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Global Impact of the COVID-19 Pandemic on Caregivers of Older Adults with Alzheimer's Disease: An Integrative Literature Review

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Abstract

Alzheimer's disease is a progressive neurodegenerative disease marked by deterioration of cognition and short-term memory, in addition to neuropsychiatric and behavioral changes, determining the need for caregivers. In view of this, the objective of this study was to globally analyze the impact of social isolation during the COVID-19 pandemic for caregivers of older adults with Alzheimer's disease through integrative literature review. Using the keywords “caregivers”, “Alzheimer's disease” and “COVID-19” and their combinations the search was performed in the Karger, PubMed and SciELO, BIREME, Dynamed, Scopus, Medline Complete and ACS Publication databases. Articles in Portuguese and English that addressed caregivers of older adults with Alzheimer's disease in the context of the COVID-19 pandemic were included, excluding those that did not include the three descriptors and that were not published between 2020 and 2023. From the 12 selected articles, caregivers' emotional disturbances and increased burden were identified during this pandemic period, determining a decline in the caregiver's mental health during the pandemic. Literature findings validate the relationship between the pandemic and the worsening quality of life of caregivers, who, due to physical and emotional overload, presented behavioral disorders such as increased stress, depression and anxiety.

Keywords: Alzheimer Disease; Caregivers; COVID-19

Introduction

The Alzheimer's disease (AD) is a progressive neurodegenerative disease that manifests itself with cognitive and short-term memory deterioration and a variety of neuropsychiatric symptoms and behavioral changes that worsen over time [1]. According to the World Health Organization [2,3] more than 55 million people (8.1% of women and 5.4% of men over 65) are living with dementia. It is estimated that this number will increase to 78 million in 2030 and 139 million in 2050.

As a consequence of the quantitative increase in this pathological pattern, it is understood that the number of formal and informal caregivers will increase concomitantly. It is noteworthy that caregivers sometimes have difficulties and is unprepared to provide care, which can lead to physical, psychological and social problems in their daily lives. This situation reflects negatively on their well-being, compromising their own health and the quality of care [4]. Multiple studies have indicated that most caregivers of older people are family members and women, especially daughters and daughters-in-law, aged 50 or over. Additionally, it should be noted that one in every 5 family caregivers is also older people. As for paid caregivers, there is also a predominance of women with an average age of around 40 years [5,6,7].

The change in routine and the imposition of social isolation due to the COVID-19 pandemic negatively affected both the life of the older person with AD and the life of their caregiver, since the delivery of care to that public was even more compromised [5,8].

In addition, the uncertainty of the future scenario in the face of the pandemic, along with the high number of deaths and the fear of being contaminated, increased anxiety and anguish among caregivers. This stress had a direct impact on the patient, who often, even without understanding the scenario, is very sensitive to the emotional state of the caregiver [9]. However, it is still unknown the long-term impact of the COVID-19 pandemic on older adults and their caregivers.

Thus, it is important to study the impact that the COVID-19 pandemic has caused on caregivers of individuals with AD in order to seek to minimize the worsening of the physical and mental health of this public. Therefore, the aim of this study was to analyze the global impact of the COVID-19 pandemic on caregivers of older people living with Alzheimer's disease through an integrative literature review.

Methodology

This is an integrative literature review, and of an analytical nature, regarding the impact of social isolation in face of COVID-19 pandemic for caregivers of older people with Alzheimer's disease. Data collection was carried out from March to August 2023, being structured from six stages: 1) selection of the research question, 2) establishment of criteria for inclusion and exclusion of studies, 3) definition of the objective to be found with the search in articles, 4) analysis of information, 5) interpretation of results, and 6) presentation [10].

The guiding question of this study was: How did the COVID-19 pandemic impact the lives of caregivers of older people with Alzheimer's disease, according to the literature, based on quantitative and qualitative studies.

