Acta Bioethica 2025; 31(1): 35-48. DOI: http://dx.doi.org/10.4067/S1726-569X2025000100035

# ETHICAL CHALLENGES RELATED TO CAPACITY, COMPETENCE AND AUTONOMY IN INDIVIDUALS WITH DEMENTIA

Valeska Delineau[1], Ivone Duarte[2], Ana Rita Ferreira[3], Lia Fernandes[4]

**Abstract**: Dementia is a syndrome characterised by the development of multiple cognitive deficits and behavioural changes that significantly interfere with various aspects of life.

The study aims to discuss capacity, competence and autonomy in individuals with dementia, and some ethical challenges related to these concepts, such as healthcare decision-making capacity, financial capacity, driving and voting. Secondarily, we aim to discuss a new ethical issue emerging from using artificial intelligence and machine learning to improve autonomy in individuals with dementia. Furthermore, we will discuss the ethical importance of obtaining informed consent for healthcare decision-making and Advance Care Planning in dementia patients.

This study provides a comprehensive overview of the complex issues related to autonomy and competence in individuals with dementia, highlighting the importance of striking a balance between upholding individual rights and protecting the well-being of those affected by the disease. In conclusion, the study emphasizes the importance of Advance Care Planning in helping patients, families, caregivers, and healthcare professionals address ethical issues related to autonomy, capacity, and competence in dementia care.

**Keywords**: autonomy, capacity, competence, artificial intelligence, decision making, dementia

### Desafíos éticos relacionados con la capacidad, la competencia y la autonomía en individuos con demencia

**Resumen**: La demencia es un síndrome caracterizado por el desarrollo de múltiples déficits cognitivos y cambios conductuales que interfieren significativamente con varios aspectos de la vida.

El estudio tiene como objetivo analizar la capacidad, la competencia y la autonomía en individuos con demencia, así como algunos desafíos éticos relacionados con estos conceptos, tales como la capacidad para tomar decisiones en salud, la gestión financiera, la conducción de vehículos y el derecho al voto. Secundariamente, buscamos abordar una nueva cuestión ética emergente del uso de la inteligencia artificial y el aprendizaje automático (*machine learning*) para mejorar la autonomía en personas con demencia. Además, discutimos la importancia ética de obtener el consentimiento informado para la toma de decisiones en salud y para la planificación anticipada de cuidados en pacientes con demencia.

Este estudio ofrece una visión integral de las complejas cuestiones relacionadas con la autonomía y la competencia en individuos con demencia, destacando la importancia de equilibrar el respeto por los derechos individuales con la protección del bienestar de las personas afectadas por esta enfermedad. En conclusión, subraya la relevancia de la planificación anticipada de cuidados para ayudar a pacientes, familias, cuidadores y profesionales de la salud a abordar cuestiones éticas relacionadas con la autonomía, la capacidad y la competencia en el cuidado de la demencia.

**Palabras clave**: autonomía, capacidad, competencia, inteligencia artificial, toma de decisiones, demencia

### Desafios éticos relacionados com a capacidade, a competência e a autonomia em indivíduos com demência

**Resumo**: A demência é uma síndrome caracterizada pelo desenvolvimento de múltiplos défices cognitivos e alterações comportamentais que interferem significativamente com vários aspetos da vida.

O estudo tem como objetivo discutir a capacidade, a competência e a autonomia em indivíduos com demência, bem como alguns desafios éticos relacionados com estes conceitos, tais como a capacidade para tomar decisões em saúde, a gestão financeira, a condução de veículos e o direito ao voto. Secundariamente, propomo-nos abordar uma nova questão ética emergente do uso da inteligência artificial e do aprendizado automático (machine learning) na melhoria da autonomia em pessoas com demência. Além disso, discutiremos a importância ética de obter o consentimento informado para a tomada de decisões em saúde e para o planeamento antecipado de cuidados em pacientes com demência.

Este estudo apresenta uma visão abrangente das questões complexas relacionadas com a autonomia e a competência em indivíduos com demência, sublinhando a importância de equilibrar o respeito pelos direitos individuais com a proteção do bem-estar das pessoas afetadas pela doença. Em conclusão, o estudo enfatiza a relevância do planeamento antecipado de cuidados para ajudar pacientes, famílias, cuidadores e profissionais de saúde a enfrentarem questões éticas relacionadas com a autonomia, capacidade e competência no cuidado à demência.

**Palavras-chave**: autonomía, capacidade, competencia, inteligência artificial, tomada de decisão, demência

---

[1] Institute of Biomedical Sciences, Abel Salazar, University of Porto, Portugal, valeska.delineau@hotmail.com

[2] Department of Community Medicine, Information and Health Decision Sciences (MEDCIDS) – CINTESIS@RISE, Center of Bioethics, Faculty of Medicine, University of Porto, Porto, Portugal.

[3] CINTESIS@RISE, Department of Clinical Neuroscience and Mental Health, Faculty of Medicine, University of Porto, Portugal

[4] CINTESIS@RISE, Department of Clinical Neuroscience and Mental Health, Faculty of Medicine, University of Porto, Portugal. Psychiatry Service, Unidade Local de Saúde São João, Porto, Portugal.

## Introduction

### *Autonomy, capacity and competence*

The word 'autonomy' derived from the Greek words *autos* ('self') and *nomos* ('rule', 'governance' or 'law'), originally referred to the self-rule or self-governance of independent city-states*(1)*. It was exclusively applied in a political context. Some centuries later, autonomy was described by Jean-Jacques Rousseau, who defined autonomy as more than a mere lack of coercion from external influences *(2)*.

After Rousseau, Kant discussed autonomy in terms of man's moral character*(3)*. In this way, autonomy does not consist solely of independence in the face of sensitive inclinations but equally in the ability to act by a moral law without the mediation of categorical and insensate hopes, considering the limits of reason*(4)*. Kant conceived autonomy with two presumptions: firstly, morality is discerned from within oneself; and secondly, moral imperatives can be deduced from an a priori moral law, the categorical imperative, which tells us to act in a way that could be a universal rule*(5,6)*.

Raanan Gillon defined autonomy (literally, self-rule) as the capacity to think, decide and act based on one's thoughts and to decide freely and independently without any hindrance*(7)*. He concluded that autonomy is a subclass of freedom or liberty. However, not all forms of freedom or liberty can be considered autonomous. In this sense, the author explained that autonomy is necessary for human beings to maintain their full quality of life and, in a certain sense, their complete freedom*(7)*.

