



Emotional Repercussion and Changes Experienced by Family Caregivers of Individuals with Alzheimer's: A Study in the Southern Region of Tocantins, Brazil

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Authors' contributions

This work was carried out in collaboration among all the authors. Author CRO designed the study, performed data collections and tests. Author EFK guided and assisted in the writing of the project, data analysis, review and final writing of the article. Author DSP was responsible by updating bibliographic research, revising and translating text. Author LAM collaborated in the initial writing of the study, data collection and analysis. All authors heard and approved the final manuscript.

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ABSTRACT

Alzheimer's disease is the most common dementia among the elderly, but unfortunately, the early symptoms are mistaken for natural aspects of age. Thus, knowledge is an excellent tool to get a diagnosis still in the early stage.

Aims: Therefore, this article addresses the psychological reactions of family caregivers of individuals with that disorder and coping conditions experienced by them.

Methods: To this end, an exploratory descriptive study of qualitative approach with semi-structured interviews with primary caregivers of individuals with Alzheimer took place, and some of the participants were appointed by indicated Regional Tocantinense Association Brazilian Alzheimer's - ABRAZ, not exceeding the expected number, the researchers received help in the indication of caregivers who were already part of this research.

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Results: Regarding the coping conditions, there was family resilience, some resorted even psychological aid, since the change in routine was essential for the welfare of the elderly. Five respondents knew little about the disease before diagnosis, however, they began to delve into the matter with a view to aid in the treatment. Thus the knowledge acquired over time only came to add, thereby contributing to an improvement in the quality of life in both parties.

Conclusion: The look of psychology facing the coping experienced by caregivers of individuals with Alzheimer's is of paramount importance, as well as knowledge of caregivers about the disease, although acquired over time, contributed to an improvement in the quality of life of both parties.

Keywords: Illness; resilience; family; Alzheimer's disease.

1. INTRODUCTION

Throughout his life, since his birth, the human being goes through an aging process, causing changes related to the passage of time, and in the elderly health concerns begin to be part of the routine of people and their Family [1].

According to a statistical analysis published by the Alzheimer's Association [2], there are 5.4 million people with Alzheimer's, 5.2 million of them aged 65 years or older. In Brazil, it is estimated that about 500,000 people have this disease [3]. There are estimates that in 2040, eight million people will be affected by AD (Alzheimer's disease), which will have a great impact on the structure of the country and, especially, on people who will have to deal with the issue more closely: caregivers [4].

The German neurologist Alois Alzheimer described the disease that bears his name, when publishing the case of his patient Auguste Deter, who at the age of 51 developed a picture of cognitive losses, becoming unable to take care of himself. At the age of 55, the patient died, only then the doctor examined his brain and studied the changes that are now known as characteristics of Alzheimer's [5].

AD is a chronic, neurodegenerative pathology that manifests itself to a greater or lesser degree of impairment depending on the stage of development of the disease, that is, there are patients who are in an initial state and do not yet have significant impairment of memory and skills physical, motor and intellectual. The various studies on AD and possible cure have not yet found a method for the reconstruction of neurons and affected areas [6].

The disease presents itself as a loss of cognitive functions (memory, orientation, attention, and language), caused by the death of brain cells.

When diagnosed at first, it is possible to delay its advancement and have more control over symptoms, ensuring a better quality of life for the patient and the family. It is common for initial symptoms to be confused with the normal aging process, so it tends to slow the prognosis of the case, thus, the family and the individual suffer the consequences [7]. About the caregiver of the person with Alzheimer's is always a great challenge, it is a care that is building daily and increasing the degree of complexity over time due to the chronic degenerative picture of the disease [6,8].

