

# Alzheimer's disease in elderly/family: Difficulties experienced and care strategies

*Doença de alzheimer na pessoa idosa/família: Dificuldades vivenciadas e estratégias de cuidado*

*Enfermedad de alzheimer en ancianos/familia: Dificultades experimentadas y estrategias de atención*

Silomar Ilha<sup>1</sup>

Dirce Stein Backes<sup>1</sup>

Silvana Sidney Costa Santos<sup>1</sup>

Daiane Porto Gautério-Abreu<sup>1</sup>

Bárbara Tarouco da Silva<sup>1</sup>

Marlene Teda Pelzer<sup>1</sup>

1. Universidade Federal do Rio Grande.  
Rio Grande, RS, Brazil.

## ABSTRACT

**Objective:** The objective is to acknowledge difficulties experienced by family caregivers of elderly individuals with Alzheimer's disease and build strategies that deal with these difficulties in the process of care for such individuals. **Methods:** This is a descriptive and exploratory study with a qualitative approach, conducted with six family caregivers of elderly individuals with Alzheimer's disease who attended a support group conducted in a city of Rio Grande do Sul state, Southern Brazil. Data were collected between July and August 2013 through the Focus Group technique and subsequently submitted to Strategic Focus Analysis. **Results:** A total of eight categories emerged, related to the physical, mental and social health of those involved and for which strategies of care for the elderly/family were developed. **Conclusion:** Family caregivers experience difficulties of a physical, mental and social nature, which can be minimized through the construction and socialization of care strategies.

**Keywords:** Aged; Alzheimer's disease; Family; Strategies; Nursing.

## RESUMO

**Objetivo:** Conhecer as dificuldades vivenciadas pelos familiares cuidadores de pessoas idosas com doença de Alzheimer e desenvolver estratégias que venham de encontro às dificuldades vivenciadas no processo de cuidado às pessoas idosas. **Métodos:** Pesquisa exploratória, descritiva, de abordagem qualitativa, realizada com seis familiares cuidadores de pessoas idosas com a doença de Alzheimer, participantes de um grupo de apoio de uma cidade do Rio Grande do Sul, Brasil. Os dados foram coletados entre julho e agosto de 2013, por meio da técnica de Grupo Focal e foram submetidos à Análise Focal Estratégica. **Resultados:** Emergiram oito categorias relacionadas à saúde física, mental e social dos envolvidos e para as quais foram delineadas estratégias de cuidado à pessoa idosa/família. **Conclusão:** Os familiares cuidadores vivenciam dificuldades de ordem física, mental e social que podem, no entanto, ser minimizadas por meio da construção e socialização de estratégias coletivas e participativas de cuidado em saúde.

**Palavras-chave:** Idoso; Doença de Alzheimer; Família; Estratégias; Enfermagem.

## RESUMEN

**Objetivo:** Conocer las dificultades experimentadas por familiares cuidadores de personas mayores con Enfermedad de Alzheimer y desarrollar estrategias que enfrenten y suporten las dificultades experimentadas en el proceso de atención a los ancianos. **Métodos:** Investigación exploratoria, descriptiva, de enfoque cualitativo, realizada con seis familiares cuidadores de personas mayores con Enfermedad de Alzheimer integrantes de un grupo de apoyo en un municipio de Rio Grande do Sul, Brasil. Los datos fueron recolectados entre julio y agosto de 2013, por medio de la técnica de Grupo Focal, y sometidos al Análisis Focal Estratégico. **Resultados:** Emergieron ocho categorías: relacionadas a la salud física, mental y social, para las cuales se delinearon estrategias de atención a los ancianos/la familia. **Conclusión:** Los familiares cuidadores vivencian dificultades de orden física, mental y social, que pueden ser minimizadas mediante la construcción y socialización de estrategias colectivas y participativas de atención a la salud.

**Palabras clave:** Anciano; Enfermedad de Alzheimer; Familia; Estrategias; Enfermería.

### Corresponding author:

Silomar Ilha.

E-mail: silo\_sm@hotmail.com

Submitted on 04/07/2015.

Accepted on 11/26/2015.

DOI: 10.5935/1414-8145.20160019

## INTRODUCTION

Aging is a natural process, which can be accompanied by problems related to physical and/or psychological health caused by the presence of personal and contextual factors that promote the onset of Chronic Non-Communicable Diseases (CNCD). Dementias are included in this context, especially Alzheimer's Disease (AD), which is characterized as an irreversible neurodegenerative disorder that begins insidiously and causes a steady decrease in motor and cognitive functions<sup>1</sup>.