Gillon describes three types of autonomy: a) autonomy of thought, b) autonomy of will and c) autonomy of action. Autonomy of thought encompasses a wide range of intellectual activities that are referred to as 'thinking for oneself', including decision-making, forming beliefs, expressing preferences and making moral assessments. Autonomy of will, or autonomy of intention, is the freedom to decide to do things based on one's deliberation. Autonomy of action is the physical ability to act*(7)*.

Beauchamp and Childress analysed autonomous action in terms of three conditions: intentionality, understanding and non-control. *Intentional* actions require plans in the form of representations of the series of events proposed for the execution of an action with intentionality. An action is not autonomous if the actor does not adequately understand it (*understandin*g), and the person must be free of any controls exerted either by external sources or by internal states that rob the person of self-directedness (*non-control)(1)*.

Autonomy diverges from the principle of respect for autonomy. Beauchamps and Childress highlight that the principle of respect for autonomy encompasses both negative and positive obligations. As a negative obligation, it requires that autonomous actions not be subjected to controlling constraints by others. As a positive obligation, the principle emphasizes respectful treatment in disclosing information and actions that foster autonomous decision-making *(1,8)*.

If autonomy is a relevant philosophical concept, capacity is essentially a practical concept. Hedge and Ellajosyula define capacity as a person's ability to make a particular decision at a specific time or in a certain situation*(9)*. In a clinical context, capacity refers to a set of cognitive functions such as memory, judgement and decision-making required to manage one's affairs and perform everyday tasks *(10)*.

Moye and Marson argue that eight major capacity domains are relevant to older persons: a) consent to medical treatment, b) independent living, c) financial capacity, d) consent to research participation, e) testamentary capacity, f) voting, g) sexual consent and h) driving. In each of these domains, there are specific issues in which a person's incapacity in one domain may not affect another domain*(11)*. In other words, capacity evaluates a specific act at a given time*(9)*.

In practical scenarios, healthcare professionals often engage in discussions about a patient's capacity. They assess whether cognitive impairment affects the ability to effectively make decisions, especially in the domains of consent to clinical treatment, independent living and financial capacity*(12)*. Additionally, they evaluate capacity to determine if an individual has the competence to handle these tasks.

Regarding competency, Fellows states, 'If capacity can be explained as a pragmatic concept, referring broadly to the ability to consent, competency is a legal term'*(13)*, and Marson concluded that competency concerns an individual's legal capacity to make certain decisions and to perform certain acts*(14)*. Moreover, there is a presumption that adults can exercise choices and make decisions for themselves until proven otherwise*(14)*.

Once the capacity of an individual has been assessed, it is possible to evaluate whether they possess competency. However, in practice, both factors are evaluated together, and some experts consider them to be the same concept*(15)*. As stated by Beauchamp, competence is the ability to perform a task*(1)*. The author justifies this position by noting that when clinicians judge that patients lack decision-making capacity, the practical effects of these judgments may not differ from those of a legal determination of competence*(1,15)*.

Although there is a connection between capacity and competence, clinical practice assessments and legal evaluations do not always share the same objectives. Therefore, it is essential to differentiate between these terms, and in this article, capacity and competence will not be used synonymously.

Determining competence is important in clinical settings, particularly concerning the informed consent (IC) form, which assesses the patient's ability to make decisions. Informed consent is the process in which a healthcare provider educates a patient about the risks, benefits, and alternatives of a given procedure or intervention*(16)*. For consent to be legally valid, the patient must be fully informed and capable of understanding the information, make a voluntary choice and have decision-making capacity*(17)*, namely the competence to sign or declare their will in the IC.

In the field of bioethics, autonomy, capacity and competence are upheld. There are two important documents, namely The Universal Declaration on Bioethics and Human Rights*(18)* and The Convention for the Protection of Human Rights and Dignity of the Human Being about the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*(19)*, which emphasise the need to protect the interests of individuals who may be incapable of making their own decisions.

In accordance with Article 7 of The Universal Declaration on Bioethics and Human Rights*(18)*, domestic laws must provide special protection to individuals who lack the capacity to consent. This includes obtaining authorisation for research and medical practice in the best interest of the individual and according to domestic law. However, the person concerned should be actively involved in the decision-making process regarding giving or withdrawing consent to the greatest extent possible.

Similarly, The European Convention on Human Rights and Biomedicine (Articles 6 and 17)*(19)* states that if an adult cannot consent to intervention due to mental disability, disease or similar reasons, the intervention may only be carried out with the authorisation of his/her representative or an authority, person or body provided by law.

### *Dementia*

Currently, more than 55 million people worldwide are affected by dementia, and it is expected that this number will triple by 2050*(20–23)*. Moreover, dementia is a significant burden for both individuals and society. Recent studies analysing data from 17 European countries estimated that the average dementia care costs for all patients varied by region. The costs were highest in the British Isles (73,712 EUR), followed by the Nordics (43,767 EUR), Southern (35,866 EUR), Western (38,249 EUR) and Eastern Europe and the Baltics (7,938 EUR)*(24)*. Due to its high prevalence, expensive costs and complex care requirements, dementia presents a significant challenge for public health systems worldwide.

Dementia, or major neurocognitive disorder, is characterised by a significant decline in one or more cognitive domains from one's previous level of ability, that interferes with everyday functioning*(25)*. Dementia should be considered a syndrome with multiple possible causes rather than a specific disease itself*(22)*.

Dementia is a progressive disease that impacts an individual's ability to perform tasks as time goes on. While those in the early stages of the disease can typically manage most tasks, the later stages can lead to a loss of autonomy, capacity, and competence, making individuals more dependent*(22)*. As the disease progresses, ethical debates arise around the capacity and competence to perform tasks such as healthcare decision-making, financial capacity, driving, and voting.

There are several causes of dementia. Alzheimer's disease is the most common cause of dementia, accounting for an estimated 60–80% of cases*(27)*. Other common causes include vascular dementia, Lewy body disease, frontotemporal dementia and mixed dementia*(26,27)*. Each type of dementia has different symptoms and progressions, which can affect certain abilities more than others.

Dementia imposes emotional and physical burdens on caregivers and families involved in patient care*(28,29)*. The burden increases over time, and the clinical characteristics of patients (including neuropsychiatric symptoms, patient dependence and functional decline), level of services and caregiver gender appear to be the best predictors of this burden*(28–31)*. Healthcare professionals, caregivers, and families are seeking alternatives to reduce costs and burdens associated with caring for people with dementia while improving their autonomy.

