

Anticipatory grief in caregivers of elderly people with advanced Alzheimer's disease**O luto antecipatório em cuidadoras de idosos com Alzheimer avançado****Duelo anticipado en cuidadoras de ancianos con Alzheimer avanzado****ID** Danielly Vanderley da Rocha¹, **ID** Debora Maciel Liotti², **ID** Laíse da Silva Dias Marcial³**ID** Lucas Felix Novaes³, **ID** Rodrigo Jorge Salles⁴**Received:** 04/01/2023 **Accepted:** 21/03/2022 **Published:** 30/04/2022

Objective: to understand how anticipatory grief is experienced by caregivers of elderly people with advanced Alzheimer's disease. **Methods:** this is a field, cross-sectional and qualitative research. A sociodemographic questionnaire and a semi-structured interview were applied. The data were treated from the content analysis. **Results:** the participants were four caregivers. Three categories were elaborated: *Feelings on the experience of anticipatory grief in care*; *Relationships and strategies in the care process*; and *Impacts of the professional routine on the caregiver's quality of life*. Family interference was pointed out as negative in the manifestation of elderly people's autonomy, impairing the care routine. It was also observed that the absence of regulation caregiver as a profession implies work overload, limited care strategies for elderly people with AD, lack of delimitation of action and negligence of self-care. **Conclusion:** the severe loss of autonomy and functionality of the elderly awakens feelings of sadness and distress in the caregivers, and it also brings them closer to the awareness of the other's death and their own mortality.

Descriptors: Caregivers; Aged; Alzheimer Disease; Bereavement.

Objetivo: compreender como o luto antecipatório é vivenciado pelos cuidadores de pessoas idosas com Alzheimer avançado. **Método:** pesquisa de campo, transversal e de base qualitativa. Aplicou-se questionário sociodemográfico e uma entrevista semiestruturada. Os dados foram tratados a partir da análise de conteúdo. **Resultados:** participaram quatro cuidadoras. Três categorias foram construídas: *Sentimentos frente a vivência do luto antecipatório no cuidado*; *Relacionamentos e estratégias no processo de cuidado*; e *Impactos da rotina profissional na qualidade de vida do cuidador*. Apontou-se a interferência familiar como negativa na manifestação da autonomia do idoso, prejudicando a rotina de cuidado. Também foi observado que a ausência da regulamentação da profissão de cuidador implica em sobrecarga de trabalho, estratégias limitadas de cuidados de idosos com DA, ausência de delimitação da atuação e negligência do autocuidado. **Conclusão:** a perda severa da autonomia e funcionalidade dos idosos desperta sentimentos de tristeza e angústia nas cuidadoras, bem como as aproximam da consciência de morte do outro e da sua própria finitude.

Descritores: Cuidadores; Idoso; Doença de Alzheimer; Luto.

Objetivo: comprender cómo experimentan el duelo anticipado los cuidadores de ancianos con enfermedad de Alzheimer avanzada. **Método:** investigación de campo, transversal y de base cualitativa. Se aplicó un cuestionario sociodemográfico y una entrevista semiestructurada. Los datos se trataron a partir del análisis de contenido. **Resultados:** participaron cuatro cuidadoras. Se construyeron tres categorías: *Sentimientos frente a la experiencia de duelo anticipado en el cuidado*; *Relaciones y estrategias en el proceso de cuidado*; e *Impactos de la rutina profesional en la calidad de vida del cuidador*. La interferencia familiar fue señalada como negativa en la manifestación de la autonomía del anciano, perjudicando la rutina de cuidados. También se observó que la falta de regulación de la profesión del cuidador implica sobrecarga de trabajo, estrategias limitadas de cuidados del anciano con EA, falta de delimitación de la acción y descuido del autocuidado. **Conclusión:** la grave pérdida de autonomía y funcionalidad de los ancianos despierta sentimientos de tristeza y angustia en las cuidadoras, además de acercarlas a la conciencia de la muerte del otro y de su propia finitud.

