REVISTA ONLINE DE PESQUISA
CUIDADO É FUNDAMENTAL
Universidade Federal do Estado do Rio de Janeiro • Escola de Enfermagem Alfredo Pinto

RESEARCH DOI: 10.9789/2175-5361.2019.v11i3.680-686

Characteristics and Difficulties of Informal Caregivers in Assisting Elderly People

Características e Dificuldades do Cuidador informal na Assistência ao Idoso

Características y Dificultades del Cuidador Informal en el Cuidado de los Ancianos

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How to quote this article:
Garbaccio JL, Tonaco LAB, *et al*. Characteristics and Difficulties of Informal Caregivers in Assisting Elderly People. Rev Fund Care Online.2019. Apr./Jul.; 11(3):680-686. DOI: http://dx.doi.org/10.9789/2175-5361.2019.v11i3.680-686

ABSTRACT

Objective: This study aims to identify the informal caregivers' difficulties in assisting the elderly patients of the *Programa Saúde da Família* [Family Health Program] in Bambuí city, *Minas Gerais* State, Brazil. **Methods:** This is a transversal research, approved by the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 0146.0.213.000-11. Seventy elderly people and their informal caregivers were interviewed and the collected data were analyzed. **Results:** The treatment of cognitive disorders in the elderly (32.9%) and the lack of knowledge about the health care delivered (20%) were the main difficulties stated by the caregivers. These results also showed a bivariate relationship with "difficulty during care": the caregivers who stated that they slept less (≤ 6 hours/night) (%), "did not have a caregiver course" (%) and did not have "leisure activity" (%); regression: individuals who affirmed that they had not completed a course for caregivers of the elderly. **Conclusion:** It was settled that actions aiming to support the informal caregiver in face of the numerous difficulties faced in the care of the elderly are essential.

Descriptors: Elderly, Informal Caregiver, Health Care, Quality of Life.

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RESUMO

Objetivo: Identificar as principais dificuldades encontradas pelos cuidadores informais de idosos em domicílio, cadastrados no Programa de Saúde da Família, no município de Bambuí- MG. **Método:** trata-se de uma pesquisa transversal, após aprovação CAAE – 0146.0.213.000-11, foram entrevistados idosos e seus respectivos cuidadores informais por meio de um questionário, dados analisado por meio de programa. **Resultados:** participaram 70 idosos e seus respectivos cuidadores, estes referiram como maior dificuldade no cuidado o Lidar com distúrbios cognitivos do idoso (32,9%) seguido de Falta de conhecimento a cerca da assistência prestada (20%). Apresentaram relação com "dificuldade no cuidado" – bivariada: os cuidadores que afirmaram dormir menos tempo (≤ 6horas/noite) (%), "não possuir curso de cuidador" (%) e não ter "atividade de lazer" (%); regressão: indivíduos que afirmaram não ter realizado curso para cuidador de idosos. **Conclusão:** tornam-se essenciais ações de apoio ao cuidador informal frente às inúmeras dificuldades enfrentadas na assistência ao idoso.

Descritores: Idosos, Cuidador informal, Assistência à saúde, Qualidade de vida.

RESUMEN

Objetivo: Identificar las principales dificultades encontradas por los cuidadores informales de ancianos en domicilio, registrados en el Programa de Salud de la Familia, en el municipio de Bambuí-MG. **Método:** se trata de una investigación transversal, después de la aprobación CAAE - 0146.0.213.000-11, fueron entrevistados ancianos y sus respectivos cuidadores informales por medio de un cuestionario, datos analizados por medio de programa. **Resultados:** participaron 70 ancianos y sus respectivos cuidadores, éstos refirieron como mayor dificultad en el cuidado o Lidiando con disturbios cognitivos del anciano (32,9%) seguido de Falta de conocimiento a cerca de la asistencia prestada (20%). En el caso de las mujeres, se observó un aumento de la mortalidad por rotavirus en los últimos años. Regresión: individuos que afirmaron no haber realizado curso para cuidador de ancianos. **Conclusión:** se convierten en esenciales acciones de apoyo al cuidador informal frente a las numerosas dificultades enfrentadas en la asistencia al anciano.