AD is considered to be the most common type of dementia among the elderly, accounting for 60 to 70% of all cases<sup>2</sup>. It is estimated that the number of individuals affected by AD surpasses 15 million worldwide and its prevalence has been increasing significantly in different age groups<sup>3</sup>. AD does not have a cure and there are no efficient treatments capable of preventing its development<sup>2</sup>. Thus, it is regarded as a relevant public health problem in the entire world<sup>4</sup>.

Its development is divided into three stages: the first one is considered to be mild, as elderly individuals experience confusion and memory loss, spatial disorientation, increasing difficulty in daily life, and changes in personality and judgment. In the second stage, regarded as moderate, this disease progresses and causes them to be incapable of performing daily life activities, in addition to anxiety, delirium, hallucinations, nocturnal restlessness, changes in sleep patterns, and difficulty to recognize friends and family members. Finally, the third and most severe stage is characterized by a great decrease in vocabulary, reduction in appetite and weight, loss of sphincter control and curling up in a fetal position<sup>5</sup>.

As the disease progresses, elderly individuals begin to depend on constant care, provided by a family member at home in the majority of cases<sup>6</sup>. Care for elderly individuals with AD is highly complex, as family members begin to have feelings that are difficult to be coped with, causing them to be socially isolated, deeply affecting their emotional systems, and leading to deprivations and changes in lifestyle<sup>4</sup>.

In this way, health professionals, especially nurses as they usually are those responsible for leading and systematizing the health care process provided to individuals in different contexts, must identify the difficulties experienced by family caregivers and develop care and support strategies for family members as they perform daily life activities of care for elderly individuals. Some studies have been conducted showing the difficulties encountered by elderly individuals with AD<sup>4,7,8</sup>. However, little has been invested to find health care strategies for such difficulties, aiming to cope with this disease whose incidence rates are increasing with the rise in life expectancy of the population.

Thus, data from the present study can provide resources to help family caregivers in their daily routine of care for elderly individuals with AD, justifying the need for and relevance of this research project. It should be emphasized that questions related to AD, family and elderly health are very important in the current

context of public policies, whose research is prioritized by the Brazilian Ministry of Health<sup>9</sup>.

Based on what has been described and given the fact that this disease has been increasing significantly with the rise in life expectancy in Brazil and worldwide, the following questions arose: What are the main difficulties encountered by family caregivers of elderly individuals with Alzheimer's disease? What health care strategies can be developed, aiming to help family caregivers in the process of care for elderly individuals with Alzheimer's disease?

In an attempt to answer these questions and in the hope of supporting family caregivers in the process of care for the elderly, the present study aimed to identify the difficulties encountered by family caregivers of elderly individuals with Alzheimer's disease and to develop strategies that help them to resolve these difficulties.

## METHODS

An exploratory descriptive study with a qualitative approach was conducted with family caregivers of elderly individuals with AD, who participated in a support group developed in a higher education institution of Rio Grande do Sul state, Southern Brazil. This research project started in 2007 and was developed by a multi-disciplinary team comprised of professors and students from the following health courses held at this institution: nursing, pharmacy, physiotherapy, nutrition, dentistry, occupational therapy and psychology.

The inclusion criteria for this study were as follows: to be a family caregiver of an elderly person with Alzheimer's disease and to be fully involved with the project. Thus, family caregivers not participating in the group were excluded from this study and a total of six individuals participated in it. Participants were individually contacted and invited by telephone, as authorized and made available to the researchers by the group coordinator.

Data were collected through the Focus Group (FG) technique, characterized as a discussion group that talks about a specific theme experienced and shared through common experiences<sup>10</sup>. It should be emphasized that the number of participants in this study is in accordance with the data collection technique selected, which recommends from three to eight people, aiming to facilitate the moderation and analysis of transcriptions<sup>10</sup>.

A total of three focus meetings were held, each lasting approximately two hours, between June and August 2013. These meetings were based on specific themes and conducted by a nurse who acted as a moderator and nutritionist, observing the FG. In the first meeting, researchers sought to identify what it was like for family caregivers to live with an elderly individual with AD. Thus, there was a long process of group discussions, guided by the following questions: What is the first memory that comes to mind when you think about AD? What does it mean to experience the diagnosis and prognosis of an elderly

person with AD and care for them? After the discussions, a FG summary was made.

