THE REPERCUSSIONS OF ALZHEIMER’S DISEASE ON THE CAREGIVER’S LIFE

 LOS EFECTOS DE LA ENFERMEDAD DE ALZHEIMER EN LA VIDA DEL CUIDADOR

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ABSTRACT

Objective: to describe the repercussions of Alzheimer’s Disease on the family caregiver’s life. Method: this is a descriptive research, with qualitative approach, developed in the North region of the municipality of Montes Claros. The family caregivers of Alzheimer’s patients participated in this study. Results: from the results analysis, five categories emerged: “Caregiver’s knowledge about Alzheimer’s disease”; “Feelings unveiled by the caregiver of the patient’s”; “Alzheimer’s disease, caregiver’s overload”; “Major difficulties encountered by the caregiver in caring for the Alzheimer’s patient”; “Strategies used by caregivers in coping with behavioral changes in patients with Alzheimer’s disease”. Conclusion: the study allowed identifying that the repercussions of Alzheimer’s Disease on the family caregiver’s life may cause negative feelings experienced by them. Descriptors: Elderly; Alzheimer’s Disease; Caregivers.

RESUMO


RESUMEN

Objetivo: describir los efectos de la Enfermedad de Alzheimer en la vida de lo cuidador familiar. Método: investigación descriptiva, con enfoque cualitativo, realizada en la región Norte de lo ciudad de Montes Claros. Resultados: desde el análisis, cinco categorías surgieron: “Conocimiento de lo cuidador sobre la Enfermedad de Alzheimer”; “Sentimientos revelado lo cuidador lo paciente con Alzheimer”; “Enfermedad de Alzheimer, sobrecarga lo cuidador”; “Principales dificultades encontradas lo cuidador lo cuidado con o paciente con Alzheimer”; “Estrategias utilizadas por los cuidadores lo enfrentamiento de las alteraciones comportamentales lo paciente con la enfermedad de Alzheimer”. Conclusión: el estudio permitió identificar que las repercusiones de la Enfermedad de Alzheimer en la vida lo cuidador familiar pueden causar sentimientos negativos vivenciados por ellos. Descriptores: Ancianos; Enfermedad de Alzheimer; Cuidadores.

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The population has been aging all over the world. The last Brazilian population census, conducted in 2010, showed that the number of elderly people in Brazil reached 10.8% of the population, corresponding to about 20.5 million individuals. The country, by 2025, shall represent the sixth country with the largest number of elderly. The increase in life expectancy, the fall in mortality and fertility rates are the main responsible for that increase in population.¹

In 2010, there was an increase in the elderly population in Brazil. Data from IBGE (2010) showed that the number of elderly in the country was 19,331,986, representing 10.13% of the population, 11.22% of the elderly lived in Minas Gerais, and 0.16% in Montes Claros.²

That change in the demographic profile results in the increased incidence of chronic and degenerative diseases, more frequent in that age group, such as the dementias.³

Dementia is considered as the loss of brain function, leading to memory loss, besides affecting the language reasoning, changing the individual's behavior. The disease is caused by a set of signs and symptoms that manifest in the individual, altering his/her health, causing physical and mental disorders.⁴ After 60 years of age, there is an increase in dementias every five years.⁵

The most prevalent dementia in aging is Alzheimer's Disease (AD), which accounts for 50% to 60% of dementias.⁶ AD is a progressive neurodegenerative dementia characterized by progressive disturbance of memory and other cognitive functions, affecting the individual’s occupational and social functioning. The memory disorder also impairs learning and evocation processes, with a gradual decrease in the acquisition of new information, until there is no new learning.⁷

AD occurs in three phases: primary (mild), secondary (moderate) and tertiary (severe), which worsens every three years. In the primary phase, the patient presents difficulties related to recent memories. Changes in personality, aggressiveness, communication difficulty, logical reasoning, and remembering familiar names are also evident. The patient is confused to make decisions, but is aware of his/her difficulties.⁴

In the secondary phase, there is an aggravation of memory deficit and personality disorders. The patient is more hostile, with difficulty of communication, (in this phase, he/she speaks more fluently, but without coherence or logic). It is also when the appearance of tremors, and greater aggressiveness occurs.⁴

In the tertiary stage, motor functions are impaired, causing the Alzheimer’s patient to become very dependent on a caregiver for the performance of daily activities, such as personal hygiene, bathing and feeding. In addition to the disorientation, the patient presents with immobility syndrome, which becomes more and more severe until death.⁴

