

Article

Artificial intelligence at the service of health: ethical and legal challenges in managing data from Alzheimer's patients

Inteligência artificial a serviço da saúde: desafios éticos e legais na gestão de dados de pacientes com Alzheimer

Inteligencia artificial al servicio de la salud: desafíos éticos y legales en la gestión de datos de pacientes con Alzheimer

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Abstract

Objective: to understand how artificial intelligence can help in the early diagnosis and monitoring of Alzheimer's disease, considering the ethical challenges related to data privacy in the health area.

Methodology: integrative literature review. A structured search was carried out in the electronic data sources PubMed, LILACS, The Lancet, MDPI and SciELO and original or non-original scientific articles were selected, without language restriction and with a five-year time limitation. **Results:** it was observed that the interface between artificial intelligence and health emerges as a promising field, especially for the management of complex diseases such as Alzheimer's. Artificial intelligence offers the possibility of more accurate diagnoses, personalized treatments and a better quality of life for patients. However, the potential of artificial intelligence is accompanied by complex ethical and legal dilemmas, especially regarding the collection, storage, privacy, informed consent, algorithmic

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discrimination, liability and use of health data. **Conclusion:** the implementation of artificial intelligence systems in healthcare requires a balance between the benefits of potential early diagnosis and the need for greater protection of patient privacy. An additional challenge to be considered is the need for impartiality and transparency in the algorithms used. There is a need to propose guidelines for the development of artificial intelligence systems that are safe, fair and transparent, that respect patients' rights and promote equity in access to healthcare.

Keywords: Artificial Intelligence; Alzheimer's; Ethics; Right to health; Algorithms.

Resumo

Objetivo: compreender como a inteligência artificial pode auxiliar no diagnóstico precoce e acompanhamento da Doença de Alzheimer, considerando os desafios éticos relacionados à privacidade dos dados na área da saúde. **Metodologia:** revisão integrativa da literatura. Realizou-se uma busca estruturada nas fontes de dados eletrônicos PubMed, LILACS, The Lancet, MDPI e SciELO e foram selecionados artigos científicos originais ou não, sem restrição de idioma e com limitação temporal quinquenal. **Resultados:** observou-se que a interface entre a inteligência artificial e a saúde emerge como um campo promissor, especialmente para o manejo de doenças complexas, como o Alzheimer. A inteligência artificial oferece a possibilidade de diagnósticos mais precisos, tratamentos personalizados e uma melhor qualidade de vida para os pacientes. Contudo, o potencial da I inteligência artificial é acompanhado por dilemas éticos e legais complexos, especialmente no que se refere à coleta, armazenamento, privacidade, consentimento informado, discriminação algorítmica, responsabilidade e uso de dados de saúde. **Conclusão:** a implementação de sistemas de inteligência artificial na saúde requer um equilíbrio entre os benefícios de um potencial diagnóstico precoce e a necessidade de maior proteção a privacidade dos pacientes. Desafio adicional a ser considerado é a necessidade de imparcialidade e a transparência dos algoritmos utilizados. Há necessidade da proposição de diretrizes para o desenvolvimento de sistemas de inteligência artificial que sejam seguros, justos e transparentes, que respeitem os direitos dos pacientes e promovam a equidade no acesso aos cuidados de saúde.

Palavras-chave: Inteligência Artificial; Alzheimer; Ética; Direito à saúde; Algoritmos.

