

Autocuidado e vivências do envelhecer de cuidadores familiares de idosos: contribuições para enfermagem gerontológica

Self-care and aging experiences of elderly's family caregivers: contributions to gerontological nursing

Autocuidado y experiencias al envejecer de cuidadores familiares de ancianos: contribuciones para la enfermería gerontológica

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RESUMO: Objetivou-se compreender o autocuidado no processo de envelhecer de familiares que cuidam de idosos no domicílio. Pesquisa qualitativa do tipo exploratória. Participaram das entrevistas cinco familiares de idosos atendidos nas consultas de enfermagem em um ambulatório de Geriatria e Gerontologia. Utilizou-se análise de conteúdo que resultou em duas categorias: o envelhecimento do cuidador familiar de um idoso e a realização de seu autocuidado; e o reflexo do cuidar de idosos por um familiar em processo de envelhecimento. Compreendeu-se que, além da tensão do papel de cuidador, o familiar convive com problemas secundários ao próprio envelhecimento, por vezes, associados aos agravos crônicos. A condição de ter que cuidar associada a esses agravos influencia na dinâmica da vida do cuidador familiar. Os familiares compreendem quais são os requisitos universais de autocuidado, mas não conseguem exercê-los, pois priorizam o “ter que cuidar” do idoso sob sua responsabilidade. O estudo contribui para o processo de cuidar de famílias de idosos pelo enfermeiro, entretanto, apresenta limitações quanto ao quantitativo da população, o que aponta para necessidade de novas investigações com aprofundamento nos custos

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sociais e financeiros que envolvam o processo de cuidar pela família de idosos no domicílio.

Palavras-Chave: Envelhecimento. Cuidadores. Cuidados de Enfermagem.

ABSTRACT: This study aimed to understand self-care in the aging process of family members who care for the elderly at home. It is a qualitative and exploratory research. The interview participants were five relatives of the elderly people's family attended in the nursing consultations of a Geriatrics and Gerontology outpatient clinic. The content analysis has been used and it resulted in two categories: aging of an elderly's family caregiver's and self-care; the reflex of caring for the elderly by a family member in the process of aging. It was understood that, in addition to the tension of the role of caregiver, the relative deals with secondary problems to the aging process itself, sometimes associated with chronic aggravations. The condition of having to care associated with these injuries, influences the life dynamics of the family caregiver. Family members understand the universal requirements for self-care, but are unable to exercise them, as they prioritize "having to care for the elderly" under their responsibility. The study contributes to the care of elderly's families by the nurse, however, it presents limitations on the quantitative population, which points to the need for new investigations with deepening social and financial costs that involve the care process by the elderly's family in the residence.

Key words: Aging, Caregivers, Nursing Care.

RESUMEN: Se objetivó comprender el autocuidado en el proceso de envejecimiento de familiares que cuidan ancianos en su domicilio. Investigación cualitativa de tipo exploratoria. Participaron en las entrevistas cinco familiares de ancianos atendidos en las consultas de enfermería de un ambulatorio de Geriatria y Gerontología. Se utilizó análisis de contenido que resultó en dos categorías: el envejecimiento del cuidador familiar de un anciano y la realización de su autocuidado; y el reflejo de cuidar ancianos por un familiar en proceso de envejecimiento. Se comprendió que, además de la tensión del papel del cuidador, el familiar convive con problemas secundarios al propio envejecimiento, a veces asociados a agravios crónicos. La condición de tener que cuidar asociada a esos agravios, influencia en la dinámica de la vida del cuidador familiar. Los familiares comprenden cuáles son los requisitos universales del autocuidado, pero no consiguen ejercerlos, pues priorizan el "tener que cuidar" al anciano bajo su responsabilidad. El estudio contribuye al proceso de cuidar familias de ancianos por el enfermero, sin embargo, presenta limitaciones en relación a lo cuantitativo de la población, lo que apunta a la necesidad de nuevas investigaciones con profundidad en los costos sociales y financieros que involucren el proceso de cuidar ancianos por la familia en su domicilio.

Palabras clave: envejecimiento; cuidadores; atención de enfermería.

INTRODUCTION

The population aging has occurred in an accelerated manner. According to IBGE¹, The group of people aged 60 years and over will increase sharply, from 13.8% in 2020 to 33.7% in 2060. The life expectancy of Brazilians may increase from 73.17 years old in 2009 to 81.29 years old in 2050².

