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ALZHEIMER'S DISEASE: PERSPECTIVE OF FAMILY CAREGIVERS IN THE FACE OF HOME CARE EXPERIENCED DURING THE COVID-19 PANDEMIC

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Geovana da Silva Lima[1], Daniela Aparecida de Souza Nunes[2], Kely Paviani Stevanato[3] and Rebeca Rosa de Souza[4]

ABSTRACT

Objective: to understand how family caregivers of the elderly with Alzheimer's disease experienced home care during the COVID-19 pandemic. Methodology Exploratory, descriptive qualitative research carried out with family caregivers of elderly people diagnosed with Alzheimer's disease in a municipality in the Northwest region of Paraná, Brazil. The interviews were conducted through home visits mediated by the Community Health Agents, the participant was invited to answer the demographic characterization questionnaire and with their authorization the face-to-face interview was recorded. Subsequently, they were transcribed and organized in the MAXQDA Plus 2020 software and analyzed using Bardin's methodological framework. Results: 12 family caregivers of elderly people with Alzheimer's disease participated in this study, the data showed that the process of caring, whether in normal times or in pandemic periods, generates physical and emotional overload, especially when this is the only responsible caregiver. Burden resulting from the change in routine, lack of freedom and social life, which can influence the caregiver's quality of life. Conclusion: the need to implement a professional support network and disseminate information on home care for elderly people with Alzheimer's disease and/or other dementias is dazzled. Offering professional, personal and emotional support contributes not only to the quality of care received by the elderly, but also to the reduction of risks of physical and mental illness by the family caregiver.

Keywords: Alzheimer's disease. Carer. Aging. Pandemic.

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[1] Nurse. State University of Paraná, Paranavaí – Pr.
[2] Master in Nursing. State University of Paraná, Paranavaí – Pr.
[3] Doctor in Health Sciences. State University of Paraná, Paranavaí – Pr.
[4] Doctor in Nursing. State University of Paraná, Paranavaí – Pr.

INTRODUCTION

Population aging is a natural, gradual and inevitable process. According to data from the 2010 Demographic Census of the Brazilian Institute of Geography and Statistics – IBGE, by the year 2025 Brazil will be the sixth country in the world with the highest rate of elderly people. In this scenario, increased longevity involves a series of physical, cognitive, and emotional changes that can contribute to the emergence of dementia and neurodegenerative diseases, such as Alzheimer's Disease (AD).[1]

Alzheimer's is a progressive and incurable neurodegenerative disease that manifests itself through the deterioration of brain functions such as cognitive function and short-term memory.[2] In addition, it causes a variety of neuropsychiatric symptoms, behavioral changes, and impairment of motor skills that worsen over time.[2, 3]

According to data from the World AD Report, from the Alzheimer's Disease International Federation (ADI), about 47 million people live with dementia worldwide. This number is predicted to increase to over 131.5 million by the year 2050. In addition, the estimated number of people with AD reaches 35.6 million worldwide, and this number continues to increase significantly.[1]

In this scenario, when the elderly person is affected by AD, he or she presents significant difficulties and limitations in the performance of his or her daily activities, requiring continuous monitoring and supervision by a caregiver, who may or may not be a family member.[1] Thus, daily care becomes complex, since it provides a significant work overload, permeated by feelings of uncertainty, hopelessness and responsibility on the part of the caregiver, and may also negatively compromise their physical and mental health.[2]

Nevertheless, in addition to experiencing enigmatic care, caregivers of people with AD, as well as affected users, experienced an important and significant global pandemic triggered by COVID-19.[4], which made the care process even more complex. In addition, the pandemic favored an increase in the work overload of the family caregiver of the elderly with AD, given the restrictions on social contact established. In this sense, it can be inferred that the family caregiver suffered from the limitations imposed by the disease.

In view of these peculiarities, it was believed that it is necessary to understand how family caregivers of the elderly with AD experienced home care in times of the COVID-19 pandemic. Thus, this study aimed to understand how family caregivers of elderly people with Alzheimer's disease experienced home care during the COVID-19 pandemic.

MATERIALS AND METHODS

This is an exploratory, descriptive qualitative research carried out with family caregivers of elderly people diagnosed with AD in a municipality in the Northwest region of Paraná, Brazil. It has an estimated population of 91,950 inhabitants (IBGE 2022), fully covered by 24 Family Health Strategy (ESF) teams, distributed in 16 Basic Health Units (UBS). The data were collected between the months of March and July 2022.

