

ALZHEIMER'S DISEASE IN THE ELDERLY PERSON/ FAMILY: POTENTIALITIES, WEAKNESSES AND STRATEGIES

Yanka Silveira Marques¹ 
Francine Casarin¹ 
Betânia Huppel¹ 
Bruna Rodrigues Maziero² 
Maria Helena Gehlen¹ 
Silomar Ilha¹ 

ABSTRACT

Objective: to understand the potentialities/weaknesses experienced by family members/caregivers of elderly people with Alzheimer's disease in daily care, as well as the strategies used by them in this context. Method: this is a step of critical action research, conducted with seven family members/caregivers of elderly people with Alzheimer's disease, participants of a support group developed at a university in Rio Grande do Sul, Brazil. Data were collected in July 2020, through semi-structured interviews developed during home visits. Data processing was performed using the Discursive Textual Analysis technique. Results: they generated nine categories – four referring to weaknesses/difficulties; one referring to the potentialities/opportunities experienced by family members/caregivers; and four referring to the strategies used by family members/caregivers. Conclusion: the data presented here can serve as a basis for the implementation of care strategies for people who experience realities similar to those of the participants of this research, thus directly contributing to the practice of care.

DESCRIPTORS: Aging; Alzheimer's Disease; Elderly; Family; Strategies.

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¹Universidade Franciscana. Santa Maria, RS, Brasil.

²Universidade Federal de Santa Maria. Santa Maria, RS, Brasil.

INTRODUCTION

Population aging is a global reality, a consequence of the drop in fertility and mortality rates, which entails an extension of the population's life expectancy. The longevity of Brazilians has progressively increased over time, as the representation of elderly people in Brazil in 2018 was about 9.2%, and projections indicate that, by the year 2060, it will reach the range of 32.16%⁽¹⁾.

Although the human aging process does not mean (coexist) living with disease, the increase in life expectancy inevitably contributes to the emergence of Chronic Non-communicable Diseases (CNCDs) and neurodegenerative diseases, such as Alzheimer's disease (AD)⁽²⁾.

AD has a neurodegenerative nature characterized by progressive memory disorders, which leads to progressive functional decline, significant impairment of autonomy and, in more advanced cases of the disease, total dependence⁽³⁾. According to data from the World Alzheimer's Disease Report, by the Alzheimer's Disease International Federation (ADI), in 2019, about 50 million people had the disease worldwide, and this number tends to increase continuously and significantly to 152 million in the year 2050⁽⁴⁾. In Brazil, it is estimated 1.2 million cases, most of them still without diagnosis⁽⁵⁾.

Due to its symptoms, AD undermines the quality of life (QoL) and autonomy of the elderly person, who starts to require singular and, sometimes, intensive care, which leads to the need for someone to support him/her⁽⁶⁾. In this context, the caregiver becomes fundamental in helping with Basic Activities of Daily Living (BADLs) and Instrumental Activities of Daily Living (IADLs), related to food, hygiene, medication control, financial administration, among others. Frequently, the care of the elderly person is performed at home by a family member⁽⁷⁾.

Accordingly, it is necessary to understand how family members/caregivers perceive this process with regard to the experienced weaknesses and potentialities, as well as the strategies developed by them to help these patients in times of difficulty, a fact that justifies the need and relevance of this research. It is also justified based on the National Agenda of Research Priorities, which encompasses issues related to CNCDs, including AD, as well as those related to the health of the elderly person as priority research topics in Brazil⁽⁸⁾.

In light of the foregoing, the objective was to understand the potentialities/weaknesses experienced by family members/caregivers of elderly people with Alzheimer's disease in daily care, as well as the strategies used by them in this context.