In the second meeting, the summary of the first meeting was mentioned again and family caregivers validated the information. Next, they reflected on possible strengths/potentials that enable family members to be stronger to live with elderly individuals with AD, as well as weaknesses/vulnerabilities experienced by them, thus hindering the care process. Subsequently, family caregivers were invited to record their reflections on paper through drawings, illustrations, writing and/or in any other way. It should be emphasized that these weaknesses/vulnerabilities refer to the difficulties experienced by family caregivers in their experience with and care for elderly individuals with AD.

Finally, the third meeting included the group summary of the previous meetings, aiming to validate this information and deepen the discussions about care strategies. The moderator had already transcribed the discussions from previous groups and sought to identify the difficulties encountered by all family caregivers who were participating in the FG. A total of eight main difficulties were found, which were written down on strips of white paper and folded by the moderator and observer. Thus, family caregivers, the observer and the moderator were invited to pick one or more paper strips and, one by one, they unfolded these and read the difficulties described.

After family caregivers confirmed that during a certain period of experiencing/caring for elderly individuals with AD they had in fact already encountered such difficulty, the group presented possible strategies to be used when facing a similar or the same situation. While family caregivers made suggestions or described what they had done in a certain situation, the moderator would lead the discussion and the observer would note down the instructions. In the end, the observer read all the strategies suggested, aiming to be faithful to what had been written down, and family caregivers validated the strategies proposed.

Data analysis began with the group summary of each meeting, as suggested by the Strategic Focus Analysis (SFA), which proposes the active participation of those involved in the study<sup>11</sup>. The SFA aims to broaden the understanding of the phenomenon being investigated, in this case, the difficulties encountered and the strategies used by family caregivers of elderly individuals with AD from the more in-depth group approach to potentialities and vulnerabilities, in addition to challenges/threats, opportunities and strategies associated with individual and group experiences<sup>11</sup>. Subsequently, the summaries of meetings were mentioned again by the main researcher, who performed a theoretical analysis, thus creating the analysis categories described in the results.

The ethical and legal principles involving human research were taken into consideration, in accordance with Resolution 466 from December 12<sup>th</sup> 2012 issued by the Brazilian Health Council<sup>12</sup>. The present study was approved by the Rio Grande Federal University Research Ethics Committee under official

opinion 092/2013. Family caregivers signed two copies of an informed consent form and kept one, while the other was given to the researchers. Participants' anonymity was maintained and they were identified by the letter "F" (Family member) followed by a number, according to the order of interview (F1, F2, F3, F4, F5, F6).

## RESULTS

Of all six family members who participated in the FG, one was a wife and five were sons/daughters. A total of five were females and one was male. They were all the main caregivers of elderly individuals with AD. Based on the analysis, the following categories emerged: Difficulty to recognize people/places; Forgetting the way home; Refusal to accept Alzheimer's disease; Difficulty to accept bathing; Difficulty to deal with money; Difficulty to control the medication by oneself; Aggressiveness of elderly individuals with Alzheimer's disease; and Risks to physical health, for which strategies of care for elderly individuals/family members were developed.

### Difficulty to recognize people/places

One of the difficulties reported by family members was that elderly individuals with AD could not recognize close people and common places, such as their own home. The reports are as follows:

*Things have gotten worse, there are times when she doesn't recognize me. Now, she's at that stage when she's talking about leaving. I arrive [at the elderly woman's home] and she says, "Aren't you taking me home? Please, take me home because I didn't tell my mother I went out!" I try to explain to her that her mother has passed away and that she's home, but it's pointless. (F1)*

*She would get up at night and say that she wasn't home. She was really lost [...] now she's at that stage when she says, "I have my home, I have my money, even if you don't accept it, I'll leave! Please, take me home!" (F3)*

### Forgetting the way home

Family members reported that, at a certain stage of the disease, elderly individuals with AD lose their sense of direction and forget the way to their own home, even when they are close, as shown in the following reports:

*My mother is someone who'd never depended on anybody until she was 70, I think she was 76 the last time she went to Italy by herself. She'd fly to Italy, spend a couple of months there and then go to São Paulo, Porto Alegre, Santa Maria, all by herself. Now, she goes down the corner and gets lost, she forgets her way home. (F1)*

*You have to care for them, because sometimes they leave home, go down the corner and don't remember the way back home. (F2)*

### **Refusal to accept Alzheimer's disease**

It is difficult for family caregivers to accept Alzheimer's disease, as reported below:

*There are many people who don't accept this disease. Here in the group I met this lady whose husband had Alzheimer's. So she said to me, "I'm not coming anymore, I don't want to know, I prefer to check him into a clinic to seeing him like this. (F1)*

