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THE FAMILY CAREGIVER AND THE ELDER WITH ALZHEIMER'S: LIMITS AND POSSIBILITIES IN DAILY PRACTICE

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ABSTRACT

Understanding the limits and possibilities coped by the the family caregiver when playing the care to the elderly person affected by Alzheimer's disease. A qualitative study based on the oral history of life. An interview was held with five family caregivers of older people affected by Alzheimer's disease, beginning after approval by the Research Ethics Committee of University Hospital Onofre Lopes - HUOL/UFRN, whith CAAE nº 09886412.2.0000.5292 and Protocol nº 215.229/2013. The daily care provides the caregiver the experience of limits and difficulties arising from the evolution of the disease, this can cause the workload on this subject. Faced.

with this reality, caring can be (re) constructed at each moment of its application, where the caregivers support group arises in order to facilitate the performance of this function and enhancing the health of the family caregiver and the elderly who receive his care.

Keywords: Caregivers; Alzheimer's disease; Aged.

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INTRODUCTION

With the increase in population life expectancy, we have seen a significant increase in the occurrence of chronic degenerative diseases, among which are dementias. Among them, Alzheimer's disease (AD) is most common in elderly people, accounting for about 50% to 70% of its incidence.[1] This is characterized by gradual loss of recent memory. It is estimated that by 2025 there will be 34 million cases of the disease in the world and it is estimated that in Brazil there are 500.000 people. [2]

With the start of AD in one of its members, the family is faced with the need to care, which can be described as perceiving the other in the way it is and as it turns out, its speech and gestures, pain and limitations.[3] Therefore, caring for a person with limitations has its particularities, where necessary, by the family caregiver, understanding and acceptance of individual and collectively. From the diagnosis of AD often the family becomes the primary caregiver. This is usually a close relative, closely linked to the affected person sometimes chooses to exercise this function, other times it is chosen. It is understood within the family that the primary caregiver is the family that performs most of the care to the person affected by the disease and is responsible for supervision, monitoring and mentoring of others who assist in this function.[4]

Family caregivers experience limits and possibilities on the exercise of care by this seek for guidance on the care of AD. Most of the time, come to health facilities shaken with the first changes resulting from the disease, making care a challenge.

The experience of being caregiver involves commitment, time and patience that require skills and fundamental qualities to carry out the activities of daily living with the family. However, these undergo changes in his own biopsychosocial and spiritual well-being because of the drastic change in his life dynamics.[5,6]

In this context, the following question arises: What are the limits and possibilities that family caregivers face in their daily lives to caring for a person with Alzheimer's disease? To answer this question the study aimed to: understand the limits and possibilities faced by family caregivers to play care for the elderly affected by AD.

METHOD

It is a qualitative study that used as a methodological reference the Oral History of Life, developed together with 05 family caregivers of people affected by Alzheimer's disease, the Group participants “Taking care of who takes care”, located in Unit Basic Health Candelária, located in Natal (RN).

Data were collected during the month of March 2013 through an interview with open questions related to the experience of being family caregivers of a person with AD and the repercussions of this in his life. At the end of each interview, notes were made in order to best record the moment and emotions.

The interview in oral history is divided into three phases, first the pre-interview, refers to the organization and scheduling the meeting for the day of recording at this stage the project is presented to the employee, nor it is informed about recording his speech, previously requiring his approval. The next step it is conducting the interview itself, in a calm and pleasant atmosphere. And the third leg, known as post-interview is the time in which to maintain the link between interviewer and interviewee, in order to maintain continuity of the process.[7]

Inclusion criteria for participation were: (1) caregiver family member of a person with AD; (2) to stay with relatives affected by the disease; (3) provide attendance to group meetings; (4) and have experience in caring for at least one year.

In the qualitative approach, oral history of life is characterized as an official picture of the employee and is considered true the version told by the narrator who is free to reveal or hide situations and experiences lived by him. In oral history the witness is considered subject of his history and this part of the process being called employee.[7] To that end, he made a cut in the oral history of life of employees from the moment they assumed the role of family caregivers. After the interview, the processing is vital, where the oral report went through the following steps: transcription, textualization and transcreation. Soon after, it was held the conference of transcribed text, allowing respondents active participation in content review. Analysis of the life stories was based on narratives of employees and their interconnections to be developed and published studies. It is worth noting, that were assigned code names, specifically the names of flowers, in order to ensure anonymity.

