RESUMO

Objetivo: analisar o cuidado, o cuidar-se e o cuidador familiar de pessoas acometidas com a Doença de Alzheimer (DA). Método: estudo qualitativo, com dez cuidadores familiares predominantemente do sexo feminino, tendo como critério de inclusão a frequência no Centro Especializado na Atenção à Saúde do Idoso, o grau de parentesco e a assinatura do Termo de Consentimento Livre e Esclarecido; e de exclusão: ter idade menor que 18 anos, não realizar o cuidado no domicílio e não estar presente no cotidiano do idoso. A coleta de dados foi realizada no Centro Especializado na Atenção à Saúde do Idoso, na cidade do Natal/RN, por meio de roteiro de entrevista elaborado e aplicado pelas pesquisadoras, iniciada após a assinatura do Termo de Consentimento Livre e Esclarecido e da aprovação do projeto de pesquisa pelo Comitê de Ética em Pesquisa da Universidade Potiguar/UnP, com o CAAE nº 0032.0.052.000-11. Conforme a análise temática houve a leitura dos questionários e as falas foram agregadas em categorias. Resultados: a maioria dos cuidadores familiares refere que estão com sobrecarga de atividades por, geralmente, realizar o cuidado sozinho. O cuidador familiar desde a descoberta da DA é submetido aos desafios da doença e diversos sentimentos, aflorados no cotidiano, onde o compromisso de cuidar do outro envolve também a prática do autocuidado. Conclusão: observa-se que é fundamental para o profissional da saúde compreender como realmente se dá o cuidar. Com isso, é preciso pensar em políticas públicas direcionadas para cuidador familiar, para promover seu bem estar biopsicossocial. Descriptores: autocuidado; doença de Alzheimer; idoso.
Human aging is a process inherent in all living beings, occurring differently in each organism. Considered to be all elderly persons who are aged from 60 years.

While aging population be considered a global process, long ago this phenomenon was only observed in developed countries. Over the years, there has been a change in the profile of the population, observing also in developing countries like Brazil, which will occupy the sixth place in the number of elderly by 2025.1

The improved quality of life, curing diseases and the use of advanced technologies contributed to be an increased life expectancy of the population mundial.2 With advancing age, a large proportion of people who had access to improved quality of life, can maintain their welfare biopsychosocial, passing thus to live more independently, without needing assistance to perform the multiple daily activities. However, some seniors need help to Activities of Daily Living (ADL), which may range from a simple aid, such as the displacement for any room in the house, to a more complex and continuous, for example, help during personal hygiene.3

Therefore the aging population, there is worldwide significant increase in chronic degenerative diseases, such as dementia common in this age group, especially among those with Alzheimer’s disease (AD) is characterized by loss of memory for recent form progressive.4

So the DA is the neurological disorder most commonly associated with aging. The more senior the person, the greater the chance of obtaining it. Thus, aged between 65 to 70 years old, around 5% to 8% have AD, while in people over 80 years this percentage may reach 40%. Considering the prevalence of 1% to 1.5% between 60 and 65 years and 45% after 95 years, this disease affects 17 million to 25 million people worldwide. In Brazil, it is estimated that there are about 1.2 million people with the disease, many of whom are still undiagnosed because much is expected to take action when you have an elderly person with memory loss.5

With the emergence of the disease, usually a family member is chosen to become a caregiver. However, not all are available to perform care activities generally, this responsibility is carried by just one person, as a child or spouse, which contributes to overloading or chose one that was chosen by the family. Be this a family caregiver or a professional contractor, has a challenging task ahead.

Note that care is to perceive the other person as it is and as it turns out, his gestures and speech, his pain and limitation. Thus, caring for the elderly has its particularities, it is important to search for a way to understand and accept individual and collective process of aging as something inherent existential process of every human being.6

In general, the family is willing to care for the elderly with AD, but not recognized as objects of care. Thus ensues the need to conduct a study on self-care of elderly relatives with AD. In fact, caregivers need to accomplish your self care, also with the aim of providing quality care. Generally, the family caregiver is alone in the task of performing the care of the elderly with AD, since this requires time and availability for part of caregivers who often have to give up their activities to meet the needs of the elderly.

Thus, one can say that knowing how caregivers has been careful to take care of other, motivated the present researchers to deepen their knowledge on this topic. It is known that in Primary commonly nurses follow the families to be consulted individually or in groups. Thus, it becomes relevant to the same understanding of who experiences the family caregivers of seniors with AD.

In this context, the question is: how the family caregiver of a person with Alzheimer’s has been caring for since becoming a caregiver today, in most cases, is not an option and planned nor chosen by the family?

To answer this question, the following objectives were formulated:

♦ Analyze caring, caring and family caregivers to persons with Alzheimer’s disease (AD).
♦ Identify the profile of family caregivers.
♦ Describe strategies for self-care.
♦ Assess the challenges in home care of elderly patients with AD.

Qualitative study, conducted at the Center for Specialized Health Care in the Elderly - CSHCE, located in the eastern city of Natal, which is a reference in Natal in the treatment of older people affected by Alzheimer’s disease and other dementias.

