Research Article

Burden, anxiety, and depression in caregivers of Alzheimer patients during the COVID-19 pandemic in the Dominican Republic

Abstract

Introduction: Alzheimer's disease (AD) advancement imposes tremendous burdens on caregivers, increasing the patient's dependency demand. Confinement and social interaction disruption increase the risk of mental health problems. We aimed to investigate the impact of the COVID-19 pandemic confinement on AD patients' caregivers, hypothesizing that the superimposed burden can affect their mental health.

Methods: We performed a cross-sectional study on 221 caregivers of Alzheimer's disease patients in Santiago, Dominican Republic. Caregivers were evaluated using the short form Zarit Burden Interview (ZBI), Beck Anxiety Inventory (BAI), and Yesavage Depression Scale (GDS) using scores and intensity as outcome measures.

Results: Participants' ages ranged from 18-76years, with 82.4% female. The intense burden was present in 59.3% of caregivers, severe anxiety in 19.5%, and 32.6% with symptoms of depression. Pearson coefficients showed positive correlations between anxiety and depression ($R2=0.298$, $p<0.001$), caregiver burden and anxiety ($R2=0.313$, $p<0.001$) and burden and depression ($R2=0.216$, $p=0.001$).

Conclusions: During the pandemic, caregivers had an intense burden. Anxiety and depression are associated with this burden; therefore, to mitigate the sequels of the worldwide COVID-19 confinement, health professionals should include a thorough caregiver mental health assessment when routine consultations resume.

Keywords: alzheimer's disease, caregivers, burden, anxiety, depression, COVID19, pandemic

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Abbreviations: AD, Alzheimer's disease; COVID-19, corona virus disease 2019; NINCDS, national institute of neurological and communicative disorders and stroke; ADRDA, Alzheimer's Disease and Related Disorders Association; CRF, case record form; ZBI, zarit burden inventory; GDS, yesavage depression scale; BAI, beck's anxiety inventory

Introduction

Alzheimer's disease (AD) persists as one of the significant causes of disability and dependency of the elderly worldwide.[1] It affects close to 6 million Americans and is the fifth leading cause of death for older than 65 in the United States.[2] Patients require regular care and assistance in as little as two years after diagnosis of early-stage AD dementia. In the United States, nearly 16 million unpaid caregivers attend to family members for more than 20 hours per week, sometimes requiring additional help from professionals. Care assistance options include in-home care, adult daycare, and nursing home care.[3] The burden placed on caregivers is likely to be heavier in developing countries where additional assistance options may not be available.

In the Dominican Republic, the estimation of AD prevalence was 12% in populations older than 65. An estimate of 65,000 people with AD or another type of dementia projected to double by 2030 and quadruple by 2050. These projections translate to 2.6% of the total population without effective interventions in the following years.[4] There are 24 annual incident cases per 1000-year person.[5] Close to 80% of Hispanic caregivers manage household tasks while over 50% assist with personal care. Caregiving is a lengthy and intense work where half have aided for at least two years, with more than half (58%) being women and 9% are aging caregivers over the age of 65.[6] In the Dominican Republic, a low resource country, for instance, the problem is worse as it does not have as many options.

Caregiver responsibilities expand as AD progresses. The recipient's needs increase, affecting the quality of life of millions of individuals.[7] The limitations imposed on occupational, social, and family activities as well as decreased time for personal needs and loss of privacy increases this burden.[8–11] Previous studies concluded that caregiver burden was associated with anxiety and depression.[12] For each point increase above their typical stress in the caregiver perceived stress scale score, the odds of elderly abuse increased by 1.9.[13] Sleep disturbances, anxiety, and depression were related to the dementia stage's advancement, and individual social factors of the caregiver.[14] Caregiving can be demanding both emotionally and physically, impacting their health and compromising their ability to provide care. Caregiver burden has become a public health concern since the health of caregivers is also at risk.[15]

The COVID-19 pandemic has brought unprecedented changes and disruptions to the typical lifestyle worldwide. Governments have advised or mandated face shielding, social distancing, and in-home isolation, particularly for the elderly or individuals with comorbidities. These measures have caused dramatic changes in most people's daily routines affecting AD patients and their caregivers. Confinement and deprivation of regular human interaction increase

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the risks of mental health problems such as anxiety, insomnia, panic, paranoia, aggression, and depression.[16] Given the ongoing worldwide confinement, we hypothesize that the burden, anxiety, and depression are likely to be prominent in caregivers of Alzheimer's patients during the COVID-19 pandemic. To test this hypothesis, we carried out a descriptive, cross-sectional, and primary source study.

