Bioethical challenges in the disease of Alzeimer: Autonomy and Independence

https://doi.org/10.56238/sevened2023.007-052

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ABSTRACT

The aging of the Brazilian population is increasing the incidence of chronic diseases, including dementias such as Alzheimer's Disease (AD). Studies indicate that AD represents most dementias in Brazil, with risk factors such as advanced age and higher prevalence in women. The case study exemplifies the diagnostic and ethical challenges of AD. Showing forgetfulness and confusion, he denies being sick, attributing the symptoms to stress. Scans show early signs of brain atrophy, but the diagnosis of AD requires ongoing evaluation. The case raises questions about the patient's autonomy and independence, especially in relation to activities such as working and driving. AD progresses from recent memory loss to aphasia, apraxia, agnosia, anosognosia, and eventual total dependence. Autonomy, defined as self-determination and the ability to make choices, is affected gradually. Judicial interdiction may be necessary to protect the patient, especially to avoid urgent decisions. The case highlights the need for ethical and bioethical approaches in the management of AD, emphasizing early diagnosis and family support. It is vital to understand AD not only clinically, but also in the context of the ethical and social implications for patients and families.

Keywords: Alzheimer's, Dementia, Autonomy, Family interdiction.

1 INTRODUCTION

Alzheimer's disease (AD) is a progressive and irreversible neurodegenerative disorder of insidious onset, which causes memory loss and several cognitive disorders (SMITH, 1999). That said, it is of paramount importance to pay attention to the fact that in the exposed disease, there is a loss of functional capacity, which can be assessed through activities of daily living (ADL) and instrumental activities of daily living (IADL). First, there is loss of IADL and, with the evolution of the disease, there is a deficit in ADLs, which determine the individual's ability to live independently and take care of himself, respectively. It is noteworthy that ADLs explore the individual's abilities to eat, go to the bathroom, choose clothes, groom and take care of personal hygiene, stay continent, dress, bathe, walk and transfer. IADLs, on the other hand, are complex skills for living independently and include: managing finances, dealing with transportation (driving or navigating public transportation), shopping, preparing meals, using the telephone and other communication devices, managing medications, and maintaining household chores (GAVASSO, et al. 2017).

From the neuropathological point of view, diffuse cortical atrophy is observed in the brains of individuals with AD, the presence of a large number of senile plaques and neurofibilar curls, granulo-vacuolar degenerations, and neuronal loss. There is also an accumulation of b-amyloid protein in senile plaques and tau microtubulin in neurofibrillary tangles (SMITH, 1999). In addition, the genetic factor is currently considered to be preponderant in the etiopathogenesis of AD among several related factors. In addition to the genetic component, toxicity to infectious agents, aluminum, oxygen free radicals, neurotoxic amino acids, and the occurrence of damage to microtubules and associated proteins have been identified as etiological agents (SMITH apud YING, 1996).

It is worth remembering that the initial symptom of the disease is characterized by the progressive loss of recent memory. As the pathology progresses, other alterations occur in memory and cognition, including language deficiencies and visuospatial functions. These symptoms are often accompanied by behavioral disturbances, including aggression, depression, and hallucinations (VITAL, SERENIKI, 2008).

In the early stages of the disease, the patient shows difficulty in thinking clearly, tends to make lapses and get confused easily, in addition to presenting a drop in their functional performance in complex tasks. There is a tendency to forget recent facts and difficulty in recording new information. As the disease progresses.

The patient finds it difficult to perform the simplest tasks, such as using household items, or even to get dressed, take care of their own hygiene, and feed themselves. In the most advanced disease, the individual ends up losing the ability to function independently, becoming dependent on a caregiver (LAKS, 1993).

As AD progresses, the patient becomes progressively more dependent, while someone, usually a close family member, begins to make decisions about his or her life, including decisions about one's own treatment. In this scenario, two main decision-making processes are adopted: a collaborative decision between the family and the patient or a decision made by the family alone.

