# EXPERIENCES OF FAMILY CAREGIVERS OF ELDERLY WITH ALZHEIMER'S DISEASE

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#### **ABSTRACT**

The aim of the present study was to understand the process of experiencing the care of the elderly with Alzheimer's disease. This is an exploratory and descriptive research with qualitative approach. The study subjects were eight family caregivers of elderly patients with Alzheimer's disease living in the areas covered by two Basic Health Units located in the municipality of Maringá-PR. Data were collected between July and August 2015 through semi-structured interviews. The thematic analysis of data resulted in three categories: "The diagnosis of Alzheimer's disease in the elderly and changes in the family caregiver's everyday life"; "The family caregiver's perception of cognitive and behavioral changes caused by Alzheimer's disease"; "Concerns experienced by family caregivers in the daily life of the elderly". It was found that the experience of the disease process generates suffering, sadness and insecurity, bringing major changes in the family context. Besides assisting the elderly with Alzheimer's disease, nurses can create opportunities for dialogue and joint definition of care strategies for living with the disease.

Keywords: Alzheimer's disease. Elderly's Health. Aging. Caregivers. Nursing care.

#### INTRODUCTION

Population aging is a worldwide reality that has been occurring abruptly in developing countries like Brazil. The decline in fertility and mortality and increased life expectancy are responsible for the change in the Brazilian age pyramid. Along with the demographic transition, there is an epidemiological transition in which non-communicable diseases (NCD) predominate over infectious and parasitic diseases, although the latter still play a role in the disease burden in the country<sup>(1)</sup>.

Among the NCD stand out dementias, among which Alzheimer's Disease (AD) is the most prevalent, accounting for 60% of the cases<sup>(1)</sup>. The AD is understood as a progressive and irreversible neurological disorder resulting from degeneration of nervous tissue, characterized by changes in cognitive, behavioral and affective functions, significantly affecting the activities of daily living<sup>(2)</sup>. This is a major cause of functional

dependence, institutionalization and death among the elderly population<sup>(3)</sup>.

In recent years the number of families caring for older people with some kind of dependence, especially caused by AD has progressively increased<sup>(4)</sup>. Most of the care to these elderly patients is carried out at home and, despite affecting all family members, there is one family member who normally takes on the responsibility for the care, which is called the primary caregiver<sup>(5)</sup>.

A caregiver is a person that provides care to the elderly who have some kind of dependence. The tasks involved in caregiving include monitoring daily activities, basic care such as personal hygiene, assisting in the administration of medication, nutrition, mobilization, and helping in visits to health services to improve the quality of life<sup>(6)</sup>. In the case of people with Alzheimer's, behavioral disorders are peculiar, manifested by agitation, wandering, verbal and/or physical aggression, memory loss, personality changes, hallucinations, sleep

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disturbances and sudden violence, with high potential to undermine the family structure, making the care more complex<sup>(6)</sup>.

Thus, caregivers are not always prepared to take on all these responsibilities and face the changes that occur in their routine, such as little time for social, family and affective life. This may cause emotional, physical and financial burden, and even illness in this family member who assumes caregiving<sup>(2)</sup>.

In this context, nursing and the health team play a key role in supporting family caregivers of elderly with AD. They can guide the care and establish a network of relationships in which family caregivers can reorganize themselves to learn to live with AD<sup>(2,7)</sup>. For this, the objective established for this study was to understand the process of experiencing the care of the elderly with Alzheimer's disease.

### **METHODOLOGY**

This is an exploratory and descriptive research with qualitative approach. The target population were family caregivers of elderly people with Alzheimer's disease residing in areas covered by two Basic Health Units (BHU) in the city of Maringá-PR. Inclusion criteria were age equal or above 18 years and playing the role of caregiver of the elderly patient for more than six months. The stipulated time limit aimed to cover individuals who started the process of adapting to the role of caregivers so that they could share their experiences.

Data collection occurred in the period from July to August 2015 using a semi-structured interview guide prepared by the researchers and applied in one single home visit. This visit was scheduled by telephone contact made with eight family caregivers of AD patients, suggested by Community Health Agents (ACS) of the BHU in question. Data collection was completed with the eight participants, since the content of the interviews, as judged by the researchers, reached the data saturation criterion, with no new information added by the subjects.