The inclusion criterion were: being the main family caregiver of the elderly person with AD in the last three months and being 18 years of age or older. The exclusion criterion was established: having some comorbidity that would hinder communication between researcher and interviewee. For the selection of participants, the researchers requested authorization from the Municipal Health Department of the study municipality and, later, they will connect the community health agents (CHA) so that, with their help, possible participants could be identified.

The initial contact with the participants took place through a home visit with the CHA responsible for the coverage area. At the time, the family caregiver was invited to participate in the study, and the Free and Informed Consent Form (ICF) was read, explaining the objective of the research, its methodological aspect, risks and benefits. In cases of acceptance, the participant can choose to participate at that time or schedule the interview on a day and time of their preference. It is noteworthy that all of them agreed to participate at the time of the home visit.

It is noteworthy that during the initial contact with the participant, as well as during the course of the interview, researchers and participants made use of Personal Protective Equipment (PPE), especially the use of masks, 70% alcohol gel and the distance of 1.5 meters between the parties, according to the recommendations of the Ministry of Health and the World Health Organization to contain the spread of COVID-19. In addition, all the material used for the development of the interview, namely: pen and MP3 audio device, were sanitized before and after use.

At the time of the interview, the participants read the ICF and, after their consent, they were invited to sign the informed consent form in two copies of the same content. Subsequently, the participant was invited to answer a questionnaire for sociodemographic characterization: gender, age, marital status, religion, family income, employment status, and clinical characteristics: comorbidities, use of continuous medications, alcoholism, smoking, physical activities, and body mass index (BMI).

For the descriptive stage of the interview, the participant was asked for authorization for the audio recording of the interview, explaining that it would be used later for the transcription of the interview and data analysis. The face-to-face interview was guided by the following question: tell me what it was like for you to take care of your family member with AD during the COVID-19 pandemic. Support questions were used, such as: what were the weaknesses and potentialities that you found in daily care? Has the COVID-19 pandemic impacted your daily care for your family member with AD? If so, how? Tell me more about it. The interviews will take place until the moment that no new information has emerged in the process of data collection and analysis, thus reaching theoretical saturation.

The interviews were transcribed in full after their completion, organized and analyzed in the MAXQDA Plus 2020 software. For data analysis, the methodological framework of the content analysis proposed by Bardin was used. The analysis process followed the pre-analysis, with transcription, organization, studies of the texts, floating reading, data separation with initial identification of relevant aspects.

Subsequently, the data were submitted to an exploration stage where the classification and aggregation of the data was developed, with identification, through colors, of the common and more specific terms, giving rise to the previous categories. Finally, in the treatment of the data, the categories were deepened through the articulation of the findings, constantly considering the objective of the investigation. Thus, the following central category was identified: *Home care for the elderly with Alzheimer's disease: the impact of the COVID-19 pandemic on the execution of care*, complemented by the categories: *Caring for the elderly with Alzheimer's: perception and perspectives of care before the pandemic* and *The pandemic period: potentialities and challenges in the daily care of the elderly with Alzheimer's.*

The study was approved by the Permanent Committee for Ethics in Research with Human Beings CAAE: 52244321.7.0000.9247, approval protocol: 5.029.324. To ensure anonymity, the strata of the participants' reports are identified by the letter P for participant followed by an Arabic numeral which refers to the order in which the interviews were conducted (e.g., P1).