Artificial intelligence (AI) and machine learning (ML) are now offering automated solutions to enhance autonomy for individuals with dementia. AI and ML have the potential to improve the lives of individuals with dementia in several ways. This includes cognitive screening and training, diagnosing and predicting dementia, as well as providing care and interventions for dementia*(32–34)*. The use of AI and ML in the context of dementia is directly related to increasing patients' independence and autonomy and improving the quality of life for patients, their families, and caregivers*(35)*. However, these news tools raise ethical and legal concerns that need to be addressed.

The purpose of this article is to discuss capacity, competence and autonomy in individuals with dementia, and some ethical challenges related to these concepts, such as healthcare decision-making capacity, financial capacity, driving and voting. Secondarily, we aim to discuss a new ethical issue emerging from using artificial intelligence and machine learning to improve autonomy in individuals with dementia. Furthermore, we discuss the bioethical relevance of informed consent (IC) and advance care planning (ACP) in dementia disease.

## Ethical issues in dementia

### *1. Healthcare decision-making capacity*

Decision-making capacity is at the core of ethical issues in dementia, involving autonomy, capacity and competence. It is impossible to conceive an autonomous person without some level of decision-making capacity. Decision-making covers a wide range of areas, but for this article, we will focus on healthcare decision-making capacity. This capacity does not differ from the general ability to make decisions but is rather encompassed by it.

The most critical instrument in healthcare decision-making is the inform consent (IC) form for medical treatment. It is an ethical and legal obligation for patients to be capable of providing consent. Therefore, a valid IC must be given by someone who can make decisions.

Appelbaum and Grisso describe the general competence criteria for making IC*(36)*: a) the ability to communicate choices; b) the ability to understand information about treatment decisions; c) the ability to appreciate the situation and the consequences; and d) the ability to use logical processes to compare the benefits and risks of various treatment options*(36)*. All these criteria must be met by individuals with dementia.

### *2. Financial capacity*

The capacity for financial decision-making can be defined as 'the capacity to manage money and financial assets in ways that meet a person's needs and align with their values and self-interest'*(37)*. Financial decision-making capacity is a critical skill for maintaining an independent life, and it is linked with capacity, autonomy and competence.

If healthcare decision-making capacity is perhaps the main concern of healthcare professionals, financial capacity is a significant concern for dementia patients and their families. In addition to issues related to obtaining IC, individuals may face difficulties in financial management since the onset of the disease, leading to potential financial losses that may go unnoticed even by close family members*(11,38)*.

Once identified, the reduction in financial capacity significantly impacts patients' lives*(38-40)*. Difficulties with shopping, managing money, paying bills, and other daily financial tasks diminish the patient's autonomy, forcing families to limit the patient's competence to prevent financial losses*(37-40)*. Reduced financial capacity not only decreases the patient's autonomy but also progressively impairs their competence.

Families are mainly concerned with avoiding financial losses, but healthcare professionals also need to be vigilant about potential exploitation and abuse by family members or others*(37,38)*. To prevent these issues, healthcare professionals should prompt patients to engage in advance care planning and make decisions about proxies in the early stages of the disease when they are able to do so*(37,38)*. Additionally, they should involve public agencies and social support organizations to assist and care for these patients*(41)*.

The advancement of specific technological tools, such as artificial intelligence, can help patients with dementia improve their financial capacity and independence*(42)*. Tools are being developed, such as virtual financial assistants, that manage payment systems and shopping, prevent losses, and enhance patient autonomy. The use of the Internet of Things (IoT) and mobile computing to address issues related to impaired financial capacity is a good example. Monitoring financial transactions, gathering real-time biometric data, and sending alerts to professionals or caregivers are just a few of the ways that the IoT can be used to support the well-being of individuals with dementia*(43)*.

### *3. Driving*

Driving is associated with an independent life, enabling daily problem-solving and social interaction through mobility. For many older individuals, ceasing to drive can result in a loss of autonomy. However, the inability to drive can also pose significant risks for both the driver and others on the road. While older individuals with normal cognitive functions may experience some difficulties, the discussion becomes more complex when it comes to those with dementia*(44–46)*.

Driving ability spans multiple cognitive domains, requiring visuospatial skills, executive function, memory, attention and motor skills*(47)*. The assessment of cognitive, physical, and psychological factors is crucial for evaluating driving capacity and determining who is fit to drive and who may not be*(48)*.

There is an important intersection between capacity and competence in driving. In most countries' legislation, physicians have the authority to determine who is fit to drive. Once visual, hearing and attention problems are identified, professionals must inform the competent authority to revoke the driving licence*(46,49,50)*.

In this case, the challenge is not the patients' assessment of driving ability but the opportunity to evaluate cognitive impairment in patients earlier. Sometimes, in the early stages of dementia, it is not possible to evaluate patients before a burdensome event occurs. A driving crash can highlight cognitive problems, serving as an opportunity to make a dementia *(51)*.

### *4. Voting*

Although voting may not be a critical issue for families of dementia patients, the possibility of voting is a significant milestone of citizenship. The vote is a universal right for most countries, and even if it is not directly related to autonomy or capacity, it is an important landmark of full competence.

To assess voting ability, most studies demonstrate a strong correlation between dementia severity and the capacity to vote*(52–54)*. The studies clarify that in severe dementia, the capacity to vote is compromised, while in most cases of mild dementia, it is preserved. In moderate dementia, an individual evaluation is necessary because the response is not clear.

The specificity of the ability to vote is that if dementia patients do not undergo a legal procedure to reduce their competence, even patients who lack the capacity for decision-making can still vote, as it is impossible to prevent them from doing so.

Karlawish et al., analyzing the American election system, identified three critical issues related to voting for people with dementia: the need to develop a method to assess the capacity to vote, identify appropriate types of assistance for individuals with cognitive impairment to vote, and create consistent policies for voting in long-term care settings*(55)*. These issues could also be considered by other countries.

The assessment of voting ability in individuals with dementia should adhere to the same general competence criteria required for giving informed consent: understanding, choice, reasoning, and appreciation. Appelbaum et al. developed a specific assessment tool for voting, evaluating if the person can understand the nature and the effect of voting, can make a choice, can engage in comparative reasoning, and is aware of the potential consequences and appreciation*(56)*.

The issue of voting competence for individuals with dementia requires specific legislation to determine if they are capable of voting and how to support them if they are able to do so. This complex topic involves patients, families, caregivers, healthcare professionals, and public health policy.

### *5. Artificial intelligence to improve autonomy in individuals with dementia*

Artificial Intelligence (AI) is a term coined in 1956 that refers to the ability of computers to mimic intelligent human behaviour with minimal human intervention*(57)*. It is a vast field of computer science that involves creating machines, systems or software that can perform tasks that typically require human intelligence. One of the subfields of AI is machine learning (ML), which focuses on developing algorithms and statistical models. These algorithms and models enable computers to improve their performance on a specific task through data analysis without requiring explicit programming*(34,57)*.