*Accepting this disease was hard for me. Because suddenly I didn't have a husband anymore, someone I could rely on. Now, I don't have a husband, but a son instead. (F2)*

### **Difficulty to accept bathing**

Another difficulty reported by family members referred to the hygiene of elderly individuals:

*She still bathes alone, but there is always a caregiver keeping an eye on her. She always fights not to bathe though, sometimes it takes three to four days for her to agree with it. (F1)*

*Today I left home and said, "I'll leave your clothes here!" Then he asked me, "Why?". I said, "Because you got to take a shower today!". Then, he replied, "Again? But I took one yesterday!". (F2)*

*The elderly person I care for was different, he would sit in the toilet, turn on the shower and think he was taking a shower! He'd let the water run but wouldn't take a shower. (F6)*

### **Difficulty to deal with money**

At a certain stage of the disease, elderly individuals with AD lose the sense of value of money, although recalling its usefulness:

*He knows what money is used for, but doesn't remember its value anymore. He thinks that he can buy a lot with only R\$ 50.00. (F1)*

*It was like this with a friend of mine, his mother had Alzheimer's and she was retired, then they would notice she had no money. He was the son caregiver and he didn't know if she was giving it when someone asked for it at the gate or if she was hiding it. Sometimes, they [elderly individuals with Alzheimer's disease] lose sense of the value of money. But they can count how many bills they*

*have in their wallet. If we take out one bill, they'll notice it's missing and they'll argue with you. (F6)*

*My mom didn't want anybody to touch her money, she hid it inside a shed. Then, one day I took her to the hospital and my sister looked for it and found R\$ 1,600.00 rolled up in a bundle of cloths. (F2)*

### **Difficulty to control the medication by oneself**

Another difficulty encountered by family caregivers was associated with medication, as some elderly individuals refuse to accept that family members/caregivers give them the medication. They want to be responsible for taking it, which usually results in its incorrect use:

*My mother went to the doctor and was soon diagnosed with this disease, so she's already taking the medication. But she would say it was a lie, that nobody would give it to her because she wasn't crazy. So she'd get mad and wouldn't let anybody give her this medication. She'd take it herself, but at times she'd change the medication and that made her feel so bad! (F1)*

*They take the medication in the wrong way. It's pointless, when it comes to medication, we have to give it. When I cared for them, we [caregivers] were the ones who'd give it to them at breakfast time to avoid confusion or forgetfulness. (F6)*

### **Aggressiveness of elderly individuals with Alzheimer's disease**

The aggressiveness of elderly individuals with AD was also mentioned as one of the difficulties encountered by family members, as reported below:

*There was a stage when my husband got very angry, I saw an aggressive and a very aggressive stage. Whenever he was restless and violent, I had to ask, "What's the name of that engine part you exchanged?". Then, he would talk to me and explain all about this engine, because this is something he loved working with. (F2)*

*[...] they (individuals with Alzheimer's disease) irritate us and make us tired. They keep asking the same questions and at times they even get aggressive, so it's hard [...]. (F6)*

*[...] there's the stage when they eat a lot, there's one when they say there's nothing to eat, and there's another when they hide things. There's the stage when they get very aggressive and I think this is one of the hardest [...]. (F4)*

### **Risks to physical health**

As a result of the disease symptoms, which mainly include forgetfulness, elderly individuals end up encountering situations

that pose a risk to their physical well-being and that of others living with them:

*We had to sell our car, because the moment we turned our backs to him, he'd go and try to turn it on. One day he got into his sister's car, put the kids in it and went for a ride [...] It was in God's hands, because we couldn't do anything, there was no way we could search for him around the city. (F2)*

*My mother picked up the ladder, went up onto the garage roof with a bucket, brush and soap to clean it, then she slipped and fell onto the floor. She fractured an entire side of her body and hit her head really hard [...]. (F1)*

*[...] one day I went to the market. On the way back, I saw a black dot on the roof of the house. When I got closer, I heard a loud noise. He'd fallen and broken the roof. It was a sunny day and when I asked what he was doing, he said he was looking for the leak that was making his house wet. (F2)*

### Strategies of care for elderly individuals with Alzheimer's disease and their families

Aiming to summarize information, Table 1 - Strategies of care for elderly individuals with Alzheimer's disease and their families - was developed, including the changes associated with this disease, the characteristics associated with this change and the care strategies. Strategies 1 through 7 follow the same order of the difficulties previously described in the categories. Strategies related to "Risks to physical health" are not restricted to a specific space, as family members understand that these are connected to the remaining ones.

