

# Mental Health of People with Dementia During COVID-19 Pandemic: What Have We Learned from the First Wave?

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Accepted 20 May 2021

Pre-press 1 June 2021

## Abstract.

**Background:** People with dementia (PWD) and their caregivers are populations highly vulnerable to COVID-19 pandemic and its consequences. A better knowledge of the living conditions during the first lockdown is necessary to prevent the risk of poor mental health (PMH) in this population.

**Objective:** The present study aimed to compare the mental health of caregivers of PWD living at home or in nursing-homes and to identify specific factors influencing their mental health.

**Methods:** We conducted an anonymous cross-sectional online survey in France from March 17 to May 11, 2020. Three hundred and eighty-nine caregivers accompanying a PWD living at home (HC) and 159 accompanying a PWD living in a nursing home (NHC) participated in the study. Caregivers' mental health including anxiety, depression, stress, and burden was assessed with self-reported standardized scales.

**Results:** Half of the caregivers exhibited PMH, including depression, anxiety, or self-reported stress. Similar PMH rates were provided whatever the PWD place of residence. Regarding HC, our results also highlighted a number of risk factors for PMH, including the fact that caregiver live with PWD, to give increased support to PWD, and to feel more isolated for managing PWD since lockdown.

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**Conclusion:** PMH was observed for caregivers of PWD during lockdown, whatever PWD living place, suggesting that concern for PWD may explain more of caregiver distress than increased material tasks. In the future, it will be necessary to pay attention to caregivers after the crisis by estimating the longer-term impact on their mental health.

Keywords: Alzheimer's disease, caregivers, COVID-19, dementia, lockdown, mental health

## INTRODUCTION

People with dementia (PWD) and their caregivers are populations highly vulnerable to COVID-19 pandemic and its consequences, including the lockdown measures enacted by various governments in the past months. In France, the Government imposed a nationwide lockdown from March 17, 2020 to May 11, 2020. During this period, people were only allowed to leave their homes to buy essential goods, briefly exercise, or seek medical help. Since most PWD are frail elderly people, they are at high risk of developing a severe form of COVID-19. In this regard, additional protective measures were enforced to limit the spread of COVID-19 among PWD. Especially, in nursing-homes, physical contact was prohibited between residents as well as between residents and visitors or professional caregivers [1]. Rapidly, visitors were banned from nursing homes as more rigorous measures were enacted. All these above-mentioned measures may have dramatically increased loneliness and negatively impacted caregivers of PWD. Furthermore, while an increase in dementia symptoms severity has been associated with the lockdown [2, 3] caregivers received less professional support during this period. Thus, the lockdown period may have exerted deleterious consequences on people caring for PWD.

A better knowledge of the living conditions and the difficulties during the first lockdown among caregivers of PWD is necessary to prevent or reduce the risk of poor mental health (PMH) in this population. Previous studies have shown that lockdown was associated with an increase in behavioral and psychological symptoms of dementia (BPSD), leading to negative consequences on caregivers' mental health [3, 4]. To date, only few studies have investigated the psychological consequences of the lockdown measures on caregivers of PWD. It has been highlighted that time of isolation had a significant negative effect on anxiety, depression, and well-being in caregivers [5–7], but little is known concerning the factors associated with their PMH. In addition, the impact of lockdown on caregiver is probably different depending on where the PWD live (at home or

in nursing-home). The objectives of this research are twofold: to compare the mental health of caregivers of PWD living at home or in nursing-homes and to identify specific factors influencing their mental health.

## METHODS

### *Participants and data collection*

We conducted an anonymous cross-sectional online survey in France from April 15 to June 15, 2020. The inclusion criteria for the study required participants to be a non-professional caregiver of a PWD living at home or in nursing-home and be at least 18 years old. In line with French regulations on health research, no ethics committee approval was required since collected data was anonymous. Participants were recruited from various sources: e-mails were sent to members of the France Alzheimer Association, information about the survey was given during medical phone appointments carried out during the lockdown or in the month following its end.