METHOD

This is a critical action research⁽⁹⁾, conducted with family members/caregivers of elderly people with AD, participants of the support group "Assistência Multidisciplinar Integrada aos Cuidadores de Pessoas com a Doença de Alzheimer (AMICA, as per its Portuguese acronym, translated into Integrated Multidisciplinary Care for Caregivers of People with Alzheimer's Disease"), developed at a university in Rio Grande do Sul, Brazil. At the time of the research, the group had an average of 20 registered family members/caregivers.

As research inclusion criteria, the following were considered: being a family member/caregiver of an elderly person with AD and participating in AMICA. As exclusion criteria, family members/caregivers with a score lower than that recommended in the Mini-Mental State Examination (MMSE) were considered⁽¹⁰⁾. Seven family members/caregivers complied

with the criteria, thus forming the corpus of this research.

The contact and individual invitation to family members/caregivers was made by one of the researchers by telephone, acquired from the project coordinator. After the participants' acceptance, home visits were made in July 2020, when data were collected using a semi-structured interview instrument specifically designed for this research, consisting of two parts. In the first, the social description of the participants was sought; in the second, there were four open questions about the daily life with the elderly person with AD.

The interviews had an average duration of 120 minutes and were recorded by the researcher on an MP3 player and then transcribed. Accordingly, data analysis was made possible, based on the discursive textual analysis technique, organized from a recursive sequence of three components: 1) unitization; 2) establishment of relationships; 3) communication⁽¹¹⁾.

Initially, the researcher examined the texts with intensity and depth in detail, forming the key category, based on the identification of the experiences of family members/caregivers of elderly people with AD in daily care. This was unitized in three base units – in the first unit, all the experienced difficulties/weaknesses were grouped; in the second, the potentialities/opportunities; and in the third, the strategies used by family members/caregivers in daily care.

Afterwards, a new reading was performed from the key category and the base units, and each report inserted in the units was read in detail and separated into different units. Finally, the last stage of the method of analysis was carried out, when the researcher developed the communication process among the different difficulties, resulting in the metatexts of description and interpretation of the investigated phenomena and description of the categories.

This research contemplates the first objective of the macroproject called "Alzheimer's disease in the elderly person/family: experienced difficulties and (geronto) care technology". Ethical precepts involving research with human beings were considered, according to Resolution 466/2012 of the Brazilian Ministry of Health⁽¹²⁾. The Project was approved by the Research Ethics Committee under Opinion number 3.920.648 and CAAE: 29816420.8.0000.5306. Participants were identified by the letter F (family member) followed by a number according to the order of the interview (F1, F2... F7).

RESULTS

Of the seven family members/caregivers, six (85.7%) were female, aged between 33 and 68 years. Three were children; three were caregivers; one was husband/partner, with time working as a caregiver between 2 and 17 years. Four lived with the elderly person with AD, three lived in separate houses and six family members/caregivers alternated the act of caring for with other people. The time in which family members/caregivers participated in AMICA ranged from 10 months to 6 years. All participants were the primary caregivers of the elderly person with AD.

The analyzed data resulted in a key category: experiences of family members/caregivers of elderly people with Alzheimer's disease. It was unitized into three base units and nine categories, as shown in Figure 1.

