Revista Tecnologia e Sociedade
ISSN: 1984-3526

https://periodicos.utfpr.edu.br/rts

Formação de cuidadores de Alzheimer: o papel das tecnologias digitais

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RESUMO

Neste artigo procuramos compreender o contributo das tecnologias digitais para o exercício da profissão dos cuidadores formais de pacientes com Doença de Alzheimer. Para concretizar este estudo, foi formulado um conjunto de proposições de investigação: (i) Os cuidadores formais utilizam as tecnologias digitais no desempenho das suas competências profissionais; (ii) As tecnologias digitais são um instrumento importante para a estimulação cognitiva de doentes com DA; (iii) Os cuidadores formais necessitam de formação para a utilização das tecnologias digitais na sua atividade. Para verificar estas proposições, adotou-se uma metodologia de investigação baseada nos paradigmas quantitativo e qualitativo. No quantitativo, utilizou-se um inquérito por questionário. Esperamos que os resultados contribuam para a implementação de políticas mais eficazes no apoio aos cuidadores formais e no tratamento de pacientes com DA, promovendo uma melhor qualidade de vida para todos os envolvidos.

PALAVRAS-CHAVE: Cuidadores Formais, Doença de Alzheimer, Educação, Formação; Tecnologias Digitais.

INTRODUCTION

In contemporary times, it is recognized that digital technologies (DT) play a central role in the economic sectors of society, as they simplify the functioning and procedures of organizations, improve accessibility to information and bring individuals closer together.

According to Silva *et. al.* (2022), in the area of health, and particularly mental health, technologies are essential. They can help slow down the progression of certain mental illnesses, such as Alzheimer's disease (AD). In this sense, DTs and their use are crucial in the exercise of professional skills to promote cognitive stimulation in AD (Yamagata *et. al.,* 2013). In this line of analysis, Koumakis *et. al.* (2019) state that training on the use of DM in the work of formal caregivers is becoming increasingly essential.

Currently, DT is becoming essential in transforming the education and training of formal AD caregivers. According to Siemens (2005) and Anderson (2008), the transition from a traditional educational model to digital environments is taking place. This change is fundamental when discussing the training of formal Alzheimer's caregivers, as it allows the necessary flexibility to adapt educational methods to the difficulties of the dynamics of this field. Thus, on the one hand, Hattie (2012), refers to the importance of learning, in the training of AD caregivers, the ability to adapt educational content to the specific needs of professionals stands out as a promising avenue, promoting more effective and relevant learning. On the other hand, Garcia-Betances *et. al.* (2015) explored the application of virtual reality and advanced simulations in the training of health professionals. These DMs offer immersive environments that allow formal caregivers to acquire specific skills related to AD, providing indispensable experiences for their practice.

The aim of this research was to make formal caregivers and other professionals working in the field aware of the urgent need for training in DT. This research is important because the use of digital technologies can offer innovative and effective tools for the cognitive stimulation of users, improving their quality of life and slowing down the progression of AD. In addition, understanding the role of DTs in the work of formal caregivers can lead to more efficient and user-centered practices, helping to reduce the stress and exhaustion of formal caregivers. In short, this could result in more effective and compassionate care, benefiting both users and the formal caregivers themselves.

METHODOLOGY

The research was carried out with the aim of evaluating the preparation of formal caregivers and the use of digital technologies in the prevention and intervention of AD in an institutional context.

RESEARCH QUESTION, PROPOSITIONS AND OBJECTIVES

We therefore formulated the following research question: **What is the contribution of DM to the profession of formal caregivers of patients with AD?**

In order to obtain answers to this research question, we defined a set of research propositions, which are presented below. It should be noted that in order to verify these propositions, based on the knowledge gained from the literature review, specific objectives were also defined for each of them:

Proposition 1: Formal caregivers use digital technologies to exercise their professional skills.

- Understand whether formal caregivers use DM in their work practice;
- Identify and characterize the DM oriented towards the professional practice of formal caregivers of patients with AD.

Proposition 2: DT is an important tool for the cognitive stimulation of AD patients.

- Identify the current policies on cognitive stimulation for AD patients;
- Identify studies that show the importance of DM for cognitive stimulation.

Proposition 3: Formal caregivers need training in the use of DM in their work.

- Understand the importance of training in DM for formal caregivers in order to promote a culture of constant updating and improvement in the quality of care provided;
- Identify the levels of training in the use of DM that formal caregivers have for the exercise of their activity.