When a patient is diagnosed with AD, there are some changes in the family’s behavior, since the disease affects all members, even in different degrees, and some members may distance from the situation, either because of shame or because they do not understand or do not know about the disease⁸. Caring for the elderly is to accept both the individual as the collective aspect of aging, which is an inherent and existential process⁹, therefore, the caring process (and the role of the caregiver) is an exercise that happens over time, unplanned.⁹

The construction of the caregiver role of an elderly person with AD occurs when there is an evolution of the illness, with the members of the system living under care. The position of the caregiver usually follows determinants of kinship, and, in most cases, spouses, daughters and sons-in-law exercise that role, with a higher prevalence of women.¹⁰

With the AD diagnosis, the caregiver becomes fully included under his/her care, and, from that condition, the family members become involved, since the diagnosis directly affects the routine of the patient’s family.²

Relatives of patients with the degenerative disease commonly use the expression “death in life”.¹¹ Therefore, with the individual’s psychic and functional impairment, the family, while dealing with the dementia process, faces the discomfort of experiencing the disease as being the death before the death itself.¹²

Most of the time, the caregiver abdicates from his/her own life to provide an integral care of the bearer, causing an overload of physical and mental strain, also affecting his/her emotional and financial side. With the disease evolution, it is common to distance the family from the care of the patient, and there is no collaboration of all the members in the care of the AD patient. That lack of division in relation to caring for the elderly results in several consequences, such as the caregiver’s overload and illness.¹⁰

The caregivers of the elderly with AD present an increase of the psychiatric...
symptoms, besides greater problems in the personal relationships, with current conflicts between the familiar members. There is also worsening in their health status, and problems are common in the professional field. Behavioral changes can occur, such as hallucinations, insomnia, delirium, signs of depression, aggression and disturbance. Thus, caregivers need constant guidance and help on the adequate strategies how to deal with the elderly with AD in difficult situations.

The health team must pay attention to the needs, difficulties and health conditions of the caregiver, also noting their expressions of discouragement, sadness and fatigue. As the disease worsens, there is need for more care, and both the caregiver as the person with Alzheimer's disease needs to receive quality care.

The Family Health Strategy (FHS), the user's preferred gateway to the Unified Health System (SUS), consists of multiprofessional and interdisciplinary teams that include doctors, nurses, community health agents, nursing assistants, oral health assistants, responsible for monitoring families in a defined territory, focused on integrated actions to promote, prevent and rehabilitate, and represents a space propitious for the provision of guidelines to the caregiver of AD.

**OBJETIVO**
- To describe the repercussions of Alzheimer's Disease on the family caregiver’s life.

**METHOD**

Descriptive study, with a qualitative approach, carried out in the northern region of the municipality of Montes Claros, Minas Gerais, Brazil, in areas covered by the FHS, at the households of the interviewees.

Family caregivers of elderly people with Alzheimer’s disease participated in this study. The inclusion criteria for participation in the research were as follows:
- Being a family caregiver for the elderly with AD or responsible for the care of elderly people with AD
- Being over 18 years old
- Providing direct and continuous care to patients with Alzheimer's Disease
- Residing in the municipality of Montes Claros-MG
- Accepting to participate in the research, by signing the Informed Consent Form - ICF

A semi-structured interview script was used to collect the data. Initially, there was a visit to the municipal health department of Montes Claros, and a copy of the project containing the proposal of the research and the Term of Agreement of the Institution-TAI was delivered. The researchers themselves, in October 2015, carried out the interviews in home visits to the interviewees of the selected FHS. The interviews took place through a previous appointment, with an approximate duration of 30 minutes and without the presence of the AD patient, so that there was no interference in the responses and the interviewees did not feel afraid to provide the information.

The data were collected by theoretical saturation. Data were analyzed from the speech fragments of the participants, using the Thematic Content Analysis technique, as well as the theoretical basis of Symbolic Interactionism.

A code represented by a letter and a number was used to identify the participants, thus ensuring the anonymity and confidentiality of the interviewees. In that way, the subjects were denominated in C1, C2, C3, C4, C5 and so, successively. The present study obeyed Resolution 466/2012 that deals with ethical care with researches involving human beings. The study participants received the Informed Consent Form (ICF).

The study was submitted for evaluation of the Research Ethics Committee (CEP) of SOBRAS with a favorable opinion (No. 48312415.4.0000.5141).

**RESULTS AND DISCUSSION**

- **Characterization of the participants**

Five family caregivers participated in the study, being four women and one men; son/daughter was the most frequent degree of kinship, with the mean age of 38 to 62 years. Most had completed high school.

