
CARE PERFORMED BY FAMILY CAREGIVERS TO DEPENDENT ELDERLY, AT HOME, WITHIN THE CONTEXT OF THE FAMILY HEALTH STRATEGY¹

Luciane Almeida Floriano², Rosemeiry Capriata de Souza Azevedo³, Annelita Almeida Oliveira Reiners⁴, Mayara Rocha Siqueira Sudré⁵

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² Master in Nursing, Faculty of the Nursing Undergraduate Course at UFMT- Rondonópolis University Campus. Mato Grosso, Brazil. E-mail: lualflori@gmail.com

³ Ph.D. in Nursing, Faculty of the Nursing Graduate Program at UFMT. Mato Grosso, Brazil. E-mail: capriata@terra.com.br

⁴ Ph.D. in Nursing, Faculty of the Nursing Graduate Program at UFMT. Mato Grosso, Brazil. E-mail: annelitaa@yahoo.com.br

⁵ Master in Nursing, Mato Grosso, Brazil. E-mail: maysrocha@yahoo.com.br

ABSTRACT: This exploratory-descriptive study was performed using a qualitative approach, with the objective to describe how family caregivers perform care to a dependent aged person. The data were collected through semi-structured interviews, performed with 24 caregivers, at their homes. The results showed that the care that is delivered with the dependent aged person is an activity that leads to changes in the lives of the caregivers, which can generate physical, emotional and social stressors. Nursing, as an essential element of the Family Health Strategy, should be careful regarding the health needs of dependent aged individuals, while also being close to caregivers, in the sense of guiding them and following the care being provided, with the purpose of providing comprehensive healthcare support, i.e., to the aged person and his or her family.

DESCRIPTORS: Caregivers. Aged. Nursing. Family health. Home nursing.

CUIDADO REALIZADO PELO CUIDADOR FAMILIAR AO IDOSO DEPENDENTE, EM DOMICÍLIO, NO CONTEXTO DA ESTRATÉGIA DE SAÚDE DA FAMÍLIA

RESUMO: Estudo exploratório-descritivo de abordagem qualitativa, que teve por objetivo descrever a maneira como os cuidadores familiares realizam o cuidado aos idosos em condição de dependência. Os dados foram coletados por meio de entrevista semiestruturada, aplicada a 24 cuidadores, em seus domicílios. Os resultados apontaram que o cuidado desenvolvido ao idoso em condição de dependência é uma atividade que leva a mudanças na vida dos cuidadores, o que pode gerar estressores de ordem física, emocional e social. A enfermagem, como elemento essencial da Estratégia de Saúde da Família, deve estar atenta às necessidades de saúde dos idosos dependentes, bem como, mais próxima dos cuidadores, no sentido de orientá-los, e acompanhar o cuidado realizado, a fim de oferecer suporte assistencial de forma integral, ou seja, ao idoso e sua família.

DESCRIPTORIOS: Cuidadores. Idoso. Enfermagem. Saúde da família. Assistência domiciliar.

EL CUIDADO BRINDADO POR EL FAMILIAR CUIDADOR DE ANCIANOS DEPENDIENTES EN EL HOGAR EN EL CONTEXTO DE LA ESTRATEGIA DE SALUD DE LA FAMILIA

RESUMEN: Estudio exploratorio-descriptivo de abordaje cualitativo que tuvo como objetivo describir cómo los cuidadores familiares realizan la atención a las personas mayores en situación de dependencia. Los datos fueron recolectados a través de entrevistas semiestructuradas con 24 cuidadores en sus hogares. Los resultados indicaron que la atención a las personas mayores en situación de dependencia desarrollados, es una actividad que lleva a cambios en la vida de los cuidadores, que puede generar un estrés físico, emocional y social. La enfermería como elemento clave de la Estrategia Salud de la Familia, debe estar atento a las necesidades de los mayores dependientes, y, más cerca de los cuidadores con el fin de orientar y supervisar la atención prestada, con el fin de apoyar la atención integral para, es decir, las personas mayores y sus familias.

DESCRIPTORIOS: Cuidadores. Anciano. Enfermería. Salud de la familia. Atención domiciliar de salud.

INTRODUCTION

Population aging is considered a global phenomenon resulting from reduced fertility and mortality, management of communicable diseases, scientific advancement and the growth of technology in health care.

By 2025, the number of aged persons will have increased 15 times compared to the total population, reaching nearly 32 million people aged 60 years or older.¹ In 2010, in Brazil, there were 20,590,599 people aged 60 years or older. In the State of Mato Grosso, in the same year, the elderly population was nearly 239,626 people.²

Aging generates economic and social demands for this age group. Thus, the government has elaborated public policies aimed at the elderly, a fact considered one of the major social achievements of the 20th century. Great challenges, however, emerged.