The caregiver can be formal or informal. The formal is a professional who provides home care, receives remuneration and usually has decision-making power, has, in general, training as a nursing assistant or technician, with training focused on the care of individuals with physical or mental pathology. The informal ones are usually family, friends, neighbors and in some cases, members of religious groups and other people in the community, can also be paid. Among the caregivers there is also the classification of primary, secondary and tertiary caregivers. The primary care providers are primarily responsible for care and tasks; the secondary ones do not have the same level of responsibility and decision as the primary ones, keeping some basic care and; tertiary works for short periods, generally having specific tasks such as purchasing, paying and receiving bills [9].

Thus, it is important to discuss the relevant role played by caregivers in the family sphere, and the dynamics of these relationships involve psychological, economic and cultural-historical partner, with the need to "investigate this context in order to understand the condition in which care is constructed, in its different dimensions and interactions between the subjects who integrate the care process" [8].

It is in this context that psychology can be inserted, with contributions through its various channels of access to human beings. Therefore, the view of the psychologist, with an understanding of the caregivers, is of paramount importance to the professionals involved in the process of treating the individual with Alzheimer's. There are difficulties both for the individual who has chronic degenerative disease and for the caregiver, but with adequate information, guidance and treatments, it is possible to delay the symptoms and have a quality life within the possibilities of the patient and better coping and support conditions for who provides care [10].

In view of the above, this research aimed to investigate the reactions in the psychological sphere, as well as the preached conditions experienced by family caregivers of individuals with Alzheimer's. More specifically, it is intended to address the impact of the diagnosis of Alzheimer's disease on the family caregiver; To investigate changes in the routine of the family caregiver after diagnosis; Verify the knowledge of caregivers/family members about Alzheimer's disease.

2. MATERIALS AND METHODS

This research aimed to investigate the reactions and impressions generated in caregivers / family members from the diagnosis of Alzheimer's disease. Thus, a descriptive exploratory qualitative study was carried out. The Regional Tocantinense of the Brazilian Alzheimer's Association indicated the total population of ten participants in the study, however, in contact with caregivers, it was found that three of individuals with Alzheimer's had died and two others were not part of the inclusion criteria, namely: Being the main caregiver of the individual with the disease; To be married or to be related up to third degree with the patient; The diagnosis of AD was performed at least six months ago, as one of the objectives was to investigate the impact of news about the disease on the caregiver and the family. Thus, the sample consisted of five caregivers of individuals with Alzheimer's, four residents of Gurupi-TO and one in Palmas-TO.

This association is located at the University of Maturity (UMA), on the Campus of the Federal University of Tocantins (UFT) in Palmas-TO. The Regional Tocantinense was created on May 3, 2012 and aims to implement several actions to

promote the dissemination, inform and raise awareness among the population on how to better deal with Alzheimer's disease. Conducts lectures, campaigns, support groups and meetings with caregivers.

Before starting data collection, the research was submitted to the Human Research Ethics Committee of the University of Gurupi, obtaining approval (opinion number 1.225.142, CAAE 47841315.8.0000.5518). After authorization from the Regional, the researchers contacted the caregivers of individuals with Alzheimer's indicated, inviting them to participate in the research and scheduling the time and place for the interview, according to the availability of the interviewees.

Regarding the sample number, initially the participation of 10 or more participants was estimated, but after the inclusion and exclusion criteria were used, only 5 participants remained. However, as it is a qualitative research, with a focus on deepening and discussing issues pertinent to the topic under study, this number was considered relevant. Corroborating, qualitative research differs from quantitative research in terms of the number of social subjects surveyed, in which this number should not be very large, but small enough to allow the researcher to know the object of study. Therefore, there is a need for further understanding and comprehensiveness, allowing analysis of non-measurable objects such as feelings, intentions, thoughts and perceptions [11].

The interview script was submitted to a pre-test (pilot interview) with the main caregiver, aiming to know the relevance and adequacy of the instrument to the research objectives. Such a pilot interview was not used for data analysis. The pilot study consists of a test on a smaller scale aiming to analyze the feasibility of the proposed procedures, materials and methods, thus making it possible to change or improve the instruments in the phase that precedes the investigation [12].