The search strategy for scientific articles included the following digital platforms: Karger, PubMed (National Library of Medicine), and SciELO (Scientific Electronic Library Online), BIREME, Dynamed, Scopus, Medline Complete and ACS Publication. The descriptors used in the researched databases were "caregivers", "Alzheimer's disease" and "COVID-19", using various combinations. Articles in Portuguese and English were included, which addressed caregivers of older adults with AD in the context of the Covid-19 pandemic. Those that did not include the three descriptors and that had not been published between 2020 and 2023 were excluded. Papers including literature reviews and Primary studies, specific for Alzheimer's Disease were included.

A total of 3,806 articles were found and 23 were selected, 1 from Scopus, 21 from BIREME and 1 from PubMed, between 2020 to 2023.

Then, they were consolidated in a spreadsheet in Microsoft Excel 2016 and cataloged with title, year of publication, inclusion status, journal, year of publication, objective and DOI, selected by content analysis with survey of information present for construction of the literature review. At the end of the survey, 12 articles were effectively used, in addition to information present in electronic channels, selected according to quality and relevance to the proposed theme. The other 11 articles were excluded as they were not relevant to the study [11].

After selecting the articles according to previously defined inclusion and exclusion criteria, the following steps were followed, in that order: exploratory reading; selective reading and choice of material that fits the objectives and theme of this study; analytical reading and analysis of texts, ending with interpretive reading and writing [10].

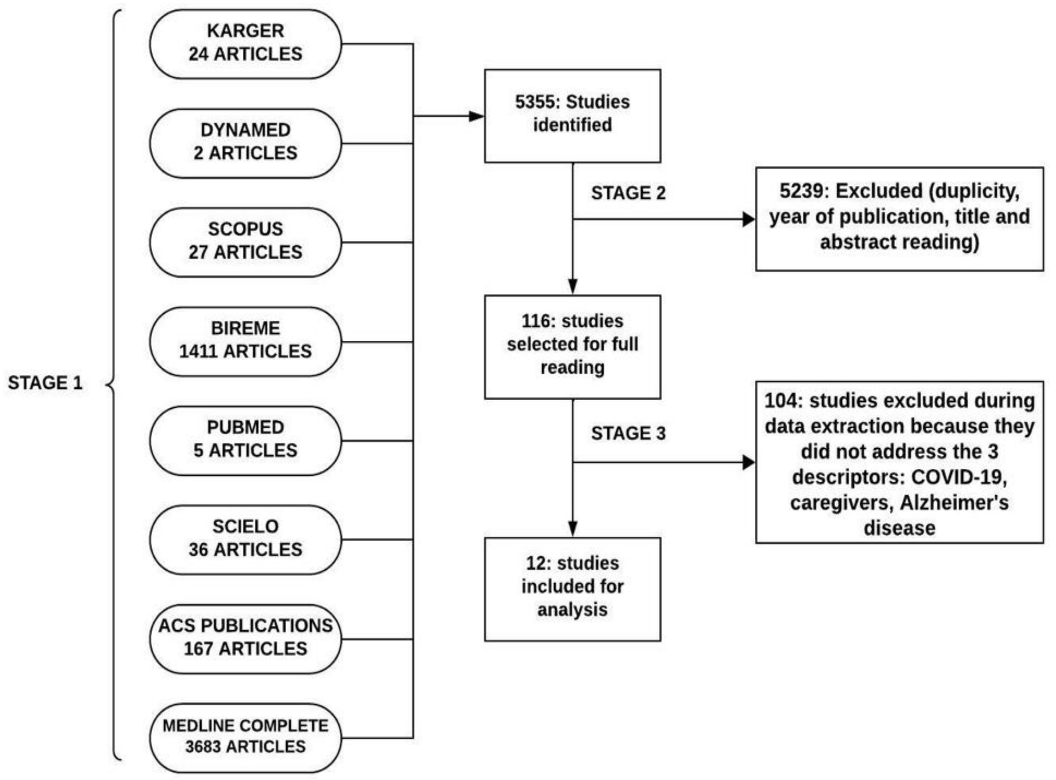

Figure 1. Shows the abstract evaluation search strategy flowchart.