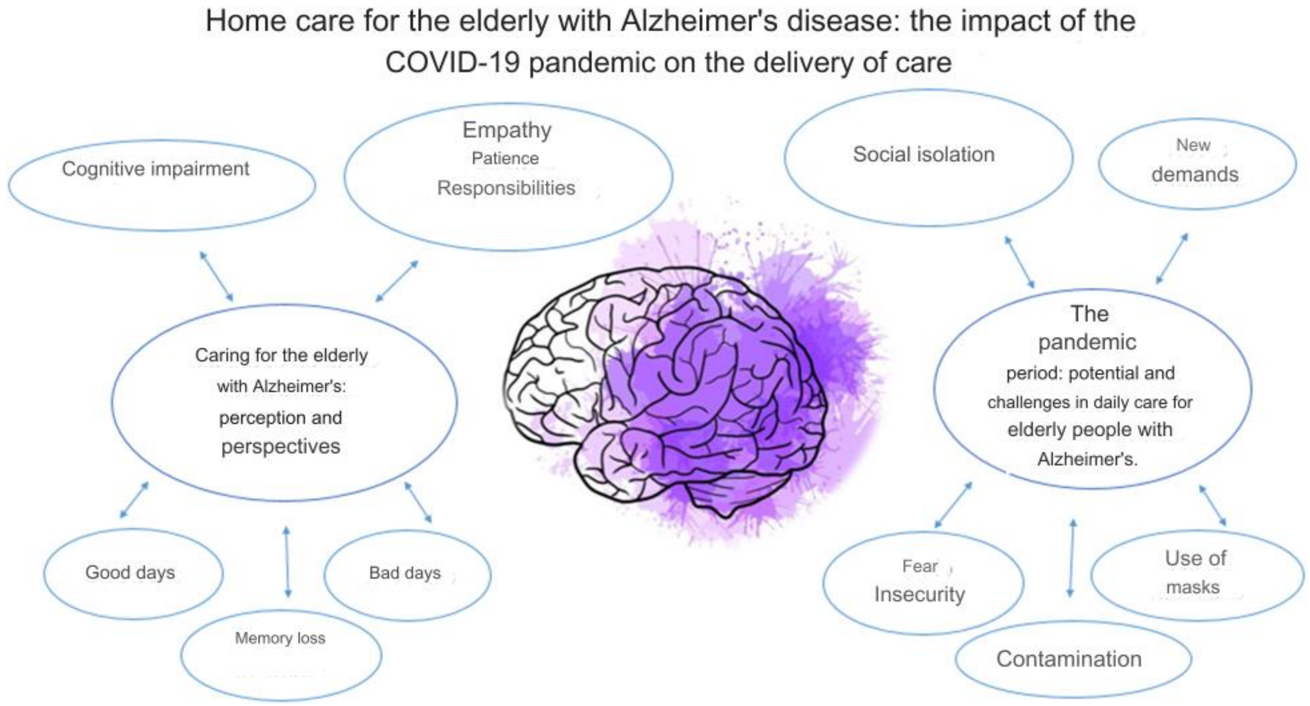
RESULTS

12 family caregivers of elderly people with AD participated in this study. Of these, four were male, aged between 39 and 70 years, ten were married, and two were single, seven Catholic, nine considered themselves white, two brown and one black, nine reported having attended high school and three higher education. Two had Diabetes Mellitus, two had Systemic Arterial Hypertension and two had heart disease, one reported routine tobacco use and one had alcoholism. Regarding the care time of the elderly with AD, there

is a variance from four months to five years. As for the family bond, two were spouses, eight sons, a daughter-in-law and a granddaughter.

The thematic categories evidenced during the data analysis process are presented below:

Figure I: Illustrative diagram of the central category and its subcategories.



The Author (2023)

CARING FOR THE ELDERLY WITH ALZHEIMER'S: PERCEPTION AND PERSPECTIVES

The daily care of the elderly with Alzheimer's disease was perceived by the family caregivers as a challenging task that is characterized according to the daily experience, with this experience being a great oscillation between good and bad days.

> [...] There are very bad days that he doesn't know where he is, he doesn't recognize his own house, he doesn't recognize his grandchildren, the people on the street, he doesn't remember that he's already eaten, sometimes he has lunch three times, sometimes he says he's already eaten and doesn't eat again and there are days when it's great it doesn't even seem like there's anything, very good days, So it's very relative, each day is a day, they have a very large oscillation from one day to the next [...] (P2).

In daily care, caregivers experienced some weaknesses, such as the risk of letting the elderly go out alone and get lost, a classic sign of Alzheimer's disease. And in this scenario, family caregivers will seek to take their loved ones for a walk, which has also sometimes been perceived as a challenging task.

> [...] The difficulties were and are to be able to keep him indoors, not to let him go out alone, I always take him for a walk practically every day, but letting him go alone is not possible, and sometimes he arrives in places he already wants to come back, come back than go, it is complicated [...] (P2).

However, the lack of memory caused by the disease also leads to impairment of basic human needs such as hygiene, comfort and food.

> [...] We always try to help as much as possible, because she forgets, her memory is slow, she doesn't remember things, so I help her in the bath, for example, sometimes she forgets that she has already taken a shower, sometimes she takes it alone, sometimes she needs help, there is the issue of taking care of her not to fall into the bathroom and so we go on living [...] (P1).
>
> [...] taking care of those who have Alzheimer's is not an easy task, they forget things, moments, here I have to take care of them all the time, for lunch I have to call about 10 times because sometimes they think they have already eaten, they forget that they have to take a shower, they forget basic care and essences of a day to day, so we take care of everything [...] (P6).

In addition to the limitations and weaknesses found in daily care, being of the opposite sex is perceived by the family caregiver as an additional limitation, since personal care such as hygiene and comfort is perceived as a complicating factor for both those involved in care. Nevertheless, the lack of knowledge about the disease and the lack of experience with care reflect as significant limitations in daily care.