AI and ML can improve individuals' autonomy, such as through the use of AI robots that can assist individuals with dementia in daily tasks and with sensors around the house that can intelligently monitor a person's behaviour*(58)*. ML algorithms have been successfully employed to automatically discriminate Alzheimer´s disease (AD) from vascular dementia (VD), reaching a classification accuracy greater than 84%*(59)*.

The topic is new and not fully discussed in the literature. For instance, there is an ethical debate surrounding AI devices that monitor and record individuals with dementia in their private lives and using care robots can create conflicts with ethical principles. The authors emphasize the tension between older adults' autonomy and privacy*(60)*. Older adults and caregivers may not be aware that robots are recording them and that these recordings may be shared with others. While these devices can enhance autonomy, prevent dangerous situations, and promote human welfare, it is unclear whether they adhere to ethical principles*(60-62)*.

The literature highlights several ethical principles and values associated with AI and ML in patient interactions that should be respected to ensure ethical practices. Among these, the principle of non-maleficence (prevention of harm) is the most explored. Other prevalent principles include self-determination, promoting human welfare, and privacy*(60–62)*.

Non-maleficence is the ethical principle of "no harm." AI systems should be designed and developed not to undermine or harm people*(61)*.

The self-determination principle refers to the right of individuals to make their own choices and decisions. This principle emphasizes autonomy and personal freedom, allowing people to control their own lives and make decisions that affect them without undue influence or coercion*(63,64)*. Remmers points out that the reduction of independence does not automatically result in an incapacity of self-determination*(63)*. According to this author, the longest possible preservation of self-determination is the main normative background legitimising the usage of assistive technologies in the home*(63)*.

Promoting human welfare involves actions and policies to improve individuals' and communities' well-being and quality of life. Welfare technologies is supposed to give better and more focused care, reduced risk and increased safety, increased coping and self-determination, make it possible to stay at home longer, avoid harm (from falling, fire, robbery), make more just resource allocation, and to promote technology development, commercialization and growth*(63-65)*.

Privacy is the right of individuals to keep their personal information and activities from being disclosed or accessed without their consent. It provides protection by maintaining confidentiality and respecting sensitive information. This is crucial, especially in contexts like healthcare, where patient data must be safeguarded. Various types of Intelligent Assistive Technology could be used to access private and sensitive user-related information. Therefore, privacy and security breaches should be anticipated and prevented by technological developers*(63-66)*.

## Discussion

### *How to address ethical issues related to dementia*

Understanding the concepts of autonomy, capacity and competence, along with their ethical and legal implications, is challenging for clinicians, individuals living with dementia and their families. It is important to know how to cope with practical situations in daily life and nowadays in emerging fields of technology.

Due to the range of issues involved, some basic principles must be applied before an intervention or restriction to support someone in making their own decisions. They are as follows, a person: a) is presumed to have capacity; b) shall not be treated as unable to decide unless all practicable steps have been taken to help him or her do so; c) shall not be regarded incapable of making a decision merely by making an unwise decision; and d) shall not intervene unless it is necessary, considering the individual circumstances of relevant person*(67)*.

The principles mentioned above are universal. They are suitable for all cases of capacity restriction, including all types of dementia diagnoses. Adults are presumed capable of making their own decisions, and any limitations to their capacity or autonomy should be viewed as an exception*(67,68)*. In cases where a person is deemed incapable of making decisions, it is important that the decision-making process still protects their best interests and does not cause them harm. To determine whether a person is incapable of making decisions, all necessary steps must be taken to evaluate both the individual and the situation*(67,69)*.

The investigation of whether individuals have the capacity and competence to provide IC, manage their finances, drive, vote or make decisions about using AI tools or participating in ML programs in the context of dementia follows a similar pattern. Nonetheless, there is no one-size-fits-all answer to all these questions.

Different tasks require different capacities to complete. There is a distinction between driving a car and voting in an election. While an individual may be capable of voting, driving a car safely is a much more complex task. We must evaluate the consequences of reduced capacity in these two tasks to ensure the best outcome for individuals without harming third parties.

Neurodegenerative diseases, such as dementia, present challenges for early diagnosis*(67)*. Families may confuse initial symptoms with typical signs of aging, leading to increased patient monitoring without a proper diagnosis. Unfortunately, this delay can cause individuals living with dementia to lose their independence and autonomy before receiving the necessary assessment and treatment, making it challenging to address ethical issues*(67-70)*.

As dementia progresses, an individual's ability to make decisions will decline, especially in the advanced stages. However, it can be challenging to determine if the disease has affected decision-making capacity during the early stages, which may occur before an official diagnosis. This ethical dilemma raises the question: Can the patient still provide informed consent or advanced directives?

To address concerns about capacity, competence and autonomy in dementia, three clinical interventions can be implemented. First, an early and comprehensive neurocognitive and psychiatric assessment of the patient must be conducted. Second, ensure effective communication and collaboration among patients, families and healthcare professionals. Healthcare professionals should provide information and support to patients and their families regarding clinical and ethical issues. Finally, encourage patients, families and healthcare professionals to collaborate in establishing an early advance care plan*(70-73)*.

Nowadays, there are an increasing number of adequate instruments available to assess the healthcare decision-making capacity of older people*(74-76)*. They can evaluate their capacity to make healthcare decisions, participate in research and engage in everyday decision-making.

Combining neuropsychological assessments and imaging exams with the analysis of dementia biomarkers can enhance the evaluation of a patient's cognitive functions and autonomy*(76-78)*. The autonomy assessment should be comprehensive, incorporating neurocognitive, neuropsychiatric, clinical, and physical evaluations*(74-79)*. This approach ensures that they receive the appropriate care and assistance through an accurate evaluation of their capacity and competence.

After a thorough assessment, it is possible to implement an intervention focused on reducing disabilities and improving autonomy*(22,35,79,80)*. Incapacities not directly connected with dementia, such as hearing loss and visual deficits can be addressed through appropriate interventions*(81-84)*. This can lead to improved cognitive assessment and accurate staging of dementia*(83)*. Furthermore, pharmacological or non-pharmacological interventions designed to treat or mitigate the behavioral and psychological symptoms of dementia have the potential to significantly enhance patient autonomy*(85)*. Continuous assessment is essential to monitor patient progress and adapt care throughout the progression of the disease*(84)*.