## DISCUSSION

From a broader perspective, human beings and all the parts involved should be analyzed, acknowledged and valued following a unique multi-dimensional approach. Isolated information or data are insufficient and placing them in their actual context is essential. Apart from this perception, it should be emphasized that the context of care for elderly individuals with AD is changed or explained by the complexity of care present<sup>13</sup>. Thus, the work of professionals must go beyond the identification of difficulties to which family caregivers of elderly individuals with AD are exposed. It should bring back ways to perform aimed at enabling greater autonomy and well-being to family caregivers of elderly individuals with AD<sup>14</sup>.

The present study showed that family caregivers of elderly individuals with AD encounter physical, mental and social difficulties. One of the difficulties reported by family members was that, at some stage of the disease, these elderly individuals can hardly recognize close people and common places such as

their own home. A study conducted in a referral health care center for elderly individuals with and without Alzheimer's disease in the city of Brasília, Mid-Western Brazil, showed that memory loss was the change most frequently reported by family members<sup>15</sup>.

Initially, AD affects the formation of the hippocampus, which is characterized as the short-term memory center, with subsequent impairment of associated cortical areas<sup>16</sup>. As the disease progresses, there is greater memory impairment, causing elderly individuals not to recognize their friends, family and other people they knew<sup>5</sup>. Acceptance of Alzheimer's disease by family members was also viewed as a difficulty by participants in this study, similarly to what was found in a study conducted in a city in the state of São Paulo, Southeastern Brazil<sup>17</sup>.

Another difficulty reported by family caregivers is associated with body hygiene and administration of medication of elderly individuals, as some refuse to take their medication and others do so incorrectly. A study performed in the city of São Paulo, aimed at identifying health care activities, conveniences and difficulties experienced by caregivers of elderly individuals with AD, showed that care actions in the routine of caregivers mainly involve activities associated with diet, hygiene and medication<sup>18</sup>.

The aggressiveness of elderly individuals with AD was also mentioned as one of the difficulties encountered by family caregivers. A study conducted in a referral center for Alzheimer's disease care with 208 family caregivers of elderly individuals with this disease in the city of Curitiba, in the state of Paraná, Southern Brazil, showed that caregivers are afraid due to the changes in behavior and personality of these elderly individuals. They reported that such changes pose risks to the well-being of both caregivers and elderly individuals<sup>6</sup>. Similar result was found in the present study.

Thus, family caregivers must know the signs and symptoms of Alzheimer's disease very well and use care strategies that support this process. It is important for family caregivers to be able to understand and manage the elderly individuals' aggressiveness and not to take their verbal and physical aggression or their lack of acknowledgement personally, despite all the care given to and actions performed for them, as this is inherent in such disease<sup>17</sup>.

Care for elderly individuals with AD was found to be associated with the maintenance of physical safety and reduction in anxiety and restlessness, among other factors<sup>19</sup>. At the initial stage of AD, the care process mainly involves supervision, aiming to prevent accidents as a result of the difficulty they have to identify risk situations<sup>20</sup>. It is known that elderly individuals with AD reject what is new and do not adapt to new conditions easily. As a result, forcing them to perform unknown activities can lead to irritability. Thus, it should be emphasized that one should work on the uniqueness of each elderly individual with AD, recognizing and valuing their habits, culture and life history<sup>13</sup>.

Another finding of the present study was the need for care strategies aimed at caregivers, as caring for elderly individuals