The interviews were recorded, transcribed and submitted to thematic content analysis proposed by Minayo<sup>(8)</sup> to identify the units of meaning that make up the communication of subjects relevant in relation to the proposed

objectives. The thematic analysis of data resulted in three categories: "The diagnosis of Alzheimer's disease in the elderly and changes in the family caregiver's everyday life"; "The family caregiver's perception of cognitive and behavioral changes caused by Alzheimer's disease"; "Concerns experienced by family caregivers in the daily life of the elderly".

Participants were identified by nouns that describe the feelings and emotions experienced during the interviews, namely: Responsibility, Patience, Servitude, Innocence, Adaptation, Discouragement, Companionship and Sadness. The research was approved by the Research Ethics Committee of Unicesumar under Opinion 1135005/2015 and met the standards set out in the Resolution 466/2012 of the National Health Council.

### RESULTS AND DISCUSSION

All respondents were female and, as for the degree of kinship, four were daughters, three were wives and one was daughter-in-law of the elderly with AD. It is noteworthy that women maintain their traditional role of caregivers in the family and this is related to the family life cycle, personal circumstances and socio-cultural values<sup>(9)</sup>.

Of the eight interviewees, four were married, three were divorced and one was widow. Regarding level of education, three women had completed high school, one had incomplete primary education, three had incomplete high school and one had incomplete higher education. The age ranged from 44 to 78 years, and four women were older than 60 years. Taking on responsibility for caring for another person creates the need for self-care, especially when the caregiver is also an elderly, since the aging process itself can cause physical limitations as well as installation of diseases<sup>(4)</sup>.

As for the elderly with AD, five were women and three were men aged between 73 and 93 years. The time spent since diagnosis of the disease ranged from 3 to 9 years.

The diagnosis of Alzheimer's disease in the elderly and changes in the family caregiver's everyday life

Both behavioral changes and cognitive deficits that precede the discovery of AD, particularly the diagnosis itself, generate situations of intense suffering. The emergence of conflicts is common because a time of difficult decisions starts<sup>(5,9)</sup>, including the designation of the family member who will take on the responsibility to provide direct care of the sick elderly, which depends on gender, kinship and bonding<sup>(6)</sup>.

Changing social roles in the family structure, the burden of the family member assigned as primary caregiver and the lack of information about the disease, about guidelines and forms of treatment are factors that prompt feelings such as anxiety, anger, sadness, distress, guilt, fear and depression, contributing to physical and psychological imbalances in the caregiver<sup>(6)</sup>.

The diagnosis of AD in the elderly represented a difficult moment for the interviewees, who expressed feelings of sadness, helplessness and fear of the unknown:

A lot of sadness because we already knew the consequences of the disease. (Responsibility)

It was terrible, because a friend of mine found her lost on the streets looking for my house. The next week I took her to the neurologist and it was through a CT scan that we discovered it, and it was very sad! (Patience)

Oh, it was very difficult, we feel we don't know how it will be and we get afraid to face the situation. I did not know if I was going to be able to take care of her, because I was not aware of anything. (Servitude)

I felt very bad, of course! To see him that way and he cannot leave home, he may go out and forget how to come back home, right? (Inocence)

The diagnosis of AD and its poor prognosis make the family system undergoe changes that affect its members with different degrees of intensity<sup>(9)</sup>. Thus, family union becomes an important coping strategy before AD<sup>(10)</sup>. The following statements report the support, unity and unity within the family after diagnosis:

Oh, we had much support, I think the family is more united now, there is more understanding between the brothers and they are very helpful too. (Adaptation)

It was a sudden change, because I had to look for a sister who lived away from me with her daughters to help me, because one person alone cannot take care of an elderly with Alzheimer's disease. (Patience)

Although the family represents an important source of support, affective relationships change in the essence with the unexpected emergence of a disease such as Alzheimer's. The management of care by the family is influenced by the meaning of caring for the members involved, by their individual characteristics, their coping strategies, intrafamily relational aspects before the diagnosis of AD, as well as the existence of support networks<sup>(6,10)</sup>.