Artificial intelligence (AI) and machine learning (ML) can play a crucial role in this intervention. They can provide cognitive training for dementia patients, as well as training apps for caregivers and family members of dementia patients to assist them in providing care*(34,35,57)*. Additionally, socially interactive robots can facilitate daily engagement for those in the early stages of dementia*(57,66,81)*. In the following years, it is expected that a multitude of digital devices will further enhance the care of dementia patients.

The interaction between healthcare professionals, dementia patients and their families and caregivers is fundamental. During the progression of dementia, patient care becomes increasingly difficult, expensive and burdensome for families and caregivers. Insufficient information about the clinical situation, treatments and their consequences hasten the progression of the disease. Discussing ethical issues with families and caregivers is important to inform and support them.

While the interventions mentioned above can help support autonomy, the most effective approach to preserving patients' decision-making abilities—and a degree of their autonomy—is to encourage advance care planning (ACP) as soon as a diagnosis of dementia is established and while patients are competent*(72)*.

ACP is a process that typically involves several voluntary discussions between an individual and any healthcare professional who is familiar with them. Aspects of ACP may include*(86)*: a) discussing the individual's understanding of their illness or prognosis; b) exploring the options available to them; c) identifying their wishes, preferences, priorities and concerns; d) refusing specific treatment if they wish to; e) advocating for someone who is unable to speak for themselves; f) appointing someone to make healthcare decisions for them using a Lasting Power of Attorney; and g) helping individuals communicate their preferences for future care. ACP after a dementia diagnosis must be based on patients' desires, values and technical care issues*(71)*. It includes financial decisions, appointing a durable power of attorney, creating a will, making treatment and clinical intervention decisions, and, when not prohibited by law, deciding on suicide assistance*(71)*.

ACP can help address the bioethical concerns that arise when using AI and ML to care for individuals with dementia. This approach can identify the preferences and limitations of these individuals regarding their future care. However, in this case, besides ACP, it is crucial to establish laws and bioethical guidelines to regulate the use and the limits of these new technologies and approaches.

The first European countries to implement ACP were the United Kingdom (UK), the Netherlands, Belgium, and Germany. In the UK, this implementation was gradually designed, starting in the 1980s. Its main directive was The Mental Capacity Act of 2005*(87,88)*. Currently, 15 of the 28 European Union countries have established specific rules on advance directives, making them legally binding in 86% of cases if they are in writing. Only seven countries require a formal advance directive to be signed before a notary, civil officer or witness. Additionally, the designation of a patient's attorney for health matters is regulated in 11 countries*(89)*.

In Portugal, Law No. 25/2012 contributes to the implementation of appropriate advance care planning. The law regulates ACP, allowing everyone to anticipate making decisions about the end of life and appointing a healthcare proxy. It is registered in the Portuguese National Health System, where the doctors responsible for the patient's care can access their preferences regarding medical treatments and end-of-life interventions.

One of the worst consequences of dementia is the burden it places on families and caregivers. Advanced directives allow patients to make decisions about their future. Establishing advanced directives is the best way to reduce the burden on patients, families and caregivers regarding future complex and sensitive decisions. This practice makes healthcare more efficient and improves the quality of life for families and caregivers.

Although ACP focuses on individuals' well-being, families, caregivers and healthcare professionals involved in the patients' care are the most indirect beneficiaries.

In the absence of advance directive planning, healthcare professionals involved in dementia care must balance between two ethical principles: autonomy and protection. Therefore, if the patient's protection against harmful situations is deemed more important in certain decisions, autonomy must be disregarded. This equilibrated duality is essential for preserving the patients' well-being as the disease progresses.

### *Limitations of these solutions for improving dementia autonomy issue*s

Although the solutions for simplifying the ethical issues related to dementia are not complex, there are some challenges in achieving these solutions.

The first challenge is the difficulty of accessing early cognitive evaluation. With the increase in life expectancy and the growing population of older people, many countries are facing an overload of public health services, which makes it impossible to evaluate patients early.

Another limitation is the difficulty families face in accepting or recognising the cognitive problems associated with their parents' or dementia denial and stigma. Today, there is a stigma surrounding a diagnosis of dementia, leading to the denial of the condition*(90)*.

In Portugal, studies have shown reduced access to public health services and a strong dementia stigma in the population which hinders early dementia intervention*(91,92)*. Other European countries, such as Austria, Belgium, Bulgaria, Germany, Greece, Ireland, the Netherlands, Romania and the UK, also encounter challenges in healthcare provision for individuals with dementia, especially in terms of healthcare access and information for patients and their families*(93)*.

The prevalence of social inequalities among older persons poses a significant challenge in accessing vital information and solutions pertaining to ethical dilemmas in dementia. As a result, we must work towards creating a more equitable and accessible system that ensures everyone has an equal opportunity to access the resources they need to make informed decisions.

All these challenges in developing and implementing dementia healthcare information and solutions stem mainly from the increasing aging population, the high cost of dementia care, and the lack of priority in healthcare policy for older individuals.

## Conclusions

Despite the different views on autonomy, capacity, competence and the ampleness of ethical issues in dementia care, the topic holds practical importance as it pertains to the daily lives of patients with the disease as well as their families and caregivers. The subject must transition from the philosophical and theoretical domain to medical practice to provide comprehensive care for dementia patients.

Healthcare professionals must be prepared and trained not only for clinical issues but also for ethical and legal considerations concerning all individuals involved in the care of dementia patients. They must understand the dimensions of autonomy, capacity and competence.

Additionally, it is essential that information regarding autonomy, capacity and competence be transparent and readily available to older individuals, caregivers and families. Similarly, information about IC, ACP and other critical directives must also be easily accessible.

Advance Care Planning is crucial for alleviating the stress and burden on caregivers and the families of dementia patients, especially about ethical concerns. It should be readily available to all stakeholders, and public health systems can play a key role in enhancing ACP awareness for patients, families, and caregivers.

Public health policies targeting older people should prioritise improving access to information on ethical dilemmas related to dementia. Moreover, these policies should include ethical guidelines that address novel situations, such as AI and ML. They should also aim to combat the stigma associated with dementia, which often leads to a late diagnosis.

Society and public healthcare policies should collaborate to create a more fair and accessible system that provides everyone with equal opportunities to access the resources necessary to enhance individuals' autonomy and quality of life in dementia, support informed decisions advance care planning, and reduce dementia ethical dilemmas.

### Declarations Ethics Approval

Not applicable

### Conflicts of Interest

The author(s) declared no conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding Sources

The authors did not receive funding from any source.