> [...] It's difficult, due to inexperience, lack of knowledge of the disease, being of the opposite sex and not being able to help with hygiene care, even being a mother is very difficult, it's complicated for both parties, for respect and also for those who are ashamed, right? Because at 90 years old, it is not common for sons to take care of their mother [...] (P4).
>
> [...] Sometimes I feel a little lost, I don't know how to deal with this disease, how to help her, I don't have knowledge about this disease, so I seek help from doctors to know what to do [...] all of this is new to me, new to her, and we are facing this new phase together, we are going through this together, But it is difficult to take care of an unknown disease like this [...] (P8).

Caring for a family member with AD reflects on a job that requires, in addition to empathy, patience and responsibility, time and dedication, in this sense caregivers feel a lack of support and help from the family in this process, with care being the responsibility of only one person, which leads to overload and sometimes dissatisfaction with other family members.

> [...] The problem is that I am the closest, I am the one who takes care of the mother on a daily basis and sometimes I feel the lack of support from my sisters who live in other cities. They do not participate in care on a daily basis and when they come to visit or call they criticize what is being done, but they are not willing to help in any way, they ignore the problem [...] it would be easier if there was more support from the family [...] (P4).

In addition to the weaknesses and limitations perceived and experienced by family caregivers, they face difficulties in hiring health professionals for home care, realizing that they are not always prepared to develop such activities, which require patience, technical knowledge and empathy for the other.

> [...] caregivers are also complicated, people don't take care of them as they should, they don't have much to do with the other's father, they think that everything they do is already too much, most of these caregivers lack professional preparation, preparation and respect for the elderly [...] it's no longer a job, it's no longer an old man, it's someone's father, he is important to someone, so with caregivers it is also difficult to find someone who really cares and who we can trust to have empathy [...] (P2).

Care in daily life also refers to following the guidelines of health professionals to the letter, realizing that they know what they are guiding and that it is best to follow the guidelines.

> [...] I try to follow the guidelines of doctors and health professionals, we comply because they are in the area, they know what they are advising [...] so I take care of her this way, I give her medications at the times that the doctor ordered, and I take care of the other things that are also important: food, hygiene, exercise, walking, these things [...] (P1).

Notwithstanding the fact that experiencing home care for the elderly with AD reflects on the family caregiver, a feeling of sadness and pity, especially when the sick individual begins to be unaware of the family and the people in their daily life

> [...] It's sad to see my father not remembering people, grandchildren, friends, it's very sad, we would like to be able to help, you know? But what to do, right? [...] (P2).
> [...] It's very sad to see her forget, not recognizing the people (people she liked the most), it's very sad, it hurts her, she doesn't know who she is and who anymore, she doesn't recognize the people around her [...] (P3).

The classic symptoms of the disease such as losing one's recent memory, and repeating the same thing several times are also perceived as a complicating factor, which over time becomes tiring in the eyes of caregivers.

> [...] They forget very quickly about recent things, right? They only talk about things from the past and about people who have passed away, they talk all the time, we explain that this has passed, and it doesn't take ten minutes to talk again, sometimes it gets tired, stresses, always hearing the same thing, and knowing that what he is saying makes no sense, it's sad we feel bad for him and for us too, It's hard to see a father in this situation, but to be honest this is quite tiring [...] (P8).
> [...] She tells many things from the past and sometimes it becomes tiring to hear the same thing over and over again, as well as to help look for what, in her head, is missing [...] (P5).

THE PANDEMIC PERIOD: POTENTIALITIES AND CHALLENGES IN THE DAILY CARE OF THE ELDERLY WITH ALZHEIMER'S

The COVID-19 pandemic is perceived by caregivers as a period that significantly compromised daily care. The fear of contamination in the face of the life habits and behaviors of the elderly favored a negative perception of childbirth by caregivers at this moment.

> [...] the pandemic impacted everyone's lives, including the Alzheimer's patient, as the lack of awareness made it (even more) difficult to understand the problem, and our care was redoubled so as not to transmit (if positive) COVID-19 [...] it was difficult to make her understand the importance of wearing a mask, the prohibition of hugs, she didn't understand, this care with hygiene and distancing was difficult [...] (P5).
> [...] I work in the health area, so the fear of contamination was even greater, I got home and removed all my clothes before entering, I lived with a mask. I did everything, it was terrible, desperate [...] (P12).

Health demands, such as going to medical appointments, were also seen as a complicating factor during the pandemic.

> [...] taking her to the doctor to control the disease was another problem, many times the appointments had to be postponed, there was a lot of fear of leaving the house with her, and getting contaminated, so we were trying to take her home, without going out, without going to the doctor, just in extreme need [...] (P3).
> Moving with her to take her to the doctor was very complicated, I took her, but I couldn't keep up, I was outside the clinic and she was there alone. It was very difficult to live this, even more so being an elderly woman and having to go to see it alone, I had no way to understand, but I had to accept [...] (P11).