Respondents reported seeking support in the family to care for the elderly, and this is found especially in their children:

For we rest on the weekend, the children also have a share, because it is when we go out, right? On weekends. My husband helps me a lot too, if I have to go to the market he stays with her in the car, right? (Adaptation)

[...] I have a couple of kids, you know, my son lives in Santo Ângelo in Rio Grande do Sul and my daughter lives here they are always aware of everything. (Discouragement)

They help, yes, they take him to the doctor when it is necessary, about bathing, I cannot expect help, right, because all of them have to work and I do not like to bathe him at night, so I give his shower early, but whe it is Saturday and Sunday, there is this one that lives down here, and another who lives there, they give him the shower, you know? But during the week, it has to be me, right? (Companionship)

The task of caring for a dependent elderly needs to be shared with the entire family in order to prevent that the burden fall on one person alone. Health professionals, especially nurses, should be involved in the process of family reorganization, encouraging them to help one another in the daily care<sup>(2,7)</sup>. In this scenario, in addition to offering care and treatment to the elderly with AD, nurses can create opportunities for dialogue and joint definition of care strategies during the course of the disease, promoting comfort, guidance and qualified listening to the anxieties presented<sup>(10)</sup>.

In the statements that follow, the family members said caring for the elderly in a comprehensive manner, what significantly altered their routine: And then I have to be alone taking care of him, then if I do something here at home, sometimes I put him there next to me and if he leaves for a while, I have to drop everything and go after him to see what he is doing right. (Inocence)

In the house, the food, I am who have to prepare it, I prepare it in my spare time, I have no time left for anything, I have to be constantly there, 24 hours for him, if I have to wash clothes, iron clothes, and that's when I can do these things. Thus, our whole life changed drastically, right! The whole routine. (Discouragement)

Because the assistance to the elderly with AD has to be costant, when faced with the large amount of hours dedicated to the care, the family member ends up reducing the time for leisure activities and abstaining from social life<sup>(11)</sup>. The findings of this study give evidence of that reality, as can be seen in the following statement:

[...] I used to go out more frequently, now I'm not going out anymore, I cannot go out because of him, I have to take care of him. (Inocence)

We have to do a total transformation and never leave him alone, when a person goes out, another has to stay, we can not leave an Alzheimer's patient alone not even for a minute because he does not know what does. (Patience)

Thus, by now I almost cannot go out because I cannot leave him alone, i leave only when scheduling. (Companionship)

A study of family caregivers registered in the Alzheimer's Brazilian Association showed that after taking on the responsibilty to provide care, family member stop going out with friends, participating in family gatherings and traveling because of the daily tasks with the elderly. The same study identified by the speech of the deponents that the life of the caregiver becomes the life of the elderly, for it is a constant monitoring, it is a resignation in favor of the care<sup>(4)</sup>.

It is observed that the care offered to the elderly with AD is permeated by feelings that are opposed. Although anger, sadness, impatience and fatigue are the feeling that stand out<sup>(4)</sup>, the literature indicates also positive feelings in the exercise of care, such as gratitude, pleasure, satisfaction and learning. In this case, it is essential that health professionals identify the aspects that promote pleasure while taking care to exalt them above the

negative feelings<sup>(4,12)</sup>.

Thus, the routine changes and heavy workloads combined with the devaluation of the primary caregiver make the primary caregiver to feel helpless<sup>(11)</sup>. Such an attitude of devaluation may come from the own patient as a result of memory loss and other losses linked to AD, which make patients unable to acknowledge the dedication of that family member, or may come from the lack of support of the own family.

Therefore, health professionals should provide training and formal support to caregivers through continuous dissemination of information on the symptoms and treatment of AD. In addition, the clinical look for early identification of the disease and appropriate referral of suspected cases may favor the elderly and their family<sup>(6)</sup>.

### The family caregiver's perception of cognitive and behavioral changes caused by Alzheimer's disease

Symptoms of AD can be described in three stages. In the initial phase, which lasts 2-4 years on average, there is difficulty to speak, significant loss of recent memory, temporal and spatial disorientation, aggression and signs of depression. The intermediate phase happens between 2 and 10 years, and presents an increasing loss of memory and early dysphasia, loss of thinking ability and motor deficits. Bed rest, aphasia, intestinal or urinary retention and adoption of the fetal position are typical in the terminal phase<sup>(10)</sup>. Among the cognitive and behavioral changes mentioned, the loss of memory is especially devastating for the family<sup>(11)</sup>.