Descriptores: Cuidadores; Anciano; Enfermedad de Alzheimer; Aflicción.

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INTRODUCTION

Dementia is a broad term used for several diseases that affect memory, cognition, behavior, personality, judgment and spatial relationships, severely interfering with daily activities¹. According to the World Health Organization (WHO), about 55 million people all over the world suffer from dementia, and there are about 10 million new cases every year. It is estimated that, in 2050, there will be 139 million cases of dementia worldwide².

Among all dementias, Alzheimer's disease (AD) is the most prevalent, representing 60 to 80% of cases. Alzheimer's is an irreversible brain disorder that mostly affects the population aged 65 years or older³. It is a progressive disease that mainly affects memory, causing a deficit in recent memory, learning difficulties, emotional instability, impaired judgment and thinking⁴. In its advanced stages, there is an impairment of the ability to respond to the environment, loss of movement control and autonomy for self-care, which makes the person with AD demand special care to perform previously simple tasks such as walking, sitting and eating⁴.

The concept of caregiver has been widely discussed based on the sociocultural changes that have occurred over time, which have come to share with society and State a type of care that was previously restricted only to family groups⁵. The concept for the act of caring is not unique, but it can be defined as a mobilizing human action that translates into respect for the suffering, values and dignity of the dependent person⁵.

It is possible to identify two type of caregivers: informal caregivers, which includes family members, neighbors, friends and the entire support network that provides care without seeking financial gain, lacking specific technical knowledge for care; and formal caregivers, who are people who perform caring for the elderly as a paid activity, who have some type of training and technical knowledge⁵.

The complexity of the care offered to an elderly person with advanced Alzheimer's requires physical, emotional and psychological preparation from the caregiver. The progression of the disease can leave the caregiver overwhelmed due to the increase in the intensity and amount of tasks performed, and they may suffer continuous psychological stress due to the cognitive decline and loss of autonomy of the assisted elderly person⁶⁻⁷. This scenario of progressive physical and cognitive decline of the elderly can lead the caregiver to suffer the emotional and psychic consequences of mourning, in what can be considered an anticipatory grief⁷.

The concept of anticipatory grief was created in the 1940s to name the lack of clear manifestations of mourning in women at the time of the real death of their husbands who were

sent to fight in the war⁸. These women had already lived through the stages of grief at the time of their husbands' departure due to the uncertainty of their survival and return, which released them from any affective ties with the deceased. Thus, anticipatory grief can be defined as the possibility of elaboration of a loss before it concretely happens, either by the announcement of a terminal illness or by the awareness of mortality, allowing a person to experience the farewell and the necessary reorganization before death⁸.

Just like mourning a real death, anticipatory grief is carried out individually and allows a person to readjust to symbolic losses experienced throughout life⁹. In old age, symbolic losses stand out as changes in roles in the family and social environment, the routine and habits experienced until then, the decline in body and cognitive functionality, and also the change in their identity, which must now be adapted to the reality of this stage of life⁹.

In advanced Alzheimer's, the process of anticipating grief not only allows the caregiver to prepare for life after the assisted person's death, but also enables the recognition of small losses that occur throughout this journey, such as changes in recent memory, difficulty to maintain conversations or solve problems¹⁰. Kovács defines that "*the death of the other is configured as an experience of death in life*"^{11:149}; it is as if the part connected to the other, through the previously established bond, also died¹¹.

The experience of caregivers in the face of the progression of the elderly person's AD makes the proximity of death real, and, through anticipatory grief, the caregiver can experience the imminent loss of the patient being cared for. In this context, the definition of anticipatory grief, although widely developed and used almost exclusively in the context of terminal illnesses⁸ to express the process of adapting to an expected loss, appears as an explanatory construct of sadness and burden evidenced by caregivers of people with dementia¹². The diseases most associated with anticipatory grief are: cancer, cerebral palsy and dementia¹².