**References**

1. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. [Internet] Seventh ed. Oxford University Press. New York, Oxford; 2013. https://medium.com/@arifwicaksanaa/pengertian-use-case-a7e576e1b6bf
2. Neuhouser F. Jean-Jacques rousseau and the origins of autonomy. *Inquiry* 2011 Oct; 54(5): 478–93.
3. May T. The Concept of Autonomy. *Am Philos Q*. 1994; 31(2): 133–44.
4. Pinto Serrão D, Delio R, Meneses B. Autonomia em Kant: pela crítica da crítica científica (The autonomy according to Kant: for the criticism of scientific criticism). *Revista de Filosofía* 2010; 35(1): 7–19.
5. Saad TC. The history of autonomy in medicine from antiquity to principlism. Vol. 21, *Medicine, Health Care and Philosophy*. Springer Netherlands; 2018. 125–37.
6. De Brito JHS, De Brito AS. A Autonomia Humana: da Filosofia à Bioética Clínica. *Revista Portuguesa de Filosofia*. [Internet] 2012; 68(4): 657–71. http://www.jstor.org/stable/23596156
7. Gillon R. Autonomy and the principle of respect for autonomy. *Br Med J* (Clin Res Ed). 1985; 290(6484): 1806.
8. Childress JF. The Place of Autonomy in Bioethics. *Hastings Cent Rep*. 1990; 20(1): 12.
9. Hegde S, Ellajosyula R. Capacity issues and decision-making in dementia. *Ann Indian Acad Neurol.* 2016; 19(5): S34–9.
10. Arias JJ. A time to step in: Legal mechanisms for protecting those with declining capacity. *Am J Law Med*. 2013; 39(1): 134–59.
11. Moye J, Marson DC. Assessment of decision-making capacity in older adults: An emerging area of practice and research. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences* 2007; 62(1): 3–11.
12. John S, Rowley J, Bartlett K. Assessing patients decision-making capacity in the hospital setting: A literature review. *Australian Journal of Rural Health* 2020; 28(2): 141–8.
13. Fellows LK. Competency and consent in dementia. *J Am Geriatr Soc*. 1998; 46(7): 922–6.
14. Marson DC. Loss of competency in Alzheimer's disease: Conceptual and psychometric approaches. *Int J Law Psychiatry*. 2001; 24(2–3): 267–83.
15. Moye J, Marson DC, Edelstein B. Assessment of Capacity in an Aging Society. *Am Psychol.* 2014; 68(3): 158–71.
16. Parth Shah A, Thornton I, Turrin D, Hipskind Affiliations JE. *Informed Consent* [Internet] https://www.ncbi.nlm.nih.gov/books/NBK430827/?report=printable
17. Poppe C, Elger BS, Wangmo T, Trachsel M. Evaluation of decision-making capacity in patients with dementia: Challenges and recommendations from a secondary analysis of qualitative interviews. *BMC Med Ethics*. 2020; 21(1): 1–8.
18. United Nations. *Universal Declaration on Bioethics and Human Rights*. Paris, France: United Nations; Jan, 2006.
19. Council of Europe. Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo Convention) *. *European Treaty Series* No164, 164 Spain: European Treaty Series; Apr 4, 1997.
20. Scheltens P, De Strooper B, Kivipelto M, Holstege H, Chételat G, Teunissen CE, et al. Alzheimer's disease. *Lancet* 2021; 397: 1577–90.
21. Nichols E, Steinmetz JD, Vollset SE, Fukutaki K, Chalek J, Abd-Allah F, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health* 2022 Feb 1; 7(2): e105–25.
22. Gale SA, Acar D, Daffner KR. Dementia. *Am J Med*. 2018 Oct [Internet]; 131(10): 1161-9. https://linkinghub.elsevier.com/retrieve/pii/S0002934318300986
23. Alzheimer's Disease International**.** *World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late*. London: Alzheimer's Disease International; 2023.
24. Jönsson L, Tate A, Frisell O, Wimo A. The costs of dementia in Europe: An updated review and meta-analysis. *Pharmacoeconomics*. 2023; 41: 59–75.
25. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders. 5th ed. American Psychiatric Publishing. Washington, DC: American Psychiatric Association; 2013.
26. Corriveau RA, Koroshetz WJ, Gladman JT, Jeon S, Babcock D, Bennett DA, et al. Cumbre de demencias relacionadas con la enfermedad de Alzheimer 2016: Prioridades nacionales de investigación. *Neurología* 2017;89(23):2381-91.
27. The Alzheimer's Association. 2023 Alzheimer's disease facts and figures. *Alzheimer's and Dementi*a 2023 Apr 1; 19(4): 1598–695.
28. Connors MH, Seeher K, Teixeira-Pinto A, Woodward M, Ames D, Brodaty H. Dementia and caregiver burden: A three-year longitudinal study. *Int J Geriatr Psychiatry*. 2020; 35(2): 250–8.
29. Gallagher D, Mhaolain AN, Crosby L, Ryan D, Lacey L, Coen RF, et al. Dependence and caregiver burden in Al-

zheimer's disease and mild cognitive impairment. *Am J Alzheimers Dis Other Demen*. 2011; 26(2): 110–4.