Biographical memory gives recognition of identity. Without remembering facts, places, and people, he says that there is less of the person every day; they are unable to relate, take care of themselves, plan their quality of life; it loses its reason, autonomy, and coherence. The impression is given that the "I" is detached from cognitive functions, ensuring its survival only (ROZENTHAL et al, 1995).

In a 2004 study on how AD patients' decision-making power about their treatment changes over the course of the disease, a group of researchers found that more than half of patients with early-stage AD still participated in decisions about their treatment, which was no longer seen in patients with more advanced stages of the disease. In addition, the caregiver's perception of burden was correlated with the greater probability of the caregiver assuming the decisions for himself, excluding the patient from the decision-making process. In this way, the physicians who accompany such patients can anticipate that this change in roles may occur over time, preparing the family for future decisions. Another interesting conclusion of the study was that regardless of the degree of dementia, older patients tend to have their decision-making power reduced and transferred to the caregiver. This aspect is very important, since the physician should warn that the patient must have the power to make decisions while his autonomy is complete, no matter how old he or she is (HIRSHMAN et al., 2004).

Among the most used clinical criteria for its diagnosis are memory impairment and at least one other disorder such as apraxia, agnosia, and aphasia. Such decline interferes with activities of daily living and, therefore, with the individual's autonomy. The approach to patients with dementia should always include the assessment and monitoring of cognitive abilities, ability to perform activities of daily living, behavior, and overall severity of the condition (ALMEIDA; NITRINI, 1998).

Screening tools that identify mild cases of dementia have been important object of study. Researchers suggest that the combination of a functional scale, which assesses activities of daily living, and a cognitive test (e.g., the Mini-Metal State Examination [MMSE]) would be complementary in individuals with suspected dementia syndrome and, as a consequence, would increase sensitivity and specificity to screen for the disease in a non-homogeneous population such as ours. from a cultural and socioeconomic point of view (MACKINNON; MULLIGAN, 1998).

Great efforts have been made to understand and treat Alzheimer's disease; however, current therapy is far from satisfactory. In fact, although treatment with acetylcholinesterase (AChE) inhibitors has consistently shown symptomatic efficacy and reduced disease progression, these drugs have produced some kind of improvement in approximately 30-40% of patients with mild to moderate Alzheimer's disease (MAELICKE et al, 2004).

In addition to pharmacological treatment, it is essential to elucidate the importance of non-pharmacological treatment in exposed disease. There is scientific evidence that indicates that cognitive, social, and physical stimulation activities benefit the maintenance of preserved abilities and favor functionality. The training of cognitive functions such as attention, memory, language, orientation and the use of compensatory strategies are very useful for investment in quality of life and for cognitive stimulation.

More active patients use their brains more broadly and more frequently and feel more secure and confident when subjected to pleasurable and achievable tasks. The selection, frequency and distribution of tasks should be judicious and, preferably, guided by professionals. The purpose of non-pharmacological treatments is not to make the person with dementia function as it did before the onset of the disease, but to function as well as possible based on new and evolving parameters. When stimulated and submitted to activities that they can perform, patients show gains in self-esteem and initiative, and thus tend to optimize the use of functions that are still preserved.

2 EPIDEMIOLOGY

The Brazilian population has been aging rapidly. According to a study by the United Nations (UN), Brazil is the eighth country that contributes the most to the increase in the world's population. According to the IBGE, in 1999, the average life expectancy of Brazilians, which was 70 years, increased to 73.1 years in 2009 - an increase of 3.1 years in a decade. 76.7 years for women and 69.1 years for men. The 2010 census of the Brazilian Institute of Geography and Statistics (IBGE) found 14.5 million Brazilians aged 60 and over. They represent 8.6% of the total population. IBGE projections show that Brazil will have 216 million inhabitants in 2025, of which 32 million (14.8%) will be elderly. In 2050, when life expectancy will possibly reach 81.2 years, there will be 52 million elderly Brazilians.