**Table 1.** Strategies of care for elderly individuals with Alzheimer’s disease and their families

Changes associated with AD	Characteristics associated with changes	Care strategies
1. Difficulty to recognize peoples, places and situations	As AD progresses, elderly individuals begin to forget things, as it is inherent in this disease	<ul style="list-style-type: none"> <li>- Be patient and try not to disagree with elderly individuals with AD.</li> <li>- Always keep in mind that elderly individuals with AD do not repeat the same questions over and over to mock or irritate you, but because they do not remember some things.</li> <li>- Do not be ironic or embarrass elderly individuals in front of other people.</li> <li>- Value what elderly individuals with AD tell you, even if you do know it is only their imagination.</li> <li>- Answer the same question as many times as elderly individuals ask you to.</li> <li>- Some elderly individuals with AD do not recognize their own home at some stage of their disease. If they ask you to take them home, do not answer that they are already home as this will make them angry and, at times, aggressive. Say you will take them, walk around the house or block, on foot or by car, return home and get in through a different door if possible</li> <li>- If elderly individuals with AD have a car, you should hide the keys. Change the place of objects that pose risk to their health or put them in a safe place.</li> </ul>
2. Forgetting the way home	At a certain stage of this disease, elderly individuals with AD often forget the way home.	<ul style="list-style-type: none"> <li>- Prevent elderly individuals with AD from leaving without you knowing where they are going.</li> <li>- If possible, follow them without their noticing it, due to their forgetfulness. Tell them you need to go to the same place.</li> <li>- Try to put a badge on the clothes of elderly individuals with their name and full address on it.</li> <li>- Warn the neighbors, explaining about their disease and leaving an address and contact number.</li> </ul>
3. Family members’ refusal to accept Alzheimer’s disease	Many family caregivers are not supported by other family members	<ul style="list-style-type: none"> <li>- Try to have family meetings to explain the situation, make group decisions and talk about this disease.</li> <li>- Share your responsibilities with the family.</li> <li>- Invite other family members to go to consultations with professionals.</li> <li>- Keep the disease diagnosis at hand to show it to other family members.</li> <li>- If possible, make a schedule with the times and days when each family member will contribute to the care. During this period, try to take at least a day off per week (one morning or afternoon).</li> <li>- Be patient when talking to the remaining family members. Remember that each individual will accept the disease on their own time.</li> <li>- If the family has sufficient conditions, seek a professional to prevent family members from being overloaded.</li> <li>- Try not to force elderly individuals to bathe so as not to embarrass or irritate them.</li> </ul>
4. Difficulty to accept bathing	At a certain stage of the disease, some elderly individuals with AD refuse to bathe, not being willing to do it or stating they have already done it	<ul style="list-style-type: none"> <li>- Try to find pleasant ways to encourage elderly individuals with AD to keep their personal hygiene and to enable them to realize they have not done it yet. Try to turn this into a game, where the elderly individual with AD plays against the family caregiver. Thus, each time they bathe, both of them score; the one who does not bathe will lose. Mark the dates and offer prizes.</li> <li>- Do not trust the sound of running water from the shower exclusively. Try to care for and help the elderly individual during bathing time without their realizing it.</li> <li>- Take the key from the bathroom door to prevent them from being locked in.</li> </ul>

Continued Table 1.

Changes associated with AD	Characteristics associated with changes	Care strategies
5. Difficulty to deal with money	At a certain period of the disease, some elderly individuals lose sense of the value of money or its existence entirely	<ul style="list-style-type: none"> <li>- Do not take money from elderly individuals with AD altogether, so they will not feel robbed, dependent or inferior</li> <li>- Identify whether the elderly individuals with AD have lost the sense of value of money or its existence. If they have forgotten about the existence of money, it can be taken away and given back little by little, according to what they need. If they have forgotten about its value, but the attachment to it remains, replace large bills for small ones, maintaining the same number of bills.</li> <li>- Inform and explain about Alzheimer's disease in the markets and other businesses close to the home of elderly individuals with this disease and leave a contact number.</li> <li>- At the more advanced stages of AD, when they have no conditions to manage their finances, even small amounts, a family member usually becomes responsible for this task. It is important to be clear about the expenses with the remaining family members.</li> </ul>
6. Difficulty to control de medication by oneself	Some family caregivers find it difficult to manage the medication of elderly individuals with AD, especially when they have other diseases.	<ul style="list-style-type: none"> <li>- Try to give as much autonomy to the elderly individuals with AD as possible. If they have conditions to take their medications alone, divide these by time into separate containers and label them as "morning", "afternoon", and "evening", or the exact times when they should be taken</li> <li>Thus, it is the caregiver who will be controlling the medication, although the elderly individuals with AD will have the impression that they will be in control and they will feel independent as a result.</li> <li>- If the elderly individuals do not know how to read or do not have conditions to do this anymore, a "sun" and "moon" can be drawn to indicate "morning medication" and "evening medication".</li> <li>- In situations when the caregiver has to give the medication, write the medication time on the container where each pill is to avoid memory lapses/wrong times.</li> <li>- Stay close to elderly individuals with AD when they have to take their medication to avoid mistakes or even to prevent them from being thrown away without you realizing it.</li> </ul>
7. Aggressiveness of individuals with Alzheimer's disease	At a certain stage of the disease, some individuals with AD can be verbally or physically aggressive	<ul style="list-style-type: none"> <li>- Try not to take things personally.</li> <li>- Remove objects that may pose a risk to elderly individuals with AD or their caregivers.</li> <li>- Never strike back.</li> <li>- Try to change the subject, draw the attention of elderly individuals with AD to other things that attract them and that they like.</li> </ul>

Source: Data from the investigation.

with AD is a highly demanding task for them and a difficult situation for everyone, whether family members or not. Similar results were found in other studies on physical and emotional overload<sup>21,22</sup>, social relationships and leisure activities<sup>21,22</sup>.