### *Questionnaires*

Two different versions of the online survey were available, one for caregivers supporting a PWD living at home (home caregivers, HC), the other one for caregivers supporting a PWD living in a nursing home (nursing home caregivers, NHC). Additionally, printed questionnaires were provided to participants who did not have a web connection. The global questionnaire is presented in the Supplementary Material. Only items from this questionnaire exploring clinical issues were analyzed for this article.

The two versions of the survey shared common questions regarding sociodemographic data, dementia etiology, symptoms duration, caregiver and PWD personal and environmental conditions during lockdown, fear regarding COVID-19 for themselves and PWD, caregivers' mental health (including anxiety, depression, stress, burden, and difficulties to feel well-rested or to practice physical activities).

Additionally, the questionnaire dedicated to HC addressed specific questions about the PWD living conditions, the support provided by the caregiver to the PWD and the intervention of professional caregivers at home.

The questionnaire completed by NHC explored the possibility offered by nursing homes to contact the PWD by phone or video or to visit him/her after the lockdown, when the measures were more flexible. Moreover, the quality of information provided to caregivers by the nursing home staff about the PWD health during the lockdown, was also investigated.

### *Caregivers' mental health scales*

Self-reported scales were used to assess caregivers' mental health (including anxiety, depression, stress, and caregivers' burden). Anxiety was assessed with the GAD-7 scale (The General Anxiety Disorder-7 [8]). This scale consists of 7 items measuring the presence and severity of anxiety symptoms, specifically linked to the *DSM-IV* criteria. Each of the 7 items is scored from 0 to 3, and the GAD-7 scale score ranges from 0 to 21. A score from 5 to 9 can be interpreted as mild anxiety, 10 to 14 as moderate anxiety, and 15 to 21 as severe anxiety. A score below 5 means no anxiety. A cut-off of 10 is recommended for identifying cases of generalized anxiety [8].

Depressive symptoms were assessed with the CES-D scale (Center for Epidemiologic Studies-Depression [9]), which contains 20 items assessing the subject's mood by evaluating the experienced symptoms or behaviors associated with depression. The frequency of symptoms onset during the past week has been measured using a 4-point Likert scale. The highest score is 60 points. A cut-off of 20 is recommended to identify major depressive disorder [10].

The caregiver's burden was assessed using the validated short version of the Zarit Burden Interview [11]. The continuous score ranged from 0 (no burden) to 7 (highest burden). This score is the sum of the answers to 7 questions to which the caregivers answered "never" (0), "sometimes" (0.5), or "nearly always" (1). A score from 0 to 1 corresponds to "no or slight burden", 1.5 to 3 to "slight to moderate burden", 3.5 to 5 to "moderate to severe burden" and 5.5 and over to "severe burden".

The level of self-rated stress was assessed with a visual analog scale ranging from 0 (no stress at all) to 10 (highest stress you can imagine). This scale was constructed specifically for the purpose of this study.

To provide clinically relevant scores according to literature, each of caregivers' mental health scores was transformed into binary variables: for the Mini-Zarit scale, a score from 0 to 5 corresponded to "no to moderate burden" and a score from 5.5 to 7 to "severe burden" [11]. Regarding the GAD-7, a score from 0 to 9 corresponded to "no or mild anxiety", and 10 and over to "moderate or severe anxiety" [8]. For self-rated stress, a score from 0 to 5.9 corresponded to "no or mild stress" and 6 to 10 to "moderate to severe stress". Finally, a score from 0 to 19 on CES-D scale corresponded to "no major depressive disorder", and 20 and over "presence of major depressive disorder" [10].

### *Statistical analysis*

Characteristics of caregivers and PWD were described and summarized using mean, SD, median, IQR or patient's repartition (percentage), and compared between HC and NHC when appropriate, using Chi2 test for categorical variables and Student *t*-test or Mann-Whitney test for continuous variables, according to Kolmogorov-Smirnov test for normality.