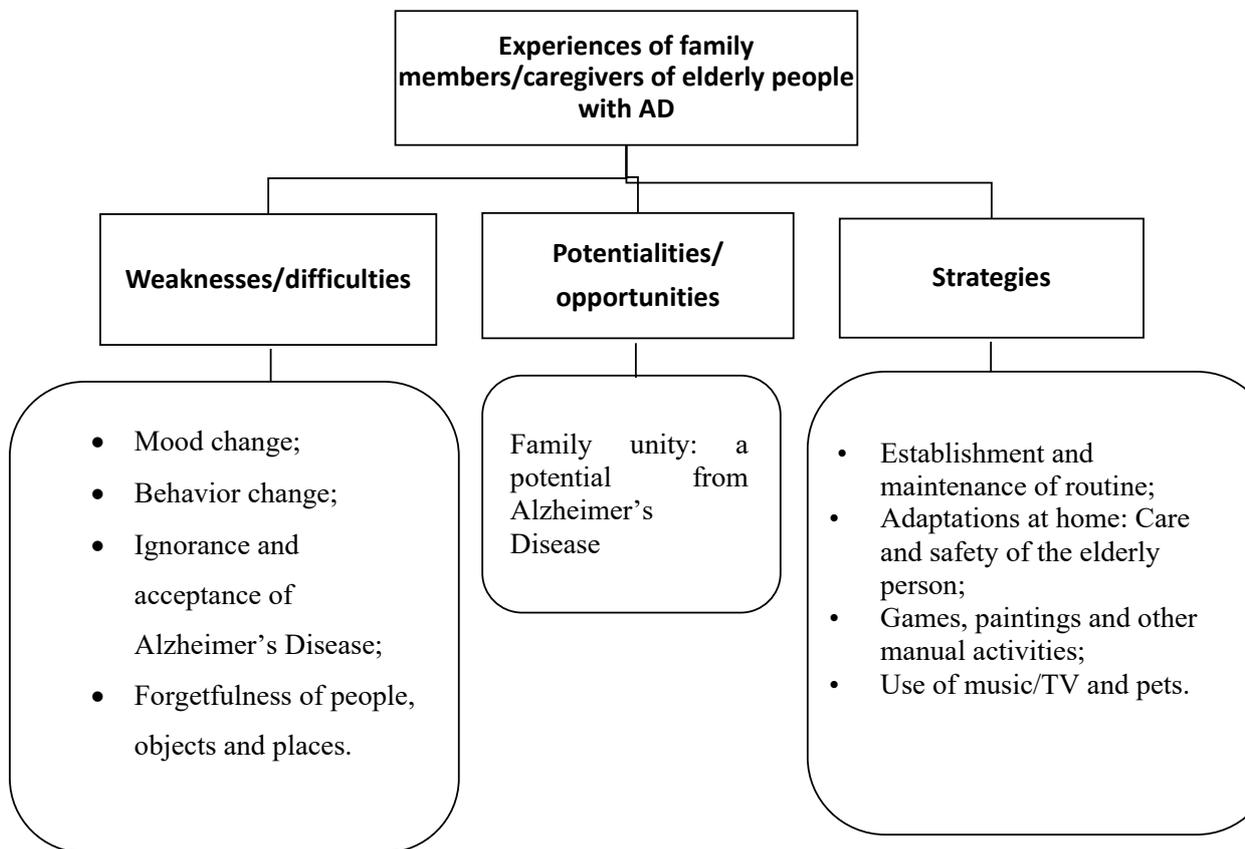


Figure 1 – Schematic representation of the relationship among the key category, base units and categories. Santa Maria, RS, Brazil, 2020
Source: Authors, 2020.

Difficulties related to mood change

Among the difficulties reported by family members/caregivers, it was mentioned that elderly people with AD, during the course of the disease, have difficulties related to mood changes, with episodes of aggression. According to reports:

[...] the lady I care for almost killed the neighbor, took the French knife. (F2)

[...] when he is not having a good day, he gets very annoyed, he gives some more confused answers [...] she (wife also with Alzheimer's) bothered him so much, so that he rolled up the newspaper and attacked himself, punched himself in the head [...] when she is not well, it becomes like she is fighting, and then she cries a lot and misses home, and sometimes she doesn't want to talk. (F5)

Difficulties linked to behavior change

Behavior change was reported by family members/caregivers as an experienced difficulty. Elderly people with AD, at some stage of the disease, lose track of time and have impairments in visual-spatial function. As reported below:

[...] she didn't accept things, nothing we said. The diaper, he used to say: "Why this bunch of diapers? What for? You're throwing money away!". So I said to her: "Mom, you wear diapers", and she said: "No, I don't wear anything, you know?" [...] and there she said: "Why did you take me to the doctor if I'm not feeling anything?". And then I had to work hard to be able to take her. (F4)

