JNUOL
Journal of Nursing
Revista de Enfermagem
UFPE On Line
ISSN: 1981-8963

ORIGINAL ARTICLE

ALZHEIMER'S DISEASE: BIOPSYCOSOCIAL REPERCUSSIONS IN THE LIFE OF THE FAMILY CAREGIVER

DOENÇA DE ALZHEIMER: REPERCUSSÕES BIOPSICOSSOCIAIS NA VIDA DO CUIDADOR FAMILIAR

ENFERMEDAD DE ALZHEIMER: REPERCUSIONES BIOPSICOSOCIALES EN LA VIDA DEL CUIDADOR FAMILIAR

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ABSTRACT

Objective: to characterize the difficulties faced by family caregivers of elderly people with Alzheimer's disease. ***Method:*** qualitative, descriptive, exploratory study, with the participation of ten family caregivers of elderly people with Alzheimer's diagnosis enrolled in Basic Health Units (BHU). The data collection was by semi-structured interview. The construction of the thematic categories was based on the content analysis of Minayo, with results arranged in four thematic categories. ***Results:*** difficulties emerged in the categories (1) Social and family support network; (2) The caregiver regarding the different stages of Alzheimer's disease; (3) Feelings experienced in the process of care and (4) Changes in personal and social life. ***Conclusion:*** for the caregivers, the greatest difficulty was the lack of social support during the care process for the elderly. ***Descriptors***: Caregivers; Aging; Dementia; Alzheimer's Disease; Mental Health; Nursing.

RESUMO

Objetivo: caracterizar as dificuldades enfrentadas pelos cuidadores familiares de idosos com Alzheimer. ***Método***: estudo qualitativo, descritivo, exploratório, com a participação de dez cuidadoras familiares de idosos com diagnóstico de Alzheimer cadastradas em Unidades Básicas de Saúde (UBS). A coleta de dados deu-se por entrevista semiestruturada. A construção das categorias temáticas baseou-se na análise de conteúdo de Minayo, com resultados dispostos em quatro categorias temáticas. ***Resultados***: as dificuldades emergiram nas categorias (1) Rede de apoio social e familiar; (2) O cuidador frente às diferentes fases do Alzheimer; (3) Sentimentos experienciados no processo de cuidado e (4) Mudanças na vida pessoal e social. ***Conclusão***: para as cuidadoras, a maior dificuldade foi a carência de suporte social durante o processo de cuidado ao idoso. ***Descritores***: Cuidadores; Envelhecimento; Demência; Doença De Alzheimer; Saúde Mental; Enfermagem.

RESUMEN

Objetivo: caracterizar las dificultades enfrentadas por los cuidadores familiares de ancianos con Alzheimer. **Método:** estudio cualitativo, descriptivo, exploratorio, con la participación de diez cuidadoras familiares de ancianos con diagnóstico de Alzheimer, registradas en Unidades Básicas de Salud (UBS). La recolección de datos se dio por entrevista semiestructurada. La construcción de las categorías temáticas se basó en el análisis de contenido de Minayo, con resultados dispuestos en cuatro categorías temáticas. **Resultados:** las dificultades que surgieron en cuatro categorías: (1) red de apoyo social y familiar; (2) El cuidador frente a las diferentes fases del Alzheimer; (3) Sentimientos experimentados en el proceso de cuidado y (4) Cambios en la vida personal y social. **Conclusión:** para las cuidadoras, la mayor dificultad fue la carencia de soporte social durante el proceso de cuidado al anciano. ***Descriptores***: Cuidadores; Envejecimiento; Demencia; Enfermedad De Alzheimer; Salud Mental; Enfermería.

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INTRODUCTION

Aging is one of the most discussed issues today due to the demographic and epidemiological transition in which Brazil and other countries are found.[1] The aging process is natural and inevitable, involving a series of physical, cognitive and emotional changes. However, as life expectancy increases, dementias and neurodegenerative diseases, such as Alzheimer's Disease (AD), can lead to cognitive and motor decline.[2]

According to data from the World Alzheimer's Disease Report, the Alzheimer's Disease International (ADI) Federation, about 47 million people live with dementia worldwide. This number is projected to increase to over 131.5 million by the year 2050. In addition, the estimated number of people with AD reaches 35.6 million worldwide and this number continues to increase significantly[3], which causes concern about the type and quality of government support that Brazilian elders will have in the future.