METHODOLOGICAL OPTIONS AND DATA COLLECTION INSTRUMENTS

In order to verify these propositions, a descriptive quantitative research methodology was adopted, applying a questionnaire survey, made available online, to all formal caregivers of patients with AD in Portugal. The questionnaire made it possible to identify patterns and trends in the current use of digital technologies by formal caregivers, as well as to assess their perception of the importance of these tools for the cognitive stimulation of patients.

Ethical and deontological principles of confidentiality were followed in its application. Through the information provided at the beginning of each questionnaire, all participants were made aware of the purpose of the research, the anonymous nature of the answers, the importance of collaboration and the need for sincerity and confidentiality and were also made aware that the data collected would only be used for the purposes for which it was intended.

In order to administer the questionnaires, it was necessary to use the convenience procedure, spreading the word on social networks and sending letters to Residential Structures for the Elderly (ERPI), Continuing Care Units, Hospitals, Specialized Clinics and Day Care Centers. This method has the advantage of being quick, cheap and easy (Hill & Hill, 2009).

The questionnaire was administered in two phases. In January 2021, the pre-test questionnaires were administered to nine participants, in order to detect any possible errors or difficulties, and some adjustments were made. Subsequently, between March 2021 and April 2024, all the questionnaires intended for the

research were applied and the data obtained was analyzed using the Microsoft Excel program. The quantitative data was also supplemented with a literature review on the issues surrounding the respective study, which provided an in-depth understanding of the theoretical context and existing practices related to the topic.

DATA ANALYSIS

To analyze the data collected, a quantitative approach was used, which made it possible to transform the answers to the questionnaire into numerical values. The Google Forms tool was essential in this process, making it easier to organize and export the data for statistical analysis. Subsequently, the data was analyzed with the help of Microsoft Excel, thus enabling the application of various analytical techniques, such as descriptive analyses and their correlations. These analyses provided a detailed and well-founded understanding of the trends and relationships present in the data surveyed, thus making it possible to draw valuable conclusions for the study.

SOCIODEMOGRAPHIC DATA

A total of 75 formal caregivers took part in this research, of which 65,30% were female, 28,00% male and 6,70% preferred not to disclose.

With regard to:

- Age: 16.00% belong to the 18-24 age group; 36,00% belong to the 25-34 age group; 21,30% belong to the 35-44 age group; 20,00% belong to the 45-59 age group and, finally, 6,70% are over 60 years old;
- Professional activity: 21,30% are social educators; 32,00% are direct action assistants; 16,00% are gerontologists; and the rest are in other professions (psychologist, sociologist, socio-cultural animator, social worker, professional firefighter, administrative, general services, students, teachers and technical directors);
- Place of work: 22,70% work in day care centers; 22,70% in home support services; 18M70% in residential facilities; and the rest work in other places (hospital, specialized clinic, long-term care units, firefighters, administration, universities and polytechnics, special education center, Santa Casa da Misericórdia, among others);
- Region where they work: 78,70% are from the north; 6,70% live on the islands; 5,30% in the south and 9,30% in the center of the country.

GENERAL DATA

With regard to the second section of the questionnaire, 78,40% of respondents said they had already had the opportunity to work with patients with AD, and only 5,30% said they had only worked with them a few times. The remainder (16,30%) said they had never worked with patients with this condition. Most of the respondents (87,00%) said that they were able to identify signs of AD in their patients and gave some examples, namely: disorientation, memory loss, wandering, difficulty performing usual tasks, progressive loss of abilities, forgetfulness, spatial-temporal confusion, language problems, short-term memory loss, repetition, incoherent speech, disruptive or inappropriate behavior, difficulty understanding the function of objects, difficulty meeting people, distrust, past

memories to the detriment of the present, greater physical strength, loss of autonomy and difficulty holding a conversation with other people. The rest (10,00%) consider that they only sometimes notice these signs. Only 3,00% said that they were unable to perceive the signs.

Following on from this, 88,50% of respondents said that they had never had specific training in the field of AD. Although the reasons were not identified, the remaining respondents (11,50%) said they had never had any training in this area. Still on the subject of training, 64,50% of respondents said they had never had specific training in cognitive stimulation, while only 39,50% said they had had this opportunity. It should also be noted that 52,00% of those surveyed said that the institutions where they work do not promote workshops related to AD and cognitive stimulation and 35,50% are not aware of this type of training offer. Only 14,50% said they had training opportunities in these areas. However, 98,60% of respondents believe that it would be advantageous to invest more in education and training on AD and cognitive stimulation.