30. Cheng ST. Dementia Caregiver Burden: a Research Update and Critical Analysis. *Curr Psychiatry Rep*. 2017; 19(9).
31. Pillemer S, Davis J, Tremont G, Hospital RI, Behavior H. Gender Effects on Components of Burden and Depression among Dementia Caregivers. *Aging Ment Health*. 2019; 22(9): 1156–61.
32. Aditya Shastry K, Sanjay HA. Artificial Intelligence Techniques for the effective diagnosis of Alzheimer's Disease: A Review. *Multimed Tools Appl*. 2024 Apr 1; 83(13): 40057–92.
33. AlHarkan K, Sultana N, Al Mulhim N, AlAbdulKader AM, Alsafwani N, Barnawi M, et al. Artificial intelligence approaches for early detection of neurocognitive disorders among older adults. *Front Comput Neurosci*. 2024; 18.
34. Veneziani I, Marra A, Formica C, Grimaldi A, Marino S, Quartarone A, et al. Applications of Artificial Intelligence in the Neuropsychological Assessment of Dementia: A Systematic Review. *Journal of Personalized Medicine. Multidisciplinary Digital Publishing Institute (MDPI)*. 2024; 14.
35. Guerrero Quiñones JL. Using artificial intelligence to enhance patient autonomy in healthcare decision-making. *AI & Soc*. 2024 May 19. https://doi.org/10.1007/s00146-024-01956-6
36. Appelbaum, Paul; Grisso T. Assessing patients' capacities to consent to treatment. *N Engl J Med* [Internet]. 1998; 316(25): 802–5. https://doi.org/10.1056/NEJM198812223192504
37. Marson DC. Clinical and ethical aspects of financial capacity in dementia: A commentary. *American Journal of Geriatric Psychiatry*. 2013; 21(4): 382–90.
38. Widera E, Steenpass V, Daniel Marson, Sudore R. Finances in the Older Patient with Cognitive Impairment: He didn't want me to take over. *JAMA* [Internet] 2011; 305(7): 698–706. https://doi.org/10.1001/jama.2011.164
39. Niccolai LM, Triebel KL, Psy D, Gerstenecker A, Ph D, Mcpherson O, et al. Neurocognitive Predictors of Declining Financial Capacity in Persons with Mild Cognitive Impairment. *Clin Gerontol*. 2017; 40(1): 14–23.
40. Nicholas LH, Langa KM, Bynum JPW, Hsu JW. Financial Presentation of Alzheimer Disease and Related Dementias. *JAMA Intern Med*. 2021 Feb 1; 181(2): 220–7.
41. Lichtenberg PA. New Approaches to Preventing Financial Exploitation: A Focus on the Banks. *Public Policy & Aging Report* 2016; 26(1): 15–7.
42. Manivannan M, Heunis J, Hooper SM, Sideman AB, Lui KP, Braley TL, et al. Use of Telephone-and Internet-Based Support to Elicit and Address Financial Abuse and Mismanagement in Dementia: Experiences from the Care Ecosystem Study. *Journal of Alzheimer's Disease*. 2022; 86(1): 219–29.
43. Nowrangi MA, Sevinc G, Kamath V. Synthetic review of financial capacity in cognitive disorders: Foundations, interventions, and innovations. *Curr Geriatr Rep.* 2019; 8: 257–64.
44. Breen DA, Breen DP, Moore JW, Breen PA, O'Neill D. Driving and dementia. *Br Med J.* 2007; 334(7608): 1365–9.
45. Duchek JM, Carr DB, Hunt L, Roe CM, Xiong C, Shah K, et al. Longitudinal driving performance in early-stage dementia of the Alzheimer type. *J Am Geriatr Soc*. 2003; 51(10): 1342–7.
46. Barbas NR, Wilde EA. Competency issues in dementia: Medical decision-making, driving, and independent living. *J Geriatr Psychiatry Neurol*. 2001; 14(4): 199–212.
47. Allan CL, Behrman S, Baruch N, Ebmeier KP. Driving and dementia: A clinical update for mental health professionals. *Evid Based Ment Health*. 2016; 19(4): 110–3.
48. Wadley VG, Okonkwo O, Crowe M, Vance DE, Elgin JM, Ball KK, et al. Investigation of Driving Performance. *J Geriatr Psychiatry Neurol*. 2010; 22(2): 87–94.
49. Ott BR, Daiello LA. How does dementia affect driving in older patients? *Aging Health*. 2010;6(1):77–85.
50. Snyder CH. CLINICAL PRACTICE Dementia and Driving: Autonomy Versus Safety. *Journal Of The American Academy Of Nurse Practitioners* 2005; 17(10): 393–402.
51. Fraade-Blanar LA, Hansen RN, Chuen Chan KG, Sears JM, Thompson HJ, Crane PK, et al. Diagnosed dementia and the risk of motor vehicle crash among older drivers HHS Public Access. *Accid Anal Prev.* 2018; 113: 47–53.
52. Appelbaum PS, Bonnie RJ, Jason Karlawish JH. Article The Capacity to Vote of Persons with Alzheimer 's Disease [Internet]. Vol. 162, Am J Psychiatry. 2005. http://ajp.psychiatryonline.org
53. Irastorza LJ, Corujo P, Bañuelos P. Capacity to vote in persons with dementia and the elderly. *Int J Alzheimers Dis*. https://doi.org/10.4061/2011/941041
54. Karlawish JH, Bonnie RJ, Appelbaum PS, Lyketsos C, James B, Knopman D, et al. Addressing the ethical, legal, and social issues raised by voting by persons with dementia. *J Am Med Assoc*. 2004; 292(11): 1345–50.
55. Karlawish JH, Bonnie RJ, Appelbaum PS, Lyketsos C, James B. Addressing the ethical, legal, and social issues raised by voting by persons with dementia [Internet]. *JAMA*. 2004; 292(11): 1345-50. http://jama.ama-assn.org/cgi/content/full/292/11/1345
56. Appelbaum PS, Bonnie RJ, Karlawish JH. The capacity to vote of persons with Alzheimer's disease [Internet]. *Am J*