Aging happens throughout life, but people only notice the changes when they are close to 60 years old, as middle age is a phase of adulthood in which the characteristics of this process become more evident³. The way people perceive the aging process can have a big influence on how they take care of themselves in the course of their lives⁴.

The actions taken to promote, maintain or improve health are based on the individual's perception of their own condition; it influences people's daily choices regarding hygiene, nutrition, exercise, access to healthcare, and any other activities⁴.

The stage of life characterized as old age, with its peculiarities, can only be understood from the relation established between the different chronological, biological, social, and psychological aspects. In this sense, it is believed that old age is difficult to define, especially when a healthy old age is desired, which must be understood in its entirety⁵.

As the number of elderly people increases, the number of people who will care for these elderly people increases as well. It is observed, as a matter of fact, that family caregivers of the elderly often go through their own aging process carrying out the activity of caring for the family member.

It is known that the care process carried out by the relative caregiver in the home is complex, as it generates physical, psychological and social isolation; lack of institutional and family support, difficulty with the environment/infrastructure to perform care and financial difficulty⁶, are some of the factors that may affect the aging process of the person who cares for the elderly, for example, physical, psychosomatic, anxiety, depression, and stress diseases⁷.

Recent studies^{8,9} have shown that families do not have knowledge and/or cannot count on the support of health services to perform care. For the family, without the necessary support for home care for the elderly, it is important to be able to deal with the alterations of aging and to be aware of the need for family structural reorganization in order to meet the demands of the care process without taking the caregiver's to a work overload.

The assistance to the elderly sometimes focuses on the quality of care at home without, however, a reflection on the conditions of the family to assume this care. Thus, the importance of the development of public policies that favor the quality of life of family caregivers is highlighted.

When reflecting on the care of the family member to an elderly person who is in the process

of aging, the concept of self-care must be clear. According to Dorothea Orem¹⁰, self-care is the performance of life-sustaining, health, and well-being activities performed by the individual for their own benefit.

Orem¹⁰ presents three interrelated theories: Theory of Self-Care Deficit, Nursing Systems Theory, and Self-Care Theory. The Self-Care Theory expresses what the author brings as a concept of self-care, relating the factors that interfere with it. The Self-Care Deficit Theory addresses the imbalanced relationship between the demand for care and the ability of a person to fulfill such demand. The Nursing Systems Theory varies from the Totally Compensatory System, passing through the Partially Compensatory System, until arriving at the Support-Education System, being modified according to the Nursing need in supplying the therapeutic demand of self-care of an individual¹⁰.

The caregivers, due to their daily care activities, can be included in the Support-Education System, because they need to develop, together with the nurse, a plan of comprehensive and individualized care so that they can acquire skills and knowledge that help them to carry out their own self-care, while taking care of a dependent family member⁹.

The initial motivation for this research emerged in the development of nursing consultations in a multiprofessional outpatient clinic of Geriatrics and Gerontology, in the Nursing Residency Program in Adult Health and as a member of the Group of Studies and Research on Self-Care and Educational Process in Health and Nursing (GAPese/CNPq), in which this theme is discussed and publications in this area are carried out.

During nursing consultations for the elderly, it was observed that family caregivers also presented demands for nursing care, either for actions related to the development of their self-care, or for the instrumentalization of the daily process of caring for a family elderly person.

Thus, in light of the above, the research aimed at understanding the self-care in the process of aging family members who care for the elderly at home.

METODOLOGY

This is a qualitative research of the exploratory type, whose analysis was guided by the Content Analysis proposed by Laurence Bardin¹¹ that defines it as:

Set of communication analysis techniques aiming at obtaining, through systematic procedures and objectives of describing the content of the messages, indicators (quantitative or otherwise) that allow the inference of knowledge regarding the conditions of production/reception (inferred variables) of these messages¹¹.

The study included a selection of five adult caregivers who were experiencing their aging

process and who met the criteria for inclusion, chosen for convenience and taking as reference the 90 elderly people who enrolled in the service. The research presents limitations regarding the quantitative of the population, once it was established the month of June of 2014 for the selection of the caregivers in nursing consultations, thus restricting the number of participants.