Her reaction, is like, revolting, at the same time that she goes away, in a little while she was no longer, she asked me [Mary]: "Where's Mary?". (Servitude)

[...] then he remembers, he calls me by my name, but it's hard, he calls me palmeiras, palmeiras is his mother, his mother passed away [...] he thinks his house not is here, ah he says that is down there. (Inocence)

She lives things back there in the past, not the present but the past, she remembers the former things only, what happened in the same day, in the afternoon, she does not know what happened. (Servitude)

She forgets most of things, especially the present things, the past she remembers, the questions she repeats every day, it is a repetition of questions that often leaves us even tired of answering. (Responsibility)

The initial stage of AD is characterized by deficits in short-term memory, which refers to memories kept in mind for seconds to minutes. At this stage, long-term memory is preserved to some extent. This corresponds to information stored for longer periods of time, lasting from one day to a lifetime. However, as the disease progresses, the latter also becomes compromised, resulting in a loss of global memory<sup>(13,14)</sup>. It is noteworthy that AD is not only characterized by memory loss, but also by distortion of memory contents, which affect both the short and the long-term memory<sup>(15)</sup>.

A study in the Alzheimer's Brazilian Association of Manaus found that most seniors had memory changes and did not remember caregivers as their family, though the elderly still recognize them as their references in daily care<sup>(4)</sup>. The same perception was found in the testimony of Sadness when she says that the elderly does not recognize her as family anymore.

Because we see a family member who no longer recognizes us like family, he knows that we represent security for him, but he does not recognize us as a family. (Sadness)

At the moment caregivers are not recognized by the patient as family, they have to face loneliness. This sentiment is expressed mainly by caregivers who were the wives of the elderly patients with AD, as they miss the relationship built throughout the history of the couple, now discontinued due to the loss of memory inherent to the disease<sup>(4)</sup>.

Behavioral changes early in the course of the disease were also reported. These include leaving home and not knowing how to go back or not knowing how to do the activities they used to do before:

That's when he began to disappear, he left home once and did not return, then I took him to the doctor and the doctor made tests and told us he had Alzheimer's disease, because those who have Alzheimer's cannot come back when they go out, they are unable to go back home. (Inocence)

He started to behave like this, then I went to the union, as my son is part of the union, I took him

there and the doctor said so "look", he asked me how was life in the countryside, we came from the countryside, I told him, then he said "it is because he stopped, he came from the place, he stopped." So he told us the brain had also stopped. Then, it is like, sleeping during the day, sitting here, taking him to walk? And then the doctor said that was what happened, he stopped once for all. (Companionship)

Behavioral changes range from disorientation in time and space to aggression towards caregivers. These attitudes may be related to the expression of the patient's needs such as thirst, hunger, pain and cold. However, the attacks can be interpreted by the caregiver as personal and purposeful, mainly due to lack of information about the diagnosis, clinical manifestations and progress of the disease. Health professionals can provide guidance on the prevention against aggressive behavior, proper management and support to the caregiver to overcome the psychological trauma<sup>(6)</sup>.

With the evolution of AD, the elderly begins to become dependent to perform the activities of daily living such as sanitizing, dressing, combing hair, going to the bathroom, and other things for which, until then, they did not need help, as reported in the statements:

The person has no longer the ability to do anything, for everything help is needed, from someone, you know. (Adaptation)

He eats well, as for bathing, I have to give him the shower, because he does not take a bath correctly [...] I have to bathe him, I have to, like, cut the meat and all in very tiny bits, he once almost choke, now all care is necessary. (Inocence)

[...] He stays in the bed until late, I am the one who bathe him, I change him, he does all with clothes. (Companionship)

Taking care of a disabled elderly in daily living activities is a task that generates large changes in the routine of these caregivers. This may cause physical and emotional wear<sup>(16)</sup>. The permanent care requires the dedication of many hours, so that the caregiver has to perform physical efforts far beyond their ability<sup>(11)</sup>. Therefore, the planning of any action geared at the treatment and support of the elderly with Alzheimer's disease should include the caregiver and the whole family<sup>(6,10)</sup>.

Aggressiveness and impatience are

behavioral changes common to most elderly patients with AD, as shown by the experiences reported by family members:

[...] Yeah, he became very aggressive, he used to be very calm, so we have to agree with everything, everything he says really [...] (Discouragement)

Hallucination, loss of sleep, restlessness, nervousness, agitation, he has no patience with the caregiver who comes here. (Responsibility)

[...] She would go to the closet and put three, four pieces of clothing, one after the other, and if you'd speak, she would become angry, she did not like people correcting her [...] (Patience)

Irregular sleep-wake patterns and night walking are common in AD. Some patients sleep more during the day and at night they start to become restless. This is known as sunset or dusk syndrome which is characterized by moments of confusion and behavior changes of the elderly. At dusk, the elderly start to find their own home unrecognizable and want to leave, becoming aggressive when stopped<sup>(11)</sup>.