[...] some days everything is perfect, but, in a short time, there are blackouts, incredible. [...] it burns things like that, it burns food [...] she forgets the gas, for example [...] grandma turns on the stove and forgets, she goes there to do her knitting and forgets the stove. (F7)

Difficulty related to the lack of knowledge and acceptance of Alzheimer's disease

The non-acceptance of the disease is still part of the family life of elderly people with AD, making the relationship between family members/caregivers difficult:

In the past, I was not aware of Alzheimer's disease, I always heard that so-and-so had Alzheimer's, there in my city, several people, but Alzheimer's was very distant for me [...], I thought that the mother was pretending it, that everything was a prank [...] it was not very easy for me to accept the condition of the mother depending on me. She caused my exhaustion and shook my emotional part. (F3)

[...] there are many families that don't accept it, there are many controversies, only those who are in there know, to try to understand, it's a cog [...][...] many times, the families are already tired, because they don't accept, and there are many disagreements and even fights in the family itself, and they (people with AD) are no longer respected. Today, they (family members) don't accept, don't believe. (F2)

Difficulties with forgetting people, objects and places

Family members/caregivers report that elderly people with AD, at some point in the disease, have undermined visual-spatial function and forget about people, objects and places, even though they are close by and part of the routine, according to the reports:

[...] suddenly, we started to notice that she got lost from home [...] and then we started to notice that she started not wanting to go out anymore, and I got surprised, then every now and then she would say: "I got lost today". One day, she got really lost, she arrived here with the police, because she was crossing the street in front of the cathedral and had a fall. (F4)

The daughter began to see that he had money in his coat pocket, but he didn't remember, he didn't remember where it was, so everything was like that, you know? There is a small market close to where they lived, so he went to the market, but some employee had to take him home, because he couldn't remember anymore and that's when they started to suspect, then they took him to the doctor. The daughter told us that some nights he (an elderly person with AD) says: "How am I going to sleep with my sister-in-law?" (Referring to his wife also with AD), that he could not sleep in the same bed as his sister-in-law, imagine what his wife would think [...] and she (wife) also does not accept much and says so: "No! Imagine! I can't, I have to sleep with my husband". (F5)

Family unity: a potentiality from Alzheimer's disease

As potentialities, family members/caregivers mentioned family unity, since it was essential for coping with the disease:

[...] I think that the grandchildren who are far away started calling more. The granddaughter who lives here is always there participating with her, helping to take care of everything [...] it has united the family, there is the frequency of the children's calls [...] I realize that the daughter has carried out more fun activities with them (father and mother with Alzheimer), this has changed. She's been spending more quality time with them, she manage to find a little time to have fun. (F5)

[...] we increasingly feel like a united family, in this sense of care and even closeness, because

we got closer in all aspects. Strengthening was a primordial thing, we looked at each other and said: "We gotta take care of the mother because she has Alzheimer. (F7)

It has brought benefits to our family, that is, a very strong unity, because we realized that we are nobody without each other. My wife and I made our children understand this, they are well aware, they accepted it very well and they still accept what we say to them in the sense of cooperation, collaboration. Therefore, that's great for us as a family, because only those who go through it know. (F8)

Establishment and maintenance of routine

Another strategy mentioned by family members/caregivers was the establishment and maintenance of a routine to help in the provision of care, facilitating daily tasks and avoiding unpreparedness for episodes of forgetfulness:

I have a separate shift schedule with all medications and diapers. In the mother's box, there is everything, because otherwise we get confused. (F3)

We strictly follow all the schedules and precautions, even the water schedule, so that we don't get confused [...] (F6)

[...] she likes the food that way, the tablecloth I leave on the table like this. It's one of her things, when she comes to the table and sees that food there, it catches her attention, and I always do it like this, I keep it. I place the shallow plate with the deep plate on top to match, and she takes the plates. (F6)