When considering the process of aging population, studies related to the emotional experiences of caregivers in the practice of caring become increasingly necessary. Thus, this research aims to analyze the experience of anticipatory grief in formal caregivers of elderly people with advanced stage Alzheimer's disease.

METHODS

This is a cross-sectional field study of a qualitative nature. The participants were professional caregivers of elderly people with advanced Alzheimer's disease. The recruitment process of participants occurred through the dissemination of the research in an extension project focused on the mental health of caregivers of the elderly.

The sample was defined by convenience, and the inclusion criteria was: caregivers of both genders and aged over 18 years; the exclusion criteria was: informal caregivers, that is, family caregivers who did not perform care as an occupational activity and the elderly person being cared for at the time of the study did not have advanced Alzheimer's as indicated by the Clinical Dementia Rating (CDR)¹³.

Data collection was carried out in three stages. The first stage involved the participants filling an online socioeconomic form presented via the Google Forms™ platform, in order to categorize them. The second stage involved inviting those who met the inclusion criteria to apply the Clinical Dementia Rating - CDR¹³.

The CDR was developed in 1979 in the Memory and Aging project at the University of Washington, validated for Portuguese by Chaves and collaborators¹³. The scale seeks to assess the stage of dementia of patients with chronic neurodegenerative diseases, and is composed of six cognitive domains: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. The categories are evaluated independently and each category can be graded into five levels of impairment: 0 = no dementia; 0.5 = questionable dementia; 1 = mild dementia; 2 = moderate dementia; and 3 = advanced dementia¹⁴. The CDR was applied to the caregivers who read each item of the questionnaire via videoconference, and those who dealt with patients at level 3 of the scale were considered.

The third and last stage of data collection refers to the semi-structured interview to understand the anticipatory grief caregivers experience. 11 questions were elaborated that addressed the themes of the caregivers' work routine, the feelings about this performance and their relationship with the assisted elderly person. The second and third stages of collection were carried out through videoconference via the Google Meet™ tool. All interviews were recorded and transcribed in full and will be stored in a safe place for a period of five years, while the recordings were destroyed.

Data from the socioeconomic questionnaire were presented descriptively. The narratives presented from the semi-structured interview script were analyzed according to Bardin's Content Analysis¹⁵. For the analysis of the material, the following steps were adopted: (1) pre-exploration of the material; (2) selection of recording units related to the focus of this study based on the repetition of themes throughout the different interviews; (3) construction of thematic categories, adopting similarity criteria between recording units grouped in the same category; (4) discussion of thematic categories based on the psychoanalytic theoretical framework on mourning and anticipatory grief.

All participants who responded to the invitation signed a Free and Informed Consent Form (FICF), authorizing their participation in the research, and were later called for an individual interview, and authorized its recording. For confidentiality purposes, fictitious names were used.

This research was submitted for evaluation by the Ethics Committee for Research with Human Beings (CEP) of Universidade São Judas Tadeu and obtained authorization under CAAE: 58976222.1.0000.0089 and Opinion No. 5,443,769 on June 1, 2022.

RESULTS

In Chart 1, information on the socioeconomic characteristics of caregivers was presented. Four women, residents of the state of São Paulo, aged between 35 and 67 years old (mean age 50 years old) participated in the study. In terms of marital status, two participants were single, one was divorced and the other had a civil union. Three participants live with at least one person and only one lives alone. The monthly family income of two caregivers is up to 1 minimum wage, while the other two is between 3 and 6 monthly minimum wages.

Chart 1. Socioeconomic characterization of caregivers. São Paulo - SP/Brazil, 2022.