So, when I started to take care of her she was very, very agitated? [...] At night too, she becomes a bit agitated, it begins at the sunset, the person wants to leave, asking, saying that she wants to go away, stay with the children and some days are better than others, and this days when she is worse, then I have a medicine, I do not usually give her the medicine, but only for those days that are worse, to help her to feel more calm at night and for me too feel better. (Adaptation)

Agitation is a syndrome that involves emotional psychomotor distress. excessive activity. aggressive behavior, irritability, disinhibition and repetitive vocalizations, which can occur at any stage of dementia, although they are more common in more advanced stages. These behavioral symptoms can be extremely stressful for caregivers, especially because many of them are not prepared to deal with these behavioral changes caused by AD. The literature points to the benefits of educational interventions and skills training to caregivers to reduce behavioral symptoms in people with dementias<sup>(17)</sup>.

Another issue highlighted in the report of the caregivers was infantilization of the elderly, since the AD patients behave just like children.

Ah, the change was taking care of her like a baby,

trying to understand her, the situation of every day. (Servitude)

I have to keep everything locked, stay 24 hours locked [...] and even so, he is bruised all over the body, if we leave him for a moment, he goes up, then he cannot jump, then he returns, hurt all over, so I have to stay 24 hours attentive, it's like a child, he became a child and we have to look after him, right? (Inocence)

[...] becomes a big kid, you have to look after as if we were caring for a child, taking care of things that can hurt, that she may not fall, that she does not get hurt, because she is sensitive to everything, so it was worrying, the gate had to be locked to prevent her to go out to the street, and all the care is like this. (Patience)

The physiological changes of the aging process involve the decline in functional capacity, which can make the elderly to become frail and dependent of care. This dependence makes the caregivers look for the elderly as if they were children, as they need assistance for activities of daily living<sup>(16)</sup>.

The report of the experience of caregivers of elderly with Alzheimer's disease is complex, considering the evolutionary aspects of the disease and the emotional, social and financial challenges faced by caregivers. Among the various expressions of nursing care, coexistence groups deserve to be stressed, as they enable caregivers to exchange experiences and knowledge and to resume social life<sup>(18)</sup>.

# Concerns experienced by family caregivers in the daily life of the elderly

After the initial and intermediate stages of AD, marked by memory impairment, behavioral disorders and cognitive disorders, progression of the disease incurs in total dependence of the elderly, which now need assistance and supervision of caregivers to perform simple daily tasks, such as eating and taking medications. It is possible to see in the statements the dedication and concern of caregivers with good nutritional and hydration status of the elderly, which involves the care with schedules for the meals and also the quality and consistency of the food, in order to facilitate swallowing and prevent possible complications (19).

Oh, it's hard because we must always be focused on her, that she may not fall, the drugs should be given at the right times, we cannot forget, care for adequate food, personal hygiene, give her much water to avoid the problem of infection. So, it is a lot of care and attention that whoever is with her on a daily basis needs to have. (Responsibility)

Ah, the concern that she does not think for herself, right, so it's like now, the state she is, you have to think about food, always giving her liquids, because one thing is dehydration, food also she is already with problems. (Sadness)

The responsibility to provide the medicine and other more complex activities such as checking blood pressure and blood glucose has also been identified in another study. This involves knowledge and technical skills, which require renunciation, patience and love from the caregivers<sup>(16)</sup>.

Another great concern pointed out by caregivers was related to the risk of falls in the elderly. The falls are still the leading cause of disability, early institutionalization and mortality in this population, and the risk is higher among people with AD, according to the literature<sup>(20)</sup>.

[...] Now, so, it's like he has started falling, sometimes is on the street and he gets hurt, right? (Companionship)

Be present as much as possible and avoid being inattentive, whoever is caring for her has to be attentive to avoid that she fall, because she fell twice and it brought very hard consequences both for her and for us caregivers. (Responsibility)

Adapting the home to prevent falls through the use of supporting accessories in the bathroom, the supervision of the elderly while they roam the house, removing carpets, putting bars on the bed, etc.<sup>(19)</sup> is a relevant aspect for increasing the independence of the elderly. In this sense, the identification of these factors and family reorganization for living with AD can be facilitated by establishing an interactive network between the family and the interdisciplinary health team<sup>(7)</sup>.

