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Advance directives for patients with Alzheimer's disease

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Update

Abstract

The older population is experiencing worldwide growth, and together with population aging the incidence of dementia is also increasing. This article examines the contributing factors to the loss of autonomy of older people affected by Alzheimer's disease in its most advanced stage based on the importance of instruments for expression of will, especially the advance directive for dementia. In order for older people with Alzheimer's disease to clarify their wishes, they need to prepare their directives preferably in the early stages of the disease, that is, when they still have the capacity to make autonomous decisions, expressing their values and preferences. However, further discussions on this issue are necessary for these instruments to be better used in the Brazilian context, and thus ensure the patients' self-determination.

Keywords: Aging. Personal autonomy. Alzheimer's disease. Advance directives.

Resumo

Diretivas antecipadas de vontade em pacientes com doença de Alzheimer

Em todo o mundo a população idosa tem crescido e, juntamente com o envelhecimento populacional, nota-se o aumento da incidência de demências. Sob a ótica da importância dos instrumentos de manifestação de vontade, e mais especificamente das diretivas para demências, este artigo analisa fatores que contribuem com a perda de autonomia dos idosos acometidos pela doença de Alzheimer em sua fase mais avançada. Para que possa esclarecer seus desejos, é necessário que o idoso estabeleça diretivas preferencialmente na fase inicial da doença, ou seja, enquanto tem capacidade de decidir por si, manifestando suas opiniões e preferências. Conclui-se, no entanto, que ainda é preciso mais debates para que esse instrumento seja usado da melhor forma possível, garantindo a autodeterminação dos pacientes.

Palavras-chave: Envelhecimento. Autonomia pessoal. Doença de Alzheimer. Diretivas antecipadas.

Resumen

Directivas anticipadas de voluntad en pacientes con enfermedad de Alzheimer

En todo el mundo, la población de adultos mayores ha crecido y, junto con el envejecimiento de la población, la incidencia de la demencia ha aumentado. Desde la perspectiva de la importancia de los instrumentos de manifestación de Voluntad, y más específicamente de las directivas para las demencias, este artículo analiza factores que contribuyen a la pérdida de autonomía de los adultos mayores afectados por la enfermedad de Alzheimer en su etapa más avanzada. Para que él pueda aclarar sus deseos, es necesario que el adulto mayor establezca directrices preferiblemente en la etapa inicial de la enfermedad, es decir, mientras tenga la capacidad de decidir por sí mismo, expresando sus opiniones y preferencias. Se concluye, sin embargo, que aún se necesitan más debates para que este instrumento sea utilizado de la mejor manera posible, asegurando la autodeterminación de los pacientes.

Palabras-clave: Envejecimiento. Autonomía personal. Enfermedad de Alzheimer. Directivas anticipadas.

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Regardless of their age, one can be considered healthy if they are able to carry out their activities autonomously, independently, even if they have a disease[1]. Among older adults, "being healthy" depends more on their autonomy and independence than on the presence or absence of diseases. In Brazil, people aged 60 years and over are legally considered an older adult according to Law 10.741/2003[2], known as the Statute of Older Adults, which guarantees and regulates this population's rights and gives it priority in care provision, treating aging as a personal right.

Chronic illnesses, which often affect older people, contribute to higher rates of disability and mortality[3]. Often associated with these diseases, dementia results from pre-existing factors and conditions and generally develops slowly, affecting the individual in various ways: moral, behavioral or intellectual[4]. Alzheimer's disease is the most prevalent cause of dementia and one of the 21st century's greatest health challenges[5]. Due to disease progression, the affected individual may feel unable to make decisions and thus become vulnerable[6]. Alzheimer is an irreversible and progressive disease, and the patient's last years are marked by severe and persistent loss of functionality.

Although dementia is extremely common in old age, currently affecting 50 million people worldwide, a number projected to reach 150 million by 2050[7], little has been discussed about its incurable and terminal nature. As a result, discussion on dementia at end-of-life is still scarce, and older people with advanced dementia have received burdensome treatments (considering the absence of benefits and change in prognosis, besides the risks involved)[8].

Considering the inevitable progression of Alzheimer's disease, palliative care becomes necessary since its diagnosis. According to the World Health Organization (WHO)[9], palliative care is an approach aimed at relieving symptoms and improving the patients' comfort and quality of life that should be offered together with the standard treatment of any life-threatening disease[9].

According to the International Association for Hospice and Palliative Care[10], palliative care is an active holistic care offered to individuals across all ages, especially those near the end of life with serious health-related suffering due to severe illness. It aims to improve the quality of life of patients, their families and caregivers.

In 2014, the European Society for Palliative Care issued guidelines for best practices in palliative care for older people with dementia[11], among which the following recommendations stand out: the patient's health conditions should be seen from the patient's perspective; in mild dementia, patients need help planning for the future; in more advanced stages, the patient's best interest should be the goal of care; and, the advance care plan should be regularly reviewed. The guidelines are in line with a person-centered approach to care and recognize the importance of autonomy.