Name	Age	Gender	Marital status	City/State	Educational level	Lives with	Family income
Amanda	35 years	Female	Civil Union	Piacatu/SP	Complete High School	3 people	Up to 1 minimum wage
Elisa	42 years	Female	Single	Diadema/SP	Incomplete Higher Education	4 people	Between 3 and 6 minimum wages
Mariana	67 years	Female	Single	Piacatu/SP	Complete Elementary School	Alone	Up to 1 minimum wage
Roberta	56 years	Female	Divorced	Santos/SP	Complete Higher Education	1 person	Between 3 and 6 minimum wages

In Chart 2, the characteristics of the participants professional practice were presented. All caregivers have completed the basic course for caregivers, mandatory for the performance of formal work, and two of the participants have completed a course of Nursing Technician. On the length of employment as a caregivers for the elderly, the participants had an average of 9.25 years, ranging from 4 to 20 years of experience in the area.

As for the number of elderly assisted by each participant at the time of the research, all of them care for a single elderly person with advanced Alzheimer's. Regarding the workload of

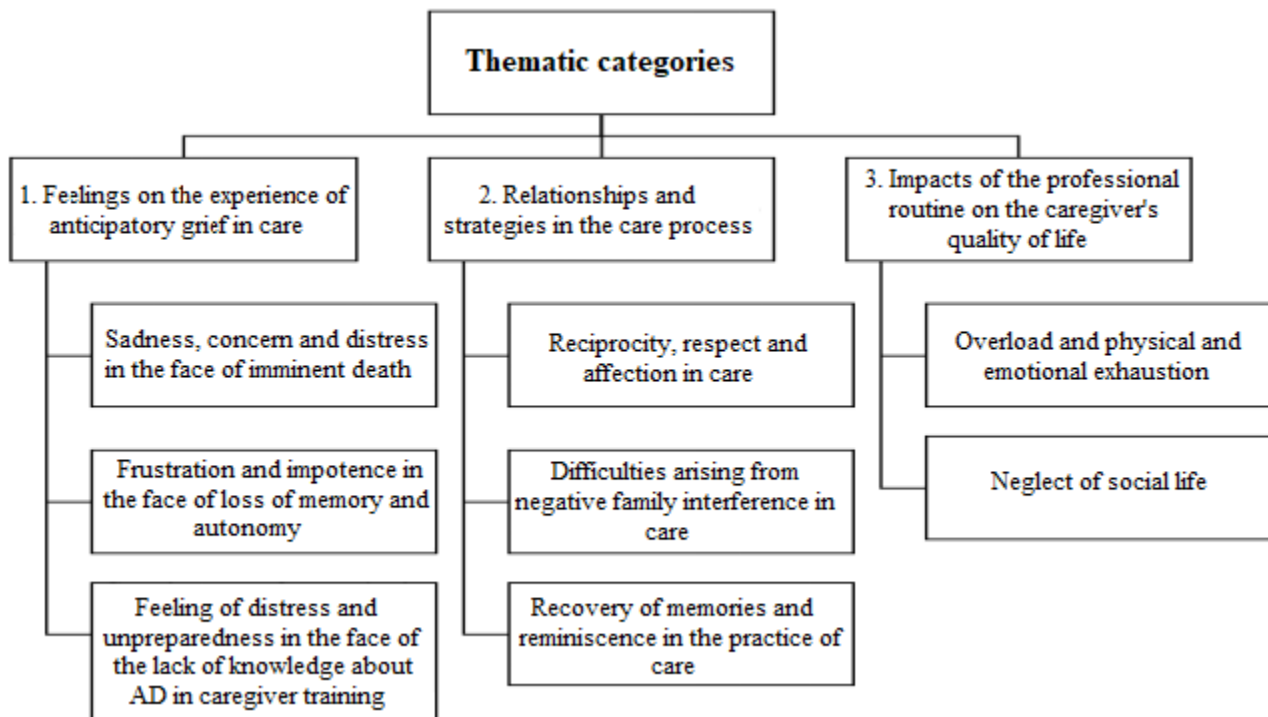
services provided, two of the caregivers work 60 hours a week, while the others work from 40 to 48 hours a week. All the elderly assisted by caregivers obtained the CDR3 score (Chart 2).

Chart 2. Professional characterization and degree of dependence of elderly people assisted by caregivers. São Paulo - SP/Brazil, 2022.