### FINAL CONSIDERATIONS

study aimed to understand the This experience of family caregivers of elderly with Alzheimer's disease. In the reports, the family members expressed feelings of fear, insecurity and sadness at the moment of discovery of the diagnosis. Changes in behavior, such as memory impairment, sleep disorders, agitation and aggression are common to people with Alzheimer's and also bring great suffering in the family context. The daily care to the elderly with Alzheimer's disease is exhausting, because it includes concerns with basic activities of daily living, such as food, hydration, medication and prevention of falls. Despite reports indicate family support in some situations, it was evident that there was physical and emotional burden of primary care providers.

Based on these results, it is essential that health professionals act in an interdisciplinary way not only in the care of the elderly, but guiding family caregivers about the disease, its phases and how to deal with conflict and suffering in the family context in order to smooth the confrontation of the disease.

This study had the limitation of not identifying the stage of disease of the elderly. We suggest attention to this aspect in further studies, since this characteristic may drastically influence the type of care provided to the elderly and consequently the intensity of participation of caregivers who could, thus, express their experiences differently.

In this context, the actions of nurses of the family health strategy is of fundamental importance because they are responsible for the overall elderly assessment and the can create new strategies geared to the needs of this population, as well as to family members, taking into account the different realities experienced. Regarding geriatric nursing, the professional training process requires adequate preparation. A performance that values the family unit and the subjectivities of the relationship between the caregiver and the elderly with Alzheimer's disease may facilitate the understanding of the limitations of carers, in addition to promoting the planning of interventions aimed at improving the quality of family life.

# VIVÊNCIAS DE CUIDADORES FAMILIARES DE PESSOAS IDOSAS COM DOENÇA DE ALZHEIMER

#### **RESUMO**

O objetivo do presente estudo foi compreender o processo de vivenciar o cuidado aos idosos com doença de Alzheimer. Tratou-se de uma pesquisa exploratória e descritiva, com abordagem qualitativa. Os sujeitos da pesquisa foram oito cuidadores familiares de pessoas idosas com Alzheimer, residentes nas áreas de abrangência pertencentes a duas Unidades Básicas de Saúde localizadas no município de Maringá- PR. Os dados foram coletados entre julho e agosto de 2015 por meio de entrevista semiestruturada. Da análise temática dos dados emergiram três categorias: "O diagnóstico de doença de Alzheimer no idoso e as mudanças no cotidiano do cuidador familiar"; "Percepção do cuidador familiar sobre as alterações cognitivas e comportamentais na doença de Alzheimer"; "Preocupações vivenciadas pelos cuidadores familiares no dia a dia com o idoso". Foi constatado que a vivência do processo de adoecimento gera sofrimento, tristeza e insegurança, trazendo grandes mudanças no contexto familiar. O enfermeiro, além da assistência ao idoso com DA, pode oportunizar diálogos e definição conjunta de estratégias de cuidados para a convivência com a doença.

Palavras-chave: Doença de Alzheimer. Saúde do Idoso. Envelhecimento. Cuidadores. Cuidados de Enfermagem.

## VIVENCIAS DE CUIDADORES FAMILIARES DE PERSONAS ANCIANAS CON ENFERMEDAD DE ALZHEIMER

#### RESUMEN

El objetivo del presente estudio fue comprender el proceso de vivir el cuidado a los ancianos con enfermedad de Alzheimer. Se trató de una investigación exploratoria y descriptiva, con abordaje cualitativo. Los sujetos de la investigación fueron ocho cuidadores familiares de personas ancianas con Alzheimer, residentes en las áreas de alcance pertenecientes a dos Unidades Básicas de Salud ubicadas en el municipio de Maringá- PR. Los datos fueron recolectados entre julio y agosto de 2015, por medio de entrevista semiestructurada. Del análisis temático de los datos surgieron tres categorías: "El diagnóstico de enfermedad de Alzheimer en el anciano y los cambios en el cotidiano del cuidador familiar"; "Percepción del cuidador familiar sobre las alteraciones cognitivas y de comportamientos en la enfermedad de Alzheimer"; "Preocupaciones vividas por los cuidadores familiares en el día a día con el anciano". Fue constatado que la vivencia del proceso de enfermar genera sufrimiento, tristeza e inseguridad, trayendo grandes cambios en el contexto familiar. El enfermero, además de la atención al anciano con EA, puede dar la oportunidad a diálogos y definición conjunta de estrategias de cuidados para la convivencia con la enfermedad.

Palabras clave: Enfermedad de Alzheimer. Salud del anciano. Envejecimiento. Cuidadores. Cuidados de enfermería.

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