With regard to working with users with AD, the respondents identified a range of resources to promote cognitive stimulation, focusing in particular on the following: paper, computer, tablet, cell phone, radio and play objects. In addition to these resources, respondents considered it beneficial to use the following tools: digital games, paper games, audiovisuals, music, drawings, words, stories and images.

The respondents admit to having some difficulties when working with AD patients, which are listed below: behavioral changes in the users, little investment by staff in the area, lack of training, poor cooperation and motivation on the part of the user, difficulty in capturing the users' attention for cognitive stimulation activities, difficulty in dealing with the frustration they often feel, feelings of denial on the part of the users, difficult communication, difficult relationships with the user's family, managing emotions, users' difficulties concentrating, creating routines and managing activities, there being no suitable digital programs for these users, little training on the disease, bipolar disorder, lack of perception of what they really feel, dealing with aggression, lack of material and equipment and establishing dialogue.

Finally, it's important to note that most of the respondents (54,50%) claim to make records during the cognitive stimulation sessions (visual, written and photographic records), with 10,20% claiming to do so only sometimes and the rest (35,30%) acknowledging that they have never had the opportunity to make the respective records.

With regard to the use of technology, 77,30% of respondents considered that the use of digital technologies could contribute to the prevention of AD. However, 22,70% were not sure about this, and the rest preferred not to answer or considered that technologies were not important for preventing AD.

Regarding the type of contribution that technologies can make to the prevention of AD, the respondents consider that there are several, namely: cognitive stimulation (proverbs, songs, photos/images...) interactivity, relaxation, greater openness on the part of users (because it is something different from usual and something new that they like to explore), greater attention, ease of use, new learning, delaying the progression of the disease, improving the user's self-esteem,

fun, creating a diary (to help the patient remember moments), creating resources and memory games.

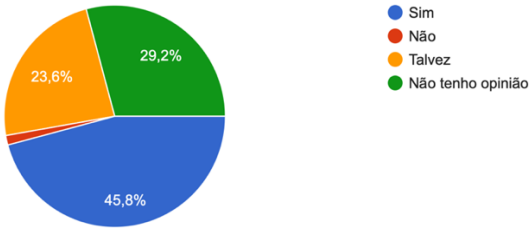
With regard to working with digital technologies with AD users, 73,60% of respondents said that they only sometimes use the respective technologies and the rest said that they had never done so.

With regard to training provided by employers in the use of digital technologies in the context of AD, 74,60% of respondents say they have never had training in this area and only 8,50% have had the opportunity. The rest were unaware of any such training. It's important to note that the majority of respondents (86,00%) who have never had training believe that it would be beneficial to invest more in education and training on digital technologies in AD.

TECHNOLOGIES FOR THE EXERCISE OF THEIR PROFESSIONAL SKILLS

Taking into account the work carried out by formal caregivers, which is probably associated with their academic training, knowledge of digital technologies and the structure of their work, we can see that, in terms of their opinion on the importance of using digital technologies with AD, 45,80% had a positive response, 1,40% had a negative response, 23,60% had an ambiguous response and 29,20% had no opinion (see Graph 1).

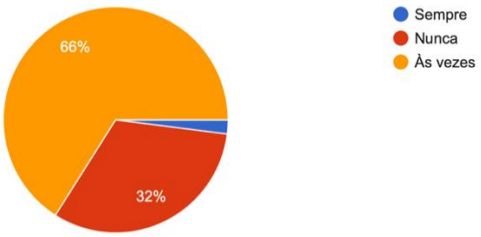
In your opinion, can the use of digital technologies contribute to the prevention of Alzheimer's Dementia?



Graph 1: Use of DT in AD

Graph 2 shows that only 2,00% of formal caregivers always use digital technologies, 32,00% never use them and 66,00% use them occasionally.

How often do you use digital technologies in your work with patients with Alzheimer's dementia?



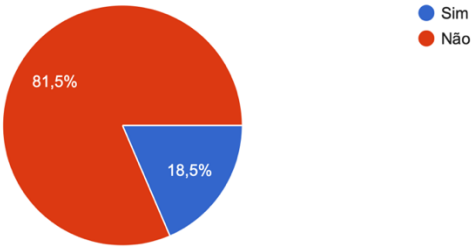
Graph 2: Use of DT

Given this data, we can see that there is a significant discrepancy between the assessment of the importance of using DM and the actual application of DM in the intervention with AD patients, which is detrimental to the application.

