

Short Communication

Needs of Dementia Family Caregivers in Spain During the COVID-19 Pandemic

Nuria Carcavilla^{a,b,*}, Ana Sofía Pozo^{b,c}, Belén González^{b,c}, Débora Moral-Cuesta^{b,c}, José Joaquín Roldán^{b,d}, Victoria Erice^{b,e} and Ana Remírez de Ganuza^{b,e}

^a*Institute of Neurosciences of Castilla and Leon (INCYL), Salamanca, Spain*

^b*Dementia Group, Sociedad Navarra de Geriátría y Gerontología, Fundación Colegio de Médicos, Pamplona, Spain*

^c*Geriatrics Service, Complejo Hospitalario de Navarra, Pamplona, Spain*

^d*Clínica Psicogeriátrica Josefina Arregui, Alsasua, Spain*

^e*Asociación de Familiares de personas con Alzheimer y otras demencias de Navarra (AFAN), Pamplona, Spain*

Accepted 12 January 2021

Pre-press 30 January 2021

Abstract. We explored the experience from caregivers of people with dementia (PwD) during mandatory confinement due to the COVID-19 pandemic in Spain. An online survey, which studied the perceptions of the main problems and consequences experienced during confinement, was answered by 106 family caregivers of PwD. Results showed that family caregivers of PwD experienced psychological problems, like anxiety, mood, sleep, or eating disorders during confinement and felt less supported when they had to handle challenging behaviors or offer meaningful activities. An innovative multi-tiered supportive approach is needed which considers a post-pandemic reality and ensures the continuity of quality care for PwD and their family careers.

Keywords: Alzheimer's disease, burden, caregivers, confinement, COVID-19, dementia, family careers, needs, pandemic

INTRODUCTION

People with Alzheimer's disease (AD) are more vulnerable during the coronavirus (COVID-19) pandemic due to their hugely dependence on family or professional caregivers [1, 2]. The protective measures during the COVID-19 pandemic [3] could have increased the difficulties in caring for people with dementia by family caregivers.

Providing care for a family member with dementia can be stressful or even exhausting, and this burden is associated with a higher risk of physical and mental morbidities [4, 5].

During the confinement, the caregivers have increased the time of care by facing the additional security measures and dealing with the fear of not being infected to safeguard the health of their family members; associated factors with increased caregiver burden [6]. Difficult access to support services has caused the breakdown of established routines with consequent negative effects for both parties.

Despite the instruction published by the Boletín Oficial del Estado (BOE) on 20 March [7] that exempted people with mental disorders from mandatory home confinement, caregiver's fear of falling ill

*Correspondence to: Nuria Carcavilla, Institute of Neurosciences of Castile and Leon (INCYL), C/ Pintor Fernando Gallego, 1, CP.37007 Salamanca, Spain. Tel.:+34 627557140; E-mail: nuriacarcavilla@usal.es. ORCID: <https://orcid.org/0000-0003-4301-2514>.

or losing loved ones added to the ignorance of this information did not make possible a good management of PwD.

Moreover, medical appointments were postponed and the health system collapsed. As much as caregivers asked for help, an increase in sedative drugs was the main response they got in almost all cases, which, far from improving the situation, increases the risk of falls and delirium for PwD and, therefore, the caregiver workload.

The objective of our research was to know the caregiver's of PwD experiences and perceptions during the COVID-19 outbreak in Spain and their consequent needs. We also highlight potential methods to provide support to meet these needs.

METHODS

Participants

Caregivers of PwD were recruited from different day care centers, as well as from the *Alzheimer's Family Association (AFAN)* in Navarra, Spain. Family members of all PwD registered in the database were invited to participate in an online survey.

The inclusion criteria were: 1) a family member providing care for and living with the PwD; 2) aged 18 and above; and 3) the PwD must have a confirmed clinical diagnosis of any type of dementia.

All participants were required to provide voluntary consent, which was obtained by email due to the existing circumstances of the pandemic.

Procedure

A descriptive cross-sectional study was conducted based on an online questionnaire created for this purpose. It was designed to be self-administered, anonymous, and to collect information on the following variables:

- a. Caregiver's profile: age, gender, relationship with a dementia patient, the time spent caring for the old adult, and if the caregiver lived with or not with the patient at home.
- b. Main problems for the caregivers during the pandemic: the most complicated moment of the day and the most complicated situations.
- c. Consequences for both dementia patients and their caregivers during the pandemic: progress of cognitive and/or physical impairment.