According to the World Health Organization (WHO), AD is considered the most common form of dementia affecting the elderly, accounting for approximately 60 to 70% of the cases.[4] In Brazil, there is no precise data on the incidence of Alzheimer's disease. However, according to data from the Brazilian Institute of Geography and Statistics (IBGE) and research conducted in other countries, it is estimated that there are approximately 1.2 million patients with AD in the country and an incidence of about 100 thousand new cases every year.[5] According to DATASUS, in the State of Pernambuco, between 2008 and 2016, there were around 176,600 cases of the disease.[6]

Dementia has a significant economic impact on the world's public coffers, costing approximately $ 818 billion at present and projected to increase to trillions by 2018.[3] This leads governments and health professionals to work hard on prevention and treatment of dementias.[7]

When the elderly present difficulties or limitations in the performance of their activities, it is necessary that they be accompanied in their routine by a caregiver who can be part of the family or not, a provider of formal or informal care.[8] In this way, the care process it becomes very complex, because new feelings arise, related to the experience, moments of constant stress and changes in their lifestyle, since the caregiver moves from being responsible for oneself to being responsible for another individual, which, in the long term , can lead to an overload for the caregiver and thus, acute and / or chronic diseases.[9] Under such an approach, the family caregiver must adapt to the changes that occur in the life of the elderly. The tasks related to care require competence, ability and responsibility generating a great psychological burden that ends up affecting the mental health of these caregivers and may lead to the development of a psychopathology.[10]

The National Policy on the Elderly (1999) considers the family, together with society and the State, responsible for providing care and meeting the needs of the elderly at home.[11] However, when it comes to social support structure in Brazil, this is ineffective and lacking an organized support network that benefits such families.[9]

In addition, focusing on the characterization of the target audience of this study, it is considered a family caregiver of the elderly the individual with a kinship relationship and who has assumed most of the responsibility of caring for the elderly with AD. Therefore, it is extremely important to identify these caregivers, to know their reality and to study ways of supporting the family members who become responsible for the continuous care of elderly individuals with AD.

Based on the above, the following research problem and guiding question emerged: What are the repercussions suffered by family caregivers of elderly people with AD during the care process in the different stages of the disease in the city of Pesqueira - PE? Attempts were made to identify the difficulties and problems faced by the family members who care for the elderly with AD. Also, the non-location of support groups for the elderly family caregiver in the municipality and, also, the lack of registration of the numbers of elderly people with AD in the city of Pesqueira - PE and their respective profiles.

OBJECTIVE

- ♦ To characterize the difficulties faced by family caregivers of elderly people with Alzheimer's disease, during the care process.

METHOD

This is a qualitative, descriptive, exploratory study carried out in the municipality of Pesqueira, in the agreste of Pernambuco, which has a population of 66,881 inhabitants, of whom 7,723 are elderly.[12] This municipality was chosen because it hosts curricular activities and extension of the Bachelor's degree in Nursing, IFPE Campus

Pesqueira, with characteristics that make possible the composition of the teaching-research-extension triad as a potentiator of multiprofessional and interdisciplinary interventions in coping with the health demands of that community.

Ten family caregivers who met the following inclusion criteria were: caregivers of elderly people with Alzheimer's disease, duly registered at the Basic Health Unit (BHU), which covers their domicile; who had a relation of kinship with the elderly; identified as primary caregiver; who have been caring for the elderly for at least six months and older than 18 years.

The sample was non-probabilistic for convenience, considering factors such as the lack of accessibility to the target public as a whole, the speed in reaching the information, as well as the low cost involved. The choice of BHU was made with the support of the Coordination of Basic Attention of the Municipal Health Department.

This research was approved by the Committee of Ethics in Research with Human Beings of the Association Caruaruense of Higher Education and Technical - ASCES, under the opinion n ° 67529517.4.0000.5203, according to the resolution 466/2012.

Data collection took place in the period from June to September 2017, conducted in a semi-structured way, allowing family caregivers to express themselves freely.