Results

The content of a diverse selection of 12 papers was extracted. The studies included were undertaken between 2020 and 2023. Among the 12 selected studies, 100% addressed aspects related to the experience and the challenges of caring for older adults with AD during the pandemic. The context in which caregivers were exposed brought repercussions at different levels such as psychosocial and emotional. 11 out of the 12 selected papers addressed aspects related to the caregiver's mental health and the emotional impacts that the COVID 19 pandemic has caused. In their entirety, such studies found increased rates of depression and anxiety, as well as emotional burden on caregivers.

Considering the methodological design proposed in this study, Table 1 shows the findings of the 12 articles included in this study.

Discussion

Alzheimer's dementia and COVID-19

Due to the pathophysiology of the disease, older people with AD may often have difficulty understanding the scenario experienced by the COVID-19 pandemic and may have difficulty remembering protective procedures, such as the use of masks, hand hygiene, social distancing or understanding the information provided to them [12].

As a result, their risk of infection increases with greater responsibility for their caregivers. In addition to exercising a differentiated and special type of care that dementia already required, caregivers had to be even more concerned with the contagion of the disease, and were forced to stay at home for too long, limiting their experiences outside of work and leading to social isolation [12].

ARTICLE	YEAR OF PUBLICATION	PUBLIC MAGAZINE	GOAL	MAIN FINDINGS
The path of hope in relationships involving older adults: the perspective from the complexity of the covid-19 pandemic	2020	Text & context nursing.	Reflect on the relationships involving the elderly during the COVID-19 pandemic from the perspective of complexity, envisioning the path of hope.	Caregivers`for the sake of caring for the elderly. Caregiver burden increases With the pandemic, the caregiver changes their way of life and further increases their physical, emotional, social and financial burden.
Dementia care during COVID-19	2020	lancet	-	Difficulty for the elderly to carry out contact hygiene measures. The burden on caregivers increases since, in addition to the previous illness of elderly people with AD, it is necessary to take care to avoid the transmission of the infection in this risk group. Caregivers due to the pandemic are isolated with the elderly with AD
Living with dementia: increased caregiver stress level in times of COVID-19	2020	Int Psychogeriatr	To study how mandatory social isolation affected the stress caregiver and care burden of family members of subjects living with dementia in the community after the initial 4 weeks of quarantine in our midst	Caregivers due to the pandemic are isolated with the elderly with AD Low rate of continuity of family visits Contact of the elderly with AD was restricted directly to the caregiver. Services that support treatment are suspended and families stop visiting the elderly.
Emotional and Mental Wellbeing Following COVID-19 Public Health Measures on People Living With Dementia and Carers	2021	J Geriatr Psychiatry Neurol.	Explore the changing impact of COVID-19 public health measures on the mental well-being of PLWD and unpaid caregivers.	Difficulty for the elderly to carry out contact hygiene measures Emotional Disorders of Caregivers Due to social shame, caregivers find it difficult to join society.
Family caregivers of patients with Alzheimer's disease during the COVID-19 journey	2021	Jpn J Nurs Sci	-	Outpatient rehabilitation services were suspended due to confinement, with the caregiver also responsible for trying to provide for this monitoring, increasing the burden.
Lessons from the COVID-19 pandemic for improving outpatient neuropalliative care: A qualitative study of patient and caregiver perspectives	2021	Palliative Medicine	Generate a person-centered description of the impact of COVID-19 from the perspectives of patients living with neurodegenerative diseases and caregivers to improve the delivery of outpatient palliative care.	Reduction in the provision of health care and other support services Caregiver mental health decline during the pandemic Telemedicine, despite being implemented to help, still has many limitations

table 1. to be cont...