Relationships between caregivers' status and PWD characteristics and caregivers' mental health scales, including Mini-Zarit, GAD7, CES-D and self-rated stress (considered as continuous variables) were assessed using Student *t*-test or Mann-Whitney test when appropriate.

To identify independent predictors of caregivers' poor mental health for HC, the association between caregivers or PWD characteristics and caregivers' poor mental health (using binary variables as defined in the 'Caregivers' mental health scales' section) were assessed with multiple logistic regressions adjusted on caregiver and PWD age, sex, number of years since dementia symptoms onset and the fact that the caregiver lives with the PWD.

For each analysis, a *p* value < 0.05 was considered to be statistically significant. All statistical analyses were performed using SPSS version 21.

## **RESULTS**

### *Environmental and relational aspects for caregivers and PWD*

#### *Caregivers and PWD characteristics*

Three hundred and eighty-nine caregivers supporting a PWD living at home ('home caregivers',

Table 1  
Caregivers and PWD characteristics

	HC (N=389) n (%)	NHC (N=159) n (%)	Test value <sup>1</sup>	p
PWD sex				
Female	206 (53.7)	119 (74.8)	21.57	<0.0001
Male	180 (46.3)	40 (25.2)		
Caregiver sex				
Female	280 (72)	127 (79.9)	2.90	0.09
Male	104 (26.7)	32 (20.1)		
Dementia etiology				
Alzheimer's disease	245 (63.5)	107 (63.7)	12.14	0.10
Parkinson's disease	23 (6.0)	1 (0.6)		
Lewy body disease	5 (1.3)	4 (2.5)		
Frontotemporal disease	28 (7.3)	4 (2.5)		
Vascular dementia	16 (4.1)	4 (2.5)		
Other diagnosis	45 (11.6)	24 (15.1)		
Unknown diagnosis	24 (6.2)	15 (9.4)		
Caregiver relationship to PWD				
Spouse	210 (54)	33 (20.8)	245.4	<0.0001
Child	153 (39.3)	113 (71.1)		
Others	22 (5.7)	10 (6.3)		
Caregiver status				
Unmarried/separated	71 (18.3)	42 (26.4)	3.42	0.07
Married/Cohabitation	310 (79.7)	117 (73.5)		
Caregiver occupational status				
Gainfully employed	139 (35.7)	59 (37.1)	0.08	0.78
Not employed	249 (64)	100 (62.9)		
	HC Means (SD)	NHC Means (SD)	Test value <sup>2</sup>	p
Caregiver age	62.99 (12.99)	61.72 (10.18)	1.09	0.28
	HC Median (IQR*)	NHC Median (IQR)	Test value <sup>3</sup>	
PWD age	80 (73–86)	83.87 (8.37)	–819	<0.0001
Time since lockdown onset	60 (57–66)	64.98 (11.40)	–4.90	<0.0001

HC, caregiver of PWD living at home; NHC, caregiver of PWD in nursing-home. <sup>1</sup>Pearson's  $\chi^2$  test; <sup>2</sup>Student *t* test; <sup>3</sup>Mann-Whitney test. \*IQR, inter-quartile range.

HC) and 159 caregivers supporting a PWD living in a nursing home ('nursing-home caregivers', NHC) participated in the study. The sociodemographic characteristics of the caregivers and the PWD are reported in Table 1. Compared to NHC, HC were significantly more often women (74.8% versus 53.7%,  $p < 0.0001$ ) and spouses (54% versus 20.8%,  $p < 0.0001$ ). PWD living in nursing-homes were older than those living at home (83.9 years versus 77.0,  $p < 0.0001$ ).

#### Fear of contracting a severe form of COVID-19

Regarding the fear about infection, 87 HC (22.5%) and 33 NHC (20.8%) thought they were at risk of developing a severe form of COVID-19. Moreover, 178 HC (46%) and 78 NHC (49.1%) thought that the PWD they cared for was at risk of contracting a severe form of COVID-19. Finally, 87 HC (22.4%) and 52 NHC (32.7%) reported having people suffering from COVID-19 in their family circle or friends

while 30 HC (7.7%) and 25 NHC (15.7%) had a relative deceased from COVID-19.