Name	Length of employment	Type of qualification	Number of elderly currently being assisted	Weekly work schedule	Would change profession	CDR* of assisted elderly
Amanda	20 years	Caregiver and Nursing Technician Course	01	60 hours	Yes	CDR3
Elisa	04 years	Caregiver and Nursing Technician Courses and Internships at ILPIS	01	60 hours	No	CDR3
Mariana	08 years	Basic Caregiver Course	01	48 hours	No	CDR3
Roberta	05 years	Basic Caregiver Course	01	40 hours	No	CDR3

* Clinical Dementia Rating¹³.

Based on the content analysis of the interviews, three thematic categories were created: *Feelings on the experience of anticipatory grief in care; Relationships and strategies in the care process; and Impacts of the professional routine on the caregiver's quality of life*, with three recording units in the first and second categories, and two recording units in the third category, as in Figure 1

Figure 1. Thematic categories and registration units. São Paulo - SP/Brazil, 2022.

Feelings on the experience of anticipatory grief in care

This category explains the main feelings identified by caregivers in the routine of care for elderly people with advanced-stage AD. These manifestations of feelings characterize the process of anticipatory grief experienced:

- Sadness, concern and distress in the face of imminent death:

There are times when I get sad, because I explain to the elderly woman that she is at her own home, and even so she thinks she is in mine, so I ask myself what kind of mind is that?, how can a person stay that way?, and with that I decided that I want to die before I get like this, in that state, so I ask God every day to take me before I get to a state similar to the patient's. Sometimes I feel like crying too. (Amanda)

This disease is very cruel and sad, the family suffers a lot, mainly because the decline is very fast. Sometimes when his son shows up, he asks if it is really his son, and so you see the family get sick along with the person, because they are also involved. (Roberta)

- Frustration and impotence in the face of loss of memory and autonomy:

In the 3 years that I've been working with the elderly woman, I've noticed the symptoms progress visibly to a serious condition, because she's not the same as when I got there, for example, when she woke up the first thing she did was pray, and today she doesn't know verbalize the prayers anymore, besides, before she drank a lot of water, today she takes a sip and says she had a full glass, that is, she lost track of what she wants to do, no longer has a say on what she wants to wear. (Amanda)

[...] *the memory is gradually being lost, because the children and grandchildren go to visit her and when I ask her not to remember that, she says that nobody went to see her.* (Mariana)

- *Feelings of distress and unpreparedness in the face of the lack of knowledge about AD in caregiver training*

I wish there was more information in caregiver courses about Alzheimer's and the other diseases. (Amanda)

I think that there should be greater preparation for both caregivers and family members, regarding the challenges of dealing with the elderly and their pathology in question. (Elisa)

Relationships and strategies in the care process

In this category, the way caregivers perceive and describe the relationship with the assisted elderly person and what strategies are used in the care process stands out.

- *Reciprocity, respect and affection in care:*

My feeling in caring is one of gratitude, because I know how to care, but in relation to the situation of the elderly woman, it is very sad, because it causes a lot of pity and distress, to be there with someone who doesn't even recognize food, and that hurts my soul. (Amanda)

A feeling of gratitude, because every day I try to provide better moments than I assist, moments of less pain, less aggressive perceptions and less mental confusion, so this is rewarding for me. (Elisa)

It's a very good relationship, he trusts me and the other caregiver who stays with him at night a lot. But with me he gets along very well. (Roberta)

- *Difficulties arising from negative family interference in care:*

The most difficult thing is that people do not respect the elderly because of the disease. His ex-wife doesn't respect it, for example, there's a woman there who cooks the food for the whole week, and he asked me to let her know that he wanted to eat stroganoff, I went there and gave it to him, and when the ex-wife arrived she got very angry, screaming, saying that I shouldn't give him stroganoff, because he can only eat it on the weekends, I even went so far as to say that he asked for it, but she said that he doesn't know anything anymore. This part of the lack of respect from family members is the biggest difficulty I face. (Roberta)

