RESEARCH

SOCIAL AND DEMOGRAPHIC CHARACTERISTICS OF ELDERLY CAREGIVERS AND REASONS TO CARE FOR ELDERLY PEOPLE AT HOME

CARACTERÍSTICAS SOCIAIS E DEMOGRÁFICAS DE IDOSOS CUIDADORES E MOTIVOS PARA CUIDAR DA PESSOA IDOSA EM DOMICÍLIO

CARACTERÍSTICAS SOCIODEMOGRÁFICAS DE ADULTOS MAYORES CUIDADORES Y MOTIVOS PARA CUIDAR DEL ADULTO MAYOR EN EL DOMICILIO

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ABSTRACT

The objective was to demographically characterize the elderly caregivers of the elderly person at home and to understand the reasons that led to the provision of this care. Qualitative research, with twelve elderly caregivers of the elderly, enrolled in a Home Care Service. A semistructured interview was used for collection. The analysis was performed using the methodologic reference of Bardin. The results show all female employees, with incomplete elementary school. Income ranged from no income and eight minimum wages; Predominated the evangelical and Catholic religion. The reasons for caring were associated with lack of choice; the Established bond between caregiver and elder; Lack of financial conditions to hire a caregiver. It was verified that the elderly caregivers presented an expected sociodemographic profile of women, wives, with a low level of schooling and income. The lack of choice was the main reason for exercising the caregiver role.

Keywords: Caregivers; Health Profile; Aged; Motivation.

RESUMO

Objetivou-se caracterizar sociodemograficamente os idosos cuidadores da pessoa idosa no domicílio e apreender os motivos que levaram à prestação desse cuidado. Pesquisa qualitativa com 12 cuidadores idosos da pessoa idosa cadastrados em um serviço de atenção domiciliar. Para a coleta utilizou-se entrevista semiestruturada. A análise foi realizada a partir do referencial metodológico de Bardin. Os resultados indicam todos os colaboradores do sexo feminino, com ensino fundamental incompleto. A renda variou entre não ter renda e oito salários mínimos; predominaram as religiões evangélica e católica. Os motivos para cuidar estiveram associados à ausência de opção; laço estabelecido entre o cuidador e a pessoa idosa; falta de condições financeiras para contratar cuidador. Constatou-se que as idosas cuidadoras apresentaram perfil sociodemográfico esperado de mulheres, esposas, com baixo nível de escolaridade e renda. A ausência de opção foi a principal razão para exercer a função de cuidadora.

Palavras-chave: Cuidadores; Perfil de Saúde; Idoso; Motivação.

RESUMEN

Este estudio tuvo como objetivo caracterizar sociodemográficamente a los adultos mayores cuidadores de personas mayores en el domicilio y conocer las razones que los llevaron a prestar dichos cuidados. Se trata de una investigación cualitativa con doce cuidadores de personas mayores inscritos en un servicio de atención domiciliaria. La recogida de datos se llevó a cabo mediante entrevistas semiestructuradas. El análisis se realizó utilizando el marco metodológico de Bardin. Los resultados revelaron que los cuidadores mayores eran todas mujeres, con enseñanza primaria incompleta. El ingreso variaba de cero a ocho sueldos mínimos; predominaron la religión evangélica y la católica. Las razones para el cuidar estaban asociadas con la falta de elección, al vínculo establecido entre el cuidador y la persona mayor y a la falta de condiciones financieras para contratar a un cuidador. Se constató que los cuidadores mayores tenían el perfil sociodemográfico esperado de las mujeres, esposas, con bajo nivel de educación e ingreso. La falta de elección fue la razón principal para desempeñar la función de cuidadora.

Palabras clave: Cuidadores; Perfil de Salud; Anciano; Motivación.

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Almeida LPB, Menezes TMO, Freitas AVS, Pedreira LC. Social and demographic characteristics of elderly caregivers and reasons to care for elderly people at home. REME – Rev Min Enferm. 2018[cited _____ ____];22:e-1074. Available from: ______ DOI: 10.5935/1415-2762.20180004

INTRODUCTION

Over the years, caregivers of the elderly people have gained prominence on the world scene. In all countries, they make substantial contributions to health and social systems, providing support and assistance to people with disabilities and/or caring for the elderly.¹

As well as developed countries, Brazil has been faced with increasingly serious health problems due to an aging population and chronic degenerative diseases. Demographic dynamics follow a pattern of population growth with changes in age structure,² which may lead to the need for a caregiver who is also often elderly, as well as affecting the profile of caregivers for the elderly population.

