ISSN 2175-5361

Federal University of Rio de Janeiro State

Journal of Research Fundamental Care Online

ISSN 2175-5361
DOI: 10.9789/2175-5361

RESEARCH

Perfil do cuidador familiar de idosos dependentes em convívio domiciliar*

Profile of the family caregiver of dependent elderly in home living

Perfil del cuidador familiar de ancianos dependientes en convivio domiciliário

Lara de Sá Neves Loureiro[1], Maria das Graças Melo Fernandes[2]

ABSTRACT

Objective: identifying the profile of the family caregiver of dependent elderly in home living, in the city of João Pessoa - PB, according to the socio-demographic characteristics, information regarding the demand for care and support for help to the performance of this care. **Method:** an epidemiological study in which 52 family caregivers of dependent elderly participated. Data collection was conducted through home interviews. **Results:** it was verified a predominance of female caregivers, children of the dependent elderly, with an average age of 52 - 62 years old, living with a partner and with the elderly, they have studied from five to eight years, with little knowledge for performing their function, as well as a deficit of support for care. **Conclusion:** the findings bring significant contributions to the elaboration of public policies directed to the quality of life of the caregivers, as well as the care given to the dependent being. **Descriptors:** Caregivers. Elderly; Nursing

RESUMO

Objetivo: identificar o perfil do cuidador familiar de idosos dependentes em convívio domiciliar, no município de João Pessoa – PB, de acordo com as características sociodemográficas, informações referentes à demanda de cuidado e ao suporte de ajuda para o desempenho do cuidado. **Método:** estudo epidemiológico em que participaram 52 cuidadores familiares de idosos dependentes. A coleta de dados foi realizada mediante entrevistas domiciliares. **Resultados:** verificou-se maior predominância de cuidadores do sexo feminino, filhos (as) do idoso dependente, com idade entre 52 e 62 anos, que moravam com o (a) companheiro (a) e com o idoso, estudaram de cinco a oito anos, com déficit de conhecimento para o desempenho de sua função, bem como déficit de suporte para o cuidado. **Conclusão:** os achados trazem contribuições relevantes para a elaboração de políticas públicas direcionadas para a qualidade de vida do cuidador, bem como do cuidado dispensado ao ente dependente. **Descritores:** Cuidadores; Enfermagem; Idoso.

RESUMEN

Objetivo: identificar el perfil del cuidador familiar de mayores dependientes en convivio domiciliario, en el municipio de João Pessoa – PB, de acuerdo con las características socio-demográficas, informaciones referentes a la demanda de la atención y al soporte de ayuda para el desempeño de la atención. **Método:** un estudio epidemiológico en el que participaron 52 cuidadores familiares de mayores dependientes. La recogida de datos fue realizada mediante encuestas domiciliarias. **Resultados:** se verificó mayor predominio de cuidadores del sexo femenino, hijos (as) del mayor dependiente, con una media de 52 - 62 años de edad, que vivían con el (la) compañero (a) y con el mayor, estudiaron de cinco a ocho años, con déficit de conocimiento para el desempeño de su función, así como déficit de soporte para la atención. **Conclusión:** los resultados aportan contribuciones relevantes para la elaboración de políticas públicas direccionadas para la calidad de vida del cuidador, así como de la atención dispensada al ente dependiente. **Descriptores:** Cuidadores; Enfermería; Mayores.

*Work extracted from the Master Thesis "Workload in family caregivers of dependent elderly from the city of João Pessoa, Paraiba, Brazil", presented at the Nursing Postgraduate Program from the Federal University of Paraiba.

[1]Nursing Doctoral Student. Postgraduate Nursing Program, Federal University of Paraiba. João Pessoa, PB, Brazil. Email: laraasn@hotmail.com. [2] Doctorate in Sociology. Professor, Federal University of Paraiba. João Pessoa, PB, Brazil. Leader of the Adult and Elderly Health Study and Research Group.