This is an achievement of humanity, without a doubt, but it is an extremely worrying situation because in the same proportion, there is a significant increase in the incidence of chronic and disabling diseases, which require constant care, worsen over time and have no cure. This is the case with dementias. Currently, it is estimated that there are about 46.8 million people with dementia in the world. This number will nearly double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050, according to data provided by the International Alzheimer's Association (ADI) 2015 Report. In addition, regarding the scope of Alzheimer's worldwide, we have the following data: in Africa, 2.2% of the population developed the disease; in North America, 6.4%; in South America, 7.1%; in Asia, 5.5%, and in Europe, 9%. Regarding age, the researchers found that individuals between 65 and 69 years old had an average prevalence of 1.17%.

Alzheimer's disease is the most frequent cause of dementia. In Brazil, the study by Herrera (2002) and his collaborators found that 55.1% of these dementias are due to AD. In another Brazilian study, Nitrini et al. in 2004 observed that after the age of 65, the rate of dementia doubled every 5 years, confirming that age is the main risk factor for the development of Alzheimer's disease and that the group of elderly people aged 80 years and over is the one that grows the most. In Brazil, the well-known Catanduva Study showed that women (59%) develop more dementia than men (41%).

3 CASE REPORT

IDENTIFICATION: M.V.R., male, 75 years old, white, married, plastic surgeon, carioca, lives in Leblon.

MAIN COMPLAINT: "I'm confused."

4 HISTORY OF CURRENT DISEASE

The patient arrives at the neurologist's appointment and before any question is asked, he exposes the following sentence: "Doctor, I'm just forgetting some things, but I think it's due to the stress of work. I'm here because my family thinks this is some disease, but I know it's due to the sheer amount of surgery I've been having." He then came to the consultation accompanied by his wife, who reported that 2 months ago he began to forget his appointments, initially the day and time of surgeries. That said, she justified this fact by the overload at work and thought it was a normal event of age. However, the patient, who always cooked on weekends, forgot the stove on, which resulted in a small fire in the kitchen, a remarkable fact for everyone in the family to think that there was something wrong with him, despite his resistance to saying that "he was not sick". Added to this, the wife also brought the information that her husband had always been an excellent driver and the week before he had forgotten the way back home and that she guided him along the way. He denies other cognitive alterations, behavioral and mood alterations.

5 PAST PATHOLOGICAL HISTORY

She reported being hypertensive for 28 years and had regular use of propanolol 25 mg. Diabetic for 20 years on regular use of metformin 850 mg. She denies dyslipidemia, HIV, tuberculosis, hepatitis, STDs. She reported prostate cancer 3 years ago, discovered at an early stage treated with prostectomy and chemotherapy that resulted in a cure. He denies hospitalizations and previous surgeries. She denies allergy and use of psychoactive substances.

6 FAMILY HISTORY

A hypertensive father and a diabetic mother, both of whom died in a car accident, at the ages of 53 and 48, respectively. Sister, 68 years old, diabetic and hypertensive. Brother died at the age of 69 from lung cancer. Children aged 47 and 50 years healthy. Denies past of neurodegenerative disease in the family.

7 PHYSIOLOGICAL HISTORY

The patient was born vaginally to term, with all vaccinations up to date. Last prostate exam: at the age of 72. No active sex life for 5 years. Relations with his wife were without the use of condoms.

8 SOCIAL HISTORY

Sedentary patient, smoker (1 pack per week for 15 years). She mentions that the diet is unhealthy, rich in fats, sweets and fried foods, justifying the fact by the lack of time. She reported a high level of stress due to work and problems with her family.

9 PHYSICAL EXAMINATION

Within the standards of normality.

10 NEUROLOGICAL EXAMINATION

Alert, without focal motor deficit, with symmetrical deep reflexes (3+/4). Cranial nerves show no alterations, normal muscle tone. Slow and symmetrical index-nose test. Slowed gait. Static balance preserved. Superficial and deep sensitivity without changes.