With the advancement of policies and the change in the population profile, it is known that there is a possibility that people will experience the aging process with health, physically well, and working. Similarly, they may fall ill due to natural physiological alterations that limit the human system, with a tendency for the emergence of chronic conditions, which may lead to loss of autonomy, physical dependence, the use of multiple drugs, in addition to emotional and social alterations.³⁻⁴

The health alterations that occur among some aged persons may make them dependent. Thus, there is a need to change the how and where care is delivered to these people (at their own home, hospitals and homes for the aged). In this sense, emphasis is given to the caregivers that take care of these aged individuals.

At home, a family caregiver is who usually takes care of the aged person. The caregiver may be defined as relative or a close one, with no training in health, who is taking care of his or her family member, or, yet, a person from the community that gradually acquired experience by taking care of sick people, and made an informal occupation out of that experience.⁵⁻⁷

According to the Ministry of Health, home care promotes family living, and reduces the length of stay as well as the complications that result from long hospitalization periods. For this reason, the Family Health Strategy (FHS) is considered as responsible for providing care to aged individuals, because these teams have access

to the houses where the aged persons and their caregivers live.⁸

Providing health care is an activity that requires knowledge, competences and skills, and, within this context, the family caregiver needs to adapt and deal with the changes that occur in the life of the aged individual.

National and international studies have shown that the care provided by the family caregiver at home is complex, as it causes physical and psychological overburden as well as social isolation; and face lack of support from the institution and from the family, difficulties with the environment/infrastructure to deliver the care and financial difficulties.⁹⁻¹²

Although the literature points at the characteristics of the care provided to the dependent aged individual, in the State of Mato Grosso, few studies address this topic in the context of home care, the role of the caregiver, and the nursing teams working with the FHS. Hence, the following question emerged: how is the care provided by the family caregiver to the dependent aged person at home, in Cuiabá-MT?

Knowing the dynamics of the family care provided to the aged individual is essential to support the health team, nursing in particular, in the healthcare service to dependent aged individuals, caregivers and families. Therefore, the objective of this study was to describe how family caregivers provide care to dependent aged individuals at home, within the context of the FHS in Cuiabá-MT.

METHODOLOGY

This exploratory-descriptive study was performed with a qualitative approach. It took place in the area covered by the Family Health Teams (FHTs) in Cuiabá, in the state of Mato Grosso, Brazil.

The participants of the present study were family caregivers of aged persons, distributed in the area covered by the 63 FHTs of Cuiabá, who met the following criteria: be the main informal caregiver responsible for the care to the dependent aged individual, having been a caregiver for at least one year, be able to communicate and be eighteen years of age or older.

Data collection was performed from July 19 to September 10 of 2010, using semi-structured interviews, with the following guiding question: "tell me how you take care of the aged person on a daily basis". The interviews were performed at

the subjects' homes, according to their availability.

The caregivers were chosen by convenience, through the reference of the FHT nurse, and the number of subjects was determined based on the need for information, considering data saturation, i.e. until the point when no new information is achieved and recurrence occurs.¹³

After being fully transcribed, the interviews were organized using the thematic content analysis technique, when the theme idea is related to a statement about a given issue, and comprises a set of relations that consist of discovering the meaning units present in the subjects' discourse, i.e., it is an analysis of meanings. Operationally, it is divided into pre-analysis (preliminary reading), exploration of the material and interpretation,¹⁴ the time when we treat the results, inferences, interpretations, with the possibility to indicate new paths for nursing practice.

The study complied with the current ethics premises and was approved by the Research Ethics Committee of Júlio Müller University Hospital, under protocol number 781/CEP - HJUM/10. To guarantee the anonymity of the subjects, the interviews were identified by the capital letter "C" (representing the initial letter of caregiver), followed by an ordinal number, in ascending order, from one to twenty four (C1, C2, C3... C24).

RESULTS AND DISCUSSION

The participants were 24 caregivers, 22 of which were female, and two male. Their ages ranged between 37 and 72 years. The main caregivers were the aged individuals' children, 15 of which were women and one man, followed by five spouses (four wives and one husband), two sisters and one neighbor.

The setting of the care provided to the dependent aged person

The care provided by the family caregiver to the aged person dependent regarding activities of daily living (ADL) has some particularities, because it is an activity that leads to important changes in the everyday lives of these caregivers, which may generate physical, emotional or social overburden.