COGNITIVE STIMULATION OF PATIENTS WITH DA WITH DIGITAL TECHNOLOGIES

As for the use of digital technologies in the intervention of formal caregivers with AD, graph 3 shows that 81,50% of respondents do not use specific cognitive stimulation and the rest (18,50%) do not.

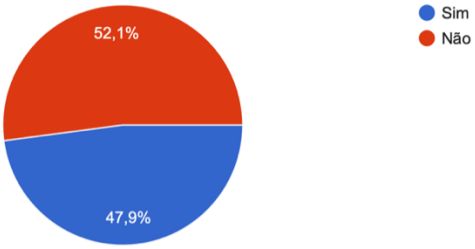
Did you have specific training in cognitive stimulation during your academic/professional training?



Graph 3: EE training

Graph 4 shows that 52,10% have training in the area of cognitive stimulation, but the rest (47,90%) have no training at all.

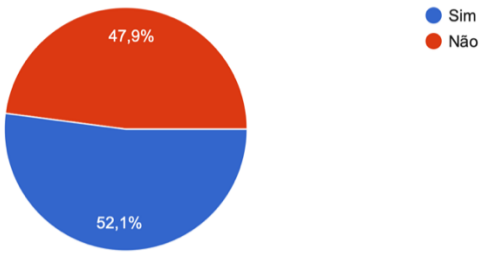
In your academic/professional training, did you have specific training in the area of Alzheimer's dementia?



Graph 4: Training in AD

Graph 5 tells us that 52,10% have no specific training in AD, and the rest (47,90%) have some specific training.

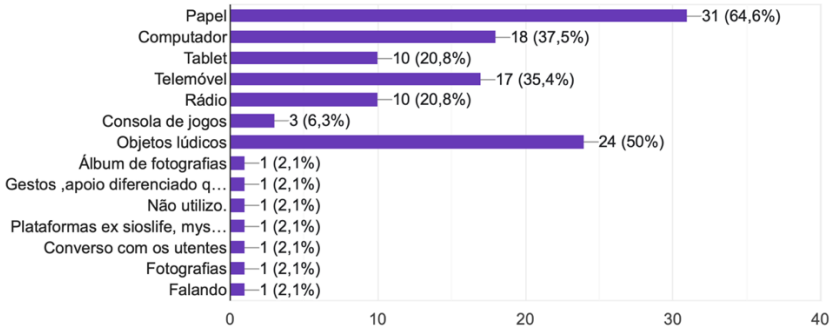
Did you have specific training in cognitive stimulation during your academic/professional training?



Graph 5: Training in EE

In the intervention, it was found that 37,50% of digital technologies are used by computers, 20,80% by tablets and 35,40% by cell phones. Nevertheless, 62,50% consider that the use of digital games is relevant for cognitive stimulation (according to Graph 6).

In your work with patients with Alzheimer's dementia, what resources do you use to promote cognitive stimulation?



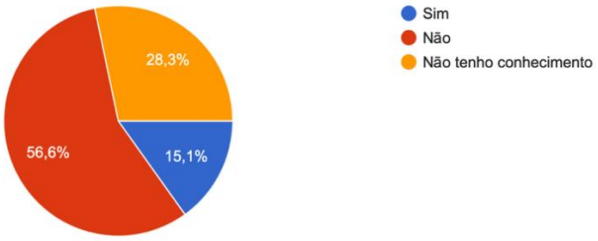
Graph 6: Resources in EE

In view of this data, we can see that formal caregivers are poorly prepared to use DM for intervention and cognitive stimulation in patients with AD. We found that the majority do not have specific training in AD or cognitive stimulation, and the DTs used are not for the purpose of cognitive stimulation. Even so, the computer, tablet and cell phone are the most commonly used DTs, without, however, being able to draw evidence of how they are used and for what purpose they are adopted (for example, potential specific software for cognitive stimulation).

DIGITAL TECHNOLOGY TRAINING FOR FORMAL CAREGIVERS

Graph 7 shows that 56,60% of institutions do not provide training in the use of digital technologies, 15,10% do and 28,30% are unaware of it.

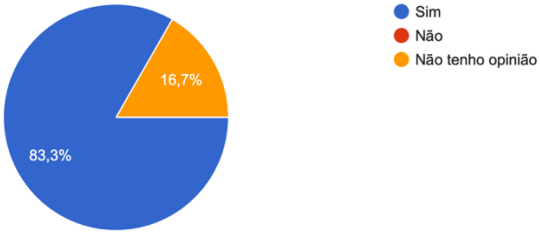
Does the institution where you work promote training actions aimed at the effective use of digital technologies in the prevention of Alzheimer's disease?