ISSN 2175-5361

INTRODUCTION

Demographic changes due to population aging process occurring nowadays are accompanied by changes in the population's morbidity and mortality profile, showing up more often, the prevalence of chronic diseases that affect mainly the elderly population and may, eventually, lead to impaired functional capacity of these individuals, or impaired ability to perform their basic activities of daily living.[1]

It should be noted that the elderly dependency, both the physical or cognitive isolation, as the association of physical dependence and cognitive imply strong pressure on social support systems in order to understand care systems to meet the specific needs of this group.

In the gerontological literature, there is a consensus that care can be implemented both by the family and by professionals and health institutions and focuses on the use of formal and informal terms to define the type of support offered to dependent elderly. Caregiver called up the professional contractor, specially trained, assisting the elderly with dependence and/or family. Is called informal caregiver, family member or friends, neighbors and volunteers without specific training, unpaid, which takes care of the dependent elderly in the family context.[2]

At the time of an event that compromises the dependency or the functional capacity of the elderly is the family that primarily is responsible, directly or indirectly, for the care to dependent elderly. The designation of a caregiver in the family, although it is an informal and due process of its own dynamics, differing depending on the historical and sociocultural context, it seems to take into account several factors: kinship; gender; physical proximity of those living with the elderly and emotional proximity .[3]

In this scenario, when most of the care actions are carried out by a single person, whether by instinct, desire, willingness or ability, it is now called primary family caregiver. The secondary caregiver is the one who takes care of the elderly occasionally, although share, somehow responsibilities with the primary caregiver.[4]

Although some research has been devoted to the study of the various characteristics of family caregivers of patients/dependent elderly, it is appropriate to the development of a new study, whereas these characteristics take different shape according to different socio-cultural contexts and family structure of caregivers. In this scenario, the present study aims to identify the profile of the elderly family caregiver dependent on household living in the city of João Pessoa-PB, according to sociodemographic characteristics, information regarding the care demand and to help support the performance of care.

METHOD

This is an epidemiological, descriptive and cross in the urban area of the city of João Pessoa, PB, through home interviews with elderly dependents and/or family caregivers (under the conditions of the elderly are unable to communicate). This study was part of the survey "Living conditions, health and aging: a comparative study", linked and funded by the National Program of Academic Cooperation (PROCAD/CAPES) between the Federal University of Paraiba and the Ribeirão Preto School of Nursing University of Sao Paulo.

Were part of the universe of the study 240 elderly people who lived in the twenty census tracts drawn, aged more than sixty years, of both sexes. In order to establish the quotas of the population and considering the socioeconomic diversity of the city, the sampling process was probabilistic, cluster, dual stage.

In the first stage, it was considered the census tract as the primary sampling unit. Thus, twenty census tracts were drawn with probability proportional to the number of households, among the 617 municipal sectors. In the second stage, visited a fixed number of households, in order to ensure the self-weighting sample, were selected when the street and the court where this search process would be initiated.

After the selection of sectors, it was identified in the municipal map of João Pessoa, the location of each sector drawn, including the neighborhoods that would be visited. Later, there was another draw in the streets that should be visited by interviewers were defined. There were recorded in the enrollment sheet, the number of elderly residents and the date of home visits to the questionnaire. Finally, imbued teams were determined to interview the elderly and caregivers of the study participants in each census tract. At the end of the pre-set interviews, where the sample density proposal was not reached, the interviewers continued the views until you get the desired number of elderly by sector. The sampling errors were fixed around 10%.

Participated in the sample 52 family caregivers of dependent elderly, or who had cognitive disability and/or physical (moderate to severe), evaluated by application of the Mini scales of mental status - MEEM[5] and Katz[6] Index. In addition, there were also considered as inclusion criteria for the study, caregivers of both genders; who did not receive remuneration for the provision of care and who were members of the old family.

Data collection was conducted through interviews with the family caregivers, from April to June 2011, following the clockwise of selected sectors. To do this, semi-structured questionnaires were used that contemplated information regarding sociodemographic characteristics of the family caregivers, care demand and help support the care performance.

For the statistical analysis we used the SPSS (Statistical Package for the Social Sciences) for Windows, version 15.0. The description of the variables was performed by calculating the distribution (mean, standard deviation, absolute frequency and relative frequency). In the stage of the confirmatory analysis for qualitative variables we used the chi-square test of Pearson (x2) or Fisher's exact test.