In the face of the pandemic, family caregivers realized that in addition to the demands and care that AD requires, they needed to worry about and protect the elderly from another disease, which brought risks and a lot of fear to people.

> [...] the pandemic brought even more limitations, in addition to Alzheimer's we had to take care of and protect ourselves from another disease, in addition to the ones he already has, we had to protect him, protect him from another evil [...] (P9).
> It was even more difficult because I couldn't catch it, it was just to catch it and die, so it was another difficult task [...] leaving the house was difficult, going to the doctor was a nightmare, not being able to let him leave the house and he didn't understand anything, you know, I thought it was our evil [...] (P10).
> [...] Covid has always hindered us, staying at home to be more careful with it, it was a little different, we need to redouble care, protect ourselves from the disease, it was complicated, a mission for more than we have gained [...] (P7).

Even more complicated was when the elderly, even with all the care of caregivers, still contracted the COVID-19 virus, a situation that brought even more concern to caregivers.

> [...] in June 2022 she contracted the COVID disease precisely because of the inappropriate use of the mask and other care, it was very difficult, because her husband also contracted it, and we to take care of it? It was a challenge, an anguish mixed with fear and concern about what could happen, even more so because she was elderly, but with outpatient treatment and home care, she was well [...] (P3).

It is possible to see that regardless of the period of care, whether in a pandemic or not, caring for the family member with AD is a difficult task that also impacts the way the caregiver perceives, behaves and means this care.

> [...] Alzheimer's causes a lot of sadness and suffering for family, friends and everyone who lives with the person with it, care is very difficult and hurts a lot those who care for it, the psychological knows? [...] I think that every day she is becoming more distant, she can't interact with people even with family members and this is very sad, very difficult [...] mood swings, lack of organization, manias, fear of being alone, all this influences daily life [...] (P9).
> [...] taking care of a person with Alzheimer's is much more than caring, you know? It's love, it's affection, it's having patience, that's what I feel for my mother and that's why I take care of her, there are days when things are easier, there are days that are very difficult and so we live one day after another [...] (P6).
> [...] I try to take care of her with affection, with love, to be patient, I try to do my best to make her feel good, and today we try to be better than yesterday and so we go on, there are good days, others bad, but it will pass [...] (P7).
> [...] Care has always been difficult, the person with Alzheimer's disease isolates himself, it is a complicated phase, which both the person and the people who care need to adapt. In the pandemic it was more difficult for sure, but before it was already complicated and now it continues to be [...] (P12).

Faith and hope that better days would come was essential to maintain strength and courage during the pandemic.

> [...] it is necessary to have faith in God and believe that the bad times will pass, as in the pandemic, it was difficult, very difficult but it has passed [...] (P4).
> [...] I was very afraid, but I also had a lot of faith, that all that would pass and that better days would come, my faith strengthened me, and made me face the barriers [...] (P10).

Finally, this research showed that the participation of the health team in the care process of an elderly person with AD was essential, both in person and through telehealth.

> The staff at the health center helped a lot in caring for the mother, this was essential, they always visited her and did all the care, the guidance, we felt safer [...] (P1).
>
> We were very well assisted during the pandemic by the staff at the health center, the team never left us helpless, they were always here [...] it was a very great and very important support for us [...] (P10).
>
> .
> Technology has made care much easier, both during the pandemic and now, WhatsApp, contact with health professionals, today I have contact with the Community Health Agent by cell phone, she makes visits, schedules appointments, the best me casa comes to serve her, whenever I need something technology helps me, this is also important [...] (P 11).

DISCUSSION

The results showed that caring for an individual with AD is always the responsibility of a family member, especially the children who become responsible for the daily care as well as for the other demands of the elderly, in this study more than half of the participants were children, which corroborates studies that also investigated the care in AD.[3]

Being affected by a neurodegenerative disease such as AD is a complex condition that leads the individual to gradually compromise their physical and cognitive functions, being at first a great oscillation of symptoms and behaviors, which leads to the perception that some days are good, others bad.[5]

By taking into account the particularities of the AD disease, especially the progressive loss of memory, family caregivers play a fundamental role, since they develop all the care pertinent to the daily life of the elderly.[6] The loss of memory, as well as the change in the behavior of the elderly, causes them to progressively lose the care of basic human needs such as food, hygiene and comfort, and the family caregiver is responsible for providing this care.[3]

