

# Impact of the Pandemic Time on the Mental Health of People with Dementia and Their Family Caregivers in Brazil and Chile: One-Year Follow-Up

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## Abstract.

**Background:** Previous studies reported the negative impact of social isolation on mental health in people with dementia (PwD) and their caregivers, but longitudinal studies seem scarcer.

**Objective:** To describe a one-year follow-up impact of the COVID-19 pandemic on PwD and their caregivers in both Brazil and Chile.

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**Methods:** This study analyzed the impact of the pandemic on the psychological and physical health of PwD and their family caregivers after one year of follow-up in three outpatient clinics in Brazil ( $n=68$ ) and Chile ( $n=61$ ).

**Results:** In both countries, PwD reduced their functional capacity after one year of follow-up ( $p=0.017$  and  $p=0.009$ ; respectively) and caregivers reported worse physical and mental health ( $p=0.028$  and  $p=0.039$ ). Only in Chile, caregivers reported more sadness associated with care ( $p=0.001$ ), and reduced time sleeping ( $p=0.07$ ).

**Conclusions:** In conclusion, the COVID-19 pandemic appears to have had a long-lasting impact on PwD and their caregivers. However, it is essential to acknowledge that the inherent progression of dementia itself may also influence changes observed over a year.

Keywords: Alzheimer's disease, behavioral symptoms, caregiver, COVID-19, dementia, follow-up studies

## INTRODUCTION

The worldwide COVID-19 pandemic has been a major challenge for the health system in the past years [1, 2]. In Latin America, and most world countries, there were extensive lockdowns from March 2020 until 2022 to ensure physical distance and to reduce virus transmission [3, 4]. Although there has been an increasing interest in the effects of COVID-19 as a disease, social isolation during the pandemic is an indirect cost of the pandemic on mental and physical health, especially among vulnerable populations, such as children, teenagers, and especially older adults [5–9].

One particularly vulnerable group is people with dementia (PwD) and their caregivers. Due to the characteristics of dementia, it is a common phenomenon that the PwD-caregiver dyad experiences social isolation which is associated with an increased feeling of stress and loneliness [10]. At the beginning of the lockdowns, it was not clear whether the social isolation would have a negative effect on the dynamics between PwD and their caregivers, especially in Latin America, but in a recent study of our group [11], we described the negative impact of social isolation in centers from Argentina, Brazil, and Chile during 2020, while COVID-19 was not controlled and strict lockdown restrictions were in place. Although several studies have reported the effect of the pandemic on PwD since then [12–15], there are only a few studies with a longitudinal evaluation to measure the impact of isolation over time in PwD and their caregivers [16–18], and none of them addresses the situation in Latin America. Some results reported a decrease in the prevalence of behavioral symptoms, especially agitation, and depression, during follow-up. While symptoms such as apathy remained a year after the pandemic in PwD in nursing homes [18]. Therefore, there is a gap in research regarding the long-lasting effects of the pandemic on PwD and their caregivers.

The goal of this paper is to report a one-year follow-up of PwD and their caregivers in Brazil and Chile. We hypothesize that the pandemic has had a significant impact on individuals with dementia and their caregivers.

## METHODS

### *Study designs and subjects*

This is a longitudinal study in which the impacts of social isolation due to the COVID-19 pandemic were analyzed on both PwD and their family caregivers with a telephonic interview in 2020 [11], and a one-year follow-up. We included PwD of any etiology and their family caregivers from three outpatient clinics in South America: two in Brazil and one in Chile.

Each clinic was responsible for the follow-up of its participants. Family caregivers were allowed to ask any questions regarding the process and only included those who had been accepted to participate and who had also signed the informed consent previously sent by email. This study was approved by the research ethics committees of the three clinical centers.

### *Data collection and processing*

Data collection was performed through telephone interviews with the family caregiver that answered two semi-structured questionnaires prepared by the study investigators, based on the instrument used in 2020 (see [11]). The questionnaires assessed changes that both PwD and their family caregivers might have had during the follow-up time from the caregiver's perspective. The information regarding PwD included neuropsychiatric and behavioral symptoms, cognitive changes, and functionality decline among others. While the caregiver's perception addressed their own physical and mental health, including symptoms such as anxiety, sleep disorders, and

Table 1

Global socio-demographic characteristics of both patients with dementia and their caregivers at baseline considering the full sample, a subsample lost at one-year follow-up and a subsample with one-year follow-up