#### PWD living at home

Regarding PWD living at home, 230 (61.2%) lived in an individual house, and 150 (38.6%) in a flat; 285 (73.3%) had access to a garden or a balcony; 45 (11.6%) reported feeling cramped in their accommodation. Furthermore, 104 (27%) PWD lived alone while 281 (73%) lived with someone, usually with their spouse (255, 66.2%); 259 caregivers (66.6%) declared that they lived with PWD.

#### Relationships between home caregivers and PWD

Since the beginning of the lockdown, 274 HC (73.1%) have reported providing more help to the PWD; 128 (43.8%) felt more isolated regarding the support they provide to the PWD. Three hundred and

forty-six (92.5%) maintained at least a contact by phone or video, and 186 (50.7%) visited the PWD.

One hundred and ninety-six HC (50.9%) declared that the relationship with the PWD was more difficult than before the lockdown whereas 189 HC (49.1%) thought it was identical or easier. Finally, 255 HC (58.7%) were more worried about the PWD than before the lockdown.

#### *Evolution of professional help for PWD living at home*

For PWD living at home, the most frequent professional help conditions were home care and day care facilities; 245 PWD (66%) had no professional caregiver before lockdown. Regarding PWD who benefited from professional caregivers before lockdown, 126 (63.3%) of the professional caregivers had to stop their activity during lockdown whereas only 73 (36.7%) continued their interventions. Eventually, while 126 PWD (34%) went to day care facilities before lockdown, this type of professional support was totally suspended during the lockdown.

#### *PWD living in nursing-homes*

NHC visits to PWD living in nursing-homes were banned most of the time during the lockdown. Therefore, many nursing-homes organized video calls via smartphones, computers or tablets. 90 NHC (62.5%) communicated by video call with the PWD. However,

only 50 NHC (31.4%) were able to communicate by phone as often as they wanted, 44 (27.7%) could call at least once a week and 65 (40.9%) could not call the PWD. Furthermore, 81 NHC (50.9%) considered that the information provided by the nursing-home staff about the PWD physical or mental health was adequate while 68 (42.8%) considered that it was insufficient and 10 (6.3%) received no information at all.

#### *Caregivers' mental health during the lockdown*

##### *Description of caregivers' mental health during the lockdown*

Caregivers' mental health during lockdown was assessed by self-rated scales. Median and interquartile range for GAD-7 score measuring anxiety was 9 (IQR 5–14) for HC and 8 (IQR 5–12) for NHC. Median CES-D score, assessing depressive symptoms, was 22 (IQR 13–31) for HC and 8 (IQR 5–12) for NHC. Median self-rated stress, assessed with an analog scale, was 6 (IQR 3–8) for HC and 7 (IQR 5–8) for NHC. Mean disease burden, evaluated with the mini-Zarit scale, in HC only, was 3 (IQR 4.5–5.5).

##### *Prevalence of PMH among caregivers during the lockdown*

The prevalence of high and poor caregivers' mental health scores and the repercussions of lockdown on

Table 2  
Caregivers mental health during lockdown – Comparison of HC and NHC

	HC (N= 389) n (%)	NHC (N= 159) n (%)	Test value <sup>1</sup>	p
Depression (CES-D > 19)				
Yes	185 (55.7)	92 (65.2)	3.70	0.054
No	147 (44.3)	49 (34.8)		
Severe burden (Zarit > 5)				
Yes	122 (32.4)	-		
No	255 (65.6)			
Self-reported stress > 5.5/10				
Yes	197 (52.3)	102 (65.0)	7.27	<b>0.007</b>
No	180 (47.7)	55 (35.0)		
Anxiety (GAD 7 > 9)				
Yes	166 (43.7)	58 (36.5)	2.40	0.12
No	214 (56.3)	101 (63.5)		
Sleep-awake cycle difficulties				
Yes	132 (34.3)	62 (39)	1.04	0.31
No	252 (65.6)	97 (61)		
Difficulties to feel well-rested				
Yes	184 (47.9)	65 (40.9)	2.24	0.13
No	200 (52.1)	94 (59.1)		
Difficulties to have enough physical activity				
Yes	183 (47.7)	70 (44)	0.60	0.44
No	201 (52.3)	89 (56)		