Resumen

Objetivo: comprender cómo la inteligencia artificial puede ayudar en el diagnóstico precoz y el seguimiento de la enfermedad de Alzheimer, teniendo en cuenta los desafíos éticos relacionados con la privacidad de los datos en el área de la salud. **Metodología:** revisión bibliográfica integradora. Se realizó una búsqueda estructurada en las fuentes electrónicas de datos PubMed, LILACS, The Lancet, MDPI y SciELO y se seleccionaron artículos científicos originales o no originales, sin restricción de idioma y con limitación temporal de cinco años. **Resultados:** se observó que la interfaz entre inteligencia artificial y salud emerge como un campo prometedor, especialmente para el manejo de enfermedades complejas como el Alzheimer. La inteligencia artificial ofrece la posibilidad de diagnósticos más precisos, tratamientos personalizados y una mejor calidad de vida para los pacientes. Sin embargo, el potencial de la inteligencia artificial va acompañado de complejos dilemas éticos y jurídicos, especialmente en lo que respecta a la recopilación, el almacenamiento, la privacidad, el consentimiento informado, la discriminación algorítmica, la responsabilidad y el uso de los datos sanitarios. **Conclusiones:** la implementación de sistemas de inteligencia artificial en la asistencia sanitaria requiere un equilibrio entre los beneficios de un potencial diagnóstico precoz y la necesidad de una mayor protección de la privacidad del paciente. Otro reto a tener en cuenta es la necesidad de imparcialidad y transparencia en los algoritmos utilizados. Es necesario proponer directrices para el desarrollo de sistemas de inteligencia artificial que sean seguros, justos y transparentes, que respeten los derechos de los pacientes y promuevan la equidad en el acceso a la asistencia sanitaria.

Palabras clave: Inteligencia artificial; Alzheimer; Ética; Derecho a la salud; Algoritmos.

Introduction

Alzheimer's disease (AD) is a degenerative condition characterized by the gradual loss of cognitive functions such as memory and reasoning. It affects millions of people globally and is one of the most prevalent neurodegenerative diseases with a direct cognitive impact^(1,2).

In the context of neurodegenerative diseases such as AD, the application of artificial intelligence (AI) has shown promise, especially due to its ability to process large volumes of clinical, laboratory and magnetic data, enabling early identification of cognitive alterations, continuous monitoring of clinical progress and personalization of therapeutic approaches⁽³⁾.

The Encyclopedia of Conscientiology explains AI as a subfield of computer science dedicated to researching and proposing computational devices capable of simulating certain aspects of the human intellect, such as the capacity for reasoning, perception, decision-making and problem-solving⁽⁴⁾.

However, in view of the significant advances made by AI in health diagnostics, caution must be exercised regarding its free use. To this end, there must be studies that make it possible to understand the appropriate use of this technology, allowing it to be used safely to avoid using the available data inappropriately⁽⁵⁾.

The incorporation of AI into healthcare systems raises a number of ethical and legal implications, particularly in relation to the management of sensitive personal data. Among the main challenges are the protection of privacy, the valid obtaining of informed consent, equity of access and the mitigation of algorithmic biases that can compromise distributive justice in health care⁽⁶⁾.

Researchers have therefore concluded that early detection of brain changes associated with Alzheimer's is the key to more effective clinical interventions and the prevention of disease progression and morbidity⁽⁷⁾.

Bioethics, defined as the systematic study of human conduct in the field of health, analyzes the challenges and ethical implications that arise from the diagnosis and treatment of diseases such as Alzheimer's. The complexity of this condition, especially its current prognosis, raises significant ethical conflicts related to patient care, autonomy and the dignity of life. The use of AI, for example in early detection or to support treatment, also generates new ethical dilemmas that need to be analyzed in the light of moral principles and values⁽⁸⁾.

The intersection between AI and health is emerging as a promising tool, especially in the management of complex diseases such as Alzheimer's. AI offers the possibility of more accurate diagnoses, personalized treatments and a better quality of life for patients⁽⁹⁾.

Given this scenario, this study aims to analyze how artificial intelligence can help in the early diagnosis and monitoring of Alzheimer's disease, in light of the main ethical and legal challenges involved in the management of health data. The aim is to contribute to the interdisciplinary debate on the need for normative guidelines that guarantee the ethical, safe and transparent use of these technologies, with a view to protecting fundamental rights and promoting equity in access to health care.

Methodology

This is an integrative review of the literature on the use of AI and the ethical and legal challenges in managing Alzheimer's patient data. The research was carried out using six stages: 1) formulation of the guiding question; 2) definition of the search descriptors; 3) definition of the inclusion and exclusion

criteria; 4) literature search; 5) critical analysis of the selected studies; 6) presentation and discussion of the results obtained⁽¹⁰⁾.