Needs of Alzheimer's Charges' Caregivers in Poland in the Covid-19 Pandemic-An Observational Study	2021	Int J Environ Res Public Health	Identify the needs, created by the Covid-19 pandemic, of caregivers of people with AD	Emotional Disorders of Caregivers showed that 75 out of 85 caregivers experienced a high level of stress during the Covid-19 period.
The impact of a global pandemic on people living with dementia and their care partners: analysis of 417 lived experience reports	2021	J Alzheimer Dis .	Using a patient-centered approach, we explore the experiences and needs of people living with dementia and their care partners during the COVID-19 pandemic as part of an ongoing assessment of dementia support services in British Columbia, Canada.	Caregiver burden increases Feelings of isolation and lack of companionship were present during the isolation of COVID-19 by caregivers.
The impact of the coronavirus on Alzheimer's disease: a narrative review	2021	Electronic Journal Collection Health	To analyze, through a narrative review, the impact of social isolation in the face of the COVID-19 pandemic for elderly clients with Alzheimer's disease and their families.	Increased emotional overload of Caregivers. Caregiver lives for the sake of caring for the elderly.
Mental health of people with dementia during the COVID-19 pandemic: what have we learned from the first wave?	2021	Journal of Alzheimer's Disease	Compare the mental health of PCD caregivers living at home or in nursing homes and identify specific factors that influence their mental health.	Caregivers have poor mental health Caregiver burden increases Emotional Disorders of Caregivers.
Neuropsychiatric symptoms in patients with dementia associated with increased psychological distress in caregivers during the COVID-19 pandemic	2021	Journal of Alzheimer's Disease	To assess neurological decline in patients with dementia and caregiver burden during the pandemic.	Worse cognition and increased psychological distress in caregivers of elderly people with AD1 are directly related Caregiver burden increases.
Overburden and correlates among caregivers of people with dementia during the COVID-19 pandemic	2021	Havana Journal of Medical Sciences	To study the characteristics of care and the degree of burden on caregivers of people with dementia during the pandemic caused by COVID-19.	Caregiver lives for the sake of caring for the elderly. It was seen that the factors: fear of getting sick and insecurity in the future, factors related to the COVID-19 pandemic, collaborated to increase the level of burden on caregivers of elderly people with AD. Caregiver burden increases.

Table 1: Results obtained from the selected articles

One of the main findings was the low rate of family visits due to fear of spreading the disease when visiting relatives. This situation meant that the contact of older adults with AD was directly and almost exclusively restricted to the caregiver [12]. In 90% of thet cases, outpatient rehabilitation services such as cognitive treatment, psychology, physiotherapy and occupational therapy were suspended due to confinement, regardless of the severity of the disease, and the caregiver is also responsible for trying to overcome the importance of this follow-up [13].

Some older adults diagnosed with AD showed neuropsychiatric alterations during confinement, even with difficulties in understanding the pandemic context, they suffered repercussions with what the COVID-19 pandemic imposed, which directly impacted the routine of caregivers [14].

The context of the caregiver of older adults with AD during the COVID-19 pandemic

Due to the COVID-19 pandemic, formal or informal caregivers of patients with Alzheimer's disease are considered one of the highest risk groups in terms of developing emotional disorders [15].

A study conducted with 417 participants showed that feelings of isolation and lack of companionship were very present due to the social distancing that was imposed. It also pointed out that caregivers were more stressed and less able to manage their well-being during the pandemic compared to the previous period [16].

It was evident that the caregiver, for the most part, changed their way of life in favor of caring for older people. It is noteworthy that this change was mostly not carried out by the caregiver's will, but by the situation imposed by the disease. As a result, there was already a great physical, emotional, social and financial overload that was even worse with the pandemic [17].

An important point observed was that spending a lot of time with the person with dementia was associated with an increase in the number of reported behavioral disorders, and it is important to encourage psychological support methods for caregivers [14].

According to a qualitative study in Cuba with 160 older adults with AD and their caregivers, it was seen that the factors: fear of getting sick and insecurity in the future, factors related to the COVID-19 pandemic, showed a strong collaboration for the increase in the level of burden on older caregivers with AD evaluated. In addition, they also demonstrated that female caregivers had higher levels of stress than male caregivers, regardless of the relationship with the person with dementia, the characteristics of the person with dementia and care arrangements [18].

A study conducted by Hanna et. al [19] in the United Kingdom showed the report of some caregivers referring to a social shame during the pandemic, since the person with AD is unable to understand public health guidelines. Thus, the action of coughing and the inability to wear a face mask or perform social distancing generate fear in the people around, and the caregiver is blamed for this, which increases their challenges.