11 COMPLEMENTARY EXAMS

Complete blood count, blood biochemistry, thyroid function tests, anti-HIV serology, GOT, TGP, GAMMA-GT, AF, vitamin B12, folic acid, VDRL, cerebrospinal fluid profile and chest X-ray were within normal limits. Magnetic resonance imaging: mild atrophy of the posterior cingulate and neocortex.

12 TRIGGER QUESTIONS

In order to propose a discussion that correlates the clinical case presented and the main theme of the work – the bioethical dilemma of autonomy and independence in AD, three triggering questions were elaborated:

Is there a compromise of the patient's autonomy and/or independence? Can the patient in the case continue to work and drive?

Should the patient be judicially interdicted?

13 DISCUSSION

AD has an insidious onset, progressive deterioration, and comprises 3 main phases: initial, intermediate, and advanced. The initial phase represents the first 2-3 years of the disease, where the patient begins to gradually lose recent memory. Over time, the intermediate phase begins 2 to 10 years after the onset of the disease, and is characterized by greater deterioration of memory, the onset of aphasia, apraxia, agnosia, anosognosia (loss of awareness of one's own disease), difficulty with vocabulary, loss of independence. At this stage, the individual may also present aggressiveness, wandering, insomnia, depression, apathy and even psychosis. In the advanced phase (8 to 12 years after onset), the patient may have difficulty recognizing his or her own family members, a severe language impairment that may evolve to aphasia, complete dependence, immobility and incontinence (FREITAS, 2011).

The diagnosis of AD is not simple and depends on consecutive consultations to be established. To have AD, the patient must have memory impairment and at least one other associated cognitive deficit, such as language, executive functions, visuospatial skills, and constructional praxis. Such impairments should have a gradual onset and a progressive decline in cognitive abilities. Differential diagnoses with other central nervous system conditions such as subdural hematoma, brain tumors, normal pressure hydrocephalus, and other types of dementia should also be ruled out. Systemic conditions that may justify the patient's clinical picture should also be excluded: hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection. Finally, it is necessary to investigate the possibility that deficits occur only in the presence of delirium or are induced by substance use.

Cognitive assessment can be performed by several tests, the most commonly used being the Mini-Mental State Examination (MMSE), the Clock Drawing Test and the Verbal Fluency Test. For the functional assessment of the patient, two main tests are most used: the Katz Index (evaluates basic activities of daily living such as self-care, hygiene, continence and eating) and the Lawton Scale (evaluates instrumental and more complex activities, such as housework and care with finances).

13.1 IS THERE A COMPROMISE OF THE PATIENT'S AUTONOMY AND/OR INDEPENDENCE?

The patient in the case notably already has memory impairment in his history, characterized by forgetting work commitments and having left the stove on and having caused a small fire in his kitchen. In addition, his wife reports that he had forgotten his way back to his house while driving, denoting a loss of spatial orientation. Therefore, it can be seen that in addition to memory impairment, at least one other cognitive field is compromised.

Although the patient's cognitive losses are well characterized in the first consultation, it is essential that the diagnosis is not made yet. To this end, more consultations should be carried out to monitor the evolution of these deficits. It is also of paramount importance to ensure that differential diagnoses of AD are discarded, as previously mentioned, demonstrating once again the importance of linking the patient (and his wife) to a longer follow-up.

However, the discussion of the consequences of the probable diagnosis of AD should be valued due to the dramatic changes that are to come in the patient's life, causing the family to reorganize itself for the necessary adaptations. Such changes are basically justified by the loss of autonomy and independence of the demented patient, as conceptualized below.

Therefore, it can be seen that the patient in the case does not yet present any significant evidence of dependence at the time of the consultation, as evidenced by the score on the Lawton scale. However, the discussion about their autonomy is much more complex and should be analyzed more deeply.

Autonomy has semantic breadth and several meanings that the word has acquired over the years, as a result of its appropriation by various pillars of the sciences, which contributed to the process of establishing it as a reference in the fields of morals, politics, sociology, and law, among others.