The inclusion criteria were: a) To be the main family caregiver of an elderly person at home; B) Being an adult in the process of aging, aged 45-59 years old; C) Be lucid and reside in the city where the research is located; D) To have participated in the nursing consultation in the month established for the selection of the research participants (June, 2014).

The research was developed in two stages: 1) in the Geriatrics and Gerontology Outpatient Clinic of the University Hospital of the Universidade Federal de Juiz de Fora, in order to select the participants during the nursing consultations performed on the elderly; 2) home visits, in July and August of 2014, aiming at carrying out semi-structured interviews with the family caregivers.

After the first phase, a telephone contact was made with the family caregivers who met the inclusion criteria, inviting them to participate in the study.

The anonymity of the participants was assured, since the interviewees were identified by numbers, according to the order of interviews (example: E1, E2).

The research was guided by the criteria established by the Directives and Norms Regulating Research Involving Human Beings, contained in Resolution No. 466/2012 of the National Health Council¹². The data collection took place after the approval of the project in the Research Ethics Committee of the University Hospital of the Universidade Federal de Juiz de Fora, according to the Opinion No. 519.179 of 02/24/2014, published in Plataforma Brasil.

The data collection was performed in July and August of 2014 during home visits to the family caregivers. To that end, a semi-structured script was adopted with the following guiding questions: how does the elderly's caregiver perceive their own aging process? And how do you take care of yourself while experiencing the fact of having to care for an elderly person at home? All the interviews were recorded through a common recorder.

The interviews were transcribed and edited using the OpenLogos® Program version 1.0.2 for interpretation, coding, and triangulation of the data¹³.

The exploitation of the material generated 16 codes related to the research question. The codes were grouped according to their similarities and each group constituted a category for the research. Thus, from the exposed stages emerged the two categories: 1) The aging of the family caregiver of an elderly person and the performing of their own self-care; and 2) The reflection of caring for the elderly person by a family member in the process of aging.

RESULTS E DISCUSSIONS

Table 1 presents the characterization of the research participants.

TABLE 1 - Characterization of the five family caregivers of elderly people at home. Juiz de Fora- MG/2014

Nº	Gender	Age	Time taken care of (in years)	Marital Status	Caregiver's Degree of Kinship	Nº Of Children	Education	Profession Current Occupation
E1	F	59	3	Married	Wife	3	High School	Nanny
E2	F	59	4	Divorced	Niece	2	High School	Housekeeper
E3	F	43	1	Married	Daughter	2	High School	General Services Assistant
E4	F	59	4	Married	Wife	0	Elementary School	Seamstress
E5	F	57	2	Separated	Daughter	3	High School	Maid

Source: The authors

The participants were women in their totality, demonstrating the feminization of care performed by family members. In studies with caregivers, it is observed that the woman is usually the one who performs the tasks of caring in the family, obeying cultural norms according to which it is the woman's responsibility the organization of the family life and the care given to the children and the elderly in the role of caregiver^{8,9}.

The prevailing age of the study was 59 years old, due to the fact that the care is exercised, for the most part, by the spouse. But it is also possible to observe the role of daughters who, when married, taking care of their homes and also taking care of an elderly person at home. In the situation of taking care of the spouse or parents, there are deep affective issues, rooted in the caregiver's previous relationship with the elderly and both with the rest of the family, as well as practical and financial issues that mix with affective motivations¹⁴.

The number of children presented reflects the decline in the birth rate of the Brazilian population and, consequently, an increase in the number of elderly people. For a population to age, it is necessary first that there is a drop in fertility, accompanied by a high relative growth of the elderly population, in the face of a past of high fertility¹⁵.

The period for which the person became responsible for the care has a close relationship with the wear of the caregiver role, because when assumed for a longer time, being in the research four years the longest period, this caregiver is exposed to greater conditions of wear. Difficulties in the execution of biological and psychosocial needs, such as sleep, rest, leisure time, are even more visible over time, since it is these conditions that trigger physical and mental exhaustion, compromising health¹⁶.

Regarding the level of schooling of caregivers, four of the participants have high school education, and this fact is directly related to the professions they have, which do not require a higher level of education.

The difficulties of access to education were much greater decades ago when compared to the current situation, especially in relation to women¹⁷. The Future generations of elderly people will reach higher levels of formal education than the current population, being better informed health consumers¹⁸. The level of schooling directly influences the care process, with educated individuals seeking more for healthcare and well-being¹⁸. Therefore, there may be an improvement in the health indicators, as people will be more demanding about the quality of care and will take better care of themselves.