Caregivers' perceptions were analyzed with descriptive statistics and the main results were presented as percentages of studied variables.

Ethics

A letter with an invitation to participate in the survey was mailed to family members explaining the objectives of the research study. Confidentiality of family members and PwD were strictly preserved through all phases of the survey process and forever after. According to the Spain law, no approval of a Medical Ethics Committee is needed for a survey research that does not involve any intervention.

RESULTS

A total of 106 participants [79 women, 27 men, with ages: 18–30 (1.8%), 31–45 (12.3%), 46–65 (55.7%) and ≥ 65 (30.2%)] answered the survey from May to June 2020. From this, 45 participants were related to the PwD as spouses, 55 were children, 2 were brother or sister, and four participants had another kinship. The time spent caring for the PwD was: <6 months (6%), 6 months–1 year (8%), 1–5 years (46.3%), 5–10 years (30.3%), and >10 years (9.4%). Regarding the form of coexistence, 71.3% of the caregivers live regularly with the PwD, while the rest were occasional cohabitants. All the surveyed participants cared for PwD in moderate-advanced stages, with a profile of moderate functional dependence.

Main problems for dementia family caregivers during the pandemic

The most difficult moment of the day for caregivers was the mid-afternoon and the situations that caused them the most problems were: not be allowed to leave home (56%), shower time (30%), time for playful activities and personal cleanliness (26% each one). Other complicated moments were: the meals and dress time (12.5% each one), and when they had to administer the medication (11.5%).

Consequences for persons with dementia during the pandemic

More than half of the respondents agreed that an increased irritability was the main consequence of mandatory household confinement for PwD, 45% highlighted the decrease in mobility, almost 41% found them sadder, 25% observed an important loss

of autonomy, 21% experienced sleep disorders and, in isolated cases, the PwD presented delusions, more confusion or they felt distrustful or exhausted. When asked careers if they had appreciated physical or cognitive deterioration in the PwD, almost 50% had appreciated both of them, followed by 22.6% who only appreciated progress in cognitive impairment, 17% who did not appreciate any progression, and 5% who only reported a progression in physical deterioration.

Consequences for dementia family caregivers during the pandemic

Regarding the perceptions on the dementia family caregiver, the most frequent feelings/problems were anxiety (57%), mood disorder (41%), sleep disorder (34%), and eating disorder (12%). We found that carrying out leisure or entertainment activities was, by far, the time in which they missed more help (46%), also at shower time (25%), bedtime (21%), personal washing (17%), dressing (12%), and having meals (10%).

Despite this, caregivers reported multiple measures they were taking to deal with these situations. Increasing the dose of medication was the most frequently used measure, without good results in most cases. However, other measures were much more creative like: going out to the balcony, seeing pictures, doing tasks like cleaning, peeling potatoes or cleaning vegetables, doing physical activities for which they even bought pedals, dancing, listening music, playing games like cards or domino, walking through the portal and the garden, making family video conferences, taking time to meditate and breathe, etc. Also, some of them found support in social services, other family members, or in specialized cognitive stimulation caregivers. Exceptionally, some caregivers decided to request a medical report that would allow them to go outside in case the PwD presented behavioral disturbances.

We also asked about the possible measures that would have relieved them in the care of the PwD. The results showed caregivers had missed professional help, especially from a specialized medical team (34%), secondly more support from family or friends (26%), and 9% missed more help from *Alzheimer's Family Association of Navarra*.

The survey ended with an open and optional question: "What would you need if this situation repeats itself?". Some of the answers were as follows:

- "Professional attention/care as an alternative to closing day centers".
- "More support measures to avoid breaking with the routines of these patients".
- "Allow these patients to take walks outside home with their caregivers without time restriction".

DISCUSSION

This research shows the effects of mandatory household confinement for PwD caregivers living in the community during COVID-19 pandemic based on their perceptions.