Descriptores: Los Cuidadores no Profesionales, Ancianos, Cuidado de la Salud, La Calidad de Vida.

INTRODUCTION

The growth of the elderly population is a worldwide phenomenon that cannot be ignored and it is increasing fast in Brazil, thus requiring urgent social policy measures to face the challenges related to this phenomenon.[1]

Health condition in aging refers to the changes that commonly require physical, psychological and social care. It includes the care of chronic noncommunicable diseases which may contribute to worsening the elderly dependency. A common and serious outcome of the chronicity and longevity situation of the elderly is physical and mental incapacity, defined as dependence on other people for conducting important tasks and essential or personal life activities.[2-3]

According to data from the *Pesquisa Nacional por Domicílios (PNAD)* [National Household Survey], nine of the 26 million elderly people in Brazil (34.6%) need continuous care.[4] Care happens effectively when people cared for feeling well and can express themselves within their limitations. Caregivers are responsible for the support, dialogue, protection, and responsibility; they should promote harmony in the environment and care relationship.

In Brazil, the family of a dependent elderly takes care of him informally in more than 90% of the cases.3,5 Knowing the profile of elderly caregivers and their difficulties allows health professionals to plan the most satisfactory care by integrating this caregiver when performing actions aimed at reducing risks, maximizing efforts, saving time, resulting in quality of life for the elderly, for the informal caregiver and the whole family.[3,5]

Faced with the complexity of the aging process and the process of caring for an elderly person, the following question was raised: "What are the difficulties of the elderly's informal caregivers regarding home care?" It is believed that the difficulties are numerous mainly due to the caregivers' lack of technical-scientific training.

The present research is justified by the fact that informal caregivers are responsible for the most care provided to the elderly and therefore more susceptible to work overload and occupational illness. In Brazil, it is projected that in 20 years the country will have the sixth largest population of elderly people in the world.[4]

Thus, it is essential that health professionals and those involved in the care process be qualified to effectively meet this imminent demand. The informal caregiver represents, within the family nucleus, the reference and the link between the elderly and the health professional. Numerous information regarding the health of the elderly may be obtained from caregivers, contributing to more accurate diagnoses and treatments. The caregiver, therefore, is an essential part of the quality of care for the elderly, yet he goes through many difficulties daily due to lack of information and lack of financial, technical and social support.[1,6]

Thus, this research aimed to identify the main difficulties faced by informal caregivers of the elderly in home care. The elderly patients were participating in the *Programa Saúde da Família (PSF)* [Family Health Program] in the municipality of *Bambuí, Minas Gerais* State, Brazil.

METHODS

This study has a cross-sectional approach, carried out in the municipality of *Bambuí, Minas Gerais* State, Brazil, in the year 2013 with elderly people and their informal caregivers. They resided in a region covered by the *Nossa Senhora de Fátima* PSF unit, which had 526 elderly people registered. This unit was chosen because it covers the largest number of elderly in the municipality.

In order to participate in the research, informal caregivers should meet the following inclusion criteria: not having professional training in the health care field, performing care to the elderly at least five days a week and

assisting them in at least one of their activities of daily living (ADLs).

Data collection was carried out through an interview with the caregivers and the elderly patients. For caregivers, a semi-structured questionnaire divided into two parts (I – a sociodemographic characterization of the caregiver; II - description of the caregivers' routine and difficulties pointed out in delivering care) were used. Also, a structured questionnaire was applied for sociodemographic characterization of the elderly patients and assessment of their ADLs by using the Katz and Lawton-Brody Lawton Instrumental Activities of Daily Living (IADL) scales.[7-8] The elderly patients with cognitive impairment were excluded from this study. Data were obtained from the caregivers.