The aging of the family caregiver of an elderly person and the performing of their own self-care

The first category addresses the changes in the aging process in the life of family caregivers and how these changes can interfere with the care of the elderly and, consequently, their own self-care.

The changes related to aging are considered a natural process that takes place over time. The biological phase, arising with bodily changes is mainly the most visible and manifests first.

The integumentary system, which includes skin, hair, and nails, undergoes significant changes and, as they are visible, the changes in this system are the most obvious and evident for both the aging individual and other people⁴. The caregivers' conception of their own aging process can be seen below.

Oh, we see the modifications by the appearance. I mean, by the body, the wrinkled face, the hair that is turning gray, there I see the difference (E1).

Now, with respect to the physical, it is the hair, the wrinkles, the sagging of the skin... (E2).

According to Eliopoulos¹⁸, aging leads to various changes in the human body: the hair bleaches and resects, flexible and straight fingers curl and become sore, there are changes in the body contours and the height decreases. With aging these changes are expected, but it is important that the nurse is aware of that and is able distinguish the changes that come with the aging process.

We slow down to do things, to interact with things, to do the cleaning. When we were younger, we had more agility, for sure. Also, I still feel that my leg is bothering me a bit, because it hurts a little, I have to walk little, walk little (E4).

The house, we find a way, there is a moment when I do not care about it, I do more things to care for him, things for him, as it is said, more urgent, right, because it's a lot (E1).

Therefore, nurses should be aware of the physical changes that are likely to occur in the aging process of these caregivers, in order to evaluate them during the nursing appointment and home visits to determine the extent of the changes that have occurred, in order to plan in response to the specific needs of these individuals⁴.

With the increase of the years lived, the experiences become maturity in the conception of the participants, who consider it as favorable because they make them more capable of facing life and add motivation to live better.

It changes everything, it changes the thinking, the body changes, the way of thinking. I feel more prepared to face reality, more mature to see the world and this is very good because you feel safe (E5).

Even being able to observe the positives aspects of aging, it is still seen by participants as a phase of decline, in which few benefits and acquisitions can be enjoyed.

It is analyzed by the statements that the conception of what is to be old is related to the negative changes brought with the increase of the age, being possible to be noticed among the participants the fear of aging, exemplified with manifestations of repulsion to the memory of the day of their birthday.

I realize that I am getting older because the years go by, we see so much that happens, then we think, "Oh my God, I'm getting there." I do not want to get there, no. On my birthday you do not do anything, because I do not want to know that I'm getting old, no (E5).

Today's society values the youth, even though they know that aging is a normal process that affects all human beings and, by having a negative view of this period of life, it makes the elderly hold on to that image, which is the one of the preconceived meanings about old age¹⁹.

The way people care for themselves in the course of their life influences how they perceive their aging process⁴. The educational practice, in the context of primary care, appears as a positive factor, contributing to the consolidation of spaces for the exchange of experiences and information, allowing the development of social interaction skills such as dance, coexistence groups, handicrafts production, and programmed tours²⁰.

Here in church there is stretching, I went once alone. I follow up there at the women's institute, mammography and preventive, I have already participated in groups for the health of women (E1).

I have already participated in the woman's group, I even have the Women's Institute card, every year I go to the gynecologist, so I take care of myself... I walk, even if not much, I do it (E4).

There is a concern on the part of the participants for the search for good quality of life and well-being, but these actions are not yet implemented in the Primary Health Care Unit (PHC) of their neighborhoods, but in other points of the Health Care Network, such as specialized outpatient clinics. Services should be able to support independent individuals to maintain the self-care ability and to avoid physical, emotional, social, and spiritual problems¹⁸.

The actions in the field of gerontological nursing can be developed by the nurses in search of a better aging, such as: the practice of physical exercises, adequate food, changes in the life habitse, search for activities of health promotion, and prevention of chronic diseases. Regular exercise should be part of the daily plan as it helps to maintain the joint flexibility, to maintain the muscle mass, to control the blood glucose levels and weight, and to promote a sense of well-being⁴. In Brazil, non-communicable chronic diseases (NCCD) are a major health problem and account for 72% of the causes of death, including circulatory diseases, cancer, diabetes and chronic respiratory disease. They reach people from all socioeconomic strata and, especially, those belonging to vulnerable groups, such as the elderly and those with low schooling and income²¹.