As described in other European studies [8–10], the most frequent caregiver profile in our sample was a middle-aged female relative, especially daughter or daughter followed by spouse, who lived with the PwD in most cases. Also, our results reinforce that mid-afternoon was the most difficult time of the day for caregivers, probably related to sundown syndrome [11].

Concerning the consequences for people with dementia and according to Canevelli et al. [12], more than 50% of caregivers in our study have observed an important worsening of neuropsychiatric symptoms in their relatives and the vast majority of them observed a cognitive impairment more frequently than functional one. This agrees with the results found by Lara et al. [8], showing that apathy and anxiety were the most common symptoms among people with mild cognitive impairment and apathy, agitation, and aberrant motor behavior among PwD during the COVID-19 lockdown. In the same line, our results identified irritability and sadness as the most prevalent symptoms.

Regarding the consequences for caregivers, more than a half stated that they had often felt anxiety, followed by mood, sleep, and eating disorders. Other studies defend that COVID-19 pandemic and the lockdown increased the levels of depression rather than of anxiety [13]. These findings are of concern to health professionals and a lot of studies note the negative effect of anxiety on caregiver burnout [14, 15], which is reported in a considerable percentage of dementia caregivers [16], being the female sex a risk factor not only for becoming a caregiver but also for experiencing caregiving as a burden [17, 18]. Also, our results showed that caregivers often feel frustrated when they do not have social and/or family support and, this is similar to the findings of Canevelli et al. [12], where caregivers complain of having

poor support in the most difficult moments, with the consequent feeling of loneliness and isolation in 54% of cases.

This frustration could be translated as dissatisfaction, displeasure, and annoyance, resulting in exhaustion, depression, stress, and ultimately, in burnout [19]. In this context, it should be noted that resilience, which often produces a large effect size on the severity of depression and anxiety in caregivers, does not seem to have a protective effect on caregivers' psychological status during COVID-19 pandemic [13].

The Spanish Ministry of Health, Consumption and Social Welfare has published a Technical Document with Recommendations for nursing homes and social health centers for COVID-19. These steps, while going in the right direction, do not take into account the needs of caregivers in community settings. The caregivers in our study reported the negative effect of the restrictions on their family members and the feeling of not having the support of public institutions, transforming their role as caregivers into a great complicated job. A clear policy of direct support for people with dementia and their caregivers living in the community is needed.

Our results reinforce the need to rely on innovation and technology in order to offer permanent support to PwD's caregivers. For this, it is essential to make these new technology-based supports accessible, breaking down the economic and knowledge barriers around it. Health and social services should strive to design practical approaches through technology that offer clinical and psychosocial services even in "normal" times, including: psychological support, resources for the management of dementia, safety measures, spaces for social connection, and physical health.

Limitations

The main limitations of our study included the small size of the sample, the inclusion of participants from a single autonomous community of Spain, and the lack of prospectively longitudinal follow-up. Another limitation was that we did not use validated instruments to measure variables such as burden of care or anxiety because our main objective was to report issues related to caregiver's experiences and perceptions during the pandemic in a preliminary way. Furthermore, the results of the study are reported prior to the pandemic by caregivers and it would be necessary to take pre-post measures to analyze the

temporal and causal relationship between them and confinement. This last point, added to the simplicity of the study design, resulted in the lack of a robust statistical analysis.

CONCLUSION

Our study confirms previous evidence related to the caregivers and PwD experiences and health outcomes during the COVID-19 outbreak in Spain.

A multi-layered supportive approach is needed that considers a post-pandemic reality where the negative effects of social isolation on people with dementia and their caregivers are minimized and the continuity of quality care is guaranteed.

ACKNOWLEDGMENTS

The authors would like to thank the caregivers who, despite the increased workload during the COVID-19 crisis, have dedicated their time to answer the survey. This research was supported by the Dementia Group of the *Navarra Society of Geriatrics and Gerontology* and by the *Alzheimer's Family Association of Navarra (AFAN)*.

Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/20-1430r1>).