Regarding ethical procedures, the research project was previously approved by the Research Ethics Committee of the University Hospital Lauro Wanderley (Protocol 679/10). Participants were informed about their objectives, the development and disclosure of results. Moreover, it had guaranteed anonymity, respecting the confidentiality of information and the freedom to give up part of research in any of its phases. After consent to participate in the study, make such a statement by the Terms of Consent.

RESULTS

With regard to the sociodemographic characteristics of the family caregivers investigated, as expressed in Table 1, there was a higher prevalence of female caregivers (96,2%). Considering the degree of kinship, 26 (50%) were child, and 14 (26,9%), spouses. Regarding the age of the caregivers, the mean (standard deviation) was 52,62 (14,4%). In the age distribution in age groups, we found that 12 (23,1%) were younger than 40 years, and likewise, 12 (23,1%), 41-50 years.

Regarding marital status of caregivers, 31 (60,8%) live with their spouse. With regard to the environment of living of the caregivers/elderly, research has shown that 49 (94,2%) were in the same home living. With respect to the education, it was observed that 24 (46,2%) studied five to eight years. All respondents reported being primary caregivers of their loved dependent, being observed higher prevalence of children playing the role of secondary caregiver (37,3%).

Table 1 - Distribution of socio-demographic characteristics of the family caregivers of elderly dependents study participants - João Pessoa-PB, 2011

Profile of the caregiver	n	%
Level of kinship		
Husband	14	26,9%
Son/Daughter	26	50,0%
Grandson/Grandaughter	1	1,9%
Son-in-law/Daughter-in-law	3	5,8%
Brother-in-law/Sister-in-law	1	1,9%
Other	7	13,5%
Age (in years)	**Average (SD)**	52,62 (14,14)
Until 40	12	23,1%
41 - 50	12	23,1%
51 - 60	11	21,2%
61 - 70	11	21,2%
71 - 80	5	9,6%
81 - 90	1	1,9%
Gender		
Male	2	3,8%
Female	50	96,2%
Marital status		
Never married or lived with companion	10	19,6%
Lives with husband/wife or partner	31	60,8%
Separated / separated / divorced	8	15,7%
Widower/Widow	2	3,9%
Living with the elderly		
No	3	5,8%

Yes	49	94,2%
Schooling (in years)		
Illiterate	3	5,8%
Read/write informal	3	5,8%
1 - 4 years	6	11,5%
5 - 8	24	46,2%
9 - 12	6	11,5%
13 or more	10	19,2%
The main caregiver		
Yes	52	100,0%
No	0	0,0%
Secondary caregivers		
None	13	25,5%
Husband / Wife / a partner	4	7,8%
Son / Daughter	19	37,3%
Grandson / Grandaughter	3	5,9%
Private caregiver	6	11,8%
Other	6	11,8%

Table 2 - Distribution characteristics of family caregivers of elderly dependents about the level of knowledge of health/illness and the need to take care of the elderly, for the care and instruction time of involvement in the role of caregiver - João Pessoa-PB, 2011.

Caregiver's profile	**n**	**%**
It is considered informed regarding health/disease of the elderly		
No	2	3,8%
Little and insufficient	8	15,4%
Little, but sufficient	23	44,2%
Well	10	19,2%
Very well	9	17,3%
It is considered informed about about taking care of the elderly		
No	2	3,8%
Little and insufficient	7	13,5%
Little, but sufficient	24	46,2%
Well	11	21,2%
Very well	8	15,4%
Had course in formal institution to care for elderly		
Yes	2	3,8%
Não	50	96,2%
Had some kind of training		
Yes	2	3,8%
No	50	96,2%
How long takes care of the elderly (in months)	**Average (SD)**	71,40 (58,20)
0 - 6	4	7,7%
7 - 12	3	5,8%
13 - 24	7	13,5%
25 - 32	2	3,8%
33 - 56	12	23,1%
57 - 68	2	3,8%
69 months or more	22	42,3%
How many days during the week are dedicated to caring for the elderly	**Average (SD)**	5,02 (0,641)
3 days	2	3,8%
4 days	1	1,9%
5 days	46	88,5%
7 days	3	5,8%
How many hours per day of the week are devoted to caring for the elderly	**Average (SD)**	17,08 (10,33)
Until 4 hours	6	11,5%
5 - 8 hours	8	15,4%
9 - 12 hours	9	17,3%