<sup>1</sup>Pearson's  $\chi^2$  test.

their lifestyle were compared between HC and NHC. These results are provided in Table 2. More than half caregivers (55.7%) exhibited major depression, and nearly one out of three (32.4%) had a severe burden. Almost half of them (43.7%) had major anxiety or stress. Finally, one third (34.3%) reported having difficulties regarding sleep quality while nearly half of them (47%) presented with difficulties to feel well-rested or to practice enough physical activity.

The number of days, since lockdown onset, was compared between caregivers with and without PMH. Regarding HC, no significant association was observed between time since lockdown onset and major depression [median 59 days (IQR 52–65) versus 59 days (IQR 52–66);  $z = -0.75$ ,  $p = 0.45$ ], major anxiety [median 60 days (IQR 52–64) versus 59 days (IQR 52–65);  $z = -0.10$ ,  $p = 0.92$ ], high perceived stress [median 60 days (IQR 57–64) versus 59 days (IQR 51.75–65);  $z = -0.55$ ,  $p = 0.58$ ] or severe burden [median 59 days (IQR 52–64) versus 60 days (IQR 55–67);  $z = -1.0009$ ,  $p = 0.31$ ]. Similarly, no association was observed between time since lockdown onset and NHC major depression [median 61 days (IQR 60–72.5) versus 63.5 days (IQR 58.25–72);  $z = -0.49$ ,  $p = 0.62$ ], major anxiety [median 61 days (IQR 59–71) versus 64.5 days (IQR 59–74.5);  $z = -0.91$ ,  $p = 0.36$ ], or high perceived stress [median 65 days (IQR 65–78) versus 61 days (IQR 58–70.25);  $z = -1.73$ ,  $p = 0.08$ ].

#### *Factors associated with HC's mental health during lockdown*

The relationships between HC and PWD characteristics and HC mental health are provided in Table 3. Women caregivers had poorer mental health as compared to men. Regarding HC, the fear of having a severe form of COVID-19 did not influence caregivers' mental health (with the exception of stress status). Likewise, the fear that PWD could have get a severe form of the disease was not related to HC's mental health (with the exception of stress status). Regarding the conditions of life, living with the PWD and because PWD feel cramped in their home were associated with poorer HC mental health scores. Having tougher relationships with the PWD, giving them more support and feeling more isolated since lockdown were also associated with poorer HC mental health. Finally, difficulties to maintain a good sleep/wake rhythm, to feel well rested and to have sufficient physical activity were related to poorer HC mental health.

Multivariate associations between HC and PWD characteristics and HC mental health are provided in Table 4. Each variable significantly linked to HC mental health in univariate analysis was entered in a separate model. The analyses were adjusted on HC's and PWD's age, sex, number of years since dementia onset, and to the fact that the caregivers live or not with the PWD. Most of the univariate analysis remained significant after adjustment on covariables, except for the relationship between increased support to the PWD during lockdown and depression status. There was a trend to an association between the fact that PWD feels cramped at home, difficulty maintaining a good sleep/wake rhythm and a higher stress level.

## DISCUSSION

The present study evaluated the mental health of caregivers supporting PWD living at home or in a nursing-home and investigated the risk factors associated with caregivers' PMH, using standardized scales. We reported that half of the caregivers exhibited poor mental health, including depression or self-reported stress, as already demonstrated in previous studies [5–7], with a very high level of statistical significance ( $p < 0.001$  in Table 3).