REFERENCES

- [1] Migliaccio R, Bouzigues A (2020) Dementia and COVID-19 lockdown: More than a double blow for patients and caregivers. *J Alzheimers Dis* **4**, 231-235.
- [2] Wang H, Li T, Barbarino P, Gauthier S, Brodaty H, Molinuevo JL, Xie H, Sun Y, Yu E, Tang Y, Weidner W, Yu X (2020) Dementia care during COVID-19. *Lancet* **395**, 1190-1191.
- [3] Gerst-Emerson K, Jayawardhana J (2015) Loneliness as a public health issue: The impact of loneliness on health care utilization among older adults. *Am J Public Health* **105**, 1013-1019.
- [4] Zhang F, Cheng S, Gonçalves-Pereira M (2020) Factors contributing to protection and vulnerability in dementia caregivers. In *Genetics, Neurology, Behavior, and Diet in Dementia, The Neuroscience of Dementia*, Vol 2, Martin C, Preedy V, eds. Academic Press, pp. 709-722.
- [5] Bertand RM, Fredman L, Saczynski J (2006) Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *J Aging Health* **18**, 534-555.
- [6] Allen AP, Buckley MM, Cryan JF, Ní Chorcóráin A, Dinan TG, Kearney PM, O'Caomh R, Calnan M, Clarke G, Molloy DW (2019) Informal caregiving for dementia patients: The contribution of patient characteristics and behaviours to caregiver burden. *Age Ageing* **49**, 52-56.
- [7] España. Instrucción 3898/2020, de 19 de marzo, del Ministerio de Sanidad, por la que se establecen criterios

- interpretativos para la gestión de la situación de crisis sanitaria ocasionada por el COVID-19. Boletín Oficial del Estado, 20 de marzo de 2020, núm. 76, <https://www.boe.es/boe/dias/2020/03/20/pdfs/BOE-A-2020-3898.pdf>, Accessed 8 August 2020.
- [8] Lara B, Carnes A, Dakterzada F, Benitez I, Piñol-Ripoll G (2020) Neuropsychiatric symptoms and quality of life in Spanish patients with Alzheimer's disease during the COVID-19 lockdown. *Eur J Neurol* **25**, 1744-1747.
- [9] The Alzheimer Society of Ireland (2020) Caring and Coping with Dementia During COVID-19.
- [10] Sharma N, Chakrabarti S, Grover S (2016) Gender differences in caregiving among family—Caregivers of people with mental illnesses. *World J Psychiatry* **6**, 7-17.
- [11] Shih YH, Pai MC, Lin HS, Sung PS, Wang JJ (2020) Effects of walking on sundown syndrome in community-dwelling people with Alzheimer's disease. *Int J Older People Nurs* **15**, e12292.
- [12] Canevelli M, Valletta M, Toccaceli Blasi M, Remoli G, Sarti G, Nuti F, Sciancalepore, F, Ruberti E, Cesari M, Bruno G (2020) Facing dementia during the COVID-19 outbreak. *J Am Geriatr Soc* **68**, 1673-1676.
- [13] Altieri M, Santangelo G (2021) The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. *Am J Geriatr Psychiatry* **29**, 27-34.
- [14] Jütten LH, Mark RE, Sitskoorn MM (2019). Empathy in informal dementia caregivers and its relationship with depression, anxiety, and burden. *Int J Clin Health Psychol* **19**, 12-21.
- [15] Savva GM, Zaccai J, Matthews FE, Davidson JE, McKeith I, Brayne C; Medical Research Council Cognitive Function and Ageing Study (2009) Prevalence, correlates and course of behavioural and psychological symptoms of dementia in the population. *Br J Psychiatry* **194**, 212-219.
- [16] Ekström H, Lundholm-Auoja N, Sölve E, Sandin-Wranker L (2020) High burden among older family caregivers is associated with high prevalence of symptoms: Data from the Swedish Study "Good Aging in Skåne (GÅS)". *J Aging Res* **2020**, 5272130.
- [17] Adelman RD, Tamanova LL, Delgado D, Dion S, Lachs MS (2014) Caregiver burden: A clinical review. *JAMA* **311**, 1052-1060.
- [18] Abajo M, Rodríguez-Sanz M, Malmusi D, Salvador M, Borrell C (2017) Gender and socio-economic inequalities in health and living conditions among co-resident informal caregivers: A nationwide survey in Spain. *J Adv Nurs* **73**, 700-715.
- [19] Nascimento HGD, Figueiredo AEB (2019) Dementia, family caregivers and health service: The care of yourself and the other. *Cien Saude Colet* **24**, 1381-1392.