	Patients with dementia			Caregivers		
	Full sample (n = 217)	Subsample lost at one-year follow-up (n = 88)	Subsample with one-year follow-up (n = 129)	Full sample (n = 217)	Subsample lost at one-year follow-up (n = 88)	Subsample with one-year follow-up (n = 129)
Age, y	77.2 ± 9.9	76.2 ± 9.3	77.9 ± 10.2	58.2 ± 14.7	56.6 ± 15.9	59.2 ± 13.8
Education, y	8.6 ± 5.6	8.8 ± 5.8	8.5 ± 5.5	12.2 ± 4.4	12.4 ± 4.5	12.1 ± 4.4
Female, n (%)	122(56.2%)	47(53.4%)	75(58.1%)	177 (81.6%)	71(80.7%)	106(82.2%)

No significant differences were observed at baseline between the subsample with lost follow-up and the subsample with one-year follow-up. Paired *t*-tests for quantitative variables and McNemar test for frequencies.

caregiver burden, among others. In this study, we used a shorter version for the follow-up. In the follow-up study we drop out questions related to sociodemographic characterization and household characteristics. These changes were made to streamline the questionnaire administration process and reduce respondent burden while maintaining the continuity of the core questions measuring the impact of dementia on families. Importantly, questions regarding the effects of the pandemic remained unchanged in the follow-up questionnaire. Family caregivers reported any changes experienced in these areas by comparing their current situation to the previous study time. There were three possible answers to these questions: yes, partially, or no. For analysis purposes, both answers (yes and partially) were considered as a change in the symptoms.

### Statistical analysis

Statistical analysis was conducted using SPSS version 22 (IBM Co., USA). The analysis focused on individuals with dementia (PwD) and their caregivers included in the follow-up, totaling 129 participants (61 from Chile and 68 from Brazil). Comparisons between PwD and their caregivers with and without follow-up were performed using paired *t*-tests for numerical variables and the McNemar test for categorical variables. Also, the severity of dementia of 212 PwD from baseline (out of 216) was divided into two groups: with and without follow-up. Severity of dementia of PwD was then compared between both groups, using chi-square test analyses. Statistical significance threshold was set at  $p < 0.05$ .

## RESULTS

A total of 216 PwD were included in this one year follow-up study: 111 PwD from Brazil (age

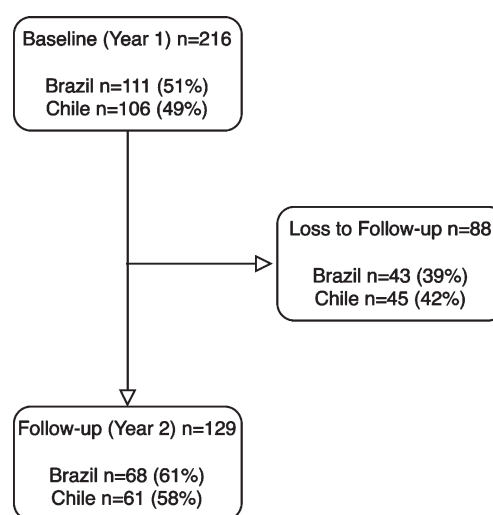


Fig. 1. Flow diagram of participants included in the follow-up.

78.0 ± 10.1 years, 57% women, with 7.6 ± 6.1 years of education) with their caregivers (age 57.1 ± 13.9 years, 81% women, with 11.3 ± 4.7 years of education), and 106 PwD from Chile (age 76.3 ± 9.5 years, 56% women, with 9.7 ± 4.8 years of education) with their family caregivers (age 59.4 ± 15.4 years, 82% women, with 13.1 ± 4 years of education). No significant differences between countries were observed in the total sample in relation to age and educational level (Table 1 for the total sample and Supplementary Table 1 for the sample divided by country). For more information regarding the follow-up process, see Fig. 1.

The baseline assessment included 40 patients with mild dementia, constituting 31.75% of the total sample, along with 41 individuals with moderate dementia, representing 32.54% of the total sample. Additionally, there were 45 patients with severe dementia, making up 35.71% of the total sample.

Table 2  
Dementia severity at baseline

Dementia severity at baseline	Full sample (N = 212)		Subsample with one-year follow up (N = 126)		Subsample lost at one-year follow up (N = 86)	
	N	%	N	%	N	%
Mild	64	100	40	62.50	24	37.59
Moderate	66	100	41	62.12%	25	37.88%
Severe	82	100	45	54.88%	37	45.12%

Number and percentage of patients with dementia according to severity of dementia. Chi-square analysis:  $p = 0.562$ .

Table 3  
Global responses of patients with dementia in a year of follow-up during the pandemic time

Responses about persons with dementia	N	Global		p
		Baseline	Follow-up	
I am feeling sadder than before	122			1.000
Yes, n (%)		60 (49.2%)	63 (51.5%)	
No, n (%)		62 (50.8%)	59 (48.4%)	
I am feeling more aggressive	121			0.013
Yes, n (%)		42 (34.7%)	52 (43%)	
No, n (%)		79 (65.3%)	69 (57%)	
I have worsened my memory	121			0.000*
Yes, n (%)		83 (68.6%)	90 (74.4%)	
No, n (%)		38 (31.4%)	31 (25.6%)	
I have reduced my functional capacity to perform ADL <sup>1</sup>	121			0.353
Yes, n (%)		52 (43%)	79 (65.3%)	
No, n (%)		69 (57%)	42 (34.7%)	
I am sleeping more during this time	121			0.000*
Yes, n (%)		20 (16.5%)	26 (21.5%)	
No, n (%)		101 (83.5%)	95 (78.5%)	

<sup>1</sup>ADL, activities of daily living. Quantitative variables were analyzed with paired *t*-tests and frequencies were compared with McNemar test; \* $p < 0.05$ .

An analysis using a chi-square test indicated no statistically significant variations in dementia severity between the group with follow-up and the group without follow-up ( $p = 0.562$ ) (please see Table 2 for details).

The follow-up showed that the perception of worsening in all areas persisted over time in both countries after the pandemic (Table 3 for the total sample and Supplementary Table 2 for the sample divided by country). There were areas in which the perception of worsening was more accentuated. In Brazil, compared to baseline, after one year of follow-up, PwD perceived a worsening in memory function ( $p = 0.001$ ), and an increase in their aggressive behavior ( $p = 0.04$ ).

In Chile, compared to baseline, after one year of follow-up, PwD reduced the functional capacity to perform activities of daily living ( $p = 0.03$ ), and perceived a worsening in memory function ( $p = 0.000$ ) while caregivers reported worse physical and mental health ( $p = 0.023$ ), and reduced sleeping time ( $p = 0.000$ ) (Table 4 for the total sample and Supplementary Table 3 for the sample divided by country).

## DISCUSSION

Our main results demonstrate that the COVID-19 pandemic affected all the dimensions measured. In Chile, we observed a worsening of the physical and mental health of caregivers, with symptoms that persisted after one year, while the diminished capacity to perform activities of daily living and memory loss of PwD were significant. In Brazil, PwD perceived increased memory loss and aggressive behavior, but their caregivers did not manifest a worsening in their own condition. Even if the COVID-19 pandemic had an effect globally as a society, PwD are a particularly vulnerable group of the population, because the majority of PwD are old and, thus, at major risk of being severely ill [19], and most of them had difficulties in maintaining proper self-care against the virus (e.g., using the face mask correctly). For this reason, the period of the pandemic caused a great burden on caregivers of PwD [20] who were exposed to even greater social isolation than they faced before the pandemic [21]. Caregivers of PwD often experience burden, especially when

Table 4  
Global responses of caregivers of patients with dementia in a year of follow-up during the pandemic time

Responses of the caregiver of patients with dementia	n	Global		p
		Baseline	Follow-up	
I have worsened my physical and mental health	123			0.057
Yes, n (%)		60 (48.8%)	83 (67.5%)	
No, n (%)		63 (51.2%)	40 (32.5%)	
I am receiving more help to care for my relative	125			0.576
Yes, n (%)		61 (48.8%)	71 (56.8%)	
No, n (%)		64 (51.2%)	54 (43.2%)	
I am crying more because of taking care of my relative	129			0.115
Yes, n (%)		56 (43.4%)	53 (41.4%)	
No, n (%)		73 (56.6%)	75 (58.6%)	
I am sleeping more during this time	129			0.000*
Yes, n (%)		36 (27.9%)	33 (25.6%)	
No, n (%)		93 (72.1%)	96 (74.4%)	

Quantitative variables were analyzed with paired *t*-tests and frequencies were compared with McNemar test; \**p* < 0.05.

providing long-term care. The increased presence of neuropsychiatric symptoms can act as a risk factor for caregiver overload [22], significantly impacting their quality of life. Some studies have demonstrated that certain neuropsychiatric symptoms better predict caregiver burden. Allegri et al. [23] highlight that hallucinations, unusual (motor) behavior, and abnormal behavior at nighttime are particularly significant in this regard. Subsequent findings have further supported these observations [24]. The impact of these neuropsychiatric symptoms, however, may be mediated by other variables, such as the caregiver's coping style [25, 26], age of the caregiver [27], dementia etiology [28], the amount of time dedicated to caregiving [29], among other factors. One of the potential direct consequences of the pandemic has been the restriction of available caregiving support, further limiting the caregiver's opportunities for activities unrelated to caregiving and negatively affecting their quality of life [30, 31].

However, there is a difference between Brazil and Chile in the emotional component associated with care. While in Brazil, PwD had an increased memory loss and aggressive behavior, there was not a significant worsening of caregiver health. The opposite phenomenon occurred in Chile, where the caregiver underwent a decline in their physical and mental well-being, without an accompanying escalation in the neuropsychiatric aspect. This difference could be mediated by the different cultural subjective processes that are characteristic of each culture which influences coping strategies [32, 33].

Nevertheless, even if several studies [21, 34, 35], reported that the pandemic had a negative impact on PwD and their families, it is not clear whether the effects were reversible once the sanitary restrictions

were lessened. Our results suggest that the effects of the pandemic on the trajectory of dementia and on the caregiver's health are long-lasting even if the restrictions of the pandemic were less severe. Studies that have reported on the follow-up of PwD and caregivers are scarce, but they are all consistent with the results reported in this study, showing the negative impact that social isolation had on PwD and caregivers [16–18]. Importantly, our results are also consistent with studies on the perception of professionals working in dementia care, who noted changes in functionality, and motor skills with more of a prevalence of falls over a two-year follow-up study [36].

The follow-up data was performed at a moment when the pandemic restrictions were still in place, although less severe, which suggests that the effects of the pandemic on the trajectory of dementia and on caregiver's health are long-lasting, with a complex relationship with the variable of physical distance, which could be mediated by other factors. However, it is important to highlight that COVID-19 non-pharmaceutical intervention policies in Brazil were heterogeneous in their implementation, which was not the case for Chile, a country that followed strict and homogeneous protocols [37]. Furthermore, up until this point, the potential implications of these variations on the physical and mental well-being of both the general population and our specific population of interest remain unexplored. It is essential to acknowledge that the circumstances in the two countries may not be directly comparable due to the differing measures implemented during the pandemic. Consequently, while our study sheds light on aspects of the experiences of individuals with dementia and their families, it is important to exercise caution when interpreting the outcomes.

A limitation of our study is the relatively small sample size and that between 39%-41% of subjects dropped out of the study for reasons that were not systematically registered. Although the severity of dementia did not differ between the groups with and without a one-year follow-up, almost half of the participants with severe dementia (37 out of 82, or 45.12%) were lost to follow-up. This represents a potential bias in our study, as is often reported in longitudinal studies on dementia [38]. It is important to mention that the study was carried out during the COVID-19 pandemic, so it was complicated to adequately monitor all participants because the only contact was by telephone. However, it did have the advantage of collecting longitudinal data from two Latin American countries, with a greater sample size than other studies from the region. A second aspect that must be considered is the progressive nature of dementia [22, 39], which could partially explain the findings besides the effect of the pandemic. Therefore, the results should be interpreted with caution.

A second limitation of this study is the utilization of a non-validated questionnaire to collect data from the relatives of dementia patients due to the COVID-19 emergency context. The absence of established validity and reliability measures may introduce biases, errors, and ambiguity in responses, impacting the accuracy of our results. In future studies, employing validated questionnaires to assess the impact of dementia on families would significantly improve the reliability and validity of the data collected.

A third limitation is that our results report the perception of the family caregiver, which is not a direct measure of the patient's health or capability. Numerous reasons could influence the perception of worsening physical or mental health of the PwD some of them related to the emotional factor of the caregiver [40–42]. Thus, future research should also consider a direct evaluation of PwD, now that the pandemic restrictions are gone.

### Conclusion

The pandemic had a notable impact on individuals with dementia, particularly leaving a lasting effect on Chilean caregivers, whose physical and mental health were significantly affected compared with Brazilian caregivers, which could be mediated by cultural and social aspects.

### AUTHOR CONTRIBUTIONS

Loreto Olavarría, MS (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Writing – original draft; Writing – review & editing); Paulo Caramelli, MD, PhD (Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Writing – review & editing); José Daniel Lema (Data curation; Formal analysis; Writing – review & editing); Caíssa Andrade (Investigation; Writing – review & editing); Alejandra Pinto (Investigation; Writing – review & editing); Lílian Viana dos Santos (Investigation; Writing – review & editing); Daniela Thumala, MS, PhD (Conceptualization; Investigation; Writing – review & editing); Maria Carolina Santos (Investigation; Writing – review & editing); Adriana Peredo (Investigation; Writing – review & editing); Alana Barroso Generoso (Investigation; Writing – review & editing); Karoline Carvalho Carmona (Investigation; Writing – review & editing); Walter Sepúlveda-Loyola (Data curation; Formal analysis); Ludmilla Aparecida Cardoso (Investigation; Writing – review & editing); Maira Tonidandel Barbosa (Conceptualization; Investigation; Writing – review & editing); Andrea Slachevsky, MD, PhD (Conceptualization; Formal analysis; Funding acquisition; Investigation; Writing – original draft; Writing – review & editing).

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## CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

Andrea Slachevsky and Paulo Caramelli are Editorial Board Members of this journal but were not involved in the peer-review process nor had access to any information regarding its peer-review.

## DATA AVAILABILITY

The data is available on request from the authors.

## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/JAD-231310>.

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