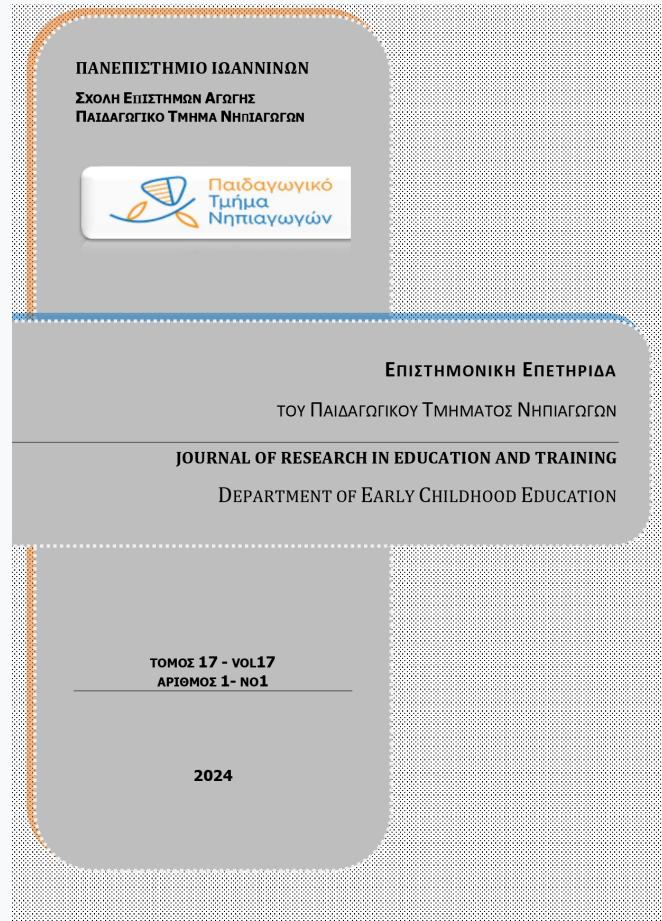


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Psychological Burden in Female Caregivers of Patients with Dementia and Associated Behavioral and Emotional Problems, during COVID-19 Pandemic Restrictions

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Abstract

Objectives: This study aims to investigate the impact of the COVID-19 crisis and the global challenge of dementia on female caregivers. Specifically, the objectives include examining caregivers' experiences before and after the pandemic and assessing the anticipated increase in caregiver burden and death anxiety. **Method:** Two groups of female caregivers matched for education, age, and patients' BPSD levels, were studied in 2019 and 2022. Data collected at Alzheimer's Hellas included demographic information and systematic neuropsychological assessments. The 97 participants, mainly caring for Alzheimer's patients, were exclusively female due to the predominant gender distribution in Greek caregiving. Measures included the Zarit Burden Interview, Neuropsychiatric Inventory, and Death Anxiety Questionnaire. **Results:** Contrary to expectations, our findings indicate that caregiver burden did not significantly increase after the pandemic ($F(1, 43) = 0.069$, $p > 0.5$, partial eta squared = 0.001). Moreover, there was no notable association between caregivers' burden and death anxiety related to the pandemic ($r = 0.159$, $p = 0.307$, $N = 43$). **Conclusion:** This study sheds light on the experiences of female caregivers in the context of the COVID-19 crisis and the global challenge of dementia. Future research should delve into a larger population of caregivers from different cultural backgrounds to gain a comprehensive understanding of caregiving experiences during times of crisis and inform the development of effective support mechanisms.

Key-words: COVID-19 pandemic; dementia; female caregivers; caregiver burden; death anxiety

1. Introduction

1.1. Covid-19 pandemic

The pandemic caused by the rapidly spreading disease caused by the SARS-CoV-2 virus has profoundly exerted influence on the global community, with significant consequences for physical, social, and psychological health. In Greece, the first confirmed case was reported on February 26, 2020, and the first death from the virus on March 12, 2020. As a result, the Greek government implemented a series of measures, including travel restrictions, school closures, closure of childcare centers, and limitations on daily activities and social interactions, to control the spread, which causes physiological and cognitive shifts and consequences for well-being. Specifically, older adults are at high risk as they have a higher likelihood of contracting the virus and experiencing its effects due to their multiple comorbidities, such as hypertension and diabetes and weaker immune systems (Shahid et al., 2020).