We aim to elucidate the impact of the pandemic in this population. This data will help develop strategies to prevent, identify, and treat the sequelae of the newly superimposed burden in the caregivers in the Dominican Republic.

Methods

Participants

We recruited the participants using the database of the Family Study of Genetic Influence on Alzheimer's (EFIGA),[17] an ongoing study with Institutional Review Board approval for over 20 years in the Dominican Republic. We selected families with at least one member diagnosed with Alzheimer's disease, previously diagnosed using a neuropsychological battery, neurological exams, and standard diagnostic images based on the NINCDS-ADRDA criteria.[18,19] The patients' relatives who appeared in the database were contacted via WhatsApp and phone call during May and June of 2020. The study was explained, and together we defined the primary caregiver. The country was on relative confinement, including a curfew from 5:00 pm to 5:00 am, school closures, and limited access to health care consults as only emergency care was been offered due to the COVID 19 pandemic.

Inclusion criteria

a) Been of legal age, and authorized to sign the informed consent form,

b) Residing at the patient's home,

c) Providing more than six months of caregiving,

d) Living in the Dominican Republic.

Exclusion criteria

a) Pregnancy,

b) Individuals with a history of depression, or taking antidepressant or psychotropic drugs,

c) Individuals in recent mourning (less than six months).

Sample and evaluation procedures

We invited to participate all individuals who answered the WhatsApp recruitment message or the phone call and met the inclusion-exclusion criteria. The database had 1,709 eligible caregivers, from which 221 consented to participate in the study. The designed case record form (CRF) contained the informed consent form, sociodemographic data, and mental health assessment instruments. Sociodemographic information included age, gender, marital status, education in years, pregnancy status, duration providing care, and living circumstances (living with the patient or not). We used Latin American validated short versions for the Zarit Burden Inventory (ZBI)[20] to evaluate caregiver burden, the Yesavage Depression Scale (GDS)[21] to assess for depressive symptoms, and the Beck's Anxiety Inventory (BAI)[22] to assess for anxiety symptoms. A digital document was prepared using Google Forms. A link was created and sent via WhatsApp to the person previously identified as the primary caregiver. To respond, they only had to open the link on their smartphone. When opening the

link, the inform consent form appeared on the first page; after reading it and accepting to participate, the caregiver could proceed to fill in the demographic section of the questionnaire followed by questions from the three different assessment tools. If the person decided not to participate in the study, it would not continue to the following pages. If the person did not have a smartphone or expressed that they did not have the skills to handle the link, one of the researchers interviewed them via telephone. When one item was not understood, the interviewer would repeat the question and options without been interpreted by the evaluator. We conducted the application of the instrument individually.

Assessment instruments

Caregiver burden

The scale used to measure caregiver overload was the abbreviated Zarit scale,[20] an instrument that aims to assess the subjective experience of overload felt by the caregiver in different areas of their life. Seeking to decrease the interview time; in our case, it was essential to optimize the caregiver's time since it was a self-applied questionnaire or by telephone interview. This Likert scale consists of 22 items with seven questions marked on gray, making the short form. Each answer has a value of 1 (never) to 5 (almost always) with a possible 7-35 points score. The result classifies the caregiver onto "no burden" (<16) and "intense burden" (>17). Intense burden status is associated with significant morbidity of the caregiver. This scale is validated in several Latin American countries. We chose the Chilean version, demonstrating great utility, a sensitivity of 100%, a 77.7% specificity, and a positive predictive value of 86.6% and a negative predictive value of 100%.[23]

Beck anxiety inventory

The Beck Anxiety Inventory[22] is a useful tool to assess anxiety symptoms. However, it is not an instrument intended to diagnose anxiety disorders, as it does not classify them and only indicates the severity of the symptoms. Its popularity lies in its simple application and practical interpretation; it also provides valuable data for at first glance approximation to this disorder.[24] This scale consists of 21 items describing common symptoms of anxiety. The respondent rates the anxiety symptoms on a 4-point scale ranging from 0 (not at all) to 3 (I can barely stand it). The breakpoint used were:

- Minimal anxiety: 0-7

- Mild anxiety: 8-15

- Moderate anxiety: 16-25

- Severe anxiety: 26-63

Depressive symptomatology

The Yesavage[21] short version questionnaire was the instrument used to assess depressive symptoms. It is one of the most widely used scales today in the elderly population. It is a self-applicable 15 item scale with dichotomous responses (yes / no). The adapted short version's reliability and validity parameters have been acceptable and similar to those of the original questionnaire. A cut-off point of 6 showed a sensitivity of 85% and a specificity of 95%.[25] The breakpoints were:

- Normal: 0-5

- Mild depression: 6-9

- More severe depression: >10

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Statistical analysis

The information obtained by the Google forms had a direct output to an Excel spreadsheet. Using SPSS version 25 (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp.), we assessed frequencies and percentages for qualitative variables and applied the Chi-square statistical test with a 95% confidence level and p-value <0.05. Determination of the degree of association between caregiver burden, anxiety, and depression, was conducted using the Pearson correlation coefficient.