This care involves several everyday tasks, which are directly related to ADL, such as oral and body hygiene of the aged person: brushing their teeth and washing their face, helping and/or giv-

ing them a bath or bed bath, change diapers, get dressed, shave, clipping nails, putting on deodorant and body lotion, comb their hair; prepare and offer them their meals; take and/or accompany them to the bathroom; help them to move around; changing their position in bed; and also sitting, getting up and lying down. Besides the specific activities of care to the aged person, the caregiver must go out to do the shopping and pay the bills. [...] *she gets up and I get her out of bed right away, because she cannot walk. I sit her in her wheel chair and take her outside (C21); I am the one who gives her the bath [...] and I also change her clothes, too. She used to change herself, but I have done that for about 10 years now. I do everything... everything. I do the laundry, clean the house, do the shopping (C15).*

One study, in the State of Alagoas, was developed with the objective to identify the profile of the caregivers of cancer patients as well as the activities they performed, the changes and difficulties. It also found that the everyday tasks performed by the caregivers with the patients include hygiene, feeding, administering medications and taking them to healthcare services.¹⁵

Meeting the health needs of the aged person are also tasks performed by the family caregiver in this study, and they include giving them the medication, taking them to a doctor's appointment, taking them to do exams and to get the medication at the health center, as well as other more complex activities, such as measuring blood glucose and blood pressure. [...] *I give her medication in the morning, then she has lunch and I give her the diabetes and high blood pressure medication. If she has any kind of pain, I give her dipyrone (C21); [...] we worry because sometimes she feels sick. I check her blood pressure, I do the diabetes test, and sometimes I have to rush to give her at least a small piece of candy so she manages to get up, because sometimes it is at 55, 65..., then I have to check the blood glucose again, until it is normal (C22).*

The caregivers have assumed, in their daily lives, activities that are beyond their training and knowledge, such as measuring blood glucose and blood pressure. These tasks are not among those in Ministry of Health caregiver's guide. In fact, it states that the use of techniques and procedures identified as legally established professions, particularly in the field of nursing, are not among the caregivers' practice.¹⁶ It should be highlighted that becoming a caregiver is sometimes not an option for some people, therefore, assuming these activities without any preparation can result in overburden.

This problem was also evidenced in a study developed in Northern Portugal, where Portuguese families take care of aged people with a high dependence level. This emphasizes the importance that these data have in the current context of the demographic changes as well as in the structure of families, and point at the clear need for a policy to support families, in addition to urgent interventions within them.¹⁷

Informal and family support comprises one of the fundamental aspects in elderly healthcare. The State, however, must be accountable for the promotion, protection and recovery of health among the elderly in the three levels of healthcare in the Unified Health System (*Sistema Único de Saúde* - SUS),¹⁸ without transferring exclusively to the families the care interventions delivered to dependent aged individuals.

Furthermore, nurses must develop health education practices that provide the conditions to evaluate the urgent needs of care and seek help from other health professionals. In this sense, the FHT nurse has a broad field of practice, as well the challenge of bringing caregivers closer and developing their potentialities.

In this setting, the caregivers describe care as something difficult and complicated, "it is not easy", because it is a continuous activity, and is usually performed by one person alone and requires patience, love, selflessness and special dedication to the aged person in their everyday life. [...] *but it's difficult, you know, it's no game, you need a lot of patience, and other things you have to renounce (C7); Sometimes he doesn't want to eat, so I blend the food, make it into a thick soup and feed him. I even feed him a bottle, because he has to eat and I can't let him starve!!! It is difficult (C23).*

A study performed in Fortaleza, with the family of people affected by a stroke, and hospitalized, also sought to discuss the difficulties for home care, also found that taking continuous care of the patient with stroke complications, dependent for the ADL, is not an easy task, and, within this context, there would be a need for secondary caregivers to exchange care shifts.¹⁹

Infantilization of the elderly

Another characteristic evidenced in the care to the aged person was that the caregiver sees him or her as child. The caregiver's infantilized perception towards the aged person may appear as related to their physical dependence they have

to the caregiver to perform the ADL, as well as to their stubbornness, resistance to care and to their personal behavior. *The aged person becomes a child [...] when you give them medication, they choke, if there is any dry food, you cannot feed it to them [...] they get stubborn, if you say something 'don't do that!!! He does it [...] (C14); [...] it is worse than looking after a newborn baby. You look at him and it's not an adult that you see, because he became a child. He makes a fuss because he doesn't want to eat, and pouts (C3); I tuck him into bed, just like a little child, you know? Then he gives a small laugh, like a little baby, so cute [...] [laughs] (C7).*

It is known that with the process of human aging, our body goes, physiologically, by a reduction of Functional Capacity (FC), and this can make it frail, and often lead to a dependence on other people.