*Psychiatry*. 2005; 162(11): 2094-100. http://ajp.psychiatryonline.org

57. Tsoi KKF, Jia P, Dowling NM, Titiner JR, Wagner M, Capuano AW, et al. *Applications of artificial intelligence in dementia research*. Cambridge Prisms: Precision Medicine. 2023;1.
58. Sprint G, Cook DJ, Fritz R. Behavioral differences between subject groups identified using smart homes and change point detection. *IEEE J Biomed Health Inform*. 2021 Feb 1; 25(2): x559–67.
59. Vinny PW, Vishnu VY, Srivastava MV. Artificial intelligence shaping the future of neurology practice. *Med J Armed Forces India*. 2021; 77: 276–82.
60. Schicktanz S, Welsch J, Schweda M, Hein A, Rieger JW, Kirste T. AI-assisted ethics? considerations of AI simulation for the ethical assessment and design of assistive technologies. *Front Genet*. 2023 Jun;14.
61. Milossi M, Alexandropoulou-Egyptiadou E, Psannis KE. AI Ethics: Algorithmic Determinism or Self-Determination? The GPDR Approach. *IEEE Access* 2021 ;9: 58455–66.
62. Harishbhai Tilala M, Kumar Chenchala P, Choppadandi A, Kaur J, Naguri S, Saoji R, et al. Ethical Considerations in the Use of Artificial Intelligence and Machine Learning in Health Care: A Comprehensive Review. *Cureus*. 2024 Jun 15; 16(6) :e62443
63. Remmers H. Environments for ageing, assistive technology and self-determination: Ethical perspectives. *Inform Health Soc Care*. 2010 Sep; 35(3–4): 200–10.
64. Novitzky P, Smeaton AF, Chen C, Irving K, Jacquemard T, O'Brolcháin F, et al. A review of contemporary work on the ethics of ambient assisted living technologies for people with dementia. *Sci Eng Ethics*. 2015; 21: 707–65.
65. Hofmann B. Ethical challenges with welfare technology: A review of the literature. *Sci Eng Ethics.* 2013; 19: 389–406.
66. Ienca M, Fabrice J, Elger B, Caon M, Pappagallo AS, Kressig RW, et al. Intelligent Assistive Technology for Alzheimer's Disease and Other Dementias: A Systematic Review. *Journal of Alzheimer's Disease*. 2017; 56(4): 1301–40.
67. Davidson H. The Assisted Decisionm-Making (Capacity) Act 2015: Interrogating the guiding principles for a person with dementia. *Int J Law Psychiatry* [Internet]. 2022; 84(July): 101819. https://doi.org/10.1016/j.ijlp.2022.101819
68. Bellhouse J, Holland A, Clare I, Gunn M. Decision-making capacity in adults: its assessment in clinical practice. *Advances in Psychiatric Treatment*. 2001 Jul; 7(4): 294–301.
69. Nicholson TRJ, Cutter W, Hotopf M. Assessing mental capacity: The Mental Capacity Act. BMJ. 2008; 336: 322–5.
70. Rossor MN, Fox NC, Mummery CJ, Schott JM, Warren JD. The diagnosis of young-onset dementia. *Lancet Neurol* [Internet]. 2010 Aug 1; 9(8): 793–806. http://www.ncbi.nlm.nih.gov/pubmed/20650401
71. Dias LM, Bezerra MR, Barra WF, Nunes R, Rego F. Advance care planning: a practical guide. *Revista Bioética*. 2022 Sep; 30(3): 525–33.
72. Chiong W, Tsou AY, Simmons Z, Bonnie RJ, Russell JA. Ethical Considerations in Dementia Diagnosis and Care: AAN Position Statement. *Neurology*. 2021 Jul 13; 97(2): 80–9.
73. Robles MJ, Cucurella E, Formiga F, Fort I, Rodríguez D, Barranco E, et al. La información del diagnóstico en la demencia. *Rev Esp Geriatr Gerontol.* 2011; 46(3): 163–9.
74. Amaral AS, Afonso RM, Simões MR, Freitas S. Decision-Making Capacity in Healthcare: Instruments Review and Reflections About its Assessment in the Elderly with Cognitive Impairment and Dementia. *Psychiatric Quarterly* 2021 Mar; 93(1): 35-53.
75. Grisso T, Appelbaum PS, Hill-Fotouhi C. The MacCAT-T: A clinical tool to assess patients' capacities to make treatment decisions. *Psychiatric Services* 1997; 48(11): 1415–9.
76. Dubois B, von Arnim CAF, Burnie N, Bozeat S, Cummings J. Biomarkers in Alzheimer's disease: role in early and differential diagnosis and recognition of atypical variants. *Alzheimer's Research and Therapy* BioMed Central Ltd 2023 Oct 13; 15(1): 175.
77. Gogishvili D, Vromen EM, Koppes-den Hertog S, Lemstra AW, Pijnenburg YAL, Visser PJ, et al. Discovery of novel CSF biomarkers to predict progression in dementia using machine learning. *Sci Rep*. 2023 Dec; 13(1).
78. Oldan JD, Jewells VL, Pieper B, Wong TZ. Complete evaluation of dementia: PET and MRI correlation and diagnosis for the neuroradiologist. *Am J Neuroradiol*. 2021; 998–1007.
79. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet* [Internet] 2020; 6736(20). http://www.ncbi.nlm.nih.gov/pubmed/32738937
80. Nowrangi MA, Rao V, Lyketsos CG. Epidemiology, Assessment, and Treatment of Dementia. *Psychiatric Clinics of North America.* 2011; 34(2): 275–94.
81. Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. *The Lancet* 2017; 390(10113): 2673–734.
82. Livingston G, Huntley J, Liu KY, Costafreda SG, Selbæk G, Alladi S, et al. Dementia prevention, intervention, and care:

2024 report of the Lancet standing Commission. *Lancet* [Internet]. 2024 Jul. https://linkinghub.elsevier.com/retrieve/pii/S0140673624012960

83. Leroi I, Himmelsbach I, Wolski L, Littlejohn J, Jury F, Parker A, et al. Assessing and managing concurrent hearing, vision and cognitive impairments in older people: An international perspective from healthcare professionals. *Age Ageing* 2019 Jul 1; 48(4): 580–7.
84. Feldman HH, Woodward M. The staging and assessment of moderate to severe Alzheimer disease. *Neurology* 2005; 65(6 Suppl 3).
85. Delineau, V. M. E. B., Ferreira, A. R., Passos, L., & Fernandes, L. The Impact of Behavioral and Psychological Symptoms of Dementia on Individual's Autonomy: a Scoping Review. *Archives of Clinical Neuropsychology* 2024, acae097. https://doi.org/10.1093/arclin/acae097
86. North Bristol NHS. Advance care planning [Internet]. https://www.nbt.nhs.uk/our-services/a-z-services/palliative-end-life-care/advance-care-planning
87. Thomas K, Russell S. Advance Care Planning in the United Kingdom – A snapshot from the four UK nations. Z Evid Fortbild Qual Gesundhwes. 2023 Aug 1; 180: 150–62.
88. Meeussen K, Van Den Block L, Echteld M, Bossuyt N, Bilsen J, Van Casteren V, et al. Advance care planning in Belgium and the Netherlands: A nationwide retrospective study via sentinel networks of general practitioners. *J Pain Symptom Manage.* 2011; 565–77.
89. Porcar Rodado E, Peral Sanchez D, Gisbert Grifo M. Advance Directives. Comparison of current legislation within the European Union. *Revista Espanola de Medicina Legal* 2021 Apr 1; 47(2): 66–73.
90. Lopez RP, Rose KM, Kenney L, Sanborn V, Davis JD. Managing Shame: A Grounded Theory of How Stigma Manifests in Families Living with Dementia. *J Am Psychiatr Nurses Assoc*. 2020 Mar 1; 26(2): 181–8.
91. Gonçalves-Pereira M, Marques MJ, Alves RF, Verdelho A, Balsinha C, Alves L, et al. Needs for Care, Service Use and Quality of Life in Dementia: 12-Month Follow-Up of the Actifcare Study in Portugal. Acta Med Port. 2024 May 1;37(5).
92. Balsinha C, Iliffe S, Dias S, Freitas A, Grave J, Gonçalves-Pereira M. What is the present role for general practitioners in dementia care? Experiences of general practitioners, patients and family carers in Portugal. *Dementi*a 2021 Aug; (20)6: 1988-2006.
93. Schmachtenberg T, Monsees J, Thyrian JR. Structures for the care of people with dementia: a European comparison. *BMC Health Serv Res*. 2022 Dec 1; 22(1).

Received: August 9, 2024
Accepted: October 4, 2024