As a caregiver, I cannot intervene by imposing anything on the elderly that does not go according to what the family determines, and this ends up making it impossible for me to deal with certain situations in order to create a suggestive environment for her. (Elisa)

- *Recovery of memories and reminiscence in the practice of care:*

He likes music, and when you start singing to him, he reconnects with life, remembering many things. That's why I took a course for "performing musicians", because I found it interesting that whenever I sang for him, he was very happy, and I felt very proud. He always asks me to sing several times, especially that song from "Trem das Onze", then seeing his joy, his son even made a list with all the songs he likes, and I find it very interesting how he reconnects. (Roberta)

When she is nervous, I've already learned to calm her down, so I put on a song by Amado Batista that she likes a lot, or I make her some tea. She cannot sing the songs, she just listens, and comments that the melody is good.
(Amanda)

Impacts of the professional routine on the caregiver's quality of life

This category deals with the perceptions of caregivers about their working conditions and the impacts generated in their lives.

- Overload and physical and emotional exhaustion:

In the past I already felt very overwhelmed, because when I started working with this elderly woman I was on the night shift, then her family members had problems with the former caregiver on the morning shift and I had to switch shifts, so it was a big change, since I was very overwhelmed and in a lot of pain, since I have issues with my bones and spine, and there were days when I couldn't even walk. (Amanda)

Last year I even sought medical help because I had very high stress levels. A sleep disorder I already had before got worse, in addition to developing a lot of anxiety and nervousness, so I started taking medication, and I looked for help to see if I should continue in this profession because I was emotionally shaken and out of patience with myself, so how could I take care of someone else. I realize that we caregivers need to take care of ourselves both physically and emotionally, so that we can be well to take care of others. (Elisa)

- Neglect of social life:

During the weekends I take care of my house, but if there's an odd job I'll do it, otherwise I'll stay at home. (Amanda)
I feel overwhelmed by the workload, where I work 5:2, and I only have days off on Saturday and Sunday, working a total of 14 hours a day, which often extends to 16 hours, that is, there are times when I am more of a guest in my own home than the person who lives there. (Elisa)

DISCUSSION

The caregivers showed different feelings triggered by their activity of caring for elderly people with advanced AD, which in its progression presents behavioral changes that affect the memory functions, the quality of sleep and intensify agitation and aggressiveness, resulting in the real loss of one's autonomy¹⁵.

The distress regarding the awareness of the imminent death of the assisted elderly person is one of the main feelings manifested by the caregivers. This result is similar to that observed in research with a caregiver of an elderly person with AD, indicating distress, anger and sadness as the main emotional aspects manifested and that are related to the responsibility assumed by the caregiver to maintain the life of the elderly person while seeing AD progress and approaching the imminent death of the elderly person¹⁶.

The responsibility to provide care and zeal to the elderly person with AD increases the fear of disability and death in the caregiver, as there is a daily emotional investment in the care

routine¹⁷. The awareness of the loss of the other from the increase in the intensity of the degenerative effects of AD is crossed by the sociocultural context that cultivates beliefs that give new meaning to life, reject the disease and deny death, further strengthening the psychological and emotional suffering that elevates the fear and hinders the subjectivation of mortality¹⁷. From the psychoanalytical perspective, contact with death itself is impossible, given the absence of psychic records about death in the unconscious. However, there are a series of questions raised from the death of others that can be valuable in self-care, in expanding self-awareness and the possibility of approaching one's own transience and mortality¹⁸.

Feelings of frustration and impotence in the face of the assisted elderly person's loss of autonomy are also present in the caregivers' interviews. The loss of autonomy of the elderly mobilizes in the caregiver the experience of saying goodbye without leaving, as the patient is physically present, but psychologically absent, since the memory is gradually being lost, which is understood as the process of depersonalization of the elderly person¹⁹. This grieving experience is called anticipatory grief, configuring itself as a dynamic process that oscillates between denial, overinvolvement, anger and acceptance²⁰.