Dadalto[12] explains that, motivated by the particularities observed in different types of dementia, geriatrician Barak Gaster published a study on previous expressions of will for health care, arguing that a specific document should be developed for dementia, which he called "advance directive for dementia" (ADD), to distinguish it from other standard advance directives. In a living will, for example, the patient autonomously expresses their wishes; according to Gaster[12], however, people with dementia should receive assistance from third parties who may bear the impact of the disease in the future.

Based on the above, this article contextualizes ADD as an instrument capable of safeguarding the autonomy of older people with dementia.

Aging or Alzheimer's?

Brazilian society is permeated by the mistaken idea that old age only brings difficulties to a person's life, which would thus be a life of losses and total dependence. This understanding only exists, however, due to the misconception that old age and disease are synonymous[13]. Normal brain aging can cause routine lapses (for example, forgetting if the car door is locked), but such lapses, when not compromising functionality, may be considered a mere lack of attention and not memory loss[14].

The human brain ends up losing some of its mass in the natural aging process, but mental functions still remain intact until the person's death. It is therefore possible for older people to reach this stage of life physically and mentally healthy. But for this, and to maintain autonomy, people need to remain active[4]. When affected by dementia, however, people progressively lose their cognitive functions, a process that impairs their capacity for independence and autonomy.

Alzheimer's disease and other types of dementia are underdiagnosed and, even when a diagnosis occurs, it is often ignored[15]. About 50% of people with Alzheimer's are not diagnosed at an early stage or, when diagnosed, do not treat it, even neglecting medical appointments, which could influence the course of the disease, since it is a progressive and multi-stage condition, going from mild symptoms to most severe ones[16]. Delayed diagnoses, however, often make people reach a doctor already without the ability to make decisions.

Many discoveries have recently been made about memory and the human brain, and research in this area has motivated several advances and attempts at treatment. A cure for Alzheimer's, however, has not yet been found, and a definitive diagnosis can only be made through biopsy or necropsy[17].

Alzheimer's disease affects older people, mostly women aged 65 or over[16]. Early-onset Alzheimer's disease may nonetheless occur in younger individuals. Among all forms of dementia, Alzheimer's disease corresponds to a high percentage of diagnoses, between 60% and 70%[16].

Slowly, and often without family members noticing it, Alzheimer's alters the individual's behavior. Apathy, for example, is a common clinical symptom[16]. Besides memory, the disease compromises manual skills (for example, the ability to paint) and executive functions, such as planning and shopping for groceries.

The affected person's speech can also become confused, hindering communication with family members and caregivers[17]. In its more advanced stage, older people may even be unable to express their preferences and values to the healthcare team, so it may act in accordance with the patients' wishes.

Autonomy of the will at end of life

The health and physical integrity of individuals must rest on principles and values such as autonomy, beneficence and non-maleficence. Autonomy – which understands individuals as agents endowed with rationality and freedom, capable of making their own choices[18] – plays an important role until the end of the patient's life. It ensures the individual's fundamental rights and dignity, since, from a legal standpoint, the constitutional principle of the dignity of the human person is a corollary of the principle of private autonomy[4]. Regarding older adults, Law 8842/1994[19] established the National Council for Older Adults to ensure the respect for the social rights of this population, especially their autonomy.

Article 1 of the Federal Council of Medicine (CFM) Resolution 1805/2006[20] authorizes the physician to limit or suspend procedures and treatments that prolong the life of terminally ill patients, with a serious and incurable disease, provided it respects the will of the person or their legal representative. The physician must therefore always respect the patient's autonomy, even in the case of a terminal condition. If the patient is unable to express their will, their legal representative should exercise this prerogative.

Before making any decision, the physician must inform the patient on the procedures that can be adopted, providing information concerning the patient's clinical conditions and therapeutic alternatives, considering the chances of success, the risks and the possibility of sequelae or complications. Communication must ensure the understanding of the patient or their legal representative, since this understanding is a prerequisite of the consent needed to perform procedures or treatments[21].

Discussions on medical ethics are no longer restricted to health professionals, having become a multidisciplinary effort[18]. Among other roles, multidisciplinary teams help communicate the diagnosis, facilitate the acceptance of treatment, alleviate secondary effects and encourage changes in the patients' lifestyle[22].

In the advanced stages of Alzheimer's disease and other similar pathologies, patients are unable to express their will, but they do not become less active in their decisions[4]. The Brazilian Civil Code, in its article 3, defines individuals under 16 years of age as absolutely incapable of acting autonomously in civil life, and in its article 4 lists the persons legally incapable of performing certain acts, namely: those aged between 16 and 18; *the chronicle drinkers and drug addicts*; *those who, for transitory or permanent reasons, cannot express their will; and the prodigals*[23].