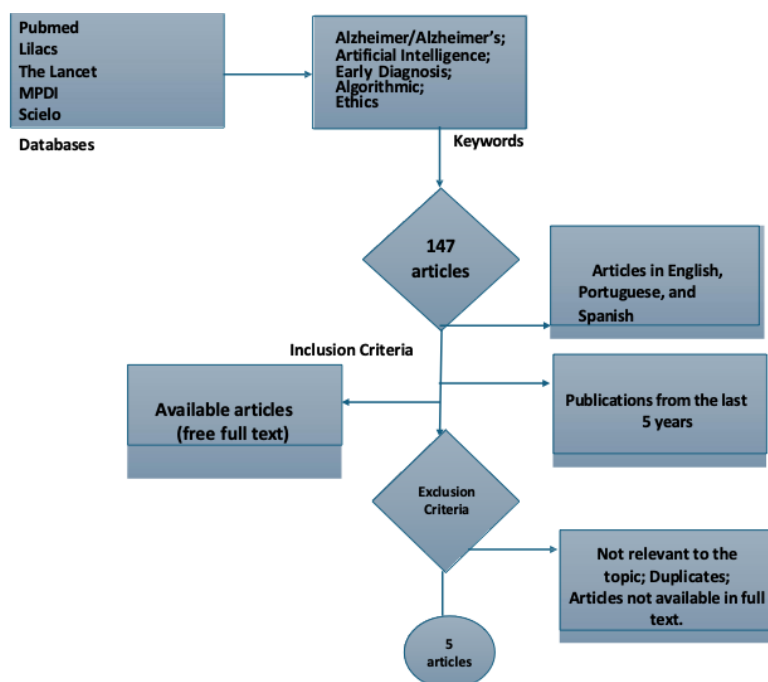
The review was conducted based on the question: How can artificial intelligence (AI) contribute to the early diagnosis and monitoring of Alzheimer's disease, considering the ethical challenges related to data privacy in the health area?

Original or unpublished scientific articles were selected, without language restriction and with a five-year time limit, from the electronic data sources PubMed, LILACS, The Lancet, MPDI and Scielo. The descriptors were selected from the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH): Alzheimer's/Alzheimer's; Artificial Intelligence/Artificial Intelligence; Early Diagnosis/Early Diagnosis; Algorithm/Algorithmic; Ethics/Ethics; which were combined using the Boolean operator "AND".

The time limitation of five years sought to include more up-to-date and recent studies, given the dynamism of the subject. The inclusion criteria adopted were all scientific articles published in full and open access, in Portuguese, English and Spanish, which directly answered the study's guiding question.

Initially, 147 articles were identified in the databases (Figure 1), of which 112 were excluded after reading the titles and abstracts because they did not directly align with the scope of the study. Exclusions included articles focused on other dementias(24), applications of AI in areas of health other than neurology(16), technical discussions of AI without clinical application in Alzheimer's disease(7), generic ethical debates without delving into disease-specific data privacy(21), duplicate articles(19), articles with restricted access(13) and those whose content was considered superficial(12). Of the remaining 35 articles, 30 were discarded after full reading because they did not provide a complete or in-depth answer to the guiding question, or because they presented data that was irrelevant to the study. Five articles were selected for their relevance and depth of approach to the subject.

Figure 1. Flowchart of the search for articles in databases



Source: Prepared by the authors

Results and Discussion

Although the government has acted correctly in regulating AI, establishing rules and guidelines for its use, it is essential to ensure that these guidelines are effectively followed. Protecting patient confidentiality and autonomy is a priority, requiring strict safeguards so that their vulnerability is not exploited⁽¹¹⁾.

The articles selected in this integrative review show that, although AI represents a promising tool for tackling complex diseases such as Alzheimer's, its use still faces significant structural and regulatory challenges.

AI has shown promising results in the management of AD, with the potential to transform diagnosis, treatment and prognosis, standing out by improving the detection of AD biomarkers using advanced neuroimaging techniques. In addition, the technology, using machine learning models, is capable of identifying early signs of cognitive decline, and its algorithms help to detect genetic and proteomic biomarkers, allowing for more agile interventions⁽⁹⁾.

Table 1 shows the studies analyzed, taking into account the title, year of publication, authors, objective, result and conclusion of the scientific article.