Graph 7: Use of DT in EE

Of the 56,6% who don't know, 83,3% consider it beneficial to promote specific workshops in the area of digital technologies (Graph 8) and the rest (16,70%) don't have an opinion.

If not, do you think it would be beneficial to invest more in education and training on digital technologies in Alzheimer's?



Graph 8: Advantages of DT in AD

In short, the results show that caregivers are poorly prepared for specific intervention in AD, particularly in cognitive stimulation and the use of digital technologies. The formal caregivers stress the importance of using these technologies, despite the fact that the institutions do not provide specific and specialized training and do not have the appropriate equipment for intervention with Alzheimer's patients using adapted digital technologies.

It can be seen that in the institutions surveyed, and this can be extrapolated to all those that provide healthcare, there is no promotion of adequate training for the use of DT. Nevertheless, the formal caregivers surveyed say that it is extremely important to promote and develop specific training, as well as the use of DM with AD patients.

DISCUSSION OF RESULTS

The data obtained in this research provides a detailed insight into the training and use of digital technologies (DT) in intervention with Alzheimer's patients (AD) by formal caregivers. The analysis revealed significant discrepancies between the perceived importance of DT and its practical implementation in daily care.

The results show that the majority of caregivers are direct action assistants and social educators, suggesting that training in digital technologies and cognitive stimulation should be adapted to the specific needs of these professionals.

The analysis indicates that a large majority of caregivers (88,50%) have never received specific training on AD, and 64,50% have had no training in cognitive

stimulation. The lack of specialized training is critical, as the literature highlights the importance of ongoing training to improve the effectiveness of interventions.

In addition, 98,60% of respondents believe that it would be beneficial to invest more in education and training on AD and cognitive stimulation. This is corroborated by Fitzgerald et al. (2021), who highlight the need for specialized training for professionals working with Alzheimer's patients in order to improve the quality of interventions and patient satisfaction.

USE OF DIGITAL TECHNOLOGIES

Although 77,30% of caregivers believe that digital technologies can contribute to the prevention of AD, the practical application of these technologies is limited. Only 2,00% use them constantly, while 66,00% use them only occasionally. Talbot & Briggs (2022) argue that integrating digital technologies into the care of Alzheimer's patients can improve quality of life and slow the progression of the disease, but lack of training and resistance to technological change can limit effective adoption.

The resources most frequently mentioned by caregivers include computers, tablets and cell phones. However, the use of these resources does not seem to be directed specifically at cognitive stimulation. Silva *et. al.* (2022) point out that the effective use of digital technologies must be guided by specific strategies adapted to the needs of patients, which implies the need for specialized training for formal caregivers.

Training offered by institutions in the use of digital technologies is limited. Only 15,10% of respondents report that their institutions promote training in this area, while 56,60% say that there is no promotion of such training. Anwar & Shamim (2011) show that a lack of institutional support and inadequate training are significant barriers to the effective implementation of digital technologies in healthcare.

The results show a discrepancy between the perceived importance of digital technologies and their practical application. Despite the general understanding of the value of digital technologies and the need for training in cognitive stimulation, the gaps in training and the lack of practical application are worrying. In this sense, it is crucial that care institutions step up the provision of specialized training and adapt their practices to incorporate digital technologies effectively.

FINAL CONSIDERATIONS

In this subsection we present the main conclusions for each of the research propositions initially formulated, in order to fully answer our research question.

TECHNOLOGIES FOR THE EXERCISE OF THEIR PROFESSIONAL SKILLS

For this proposition, we conclude that the work carried out by formal caregivers regarding the use of DM in the intervention of AD patients is mostly positive, despite the fact that, in professional practice, it translates into little use.

We observed that, although many caregivers recognize the potential benefits of DM for improving their professional skills and the quality of care offered to

patients with AD, there are significant barriers that prevent its widespread implementation. One of the main barriers identified is the lack of familiarity and practical knowledge of DM on the part of formal caregivers. Many healthcare professionals reported having received limited or no formal training on how to effectively use these tools in the context of caring for AD patients. In addition, concerns about the security and privacy of patient data were also cited as reasons for reluctance to adopt new DM. Another significant challenge is the lack of institutional support and adequate resources to facilitate the integration of DM into the work environment of formal caregivers. Many healthcare institutions lack clear policies and guidelines on the use of digital technologies in the care of patients with AD, which can create uncertainty and hesitation among professionals.