Law 13,146/2015[24], known as the Statute for the Person with Disability, provides for the respect and promotion of equality in the exercise of the rights and freedoms of persons with disabilities. Its purpose is the inclusion of these individuals, defined as those with long-term impairments of a physical, mental, intellectual or sensory nature, which may hinder the individual's participation in society when compared with other individuals who do not have such impairments[24].

In this respect, the Statute for the Person with Disability considers individuals and their capabilities based on their degree of autonomy[25]. According to Sá and Oliveira[26], the individual is presumed capable until the State, through a court decision, considers them incapable, thus limiting their civil rights. Other forms of state tutelage are established in specific norms, such as the Child and Adolescent Statute, the Statute for Older Adults and the Statute for Persons with Disabilities.

People with limited cognitive ability to provide informed consent, such as those with mental disabilities, must have a representative to give consent on their behalf[25]. Although patients with dementia still have the ability to make decisions at the time of diagnosis, most will eventually lose it[27]. The principle of autonomy should still be assured in these cases, as it guarantees not only a person's freedom of thought and action, but also enables others to participate and give assistance[28].

Although it is yet not clearly known what persons with dementia experience, research shows that even in the most advanced stages of the disease, people are still able to experience emotions and communicate them through non-verbal means[29]. Considering the evolution of Alzheimer's disease, we must discuss the importance of the advance directive as a guarantee of autonomy for these patients.

Dementia-specific advance directives

As it involves older people's life story, will, vulnerability and autonomy, Alzheimer's disease is a complex issue that raises questions which bioethics can help answer[30]. One must discuss, for example, the change in medical-legal paradigms to ensure the patients' dignity and quality of life, respecting their will even when they cannot express it[4].

In Brazil, CFM Resolution 1,995/2012 addresses the advance directives of will (ADW), defined as the *set of wishes, previously and explicitly expressed by the patient, about the care and treatments they want, or not want, to receive at the time they are unable to express, freely and autonomously, their will*[31]. The resolution is based on the discussion about the proportionality of end-of-life care.

Despite the increase in the number of patients with Alzheimer's disease, few are the therapeutic options backed by scientific evidence and we saw a decade-long hiatus in the discovery of new drugs. But most of these drugs only mitigate cognitive and behavioral changes, without altering the pathophysiology of the disease, which is therefore currently considered incurable.

The prolonged course of Alzheimer's can lead family members and health professionals to misapprehend its incurable nature[32]. This leads to the importance of ADW being underestimated. If applied early on, however, such directives can be an instrument to guarantee the patient's autonomy when they are no longer able to express their values and preferences.

ADWs are only valid if the person is lucid and conscious at the time the document is prepared. Only in this case can the decisions registered in the ADW be considered when the patient is no longer able to speak for themselves[30]. As long as authorized by the patient, the document must be attached to the medical record or transcribed by the doctor. Medical professionals are legally presumed to act in good faith, and their acts have legal effect, even in the absence of witnesses or signature[33].

There are different types of ADW: living will, durable power of attorney for health care, psychiatric advance directives, dementia advance directives, birth plan and no-resuscitation order[12].

Living will is a document where the capable person states which medical treatments they accept or reject if, in the future, they become unable to express their will. This document must not contain any clause that goes against the legislation in force[34]. Durable power of attorney for health care, also known as "durable mandate," refers to the appointment of an attorney with powers to make decisions regarding treatments based on instructions given by the patient[34].

Psychiatric advance directives describe the patient's preferences in psychiatric treatment, ensuring that these are respected if the person is deemed unable to decide autonomously. Birth plan, as its name suggests, deals with a pregnant woman's decisions regarding possible occurrences at childbirth. Non-resuscitation orders, on the other hand, emerged in the United States in the 1970s, when they began to be disclosed in hospital communication protocols[12].

Dementia syndromes challenge the classic ADW, as established by the Patient Self-Determination Act, an US law dating back to the 1960s. An advance care plan including the person's wishes regarding their long-term health care is therefore needed, since these syndromes tend to have a prolonged course[30].

According to Assumpção[35], the living will is the best suited instrument for expressing the person's wills, documenting more securely the wishes of each individual and preventing any family dilemmas. For Torres da Silva[4], the living will and the durable mandate are useful legal instruments to preserve the individual's autonomy in medical decisions and end-of-life situations. But the author also points out that, although these instruments can adequately meet the needs of a patient with Alzheimer's or other types of dementia, a more detailed document is still necessary given the complexity of such pathologies, which involve caregivers and family members and therefore become a social issue.

For Gaster, Larson, and Curtis[36], standard advance directives – and among them the living will – are not the best alternative for patients with some form of dementia, such as Alzheimer's, since the disease has particularities that require special attention. The authors thus propose a specific document: the advance directives for dementia.

Gaster, Larson, and Curtis[36] state that the ADD must be amended over the whole course of the disease. That is, the need for the provision and continuity of treatments should be considered based on the progress of the pathology[36]. To disseminate this instrument for the protection of autonomy, the authors provide an open access model. But this instrument has yet to be validated in Brazil.

Alzheimer's patients show a higher level of loss of autonomy compared with other older people. The disease has several stages and, as it progresses, the older person's dependence on others increases, eventually hindering even the fulfillment of routine tasks[4]. The American Alzheimer Society[37] considers that, in the disease's early stage, the person is still capable of understanding the meaning and importance of a given legal document, having the ability and legal capacity to understand the consequences of their actions and document their wills.

As long as they have legal capacity, patients must participate in the planning of their care. An ADD can thus be prepared before, during or immediately after the diagnosis of dementia, as long as the patient has the necessary capacity. Importantly, the precise moment in which the document is prepared is crucial for its ethical validity[38].

The Mental Capacity Act (MCA) 2005[39] implemented in England and Wales, provides a legal framework to empower and protect vulnerable people who are unable to make their own decisions. It establishes that the assessment of a person's mental capacity for decision-making, which can vary over time, should be part of the care routine. Until proven otherwise, it must be assumed that the patient's capacity is preserved.

The MCA is based on five principles[39]. First is the presumption of capacity: every adult has the right to decide autonomously and must be assumed to have this capacity unless proven otherwise. Second is that every individual has the right to be supported in their decision making and must be given all appropriate help before anyone concludes that they cannot make their own decisions.

The third principle is the right to make decisions that may be seen as eccentric or unwise. The fourth principle concerns the person's best interests: anything done for or on behalf of people without capacity must be done in their best interests. Finally, the fifth principle is that of the least restrictive intervention: interventions done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

The MCA also provides tests for assessing a person's decision-making capacity at a particular stage of the disease, adopting diagnostic or functional criteria – the former considers impairment of the mind or brain; the latter, the lack of capacity to understand, retain and use information or communicate a decision.

Ethical guidelines are essential to ensure that physicians and other professionals who treat patients with dementia will discuss the directives as soon as possible after a diagnosis is reached[40]. Despite the importance of ADD, however, they have yet to be accepted in several US states.

Sulmasy and Snyder[38] point out that ADDs previously prepared by patients who lost decision-making capacity are vague, inflexible, ignored or unavailable. The authors report that most patients are unable to anticipate future problems, and that health surrogates are able to ensure the respect for the patient's values in only two-thirds of the cases. Sulmasy and Snyder reaffirm the ADD's importance and superiority, but advocate a substitute model in which decisions are patient-centered, considering the values and preferences of family members and the clinical medical opinion. A possible objection to this model would be, according to the authors, the reintroduction of paternalism.

Health professionals and society must discuss the issue of autonomy. Health professionals in particular, due to their proximity to the conflicts emerging in the care of patients with dementia, need to become familiar with instruments that evaluate the individual's capacity to understand and assess situations and express decisions based on values and preferences.

Final considerations

This article raised questions regarding health issues and the preservation of autonomy in old age, since aging may also bring limitations and pathologies such as dementia, which specifically affect older people. The most emblematic case is that of Alzheimer's disease, the most common form of dementia, and which, due to its particularities, involves many actors: doctors, researchers, family members, caregivers and patients.

Alzheimer's disease, which tends to have a prolonged course, affects the autonomy of the older adult affected. Studies recommend, therefore, that patients should receive help to plan for the future in the disease's early stages. Consequently, it is important to continuously assess the older person's decision-making capacity at each stage of the disease.

ADWs may be used to document and clarify the individuals' values, wishes and preferences regarding medical procedures and care. In Brazil, however, no legislation on ADWs and their various types exists. This legal gap makes it paramount to pay attention, when drafting a directive, to not include clauses that are illegal and, consequently, cannot be carried out.

Due to the complexity of the different types of dementia, advance directives for older people need to be prepared considering their specific disease. Advance directives of will, thus, can be called "advance directives for dementia." This document should be drafted as soon as the older person is diagnosed with the disease, before its progress compromises their autonomy.

ADD allows patients to ensure that their preferences and values related to health care are respected in the disease's most severe stage, when expressing themselves will no longer be possible. This reduces concerns about the changes caused by the disease over time. It should be noted, however, that the document should be adapted as the dementia progresses, considering the different situations that arise over its course and further discussions between those involved in the patient's treatment and care.

In conclusion, it is a matter of urgency to discuss the ADD in the Brazilian context. Such discussion should take place not only within health institutions, but also include society as a whole, since ADD is a fundamental instrument to guarantee the self-determination of patients with dementia.

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