An adequate and balanced diet, regular physical exercises, search for pleasurable activities that reduce stress, decrease alcohol and tobacco damages, significant decrease in self-medication, and stimulating social coexistence can reduce these deaths due to avoidable diseases^(15;22).

According to the VI Brazilian Hypertension Guideline²³, in 2001, around 7.6 million deaths worldwide were attributed to elevated blood pressure (BP), 54% due to stroke, and 47% due to ischemic heart disease (IHD), most of them in countries of low and medium economic development and more than half in individuals between 45 and 69 years old. In our country, cardiovascular diseases (CVD) have been the main cause of death.

Given this, family caregivers are exposed to the risk of developing pathologies and injuries, and being a caregiver can be an aggravating factor to their health, since they leave their self-care in the background. Some risk factors can be prevented and it is up to the nurse to take actions to prevent these risks, supporting the caregiver in the care of the elderly and facilitating the practice of developing their self-care.

It possible to observe in the excerpt from E5 the concern about becoming dependent upon aging, and for this to happen, she seeks actions that will provide quality of life in old age.

(...) And now I know that in order not to be a dependent elderly, I need to do gymnastics, so I'm healthy, I'm already starting to take care of myself because this is when I have to start doing something for myself, for not having a very bad old age... I will try not to be cachectic in order not to give work to others (E5).

When talking about healthy or successful aging, health professionals have their definitions on the subject, but it is important to take into account how these individuals define the ideal aging and how they consider the possibility of achieving this aging⁴.

The caregivers express concern about becoming dependent and, for this to happen, they seek an active and healthy aging. This concern is associated with a sense of doubt, in case they need a caregiver, if they would have someone to help them.

I have a lot of concern, I hope my kids help me, but I do have concerns, I do. They work, hardly have time for father and mother... When I need something, my daughter helps me, but she is always complaining that she does not have time. It will be difficult, it will be difficult (E1).

Even if they express this uncertainty in the speeches, the Federal Constitution of 1988 guarantees the responsibility of the family to care for the elderly, in its article 230: "The family, society, and the State have a duty to support the elderly, ensuring their participation in the community, defending their dignity and well-being, and guaranteeing them the right to life"²⁴.

The family support brings comfort to the caregivers, and its lack can create insecurity. But this support should be found in health professionals, which would be extremely relevant for this caregiver, arousing a sense of security in the face of the assistance actions offered. The nurse, especially the one from PHC, should be the reference professional for this caregiver, so that the person can find support to promote their aging and self-care.

There are several factors that influence self-care, and caring for an elderly person at home is a difficult factor for this practice, since there are several changes in the family caregiver's daily life. Having to take care of an elderly person generates an overload for the caregiver who, often, stops doing for himself/herself by having to do for the other.

The change in daily activities, in addition to the care of the dependent family member, ends up overwhelming the caregiver who may suffer physical tiredness, depression, abandonment of work, changes in conjugal and family life, which damages not only himself/herself but also the person to be cared for²⁵.

The caregiver's overload was observed among family caregivers of the elderly, who demonstrated that they did not know how to manage these changes in their daily lives.

There are moments I do not believe I can handle it. You know, it's a lot. There are moments

that I, that I need help, help to take care of him, because there are moments when I feel alone, alone (E1).

There is always an incredible overload. When you look after the elderly is always an overload, I always say that (E2).

The lack of assistance by other family members in the demands of care for the elderly can be understood, especially the lack of relay in care activities among the relatives. Family caregivers dedicate themselves permanently without the help of other family members in the division of the routine tasks. However, the nurse must carry out an action plan directed to the support of the families with the objective of minimizing the levels of overload, promoting an environment that meets the needs of the elderly and the family, contributing to the establishment of a good interfamily dynamics.⁸

Among the difficulties pointed out by the caregivers, there is the accumulation of domestic activities and the fact of having to take care of the elderly. They report that the home care and its responsibilities related to the direct care of the elderly generate a lot of work and possibly contribute to the high levels of emotional overload and discomfort.

She always wants me around. When she needs, she has me as a reference, there is often no time left for me to take care of myself. I need to always stay with her to do all of her stuff (E3).

The changes in the caregiver's daily life influence his/her own health, since the routines are no longer the same when there is someone who needs his/her care.