The points in the Katz scale were added and the total score was the sum of "yes" answers. This scale features three classifications based on the elderly's dependency on others to perform basic daily activities: independence, partial dependence, and important dependence. The maximum score on the Lawton Brody scale is 27 points, also having three classifications for the elderly's dependency when performing instrumental daily activities: independent, partial dependent, and dependent.

Data were tabulated and statistically analyzed with the Statistical Package for the Social Sciences (SPSS), version 13.0. The Chi-square test and Fisher's test were used to validate the association ($p<0.05$) in the bivariate analysis. The variables that presented p-value less than 0.2 advanced to the adjustment stage of the final model in multivariate analysis.

This research obeyed ethical precepts and was approved by the Ethics and Research Committee of the *Pontifícia Universidade Católica de Minas Gerais*, under the CAAE No. 0146.0.213.000-11. The caregivers and the elderly who participated in the study signed the Term of Free and Informed Consent, as well as the legal representatives of the elderly cognitively compromised.

RESULTS AND DISCUSSION

From a total of 526 elderly participants, 120 had informal caregivers with the inclusion characteristics determined by this research. Fifty of them were not located, did not accept to participate or started but subsequently gave up. Thus, the research sample was constituted by 70 elders with their respective informal caregivers.

The majority of the participants were female (n=42/60%), retirees (n=56/80%), and widowers (n=33/47.1%), having a mean age of 77.6 years (min 60, max 92), up to four years of education (n=44/62.9%), and a monthly income of up to one minimum wage (n=50/71.4%). Other sociodemographic data of the elderly participants are shown in **Table 1**.

Among the caregivers participating in this study, the majority were female (n=59/84.3%) and married (n=39/55.7%), having a mean age of 50 years (min 20, max 78), (n=33/47.1%) and a monthly income of up to one minimum wage (n=39/55.7%). Regarding the degree of kinship with the elderly participants, 37 (52.9%) were children, 12 (17.1%) were spouses, five (7.1%) were siblings, six (8.6%) had another kinship and ten (14.3%) were not related (**Table 1**).

Table 1: Sociodemographic profile of the elderly patients and their caregivers.

Variable	Elderly People		Caregivers	
	n=70%		n = 70%	
Gender				
Female	42	60	59	84.3
Male	28	40	11	15.7
Marital Status				
Married	27	38.6	39	55.7
Widowed	33	47.1	3	4.3
Single	6	8.6	19	27.1
Divorced/Estranged	4	5.7	9	12.9
Education				
Illiterate	21	30	5	7.1
Literate*	27	39	4	6
≤ 4 years of study	44	62.9	33	47.1
5 to 8 years of study	2	2.9	7	10
> 8 years of study	3	4.3	25	35.7
Income type				
Retirement	56	80		
Pension	11	15.7		
Other	1	1.4		
Income value (wages)				
Up to one	50	71.4	39	55.7
Up to two	15	21.4	17	24.3
Between three and six	4	5.7	7	10
None	2	2.9	7	10
Having an illness				
Yes	69	98.6	39	55.7
No	1	1.4	31	44.3

*Literate people considered in this work are those that know how to read and write even though they never attended school.

Considering their health status and disease occurrences, the elderly reported suffering mainly from hypertension (n=41/58.6%), depression (n=14/20%) and diabetes (n=13/18.6%). Furthermore, some elders had more than one disease.

According to the Katz index, 34 (48%) of the elderly had significant dependence, 21 (30%) had partial dependence and only 15 (22%) were independent. Regarding the level of dependence for the performance of IADLs according to Lawton Brody's scale, 34 (49%) have significant dependence, 21 (30%) are partial dependents and 15 (21%) are independent.

Regarding the health situation of the caregivers, 39 (55.7%) reported having a disease: hypertension (n=21/30%), depression (n=11/15.7%), diabetes (n=8/11.4%), rheumatic diseases (n=7/10%) as well as congestive heart failure (n=4/5.7%). Nevertheless, some caregivers (n=15/21.4%) had more than one disease.