The word autonomy derives from the Greek: Autos = own; Nomos = norm, rule, law. It means self-determination, self-government. It refers to the existence of options, freedom of choice and requires the individual to be able to act in accordance with the deliberations made. It presupposes that the person must be free from coercion and interference both internal and external; social, biological, and psychic factors are contributing variables to the composition of autonomy (SILVA, 2012).

Bioethicists list two presuppositions of autonomous action, without which it is not constituted: capacity and voluntariness. Ability is related to the ability to do something and, particularly in the principle of autonomy, has to do with the understanding of the circumstances and consequences that involve a given decision; In this sense, age-biological development, physical and psychological integrity, and possession of the information necessary for a given position are at the level of capacity. In the field of voluntariness, the free manifestation of the will of the decision-making individual, the freedom to act, is inserted, requiring that he be unsubmissive to coercion, manipulation or persuasion (BEAUCHAMP; CHILDRESS, 2002).

Independence is centered on functional capacity. Addiction in its broad sense means " a state in which the person is unable to exist or function satisfactorily without the help of someone ". The complexity of the concept of autonomy lies in the myth that dependence of any and all kinds leads to the loss of autonomy, leaving the elderly person without choices or their own will. (PESSINI, 2006) This reinforces a stereotyped perspective in relation to the elderly, emanating the idea that every elderly person with physical or social dependence has compromised autonomy. This understanding contributes to strengthening attitudes that disregard the elderly person as a participant in the existential process and early decision-making. Seen in this picture, we see a statement by Bellino (1997) "focuses on the respect of the autonomous choices of individuals and has as its purpose the well-being and quality of life". Respect for the autonomy of the person is very recent and requires a work of awareness of their condition as an autonomous agent. Respect for autonomy is closely linked to the maintenance of the dignity of human nature.

Therefore, it is possible to understand the complexity that involves patients (and their families) who are diagnosed with a disease that interferes with their capacity and/or voluntariness, compromises their autonomy and can also affect their independence. As the disease progresses, the progressive deterioration causes people to experience increasing difficulties in managing their lives, which makes them dependent on help to carry out simple daily tasks. As the disease progresses, the loss of autonomy becomes clearer, where the individual reduces or completely loses the capacity for self-government, making it even more difficult to accept the pathological and social diagnosis (BURLA 2014).

Unlike independence, which can be clearly assessed and even quantified by questionnaires and scales, the concept of autonomy is more complex, and therefore more complex. hardly evaluated. The literature differs on whether autonomy is an absolute or relative concept. Some authors affirm the possibility of the existence of "partial autonomy", which varies according to the degree of cognitive impairment of the patient. Such disagreement is central to the discussion of whether or not a demented individual should have his or her decisions appropriated by a healer.

Especially in cases where AD is in an early stage with mild memory loss (such as the patient in the case in question), the dilemma of whether or not to still have autonomy becomes even more critical, as will be discussed below.

13.2 CAN THE PATIENT IN THE CASE CONTINUE TO WORK AND DRIVE?

Understanding the definition of dementia as cognitive and intellectual deterioration associated with the reduction of an individual's global functional capacity, we saw that from the diagnosis of Alzheimer's Disease, the patient already has impairment of his autonomy, implying an inability to self-determine. Thus, the patient in this case would be unable to drive and continue working (ABREU, 2005).

However, attention should be paid to the patient's quality of life, since there are no conditions for the exercise of their freedom. It is of paramount importance that the decisions made by the professionals who assist them and their families respect their dignity, generating a certain protection for the patient. This protection converges with the already consolidated meaning of the concepts of the principlist approach: beneficence, non-maleficence, justice and, especially, the crowning achievement of autonomy, lost forever in the devastation of Alzheimer's disease (BURIÁ, 2014).