The involvement of family members in activities and demands for care, along with the exercise of domestic tasks and other family responsibilities, cause caregivers to neglect their self-care and the care for their own health conditions⁹.

When reporting on their daily life, the family caregiver highlights their difficulties in self-care, and the lack of time is the most frequent justification.

I need to take my bath in a hurry, because then she stays alone and she calls me all the time, everything I do I need to do fast (E2).

I am sorry, I am, I do not have much time to take care of myself (E1).

What can be observed is that these caregivers fail to perform with quality the universal requirements of self-care by leaving these activities in the second position in their lives, having as priority the care of the other.

The "caregiver role tension" is included among nursing diagnoses, being identified as "a state in which the individual is presenting physical, emotional, social and/or financial overload in the

process of caring for another person”²⁶.

The deficit in the performance of the caregiver self-care is related to the difficulties in reconciling self-care with family care activities¹⁰. These situations indicate the need for actions to support the family caregiver and health education, developed by the nursing and multiprofessional team, that provide better care conditions for the dependent elderly population, and that meets the specific knowledge and skills necessary for the family caregiver to play the delegated role.

Nurses should be able to recognize the individual’s specific difficulties and the degree of self-care limitation for appropriate nursing interventions to be planned⁴. It is evident the importance of the implementing educational groups, the home visits and, in addition, the development of the nursing consultation is at the level of primary or secondary care, aiming to meet the demands of the caregivers.

The reflection of caring for the elderly person by a family member in the process of aging

Caring is an inherent condition for a human being, but when that care needs to be developed for you and for another person, it can become a challenge.

The role of the caregiver is to accompany and assist the cared person by doing only what he/she cannot do on his/her own, not being part of his/her routine techniques and procedures characteristic of legally established professions, particularly in the nursing area²⁵. And from the caregiver’s reports, they did not find support in the health services and often had to play roles for which they were not prepared to. The lack of support, especially from APC, creates a sense of insecurity.

In the medicine part, these things we can get to do... (E1).

Here there is only doctor, medicine, so when it is necessary, but only then, if I need something else, there is not... (...) To take care of her we only receive the medication (E3).

It is observed, through the reports, that the actions offered in the PHC are restricted, being, in most cases, medication distribution, BP measurement, and medical consultations. The actions must take into account the principle of integrality, in which the actions of promotion, prevention, treatment, and rehabilitation are part of the care.

The support of the Brazilian Health System in all its spheres: primary, secondary and tertiary care; as well as the care of nurses, whether through guidelines through educational practices, or through support through other care strategies, contributes to care.

With Home Healthcare (HH), the care network is complemented, enabling the continuity of care at the individual's home, guaranteeing comprehensive and resolute assistance in the health-disease process²⁷.

The caregivers reported medical consultations as a prevailing form of care, as might have been noted in previous and subsequent speeches, which refers to the conservationist thinking of focused medical care.

Look, here at least, at the unit here, on our street, when we need we have a good care, we have a very good doctor, a pediatrician too, a gynecologist if you need (E3).

It is observed that when relatives reported needing care, they had the medical assistance as a reference. This fact makes us reflect on the role of the multiprofessional team in PHC and as a component of this team, the nurse.

There is a nurse there, but I never went through the care with her; no consultation or anything (E2).

(...) except for a wound that there is a nurse there who looks, you know (E3).

The caregivers showed limited knowledge about the nursing actions carried out within the scope of PHC, especially regarding the promotion and preventive actions, which are fundamental in this level of attention.

The educational groups, when performed by nurses to caregivers, can provide relief, decrease feelings of emotional overload and discomfort, as well as promote their well-being, since the caregiver perceives that he/she is not alone, he/she sees that doubts and difficulties are not just his/hers, that their experiences may be valuable to other caregivers and thus they can form a supportive network among them²⁵.

Despite all the difficulties found in the organization and support of the health services, the participants raised as an important factor the lack of capacity of care of the health professionals to the specificities of this population group. Health professionals are not yet qualified for care for the elderly, and this was noted by the majority of the participants, in which there was dissatisfaction regarding the PHC care.

I think there are some professionals who are 'rude,' they barely talk to us, they do not ask, they just want to know what you have and that's it, they give you a shot and they do not want to know it, right, I think some are not prepared, it is my point of view (E3).