The caregiver and the care provided: particularities and difficulties

The main reasons given by caregivers to perform this function were the degree of kinship (n=55/78.6%) followed by the pleasure of caring for the other (n=11/15.7%) and lastly the financial needs (n=3/4.3%) because there were no conditions of establishing a formal caregiver contract.

Concerning the time of care, a large proportion (n=25/35.7%) delivered care between two and four years, 17 (24.3%) over seven years, 14 (20%) between five and seven years, ten (14.3%) for a period equal to or less than six months, and four (5.7%) for up to one year.

Considering the daily dedication of the caregivers, 25 (35.7%) stated that they cared for the patient four or more hours/day, 20 (28.6%) performed it full time, 14 (20%) up to eight hours/day, and 11 (15.7%) in a period of up to twelve hours/day.

When questioned about the pleasure they feel in caring, 64 (91.4%) caregivers reported giving importance to the activities they performed, 44 (62.9%) lived in the same residence as the elderly patient, and 17 (24.3%) reported not receiving assistance from others.

Considering the technical training for delivering care, 59 (84.3%) caregivers reported having no professional qualification, thus exercising their functions according to the knowledge acquired in daily practice. The main difficulty identified by the caregivers was dealing with cognitive disorders of the elderly patient (n = 23/32.9%). Other results are listed in **Table 2**.

Table 2: Main difficulty reported by the elderly caregivers. N=70.

Elderly caregivers' difficulties	n	%
Dealing with the elderly patient's cognitive disorders	23.0	32.9
Lack of knowledge of the assistance provided	14.0	20.0
Lack of family or professional help	13.0	18.6
Lack of physical, human and financial resources	10.0	14.3
Difficulties in executing basic care (hygiene, food, locomotion)	4.0	5.7
No difficulty	6.0	8.6

Most caregivers (n=40/57.4%) reported performing all types of care for the elderly, including hygiene, feeding, locomotion, and medication.

Regarding the assistance provided by health professionals from the Basic Health Unit (BHU), 61 (88%) caregivers reported receiving visits and highlighted the assistance provided by the community health agent (n=45/73.4%), (n=15/25%), the physician (n=12/19.1%) and the nurse (n=8/13.2%). Regarding the evaluation of the quality of the guidelines received by health professionals, 41 (58.6%) caregivers evaluated them as insufficient, 19 (27.1%) evaluated them as good and ten (14.3%) evaluated them as optimal.

The bivariate analysis showed that there was a relationship ($p<0.05$) between the difficulty in delivering care (mentioned by the caregivers) with "sleep", the presence of professional "caregiver course", and "leisure activity". Those caregivers who reported sleeping less (≤ 6 hours/night) had more difficulty in providing care, as with "not having a caregiver course" nor "leisure activity". The variables presented in **Table 3** presented $p<0.2$ and would be used in the multinomial regression model. Nonetheless, because they represented a zero value, they were not used and marked with an asterisk.

Table 3: Bivariate analysis between the sociodemographic and health variables of the caregivers with the "having or not having difficulties in assisting the elderly people" outcome variable. N = 70.

Variable	n (n=70)	Having difficulty: *Yes* (n=6) (n/%)	*No* (n=64) (n/%)	*p-value* Fischer test
Marital Status				0.175
Married	39	2 (5.1)	37 (94.8)	
Single	19	4 (21.0)	15 (79.0)	
Estranged/Divorced	9	-	9 (100)	
Widowed	3	-	3 (100)	
Sleep				***0.001***
≤ 6h	36	-	36 (100)	
> 7h	34	6 (17.6)	28 (82.4)	
Having caregiver qualification*				***0.045***
Yes	11	3 (27.3)	8 (72.7)	
No	59	3 (5.0)	56 (95.0)	
Kinship with the elderly patient				0.195
Son	37	4 (10.8)	33 (89.2)	
Spouse	12	-	12 (100)	
Not having	10	-	10 (100)	
Other kinship	6	2 (33.3)	4 (66.7)	
Brother	5	-	5 (100)	
Having another activity*				0.102
Yes	34	5 (14.7)	29 (85.3)	
No	36	1 (2.7)	35 (97.3)	
Having an illness*				0.081
Yes	31	5 (16.1)	26 (83.9)	
No	39	1 (2.5)	38 (97.5)	
Having a leisure activity				
Yes	33	6 (18.1)	27 (81.9)	***0.008***
No	37	-	37 (100)	