Adaptations at home: care and safety of the elderly person

Adaptations at home were also reported as a strategy for the care and safety of the elderly person, thus preventing undesirable events and accidents:

I've taken all the rugs out, he's still dragging his feet and I'm afraid he might fall. At night, I have a light in the room so he doesn't get up in the dark, I'm afraid because sometimes I sleep tired and he wakes up. When I see him moving, I get up, I'm afraid he'll get out and trip [...] there are those grab bars in the bathroom, it helps him steady himself and there's a non-slip mat so he doesn't fall when he's wet. (F1)

[...] we needed to put a stool for her to sit in the shower stall, there are a few things there in the bathroom (grab bars) for her to hold on to. [...] the gate is always locked [...] (F4)

[...] if there was any furniture in the room, we had to move it away so she wouldn't get hurt [...] we stopped waxing the floor to prevent falls. (F6)

Games, paintings and other manual activities

As a strategy to stimulate the cognitive and motor functions of the elderly person, family members/caregivers used games, paintings and other manual activities, according to reports:

The games on the table, she often participated in the dominoes, she counted correctly, we made her count the marbles and find another matching piece [...] (F4)

[...] some activities like that, playing cards. My good! It works super well, she loves it! I did a kind of memory game, but I don't leave them turned over, so she has to find them, I leave them visible, I choose one and say: "Let's find this card here". Accordingly, she looks for it and puts them together, she loves it. [...] She responds very well, some days she is very fast. I don't always do the same thing, sometimes I tend to spread out all the pieces and ask her

to help me only with the animals, she has to pick up all the pieces that are animals. I don't put too many pieces, so I don't overload. [...] sometimes she doesn't want to talk so I say: "Let's play something? She accepts, then we play and we talk during the game, and she is already laughing in the end [...]" (F5)

[...] I take her with me to the kitchen, she sits down doing the activity that I print and I take her to cut [...] I've done a portfolio with her since 2013, she paints things while cutting and helping me to do. (F6)

Use of music/television and pets

The promotion of conversation through television programs, as well as music and the presence of pets, was essential strategies for family members/caregivers to identify achievements in the care and development of the disease:

Music and television stimulate them cognitively. I used to say this: "Let's talk about what was on television? Even if it's a cartoon, enjoy it and say: 'Oh, how beautiful that color is!'" [...] she paints; so the first time I started, she didn't want to know about a paintbrush, and then I said: "What do you think about putting your little fingers?" She accepted, and then we went with our bare hands, and that's wonderful, the best thing there is. (F5)

[...] and the dogs, now she has a little bitch there, they love those dogs, they're their fun and it's pretty good! They're their little companions, it's therapy, a way to distract themselves at home. [...] I talk to the daughter via WhatsApp and ask if everything is ok, and she says she has been doing some activities. [...]" (F5)

DISCUSSION

Mood changes and outbreaks of aggressiveness were reported as difficulties experienced by family members/caregivers in the present study. Similar data were found in a study developed at a Geriatrics and Dementia Outpatient Clinic of a Tertiary General Hospital (SP), which highlighted that, of the 96 elderly participants, 61 (63.5%) had apathy/indifference and 48 (50, 0%), agitation/aggressiveness⁽¹³⁾.

Cognitive changes that influence behavior were also weaknesses found in the present study, with loss of time and space orientation at some stage of the disease. A study developed in the city of Teresina-PI underlined the need to understand the memory impairment of the elderly patients affected by AD, in addition to showing the importance of attention and care with memory lapses⁽¹⁴⁾.

The memory and changes in the behavior of the elderly person with AD are more or less affected according to the stage of the disease, which comprises three phases: initial, intermediate and terminal⁽¹⁵⁾. In the intermediate phase, there is an increasing loss of memory, motor difficulties, agitation, aggressiveness, language difficulties, reasoning difficulties and difficulties related to the ability to maintain BADLs⁽¹⁵⁾.