We do not see much concern on the part of professionals; there are few who really care about the elderly... (E2).

In 2006, through the Administrative Rule No. 399, the Pact for Health was announced, which has three axes: the Pact in Defense of SUS, the Management Pact of SUS, and the Pact for Life - this one has as priorities and responsibilities the elderly population. The Health of the Elderly aims at some goals, among them: the training and ongoing education of health professionals of SUS in the area of health of the elderly; dissemination and information about the National Policy of the Elderly's Health for health professionals, managers and SUS' users²⁸. From this context, it is observed the importance of having professionals who are able to meet the specificities of the elderly population. The relatives interviewed find difficulties in the search for assistance in the care of the elderly, because, despite all the efforts made, these family caregivers cannot count on the help of other relatives, health services, and health professionals, who are called deadlocks for a quality care.

Here the unit helps very little, doctor it must be from 3 to 4 years that I do not consult here, because we cannot even schedule, you have to get up at 2 o'clock in the morning to manage to schedule, I will not do it (E4).

We have difficulties to make an appointment with the doctor, there is not, we have to go to the line and wait like everyone else. And sometimes he has to go along, and when he gets there he does not have much patience, because of his illness... (E1).

Among the priorities of the Pact for Health, in the Health of the Elderly Person, it is necessary to respect the preferential embracement in health units, respecting the risk criterion²⁸. This is not the reality found by family members, which is a worrying factor, since the disease in the elderly person is a considerable risk factor, requiring priority attention for this age group.

The family caregivers were worried about the difficulty of accessing the health services, worsening of the clinical picture, and possible readmissions, since it is more prevalent in this age group, due to factors that add up to age. The decline in the clinical health conditions of these elderly people leads to a greater burden on the caregivers, since the elderly will require more care at home or an accompanying person while they are in the hospital.

With the experience that we have, that I have, I know perfectly well that every hospitalization is a relapse, and then the condition is getting really terrible until it enters the vegetative phase, which is a very painful phase (E2).

Faced with this situation, there is a need to think about a strategy to improve the organization of the service and assistance to the elderly in a systematized, comprehensive way and according to their peculiarities; intervening in a way to prevent health problems and assist the individual throughout longevity, minimizing fragilities that will interfere in independence and autonomy,

reflecting on their self-esteem and quality of life.

One of the goals of the National Senior Citizen Health Program (NSCHP) is to increase the quality of the services offered by SUS to work on the details of the elderly person's life²⁹. When the elderly and their caregivers know their rights, these difficulties can be mitigated, as they tend to go after them.

The elderly also have their laws, they know it, say something to the elderly to see if they do not know... See my mother, she must know more about the elderly's statute than I do (E5).

Regarding all the public policies for the elderly, there are still few who really know it. Among the priorities of the Pact of the Elderly Person is the importance of the dissemination and information about the National Health Policy of the Elderly Person for health professionals, managers, and SUS' users²⁹. When they reported knowing their rights, they expressed positive feelings because they were more secure and felt entitled to be assisted.

Nurses should be able to contribute to the fulfillment of care rights for caregivers and the elderly, and to influence the elaboration and implementation of public policies aimed at a resolute and humanized care, so that caregivers can enjoy an independent and quality aging.

CONCLUSION

The caregiver who is in the process of aging and performs the activity of caring for an elderly person at home deserves special care. It is important to develop health actions aimed at this population, so that it contributes to an active and healthy aging, as well as assisting the care of the elderly and avoiding the caregiver's overload.

Among the nursing actions, the health education must be emphasized, which needs to be developed, either in primary care, through home visits and educational groups; or in secondary care, through outpatient consultations, in which the multiprofessional team, especially the nurse, should take advantage of the opportunity to teach and clarify doubts of the elderly and their families; be it in tertiary care, in the preparation of the patient and family during the entire hospitalization for the moment of discharge.

This study contributes to the process of caring for the elderly's families by the nurse, and it highlights the value of awakening in the professionals of the multiprofessional home care teams the urge of including care and attention to the family caregiver.

Despite the limitations presented by this research regarding the quantitative population, its exploratory character, faced with a little known theme, identified the need for further investigation intended at deepening the social and financial costs that involve the process of caring for the elderly family at home.

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Article submitted on 13/04/2017

Article approved on 26/07/2017

Article posted in the system on 20/09/2017