The first contact with the caregivers was carried out through a home visit (HV) of the researchers, together with the Community Health Agents (CHA), in their respective areas of coverage, according to the following steps: active search together with the teams from each unit to schedule home visits; home visit for the presentation of the Free and Informed Consent Term (FICT), which, after reading and agreeing, was signed by the subjects of the research; interviews with family caregivers of elderly people with Alzheimer's, respecting the ethical precepts that govern researches with human beings and obeying the semi-structured script and the guiding questions. The interviews had an average duration of about 40 minutes, were transcribed and double checked.

A questionnaire was filled out with sociodemographic variables and health conditions containing: age, sex, schooling, marital status, relationship, profession or occupation, number of children, compensation, self-reported disease and time spent on care. The second part of the questionnaire was composed of guiding questions that question all the aspects related to the research objectives, namely: 1) What is the greatest difficulty (s) in relation to the care? 2) What do you do to try to overcome the difficulties around care ?; 3) Is the care process shared with other people ?; 4) How is the division of schedules between those who participate in the care? 5) Have you developed any health problems during the care process ?; 6) If so, what guidelines did you receive from health professionals to solve the problem ?; 7) What is your feeling about care ?; 8) Name and describe what feelings you have felt throughout the care process ?; 9) What was the worst phase of the disease? Because?; 10) The time offered for care allows you to have leisure time?.

The content of the interview was transcribed in the form of each caregiver and then passed on to Microsoft Word 2010 and analyzed using a two-step analytical process. Thematic manual coding of interviews was performed twice: first, with the objective of developing and refining the range of codes and then, in order to abstract the essential categories and themes in the data.

The reports were submitted to the content analysis, in the category modality that is characterized by a set of communication analysis techniques, which uses systematic procedures and objectives that describe and give meaning to the messages, and unfolds in the following phases: pre-analysis, exploitation of the material and analysis and interpretation of the data obtained.[13]

After analyzing the interviews with the caregivers, four categories were defined concerning the repercussions of the care process for elderly people with Alzheimer's disease: 1) Social and family support network, characterized by family members, professionals and the community to which the caregiver belongs; 2) The caregiver regarding the behavioral changes of the elderly in the different phases of Alzheimer's, regarding the different forms of coping; 3) Feelings experienced in the care process, in which the feelings experienced by caregivers are explained; 4) Changes in personal and social life, related to the adjustments and abdications performed by caregivers;

Each participant was randomly coded with the letter C, referring to the term caregiver and numbering of one to ten, according to the total sample, for example, C01, C02, C03, ..., in order to guarantee the anonymity of individuals.

RESULTS AND DISCUSSION

All participants were female, emphasizing the role of the gender responsible for caring for their relatives, and [14-6] 70% were between 51 and 60 years of age, characteristic of those of other national studies.[15,17-8] It is important to emphasize that one of the caregivers is 60 years old. In this age group, the individual needs to be cared for because they present common limitations in the aging process and sometimes find their health more fragile, which leads to the onset of pathologies.[9,19] This factor interferes even more in quality of care.

Of the total participants, 60% are married; 70% care for their mother; 10%, grandmother and 10%, mother-in-law and 70% have children. These data are consistent with some studies that focus on caregivers of the elderly.[9,15] As for schooling, 50% completed secondary education resembling national studies.[9,16,20]

As for the family income, 60% of the caregivers interviewed had a gain of more than three minimum wages. Despite this, difficulties were reported regarding the financial costs to care for the elderly with AD. Having sufficient resources benefits the health condition of both the caregiver and the elderly, not just having love and consideration. Of the ten participants in the research, 90% reported having a profession. Of these, 55.5% are active. Regarding the occupation, 60% reported not having and, of the four that they have, 50% attributed the role of caregiver to the elderly as an occupation.

The time of care ranged from six months to 22 years. There is an equivalence in the data related to those who care for an approximate period of one to five years and those who care for ten years or more, both representing 40% of subjects.