Table 1. Articles selected for the review

Title Year	Year	Author	Objective	Results	Conclusion
Bioethical challenges of using artificial intelligence in hospitals ⁽¹¹⁾	2022	Nunes, HC; Guimarães, RMC; Dadalto, L.	To propose a reflection and encourage debate on the possible bioethical challenges of using AI in hospital healthcare.	The state has been exercising its duty by regulating the use, establishing principles and imposing limits on AI, but it is necessary to guarantee the patient that the rules will be complied with, protecting their privacy and consent, given their vulnerability.	Social control of new technologies and their limits must be established in order to preserve and promote the dignity of the human person, as well as effectively regulating such innovations, so that technology is at the service of humanity, not the other way around.
The Road to Personalized Medicine in Alzheimer's Disease: The Use of Artificial Intelligence ⁽¹²⁾ .	2022	Spínola, AS; Baldeiras, I; Arras, JP; Santana, I.	Overview of the main characteristics, current applicability and future prospects for the implementation	The various AI algorithm models require further testing and validation in real conditions (the clinical context), and time is needed to see how well	Improved techniques are needed to help recognize the strengths of the technology area, motivating the creation of projects for

			of AI in the area of health , especially in dementia and Alzheimer's disease research.	they work. Effective treatment of Alzheimer's disease remains a challenge, and multidisciplinary collaboration and multicenter studies are crucial to advance research.	preventive therapies and the involvement of multidisciplinary teams. These techniques represent a tool that would only enrich basic sciences and clinical practice by working together to achieve a mutual goal: improving health care in dementia.
Artificial intelligence for older people receiving long-term care: a systematic review of acceptability and effectiveness studies Loveys ⁽¹³⁾ Artificial intelligence for older people receiving long-term care: a systematic review of acceptability and effectiveness studies)	2022	Loveys, K; Prina, M; Axford, C; Domènec, OR; Weng, W; Broadbent, E; <i>et al.</i>	To identify which AI-enhanced interventions have been tested in long-term care services, which have been shown to be effective and which have been shown to be acceptable.	The results showed varying acceptability of these technologies and inconclusive evidence about their effectiveness. Social robots have shown some potential to improve social participation and mood, but the diversity of studies and their methodological limitations (such as small sample sizes and risks of bias) have made definitive conclusions difficult. Although AI has the potential to improve CLD, more research is needed to validate its effectiveness and ensure its ethical and appropriate use.	The diversity of studies on AI in long-term care (LTC) makes it difficult to draw conclusions about its benefits. Despite promising results, more standardized research is needed, following guidelines such as CONSORT-AI. It is crucial that AI solutions meet the needs of the elderly, recognizing that not everyone will benefit. Until then, these interventions should be seen as technological developments, not proven solutions for CLD.

AI-driven innovations in Alzheimer's disease: Integrating early diagnosis, personalized treatment, and prognostic modelling, Ageing Research Reviews ⁽⁹⁾	2024	Mayur, K; Nitu, W; Pawar, R; Ballal, S; Kumawat, R; Goswami, M; Khalid, M; Brijesh, T; Upaganlawar, A; Umekar, M; Kopalli, SR; Koppula, S.	To demonstrate the transformative potential of AI in the management of Alzheimer's disease and to explore advances in AI, with a focus on early diagnosis, personalized treatment and prognostic modeling.	The article presents promising results of AI in the management of Alzheimer's disease (AD), demonstrating its potential to revolutionize the diagnosis, treatment and prognosis of the disease. In early diagnosis, AI stands out by improving the detection of AD biomarkers through advanced neuroimaging techniques. In addition, machine learning models are able to identify patterns of early cognitive decline, while AI algorithms help detect genetic and proteomic biomarkers, enabling earlier interventions.	Artificial Intelligence represents a revolutionary power in Alzheimer's research and clinical practice. By boosting the development of predictive models, improving diagnostic accuracy and creating individualized treatment methods, AI offers unprecedented opportunities to improve early identification, tailor therapies and monitor the evolution of the disease. The combination of advanced neuroimaging analyses, personalized medicine, digital biological indicators and interpretable AI is paving the way for more effective interventions and better patient outcomes.
Algorithmic identification of persons with dementia for research recruitment: ethical considerations ⁽⁶⁾	2024	London, AJ; Karlawish, J; Largent, EA; Hey, SP; MacCarthy, EP.	The article explores the ethical challenges of using algorithms to identify patients with dementia in Alzheimer's	Six main ethical concerns were identified in the use of algorithms to identify people with dementia: controversy over waiver of consent, risks to privacy,	The use of algorithms to identify people living with dementia and improve recruitment to clinical trials raises a number