13 hours or more	29	55,8%

With regard to the characteristics of family caregivers related to the specific issues of care demand, occur-the conditions outlined in Table 2, highlighting the following results: 23 (44,2%) caregivers are considered little, but sufficiently informed about the elderly's disease, 24 (46,2%) also say little, but sufficiently aware of the need to take care of the elderly, 50 (96,2%) said they did courses on caring for the elderly, provided by institution formal, and said it did not receive any training.

In respect of the time spent in care by caregivers, measured in months, the survey showed an average (standard deviation) of 71,40 (58,20). As regards the number of days of the week that caregivers were involved in the provision of care, there was an average (standard deviation) of 5,02 (0,641), highlighting 46 (88,5%) of them took care of five days a week. Considering the number of hours per day that caregivers were devoted to the care, 29 (55,8%) expressed that spend thirteen hours or more per day during the week, which is an average (standard deviation) of 17,08 (10,33).

Table 3 - Distribution on the support or help in the provision of care for the elderly dependent - João Pessoa-PB, 2011.

	Help to take care of the elderly			
	No	Sometimes	Always/almost always	Does not apply
Activity	n (%)	n (%)	n (%)	n (%)
Body hygiene	18 (34,6%)	15 (28,8%)	18 (34,6%)	1 (1,9%)
Oral hygiene	25 (48,0%)	16 (30,7%)	10 (19,2%)	1 (1,9%)
Eliminations	23 (44,2%)	19 (36,5%)	9 (17,3%)	1 (1,9%)
Care for the skin	21 (40,3%)	18 (34,6%)	12 (23,0%)	1 (1,9%)
Feeding	20 (38,4%)	18 (34,6%)	13 (25,0%)	1 (1,9%)
Medication	22 (42,3%)	17 (32,6%)	13 (25,0%)	0 (0%)
Sleep and rest	30 (57,6%)	13 (25,0%)	8 (15,3%)	1 (1,9%)
Physical activity	32 (61,5%)	6 (11,5%)	6 (11,5%)	8 (15,3%)
Leisure	30 (57,6%)	9 (17,3%)	10 (19,2%)	3 (5,7%)
Physiotherapy service	32 (61,5%)	6 (11,5%)	8 (15,3%)	6 (11,5%)
Return to consultations	15 (28,8%)	15 (28,8%)	20 (38,4%)	2 (3,8%)

As Table 3 sets out, caregivers had lower support to care for the dependent elderly for activities related to physical exercise (32; 61,5%) and physiotherapy service (32; 61,5%). In turn, there was more support for the activity related to the return of the elderly to appointments (20; 38,4%).

DISCUSSION

The family has been identified in the literature as the main source of support and care for the elderly. By providing care, the family members of elderly dependency meet

fundamental socio-cultural norms for the continuity of society. In this perspective, the award of the caregiver role to some members, and not the other, has not been made arbitrarily, but obeying social norms that involve the relationship to the elderly (with priority for spouse and children), gender (predominantly women), physical proximity (especially those living with the elderly) and emotional closeness. [3, 7]

Regarding the caregiver kinship degree with the elderly, it is emphasized that the ties of affection from the existing ties of consanguinity determine the support of family members to your needy one, even at the expense of their quality of life.[8] In this study, the prevailing number of children (26; 50%) as the function of caregivers, followed by spouses (14; 26,9%). This finding is contrary to that found in most studies dealing with this matter, since it points the spouse as the primary family caregiver, followed by children. Note that in this study there was a higher prevalence of widowed elderly dependents, which means fewer spouses.