♦ Family and social support network

In the discourse of the majority of caregivers, it is noticed that there is disappointment and difficulty in the lack of help in the process of caring for the elderly, both by professionals and family members, by overloading them in the daily routine. In the reports below, a paradox exists between the terms care and help, considering that the term help was attributed to someone who stayed with the elderly sporadically, while the primary caregiver needed to solve problems related to the home, the elderly or himself itself, and there is no "help" in the care process.

> *Lack of support, monitoring (professionals), guidelines (C05)*
>
> *The person alone is very difficult to change diapers. With two people it is much easier (C03)*
>
> *[...] I do not have the conditions to do things alone ... I do not have certain people to help (other children of the elderly), that when they come, they put some defect, they speak badly (C01)*
>
> *[...] when you need the family you do not have (C06)*

Primary caregivers, that is, those who are primarily responsible for care, are frequently the ones who suffer the most from the burden related to the care of the elderly on a daily basis, because they are more time-consuming in tasks such as bathing, medication administration, domestic activities, financial control, and medical care.[21]

Care involves concern, responsibility, and a sense of affection for others. It comes into existence when the life of being cared for is important to its caregiver, bringing the desire to participate in his life, in moments of suffering and happiness.[1]

This process of care even carried out with the affection of a family member, over a long period of time, becomes stressful and tiring for the caregiver because it is not shared with other people, [15,22] overloading, particularly, the caregiver main. Therefore, for the participants interviewed the routine is considered exhaustive.

When the process is organized and distributed among other agents it becomes less draining. As a consequence, the negative impacts of this task are less present in the lives of these individuals. The existence of an effective support network not only helps to organize care for the elderly, but also causes a great deal of reflection on the self-care of the family caregiver, mentioning, for example, family support and / or religious groups.[22]

The subjects of this research, when directed by health professionals, were directed to take care of their physical or psychological symptoms by means of medication or, even, the reduction of routine activities for the improvement of physical symptoms, as can be observed in the discourse of two of the caregivers:

> *I went to the doctor, I'm taking the medication he went through ... the doctor told me not to do anything else (C01)*
>
> *Neurologist oriented to take soothing [...] (C09)*

The role of caregiver, by itself, does not allow the individual to simply abandon their tasks to improve health problems developed. The professionals who guided these caregivers demonstrated a certain limitation to deal with the person responsible for the elderly and the problems developed during the care. Caregivers' health problems can be minimized with qualified care from health professionals if they know the representations that surround the family dynamics of caregivers of AD.[18]

The work of health professionals, including those of Nursing, involves ensuring the physical and mental well-being of the caregiver as well as promoting health education about AD in order to improve their quality of life and thus improve quality of the elderly. This is not an easy task, since the caregiver must be willing to absorb all the professional's guidelines using the coping strategies available at the moment.[23]

♦ The caregiver facing the different stages of Alzheimer's

During the interviews, difficulties were reported regarding the characteristic behavior of AD, which varies with the progression of the disease, as well as the aggressiveness and the sunset syndrome, that is, the agitation and mental confusion that affect the elderly with AD in the afternoon.[22] And the main way to deal with these problems was the conversation or bargain:

> *The only difficulty is to get around [...] (C04)*
>
> *At bedtime, she does not want to take a bath [...] bedtime (C06)*
>
> *She is stubborn, she does not sleep at night, she wants to leave, she wants to go after her little children (she has not) (C07)*
>
> *The night is the worst moment because she totally loses her lucidity, says that she did not eat, asking the time, swearing, wants to give her (husband of the caregiver), screams at dawn, wants to go home to her (C09)*
>
> *She does not know how to respond more, not knowing if she is well if she is not, if she feels pain or not [...] (C10)*

This difficulty in dealing with the overload and responsibility of caring for an elderly person with Alzheimer's disease comes from the lack of preparation and ignorance of the disease, the way of acting at each stage, the understanding of the elderly and their behavioral change and even the difficulty to understand their own feelings.[24] Therefore, it is difficult for the caregiver to identify what is characteristic of aging and what is characteristic of AD.

Of course, the clinical course and complications of AD increase the negative repercussions on the life of the caregiver, the elderly, the family, and the social environment of all.[25] Unpreparedness to deal with the changes that accompany the illness and the lack of information make them more insecure and unstable conditions leading to mood swings and impairment of their health.[17]

Thus, the caregiver sees himself totally in the duty to provide care for the elderly with AD, and this leaves him susceptible to several factors that can lead him to increase the overload pertinent to care.[20]

With regard to the health problems developed by the act of caring, family caregivers reported negative repercussions in both the physical and mental aspects, considering the elements as spine pain, insomnia, depressive mood and stress.

> *Pain in the spine [...] in the diaper exchange [...] The psychological is shaken (C08)*
>
> *[...] nervous system, from time to time I'm crying, I do not sleep well at night (C06)*
>
> *I think I'm kind of crazy (C09)*
>
> *[...] stress, pain in the wrists (C03)*

The quality of sleep is linked to several intrinsic and extrinsic factors and it is a subjective theme. Therefore, care for the elderly with AD on time would not be enough to define insomnia. However, statistics show that among more than ten million adult caregivers of elderly people with dementia, two-thirds of them experience some form of sleep disorder.[23]

● Feelings experienced in the care process

The feelings are experienced in an ambiguous way since the caregivers go through a mix of emotions in the day to day that concerns the human essence. This ambiguity "in the relation of dedication to the family does not appear as a contradiction, but as complementary profiles, as a perceptive experience in which beauty and thorn are part of the same rose" .[26: 283]

In this sense, another relevant repercussion observed in the speech of the caregivers refers to the feelings experienced during the whole time of care. Feelings classified according to the positive and negative elements having, as positive, those feelings of pleasure in caring, love, gratitude and patience.

> *[...] when my mother went to give me other people to raise me, she did not allow me and raised me [...]. I take care of her with great pleasure, because she is my grandmother (C02)*
>
> *Happy that I take care of her. My mother to me is everything [...] I feel love for her (C06)*
>
> *Happiness and love ... (C03)*

> *[...] love, a lot of patience [...] (C07)*
>
> *It has to do with much love itself, a lot of patience (C10)*

As can be seen in the speeches of C02 and C06, the expression of the feeling of satisfaction in caring for a family member, which, in this case, has a direct relation to the mother's representation transmuted in gratitude and retribution for actions related to the past fruits of the relationship between elderly caregiver.

In this sense, the act of caring for a family entity and doing something for the comfort of the elderly patient produces feelings of well-being for the caregiver, for the importance that the elderly person has in his life history, [27] forming a firm link to care more effective.

Patience may also be related to overload as the interviewees' discourse demonstrates this feeling as a quality / skill necessary for care. Impatience is present in the caregiver's daily life, as she is susceptible to losing such "ability" due to the elderly's illness, if care tasks are not easily controlled. Working out such a skill becomes a daily challenge.[9]

Other feelings that the subjects of the research experience or experience negatively affect their lives, varying according to the different situations of the day to day. Anger for caring for someone who does not feel affection, due to situations experienced in the past and that caused disaffection and rancor, even if this someone is the mother herself; repentance for not taking better care in the past; sadness over lack of family support; fear for the future of the elderly and their possible loss; the penalty for the disease of the elderly; the dissatisfaction with not wanting to take care of, but to feel the obligation to do so and the dissatisfaction with the family for not having the help of the other relatives.

> *At first I was very angry [...] Stress, I was shaken, sadness (C01)*
>
> *[...] I am sad because I do not have certain people "to" help (C02)*
>
> *I feel that I'm going to lose her (cry) ... it's bad, when you need the family, you do not have (C06)*
>
> *Stress, anger, thinking he was feigning, anguish, sadness, feeling of "why with us" [...] fear of it falling (C07)*
>
> *Fear, stay alert, stay alert! (C08)*
>
> *Feather. And sometimes she does not feel [...] it's as if she's paying for what she did in the past [...] I have no satisfaction in caring (C09)*

Such feelings are related to the behavioral and personality changes during the evolution of AD and stressors of daily care.[9,15] Anguish, anger and fear may arise due to the lack of knowledge about Alzheimer's disease.[16]

Still on the feelings, some of the caregivers' reports related to the care responsibility and perception of care emerged. Such a strand is manifested by relating to the feelings of caring for obligation, giving or even dissatisfaction with feeling that you could have done or were doing better.

> *I try to give myself what I can to see her well (C01)*
>
> *Delicate thing, responsibility (C04)*
>
> *You could take better care (C05)*

This feeling of "living to care", donating one's own life to the other, prevents the caregiver from attending to his or her own psychosocial needs.9 This feeling can be related to commitment in respect and love for the elderly.[15]

♦ Changes in personal and social life

The renunciation appears as a considerable repercussion of care in their day to day. Caregivers were able to clearly perceive the particular and interpersonal changes in their lives due to care. There were changes in the routine of spouses, as observed in the testimony of C01.

> *Changed routine [...] relationship (with spouse), detachment (C01)*
>
> *I stopped making my life "to" take care of it [...] (C06)*

Continual care deprives them of following their lives in the private, social, and professional spheres, and there may be changes as part of the renunciations. These changes may include adapting previously performed work to a domestic activity or occupation, as in the case of C10, which had to give up a profession for a home-based activity. Thus, responsibility for care interferes in interpersonal relationships, especially among family members, generating conflict of interest and habit change.[9]

Another important point is the report related to role reversal, an aspect raised by one of the caregivers, in which the roles of mother-daughter are reversed in a gradual way depending on the evolution of the disease in each individual. This shows disappointment with the situation of the caregiver and the elderly.

> *[...] how is the person a mother and become a child? (C07)*

Caregivers, over time, assume a different position in the family and social group and, in an attempt to give new meaning to life, leave the family membership to assume the role of caregiver.[26]

Most caregivers do not have time for leisure, socially depriving themselves of activities previously performed or that bring benefits to their physical, mental and social health. It is possible to perceive the availability of time in relation to the care of the elderly and the abdication of the time of self-care.

> *I have not, because it is a disease that requires your whole time (C03)*
>
> *[...] my time is only dedicated to it (C06)*
>
> *Nothing, no, I have to ask one person to stay, I do everything (C07)*
>
> *None, I will not even go to the bakery not to "leave it" alone (C09)*

Social deprivation is one of the points most discussed by several authors, because the caregiver abdicates activities that were of their interest to dedicate themselves to integral care for the elderly. This caregiver moves away from social interaction, failing to participate in meetings, family reunions, travel and other recreational activities.[9,18]

In some cases, caregivers exchange leisure activities, in the external environment, by domestic activities, by electronic means, as a way of maintaining social life, 15 as reported by C10 in the speech below.

> *Yes, short, but it has. We listen to music, sing, dance (C10)*

On the other hand, when there is time available for leisure, as in the case of C08, this is compromised due to anxiety and concern in the quality of the assistance exercised by other people, not enabling the satisfactory completion of leisure moments. This report can also be understood as assigning total responsibility to oneself for the care of the elderly.

> *[...] Sometimes, when there is someone to stay [...] I am worried if she is being well cared for (C08)*

C08's concern to leave the elderly unassisted reveals that the family caregiver chooses to be present in the life of the elderly with AD. Refers to being, "to be with, regardless of everything that happens or will happen”.[15:238]

CONCLUSION

The study evidenced that the family caregivers of elderly people with AD manifested, through their speeches, dissatisfied with the lack of professional, social and family support regarding the activities of the care, which possibly contributes to an increase of the level of overload. In addition, there was a lack of knowledge on the part of the caregivers about Alzheimer's disease and, consequently, the changes that it can cause. Such situation may reflect on the negative or positive feelings they experienced during the care process and also on the quality of care provided to the elderly.

Given the importance of the subject, it is necessary to recognize that the caregiver is a constituent being of this process and that it needs support in several aspects, whether social, individual or family, because - without support - this is subject to illness affecting their quality of life and that of the elderly to whom care is given.

Therefore, it is proposed to the managers, as well as to the population concerned, the creation of a support network in the municipality in which the study was carried out aiming at improving the quality of life of all agents involved in the care process.

This study had some limitations: the number of samples, which was non-probabilistic, and convenience, which limits the possibility of surpassing the totality of family caregivers of elderly people with Alzheimer's disease in the studied context. In the city, there is no record of the number of elderly people with AD, which is also a limitation.

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Submission: 2017/12/28
Accepted: 2018/03/25
Publishing: 2018/07/01

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