In this study, it was possible to understand that such peculiarities occur routinely in the different families investigated, the Brazilian literature on daily care of elderly people with AD also evidenced these results1-3, thus allowing the generalization of these findings in the investigated theme. For these researchers, family care tends to assume responsibility for this care, which progressively extends according to the evolution of the disease, making the elderly increasingly dependent on help for the development of activities of daily living (ADL).[1-3] From this perspective, in addition to memory loss, symptoms include mental or spatial confusion, loss of decision-making, changes in behavior, mood and personality, and progressive loss of ADLs such as work and social activities.[7]

The lack of knowledge about the disease as well as the lack of training and preparation for daily care was also understood as a challenge by the participants, similar results were also evidenced in a study published in 2018 which showed that there is still a need to train and prepare the population for this care, with nursing being the link and responsibility for this work "the work performed by nursing must have as its ensuring the physical and mental health of the caregiver, using mechanisms that aim to promote health, especially in cases of dementia, improving the quality of life of all those involved in the care of the patient and the elderly themselves".[1]

Caring for an elderly person with Alzheimer's was elucidated in this study as a task that generates physical and emotional overload for the family caregiver, especially when this is the only responsible caregiver. This burden is due to a change in routine and habits, as well as the lack of freedom and social life after the disease, requiring an abdication of the previous life, such peculiarities can favor a negative perception of care and negatively influence the physical and psychological health of both the care and the individual being cared for.[3]

The COVID-19 pandemic, experienced by Brazil and the world since 2020, has brought even more concern and limitations in the daily care of the elderly with AD, since the elderly public has become the most vulnerable risk group to contamination and complications from the coronavirus8-9, from this perspective, the world has witnessed the significant loss of elderly people during the pandemic, most of the time with associated degenerative comorbidities, as well as AD, which was a double blow for family members and/or caregivers of these elderly people10.

From the perspective of daily care, this study allowed us to identify that the pandemic brought fear, limitations and made daily care even more difficult, especially with regard to routine care, such as the use of masks, a fact pointed out by the participant care as something complex, since the elderly did not understand, did not accept and did not remember the need and importance of using this equipment to protect against the disease. In this sense, the use of masks by the elderly during the pandemic was also pointed out by other studies as a complex equipment and sometimes with a greater potential for contamination due to inappropriate use and non-use of the equipment.[8-11]

The mandatory use of masks has become a complex task for the entire population, however, for the elderly diagnosed with AD and other dementias, this process has become even more difficult, since in addition to the special need for care and/or supervision of activities of daily living, they began to experience the need for specific care against COVID-1910-11. Despite the loss of recent memory, the lack of motor skills, as well as the difficulty in understanding, made the elderly more vulnerable and susceptible to contamination12-13.

Another limitation identified in this study is due to social distancing and the need for home isolation, family care reported that the elderly could not understand why they could not leave the house or even receive visits from loved ones, this need for care was sometimes seen as a limitation imposed by the caregiver, and it was not possible to explain to the elderly the emerging need for this practice.[8-14] From this perspective, protecting the elderly from COVID-19 was another attribution linked to family caregivers in daily care.

As potentialities experienced in this period, faith in God, hope for better days and the support of health professionals became essential, strengthening the care process of the elderly with AD. Previous studies that investigated AD during the pandemic period observed that the physical and mental state of family caregivers of elderly people with AD was fragile, however, in some cases there was also the support of the health team, through the dissemination of information and assistance in daily care15-16, favoring the provision of care with more quality and effectiveness.

Likewise, the literature notes the emerging need to expand health care aimed at family caregivers of elderly people with AD and/or other dementias, since the lack of information and knowledge favors the occurrence of complications and consequently complexity of care16.

In this sense, this study also shows that there is an emerging need for updates in the context of care for elderly people with AD, updates aimed at the caregiver, which favors the execution of home care aimed not only at the elderly but also at the hospital.

In agreement, Alzheimer Disease International (2019) draws attention to the need to implement psychosocial support networks and support for this public, in order to minimize the occurrence of mental illness in family caregivers, as well as to favor quality care for the elderly. The implementation of support networks can also favor a significant reduction in caregiver stress and burden, which can also be implemented virtually, since we live in a computerized environment, where technology and access to information are found in the palm of our hands[11,16-17].

A study published in 2022 that aimed to report the experience of the extension action of telephone calls to family caregivers during the period of social isolation due to the pandemic caused by COVID-19, showed that the use of telephone calls during the pandemic period allowed the identification of the strengths and weaknesses existing in the daily care of family caregivers, realizing that the physical and emotional overload of this audience had a significant increase during the pandemic. Nevertheless, this study concluded that caregivers need support and attention in the execution of home care actions, in order to ensure quality care with problem-solving capacity, whether in normal times or in pandemic periods, such as the one experienced by COVID-19[18].