Regarding familiarity, the study found that most caregivers were women (daughters). This fact may associate with gender issues, since women, throughout history, many times, is the one who develops the caregiver role. Such event finds support in the affirmation that a daughter or the wife is usually who assumes the role of caregiver and is responsible for that person. The woman has a maternal instinct; when taking care of a sick person, she becomes gentle, comprehensive, and has a great capacity for love and detachment.

From the results analysis, five categories emerged: “Caregiver’s knowledge about...
Alzheimer’s disease”; “Feelings unveiled by the caregiver of the Alzheimer’s patient”; “Alzheimer’s disease, caregiver’s overload”; “Major difficulties encountered by the caregiver in caring for the Alzheimer’s patient”; “Strategies used by caregivers in coping with behavioral changes in patients with Alzheimer’s disease”.

♦ Caregiver’s knowledge about Alzheimer’s disease

When questioned about the knowledge of Alzheimer’s disease, most caregivers presented little knowledge about the AD process, as shown below:

Very little; it is just the question of forgetfulness of memory where people return to the events of the past and forget the things of the present (C2).

I know little about the subject, right? The little bit I know is that the person is going to forget about the short term or the long term (C5).

I know she forgets things, and lose memory that we talk about, sometimes she does not want to eat (C4).

The lack of knowledge on AD may contribute to the lack of understanding of caregivers on the difficulties of the elderly, as well as compromise their independence and autonomy, originate conflicts and generate stresses and anxieties, for both the elderly as the caregiver.

♦ Feelings unveiled by the caregiver of the Alzheimer’s patient

Daily care can lead to the narrowing of affective bonds, intimacy and reciprocity between caregivers and the one cared for. Such daily care that favors a very close relationship sometimes creates conflicts between caregiver and the person cared for.

In that way, that relationship can cause feelings of oppression, grief, sadness, among others. When it comes to a relative, the bond can become greater and the relationship of compassion and solidarity causes the caregiver to be subjected to that mix of feelings in the face of that situation.

In this sense, the objective of this category was to identify which feelings involve the caregiver of the AD patient. The feelings that stood out were sadness, tribulation, fatigue, impotence, indignation, revolt, etc.

I am sad to know that he is in this prostrate situation (C1).

A little difficulty for being a layperson in the subject, until you realize the situation and do not know how to deal with the situation, so until you learn what it is, it generates a lot of tribulation in us, even fatigue, and it becomes very exhausting in life; you have to work, you have to deal with it all (C5).

It is of revolt, pain, many things, sadness, impotence, wanting to do more and having no condition (C2).

In the relationship between caregiver and patient, there may be varied and contradictory feelings, such as anger, stress, nervousness, irritation, crying, guilt for the illness, compassion for the debilitated family member, impatience for the obligation to offer care and support. Furthermore, that simultaneity of feelings makes caregivers more vulnerable to psychiatric disorders, hypertension, digestive symptoms, family and work conflicts.

♦ Alzheimer’s disease, caregiver’s overload

In this category, focus of this research, the objective was to understand the repercussions that Alzheimer’s disease has on the caregiver’s life. The caregiver’s overload, which greatly affects his/her life, stands out, even preventing the caregiver from living, as exemplified by the statements below:

It affects in every way, I feel always overwhelmed, because I see that I am sacrificing a lot my family, my children are being harmed, my husband, and especially myself because sometimes, I have a term here at home that no one can scold her, I can, because I stay with her daily, I deal with her all the time […] who cares for a person in this state cannot have a life other than their life (C2).

Yes, I feel overwhelmed, both me as my brother, since we are men and have to take care of her, who is a woman, then we, since we know little too, we often cannot completely deal with this situation as I have said before (C5).

Pause to answer. Then she responds: no, I do not feel overwhelmed, (showing sadness during speech), […] Look, before this disease, we had a greengrocer, we worked together, but when I saw that he could not handle anymore, he was forgetting everything, I ended up closing it and started to dedicate to his care (C1).

Caregivers often care much more about providing care than about caring for themselves, giving most of their time to that role. Such behavior can become quite physically and psychologically harmful to the caregiver and compromise the care of the elderly.

Changes in caregivers’ lives affect their daily activities. Family caregivers tend to distance themselves from family and social life as the illness of the one cared for progresses. In that way, there is usually an overload of emotion and activities, which
changes the life of the one who compromises to take on that caregiver role. 20

Since the care act can generate emotional and physical exhaustion, the caregiver should take some time for him/herself, for leisure, to distract, to feel more emotionally prepared, and not to compromise the provided care. 21

Given the challenge of dedication to the elderly, the caregiver restricts his/her life to donate his/her time and energy only to the patient, forgetting his/her desires and difficulties. 24

◆ Major difficulties encountered in caring for the Alzheimer’s patient

The purpose of this category was to understand how AD affects the caregiver’s dynamics and routine. The greatest difficulty found by caregivers was providing care to the Alzheimer’s patient without the help of another person, which makes care tiring and stressful.

