
ALZHEIMER'S DISEASE: THE EXPERIENCE OF ILLNESS FROM THE PERSPECTIVE OF FAMILY CAREGIVERS¹

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ABSTRACT. The Alzheimer's disease is characterized by being a degenerative disease that affects the brain, promoting progressive impairment of mental function. The disease progresses to a stage of total dependence, which requires the assistance of health professionals and family caregivers. This study aimed to describe the relationship between the patient and family caregiver; and, to understand how the family caregivers experiences the care. The methodology adopted was the oral history with the technique of semi-structured interview and content analysis. The themes were: Family Caregivers and patients: initial experience; The discovery of the disease: how it happens; How the family caregiver experiences the disease. The experience of care for patients of Alzheimer's disease requires changes in the family dynamics of caregivers, which require knowledge about the disease, symptoms and evolution. These changes generate anxiety and despair in family caregivers and adaptation to exercise the care in different situations that are emerging with the disease.

Keywords: Alzheimer's Disease; family; caregivers.

DOENÇA DE ALZHEIMER: A VIVÊNCIA DA DOENÇA NA PERSPECTIVA DOS CUIDADORES FAMILIARES

RESUMO. A doença de Alzheimer caracteriza-se por ser degenerativa e que afeta o cérebro, promovendo progressiva alteração da função mental. A doença evolui para uma fase de total dependência, o que exige a assistência de cuidadores familiares ou profissionais de saúde. Este estudo teve como objetivos descrever a relação entre o doente e o cuidador familiar e compreender como o cuidador vivencia esse cuidado. A metodologia adotada foi a história oral, com a técnica da entrevista semiestruturada e análise de conteúdo. Os temas encontrados foram Cuidadores Familiares e o doente: vivência inicial; A descoberta da doença: como acontece; Como o cuidador familiar vivencia a doença. A vivência do cuidado ao portador da doença de Alzheimer exige mudanças na dinâmica familiar dos cuidadores, os quais necessitam de conhecimento sobre a doença, sintomas e evolução. Essas mudanças geram ansiedade e desespero nos cuidadores familiares e uma adaptação para o exercício do cuidado nas diversas situações que vão emergindo com a doença.

Palavras-chave: Doença de Alzheimer; família; cuidadores.

ENFERMEDAD DE ALZHEIMER: LA EXPERIENCIA DE LA ENFERMEDAD DESDE LA PERSPECTIVA DE LOS CUIDADORES FAMILIARES

RESUMEN. La enfermedad de Alzheimer se caracteriza por ser una enfermedad degenerativa que afecta el cerebro, la promoción de deterioro progresivo de la función mental. La enfermedad progresa a una etapa de dependencia total, que requiere la asistencia de profesionales de la salud y los cuidadores familiares. Este estudio tuvo como objetivo describir la relación entre el paciente y el cuidador familiar; y, entender cómo el cuidador experimenta esa atención. La

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metodología adoptada fue la historia oral con la técnica de la entrevista semiestructurada y el análisis de contenido. Los temas encontrados fueron: Los cuidadores familiares y el paciente: experiencia inicial; el descubrimiento de la enfermedad: cómo se produce; cómo el cuidador familiar experimenta la enfermedad. La experiencia de la atención para los pacientes de la enfermedad de Alzheimer requiere cambios en la dinámica de los cuidadores familiares, que requieren conocimientos sobre la enfermedad, los síntomas y la evolución. Estos cambios generan la ansiedad y la desesperación de los familiares cuidadores y una adaptación de la atención en las diferentes situaciones que van surgiendo con la enfermedad.

Palabras-clave: Enfermedad de Alzheimer; familia; cuidadores.

Introduction

Increased longevity and improved population health conditions contribute to the increased prevalence of dementia syndromes in elderly people. It was estimated in 2010 that 35.6 million people in the world were suffering from dementia, with the number of new cases each year being almost 7.7 million, which implies a new case every four seconds (WHO, 2012).