These findings were observed in both caregivers of PWD living at home or in a nursing-home. In addition, our results highlighted several risk factors for caregivers' poorer mental health, including being a female caregiver, living with the PWD, the fact that the PWD feels cramped at home, providing increased support to the PWD during the lockdown, and feeling more isolated regarding the support provided to the PWD since lockdown.

#### *Caregivers' mental health*

A major result of the present study is the strikingly high prevalence of PMH among caregivers of PWD during the lockdown period. Indeed, about half of them had a major depressive disorder or major anxiety, and one third a severe burden. These rates were higher than those reported in general population during COVID-19 pandemic, estimated to be between 20 and 30% for depression [12–14], and from 11 to 30% for anxiety [12, 13]. Outside a context of lockdown, supporting a PWD is already a stressful experience associated with detrimental effects on the caregiver's psychological health [15] and responsible for a high level of burden [16]. A meta-analysis previously

Table 3  
Association between caregivers and PWD characteristics and caregivers mental health for PWD living at home – Univariate analysis

	Caregivers mental health Scales											
	Mini Zarit <sup>1</sup>			GAD 7 <sup>1</sup>			CES-D			Self-reported stress <sup>1</sup>		
	Median (IQR)	z	p	Median (IQR)	z	p	Mean (SD)	t	p	Median (IQR)	z	p
Sex of participants												
Women	4.5 (3.5–6.0)	-3.67	<0.0001	9.0 (5.0–15.0)	-2.71	0.007	23.07 (11.68)	2.63	0.009	6.0 (4.0–8.0)	-3.48	0.001
Men	3.5 (2.5–5.0)			7.0 (3.0–12.0)			18.80 (10.49)			5.0 (2.0–7.0)		
Sex of PWD												
Women	4.0 (3.0–5.5)	-1.92	0.05	8.0 (4.0–13.0)	-2.22	0.03	20.54 (11.70)	0.02	0.27	6.0 (3.0–7.5)	-1.1	0.27
Men	4.5 (3.5–5.5)			9.0 (5.0–15.0)			23.58 (11.03)			6.0 (4.0–8.0)		
Fear of COVID-19												
PWD at risk of severe COVID-19												
Yes	4.5 (3.0–6.0)	-1.65	0.10	9.0 (5.0–15.0)	-1.71	0.09	22.48 (11.78)	1.28	0.20	6.0 (4.0–8.0)	-2.26	0.02
No	4.0 (3.0–5.5)			7.0 (3.0–11.0)			10.56 (1.35)			5.0 (3.0–7.0)		
Caregiver at risk of severe COVID-19												
Yes	4.5 (3.5–6.0)	-1.51	0.13	9.0 (5.0–15.0)	-1.72	0.09	11.28 (1.37)	1.77	0.07	7.0 (5.0–8.0)	-3.87	0.0001
No	4.5 (3.0–5.5)			8.0 (4.0–13.0)			10.91 (0.96)			5.0 (3.0–7.0)		
Life conditions of Caregivers and PWD												
PWD lives alone												
Yes	4.5 (3.0–5.5)	-0.34	0.74	8.0 (5.0–12.0)	-0.98	0.33	20.02 (11.51)	1.02	0.30	6.0 (4.0–8.0)	-0.61	0.54
No	4.5 (3.0–5.5)			9.0 (5.0–15.0)			21.86 (10.95)			6.0 (3.0–8.0)		
Caregiver lives with PWD												
Yes	4.5 (3.5–6.0)	-2.8	0.005	10 (5.0–15.0)	-2.98	0.003	23.57 (10.31)	3.94	0.0001	6.0 (4.0–8.0)	-1.06	0.29
No	4.0 (2.6–5.5)			7.0 (4.0–12.0)			17.19 (11.41)			5.5 (3.0–7.0)		
PWD cramped in his home												
Yes	6.0 (4.5–6.5)	-4.59	<0.0001	13.0 (8.5–17.5)	-4.04	<0.0001	25.85 (11.35)	2.21	0.02	7.5 (5.0–8.0)	-3.23	0.001
No	4.5 (3.0–5.5)			8.0 (4.0–13.3)			20.72 (10.91)			6.0 (3.0–7.0)		
Professional home life support												
Stopped	4.5 (3.5–5.5)	-0.34	0.73	8.0 (5.0–14.0)	-0.03	0.98	21.17 (11.53)	1.52	0.13	6.0 (4.0–8.0)	-1.03	0.31
Continued	4.5 (3.0–6.0)			9.0 (5.0–14.0)			22.48 (11.22)			6.0 (4.0–8.0)		
Relationships with PWD												
Evolution of relationship with PWD												
Same	3.3 (2.5–4.5)	-7.84	<0.0001	6.0 (3.0–10.0)	-6.31	<0.0001	18.46 (10.51)	5.09	<0.0001	5.0 (2.0–7.0)	-6.35	<0.0001
More difficult	5.0 (4.0–6.0)			11.0 (7.0–16.0)			25.31 (11.54)			7.0 (5.0–8.0)		
Caregiver helps PWD more												
Yes	4.5 (3.5–6.0)	-5.03	<0.0001	9.0 (5.8–15.0)	-4.02	<0.0001	23.27 (11.62)	2.84	0.005	6.0 (4.0–8.0)	-5.10	<0.0001
No	3.5 (2.0–5.0)			6.0 (3.0–11.0)			18.80 (10.58)			4.5 (2.0–6.0)		
Caregiver feels more isolated												
Yes	5.0 (4.0–6.0)	-9.03	<0.0001	10.0 (6.0–15.0)	-6.17	<0.0001	24.79 (11.46)	6.01	<0.0001	7.0 (4.0–8.0)	-5.3	<0.0001
No	3.0 (2.0–4.5)			6.0 (3.0–10.0)			16.36 (9.47)			5.0 (2.0–7.0)		