The presence of depressive symptoms in the caregiver may also be related to the current grieving process based on the emotional reactions triggered by the experience of care. Variables such as the level of professional experience and the intensity of suffering inherent to the experience of anticipatory grief are crossed by the personality of the caregiver, and may present characteristics of resilience and elaboration of losses related to the personality of the elderly during the progression of the disease or respond to the process of anticipatory grief with greater intensity of pain, anger and emotional suffering²⁰.

Another feeling mentioned by two caregivers was unpreparedness regarding specific knowledge about AD. Despite the sensitivity to the necessary care related to AD that some caregivers may present, the lack of specific knowledge about the changes expected for each phase of the disease, the impossibility of cure and the lack of knowledge of available strategies to maintain the quality of life of these people, contribute to the emergence of conflicts, fear, stress and anxiety, both for the elderly and for the caregiver^{6,21}. Clarifying the caregiver about the evolution of AD and its possible complications favors the practice of care, considering that access to information not only helps in care but also in understanding feelings and difficult moments that may arise²¹.

The caregivers' relationship with the assisted elderly and the care strategies adopted were also aspects mentioned. All caregivers consider work relationships as humanized and non-commercial. Three caregivers recognize the aspects of reciprocity, respect, trust, affection

and compassion present in the relationship they have with the elderly people who receive their care.

These aspects corroborate the results of other studies²²⁻²³. The empathetic posture manifested by caregivers as a necessary action for a quality and respectful care strategy, as well as the possibility of benefiting caregivers with personal transformations based on the positive experience of care²². Compassion can be considered as the emotion that makes care work possible, its absence makes depersonalization of care more likely, resulting in inhuman care²².

The intimate relationship established between caregiver and elderly person due to the deep daily involvement of care, shared information and secrets and the constant, and sometimes unique, presence that the caregiver occupies in the life of the assisted elderly person, may characterize this relationship no longer as a professional one, but as a personal one. This change in the relationship can favor the caregiver's suffering when witnessing the decline of the elderly and the approach of their mortality, which indicates the need for emotional support for caregivers²³.

In relationships with family members, caregivers perceive a negative interference in the daily life of the assisted elderly person, from the distance and their difficulty in respecting the will and limitations expressed by the elderly. Of the possible motivations for the separation of family members of elderly people with AD, it is possible to mention: losses experienced in the relationship with the elderly, such as identity; pre-established roles that need to be reorganized, such as intimacy and freedom; as well as the impossibility of keeping future plans and the change in communication²⁴.

The autonomy of the elderly goes beyond the concepts of dependence and independence, it is related to the right of this person to manifest and be attended to in their own will, whether these are about their health, care, food or whatever their preferences are. In Bioethics, there is the concept of "existential autonomy", which characterizes this type of manifestation of will, and it emphasizes the need for discernment and preserved conscience for roles to which this manifestation is accepted²⁵.

However, caregivers and family members can also use prior knowledge about the elderly person with advanced AD to exercise their preferences in care strategies and preserve their personality, even in the midst of the depersonalization resulting from the progression of the disease²⁶. The caregivers mention in their speeches that they usually ask the elderly about music and food that were part of their lives, and, by offering this to them, there is a manifestation of satisfaction and well-being, as it revives memories and brings elements of their identity to the present.

Among the care strategies used by caregivers, two mentioned the use of recreation with music as a form of care to ease the stress and aggressiveness of the elderly. It is also a practice that produces well-being for the elderly and caregivers, as well as the opportunity to rescue memories and biographical aspects and personal preferences of the elderly. The songs are chosen by the elderly, and, from them, they rescue moments lived and are happy with the memory of the past that becomes present.

Memory goes beyond neurological understanding and is related to the passage of time and the subject's history. It is in it that experiences are inscribed in a subjective way throughout life and it is from it that the rescue of memories and the possibility of meeting with oneself in different times come from, as a way of recovering the identity and articulation between the past and the present²⁷. This phenomenon is known as reminiscences, which can be understood as the rescue of past experiences that are updated to the present and recognized by the subject as part of their history²⁷.