Perhaps caregivers see aged people as a child, due to the relationship of physical dependence that they establish with the caregiver, particular in ADL, and, in this context, they believe that if this care is not performed, the needs of the elderly may not be met.

In the aging process, some physiological changes become more noticeable and the aged person's functional capacity may be or become compromised. In this sense, dependence, loss of autonomy, and compromised functions that make it difficult to perform simple everyday activities may emerge in the elderly, thus requiring constant care.²⁰

However, if the caregiver infantilizes the aged person, disregarding him or her as an adult, with their experience, history, intellectual and cognitive capacities, among others, they (caregiver) may be showing a negative and inappropriate attitude towards the elderly, and, thus, contribute to the loss of autonomy as well as to establishing an emotional dependence to the caregiver, to the point that the aged person begins showing a childish behavior.

A study performed with the objective to analyze the understanding of dependence between formal caregivers of aged persons in a home for the aged showed that caregivers see dependence as a natural event, expected of old age, that may or may not be associated with pathological processes, leading to limitations. Caregivers also reported that psychological or affective dependence surpasses physical dependence. However, it appears that they do not realize that life in a home for the aged, the lack of privacy, paternalist attitudes and

the infantilized treatment towards the elderly may determine an affective-emotional and behavioral dependence of the elderly.²¹

Skills developed to provide the care

In order to handle the complexity of the tasks, the caregivers develop some skills with the purpose to make their everyday tasks easier, as well as those aimed at avoiding accidents and health complications to the elderly, promote their physical and mental well-being, organization of the physical environment, development and use of care technologies and care with the diet to manage body weight. The following statements describe some of these skills: *the first thing is his bath, then I change him, and I always put some ointment on him, an oil, to avoid wounds and rashes (C23); [...] if he needs to go to the bathroom, you have to go with him. In fact I created a sort of plastic chamber pot to make things easier, because he wets himself all the time, so I have to change his clothes because he gets wet (C7); [...] so I take that care so he doesn't gain weight [...], in fact, I even control him a little, because he eats everything [...]. In fact, I have to shred his meat, fish, chicken, bread or else he chokes (C14).*

Other skills were also pointed out in a study, in which the family caregivers revealed the importance of talking while providing the care, demonstrating the need for affection in the home care environment, and the concern by the caregiver, in addition to performing the body care.²²

As we may observe, the family caregiver uses several strategies/ways of care with the aged person, because their job is more than simply wanting to take care of their relative, considering the complexity of the care. It involves knowledge, the development of skills, initiative for the promotion, treatment and recover of health of the elderly; a job which caregivers themselves define as "difficult", one that requires patience, love and even resignation of their own life project. All of this has contributed for caregivers to live with a daily physical, emotional and social overburden.

In view of the care skills developed by the family caregivers, the FHS has a fundamental role among the elderly, caregivers and families. The current policy aimed at the health of the aged recommends that the family, as a rule, should take care of the aged person, and evidences the need to establish qualified and constant support to those responsible for that care, i.e., the caregivers. Therefore, there is a proposition that primary healthcare,

by means of the Family Health Strategy, should perform a fundamental role in the care to the elderly, caregiver and family.²³

Within this context, the work of the FHT nurse is relevant, considering they evaluate the need of the elderly and the family, taking into consideration the different realities experienced by the family caregivers of dependent aged persons at home.

FINAL CONSIDERATIONS

It was observed that the care delivered to dependent elderly is an activity that changes the lives of the family caregivers, which can cause physical, emotional and social overburden.

This care involves activities related to the need of the elderly for the ADL and IADL, as well as health needs. For this reason it was classified as a difficult task, as it must be performed uninterrupted and, most times, by one single caregiver.

Family caregivers usually see the aged person as a child and this perception is at times related to the physical dependence that the elderly has to the caregiver, and at others to their personal behavior, which is of stubbornness and resistance to the care. The infantilization of the elderly occurs due to an excessive concern by the caregiver in meeting the survival needs of the dependent aged person, or the disregard of the aged person as an adult.

While performing the everyday care to the aged person, the caregivers develops skills for the care with the objective to make their activities easier such as avoiding accidents and health complications, promoting the physical and mental well-being of the elderly, organizing the physical environment, developing and using care technologies and care with the diet.

Considering the future estimates that the Brazilian elderly population is increasing, it becomes evident that there is a need to recognize and meet the needs of the caregivers of the elderly, within this context, through FHS professionals. Nursing, as an essential element of the FHS, should be careful about the health needs of the dependent elderly, and also be closer to the caregivers, in order to guide them and follow the care, with the purpose of proposing interventions that aim at the broadened healthcare support, i.e., to the elderly enrolled in their covered area and their families.

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