By fully dedicating themselves to elderly individuals with AD, family caregivers can become physically and mentally tired and stressed, which tends to be worse if they are alone, without the

help of others<sup>20</sup>. Studies have shown that one of the difficulties encountered when caring for these elderly individuals is precisely care without work rotation<sup>17,18</sup>. Caring for elderly individuals with AD goes beyond the willingness to provide care, due to the complexity it requires, including knowledge, development of abilities, and initiatives that require one to be patient and loving and to sometimes abandon one's life project. These facts

contribute to family caregivers experiencing physical, emotional and social overload in their care routine<sup>23</sup>.

Thus, a study conducted in Portugal emphasizes the need for health policies that support families caring for elderly individuals at home and urgent interventions for these individuals<sup>24</sup>. Nurses are the health professionals who are closely associated with this process, as they are the ones spending more time with individuals and families and as they have the ability to interact with the remaining areas of knowledge. As a result, they can instruct families/caregivers and develop a health care and strategy plan that qualifies the process of care for elderly individuals with AD<sup>17</sup>.

## CONCLUSION

The present study enabled us to understand that family caregivers encounter difficulties of a physical, mental and social nature that pose some challenges when living with and caring for elderly individuals with Alzheimer's disease. However, these challenges can be minimized through the development and socialization of group care strategies.

In this sense, this study enabled the construction of strategies aimed at the main difficulties encountered by the group of family members participating in it. Thus, this study is innovative, as the strategies were built in a collective and participatory way, founded on their experiences and using simple understandable language. Thus, it is believed that strategies emerging from this research project can help other families and caregivers in the process of care for elderly individuals with AD.

The present study had some limitations, among which was the difficulty to gather family members to develop the focus groups. However, participants organized and reorganized themselves many times to enable the group to be effective, including meetings that were cancelled and set up again with the purpose of reaching the proposed goals.

In contrast, this study had some positive aspects such as the data collection and analysis method used, which allowed the process to be dynamic, circular and multi-dimensional, thus enabling one to understand the phenomenon under investigation, whose participants and researchers were actors and authors of new meanings. These factors contributed to the effectiveness of this study, which has characteristics that enable it to support the innovation and reflection on Nursing/Health care practices.

The results of this research project can promote discussions and reflections among nursing/health professionals and family members/caregivers, and in families and society as a whole, aiming to improve care for elderly individuals and families. In this sense, it is recommended that these strategies should be used in the health care/clinical practice of nursing/health professionals working with elderly individuals and families experiencing Alzheimer's disease and by family members/caregivers of elderly individuals with this disease in their routine care.

However, understanding the complexity involved in the issue of care for elderly individuals with AD in the family environment, it is suggested that more studies should be conducted, aiming to help family members/caregivers of elderly individuals experiencing this condition.