1.2. The phenomenon of Dementia

However, parallel to this, there is another, even more dangerous "pandemic" evolving worldwide, that of Dementia. Dementia has been described as one of the most significant challenges for the medical community, as every three seconds, a person is diagnosed with the condition. Despite significant advances in medical treatments for diseases previously considered incurable, the global prevalence of Dementia continues rising, and it is expected to reach 152 million by 2052, compared to the current 55 million (Alzheimer's Disease International, 2019). According to the OECD, the number of people suffering from any form of Dementia in Greece is approximately 200,000, estimated to exceed 300,000 by 2037. The exact causes of the disease have not been found, but it is inevitable that genetic, environmental, and lifestyle factors interact and can contribute to this complex neurodegenerative disorder. Therapeutically, pharmacological interventions or non-pharmacological interventions are applied to mitigate the effects of Dementia.

1.3. Dementia in Coronavirus-period

As expected, older adults with Dementia were a particularly vulnerable group during the onset of the COVID-19 pandemic. They faced increased difficulty in remembering safety measures and self-isolation protocols, leading to challenges in adhering to them (Brown et al., 2020). Consequently, their isolation for protection from the virus resulted in social disengagement and disruption of their therapeutic routines, leading to increased boredom due to lack of activities and worsening of their condition. That brought confusion, depressive symptoms, anxiety, sleep problems, and helplessness

(Raneiro et al., 2020; Vaitheswaran et al., 2020). This cascade effect also had implications for behavioral and psychological symptoms (BPSD) associated with neurocognitive disorders (NCD), such as delusional ideas, apathy, irritability, wandering, abnormal motor behavior, agitation, and more. Research indicates that the exacerbation or onset of these symptoms during the COVID-19 quarantine affected nearly 55% of patients with dementia (Canevelli et al., 2020). Specifically, the restriction of the movement led to a suspension of initiative (apathy), reduced mobility, and diminished willpower while simultaneously causing increased hyperactivity (anxiety, agitation) (Simonetti et al., 2020). Generally, these symptoms are a significant part of neurodegenerative diseases and greatly affect the independence and functionality of patients while reducing the quality of life for both caregivers and patients (Fauth EB et al., 2014). Overall, they contribute to over 33% of the impact associated with Dementia (Adelman et al., 2014). While underlying factors contributing to the development of BPSD, regardless of the specific symptom, appear to be neurodegeneration, the type of Dementia, the severity of cognitive decline, reduced functional abilities, and to a lesser extent, increased caregiver burden, dysfunctional communication, and lack of disease-specific activities (Kolanowski et al., 2017).

1.4. Caregiving in SARS CoV-2 pandemic

The care of a patient with Dementia, especially in Greece, is usually undertaken by family members such as spouses and children due to the high cost of care, the strong family bonds that characterize our country, and generally due to a high sense of responsibility (Triantafillou et al., 2006). As the aging population continues to accelerate and medical advancements prolong human life, the number of patients with chronic diseases requiring home care also increases, leading to a shift from institutional to family care. Informal caregivers often do not seek help from their social circle professionals, or specialized centers related to Dementia, even though caring for a dementia patient puts pressure on their financial situation and mental and physical health (Novais et al., 2017). This negatively impacts the quality of life of these individuals and their families, who seem to experience neglect and imbalance, as the caregiver's work never stops (Cohen, 2000). The isolation due to restrictive conditions, uncertainty about a possible illness, and return to normalcy contributed to further caregiver exhaustion (Carpinelli Mazzi et al., 2020). However, the disrupted routine of patients also caused significant concern to the caregivers as the provision of social care from day centers and professionals was limited. The absence of activities created intense stress for patients and caregivers, who had to create a new reality and daily life using technology, an unfamiliar and incomprehensible area for many, resulting in helplessness (Alves et al., 2020; Armstrong et al., 2020). Employment was another significant area affected in terms of caregivers, as many experienced suspension, creating additional economic insecurity on top of the demands of therapies.

Additionally, these individuals lost their only outlet from the disease and continuous contact with the patient (Greenberg et al., 2020). As can be understood, social and physical restrictions, along with an isolated patient, gave rise to feelings of suffocation, dissatisfaction, and intensifying conflicts (Andreakou et al., 2020). The neuropsychiatric symptoms further intensified the psychological impact left by COVID-19 on caregivers, increasing their psychological burden, especially for caregivers of Alzheimer's (Boutoleau-Bretonniere et al., 2020). Additionally, the observed increase in burden only applied to caregivers whose patients already had neuropsychiatric symptoms before the quarantine, not those whose patients developed them during the restrictive conditions, as they were less severe and did not persist long enough to increase the burden (Pongan et al., 2021). This situation was obvious in that it made it difficult for caregivers to manage not only the illness of their loved ones but also a new, precarious condition that was threatening them. However, this does not mean that the caregiving experience is always negative, as it provides feelings of pleasure, usefulness, and contribution. The nature of the caregiving experience depends on how the caregiver approaches and defines the experience, such as whether they have introduced consistency towards a higher goal in their overall experience (Andrén & Elmståhl, 2008; Etters et al., 2008), as well as other subjective and objective factors (Liu et al., 2020). Possible burdensome factors include the long duration of care, as well as monitoring and daily assistance, along with the decline in the patient's cognitive and functional abilities, as all these contribute to feelings of guilt and insecurity in the caregiver (Cheng, 2017; Colombo et al., 2011). This daily interaction with the patient is burdensome for the caregiver's mental state and often leads to depressive symptoms, neglecting their health and rendering them unable to fulfill other roles in their life (e.g., parent, spouse, employee, friend) (Armstrong et al., 2020; Daley et al., 2019). However, if the burden was measured on a caregiver, it would be obvious that it is subjectively perceived, beyond all the factors mentioned earlier, such as the progression of the patient's condition or the lack of knowledge, but also it is related to the caregiver's mental resilience (Garcia-Ptacek et al., 2019).

1.5. Female caregivers

Regarding female caregivers, usually spouses or daughters of patients take on the caregiving role. Spouses spend more time with the patient due to their retirement, while daughters are more likely to work concurrently and experience conflicts in their daily schedules (Pinquart & Sorensen, 2011). Additionally, spouse-caregivers usually take care of their husbands with Dementia. In contrast, child caregivers care mostly for their mothers (Rigby et al., 2019). The physical restriction that spouses experience due to their age often makes caregiving challenging, and they report more severe symptoms of depression (Pinquart & Sorensen, 2011). Several international studies also report a

more significant psychological burden, and more involvement in spousal care, while the placement of the patient-spouse in a nursing home occurs later in the course of the disease when the wife cares for the husband (Maseda et al., 2014).

1.6. Death Anxiety

Death anxiety is considered a fundamental fear and one of the core elements of existential perspectives (Neimeyer, 1994). Specifically, it is the feeling of panic, fear, or heightened anxiety caused by the thought of death, the abandonment of the world, and what happens after the earthly life. Being in the presence of a patient, generally, and witnessing their deterioration causes anxiety in the family circle about their own impending death (Yalom, 1980). This fear can intensify during critical periods and stages of life, such as a pandemic (Yalom, 1980). The SARS-CoV-2 virus brought death anxiety to the surface and heightened preexisting anxiety in different populations and it was affected by sociodemographic factors such as fear of COVID-19, gender, and occupation (Özgürç, et al., 2021). Daily exposure to the number of COVID-19 victims through the media and the use of protective masks and antibacterial products constantly reminded people of the acute condition of the pandemic, resulting in heightened death anxiety. However, even more burdensome for the development of death anxiety was the prohibition of social interactions and the unexpected death of loved ones, resulting in feelings of loneliness, which fragmented mental health (Damirchi et al., 2020; Ozyurek & Atalay, 2020). Those who mainly experienced death anxiety due to the COVID-19 pandemic were healthcare professionals who were at the center of the fight against coronavirus, women, and older adults because of the many physical problems, chronic illnesses, movement disorders, physical disabilities, and dependence on others. Retirement and subsequent loneliness can also contribute to death anxiety in the elderly (Menzies & Menzies, 2020). Numerous studies have highlighted the influence of COVID-19 on death anxiety, particularly among caregivers. The increased mortality risk due to the multiple comorbidities of dementia patients generated significant concern about caregivers' ability to provide adequate care and worry about the potential impact of the virus on the health of their loved ones. Specifically, death anxiety is higher in caregivers who have more difficulty accepting the patient's impending death, while those who appear to have accepted death are more capable of accepting their transience in life (Bachner et al., 2011; Neimeyer et al., 2004). Similarly, the non-acceptance of death leads to a reduced ability to manage the stress associated with caregiving, as caregivers who are terrified by the thought of death do not adequately cope with the duties of caring for a person who reminds them that death may be very close (Semenova & Stadtlander, 2016).

1.7. Aim and Hypotheses of the Study

This study was conducted to examine whether the mental burden of female caregivers of people with dementia and neuropsychiatric symptoms has been affected due to the conditions of confinement in the context of the COVID-19 pandemic. Psychological burden, as defined in the literature, refers to the emotional, cognitive, and subjective impact experienced by individuals who are engaged in caregiving or facing challenging life circumstances. It encompasses the mental strain, stress, and emotional challenges that individuals undergo, often associated with factors such as caregiving responsibilities, traumatic events, or chronic stressors (Zarit, et al., 1980).

Hypotheses A posited that caregivers' burden would increase after the second lockdown (after the first of February 2021) in Greece, as compared to the years before restrictions.

We also hypothesized (B) that the increased mental burden of the women - caregivers after restrictions would have a positive correlation with caregiver death anxiety due to pandemic conditions.

2. Method

2.1. The design of the study

The data of two groups of female caregivers matched for caregivers' educational level ($F(1, 43) = 3,342, p < 0.001$), age ($F(1, 43) = 0,282, p < 0.001$), and the level of behavioral and psychological symptoms of dementia (BPSD) ($F(1, 43) = 0,021, p < 0.001$), exhibited by their patients, were examined for the study. The division of the groups was based on the timing of data collection (2019, before the first lockdown in Greece, and 2022, after the end of the second lockdown) to identify any differences that may have arisen due to the restrictive conditions as regards their psychological burden. The data was collected in the daycare centers of the Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas). Demographic information, as well as the scores from measures of the psychological burden of the caregiver and the behavioral and emotional problems of the patients, were collected as part of the systematic neuropsychological assessments taking place in Alzheimer's Hellas. The Death Anxiety Questionnaire was administered via telephone, only to the participants from the 2022 group.

2.2. Participants

The convenient sample consisted of 97 female caregivers, with a mean age of 54.26 (SD=11,970) years and a mean educational level in years of schooling, of 14.37 (SD=3,154) years, who were caregivers of patients displaying behavioral and psychological symptoms (NPI score ≥ 11) during the two phases of the study (Nunes et al., 2019), while the majority of patients were diagnosed with Alzheimer's disease (N=78). We decided to use the data only from female caregivers, as there is a significant lack of male caregiver population, and overall, over 81% of formal and informal caregivers in Greece are represented by women who dedicate up to 50% more time to caregiving. Furthermore, women undergo more negative consequences of caregiving (depression, anxiety, psychological burden, and sleep disorders) (Sharma et al., 2016).

2.3. Measure

2.3.1. Zarit Burden Interview (ZBI) (Hebert et al., 2000) (Kalokairinou- Anagnostopoulou & Alevizopoulos, 2006)

The ZBI is a valid, reliable, comprehensive self-report tool for assessing caregiver burden. It has been validated for the Greek population since 2005. The revised version of the scale with 22 items, reflecting the feelings of caregivers of dementia patients and the impact of caregiving has an excellent general reliability that was measured with Cronbach's alpha ($\alpha = 0.93$), as well as the reliability of the factors ("personal strain", "role strain", "deprived relations" and "management of care") that were created through the validity test. Caregivers indicate their agreement on a 5-point Likert scale (0=never to 4=nearly always) with statements such as "Do you feel angry when you are near your relative?" or "Do you feel pressured/anxious when you are near your relative?". Higher scores indicate a higher burden, with a maximum score of 88 (Zarit, 1990). Specifically, scores ranging from 0 to 21 indicate minimal or no burden, 21 to 40 indicate mild to moderate burden, 41 to 60 indicate moderate to severe burden, and 61 to 88 indicate severe burden (Hebert et al., 2000; Zarit, 1990).

2.3.2. Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) (Politis, A. M., et al., 2004)

Neuropsychiatric symptoms are identified and assessed using the Neuropsychiatric Inventory (NPI) tool. The H- NPI (Hellenic translations of the NPI) has a high degree of internal consistency reliability (.76) and the total score is calculated by multiplying the frequency and severity ratings for each domain (e.g., delusions, agitation, or motor disturbances) and summing them, resulting in a range of zero to 144 points. The score considered most suitable for differentiating cognitively

normal individuals from patients with Dementia or Mild Cognitive Impairment is 11. Therefore, our research used a cut-off score of 11 and included patients with an NPI score ≥ 11 (Nunes, P., 2019).

2.3.3. Death Anxiety Questionnaire (DAQ) (Conte, Weiner, & Plutchik, 1982) (Polemitou & Vantarakis, 2019)

The DAQ is a valid self-report instrument with high internal consistency (.83) and test-retest reliability (.87) (Conte, Weiner, & Plutchik, 1982). It measures four different aspects of personal death-related anxiety: fear of the unknown, fear of suffering, fear of loneliness, and fear of personal extinction. Participants rate their agreement with each statement (15 items) on a 3-point Likert scale (0=not at all to 2=very much), such as "Do you worry that death might be painful?" or "Does the thought that you might be permanently lost after your death worry you?". The possible total score ranges from 0 to 30, with higher scores indicating greater death anxiety (Conte et al., 1982).

2.4. Ethics

The research received approval from the Bioethics Committee of the Greek Association of Alzheimer's Disease and Related Disorders, by the guidelines of the General Data Protection Regulation (EU) 2016/679 enacted by the European Parliament and the Council on April 27, 2016. This regulation is designed to safeguard the personal data of individuals during processing and facilitate the free movement of such data. Additionally, the study adhered to the principles outlined in the Helsinki Declaration. All participants in the study were provided with an information sheet, and after reading it, they signed an informed consent indicating their agreement for the research team to use their anonymized personal data, including gender, age, education, and performance in neuropsychological tests, for research purposes. Participants were also given the option to withdraw from the study at any time without facing any penalties.

3. Results

The IBM SPSS Statistics version 27 was the chosen program for the statistical analysis and the statistical significance was set at 0.05. To examine whether the burden of caregivers increased after the second lockdown in Greece We used the Univariate Analysis of variance. Pearson correlation coefficient was the measure We used to see the relationship between the DA score and the ZBI score on caregivers of the 2022 group.

For both pre-COVID and post-COVID groups, the mean ZBI scores were 38.87 (SD = 13.974) and 38.07 (SD = 16.282), respectively. A between-subjects effects analysis revealed no statistically significant differences between the groups ($F(1, 43) = 0.069, p > 0.5$), with a small effect size (partial eta squared = 0.001), suggesting the absence of substantial differences.

The association between Zarit Burden Interview (ZBI) scores (M=38,07) (SD=16,282) and Death Anxiety (DA) (M=11,12) (SD=4,646) scores were examined through the Pearson correlation coefficient. The analysis did not find a statistically significant correlation ($r = 0.159, p = 0.307, N = 43$), indicating no relationship between caregiver burden and death anxiety levels.

4. Discussion

In this research, we investigated the impact of the COVID-19 pandemic on the burden and death anxiety experienced by female caregivers of patients with various forms of dementia. Our study utilized a criterion-based sampling method, specifically targeting caregivers with patients exhibiting behavioral and psychological symptoms of dementia (BPSD), as measured by the Neuropsychiatric Inventory (NPI) score of ≥ 11 . Our sample consisted of 97 participants, split into a pre-COVID-19 group (N=53) and a post-COVID-19 group (N=44). Contrary to our initial hypothesis, the results suggest that the burden experienced by caregivers did not significantly increase after the COVID-19 pandemic. Regardless of whether the data was collected before or after the pandemic, the mean Zarit Burden Interview (ZBI) scores were similar and did not show any statistically significant differences between the two groups. This finding is not confirmed by some research sources that show the negative effect of COVID-19 on the level of the psychological burden of caregivers, revealing notably high levels of burden, with Borg et al., (2021) indicating that 32.4% of caregivers experienced severe burden (Borelli et (Raneiro et al., 2021)). However, it seems that the increased burden is related to specific factors and does not arise purely from the condition of COVID-19. For example, the increased psychological burden in the pandemic was seen in caregivers of patients with an advanced stage of dementia (Cohen et al., 2021), either with frontotemporal dementia of a behavioral type (Boutoleau-Bretonniere et al., 2020) or patients with worsening cognitive status (Borelli et al., 2021), but also in caregivers with reduced resilience (Altieri & Santangelo, 2021). Something that explains our results is that the majority of our population in the post-COVID group (N=31) has received professional help through psychoeducation and support groups. According to the literature, interventions for caregivers, especially that of psychoeducation with the active

participation of the caregiver, have a significant positive effect on mental burden, psychological well-being, and depressive symptoms (Chien et al., 2011) (Pinquart & Sørensen, 2006).

Additionally, we found that there was no statistically significant correlation between caregiver burden, as measured by ZBI scores, and death anxiety, as measured by DAQ scores. This indicates that the burden of caregiving during the pandemic did not necessarily connect with higher levels of death anxiety among caregivers, due to the pandemic. The new condition of confinement seems not to have had as negative an effect as we assumed. Death anxiety was not found to be highly elevated ($M=11,12$) about the average death anxiety experienced by a person (8.5) (Conte, Weiner, & Plutchik, 1982), while the same applies to the psychological burden as mentioned above. Moreover, death anxiety is correlated with having physical problems, psychological distress, weaker religious beliefs, lower ego integrity, lesser life satisfaction, and reduced resilience (Fortner & Neimeyer, 1999). The psychological burden of caregivers is also directly related to these factors and appears mild to moderate after COVID-19. These factors may mediate the relationship between death anxiety and psychological burden, and it justifies the reason for which the death anxiety of caregivers is close to that of the average person. This not statistically significant correlation between psychological burden and death anxiety highlights the need to find other mediating factors as we did not find a significant correlation, while in other studies the negative effect of COVID on death anxiety (Menzies & Menzies, 2020) and psychological burden (Borelli et al., 2021) is highlighted.

While this study contributes deep understanding of the experiences of female caregivers of dementia patients, it is crucial to acknowledge its limitations. The study has sampling bias because it is focused exclusively on female caregivers, limiting its generalizability to the broader population of dementia caregivers, including males. The relatively small sample size, especially in the pre-COVID-19 group, may have limited the statistical power to detect subtle differences. Data was, also, collected from a single location in Greece, potentially restricting the generalizability of findings to different cultural contexts. Finally, the death anxiety questionnaire (DAQ) we used was not adapted and weighted in the Greek language, which made the data we collected not so reliable and representative of the Greek population.

Building on the findings of this research, several avenues for future investigation and intervention emerge. Future research should strive to include a more diverse caregiver population, including male caregivers, to have a more comprehensive perception of the impact of caregiving on different groups. Furthermore, longitudinal studies that track caregiver experiences over an extended period, considering both pre and post-pandemic periods, could provide a more nuanced understanding of the prolonged effects of the pandemic caused by SARS-CoV-2 on caregiver burden and death anxiety. It

is crucial to develop and evaluate support strategies for caregivers, as our findings suggest that professional help alone may not be sufficient to alleviate caregiver burden. These strategies could encompass psychosocial support, respite care, and training programs to equip caregivers with effective coping mechanisms. Expanding research to multiple cultural contexts can additionally help identify cultural variations in caregiver experiences and the impact of pandemics on caregiving. While research interest must also be directed toward the factors that increase death anxiety and how this affects family caregivers.

In conclusion, this study sheds light on the experiences of female caregivers of dementia patients in the context of the COVID-19 pandemic. While our findings suggest that the pandemic did not significantly exacerbate caregiver burden or death anxiety, further research and support services are needed to communicate the complex and multifaceted challenges that caregivers face, particularly in the ever-evolving landscape of healthcare and global crises.

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