In view of this, the work of nursing stands out, a profession seen as the link between the population and the health services, as well as the one that care is the essential part of the profession. In this sense, nursing inserts a look at care that goes beyond knowledge and care techniques, favoring health promotion and disease prevention through work that values the uniqueness of human beings and their families[19]. Thus, nursing can be seen as the model professional category for the implementation of the support network for family caregivers of elderly people with AD and/or other dementias.

In view of the demands arising from the pandemic, as well as the gradual and irreversible course of AD, family caregivers of these elderly people suffer stress and significant work overload on a daily basis, which can lead this public to physical and mental illness[14-15]. As AD evolves, the responsibilities of caregivers increase, which can further favor the risk of illness. In this sense, it is noteworthy that such risks were more significant during the pandemic, especially due to the complexity of the period experienced.

From the findings of this study, it was possible to perceive that with the increase in the population's life expectancy, AD is increasingly emerging, and in this sense it requires more and more attention, preparation and training for care, both at home and at other health care points. Home care, whether developed in pandemic periods or not, reflects on a complex activity that requires, in addition to training, empathy, responsibility, and patience on the part of those who care.

The low number of participants can be considered a limitation of this study, and it is not possible to generalize the findings, however, they can be considered valid, since it allows to demystify the care of the elderly with AD in the home environment, as well as to understand how family caregivers perceive, behave and signify this care in their daily lives. Understanding this phenomenon in the pandemic period also contributes to understanding the fragility of the elderly with AD in the face of a new threat, the peculiarities of care, as well as the limitations and fragilities exposed by caregivers.

FINAL CONSIDERATIONS

The results showed that caring for the elderly with Alzheimer's, whether in pandemic periods or not, reflects on a challenging task that requires physical, technical, and emotional skills from the caregiver that favor daily care. The lack of knowledge about the disease, the overload of care, as well as being of the opposite sex, are perceived as weaknesses in daily life, however, they are characterized as a situation that, even though it is difficult, is gratifying, since in addition to care, the family bond, love, affection and respect for the elderly are involved in this process.

The pandemic period brought limitations, fears, insecurities and new responsibilities, especially in the face of the risk of contamination of the elderly. This was meant as a complex period that in some cases was minimized by professional support, elucidating the importance of creating bonds and support between family and health team.

In this sense, understanding the experiences and perspectives of family caregivers about the daily care of the elderly with AD allows us to demystify care, as well as to broaden the view of health professionals and the community in general about the peculiarities of this process and the importance of care. Thus allowing the elucidation of gaps that need attention, care and professional education that envisions quality care.

Therefore, the need to disseminate information about the daily home care of elderly people with Alzheimer's is dazzled, in order to contribute to the evolution of knowledge, as well as to the organization and reorganization of educational practices and care in the field of health. Taking care of those who care, as well as offering professional, personal and emotional support, contributes not only to the caregiver but also to the quality of care offered to the elderly.

REFERENCES

1. Silva, M. I. S., Alves, A. N. O., Salgueiro, C. D. B. L., & Barbosa, V. F. B. (2018). Doença de Alzheimer: repercussões biopsicossociais na vida do cuidador familiar. *Revista de Enfermagem UFPE on line*, 12(7), 1931–1939.

2. Rodrigues, T. de Q., Castro, A. da S. de, Conceição, T. F. da, Leite, J. G. A. M., Ferreira, V. H. S., & Faustino, A. M. F. (2020). Impacto da Doença de Alzheimer na qualidade de vida de pessoas idosas: revisão de literatura. *Revista Eletrônica Acervo Saúde*, 12(4), e2833. Recuperado de https://acervomais.com.br/index.php/saude/article/view/2833

3. Mattos, E. B. T., & Kovács, M. J. (2020). Doença de Alzheimer: a experiência única de cuidadores familiares. *Psicologia USP*, 31(1986), 1–11.

4. Costa, R., Lino, M. M., Souza, A. I. J., Lorenzine, E., Fernandes, G. C. M., Brehmer, L. C. F., Vargas, M. A. O., Locks, M. O. H., & Gonçalves, N. (2020). Ensino de enfermagem em tempos de COVID-19: como se reinventar nesse contexto? *Texto Contexto Enfermagem*, 29(e20200202), 2–4.

5. Sales, J. N. F., Miranda, R. N. C., Silva, M. A. S., Batista, E. S., Silva, J. R., et al. (2019). A enfermagem no cuidado com o idoso portador de Alzheimer. *Revista Eletrônica Acervo Saúde*, 18, e235.