In terms of care, the literature has shown the reciprocal debts, some legacy and generational transmissions as essential factors in choosing or determining the primary caregiver. In this context, the moral duty of filial responsibility has been identified as a driver of commitment made by children for the provision of care to dependent elderly. This duty is grounded in reverence, gratitude debit or reciprocity of children as well as the feelings of friendship and love. [9]

The performance of the care exercised by the spouses, in turn, is mainly related to the commitment made at the time of marriage, when they are identified contracts, promises and marks a time when most couples would stay together until death, passing to realize the act of caring as a normal consequence, intrinsic to own marriage.[8]

The average age of family caregivers in this study was 52,62 years, which is consistent with the findings of other studies.[10,11,12,13] It was evident that most caregivers is in the adult age group, middle-age, which may be related to the high number of children that perform this function or female spouses, tend to be younger than their peers. With regard to gender, the results show substantial proportion of women playing the role of family caregivers (96,2%), confirming the results of other studies.[8,12,14,15] Nevertheless, we stress that the assignment of roles and tasks of caring follow cultural norms expecting woman the organization of family life, the care of children and the elderly and all that is related to home.[7] Thus, despite women's emancipation and their growing presence in the labor market, women still tend to take care of the home environment and the health of its members, from children to the elderly and dependents.

In this study, it was found that only 3,8% of family caregivers were male. It should be noted, however, that participated in this research only major family caregivers. Despite this, the literature points to the massive participation of women playing more the role of secondary caregivers than primary care providers. In general, men are more involved in secondary or tertiary care, as material aid, participation in outdoor activities such as taking care of the economic interests of the elderly, and collaboration instrumental help tasks involving displacing them.[7] In this study, most secondary caregivers were children of dependent elderly, however, a considerable portion did not have that type of caregiver.

In relation to marital status, most family caregivers reported living with spouse or partner. In this context, the presence of a companion can be of benefit, emotional and

instrumental support, and may cause family friction when the commitment of the caregiver is not well accepted by his companion.

A substantial proportion of family caregivers mentioned live with the elderly (94,2%), which is consistent with results of other studies.[13,14,17] In the analysis of this reality, it is noted that the co-residence living of caregivers of dependent elderly, people can be seen as favorable to them, as their care needs can be met promptly. However, the caregiver can view this situation negatively, because of the large exposure to the effects of the care process that the experience provides.[14]

With regard to schooling, 46,2% of caregivers have five to eight years of study. This result runs counter to what has been found in most studies, where there is low level of education among caregivers.[13,14,18]

In particular, the significant relationship between the level of education and the level of knowledge required for the care of performance, which involves from knowledge necessary to carry out the basic instrumental activities of care, to those related to the diagnosis, prognosis and complications of diseases of the dependent elderly. Nevertheless, when asked whether they felt informed about the health and/or disease of the elderly and how to take care of it, most of the study caregivers responded that little, but enough. A large proportion also said not to have had any kind of training or ongoing formal institution to take care of the elderly.

Although the caregiver has an important role in home health care model, most of the population of informal caregivers still lacks the necessary information and support assistance[17], which is a risk factor for the quality of care provided, as well as the maintenance of the caregiver own quality of life.

Regarding the care of demand, the study caregivers spend an average of five days a week and seventeen hours a day to take care of the elderly. The dedication of more time to the elderly is related to increased availability of family caregivers. Caregivers who have less family commitments (take care of son, grandchildren) and who do not have professional jobs have more time to caring for the elderly, what, in general, favors it, but it can cause stress or workload in caregivers.

As regards the support or help in the provision of care, most caregivers received additional assistance activity related to the return of the old appointments. This implies that the support was more present to less instrumental activities and with lower levels of difficulty. There are activities commonly performed by secondary caregivers. Furthermore, it was found that family caregivers had less support for caring for the elderly in activities that require more physical effort, such as the performance of physical activity and physical therapy.

CONCLUSION

The survey results allowed the conclusions presented here: with regard to the characteristics of family caregivers, it was found, in general, that almost all were women, children of the dependent elderly, aged between 52 and 62, lived with a partner and with

the elderly, studied five to eight years with a lack of knowledge and training to perform their function, as well as support for the care deficit.

We must highlight the valuable collaboration of the analysis of these findings, given that these characteristics have an important influence on the caregiver's quality of life and care given to the loved one. Whereas family caregivers share of poor visibility, because of the health care structure deficit and, often, the devaluation of their work is done worth noting the relevance of new research about care of the implications on the lives of caregivers of so that it is invigorated the urgent need to implement public policies and actions towards the establishment of formal and emotional supports for these people.