Ethical considerations

The current study was conducted following the Declaration of Helsinki and approved by the Bioethics Committee of the Faculty of Health Sciences of the Pontificia Universidad Católica Madre y Maestra (COBE-FACS).

Results

The characteristics of our patient population are listed in Table 1. A total of 1,709 individuals were eligible for our survey, of which 221 responded, for a response rate (12.9%).

Table 1 Demographics of caregivers of Alzheimer patients during COVID-19

N=221(%)	
Age (range)	18-76
Female/Male	182(82.4)/39(17.6)
Education (years)*	11.4±4.17
Marital status (%)	
Married	81(36.7)
Single	61(27.6)
Divorced	31(14)
Partnered	35(15.8)
Widow	13(5.9)
Caregiving time (years)*	3.2±1.2
Relationship with patient	
Wife/husband	23(10.4)
Father/mother	140(63.3)
Brother/sister	19(8.6)
Grandparent	14(6.3)
In-law relative	8(3.6)
Neighbor	4(1.8)
Patient	4(1.8)
Professional caregiver (%)	19(8.6)

*Mean and Standard Deviation

Caregiver burden: The application of the Zarit scale showed an intense burden on 131 caregivers (59.3%). Of these, 81.7% were female. Most overburdened caregivers (67.2%, n=88) had spent close to 4years caring for the patient, and 31.3% (n=41) were between the ages of 46 and 55. Chi-squared tests revealed a statistically significant difference between caregiver age and burden score (p<0.05), and marital status and burden score (p<0.05).

Anxiety in caregivers: According to the BAI, minimal anxiety was present in 33.9%, mild in 23.1%, moderate in 23.5%, and severe in 19.5%. Out of the caregivers with severe anxiety, 86.1% were female, 44.2% were between ages 56-65, and 62.8% devoted around four years to caring for the sick patient. There was no statistically significant difference among these variables.

Depression in caregivers: Symptoms consistent with depression were present in 32.6% of caregivers (n=72). Of these, 72.2% showed mild, 18.06% moderate, and 9.7% severe depression. Of the caregivers with severe depression, 85.7% were female, 28.6% belonged to the 26-35, and 46-55 age ranges for 57.2% of the sample, and 42.9% devoted nearly four years to the care of the patient. There was no statistically significant relationship between depression scores and other survey items.

Relationship between caregiver burden, anxiety, and depression: Pearson coefficients showed positive correlations between anxiety and depression (R^2= 0.298, p < .001), caregiver burden and anxiety (R^2=0.313, p < .001), and burden and depression (R^2=0.216, p< .001) as depicted in Table 2.

Table 2 Pearson correlation coefficient between caregiver's burden, anxiety, and depression

Correlation		Anxiety	Depression	Burden
Anxiety	Correlation	1	.298**	.313**
	Significance(p)		<.001	<.001
	N	221	221	221
Depression	Correlation	.298**	1	.216**
	Significance(p)	<.001		.001
	N	221	221	221
Caregiver Burden	Correlation	.313**	.216**	1
	Significance(p)	<.001	.001	
	N	221	221	221

**Correlation is significant at the 0.01 level (2-tailed).

Discussion

Our study investigated the impact of the COVID-19 pandemic on the mental health indicators of caregivers of Alzheimer's disease patients in the Dominican Republic. Consistent with our hypothesis, our findings disclosed a relationship between caregiver burden and anxiety, anxiety, and depression, and burden and depression, suggesting that caregivers of AD patients experienced significant burden, anxiety, and depression during the confinements due to the COVID-19 pandemic. However, the reported scores and degrees varied substantially among our participants, from no symptoms to severe symptoms as assessed by the different scales.