Reminiscences are on the elderly's *Self* as a way for them to reaffirm their existence and protect themselves from the process of depersonalization that can occur in old age²⁷. Thus, the practice of recreation with music adopted by caregivers in their care routine for elderly people with AD also enables the integration of past and present, allowing the elderly person to contact the pleasant memories that precede the changes imposed by AD²⁷.

Caregivers also highlighted the physical and emotional exhaustion that the activity produces in their lives. The cause of the elderly person's dependence is one of the factors with the greatest influence on the health and well-being of the caregiver in their work, and caring for elderly people with cognitive impairments, such as AD, impairs the caregiver's health to a greater extent due to mood swings, possible aggressive behavior and reduced physical ability, when compared to the care of physically dependent elderly people²⁸.

The analysis of work overload should also consider the context of the profession of caregiver for the elderly. In Brazil, the occupation of caregivers is not yet regulated and is not recognized as a profession, which makes it difficult for these professionals to work and directly affects the quality of the care offered, due to the lack of knowledge of their rights and duties, which encourages the overload of activities of the care routine and the insertion of other tasks, such as domestic tasks, which are not directed to the assisted person²⁸. As reported by the participants, the high weekly workload shows the damage to performance due to the absence of professional regulation.

Associated with the problem of regulating the occupation of caregivers as a profession, another important aspect is the feminization of care and the social inequality suffered by

women, which can be observed in the study from the exclusive presence of women as caregivers. According to research by Fiocruz²⁹, in 2021, 91.2% of formal caregivers were women, while only 8.8% were men. It is also noteworthy that they are mostly black women, with low income, with less access to education and with an average age of 43 years. These data represent the social inequality experienced by contemporary women and contribute to the naturalization of the scenario of double or even triple working hours that women in the labor market face²⁹.

The physical and emotional exhaustion inherent to the occupation of caregiver associated with common life concerns leads to a lack of interest in participating in activities of one's own life, progressively distancing oneself from social and leisure activities in which one usually participates³⁰. Negligence of self-care is present in the caregivers' reports, as well as the tendency, during off days or vacations, to seek other jobs as a means of supplementing their income. This perspective may be a product of the devaluation of the work of caring for the elderly, associated with the absence of a clear delimitation for carrying out professional activities, causing the precariousness of the remuneration offered to these professionals²⁸.

CONCLUSION

It was possible to identify that the care of an elderly person with advanced AD is marked by feelings of sadness, concern and distress in the face of the progression of the disease, which causes severe loss of autonomy and functionality of the elderly, bringing caregivers closer to the death of the other and also of their own mortality.

The negative interference of family members can influence the autonomy and manifestation of the elderly person own will, harming the routine of caregivers regarding the provision of care. As a way of managing the depersonalization process resulting from AD, the caregivers adopt the use of music as a means of biographical recovery and the possibility of well-being for the assisted elderly person.

The absence of a specific tool for the care demands of an elderly person with AD makes caregivers feel insecure about the best care strategies. The difficulty of establishing efficient care strategies overload the caregivers' work routine and interfere with their physical and emotional health.

The problem of non-regulation of the profession of caring for the elderly in Brazil directly interferes with the health of caregivers, due to the lack of delimitation of the workload, minimum wage and clarification of functions to be developed. It was observed that self-care

negligence may be a reflection of work overload and lack of discrimination of activities in the work routine.

As for the limitations of the study, it was observed that only women volunteered to participate in this research. Therefore, it was not possible to analyze how male caregivers experience anticipatory grief. There was also a lack of specific studies on the topic of anticipatory grief and formal caregivers, which limited data exploration. With this, the relevance of new studies that expand the understanding of anticipatory grief of formal caregivers of elderly people with advanced Alzheimer's is highlighted.

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