The non-acceptance of the disease, according to the participants of this research, makes the relationship between family members/caregivers difficult and, therefore, they are highlighted as weaknesses. Data of this nature were also highlighted in other studies, which showed that, although people know the main signs of AD, some manifest an attitude of denial and do not consider them related to the pathology⁽¹⁶⁻¹⁷⁾.

Another difficulty revealed in the present study was that elderly people with AD, at some point during the illness, forget people, objects and routine places. A study identified that the loss of memory of a person with AD is experienced with great distress by family

members, who can associate it with a loss of the person ⁽¹⁸⁾. AD-related forgetfulness happens in the early stages of the disease, when recent memory loss occurs, leading to the forgetfulness of objects and people with whom the elderly person does not live on a daily basis, progressing to difficulty in performing IADLs ⁽¹⁵⁾.

As a potentiality to face the disease, it was possible to identify the family unity. A study that had the objective of identifying the contents associated with the care process and, consequently, check the validity of current concepts of ADL, showed similar data when presenting that help/support from other family members contributed to the existence of planned interventions focused on the whole family ⁽¹⁹⁾.

The unity and support of the family during the coexistence and care of the elderly person with AD are necessary, since the coexistence with the elderly patient in this condition is sometimes permeated by exhausting situations. Nevertheless, they can be minimized through a greater distribution of attributions among family members, thus avoiding the concentration of responsibilities in a single person ⁽²⁰⁾.

The establishment and maintenance of a routine to help with care was a strategy that facilitated the daily tasks of caring for the elderly person. This data is in line with a study, which determined that the interrelationship between caregivers and health professionals seeks to follow-up the elderly daily during drug treatment, in order to avoid errors or loss of medications ⁽²¹⁾.

According to the participants of this research, the uncertainty caused by undesirable events and accidents generated adaptation strategies at home. A study, with the objective of identifying main behavioral changes and distinctions in the overload imposed on the caregiver of elderly people with AD, showed undermined safety as the main concern, representing 23% of behavior changes, thus encouraging the caregiver to mobilize personal resources, within the care dynamics ⁽²²⁾.

As a stimulus for the cognitive and motor conditions of elderly people with AD, family members/caregivers used games, paintings and other manual activities. A study shows that cognitive stimulation, together with the application of mental status assessment tests, is relevant and has been ensuring improvements in the cognitive status of elderly people ⁽²¹⁾.

Another strategy used by family members/caregivers in the present study, with a view to assisting in the routine of family members/caregivers, was encouraging conversation, television programs, music therapy and the presence of pets. A similar strategy can be identified in a study that underlined the benefits of using music, sharing selfies/videos, visiting the cinema, among other strategies with the elderly person ⁽¹⁹⁾.

The limitations of this research refer to the questions inherent to qualitative research, which by nature does not intend to generalize its results, as they are unique experiences of a group of family members/caregivers.

FINAL CONSIDERATIONS

This research allowed us to understand the potentialities, weaknesses and strategies experienced by family members/caregivers of elderly people with AD. As a potentiality, the family unity based on AD was highlighted; as weaknesses, changes in mood and behavior of the elderly person with AD; the difficulty of self-care of family members/caregivers and the lack of support; the lack of knowledge and difficulty in accepting AD, as well as the forgetfulness of people, objects and places by the elderly person.

As strategies, family members/caregivers mentioned: the need for care alternation; the establishment and maintenance of routine; adaptations at home for the care and safety

of the elderly person; the implementation of games, paintings and other manual activities; the use of music and pets as stimuli for the elderly person.

The data presented here directly contribute to the practice of care, since they can serve as a basis for implementing care strategies for people who experience realities similar to those of the participants of this research. Nevertheless, it is understood that more research needs to be developed, given the complexity of care and daily coexistence with an elderly person with AD.

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Corresponding author:
Francine Casarin
Universidade Franciscana – Santa Maria, RS, Brasil
E-mail: fracasarin@hotmail.com

Role of Authors:

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