Burden scores ranged from 1-35, where more than half of the participants showed an intense burden. In a previous study conducted in this cohort,[12] 36% of caregivers reported a severe burden on the Zarit scale compared to the present study, where 59.3% reported similar symptoms. The substantial increase in the population's burden score during the pandemic may be due to the worsening of the patient's symptoms and the lack of social and healthcare services during the confinement.[26] A study in Nuevo Leon, Mexico, found

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moderate to severe caregiver burden associated with increases in AD patient behavioral problems.[27] These may not be the only causes of the increased burden. In the present study, half of the burdened caregivers were in the age bracket 44-55; this is also an aging population that may have added concerns such as health problems, financial constraints, and other family compromises. A previous study highlighted that older adult caregivers have extensive personal strains independent from family member disease severity.[28]

Anxiety scores ranged from 0-49, with close to half the participants portraying a moderate-severe degree of anxiety. Two-third of our participants devoted more than four years to care. Results from similar studies showed that severe anxiety was present in caregivers who live with the AD patient. With poor-quality relationships predicting caregiver anxiety and depression,[29] the greater length of duration caring for the patient has been associated with increased anxiety levels.[30] A contrasting study found that there was a considerable reduction in anxiety and depression after the first year of care but an increase in the burden level.[31]

Depression scores ranged from 0-13, with one-third of participants displaying symptoms of depression. A previous study showed that social disconnectedness and perceived isolation were predictors of higher depression symptoms,[32] while another study found that depressive, cyclothymic, and anxious temperament traits are contributory factors on the expressed emotions among caregivers of AD,[33] those expressing emotions were clinically depressed and more burdened.[34]

Our findings are not isolated and corroborate an epidemiological study in China during the initial phase of the novel coronavirus outbreak, where more than half of the participants rated the overall psychological impact of the epidemic as moderate to severe.[35] These findings corroborated an existing metanalysis of hospital setting reporting high burden of mental health problems not only on patients but in informal caregivers or healthcare providers who experienced isolation or quarantine in a similar context as a measure of infectious disease transmission prevention.[36]

Strengths and limitations

A particular strength of this study is the use of the database of the Family Study of Genetic Influence on Alzheimer's (EFIGA), part of the National Institute on Aging Late-Onset Alzheimer's Disease Family Study.[17] Our database includes mostly AD informal caregivers in the Dominican Republic. Additionally, the assessment tools were designed to be auto-applied, this design may have allowed respondents to answer in their own time and with ease of added pressure. Nevertheless, some limitations to our study should be addressed. First, the pandemic's greater impact was in March. When the people did not go out of their house, there was a higher mortality rate, with elderly patients being most vulnerable, and there was more tension regarding this novel crisis. Our study started two months into the pandemic, and people may have been more adjusted to the drastic changes. Second, when we contacted the caregivers, they were skeptical of our survey. At the time of recruitment, there was a wave of fraudulent schemes surrounding the ongoing pandemic. They reached the principal investigator to confirm the veracity of the ongoing study. Third, additional burden such as engaging in work outside the house, change in employment, having to care for a child, and limited access to healthcare for the person with AD were not assessed on this study. Finally, since it was a web-based survey, we do not know if the responder was indeed the primary caregiver of the AD patient. Future research should perform in-person evaluations and longitudinally assessment of the mental health of caregivers.

Recommendations

Our findings are likely to have three practical consequences. First, we know that an ample degree of burden, anxiety, and depression is present in AD caregivers during the COVID-19 pandemic. This suggests that rapid social changes, stressful conditions, and confinement limiting human interactions play a significant role in the vulnerability to mental health illnesses. Consequently, thorough assessment and follow up should be implemented to caregivers when routine medical consultations resume. Secondly, given the notoriety of also aging caregivers, emphasizing the evaluation of the overall burden is necessary to reduce the imposed load of aging on caregiving and vice versa. Third, even though our results come primarily from a female predominant caregiver sample, and males seem to be less open to share information about their situation, special consideration should be given to the male counterparts' mental health condition. Finally, community support groups, journaling, and the use of apps to manage daily routine are potential services that could be introduced to stressed caregivers. An important but unanswered question is how these global lifestyle changes, turning into the new normal, will affect the caregiver's mental health long term. Considering that it was not possible to register the pre-pandemic mental health and compare the increased burden, anxiety, and depression during pandemic, additional research is needed to understand how this superimposed burden will translate to their overall health and how post-COVID-19 mental care can be improved.

Conclusion

The subjective burden, anxiety, and depression experienced by caregivers during the confinement are impressive. All surveyed caregivers reported some degree of burden, being the most relevant moderate to severe. This may lead to idiosyncratic mental health illnesses and be detrimental to the overall health conditions. The new lifestyle changes have revealed the need for special attention to mental health disorders in caregivers of AD patients. Therefore, the support of professional experts in mental health, during and after the pandemic, is crucial to mitigate the confinement sequels on caregivers' mental health effectively.

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Conflicts of interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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