*Variables that were used in the logistic regression

The multinomial regression with the "having caregiver qualification", "having another activity", and "having an illness" showed that there was a relationship between the individuals who stated that they had professional qualification as elderly caregivers with the less chance (0.14 times) of having difficulty in delivering care.

Table 4: Results of the multivariate analysis for the "having or not having difficulties in assisting the elderly people" outcome variable. n=70

Variable	OR (CI95%)	*p-value*
Having caregiver qualification		***0.03***
Yes	0.14 (0.2-0.8)	
No	-	

Aging should not be perceived as synonymous with subjection and illness. Nevertheless, when it implies functional limitations, assistance and continuous supervision are needed. According to this study's results, these care actions are performed by informal caregivers, being most of the time a grown child or spouse of the elderly patient. The literature points out the tacit existence of a Brazilian social norm, which states that is the responsibility of the grown children and spouses to take care of their relatives, which was also observed in this study.[3,9,10]

Since the days of yore, the process of caring is influenced by customary precepts, being performed by a relative. Consequently, women became the representative of this practice because of their intrinsically cozy impulses. Evidence from this research shows that custom is still commonplace as most informal caregivers were females who exercised this function due to the degree of kinship with the elderly patient, which is in a good agreement with the literature[10].

According to the analysis of functionality by both the instruments used, approximately half of the elderly participants presented significant dependence. Thus, care became constant and more tiring especially for informal caregivers because numerous changes occur in their routine in order to provide care to the elderly patient. It was noted that when this care is performed full time, which was observed as the second most recurrent option in the study (20/28.6%), and without the help of other relatives or professionals (11/15%), the chance of occurring emotional, social, physical and financial overload increases with time and the worsening of the elderly patients' dependence, thus constituting a major public health problem[5].

When considering the monthly income and education of the elderly patients and their caregivers, there was a predominance of up to four years of study and a monthly income of up to one minimum wage in both groups. There is a negative correlation between these variables as low education leads to limit the care actions that the elderly patients could have performed in themselves, increasing the caregivers' activities and overloading them, also requiring knowledge that goes beyond their competencies in some situations. It should be noted that 59 (84.3%) caregivers stated that they did not have a training course that would support care provided to the elderly patients, making it happen through daily practice. This fact can be found in the literature, which reveals that the care skills are built through daily practice. The family learns from its mistakes and successes by means of trials.[11] It is inferred that there is a financial burden on both parties, considering that certain levels of functional disability of the elderly patients demand financial resources to maintain their health, which generally exceeds the limit of a minimum wage and forces the caregiver to afford certain expenses. The literature points out that one of the main difficulties to be faced is the scarcity of financial resources, which causes anguish to the caregiver who wishes to offer the best for his elderly relative.[11-12]

With regards to the assistance provided by health professionals of the Basic Health Unit (UBS), although 88% of caregivers reported receiving visits, more than half of them evaluated the quality of the received guidelines as insufficient. Visits by nurses and doctors were below 20% and even community health workers did not reach 80%. It was observed that the absence of qualified professionals to work with the elderly population and the lack of protocols for care delivery were a hindrance, which corroborates with the literature.[13]