With increasing longevity, elderly people caregivers will tend to increase attending to other elderly people.³ Studies point out that 16% of these caregivers are in the age group between 61 and 70 years old² and they are the spouses or their children.³ They usually provide care to the elderly person when the elderly person has a high level of dependence on self-care.⁴ Caregiving is governed by cultural norms that give women the tasks and roles of protection.³

The degree of involvement of the elderly with care tasks come from the health status, status and prognosis of the illness of the caregiver, the quality of the family relationships, the quantity and quality of the formal support received, among others.³ Several care situations determine positive and negative aspects of the role of the caregiver. The strong connection between them and the care provided is the main positive aspect. On the other hand, the accumulation of functions is seen as a difficulty.⁵ However, many caregivers are able to cope well with caring tasks without feeling burdened.³

Motivations can explain the reasons why a person engages in particular behaviors, such as helping someone. It may emerge from internal desires or external pressures.⁶ External pressures are most pronounced for women, especially single, low-income and not working women.

Caregiver support represents a new challenge for the Brazilian health system. Thus, knowing the profile of elderly caregivers and understanding the motivation for them to care for the elderly person is important not only to identify their needs and desires but also to seek ways to promote their health, wellbeing, and quality of life (QOL). In this context, the objectives of this study were to sociodemographic characteristics of the elderly caregivers of the elderly person at home and understand the reasons for caring for the elderly person.

METHODS

This is a descriptive research with a qualitative approach, carried out in two bases of a public home care program in the city

of Salvador, Bahia, Brazil. Participants were elderly caregivers, who performed care of any nature for the elderly person. The inclusion criteria adopted were: elderly caregivers of the elderly person aged 60 years old or older, registered at the two home care services. The exclusion criteria were: elderly caregivers who had illness or limitations that made the interview impossible; elderly caregivers who were not found at home after scheduling two visits.

The search for caregivers was through consultation with the social service record, which is the social assessment paper sheet of eligibility used by the program, found in the medical records of the people registered, where the caregiver and other residents of the house were identified, as well as their ages. In this way, all medical records of the elderly patients hospitalized in the program were collected, and the age of the caregivers was investigated. The survey of the medical records identified that 17 patients had elderly caregivers aged between 60 and 77 years old. There were three of them excluded because they were only responsible for signing the social assessment paper sheet for eligibility of the service, but did not provide any kind of care to the elderly person; two did not agree to participate in the research. In the end, 12 participants met the inclusion criteria of the study.

The approximation with the selected participants occurred from three home visits. The first visit was carried out with SAD professionals and aimed to establish dialogue/communication with the participants. After that moment, the researchers carried out the visits without the follow-up of the service. The second visit had the purpose of presenting the study and the informed consent form to the participant, and the third visit aimed to conduct the interview with the caregiver.

The semi-structured interview was conducted between January and July 2015, on a date and time previously scheduled, in a private place at home. They were recorded and conducted through an instrument composed of the participant's sociodemographic data and the following guiding question: What prompted you to be the caregiver of the elderly person?

The analysis of the interviews was carried out based on the thematic categorical analysis proposed by Bardin.⁷ After the transcription of the interviews a floating reading of the content of the testimonies was carried out, seeking to establish the contact with the material. Several readings of the interviews were made at different times to know, analyze and systematize the ideas and impressions about the studied individual.

Subsequently, the researchers carried out the exhaustive reading of the interviews to favor the construction of the categories, the identification of the recording systems and the context units of the statements. The statements were organized into categories and later treatment of the data, inferences, and interpretation.

The ethical aspects were respected in all stages of the research, according to Resolution of the National Health Council in 466/12. This work was approved by the Research Ethics Commit-

tee n° 655,391, on 05.21.2014. Flower codenames were used to preserve the anonymity of the participants.

RESULTS

Participants were 12 elderly people aged 60 to 77 years old, all of them female, mostly wives. The others were daughters and sisters, and one participant took care of two elderly people, the husband, and the mother. As for marital status, most interviewees were married, single, divorced and widowed. They all lived in the home of the elderly person.

An elderly woman worked as an accountant, the rest of them was housewives; three were not primary caregivers. Income ranged from no income and eight minimum wages. Five of them reported having no income, five had a minimum wage, one received two minimum wages and one had eight minimum wages. As for race/skin color, most caregivers declared to be brown (8), two were black and two were white.

Education level varied between illiteracy and higher education. Five of them had incomplete elementary school, and three had secondary education. One had a higher education, one had an elementary school, one had preschool and one was illiterate. Regarding the religion, the evangelical and Catholic ones stood out, with five caregivers each; and two were spiritist.