Within the health system, it is extremely important that nurses and other professionals involved can provide interventions aimed at improving health and functional for the elderly, as well as guidance to families who care to a dependent one. It is worth noting that the goal of these interventions should not be just to manipulate family members as caregivers, but as people who also need care.

REFERENCES

1. Veras R. Envelhecimento populacional contemporâneo: demandas, desafios e inovações. Rev. Saude Publica. 2009; 4(3): 548-54.

2. Brasil. Ministério da Saúde. Portaria n. 2.528, de outubro de 2006. Política Nacional de Saúde da Pessoa Idosa. Brasília; 2006.

3. Queiroz ZPV. O impacto do cuidado na vida do cuidador de idosos: fator de risco de negligência doméstica em idosos dependentes. IN: Berzins MV, MalaguttI W. Rompendo o silêncio: faces da violência na velhice. São Paulo: Martinari, 2010. p. 295-307.

4. Diogo MJDE, Duarte YAO. Cuidados em domicílio: conceitos e práticas. IN: Freitas EV (org). Tratado de Geriatria e Gerontologia. Rio de Janeiro: Guanabara, 2002. Cap. 92, p.762-67.

5. Folstein MF, Folstein SE, Mchugh PR. Mini-Mental State: a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res.1975; 12: 189-98

6. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The index of ADL: a standardized measure of biological ans psychosocial function. JAMA. 1963; 185(12): 914-9.

7. Neri AL, Sommerhalder C. As várias faces do cuidado e do bem-estar do cuidador. IN: Neri AL. (org). Cuidar de idosos no contexto da família: questões psicológicas e sociais. 2 ed. São Paulo: Alínea, 2006. Cap. 1, p. 9-63.

8. Braz E, Ciosak SI. O tornar-se cuidadora na senescência. Esc Anna Nery Rev Enferm. 2009; 13(2): 372-77.

9. Silveira TM, Caldas CP, Carneiro ZCT. Cuidando de idosos altamente dependentes na comunidade: um estudo sobre cuidadores familiares principais. Cad. Saude Publica. 2006; 22(8): 1629-38.

10. Amendola F, Oliveira MAC, Alvarenga MRM. Qualidade de vida dos cuidadores de pacientes dependentes no programa de saúde da família. Texto Contexto Enferm. 2008; 17(2): 266-72.

11. Fonseca NR, Penna AFG, Soares MPG. Ser cuidador familiar: um estudo sobre as consequências de assumir este papel. Physis. 2008; 18(4): 727-43.

12. Fernandes MGM, Garcia TR. Determinantes da tensão do cuidador familiar de idosos dependentes. Rev Bras Enferm. 2009a; 62(1): 57-63.

13. Gratão ACM, Vendrúscolo TRP,Talmelli LFS, Figueiredo LC, Santos JLF, Rodrigues RAP. Sobrecarga e desconforto emocional em cuidadores de idosos. Texto Contexto Enferm. 2012; 21(2): 304-12.

14. Fernandes MGM, Garcia TR. Atributos da tensão do cuidador familiar de idosos dependentes. Rev Esc Enferm USP. 2009b; 43(4): 818-24.

15. Martins JJ, Borges M, Silva RM, Erdmann AL, Nascimento ERP. O processo de viver e de ser cuidado de idosos e a percepção dos cuidadores. Cogitare Enferm. 2011; 16(1): 96-103.

16. Salgueiro H, Lopes M. A dinâmica da família que coabita e cuida de um idoso dependente. Rev Gaucha Enferm. 2010; 31(1): 26-32.

17. Martins JJ, Albuquerque GL, Nascimento ERP, Barra, DCC, Souza WGA P, Acheco WNS. Necessidades de educação em saúde dos cuidadores de pessoas idosas no domicílio. Texto Contexto Enferm. 2007; 16(2): 254-62.

Received on: 01/09/2015
Required for review: no
Approved on: 12/11/2015
Published on: 30/12/2015

Contact of the corresponding author:
Lara de Sá Neves Loureiro
João Pessoa - PB – Brasil
Email: laraasn@hotmail.com