Before starting the interviews, the research objectives, procedures, the right to voluntary participation and to withdraw from the study at any time were explained, the Informed Consent Form was read and signed by the researchers and participants, with delivery of a copy of the document for each party. The questionnaire previously prepared had the objective of

analyzing the perception of the dynamics of care and the impact experienced by providers after the diagnosis of Alzheimer's disease. It is noteworthy that the interviews were conducted individually, on the days and times when the participants were available, having been recorded on audio, with their authorization, in order to facilitate the interaction of the study participants and the subsequent analysis of the transcribed data.

The interviews with the caregivers were transcribed and analyzed according to the parameters of the content analysis [12]. In this technique, successive readings and rereadings of the material produced were performed, seeking to identify emerging contents in the interviewees' reports and organize them in a coherent manner with the research objectives. Regarding the return of the results of this research, contact and returned was made to the association with delivery of a copy of the final work to the place and to the interviewed caregivers who showed interest in obtaining it.

3. RESULTS AND DISCUSSION

The selected sample consisted of five participants, of both sexes, caregivers of the nuclear family (son and spouse), aged between 33 and 69 years (Table 1). For the caregiver, the

initial C was used, followed by numbering to identify the research participants. Among the results, four thematic axes were found, covering affectivity and caring, changes in routine, knowledge of the disease and coping conditions.

3.1 Act of Caring and Affection

Through the interviews, when investigating the reactions in the psychological sphere and the coping conditions of the caregivers, it was noticed in the interviewees that, despite the changes in their routines, of often feeling both physical and emotional tiredness, they feel pleasure in caring of this sick relative. This aspect can be visualized (Table 2) in which four caregivers refer to affectivity as a facilitator in the care of the family members with Alzheimer's. This data that corroborates with research conducted with five caregivers, in which care stands out as more than an act or an attitude, besides being an occupation, responsibility, is also an effective development [13].

Another relevant aspect concern the reversal of roles that is configured in the relationship, because it is the dependence of the patient quite evident, in which the person with Alzheimer's is like a child to be cared for, reflecting on the part of the caregiver a mixture of affection and impatience [14].

Table 1. Sociodemographic variables of caregivers of individuals with Alzheimer's in the state of Tocantins

| Initial | Age | Schooling | Sex | Kinship with the person with Alzheimer's |
|---------|-----|-------------------|-----|--|
| C1 | 33 | Graduate | M | Son |
| C2 | 45 | High school | M | Son |
| C3 | 47 | Graduate | F | Daughter |
| C4 | 68 | Elementary School | F | Wife |
| C5 | 69 | High school | F | Wife |

Source: elaborated by the authors

Table 2. Perception of caregivers in relation to the act of care and affection

| Caregiver | Care and affection |
|-----------|---|
| C1 | [...] I see no difficulty in caring for a person with Alzheimer's just had learning. [...] The person with the disease she goes back to being a child you get affection you go in love, you will love every day more. |
| C2 | You have to have dedication and affection to take care of the person. |
| C3 | So it was a process that for me is much easier to accept the disease by the philosophy of life I have. |
| C5 | The most important thing is attention, affection, love and we become aware that the person is sick. |

Source: elaborated by the authors

3.2 Routine Modifications

According to the statements, a total change in the caregiver's routine is perceived, in view of the involvement of the elderly with Alzheimer's disease, which was verified as emerging content in the report of four caregivers (Table 3), which refer to the process of changing their habits after diagnosis. Alzheimer's disease demands care according to the needs of the elderly, and in turn, significantly alters the daily life of the caregiver modifying even their quality of life [15].

The change in family routine occurred among all interviewees, and they had to give up careers and pleasures of life in order to affect, first, the well-being of the relative.

In view of the reports, it is perceived that the change in routine is inevitable, taking into account that the individual with Alzheimer's lacks greater attention, generating an overload on the caregiver after these adaptations in favor of the better being for the patient. Thereby, Fonseca e Borges [15] complements that the burden of caring for a family member with dementia, in addition to emotional exhaustion, may even compromise his physical and mental health condition.

3.3 Knowledge about the Disease

Regarding the knowledge of caregivers about Alzheimer's disease, they reported that before the diagnosis of the family member did not know to deepen the pathology, so at first the adaptation process was impaired. Taking into account that the faster seeking professional help for the detection of the pathology the better the quality of life, as it will slow its progress in the initial phase. Such data can be displayed in (Table 4).

After the diagnosis of the family member, the caregivers began to research on the subject, thus exceeding expectations, in order to seek information for understanding and assistance of the elderly.

[...] doctor spoke [...] the last thing that stopped was the motor part, [...] it is not always so, because the father stopped first the motor part for later ... so much so that even today dad knows us.. after 15 years. [...] The relationship of family members with the person with Alzheimer's makes a big difference in the progression of the disease [...] and the diet, [...] things that make the

effect of the remedy more intense. (C3) (Table 4).

According study about DA knowledge [16], most people are unaware of the characteristics of Alzheimer's, first, because they don't know about ABRAZ (Brazilian Alzheimer's Association), which has the primary role in disclosing enlightening information about the disease, which would probably increase the number of people who would seek the assistance of professionals earlier.

"There are even people who have Alzheimer's and don't know. The family thinks it's a lapse right, and it's leaving, so I think, like this, that if there was just like ABRAZ, it seeks to help spread everything, the medical class should have more disclosure for people to know this disease, so that family members would seek." (C5) (Table 4).

The excerpts above corroborate data indicating that the family, most of the time, is not prepared to receive the diagnosis, even because it does not gain knowledge about the disease, so it feels difficult to manage the new reality, raising concerns about care that individual will need [5].

3.4 Coping and Professional Assistance

Regarding coping conditions, the impact of news on the diagnosis of Alzheimer's disease is alarming. The fact that it is a chronic degenerative disease is already something that scares, in addition, the interviewees did not expect, due to having been the first case of all the families. Coping with the situation can be painful, for this reason, caregivers start to seek professional help, in order to contribute to the resilience of the situation affected.

In this sense, the establishment of a bond between professional / patient / family is of great relevance, as this resource presupposes an approximation for the understanding of the sick person. With an empathetic and humanized posture, the professional can assist in the disease acceptance process both for individuals with Alzheimer's and for family members and caregivers, providing guidance and technical support in the face of the new reality [17].

When it comes to resilience in the family context, the psychologist plays an excellent role, according to the sample of reports referred to in (Table 5).

Through the reports, the impact of Alzheimer's disease on the family caregiver and the difficulties faced by them was noticeable. As shown by reports below.

"It was difficult because he started to get violent [...] I couldn't see him as a sick person, I kept seeing as my husband and thought all that was to assault me, then I started attending here (ABRAZ)". (C5) (Table 5).

"For me, it's complicated because we used to drink chimarrão together, talk, and now we don't have it anymore, there's no more talk because if he talks, I don't understand and then I get nervous." (C4) (Table 5).

The work of the professional health team is essential because the difficulties encountered by the elderly with Alzheimer's and his family caregiver are diverse. Thus, the use of new methods that helps alleviate the disease, autonomy, quality of life, among others, since no isolated approach in the health area can account for complexity [18].

The discovery of a chronic degenerative disease of a close relative is still mourning to be elaborated, as it will cause the loss of the health and autonomy of the loved one. In this sense, both will have to adapt to a new reality that is indeed a consequence that anyone is vulnerable to being affected, which no one imagines occur in their family sphere. According to the

Table 3. Change in the routine of caregivers of individuals with Alzheimer's

| Caregiver | Changes |
|-----------|--|
| C1 | My routine today is more limited [...] because he is unable to take care of himself, so everything depends on me. So today, my daily life is limited. |
| C2 | It changed in relation to taking care of both, because even I wasn't talking to you, taking care of him today is special care, child care. |
| C4 | My routine has changed and a lot, I leave home a lot, now I'm not leaving almost, [...] and I sometimes go into depression too, but I like to take care of it. |
| C5 | It diminished my work, I worked a lot less, and now even I'm almost stopping. |

Source: elaborated by the authors

Table 4. Knowledge of the disease, before diagnosis

| Caregivers | Knowledge |
|------------|---|
| C1 | I had no knowledge not only heard of it, but I hadn't gone into the subject. |
| C2 | I just saw it talking, but I didn't know. |
| C3 | I'd read a few things, I knew what it was, but I didn't know anything in-depth, I didn't know it. |
| C4 | Nothing, I didn't even know what that was. |
| C5 | No, before the diagnosis, [...] knew lightly, knew that the person forgot. [...] I started to distrust, I started to comment with the clients, then there was a client who was a psychologist, said: look he must be with Alzheimer's, she began to explain to me, so I became aware. |

Source: elaborated by the authors

Table 5. Coping and professional assistance

| Caregiver | Coping |
|-----------|---|
| C1 | You have no idea what Alzheimer's is, right with coexistence you will face what is even the reality of the problem how serious it is. |
| C2 | When it comes to the news even that it was Alzheimer's catches us like this, like, a shock right, you never think that's going to be a reality, but unfortunately, it's the truth. |
| C3 | Before I was totally independent, I had my life alone and then suddenly I had to change everything, then I went to the psychologist because I didn't realize it. |
| C5 | So actually when the record fell was when I went to the psychologist this last time. [...] This help that ABRAZ gives is very good too, and you psychologists, future psychologists will help, as I had very great help from my psychologist. |

Source: elaborated by the authors

interviewees' reports, it was observed that the look of psychology emphasizes the understanding of the caregiver in an empathic way, helping him to acquire resilience to cope with the situation [19].

4. CONCLUSION

The look of psychology focused on coping experienced by caregivers of individuals with Alzheimer's is of paramount importance since the caregiver will need special attention in order to adapt to the new situation. The psychologist together with the client may develop strategies to obtain a better quality of life aiming at reducing damage, such as the development of pathologies caused due to stress.

It is noteworthy that there is family resilience among the interviewees, but for this to occur some resorted for professional assistance, such as individual and group therapy, as well as meeting with other caregivers who are part of the Brazilian Association of Alzheimer's (ABRAZ), in this sense, it is important to emphasize that the caregiver needs this look aimed at him, so that he understands his fears, anguish and values his achievements. It is not easy to process becoming a caregiver, because the change in the routine of the same will be indispensable since the person with Alzheimer's will need special attention, just as a child lacks.

Regarding psychology and intervention in situations involving AD, it is important to note that the psychologist's performance will be the context of biopsychosocial changes with the individual affected by the pathology and with the family member and caregiver. One of the first aspects to be worked on refers to the knowledge about the disease, guidelines, welcoming listening to fears and feelings facing the process of falling ill and the responsibilities for the caregiver. It should be clear that, even with no prospect of a cure, it is important to encourage preserved cognitive skills, social interaction and leisure activities, that is, seeking quality of life. Group therapies, psychotherapy, associations, help groups, lectures, among others, can also be auxiliary resources for the family caregiver.

Therefore, the qualification of psychology, as well as other areas involved is of great seriousness, aiming at the reception of the caregiver and the person to be cared for. Thus, the development of public policies as strategies aimed at clarifying the disease contributes significantly to the

diagnosis still in the initial phase, and management to deal with the situation, in order to prevent greater damage.

CONSENT

The Informed Consent Form was read and signed by the researchers and participants

ETHICAL APPROVAL

The research was submitted to the Human Research Ethics Committee of the University of Gurupi, obtaining approval (opinion number 1.225.142, CAAE 47841315.8.0000.5518)

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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