For this research we selected ten family caregivers who had a family member with Alzheimer’s disease in their daily intercourse, which are treated at specialized center.
We used a structured interview individually applied to family caregivers along with generating questions related to the caregiver.

On first contact with the family caregivers, the authors of the study explained the purpose of the study, its objectives, explaining that their participation was free, could leave the trial if he wished, and they are guaranteed anonymity. After the positive response of caregivers to participate in this, he presented the Term of Informed Consent (TIC) and each participant signed.

After the reading of the interview scripts, the lines were aggregated into categories. The study of caregivers’ speech was based on technical analysis thematic, it possible to identify the nuclei of meaning that makes communication.

To describe the profile of these families used the names of flowers, according to ethical principles. The conduct of the study complied with the acceptance and free consent, according to Resolution 196/96 of the National Health Council, on human research.

The study was initiated after approval of the research project by the Ethics Committee in Research - ECR of Potiguar University/UnP with protocol no. 0032.0.052.000 and authorization of the Municipal Health.

RESULTS

The family caregivers in this study were aged equal or preferably greater than sixty (60) years (70%), and mostly female (80%). Regarding the relationship to the person with AD, we highlight the children (70%), followed by other relatives (30%) and spouses and brothers.

Generally, this choice is determined throughout the life of the one who is chosen to care. It is common in Brazil single women are predestined to care for parents in old age, considering also the fact that it is historically considered a caregiver par excellence.

The choice of approach is by kinship. So often carers are children and spouses. The educational level of these people ranged from four to eight years of study. 40% of these caregivers were professionals and some had no other occupation (60%).

The fact that no definite occupation contributed also to be chosen to take care of the elderly patient in his home. Generally, performing some work does not purport to care for and are released by the family due to lack of time to pursue other activities.

In relation to leisure, drew attention to the fact that family carers (70%) abandoned this possibility in favor of taking care of each other. It is important to remember that leisure generates quality of life. The absence of this activity in humans generates negative feelings such as stress, anxiety and adoecimento. Actually, all caregivers should be careful to take care of each other, which serves as a warning to all professionals, particularly nurses.

From the discovery of the disease through a probable diagnosis, the family caregiver will have a long walk ahead. The disease lasts around 12 years of the initial phase to the advanced stage.

Usually a family member accompanies a long period of time the family, as can be seen in the speeches of Azalea, Violet, Hydrangea and Daisy:

[…] It’s been ten years. (Azalea)

Vai doing five years on May 5 that I take care of her. (Violet)

For seven years, in relation to the death of my father ... It was the period that she began to develop this framework Alzheimer’s. (Hydrangea)

In the last two years. My mother had care of my grandmother who had Alzheimer’s. (Daisy)

Experience caring for the elderly with Alzheimer’s is a long process and it differs at each stage of the disease. Generally, this activity is carried out at an early stage of the disease, extending to the advanced stage. In the latter, it is customary to divide the care of a health professional.

It can be seen that the role of family caregiver is to help achieve the needs of the patient during the aggravation or present difficulties when executing las.

The caregivers interviewed indicated that in his reports on the challenges that Alzheimer’s provide are encountered daily by various feelings, being seen often, stress, sadness, tiredness, as can be seen in the statements below.

Some days I’m a little stressed and worried, but resigned. (Carnation)

A great pleasure. It is an old child because she does not identify things. Greater love and affection. (Rosa)

I feel good, and at the same time sad, because she was very active […] I am happy to take care of her. (Daisy)

[…] Sometimes it has the burden of the day-to-day, but it is normal. I ask God for health care for him. He has no one to take care of him. When the children go home, they’re wanting it to go away. (Azalea)

I feel very happy because my mom says I have a lot of patience. (Gardenia)
Caring is part of human nature, going beyond meeting the needs of others.

The family caregivers are subject to the psychosocial effects of Alzheimer's disease, making it important pieces in the context of scientific research on the resulting overhead generated by the effect of the care of the elderly with DA.\textsuperscript{1,2}

It is noted from the speech of Margaret and Gardenia that despite the presence of stress, care is pleasurable, produces satisfaction and gain for both. However, one must be careful that this does not render the caregiver feeling cocky enough to think you can handle this demand alone. The caregiver must cope with the demands of family devotion and affection, without forgetting that also needs to have their demands assisted.\textsuperscript{3}

Sit from the speech of Carnation and Azalea fatigue and stress that accompany everyday life of caregivers. In this context, alert to the possibility that the nuclear family can be marked at the time of mixed feelings as love and anger, anguish and melancholy.\textsuperscript{9}

Thus, one realizes that becoming a family caregiver is not an easy task for the family. Experiencing this paper implies changes and reorganization of services, and require involvement with others: BE before this so well known and loved, but now is very different.