			<p>research, highlighting how underdiagnosis, social inequalities and limited access to healthcare hinder the inclusion of diverse populations. It wants to promote a discussion on how to address these issues in order to conduct more responsible and inclusive research.</p>	<p>potential to exacerbate inequalities in access to healthcare, possibility of harms such as anxiety and stigma, need for validity and reliability of algorithms, and importance of transparency and accountability of developers. In addition, the article emphasized the need to align algorithmic identification with effective clinical care, prioritize clinical evaluations over direct recruitment to studies, and conduct prospective studies to evaluate the performance of algorithms in real-world conditions.</p>	<p>of complex ethical concerns. While this approach may offer potential benefits, such as early identification of at-risk individuals and improved trial efficiency, it is crucial to address issues related to informed consent, privacy, fairness and the potential for harm to participants. The responsible implementation of these algorithms requires a careful assessment of the risks and benefits, as well as the adoption of measures to protect the rights and well-being of the individuals involved. It is essential that researchers, ethics committees and policymakers work together to develop clear and rigorous guidelines that ensure the ethical and equitable use of algorithmic identification in dementia research.</p>
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Source: authors

From a clinical point of view, the studies highlight that AI has the potential to significantly improve the accuracy of early diagnosis of AD. Automated analysis of imaging scans using machine learning algorithms, for example, enables the identification of subtle neurodegenerative patterns that often escape conventional clinical perception. This data processing capacity also extends to the analysis of genetic biomarkers and protein production, making it possible to intervene at earlier stages of the disease, with the prospect of improving patients' prognosis and quality of life⁽⁹⁾.

However, the effectiveness of these applications depends on the quality and representativeness of the data used in algorithmic training. As pointed out by London *et al.*⁽⁶⁾ the under-representation of certain populations in databases can generate biases that compromise the fairness of diagnoses, increasing existing inequalities in access to healthcare. This finding reinforces the need for continuous validation of algorithms in different clinical contexts and ethical governance of the data used in the development of these tools.

AI represents a revolutionary force in Alzheimer's research and clinical practice. By driving the development of predictive models, it improves diagnostic accuracy and makes it possible to create individualized treatments. The technology offers unprecedented opportunities to improve early detection, personalize therapies and monitor the progression of the disease. The combination of advanced neuroimaging analyses, personalized medicine and digital biomarkers is paving the way for more effective interventions with better outcomes for patients.⁽⁹⁾

In addition to the technical issues, there are also legal aspects, individual challenges such as guaranteeing patients' autonomy, informed consent and privacy, as well as collective challenges involving how society should deal with new technologies. As discussed by Nunes, Guimarães and Dadalto⁽¹¹⁾ the ethical use of AI in healthcare presupposes not only compliance with current legislation, such as the General Personal Data Protection Act⁽¹⁴⁾ in the Brazilian context, but also the implementation of institutional practices aimed at transparency, auditing and information security. Data protection takes on an even more critical role in the case of Alzheimer's patients, whose progressive loss of cognitive autonomy makes it difficult to understand and validate informed consent.

For Loveys *et al.*⁽¹³⁾ clear communication about data protection and privacy processes for patients should be a concern for future work, given the acceptability and absorption of new technologies that emerge for patients requiring long-term care.

Several benefits can be achieved by AI in diagnostic imaging, given its great capacity for image processing and pattern recognition, especially in a degenerative disease that is still incurable, such as Alzheimer's⁽⁹⁾.

The use of algorithms to identify people with dementia and optimize recruitment for clinical trials brings with it a series of complex ethical dilemmas. Although this strategy can offer advantages, such as early detection of individuals at risk and greater efficiency in research, it is essential to consider issues of informed consent, privacy, fairness and the risk of causing harm to participants. The responsible implementation of these algorithms requires a careful analysis of the risks and benefits, as well as the adoption of measures that protect the rights and well-being of those involved. It is crucial that researchers, ethics committees and legislators work together to create clear and strict guidelines, ensuring the ethical and fair use of algorithmic identification in dementia research⁽⁶⁾.