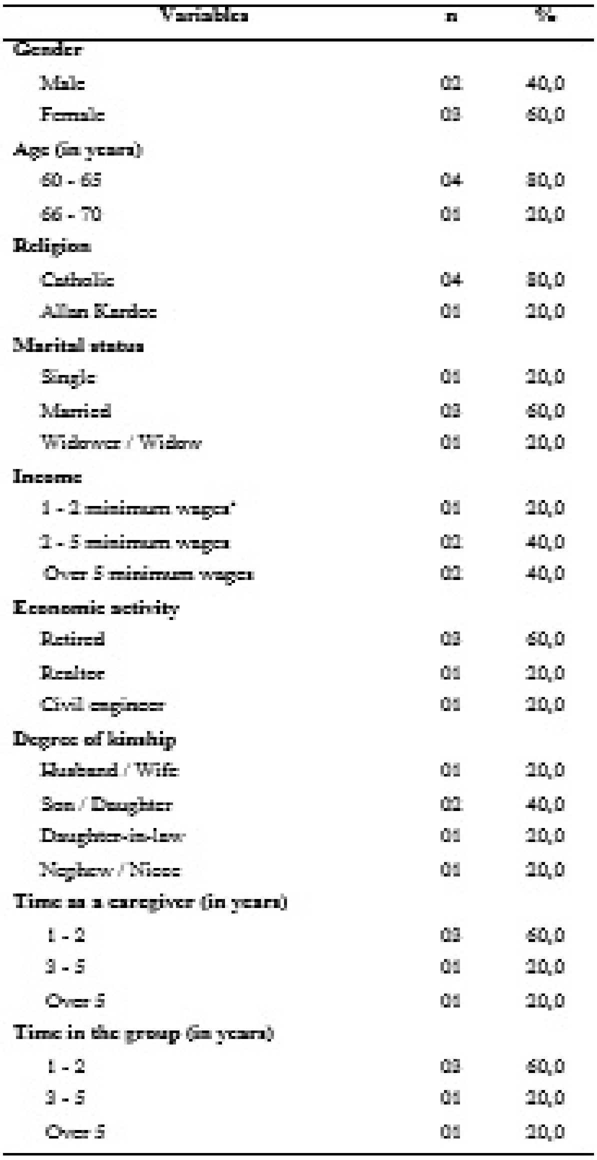
Because it is a research involving human subjects, the study was conducted according to ethical principles of Resolution 466/2012 of the National Health Council; through the favorable opinion by the Research Ethics Committee of the University Hospital Onofre Lopes, with CAAE: 09886412.2.0000.5292 and Protocol: 215.229/2013.

RESULTS

Characterization of family caregivers

According to Table 1, most family caregivers are female (60 %), between 60 and 65 (80 %), has as their creed Catholicism (80 %), married (60 %) with income of 2-5 times the minimum wage (40 %) and above 5 minimum wages (40 %), retired (60 %), the degree of kinship are the children (40 %), shall exercise care for 1-2 years (60 %) and participates in the group between 1-2 years (60 %).

Table 1 - Socio-demographic characteristics of employees survey. Natal/RN, Brazil, 2013.



Variables	n	%
Gender		
Male	02	40,0
Female	03	60,0
Age (in years)		
60 - 65	04	80,0
66 - 70	01	20,0
Religion		
Catholic	04	80,0
Allan Kardec	01	20,0
Marital status		
Single	01	20,0
Married	03	60,0
Widower / Widow	01	20,0
Income		
1 - 2 minimum wages*	01	20,0
2 - 5 minimum wages	02	40,0
Over 5 minimum wages	02	40,0
Economic activity		
Retired	03	60,0
Realtor	01	20,0
Civil engineer	01	20,0
Degree of kinship		
Husband / Wife	01	20,0
Son / Daughter	02	40,0
Daughter-in-law	01	20,0
Nephew / Niece	01	20,0
Time as a caregiver (in years)		
1 - 2	03	60,0
3 - 5	01	20,0
Over 5	01	20,0
Time in the group (in years)		
1 - 2	03	60,0
3 - 5	01	20,0
Over 5	01	20,0

Source: Research data. n=05; *Minimum wage = R$: 510, 00

Take care of the elderly with Alzheimer's:

possibilities and difficulties

The experience of family caregivers of seniors with Alzheimer allows this set care in several ways:

[...] It is to have patience and much love [...] and try to do the best for the affected person. (Chrysanthemum)

[...] Caregiver is a mission that is not easy, we have to prepare ourselves spiritually and physically. (Violet)

[...] Caregiver is for me challenging, stressful and very difficult, especially at first. (Orchid)

In order to minimize the impacts of Alzheimer's in his own life, the family caregiver just adapting to the reality, as the following:

[...] I have to travel in her world, some people may think me a madman, but I do it to have quality of life [...] (Lily)

[...] I have concluded that we should not upset her [...] the more you do it, the more you will suffer [...] (Lily)

Some personal characteristics are improved during caring, allowing the caregiver that suits this new fact, as can be observed in the speech below:

[...] Everything that is done within the care have to be very loving and caring [...] a lot of patience too, because the disease progresses very fast, it needs to walk with her in their procedures in daily care, you need to adapt your life to disease. (Azalea)

The speeches, then, portrays the tumultuous of emotions arising from caring for the elderly:

[...] My father does not recognize me anymore [...] it is very painful for me. Shocked! (Violet)

[...] It was a thud know that my wife was stricken with this disease [...] I became very sad and worried [...] (Chrysanthemum)

In the speech below caregivers express the importance of self-care, as well as the difficulty of applying it and prevent illness resulting from own care.