To care for others we must be careful. It is possible to understand that the commitment to caring for others, whether a relative or not, also involves the practice of self-care, self-esteem, self-worth.\textsuperscript{13} However, in the speeches of Gerbera, Carnation and Sunflower notices the lack of time to perform activities that are cares for them, as can be seen in the statements below:

\begin{quote}
\textit{I do not take care. Poor me. I do not have time even to sleep. My sister takes 15 to 15 days to take care of her. Do not have time to hang out with my husband. I miss. (Gerbera)}

\textit{I'll take care of it more than me. When I take care of her, I forget myself. I have experienced dizziness, a headache, but I'm looking for treatment. (Carnation)}

\textit{Do not have much time to care, to leave, to distract me, to go to church. (Sunflower)}

\textit{[...] I have time for myself, I try not to live my life anyway, I try to combine the two things, my family and my mother. (Daisy)}

Taking care of yourself to take care of each other is essential and important for the caregiver, but also for the elderly who receive their attention. Some carers who carry out this activity daily end up forgetting you, not sparing the care necessary for their own physical and psychological well being.

Over time, the physical signs of tiredness. Alert to the importance of guiding caregivers about the importance of autocuidado.\textsuperscript{1,3} The lack of care for himself jeopardizes the quality of life of the caregiver and therefore the person who is in their care.

Taking care of yourself is the essence of living humano.\textsuperscript{14} Therefore, self-care is a human condition, making the care of others a temporary condition that renders a human being to another. But this can not forget to take care of it for your own good.

The family context can provide other care requirements beyond those needed for the elderly with Alzheimer's disease. The changes occurring in the lives of family members and are perceived by them as per the content of the following statements:

\begin{quote}
\textit{[...] I do not have that time that I had to stay carefree. Always have that burden on me. (Sunflower)}

\textit{[...] As he left and traveled more, I had more freedom to do my thing, living my life. Now he is very dependent on me. (Azalea)}

\textit{[...] I walked most of it, not a lot of love and affection exchanged, now it is gone. (Daisy)}

\textit{[...] I was more rebellious, did not take shit back home, after I started getting closer to her I'm someone else. She is so innocent, she changed my life. (Violet)}
\end{quote}

The changes in the lives of family caregivers are visible! This reorganizes itself to account for this new activity. The ideal was that this reorganization also took into account their demands.

You need to be clear on the type and amount of help the caregiver needs to perform the task of caring for a relative with demência.\textsuperscript{10} It can be seen in the speeches of Sunflower and Azalea discovering that now they will have to rebuild their lives realizing the demands of people who care. However, it is necessary that they see themselves and see themselves as being who also need care.

The behavioral changes occur in both subjects: Alzheimer's patient and caregiver. For Daisy and Violet were before the approach that the disease was not possible. In this sense, it is clear that care requires major changes in the lives of family caregivers, such as changes in social relationships, emotional states.\textsuperscript{3}

The mental universe who cares for a person with Alzheimer's is filled with questions. The biggest question is whether they do also have the disease, while others feel powerless in the
face of uncertainty that can cause illness by not having definitive treatment. Those are questions that remain portrayed in the statements below:

**Sorry fear, by being afraid of having Alzheimer’s, because of my parentage. Many people in my family had. (Rose)**

[...] You feel helpless! (Daisy)

It's just the fear there is no cure for this disease, for all I know, because I am secular. I'll Never have a cure for this disease? It is often worse than cancer, disables a person healthy. (Hydrangea)

[...] I am resigned. I have a little faith, hope she improves. (Carnation)

I'm very sorry for him, his suffering can not help but connect like my other family, he left two years without care. (Tulipa)

It can be seen in the words of Rose, Hydrangea and Daisy certain fear about their own future. Generally, this occurs due to lack of cooperation from other family members, having to face challenging situations in the realization of elderly care.

The dilemmas and uncertainties at home and the lack of an adequate support network for families may involve physical health of family caregivers, even causing these adoeimento. The importance of the support groups for caregivers of patients with dementia where not only are seen as caregivers, but as people.

Regarding belief, this same author in the study, there are similarities with that score in this study: the belief in a higher being, faith, as reported Carnation, is part of the strategies of caregivers to face the harsh reality of having a family with Alzheimer's disease.

**CONCLUSION**

The completion of this study enabled the authors to understand the process of experiencing the care of the elderly with Alzheimer's disease in the view of the family caregiver. The results show that respondents care demand for long years and challenging.

Each year the person with AD experiences the loss of autonomy and independence, which creates the condition for disqualification of human life and suffering and burden on families and particularly for caregivers.

From the discovery of the disease through diagnosis compatible, the family caregiver will have the big walk ahead to the challenges that Alzheimer's provides. Several feelings are touched upon in everyday life who chose or was chosen to care for the sick, being seen often, stress, sadness, and fatigue in these people. The commitment to caring for others, whether or not a family member, also calls for the need of a practice of self-care.

It was observed that several changes occur in the lives of family caregivers who are perceived by them as a reorganization strategy to account for this new challenge of caring for a person with AD. Still, it was found that among caregivers is the fear of contracting the disease, disabling and incurable, which makes them feel powerless in the face of uncertainty that causes the disease.

Undoubtedly, the experience of this experience on the part of family caregivers was very personal. However, understanding how caregivers experience may help health professionals, particularly nurses, in program planning guidance to caregivers in order to provide them a better understanding of the disease, how to care and how to take care of.

**REFERENCES**