## REFERENCES

1. Seima MD, Lenardt MH. A sobrecarga do cuidador familiar de idosos com Alzheimer. *Texto Contexto Enferm.* 2011; 10(2): 388-98.
2. World Health Organization. [Internet]. Dementia: a public health priority. Geneva: WHO; 2012 [citado 2015 jan 15]. Disponível: [http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1)
3. Alzheimer's Association. Alzheimer's disease facts and figures. *Alzheimer's dementia.* 2012; 8(2): 131-8.
4. Oliveira APP, Caldana RHL. As repercussões do cuidado na vida do cuidador familiar do idoso com Demência de Alzheimer. *Saúde Soc.* 2012 jul/set; 21(3): 675-85.
5. Sales ACS, Reginato BC, Pessalacia JDR, Kuznier TP. Conhecimento da equipe de enfermagem quanto aos cuidados com idoso Portador da doença de Alzheimer. *R. Enferm. Cent. O. Min.* 2011 out/dez; 1(4):492-502.
6. Seima MD, Lenardt MH, Caldas CP. Relação no cuidado entre o cuidador familiar e o idoso com Alzheimer. *Rev. Bras. Enferm.* 2014 mar/abr; 67(2): 233-40.
7. Pinto MF, Barbosa DA, Ferreti CEL, Souza LF, Fram DS, Belasco AGS. Qualidade de vida de cuidadores de idosos com doença de Alzheimer. *Acta Paul. Enferm.* 2009 set/out; 22(5):652-7.
8. Borghi AC, Castro VC, Marcon SS, Carreira L. Sobrecarga de familiares cuidadores de idosos com doença de Alzheimer: um estudo comparativo. *Rev. Latino-Am. Enfermagem.* 2013 jul/ago; 21(3): 876-883.
9. Ministério da Saúde (BR). Agenda Nacional de Prioridades de Pesquisa em Saúde. 2ª ed. Brasília: DF; Ministério da Saúde; 2008.
10. Barbour R. Grupos Focais. Porto Alegre: Artmed, 2009. 216p.
11. Backes DS, Colomé JS, Erdmann RH, Lunardi VL. Grupo focal como técnica de coleta e análise de dados em pesquisas qualitativas. *O mundo da saúde.* 2011; 35(4): 438-42.
12. Conselho Nacional de Saúde (Brasil). Resolução nº. 466, de 12 de dezembro de 2012. Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. *Diário Oficial da União.* 12 dez 2012; Seção 1.
13. Cassola TP, Backes DS, Ilha S, Souza MHT, Cáceres KF. Adaptive processo f caregivers of a person elderly with Alzheimer: contributions of nursing. *J Nurs UFPE on line.* 2014 [cited 2014 Oct 20]; 8 (supl. 1):2243-8. Available from: <file:///D:/Usu%C3%A1rio/Downloads/5319-59684-1-PB.pdf>
14. Ilha S, Zamberlan C, Rosa RT, Viero M, Piexak DR, Backes DS. Grupo de apoio multidisciplinar com cuidadores de idosos com Alzheimer: sentimentos vivenciados. *Revista Nursing.* 2012; 14(168):244-9.
15. Falcão DVS, Bucher-Maluschke JSNF. Filhas que cuidam de pais/mães com provável/possível doença de Alzheimer. *Estud. psicol. (Natal).* 2008 set/dez; 13(3): 245-56.
16. Valente GSC, Lindolpho MC, Santos TD, Chibante CL, Aquino A. Sistematization of nursing care to the elderly with Alzheimer's disease and depressive disorders. *J. Nurs. UFPE on line* [on line]. 2013 [cited 2014 Oct 20]; 5 (esp): 4103-11. Available from: <file:///C:/Users/Andre/Downloads/4194-40668-1-PB.pdf>
17. Vedullas RA, Ferreira M, Nogueira VO. Dificuldades enfrentadas pelo cuidador familiar mediante o paciente com mal de Alzheimer em fase avançada. *Saude Colet.* 2011; 08(50): 109-13.
18. Sakman R, Cavalcante MBG, Puggina AC. Facilidades e dificuldades do cuidador familiar de idosos com doença de Alzheimer em domicílio. *Revista Enfermagem Atual in Derme.* 2013; 65.

19. Lin LC, Wu SC, Kao CC, Tzeng YL, Watson R, Tang SH. Single ability among activities of daily living as a predictor of agitation. *J. Clin. Nurs.* 2009; 18(1): 117-23.
20. Ricci M, Guidoni SV, Sepe-Monti M, Bomboi G, Antonini G, Blundo C. Clinical findings, functional abilities and caregiver distress in the early stage of dementia with Lewy bodies (DLB) and Alzheimer's disease (AD). *Arch. Gerontol. Geriatr.* 2009; 49(2): 101-4.
21. Diel L, Forster LMK, Kochhann R, Chaves MLF. Sociodemographic profile and level of burden of dementia patients' caregivers who participate in a support group. *Dement Neuropsychol.* 2010 jul/set; 4(3): 232-7.
22. Morais HCC, Soares AMG, Oliveira ARS, Carvalho CML, Silva MJ, Araujo TL. Burden and modifications in life from the perspective of caregivers for patients after stroke. *Rev. Latino-Am. Enfermagem.* 2012 Sep/Oct; 20(5): 944-53.
23. Floriano LA, Azevedo RCS, Reiners AAO, Sudré MRS. Care performed by family caregivers to dependent elderly, at home, within the context of the Family Health strategy. *Texto Contexto Enferm., Florianópolis.* 2012 Jul/Sept; 21(3): 543-8.
24. Araújo I, Paúl C, Martins M. Living older in the family context: dependency in self-care. *Rev. Esc. Enferm. USP.* 2011 Ago/Sept; 45(4):869-75.