Some authors believe in a concept of relative autonomy, since the patient with Alzheimer's Disease gradually loses his cognitive capacities, and may also have a certain degree of independence, which, despite being, conceptually, different from autonomy, has an extreme correlation between them. This fact is often seen in the early stages of the disease, in which the patient is still able to perform his activities, and at this moment to state that he is unable to decide for himself is a very large "reality shock", which can hinder the acceptance of his disease and the longitudinality of the medical follow-up.

Thus, it is worth highlighting Oliveira's reflection on the documentary Clarita, by Thereza Jessuroun 37: We will not be able to understand an existence that is dramatically silent except in a deep silence of meditation. This is how it becomes possible follow Clarita's journey to the bottom of her own well and participate in her loneliness. After all, each of us also has our own rock bottom, which hides inside secrets, stories and the very roots of our freedom. A background that also mixes inside, in a state of dramatic fusion, past, present and future projects. A past that is the sacralization of all memories; a present that is the ephemeral consummation of attention and a future that ceases to be hope and is the very dignity of waiting. (OLIVEIRA, 2007)

13.3 SHOULD THE PATIENT BE JUDICIALLY INTERDICTED?

The interdiction or curatorship is a measure of protection created by civil legislation that serves as a protection to preserve the interdicted person from certain risks that involve the practice of certain acts, such as, for example, preventing people from taking advantage of the patient's lack of judgment to perform unfair maneuvers causing various damages, mainly of a patrimonial and moral nature. For example, we could mention the sale of a property, a vehicle, withdrawal of money from the bank, issuance of checks, among others.

The interdiction declares the incapacity of the patient who will not be able to personally practice or exercise certain acts of civil life on his own, and for this purpose he needs to be represented by a curator. The Curator is the representative of the interdicted patient, appointed by the judge through legal analysis, who will exercise all the acts of civil life in place of the interdicted patient. He will manage his assets, sign documents, and take care of the patient's civil life.

The interdiction is done through a judicial process, and for this purpose, the performance of a lawyer is necessary. However, in some specific cases, the Public Prosecutor's Office may act, in which case representation by a lawyer is unnecessary. In the interdiction process, the patient will be evaluated by a medical expert who will attest to the patient's ability to discern, the report issued will serve as guidance for the judge to decide whether or not to intervene, based on jurisprudence. In addition, the patient and healer should be brought before the judge (if possible) so that the judge can meet him.

Without the act of interdiction to protect the patient with AD, he is fully responsible for his acts, and may harm himself. Thus, once the disease is diagnosed, the family's guidance on this legal aspect becomes fundamental in the protection of the patient.

14 FINAL THOUGHTS

The group was able to identify that there is a notorious lack of consensus on definitions such as autonomy and independence in the bibliographic references used for the proposed work. In addition, the lack of bioethical reflections on this theme was noted by most of the authors studied.

In another aspect, the group observed that there is a consensus among the studies analyzed that AD has negative repercussions not only for patients with this pathology, but also for family members and their caregivers. In addition, no references were found about specific government assistance in our country to family members and patients with this dementia, leaving the responsibility of care only linked to the family members themselves.

It is necessary to emphasize the importance of early diagnosis of AD, not with the intention of depriving patients of decisions about their own lives, but with the objective of protecting them and minimizing the harm to their health, initiating an approach that aims to slow down the progression of the disease and allow the greatest degree of independence for as long as possible. In addition, early diagnosis is also of great value to prepare the family for future adaptations necessary in the management of patient care, since their performance in activities of daily living will be increasingly impaired by the loss of memory and other cognitive fields.

During the elaboration of the work, the group was able to better understand the pathology, its diagnosis, treatment and, mainly, the moral and ethical dilemmas that arise from the diagnosis of the disease. Only from this more in-depth study on the subject was it possible to understand a little more about the difficulty and complexity faced when receiving a diagnosis of AD, both by the patient and by the family. Finally, based on the scarcity of studies addressing the ethical dilemmas discussed here, it is essential that new studies be published on this very complex topic experienced by thousands of Brazilian families on a daily basis.

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