[...] We need to take care also to take care of each other, but this is much pruned. (Violet)

[...] If you are not calm and patient, you get despair and sick [...] (Azalea)

The family caregiver of everyday life can lead to changes in several areas of his life, as is explicit below:

[...] Alzheimer's disease came and disrupted my life, live recluse [...] I have concluded that [...] disrupts the family emotionally, financially, not counting family issues [...] (Lily)

[...] Have to find a less stressful way for me, it's too difficult, but not impossible [...] (Chrysanthemum)

Moreover, it can be observed the current workload of caring for the elderly with AD:

[...] My wife that is also caretaker, recently had a heart attack, it was certainly caused by excessive worry and care [...] by Alzheimer's disease. (Lily)

Among the many difficulties that the family caregiver faces in everyday life by providing care to the person affected by the AD that prevailed in the speeches of employees is the lack of interest, support and help of family:

[...] The great difficulty I feel is that for now do not have much support and help the family in care [...] my children live here [...] but I feel they are very absent, only help me financially [...] (Chrysanthemum)

[...] The family assumes the disease, not to help care for, can never, I usually say that it is the family hummingbird comes, kisses and back to his home [...] (Lily)

However, they end up adapting to this care alone, as can be seen below:

[...] What bothers me is only not having family support [...] at the beginning was very angry with this situation [...] no one visited nor offered help [...] already suffered a lot with this, but today don't care anymore. (Orchid)

Still, there are other listed difficulties, which are present below the narratives of employees:

[...] My difficulty is in care, there are days when a lot of work to get her out of bed, she did not want to get up at all [...] (Orchid)

[...] I had trouble during Dad's hospitalizations [...] the person with Alzheimer's disease does not like to be confined, like freedom [...] (Azalea)

[...] There are the limits imposed by the disease, especially of social life [...] (Violet)

The family caregivers support group: breaking paradigms and basing the handle

When telling their stories, all caregivers recognized the importance of their Group "Taking care of who takes care". At the meetings, they share experiences, receive guidance and learn how to deal with the AD.

[...] It is this group that is supporting me, giving me allowance so you can make the best [...] the group fully supports, there is exchange of experiences, and one helps the other [...] Chrysanthemum

[...] For me the group was all, the door of hope for knowledge, exchange of ideas, experiences of other people who care for their loved ones [...] the group is only strengthen me, every day, every meeting I participate I leave lit, stronger, fuller knowledge to continue taking care of my father. (Violet)

[...] without him I would not know how to stay. There are days when the group get emotional and still cry, depending on the topic discussed. Some days I get lower, a little sad, but I go out very good of the group [...] with this group of caregivers was that I found support and quiet, the name is that, quiet, both to look after me and to take care of it . (Orchid)

[...] The group to me fell from the sky. There felt supported by carers and also gave support to them. It's a constant learning [...] with the group helps people realize you have a light at the end of the tunnel. (Azalea)

DISCUSSION

The predominance of women in this study corroborates the statement in others, reporting that the majority of caregivers are female.8-10 This may be associated with gender issues, for the woman, throughout history, is who performs the role of caregiver, mainly due to the maternal instinct, and this is still an expected allocation by the Brazilian society.[4, 11]

Thus, practice care demand commitment, patience and time. To be responsible for the care of their loved one with AD, the family caregiver becomes an essential element in the care process, because the essence of being human is simply in care.[12]

The essence of care presents itself to the extent that there is the existence of someone important for you. Thus, the subject is now available to the other through the dedication and active participation in their living.[12]

Family caregivers are subject to change in your lifestyle and well-being, due to the activities performed by them in the care.5 Often need to adapt to the elderly being careful in order to mitigate the disease's impact on their life, so the care is based on how inspiring component of a new paradigm of user-friendliness.[12]

So that there is harmony in the interaction between the person with AD and his family, he needs to occur to adapt to the new scenario, mainly by the caregiver as AD causes gradual cognitive losses, behavioral and emotional changes. In this circumstance, to be caregiver is essential a lot of love, patience, time, dedication, warmth, energy and effort.[13]

In the course of life the human being brings endless experiences, which can be described as positive and negative, and arising from the search, the meeting, of course, the perplexity and the plunge into being.[12]

The caregiver's role becomes increasingly difficult as the disease progresses, because the affected person becomes more dependent, which requires time, dedication and even greater care from the caregiver. In this construct, it tends to abdicate their life priorities in favor of care and could interfere with their quality of life. In addition, monitor the phase involution of a loved family caregiver imposes on a state of great weakness, anxiety, and other feelings.[13]

Therefore, there may be significant changes resulting from the disease on quality of life of caregivers, the physical, emotional and social aspects happen, especially when the person affected by AD presents its most compromised functional capacity.[14]

So, the quality of life is defined as the individual's perception contemplating several meanings derived values, individual and collective experiences and knowledge[14]. This concept is considered very complex due to treating yourself to relations between the means and biopsychosocial aspects, in addition to beliefs advocated by the individual.