Considering the comorbidities, nine reported having different types of diseases, with hypertension and diseases related to the locomotor device as the most frequent, such as disc hernias and arthrosis. The time caring for the elderly person ranged from nine months to 35 years.

Given the daily workload of care offered, nine caregivers reported caring throughout the day. Three reported caring for seven, twelve and eighteen hours a day. Eight reported not receiving support to perform care. Half of the caregivers stated that they had received some type of training/guidance to carry out the care.

Regarding the reason that the elderly caregivers took care of the elderly person, three categories were taken: a) lack of choice; b) bond established between the caregiver and elderly person; c) lack of financial conditions to hire a caregiver, presented below.

LACK OF CHOICE

The lack of choice to become a caregiver was a frequent discourse in the reasons identified by the elderly women to care for the other. They play this role because they had no alternative, given the situation experienced:

She had no other person, her brothers did not want to. Each one quit. And she is my mother. I had to stay with her. I could not give up. (Violet) If there's no caregiver, Where will I throw him? If relatives do not want to, there is only me and the children to take care. (Daisy)

I had no choice. I had to be myself, didn't I? I was the only one stronger. (Acacia)

I believe it is the same need. There was no one else to do it. She already lived with me. (Magnolia)

The lack of alternatives to meet the demands of the elderly care in the home environment contributed to the fact that the elderly women in the research felt responsible and in the duty to care for the other:

I'll lie if I say I'm satisfied with that. But if there's no other way, I'll do what? If he got in my way and he needs help, I have to go! (Rose).

When we were living, he was not sick. The illness came later, would you leave him? (Orchid)

If I chose, I would not care, would I? I was not going to choose that for myself. I fell sick here, I had to take care. (Daisy)

A choice? You have no choice, I think it's an imposition, isn't it? I prefer the choice because enforcement is a thing that is required. (Violet)

Although Violet makes a brief reflection on the reason that motivated her to take care, from the perspective of the choice or imposition, it is noted that there is an attempt to camouflage the real answer to this questioning. Violet chooses to respond that caring for the elderly person was her choice. However, the analysis of speech as a whole enables to identify that caregiver had no choice. Answering that taking care of the other was optional is translated into a more socially acceptable response.

BOND ESTABLISHED BETWEEN THE CAREGIVER AND ELDERLY PERSON

Coexistence, love, family ties and marriage were also expressed as motivating reasons:

The love for him and the coexistence of so many years, isn't it? (Jasmine)

The main person to take care has to be us. We are married, we have our husband, we have to watch over him. (Hydrangea)

He was always a good husband, a good father, a good friend. I had no reason to abandon my husband. (Gardenia)

We already lived together, the tendency is to take care, isn't it? If we are already in the house, the companion we are responsible for everything. (Magnolia)

Some elderly caregivers took care to give back the care and attention that the other offered at some point during the relationship. Another one takes care because they recognized the older person's effort and positive attitude:

He was a very caring person. I've never lacked anything, he always gave me everything. He deserves to be taken care. (Rose)

He helped me so much! Did I ever tell you when I had the accident? He took so much care of me! (Jasmine)

The actions of the cared elderly person throughout life were evaluated in decision making to take care. Caregivers stated that they chose to care for the decision, mainly in love, affection, attention, marriage and family relationships:

I say it was a choice, see? Because I do not stay away from him every day. I could even have people 24 hours a day (Bromeliad).

No, it was my choice, because we're going to do in September 40 years of marriage. I think if we're married, we have to take care of the other, right? (Hydrangea)

Our choice. My family, I always enjoyed taking care. (Acacia)

It was my choice because he never mistreated me. He was always a good husband. (Gardenia)

Of course, I had to take care of my husband. If I live with him, he gets sick, I will not despise him. (Magnolia)

The care given by social imposition was also identified as a motivating reason for being a caregiver. There is socially the obligation to care attributed to the wife, who is treated naturally in these situations.

LACK OF FINANCIAL CONDITIONS TO HIRE A CAREGIVER

The absence of possibility for the family to hire people to assist in the care of the elderly was present in the discourse of caregivers: Lack of finding a person to work, because they only want minimum wage. I cannot afford to pay. (Tulip)

Lack of money too. (Bromelia)

Choosing to be a caregiver may mean a complex decision to make, especially in cases where the caregiver is a family member. There is no other person to assist in this task, as well as the financial condition to bear the costs.

DISCUSSION

Women are more prevalent in performing any kind of care. Married women are more likely to provide care than divorced, separated, widowed and unmarried women. Older women are significantly more likely to be caregivers than men.¹

Historically, women have the social role of providing care for the home, children, and husband. In the past, she did not perform extra-community roles and providing more availability and learning to take care of the family.⁴ Care is conditioned to gender. This role always corresponds to women, especially if dedicated 24 hours.⁸

The caregiver family, besides being understood as a partner of the elderly person, should be a care unit as a client or patient of social and health services. It is essential to know and follow this emerging demand to build a more dignified and welcoming society for the long-lived elderly population.⁹

The caregivers of the research lived with the elderly person and experienced an exhausting routine of care. The fact of living with the elderly who are caring causes a duality of interest. Living with the elderly person favors them to have the demands of promptly care. On the other hand, it may be a negative situation for the caregiver, since there is great daily exposure to the effects of the caring process, which can lead to high levels of tension.⁴

The lack of income of the participants characterizes the social vulnerability they are exposed. Caregivers who did not have an income survived with income from the elderly person they care who is often insufficient to maintain him, maintain the home, and care for the other. Also, the absence of income hinders the caregiver to seek care assistance from paid employment. This study shows that 30.4% of elderly caregivers do not have income and 34.8% receive a minimum wage, 63% have income from other sources, except retirement income and caregiver's salary.¹⁰

Most elderly caregivers had incomplete primary education, a fact that gives rise to concern about the care offered. Level of education may influence the knowledge and understanding needed to implement care. Caregivers are people who receive information and guidance from the health team, so it is important to know their education level. The effective understanding of health education actions is related to people's learning ability.

The predominance of chronic non-communicable comorbidities can contribute to increase the work overload and decrease the quality of life of the elderly caregivers. Comorbidities, together with the number of years of care and the number of hours that provide daily care at home, can aggravate this situation. An elderly woman who has been caring for 35 years has been identified.

The elderly person may be fragile or have a decline in health and put the continuity of care of the other at-risk.¹ It is rare to find an elderly person who does not have at least one chronic illness, but most importantly, it is not the existence of some disease, but the limitations that it produces. The most important for an elderly person is not the diagnosis of a specific disease, but how much it limits him to maintain his autonomy and functional independence, that is, to preserve the capacity that allows him to carry out his activities of daily living by himself.¹¹

The caregivers of the research were responsible for providing all types of direct and indirect care for the elderly person at home. Most of them did not receive support and/or did not share care with family members or outside people. This factor contributes to affect their quality of life and leisure, bringing negative consequences to daily life.

Study on factors associated with the quality of life of caregivers of elderly in-home care argues that caring for a dependent person modifies the caregiver's lifestyle, depending on the needs of the elderly person. The activities of recreation and social interaction are changed and give the caregivers the feeling of not having the autonomy to manage their own lives and to live around the elderly person.¹²

Half of the elderly caregivers did not receive any type of training and/or guidance to provide care for the elderly patient. This data shows the complex care provided by caregivers. There are procedures that are exclusive of legally established higher level professionals. When they are performed incorrectly, they can compromise the state of health and cause damages in the life of the elderly person. There are also invasive procedures performed by elderly caregivers, such as orotracheal aspirations, blood glucose check, bladder catheterization and complex dressings.

It is important to think of alternatives that may offer adequate knowledge to perform such procedures, as it is known that this is a routine of caregivers. Also, it is necessary to supervise the initial implementation of care, aiming at the improvement and correct implementation of the technique, as well as to support the elderly caregivers in the perspective of overcoming insecurities, which may originate in the initial implementation of the procedures at home. The hospital network, the Family Health Strategy and the Home Care Service can help in the training of the elderly caregivers and in the initial supervision of the procedures to share this knowledge, not only transfer responsibility for care.

The provision of healthcare is an activity that requires knowledge, skills and abilities and demands of the family caregiver adaptation, as it needs to coexist with the changes that occur in the life of the elderly person. Family caregivers have assumed daily activities of care that go beyond their preparation and knowledge to do so.¹³

The findings of this study indicate different reasons for elderly caregivers to provide care to the elderly person at home. The most prevalent reason was the lack of choice. These results are in line with another study, in which all caregivers stated that they had no choice but to adopt the role of caregiver because there was no other person to perform this role.⁵

The lack of choice to care for the elderly patient emphasizes duty and obligation, among the reasons that lead the elderly to care for the elderly in the home. Although care has not been the first option, some elderly women are willing to continue caring.

Obligation and reciprocity of care are higher in spouses than in other family members and not family members. The existence of high levels of obligation and reciprocity in spouses may be because the obligation is the motive that triggers care and balanced reciprocity is the reason for maintenance.¹⁴

The motivations for caring influence the well-being of the caregiver and, possibly, the caregiver.¹⁵ The elderly person's life trajectory can influence the caregiver's decision making, as well as determine the quality of the current relationship established in the daily life between them. When the care relationship is not satisfactory for both, it can lead to negative situations, such as the occurrence of violence.

Domestic violence is a large social problem that affects a large number of older people throughout the world. It is shown not only by physical violence but also by more subtle ways, which causes long-term impact, affecting the psychological and social sphere.¹⁶

Caregivers affirm that the motivation to adopt this role was based on their kind nature, emotional ties and marriage vow.⁵ The family bond promoted by marriage also motivated the elderly women in the research to take care of the family member at home. It is noticed that some caregivers associated the responsibility of taking care of the other to the matrimonial obligation.

The obligation to care was also present in other family relationships, like the mother and the daughter. The moral value was the main cause by deciding to take responsibility for care, considered as an obligation, because it is a direct family of the person in need of care, especially if the relationship is a mother and a daughter.

On the other hand, elderly caregivers who take care for the elderly at home expressed positive feelings as a trigger for decision making, which may help them find meaning to continue to perform their role. This study reveals that the caregiver's love and tenderness are affective reasons prevalent in caring for the elderly.¹⁷ On the other hand, elderly caregivers show negative changes in their life from the moment they take on the role of caregiver, starting because they feel tired. However, they hope that the person they take care is happy and well-being in the time they have left.¹⁸

In the family, the work of the caregiver is not recognized, neither by other members of the family, nor by the person taking care, and this aspect is the most difficult to bear. If the caregiver benefits from the caregiver's pension, it is even less recognized, considering that this benefit justifies the sacrifice of the caregiver's life.⁸

The values in the role of caregiver range from inner peace to doing things in the best possible way, to the hardness of the sacrifice to renounce their own daily needs. It is unanimous that the role of caregivers is not remunerated and therefore they must find the strength and courage to move forward,⁸ also expressed by the caregivers of this study.

Some factors predict meaning in caring for people with dementia. More sense was considerably predicted according to the high religiosity, high skills, high intrinsic motivations and low prison in the role of the caregiver. The link between extrinsic motivation and meaning suggests that it may be aware of their reasons for care that helps them find meaning in their role as caregivers.⁶

FINAL CONSIDERATIONS

The findings identify all female caregivers. They are naturally delegated to assume the role of caregivers. The fact that women take care of themselves continuously contributes to a better health situation when compared to men. This puts them in a position to be potential people to care for the other.

The participants were predominantly married, brown, with Catholic and evangelical religions, incomplete elementary school, no income or with an income of a minimum wage. They assumed a routine of intense, uninterrupted and complex work. They performed various activities of direct and indirect care, which ensure the maintenance of the elderly person's care, enabling to seek alternatives to meet their demands for support.

We found several reasons for elderly caregivers to care for the elderly at home. The lack of choice, lack of financial conditions to hire caregivers and establish bonds between the elderly and the caregiver are highlighted.

The motivation to care for the elderly person at home can impact on the daily care carried out by the caregivers and, also, cause changes in their quality of life and well-being. Positive feelings can aid in decision making to take over and remain in the caregiver role.

The elderly caregiver has become an option to meet the care needs of contemporary society since longevity is a world reality. In this context, the family still represents the main

source of support expected for home care and should receive the indispensable support networks of the home care services for the home practice.

The study contributes to reducing a lack of scientific knowledge on the participant. It offers elements that allow healthcare professionals to take a more active stance against the demand of elderly people taking care of the other at home. Also, it sensitizes to accompany and instrumentalizing the caregiver in the care of the elderly, besides assisting him, enabling improvements in their living, since home care is still directed to the patient and not to their caregiver.

The results point to the need to create an instrument capable of guiding health professionals to care for the elderly caregiver in the home, so home care is directed not only at the sick individual, as it is nowadays but, also, for those who care.

This research has the scarcity of studies with elderly caregivers of other elderly people at home as a limitation, especially at the national level. Another limitation was the performance of the research in only two scenarios of home care service in the capital, which cannot be generalized to other contexts. In this sense, it is necessary to invest in new research in this subject, to better understand this reality and contribute to this segment of the population that grows and assumed the role of caregiver of the elderly person at home.

ACKNOWLEDGMENT

To the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior by the grant of the master's scholarship.

This article is part of the results of the master's thesis titled: "Elderly caregiver's experience in home care for the elderly person".

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