The emotional impact of the pandemic on the caregiver

In a survey in France with 89 caregivers who accompanied patients with dementia at home and 159 who accompanied patients with dementia residing in a nursing home, it was shown that more than half of the caregivers had poor mental health, including depression, anxiety and self-reported stress during the first lockdown of the COVID-19 pandemic. The increase in this rate was similar both in caregivers of patients with AD who live at home and those who live in a nursing home. The study has shown an associated increase in depression, anxiety and stress due to the period of confinement, which negatively impacted the daily lives of caregivers, since it reduced intimacy and social life, while increasing the demand for patient care, all of which causing emotional overload [20].

The worsening of cognition and the increase in psychological suffering of caregivers of older people with AD are directly related. This relationship was accentuated in the pandemic, since the severity of dementia is amplified by the decrease in group activities, rehabilitation therapies, decrease in physical exercise and reduction in social interactions. Because during the pandemic this environmental support was substantially reduced, patients with dementia increased their demand for help and, thus, caregiver burnout was a consequence generated [21].

In a mixed methods study with 90 caregivers of people with dementia, it was seen that these caregivers experienced greater stress and tension since the beginning of the pandemic when compared to the period before the blockade. This happened due to changes in the roles and responsibilities of caregivers, as the provision of health care and other support services was reduced, thus generating a decline in the caregiver's mental health. Another aspect addressed in this study was about telemedicine, which despite having been implemented to help improve access to health care, has many limitations and does not replace face-to-face human interaction [22].

According to a survey in Poland in 2021, with 85 caregivers, 75 of them experienced a high level of stress in the pandemic, with no major changes regarding the caregiver's place of residence, whether with the person being cared for or in different households during the pandemic.

Studies have shown an overload of care on the part of the caregiver, which in itself is exhausting and demanding on their physical and mental health. It is also important to highlight the impact of the Covid-19 pandemic as an aggravating factor of this burden in a period of uncertainty regarding the scenario of the disease, the impact of exposure of older adults and their caregivers to the virus and social isolation. The limitations of this study relate to the need to better identify the profile of this caregiver in the literature, in terms of gender, age, work (formal or informal), in addition to demonstrating the activities carried out by caregivers before and after the pandemic context.

Limitations

This review has some limitations. Firstly, there are different databases available for research. Karger, PubMed, SciELO, BIREME, Dynamed, Scopus, Medline Complete and ACS Publication used in the search are among several existing ones; thereby potential papers that would be suitable for this review were not included. Another aspect is that publications addressing COVID-19 just gained attention on research agenda few years ago, which explains the scarce number of papers on the topic.

Conclusion

The findings of this review were listed, highlighting the worsening of AD patient care during the pandemic and, mainly, the increase in the caregiver's difficulties, with all their problems and implications linked to their own health and quality. of care.

It is noticed, through the analysis of the articles, that there is, in fact, a significant worsening of the quality of life of the caregiver in the pandemic period, since their overload, mainly physical and emotional, generated behavioral disorders arising from the increase in stress, depression and anxiety. This can be explained by some factors, such as the fact that many patients with such dementia are unable to follow the correct practices of collective protection, increasing the caregiver's risk. Consequently, the demand for these patients intensifies, as well as generating insecurity for the caregiver in their own family, due to the greater risk of contagion, in addition to increasing the caregiver's time with the patient with Alzheimer's in periods that would normally be off work.

The aforementioned findings, therefore, reinforce the relationship between the pandemic and the increased burden on caregivers, when compared to the pre-pandemic period. Thus, it is necessary to provide professional and systemic support, mainly addressing the mental health of these caregivers, in order to prevent the emotional exhaustion of such workers, which can improve their quality of life and, consequently, the quality of life of the older adults with AD. Finally, it is revealed the need for urgent implementation of a continuing care policy that includes the caregiver and their needs "from and to" the care of older people.

Declarations: This article does not require IRB ethical approval.

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