These changes occur due to stressful and heavy daily burden of care faced by the caregiver, resulting in decreased self-care, social and affective life and leisure time.15 It also causes changes in the life of the affected person also destabilizes the family context in which it is inserted, bringing as a result the physical and emotional distress for those involved, just overhead.[11]

Moreover, the provision of care to people affected by AD also generates extra work with physical wear and emotional.[16] This brings great impact on the family, requiring increased attention from health professionals. These should include family planning of their actions in the care process, seeking to provide reducing the vulnerability of the people involved in the process of care.
The lack of family support is sharp, family caregivers express a need for family support, not just by the financial support of their families, let alone the support of contracted people. Thus, the care process can cause a crisis in the family caregiver performance and a workload in his life.[16]

In the survey with 208 family caregivers of people affected by AD, assessed the level of workload, which prevailed moderate.[17] It is a reality that needs to be taken seriously, where supportive measures should be taken in order to not reach the negative physical, emotional, social and spiritual caregiver, as this due to the emotional involvement between caregiver and who is taken care of, and also by modifying the relationship between them from reciprocity to dependence.

It is noteworthy that the family caregiver usually does not have training and expertise to assist his practice, has only the experience acquired throughout his life path. So, for that care be improved and to be successful, you need support and guidance of health professionals. Therefore, it is essential that they know and understand the reality of routine of every caregiver with his relative affected by AD, considering that this experience is very specific, it depends on the dynamics and history of each family.

At the beginning of AD ignorance of how the disease develops, which causes and how to deal is an obstacle that impairs much of the care performance for some caregivers. The participation of employees in the Group “Taking care of who takes care” contributed to moderate these doubts and anxieties.

The interruption of interpersonal relationships, mainly between the caregiver and their family members may be the result of AD. Moreover, it has a considerable financial burden on the family.[18] For these reasons, among many others existing in the context of AD, is of extreme importance the existence of support groups that offer support and self-help for family caregivers of people with Alzheimer’s disease, and instigate the search, collective strategies to confront the problems faced by them, critical to the bio-psychosocial well-being of the elderly with AD and the own caregiver.[18]

The support group seeks to provide guidance about AD, the care provided, and the issue of self-care, as the disease presents a progressive and long form. Thus, the caregiver must be prepared to face new situations that are likely to appear in his daily life with the person affected by AD, providing the exchange of experiences in which the participants benefit from finding answers to their doubts, anxieties and concerns, so that their quality of life is encouraged.[6]

It is observed that each employee has a unique way of dealing with AD and their role as well as by the impact in their life. Factors as support of family, faith, resignation, resignation before the disease, supporting a support group, among others, are used as ways of strengthening so that they can continue on their journey. It is noteworthy that these factors vary from one caregiver to another, since they are influenced by existing beliefs and values in your own life story.

FINAL NOTES

Being a family caregiver of a person affected by AD is a challenge to be exercised for a prolonged period. It begins to relate to the pain, stress and burnout, which involves many sacrifices in life. One must consider the situation experienced by family caregivers and elderly patients with AD as a public health issue, which requires investments in social and care programs and promoting the health of people affected by AD and also their family policies.

Despite these impacts, all seek to improve their quality of life and their relatives with AD. But for this improvement is achieved, other issues must be considered, such as the guarantee of constitutional rights, the provision of support to health professionals, family and society to face these difficulties arising from the DA.

Health professionals need to understand the elderly caregiver difficulties in dealing with AD, forward to the numerous situations experienced. In each situation it is of vital support in guiding the care and coordination of activities related to health promotion and protection, in order to create conditions for a quality life. It called for the need for all schools, colleges and forming health professionals universities awaken future professionals to the importance of support to the caregiver and elderly.

And the creation of support groups for family caregivers across the Attention Network Basic in the country’s health, where the multidisciplinary team can work with caregivers and individuals affected by AD through the use of strategies that provide welfare, greater autonomy and quality of life, contributing to minimize the impact of disease and overhead, providing more safety and efficiency in the execution of care.

Thus, the scientific and social relevance of this theme in the field of the health team contributes to the work of health professionals towards family caregivers and the own people affected by AD. And, still, stimulate other researchers to advance in this field of research and action.

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