Alzheimer's disease (AD) is a severe and disabling neurodegenerative disease, being considered the most common dementia syndrome worldwide, accounting for more than 60% of all cases of dementia (WHO, 2012; Vinters, 2015). In AD, there is a progressive impairment of the cognitive, behavioral and functional function of the individual, generating the need for progressive home care, which is performed predominantly by caregivers belonging to the patient's own family (Lemos, Gazzola, & Ramos, 2006; Verdullas, Ferreira, & Nogueira, 2011; Brasil & Andrade, 2013).

Due to the advancement and worsening of the clinical condition of the patient, there are needs related to the management of behavioral problems and to individualized emotional and social demands (Cadieux, Garcia, & Patrick, 2013). Family caregivers, in addition to understanding the differential needs of each stage of Alzheimer's disease, deal with the inherent difficulties of the individualized care of the family member in the process of dementia and the challenges that these difficulties represent from the economic point of view and of overload for the caregiver himself (Chan, 2010; Gutierrez, Silva, Guimarães, & Campino, 2014).

The family, as caregiver, plays an essential role in the daily life of patients with AD, assuming increasing responsibilities as dementia progresses. In addition to engaging in activities of daily life, such as administering finances and medications, family progressively engages in basic routine activities such as personal hygiene, bathing, and feeding tasks. Usually these tasks are assumed unexpectedly and without prior preparation, embedding an emotional overload to the family that is still adapting to the new health condition assumed from the diagnosis of Alzheimer (Cruz & Hamdan, 2008).

It is common for family caregivers to receive little or no support in the care of their relatives, reflecting a health system that offers scarce resources to home and community care, preferentially dedicated to a traditional approach focused on the identification and management of the characteristic symptoms of the progress of dementia (Gutierrez et al., 2014).

Interdisciplinary health programs aimed not only at the elderly but also at the family members are essential to achieve the best possible functional status at each stage of Alzheimer's disease (Falcão & Bucher-Malusckke, 2009).

It is for health professionals to understand the needs arising from the progression of Alzheimer's disease, the changes in family dynamics and, the consequences generated in the individual with the illness and in the caregiver. There is a need for psychosocial actions focused on improving the health and well-being of this individual with AD. The health professional, in collaborative activities, among the various competencies in the multiprofessional team, promotes actions for maintenance of physical safety of the customer, reduction of anxiety and agitation, improvement of communication, promotion of independence in daily self-care activities within the possibilities, care for the needs of socialization, promotion of respect for privacy, maintenance of adequate nutrition, management of sleep pattern disturbances and, mainly, support and education of the family members responsible for the care (Luzardo & Waldman, 2004; Arruda, Alvarez, & Gonçalves, 2008; Santana, Almeida, & Savoldi, 2009).

It is possible for health professionals to develop strategies of health care that meet a partnership between the family and the multiprofessional team that results in a more comprehensive assistance to

the needs for psychosocial rehabilitation of the customer, based on greater knowledge about the experiences of family members caring for AD (Alzheimer's disease) patients. Given this, some questions emerge: how does the relationship between family caregivers and AD patients happen? What happens in this process? Is there a change in the perception of the family member in relation to the conditions of the patient with AD throughout the course of the disease?

In order to respond to these concerns, this study was elaborated with the purpose of describing the relationship between the AD patient and the family caregiver; and, understand how the caregiver experiences this care through his words.

Method

A qualitative research was carried out, which consists of the deepening and understanding of the phenomena studied, interpreting them according to the perspective of the participants of the situation, and with the necessity of the researcher to be in direct and prolonged contact with the field to capture the meanings of observed behaviors (Minayo, 2015).

This research complied with the recommendations of Resolution No. 466 of December 12, 2012, by the National Health Council of the Ministry of Health (CNS/MS), with the approval of the Committee on Ethics in Research of the Federal University of Alfenas- UNIFAL-MG, in the city of Alfenas-MG. As a form of protection and confidentiality, employees will be presented under the pseudonym of flowers.

Within this study we sought to understand what permeates the reality of the individual and not only the determination of what is correct or not (Minayo, 2015). Besides, qualitative research is based on the process of interpreting particular realities and not on quantifying them (Patton, 2014).

For data collection, the method used was the Oral History, which consists of the collection of narratives using electronic devices. It is intended to collect testimonies, promote analyses of social processes of present and facilitate the knowledge of the immediate environment. Oral history is understood as the passage from oral to written code, and there are three types of Oral History, such as the Oral History of Life, Thematic and the Oral Tradition (Meihy & Ribeiro, 2011).

In this study, it was used the Oral History of Life, since it refers to the narrative of the whole life experience of a person, who tells his story, according to his will, being sovereign to reveal or hide cases, situations and people (Meihy & Ribeiro, 2011).

In this sense, it is important to define some concepts, such as the Community of destination; Study Colony; and, Network (Meihy & Ribeiro, 2011). The first one, Community of destination, is the central motif that identifies the gathering of people with some related characteristics. In this study, families of patients with Alzheimer's disease formed the community of destination. The family that experiences the care to the patient with Alzheimer's disease formed the study colony. In addition, in this study, the Network even being defined as a subdivision of the colony was formed by the three family caregivers, who were called collaborators. They receive this denomination because they are the deponents or the interviewees, who have their role changed, ceasing to be mere informants, becoming actors, subjects, and objects of research.

The present study had as inclusion criterion the relatives who experience care for Alzheimer's patients, without professional training. Trained family members and professionals who experience care for these patients were excluded. This choice was based on an academic visit to a Family Health Program (FHP) associated with the university, in which the researchers are located. At the visit, some micro areas, which had elderly people with Alzheimer's disease, were indicated. Of the three micro areas pointed out, only in one was found the family in which the inclusion criteria could be considered.

For data collection, it was used the semi-structured interview technique. The interview has steps, that is, pre-interview, interview and post-interview. For the interview, three guiding questions were used: Tell me about your life with the Alzheimer's disease patient; Tell me, how has been this process of caring for you?; What happens during this process? Has anything changed? What have you done in the face of this change? These cited questions were responsible for starting the dialogue with the collaborator and for giving rise to other questions during the interviews (Meihy & Ribeiro, 2011).

The locations and dates of the individualized interviews were scheduled according to the possibilities of the collaborators. There was some caution with the choice of location, avoiding noises and interruptions, and as to the request for recording. These interviews occurred in the home of family members of the Alzheimer's disease patient.

From the interviews, the respective transcriptions were made, changing the stage of oral recording to written, and this process incorporates the absolute transcription, textualization, and transcription (Meihs & Ribeiro, 2011). These are called absolute transcriptions, in which the complete passage of the dialogues and sounds as they were captured occurs; Then corrections were made according to the intentional meaning given by the narrator who articulated his thinking with the words. This work was checked by each narrator who legitimized it.

The next step was the textualization. At this stage, the questions were merged with the answers and the text became predominantly of the narrator. From the concepts of Meihs and Ribeiro (2011), during the processing of textualization a vital tone was chosen, which corresponded to the sentence that served as epigraph for the reading of the narrative. Therefore, the chosen phrase worked as a beacon to guide the work.

The last stage of the transcription was the transcription, which is a text re-created in its fullness, meeting the combined agreements with each collaborator who legitimized the final text at the time of the conference.

Using a set of communication analysis techniques, called Content Analysis, described by Bardin (1977/2011), which aim to obtain indicators that allow the inference of knowledge relating to the conditions of production or reception of these messages, we achieved the texts referred as narratives. These, have preserved in themselves a certain subjectivity, because behind the apparent discourse a meaning that should be discovered is hidden. Thus, the Thematic Analysis allowed us to discover the nuclei of meaning that make up the communication and whose presence, or frequency of appearance, can mean some fact for the analytical objective chosen, which were designated as themes. These themes were represented in sentences in this study. Therefore, we sought a text after another, a text that is not apparent already at the first reading and that needs methodological rigor so that it can be unveiled.

Results and discussion

The oral history reported by the family of the AD patient provided profuse data of life experiences while they coexist and face the chronicity conditions of the disease in the midst of a whole context of family and society. According to the adopted method of thematic analysis of oral history for the search of explanatory results of thematic categories, we obtained the emergence of four major themes.

Revealing the data

The collaborators belong to the target community of families of AD patients, being the colony and the network of study formed by three family members who experience the care to the AD patient.

Unveiling the study colony

Carnation is the spouse of the client with Alzheimer's disease. He is 82 years old, lives with the client with AD; he is retired and self-employed. Magnolia and Daisy are the client's daughters. Magnolia is 55 and Margarida, 45. Both are married and have children. Margarida is a housewife and has 2 children (one is 20 and the other is 11 years old). Magnolia is a cleaner and has 5 children (two married daughters and the other three are over 20 years old). In addition to these two daughters, there are 6 more children who did not want to manifest because they do not participate in the care of the AD carrier. This is 72 years old and her symptoms started 5 years ago. Today she is at a very advanced stage of the disease and no longer speaks, walks, feeds alone and presents urinary and fecal incontinence.

The following are the themes revealed in the narratives:

Theme 1- Family Caregivers and the patient: initial experience

Generally, the AD carrier is assisted at home by members of his or her family. It is the family member who assumes the role of caregiver, even if, for the most part, he/she does not receive specific training to develop this role. In our study, the care is carried out at home, by the daughters and their spouses.

The following is the spouse's report:

I am 73 years old. I have always been very nervous; I have always liked everything very right. My wife always respected me a lot, everything I said, she obeyed me. We lived in the countryside. I always watched the newspapers, listened to the radio news. But she never liked it. What she liked most is to sing and talk. She always took care of the house and the children ... and now she is not that old woman anymore ... (Carnation).

The daughters, for their part, reported:

"I am 45 years old, I am married, I have two children, and for four years I have been caring for my mother who has Alzheimer's disease (silence)" (Margarida); and "I have contact with an Alzheimer's carrier: my mother... In the beginning, it was very difficult to reconcile all those things. I am married and have five children. My children are young. I take care of my house, my children, work and take care of my mother" (Magnolia).

The act of caring means assisting someone who has physical, psychological, clinical and social needs. The main family caregivers are those who are closest to the sick relative, that is, often the spouse and children (Celich & Batistella, 2007). Therefore, it can be seen that those who are responsible for almost all charges and care for the elderly with AD, and for whom the routine activities are reserved, are characterized as main caregivers.

Due to the complexity and epidemiological importance of AD, new findings on the causes and course of the disease are frequent, however the knowledge of the family is still limited and doubts about the chronicity of the disease and the best approach to care are also frequent (WHO, 2012; Vinters, 2015).

In this study, the involvement with AD was characterized as unexpected, it was a surprise to the family, especially because they had no knowledge about AD. Although the number of people with Alzheimer's disease (AD) has increased, the collaboration for the scientific knowledge on the part of the families is still scarce (Verdullas, Ferreira, & Nogueira, 2011). In addition, as for the symptoms of AD, the patient develops significant changes with the progression of the disease; however, the health professionals have not made the disclosure of this information. The caregivers report having knowledge of the diagnosis, but not of the symptoms (Luzardo & Waldman, 2004).

It is interesting to note that caring for AD carriers in the family, as found in our study, is carried out predominantly by women, and the involvement of men in these care has been associated with marital obligation (Lemos, Gazzola, & Ramos, 2006). As we have seen, female caregivers are the daughters of the AD carrier and are at maturity, reinforcing the social importance of the children in our culture as a source of security in old age to parents (Falcão & Bucher-Maluschke, 2009).

Theme 2- The discovery of the disease: how it happens

The onset and the discovery of AD in the view of family caregivers present as a process, being understood as process that which has continuity over a time. The manifestations of the disease occur gradually, with stages ranging from a little forgetfulness to total dependence on personal hygiene and food activities. The caregiver is constantly surprised by the symptoms of the disease, as revealed in the following reports.

Daisy said:

She started doing things she did not do before (silence)... She was already very discouraged with life (silence)... About this disease, I did not fully know the cause; none of us children, nor my father, knew about the disease. We are trying to find out more about the Alzheimer's disease.

Magnolia reported:

She has been presenting this disease for three years... and it was discovered that my mother was suffering from Alzheimer's disease. When I told my siblings, they thought I was lying... my siblings did not know anything about the disease. At first, I was very scared!

Carnation, in turn, reported:

When she started getting sick, she wanted to go to church every day. I told her that in the city where she was born, a woman did not leave the Church and because of that, she went crazy. When she started asking to go to the Mass, I did not allow, I locked the doors and I was very nervous, because I thought this was not sickness, but rather silliness on her part!

In this study, in the view of the family caregiver, this process reveals itself as an unexpected event, something that no one knows about. This fact agrees with the point that constant care becomes ever more complex and the caregiver is gradually absorbed as the care load increases (Luzardo & Waldman, 2004).

Lack of knowledge about the disease generates anxiety crises and despair in the caregivers before the sick person. Not knowing how to cope with the symptoms and the evolution of the disease, caregivers rely only on the pharmacological treatment, and hence the need for a significant change in family dynamics resulting from the adaptation to the disease (Vilaça et al., 2005).

The lack of knowledge of the disease by caregivers reflects the difficulty in establishing efficient care strategies from the beginning of the disease. From the difficulties experienced, the caregivers understand the progression of the disease and learn to provide a more effective care. However, in this period of discovery, many crises and sufferings permeate the relationship between the caregiver-AD patient binomial.

Theme 3- How the caregiver experiences the disease

For the caregivers, the memory loss in AD is very significant, as shown in the following testimonial:

One day we went to the market and she got lost... When people visited us at home, she did not give attention to them; instead of talking, she wanted to clean the house (silence)... She would pick up the dirt on the floor at the wedding parties! I could no longer recognize my wife ... she seemed another person there ... everything she started to do, I never imagined that someday she would be able ... (Carnation).

The difficulty of understanding and communication on the part of the sick person, and of facing the disease by family members is revealed in the speech of one of the caregivers:

... we would take her where she was asking to go, to show her that what she thought was not what had happened, that what she thought was not true, that she could be quiet, since no one had died... For her not to escape, we had to leave the doors all locked... It seems that she was no longer recognizing her own family... My father was very angry about this! He ended up forbidding her to go, and then she started crying. My father made the food alone, cleaned the house, and when she started asking to go to church, they ended up arguing (Daisy).

It is only with the experience of living with the disease that the family develops care strategies. Caregivers realize that the AD carrier gradually loses consciousness and becomes very dependent. With this experience, the research collaborators understood that there should be a more tolerant treatment, with patience and affection in relation to the clinical manifestations of the AD patient. These revealed facts show that, since there is no lucidity in the patient, there is no way for the caregiver to convince him to accomplish his activities for himself.

The progression of the disease occurs as a wear and tear because, in this speech, the caregiver perceives the Apraxic/Aphasic/Agnostic syndrome (Yesavage, Brooks, Taylor, & Tinklenberg, 1993):

... because my mother can no longer dress correctly and does not know what a fork is for... she no longer talks like she used to... we try to talk to her, but she does not understand and speaks nonsense, and is always irritated or still because we do not understand her... she has that phase of remembrance

and forgetfulness... not even the children themselves she recognizes... With the disease, many expenses came (Daisy).

The experience of caregivers with the disease requires knowledge about the degree of aggressiveness that AD patients can develop (Celich & Batistella, 2007). Magnolia expressed this remark regarding the aggressiveness of the mother: *"For some days my mother is very calm, but there are days when she even wants to hit us, she becomes very aggressive in a few days"*.

With the development of the disease, the dependence of the patient on the family caregiver becomes more and more intense. It reaches a period of evolution, in which the sick person is restricted to the bed, since he/she is no longer able to do anything alone (Luzardo & Waldman, 2004). This fact was revealed in the following statements:

... the longer my mother stays in her world, the more difficult it will be for her to walk again. While she had not fallen, it was easier to give her a bath, now she has much trauma, she is afraid of falling again and starts to scream, my father is worried. Sometimes she says the water is too hot, but it is all in her mind (Daisy).

Cravo reported: *"My daughters help me a lot here, they shower her, they give the food (pause). I give lunch and coffee. We share the tasks, because my wife only stays in bed (silence)."*

The neuropsychological profile of the AD carrier changes with the evolution of the disease, and the memory loss has consequences in the life of the person and the family caregivers who begin to exercise all the care functions, without even having some kind of specific knowledge for this role (Chan, 2010).

Theme 4 - The experience of Caring: significant changes

The demands of care generated by the evolution of the disease influence the daily life of the caregiver, transforming his life context (Luzardo & Waldman, 2004). Many challenges often characterized as stressors for caregivers emerge (Vilela & Caramelli, 2006). Besides, there are also significant changes in the relationship between caregivers and patients:

My life has been much more stressful, more busy, more disturbing (silence)... We, the children, have very little meetings, so as not to cause fights... Communication in the family is very flawed!... we children, we had to reconcile work, family, to manage helping my mother and father. It was very difficult, but I was able to adapt, I had even to stop working (Daisy).

Some caregivers devote themselves so much to care that this involvement results in job losses and quality of life. The main caregiver in this study showed more dedication to care; however, she left her job to take time to help the sick mother. She reported having to choose this difficult choice because none of the other siblings was willing to help, and that the distribution of the tasks by the family caregivers in care was difficult. These results demonstrate how family communication and knowledge of care needs become inefficient (Lenardt, Silva, Willig & Seima, 2010).

There is a great involvement between the caregiver-AD carrier binomial. As a family member who is sick, the family caregiver seeks, with all his strength and opportunities, to ensure the maximum comfort to the AD carrier, as Margarida reported: *"I always take care of her with great affection. It has to be a more friendly treatment, with more patience; and all this needs to be trained when the disease is discovered. As tired as I am, I never forget my mother (cry)"*.

Magnolia mentioned:

"You must be patient and gentle with people with Alzheimer's disease. At the same time they are very calm, they can suddenly become aggressive... We must have much love and patience with our mother".

Carnation said:

Only after my daughters told me about this disease that I understood why my wife acted so strangely. I calmed myself down, because I understood that nothing I said to her would make difference, because she no longer knew anything.

The main caregiver attracts so much activity to himself that physical and emotional overload is inevitable. Many of these, although there are other persons in the family that may help with care, encounter obstacles in getting such help, especially when the assistance is voluntary.

It is common for family caregivers to give themselves to care others and they do not realize the need to care for themselves. They accomplish activities that are sometimes above their physical and mental conditions, and not infrequently begin to become ill themselves (Celich & Batistella, 2007). The high emotional load can lead to a great number of disorders, making it necessary for the caregivers to adopt strategies so that they do not become ill either (Luzardo & Waldman, 2004).

Our data showed overload on caregivers and disarticulation of family dynamics for adaptation to the new imposed needs. This overload implied stress, anxiety, abandonment of employment, impairment of the quality of life, and deficiency in the self-care of the caregivers themselves.

The action of the health team in this situation is necessary. From home visits, and their scientific knowledge and attributions, they can contribute to the orientation about the disease to family caregivers, besides helping to systematize a healthier family dynamics (Vilaça et al., 2005).

These factors are very relevant when seeking to provide comprehensive health care and promote a good relationship between the family caregiver and the AD patient. The facts revealed in this study call attention to a scenario that occurs in many families, in which the family members themselves place themselves in the position of caregivers, without any preparation. That is, the reported difficulties may be a starting point for planning effective assistance together with family caregivers of patients with AD.

Final considerations

Brazil has observed a progressive increase in the incidence of dementias associated with the aging of its population, with the Alzheimer's disease being the most prevalent of them. Individuals affected by this disease receive home care, mainly from their relatives. Investigations that allow knowing the experience of these relatives extend the possibilities of health strategies to Alzheimer's disease patients and their families on the part of multiprofessional team.

Our data illustrate the entire pathway experienced by relatives from the onset of the Alzheimer's disease until the present moment, allowing a better understanding of the difficulties experienced by the family members and the patient with the disease.

The experience of the family caregiver changed the dynamics of the family, determining an exchange of family roles, requiring a full dedication, establishing new rules of coexistence and demanding decision-making processes that did not exist before the manifestation of the disease. The reports show that family members assume the duties of caregivers of the Alzheimer's patient as a family role to be developed during the whole time of disease progression. These people do not have prior knowledge of the pathology and develop a learning throughout their experience. Family care therefore becomes a challenge to overcome every day.

Caring for Alzheimer's disease patient requires changes in family dynamics in order to better adapt to the new imposed lifestyle. Health professionals need to be sensitive to these family changes, which go beyond the clinical needs of the patient with Alzheimer. In order for family members to meet the increasingly needs of the Alzheimer's patient as caregivers, it is important for the health team to prepare them and help them find possible ways towards a quality care and a satisfactory family life.

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