6. Anjos, Z. S., Lohmann, P. M., Medeiros, C. R. G., & Brietzke, A. P. (2022). O cuidado de enfermagem na doença de Alzheimer: uma revisão integrativa. *Research, Society and Development*, 11(7), e37911728874. https://doi.org/10.33448/rsd-v11i7.28874

7. Alzheimer's Association. (2018). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia*, 14(3), 367–429.

8. Junior, J. C. P. R., Melo, G. O., Cardoso, V. N. S., Franca, G. S., Silva, G. O., & Gentil, V. N. (2021). O impacto do coronavírus na doença de Alzheimer: uma revisão narrativa. *Revista Eletrônica Acervo Saúde*, 13(8). https://doi.org/10.25248/REAS.e8470.2021

9. Kontoagelos, K., Economou, M., & Papageorgiou, C. (2020). Mental health effects of COVID-19 pandemia: A review of clinical and psychological traits. *Psychiatry Investigation*, 17(6), 491–505.

10. Bianchetti, A., Rozzini, R., Guerini, F., Boffelli, S., Ranieri, P., Minelli, G., Bianchetti, L., & Trabucchi, M. (2020). Clinical presentation of COVID-19 in dementia patients. *The Journal of Nutrition, Health & Aging*, 24(6), 560–562. https://doi.org/10.1007/s12603-020-1389-1

11. Mattos, E. B. T., Francisco, I. C., Pereira, G. C., & Novelli, M. M. P. C. (2021). Grupo virtual de apoio aos cuidadores familiares de idosos com demência no contexto da COVID-19. *Cadernos Brasileiros de Terapia Ocupacional*, 29, e2882. https://doi.org/10.1590/2526-8910.ctoRE220

12. Huali, W., Li, T., Barbarino, P., Gauthier, S., Brodaty, H., Molinuevo, J. L., Xie, H., Sun, Y., Yu, E., Tang, Y., Weidner, W., & Yu, X. (2020). Dementia care during COVID-19. *The Lancet*, 395(10231), 1190–1191. https://doi.org/10.1016/S0140-6736(20)30755-8

13. Schapira, M., Cohen, G., Guajardo, M. E., Martinez, D., Schapira, M., Seinhart, B. D., & Soderlund, M. E. (2020). Reflexiones sobre vivir con demencia en épocas del COVID-2019. *Archives of Gerontology and Geriatrics*, 34(1), 19-20.

14. Mattos, E. B. T., & Kovács, M. J. (2020). Doença de Alzheimer: a experiência única de cuidadores familiares. *Psicologia USP*, 31, e180023. https://doi.org/10.1590/0103-6564e180023

15. Holmes, E. A., O'Connor, R. C., Perry, V. H., Tracey, I., Wessely, S., Arseneault, L., Ballard, C., Christensen, H., Cohen Silver, R., Everall, I., Ford, T., John, A., Kabir, T., King, K., Madan, I., Michie, S., Przybylski, A. K., Shafran, R., Sweeney, A., Worthman, C. M., & Bullmore, E. (2020). Multidisciplinary research priorities for the COVID-19 pandemic: A call for action for mental health.

16. Chan, E., Gobat, N., Kim, J. H., Newnham, E. A., Huang, Z., Hung, H., Dubois, C., Hung, K., Wong, E., & Wong, S. (2020). Informal home care providers: The forgotten health-care workers during the COVID-19 pandemic. *The Lancet*, 395(10242), 1957-1959. https://doi.org/10.1016/S0140-6736(20)31254-X

17. Alzheimer's Disease International – ADI. (2019). *World Alzheimer Report: Attitudes to dementia*. London: Alzheimer's Disease International.

18. Oliveira, S. G., Oliveira, R. G., Fonseca, M. R., Mello, F. E., & Almeida, C. (2022). Diálogo com os cuidadores familiares a partir de ligação telefônica na pandemia. *Extensio: Revista Eletrônica de Extensão*, 19(41), 91-104. https://doi.org/10.5007/1807-0221.2022.e82278

19. Batello, G. V. V. A. T., Guimarães, M. A. S., Pereira, I. A. C., Bandeira, M., & Nunes, D. P. (2020). Cuidadores de idosos em situação de pandemia: Reflexões sobre o cuidar e ser cuidado. In R. F. Santana (Org.), *Enfermagem gerontológica no cuidado do idoso em tempos da COVID-19* (2ª ed., pp. 20-24). Brasília, DF: Editora ABEn. https://doi.org/10.51234/aben.20.e02.c03