The greatest difficulty was when he had to stay in wheelchair, because he is too heavy and I could not take him from bed to put in the chair, so I had to hire an assistant, a lady comes every day, to bath him, in the morning and afternoon (C1).

Look, the greatest difficulty I find is during bed time, because it is like I say to my husband, for me, it is a pleasure to take care of my mother, because, every day that goes by, it makes me change as a human being [...], thus, this time is hard, because, if she slept well at night, we could take a break at night [...]. Everybody has to sleep at night [...]. It does not only mess up with my sleep, but also with theirs, then everybody ends up getting angry (C3)

It is like I was saying, it is hard to stay with her because she is too weak. (Crying) (C4).

The AD progression emphasizes the need for care in full time, which makes the elderly dependent on care. In that way, the caregiver is involved in all daily activities of the elderly, from the Instrumental Activities of Daily Life (IADL), such as managing the finances and medications, and increases his/her responsibilities regarding the Basic Activities of Daily Life (BADL), such as personal care tasks of hygiene, bath and feeding.

Similarly to other studies, situations the elderly previously performed easily, they cannot perform them currently, so that they need a caregiver in all moments. 25 The interviewees also mention the physical wear as one of the greatest difficulties when caring for those elderly, since the caregiver sees him/herself as the one who keeps the adaptations that the disease brings. 26

The excessive care activities, along with the care overload on only one family member, produce feelings of disability and personal wear in the caregiver. 19

◆ Strategies used by caregivers in coping with behavioral changes in patients with Alzheimer’s disease

The behavioral changes, such as “calling for people who already deceased”, or saying “I want to go home”, disturbance, insomnia, depression, aggressiveness, are very common in Alzheimer’s Disease. Therefore, this category intended to identify mechanisms of coping with those changes by the caregiver. That questioning allowed realizing the need to search for emotional consolation or comfort in religions or in God.

First, I try to keep calm, search for God [...]. Look, I am Evangelic, I go to the church every day, I believe that, without God in life, I could not take it, but he gives me strength every day, sometimes people question me and say “I do not know how you put up with that situation and are always happy!” The truth is that we cannot feel sad, but we need to ask God to be stronger every day. (C1)

[...] When I am alone, I use music a lot, praise, DVD, you know, trying to distract her mind a little, it is when she gets quieter, listening. So, the music is very quiet, it draws her attention [...]. (C4).

[...] I try to calm him down, sometimes I sing for him to sleep, pray, get the chaplet, hold his hand, we pray, and, when I am praying, he calms down, he keeps quiet, you know, it looks like his heart [...]. Sometimes I put him in bed, take the chaplet, put it in his hands, and he falls asleep. Sometimes I sing, just like I sing for a boy, like when I sing for my grandchildren to sleep. I talk to him as if I was talking to my grandchildren, then he sleeps, a little bit, but he sleeps, which gives us a good rest (C3).

The increased care frequency in daily life activities results from the time-space disorientation, along with recent memory and behavioral changes, which requires coping conditions, in order to provide care, comfort, relief and safety, and, with that, reduce the possible tensions. 27

Healthy coping strategies, such as healthcare, leisure moments, faith, social network and external family support, can make the act of caring for an Alzheimer’s patient a less painful and more shared process. 28

The repercussions of Alzheimer’s disease...
CONCLUSION

This study allowed describing the main repercussions of Alzheimer's disease in the life of the family caregiver, such as negative feelings experienced by them due to the lack of knowledge about AD.

The overload experienced by the caregiver leaves him/her exposed to several factors that lead to stress and physical and emotional exhaustion, considering the total obligation to provide care to the Alzheimer's disease patient. The family is the main point of support for the AD patient, as long as a single member does not perform the care alone, for he/she may develop psychological problems that affect his/her family and social life. Such fact refers to the need for greater assistance and guidance of FHS professionals to provide information to the family of the elderly with AD on the disease and its evolution, in the development of educational and recreational activities aimed at the integration of the family into the social and individual caregiver's life.

It is necessary to recognize that the caregiver is a person, who requires specialized interventions in the matters related to the care given by him/her. Support is critical to his/her health and quality of life and, consequently, to the care provided to the elderly with AD, since physical and emotional exhaustion can turn him/her into a potential patient.

REFERENCES


The repercussions of Alzheimer's disease...