As highlighted by Mayur *et al.*⁽⁹⁾ AI demonstrates significant results in aiding drug discovery, virtual screening and drug reuse. It also allows therapeutic interventions to be adapted, predicting

possible individual responses to treatments and monitoring patient progress, making it possible to dynamically adjust care plans.

From a medical point of view, it is important to note that although there are clinical guidelines for diagnosing probable AD, there are still challenges in providing a definitive diagnosis, since this can only be acquired post-mortem. For this reason, patients with AD should be assessed at baseline with Magnetic Resonance Imaging and Positron Emission Tomography and continue these procedures alongside clinical follow-up.⁽¹²⁾

Silva-Spínola et.al.⁽¹²⁾ describes imaging tests as a crucial tool in the characterization of Alzheimer's disease, as they allow the structural state of the brain to be assessed and are generally used to establish existing neurological damage or atrophy. However, the use of AI in processing large volumes of information can result in diagnostic discrepancies due to unavailability or inconsistency of data due to human error, which could offend people's right to a correct diagnosis and adequate treatment with comprehensive health care.

In the same vein, Mayur *et al.*⁽⁹⁾ and Loveys *et al.*⁽¹³⁾ argue that the results of AI-enhanced intervention research should be standardized, ideally with a prioritization exercise so that the evidence is more easily comparable.

Although AI has the potential to improve long-term care, more research is needed to validate its effectiveness and ensure its ethical and appropriate use⁽¹³⁾. Diagnostic standards can pose barriers to identifying patients living with dementia, especially AD, using information associated with this condition⁽⁶⁾. It is crucial to ensure that the algorithms used are fair, impartial and transparent, avoiding discrimination and algorithmic bias.

As noted in the studies, AI represents a major transformative force in AD research, advancing the improvement of diagnostic accuracy and the development of personalized treatment approaches and opening up avenues for more effective interventions with better outcomes for patients⁽⁶⁾.

Conclusion

The literature has shown that the use of AI in healthcare, especially in the context of AD, represents an opportunity to improve diagnosis and care. However, as evidenced throughout this study and in light of the analysis of the selected articles, this innovation also raises important ethical and legal challenges that cannot be ignored.

There is a need to improve the relationship between health professionals and machines, and for more research to validate the effectiveness of the technologies and guarantee their ethical and appropriate use, always bearing in mind that the diagnosis should not be made by AI, but only with its help.

Although AI has the potential to transform care for Alzheimer's patients, it is essential to address issues related to data privacy, informed consent and algorithmic bias. The lack of specific guidelines and ambiguity over legal liability are obstacles that need to be overcome in order to guarantee the trust of patients, families and healthcare professionals in the use of these technologies.

Respect for ethical principles must always be prioritized, so that the main objective is the patient's interest and the humanization of care, rather than technological pioneering.

The review shows that the intersection between AI and health requires a joint commitment between technology developers, health professionals, legislators and society. Only in this way will it

be possible to fully exploit the benefits of the technology, while mitigating the ethical and legal risks, guaranteeing a safer and more humanized future for the care of Alzheimer's patients.

In short, given the challenges identified, it is recommended that future research invests in standardized, multicentre methodologies with greater population representation. In the ethical and legal field, it is necessary to develop specific regulations to ensure algorithmic transparency, protection of sensitive data and accountability in the event of failures.

The results reinforce the importance of an interdisciplinary approach that brings together technology, bioethics, law and medicine, promoting the responsible use of AI in health and ensuring that its advances do not occur to the detriment of patients' fundamental rights.

Conflict of interest

The authors declare that there is no conflict of interest.

Authors' contributions

Marques CP contributed to the conception/design of the article, data analysis and interpretation, writing of the article, critical revision of its content and approval of the final version. De Souza LVCC contributed to the conception/design of the article, data analysis and interpretation, writing of the article, critical revision of its content and approval of the final version. Coltri MV contributed to the design of the article, data analysis and interpretation, critical review of its content and approval of the final version. Franco A contributed to the design of the article, data analysis and interpretation, critical revision of its content and approval of the final version.

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