Primary health care (PHC) has the objective of preventing diseases that may lead to elderly hospitalization because it is costly and puts at risk prolonged hospitalizations that often lead to decrease in the functionality of the elderly and increase the demands of direct care from the caregivers. There is a strong relationship between the loss of the elderly functionality with a decrease in their quality of life and the caregiver. Therefore, the Family Health Strategy is a basic and essential point in guaranteeing to age with fewer illnesses, preserved functional capacity, autonomy, and independence. Interdisciplinary multidimensional evaluation of the elderly and networked assistance actions guarantee individualized support to the elderly/caregiver incorporating evaluation methods and short and long-term interventions. Unfortunately, there are numerous flaws in the PHC performance characterized by lack of human and financial resources, lack of knowledge of the flow and network system, and the particularities in caring for the elderly, often treated only as an aged adult.[14-15]

Considering the main difficulty found by caregivers in explaining how to deal with cognitive disorders of the elderly patients (35/50%), it is evident that the functional deterioration resulting from the disease has vast consequences for the life of the subject and his/her relatives, as it is increasingly necessary to obtain sufficient information about this disease or its treatment for care delivering, as well as deep emotional support.[16] Concrete educational psycho actions can reduce the stress resulting from the impact of the disease, improves the sense of competence and self-esteem of caregivers, reduces anxiety and depressive symptoms, as well as helps to manage emotions and use more effective problem-solving strategies.[17] Dementia, especially at a more advanced stage, causes frequent behavioral disorders such as agitation, excessive ambulation, repetitive speech, verbal and physical aggression that increase stress levels, physical overload, and dissatisfaction to caregivers.[18]

Interestingly, in this study, there is no mention by the caregivers of physical tiredness or another complaint that referred to themselves. In health services, care for the elderly is often carried out by caregivers, who are not seen as people that also need care. It is an unfavorable reality since the caregiver needs to be valued, welcomed and listened to have minimum conditions for caregivers to assist the elderly. Considering the factors related to violence against the elderly, the lack

of skill from informal caregivers and work overload are the major causes of various forms of abuse.[14-15]

Hence, the great vulnerability of informal caregivers is evidenced due to the absence of satisfactory guidelines: they deliver care for the elderly patients at the same time that they carry out their daily life activities. This vulnerability is also a result of their clinical conditions; the caregivers reported having one or more pathologies: hypertension (30%) and depression (15.7%) being the most predominant; diabetes; rheumatic diseases; and congestive heart failure. According to the literature, middle to high levels of anxiety, stress and chronic systemic diseases such as hypertension and diabetes affect caregivers.[14-15]

Studies that seek to elucidate the main difficulties encountered by home elderly caregivers are promising because these caregivers take responsibility for care without previous training. The caregiver's orientation about situations that may imply greater risks to the health of elderly patients, besides improving the provided care, makes it more humanized and reduces the burden on the caregiver.[5]

Cultural, social, and demographical consequences need to be discussed, as well as the guidelines provided by health professionals from BHUs and clinical conditions of both caregivers and elderly patients because all these factors act either as facilitators or complications, thus significantly influencing the care provided to the elderly patients.

CONCLUSIONS

The rise of the elderly population occurs in an accelerated way. In Brazil, due to cultural reasons, children or spouses often assume the responsibility of assisting all the activities of the dependent elderly patient. Thus, the aging process when accompanied by some functional-dependent pathology implies directly in the existence of a caregiver and indirectly in obstacles to the accomplishment of certain IADLs or even ADLs.

Taking into account the complexity of the aging process and the problem of an informal caregiver commonly without technical and scientific training to conduct care for the elderly, there is a susceptibility to physical, psychological, financial, and social overload due to the cognitive disorders that usually affect the elderly, the level of dependence, or the time needed to provide care.

Given the aforementioned, the existence of public policies aimed at elderly informal caregivers is also favorable, as well as an adequate qualification of the professionals who work specifically with this population, considering possible impacts on the whole assistance.

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Received on: 24/07/2017
Required Reviews: 11/09/2017
Approved on: 03/11/2017
Published on: 02/04/2019

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The authors claim to have no conflict of interest.