Given these challenges, it is essential that measures are taken to train formal caregivers and promote an organizational culture that values innovation and the use of DM to improve professional practice. This could include the development of programs on the use of DM, as well as the implementation of institutional policies that encourage and support the adoption of tools such as computers, cell phones and tablets.

COGNITIVE STIMULATION OF PATIENTS WITH DA WITH DIGITAL TECHNOLOGIES

The use of digital technologies by formal caregivers with AD does not occur in the majority of cases, and specific cognitive stimulation is either not developed due to lack of training or lack of equipment. Some DTs were found to be used without, however, being used for the specific purpose of cognitive stimulation. Instead, they are often used more generally, for entertainment or communication, without taking advantage of their full potential to promote patients' cognitive function. Nevertheless, the majority of respondents consider digital games to be relevant for cognitive stimulation. This suggests a recognition of the potential of DM in this context and highlights the importance of providing resources and adequate training to enable caregivers to use these tools more effectively. Given these challenges, it is essential that steps are taken to empower formal caregivers by providing them with the necessary training and resources to effectively integrate digital technologies into the practice of caring for patients with AD. It is therefore important to promote awareness of the benefits of cognitive stimulation and encourage a more systematic and evidence-based approach to the use of DT for this purpose.

DIGITAL TECHNOLOGY TRAINING FOR FORMAL CAREGIVERS

Based on the results obtained, we found that there are significant gaps in the preparation of formal caregivers for specific intervention in AD, especially with regard to cognitive stimulation and the use of DM.

Although formal caregivers recognize the importance of DM in improving the quality of care offered to patients with AD, many report not having received specific and specialized training in this regard. It is worrying to note that health institutions are not providing the necessary training to enable formal caregivers to use DM effectively in the care of patients with AD.

Lack of access to suitable equipment is also a problem, preventing caregivers from implementing adapted and personalized digital interventions to meet patients' specific needs. This gap in the training and preparation of formal

caregivers represents a significant challenge that needs to be addressed urgently. It is therefore essential that healthcare institutions recognize the importance of DT training for formal caregivers and implement specific and specialized training programs in this regard. In addition, it is necessary to ensure that caregivers have access to the appropriate equipment and resources to implement digital interventions in an effective and integrated way in the care of patients with AD.

When examining the results of this study and considering the answers provided by the respondents, it is clear that AD remains a significant concern, especially for those who are institutionalized and dependent on formal care. It is therefore essential that all those involved - formal caregivers, health institutions, policymakers and researchers - work together to implement comprehensive measures. This implies the creation, development and applicability of accessible, evidence-based training plans, the allocation of adequate funding for DT tools and equipment, the promotion and implementation of an organizational structure that prioritizes continuing education and innovation in the care of patients with AD.

Training Alzheimer's Caregivers: The Role of Digital Technologies

ABSTRACT

The abstract should state clearly and concisely: the problem, the overall objective, the methodological approach, methods, main findings and the contribution of the article to the field. In this article we seek to understand the contribution of digital technologies to the exercise of the profession of formal caregivers of patients with Alzheimer's disease. In order to carry out this study, a set of research propositions was formulated: (i) Formal caregivers use digital technologies in the performance of their professional skills; (ii) Digital technologies are an important tool for the cognitive stimulation of patients with AD; (iii) Formal caregivers need training in the use of digital technologies in their activity. To verify these propositions, a research methodology based on quantitative and qualitative paradigms was adopted. The quantitative approach used a questionnaire survey. It is hoped that the results will contribute to the implementation of more effective policies to support formal caregivers and the treatment of patients with AD, promoting a better quality of life for all those involved.

KEYWORDS: Formal Caregivers, Alzheimer's Disease, Education, Training; Digital Technologies.

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Recebido: **16/08/2024**
Aprovado: **27/06/2025**
DOI: 10.3895/rts.v21n64.18991

Como citar:

SILVA, Catarina; VAZ, Cátia; GONÇALVES, Bruno F. Formação de cuidadores de Alzheimer: o papel das tecnologias digitais.

Rev. Tecnol. Soc., Curitiba, v. 21, n. 64, p.204 a 218, abr./jun., 2025. Disponível em:

https://periodicos.utfpr.edu.br/rts/article/view/18991

Acesso em: XXX.

Correspondência: