lived with the elderly. Some studies show that, besides gender and family relation factors, being chosen or deciding to take responsibility for care tasks may depend on other events, like living in the same house. Living together may mean better living conditions, for older as well as younger generations<sup>(20)</sup>.

When asked about receiving help, most caregivers reported that they do not receive help from other people, neither relatives nor professionals. When performing their role alone, caregivers feel overburdened. When one single person delivers the care, this may generate stress<sup>(21)</sup>. Studies involving caregivers also show that, when caregivers assume care for the elderly at home alone, they frequently manifest their discomfort and feeling of solitude, when they do not feel support from other family members<sup>(22)</sup>.

As for the family functioning the caregivers reported, most interviewees (82%) affirmed that family functioning was good. In literature, studies were found that are compatible with our findings<sup>(11-12)</sup>.

A study developed in São Paulo City compared the result of the Family APGAR among independent (n=98) and dependent Brazilian elderly patients (n=51) and their caregivers (n=51). Results showed that the mean total Family APGAR score differed among the study groups and was higher for independent elderly, followed by dependent elderly and caregivers. The lower mean score for the caregiver group, similar to the present study results, although it suggests a less favorable view of the family system, still totalizes a score that classifies the family dynamics as *good functioning*<sup>(11)</sup>.

In a study developed in Colombia, subjects were 35 functionally dependent elderly patients and their caregivers. The results show that, out of 35 caregivers, 19 did not report any burden and obtained scores that indicated good family functioning. Sixteen caregivers, on the other hand, reported an overburden due to the care activities and obtained scores indicating moderate or high levels of family dysfunctions. The authors found that, the greater the caregiver’s burden, the lower the Family APGAR score, indicating family dysfunction<sup>(12)</sup>.

Although most studies found reveal good family functioning, further investigations in this area are needed, as

research is still scarce. The increased prevalence of dementias and the growing need for a caregiver point towards the need for studies on the family functioning of elderly patients with cognitive impairments from a family perspective, with a view to enhancing the quality of care in this context.

## CONCLUSION

No significant correlation was found between the Family APGAR and social vulnerability, gender and age groups of caregivers to elderly patients with cognitive impairment. Statistical significance was found, though, between the family APGAR and the number of people living at the elderly patient's home, indicating that, the more people live with the elderly, the better family functioning will be.

## REFERENCES

1. Veras R. Envelhecimento populacional e as informações de saúde do PNAD: demandas e desafios contemporâneos. *Cad Saúde Pública*. 2007;23(10):2464-6.
2. Nascimento LC, Moraes ER, Silva JC, Veloso LC, Vale ARMC. Cuidador de idosos: conhecimento disponível na base de dados LILACS. *Rev Bras Enferm*. 2008;61(4):514-7.
3. Nitrini R, Caramelli P, Herrera Junior E, Bahia VS, Caixeta LF, Radanovic M et al. Incidence of dementia in a community-dwelling Brazilian population. *Alzheimer Dis Assoc Disord*. 2004;18(4):241-6.
4. Arán M, Peixoto Junior CA. Vulnerabilidade e vida nua: bioética e biopolítica na atualidade. *Rev Saúde Pública*. 2007;41(5):849-57.
5. Shepard MP, Mahon MM. Vulnerable families: research finding and methodological challenges. *J Fam Nurs*. 2002;8(4):309-14.
6. Paula JA, Roque FP, Araújo FS. Qualidade de vida em cuidadores de idosos portadores de demência de Alzheimer. *J Bras Psiquiatr*. 2008;57(4):283-7.
7. Fernandes MGM, Garcia TR. Determinantes da tensão do cuidador familiar de idosos dependentes. *Rev Bras Enferm*. 2009;62(1):57-63.
8. Rodrigues SLA, Watanabe HAW, Derntl AM. A saúde de idosos que cuidam de idosos. *Rev Esc Enferm USP*. 2006;40(4):493-500.
9. Pavarini SCI, Barham EJ, Mendiondo MSZ, Filizola CLA, Petrilli Filho JF, Santos AA. Família e vulnerabilidade social: um estudo com octogenários. *Rev Latino Am Enferm*. 2009;17(3):374-9.
10. Duarte YAO. Família: rede de suporte ou fator estressor: a ótica de idosos e cuidadores familiares [tese]. São Paulo (SP): Programa de Pós Graduação em Enfermagem, Universidade de São Paulo; 2001.
11. Smilkstein G. The family APGAR a proposal for a family function test and its use by physicians. *J Fam Pract*. 1978;6(6):1231-9.
12. Ocampo JM, Herrera JA, Torres P, Rodríguez JA, Loba L, García CA. Sobrecarga asociada con el cuidado de ancianos dependientes. *Colombia Med [Internet]*. 2007 [citado 2011 jan. 15];38(1):40-6. Disponível em: <http://redalyc.uaemex.mx/src/inicio/ArtPdfRed.jsp?iCve=28338107>
13. Bertolucci PHF, Brucki SMD, Campacci SR, Juliano Y. O Mini Exame do Estado Mental em uma população geral: impacto da escolaridade. *Arq Neuropsiquiatr*. 1994;52(1):1-7.
14. Nitrini R, Caramelli P, Bottino CMC, Damasceno BP, Brucki SMD, Anghinah R. Recomendações do Departamento Científico de Neurologia Cognitiva e do Envelhecimento da Academia Brasileira de Neurologia. *Arq Neuropsiquiatr*. 2005;63(3-A):720-7.
15. Santos AA, Pavarini SCI. Perfil dos cuidadores de idosos com alterações cognitivas em diferentes contextos de vulnerabilidade social. *Rev Gaúcha Enferm*. 2010;31(1):115-22.
16. Lemos ND, Gazzola JM, Ramos LR. Cuidando do paciente com Alzheimer: o impacto da doença no cuidador. *Saúde Soc*. 2006;15(3):170-9.
17. Glzman JM. Quality of life of caregivers. *Neuropsychol Rev*. 2004;14(4):183-96.
18. Cruz MN, Hamdan AC. O impacto da doença de Alzheimer no cuidador. *Psicol Estudo* 2008;13(2):223-9.

19. Martins JJ, Albuquerque GL, Nascimento ERP, Barra DCC, Souza WGA, Pacheco WNS. Necessidades de educação em saúde dos cuidadores de pessoas idosas no domicílio. *Texto Contexto Enferm*. 2007;16(2):254-62.
20. Camarano AA, El Ghaouri SK. Famílias com idosos: ninhos vazios? Rio de Janeiro: IPEA; 2003.
21. Simonetti JP, Ferreira JC. Estratégias de coping desenvolvidas por cuidadores de idosos portadores de doença crônica. *Rev Esc Enferm USP*. 2008;42(1):19-25.
22. Luzardo AR, Waldman BF. Atenção ao familiar cuidador do idoso com doença de Alzheimer. *Acta Sci Health Sci*. 2004;26(1):135-45.

#### Acknowledgements

We are grateful for the funding of the São Paulo Research Foundation (FAPESP) and the Coordination for the Improvement of Higher Education Personnel (CAPES).