(Continued)

Table 3  
(Continued)

	Caregivers mental health Scales											
	Mini Zarit <sup>1</sup>			GAD 7 <sup>1</sup>			CES-D			Self-reported stress <sup>1</sup>		
	Median (IQR)	z	p	Median (IQR)	z	p	Mean (SD)	t	p	Median (IQR)	z	p
Consequences on caregiver lifestyle												
Difficulty maintaining a good sleep/wake rhythm												
Yes	5.0 (3.5–6.0)	-4.54	<0.0001	11.0 (7.0–16.0)	-4.54	<0.0001	26.85 (10.32)	5.27	<0.0001	7.0 (5.0–8.0)	-6.12	<0.0001
No	4.0 (3.0–5.5)			7.0 (4.0–13.0)			19.53 (11.27)			5.0 (3.0–7.0)		
Difficulties to feel well-rested												
Yes	5.0 (4.0–6.0)	-7.45	<0.0001	11.0 (7.0–16.0)	-6.93	<0.0001	27.37 (10.35)	-8.17	<0.0001	7.0 (5.0–8.0)	-6.39	<0.0001
No	3.5 (2.5–5.0)			6.0 (3.0–11.0)			17.23 (10.21)			5.0 (2.0–7.0)		
Difficulty getting enough physical activity												
Yes	4.8 (3.5–6.0)	-3.29	0.001	9.0 (6.0–15.0)	-2.71	0.007	24.47 (10.31)	3.36	0.001	7.0 (4.0–8.0)	-3.26	0.001
No	4.5 (2.5–5.5)			7.5 (4.0–14.0)			19.88 (12.11)			5.0 (3.0–7.0)		

Student *t* tests or Mann-Whitney tests; <sup>1</sup>Mini-Zarit, GAD-7 and stress self-rated scale were non-normally distributed.

Table 4

Association between HC and PWD characteristics and caregivers mental health for PWD living at home – multiple logistic regressions adjusted on caregiver and PWD age and sex, number of years since dementia symptoms onset and the fact that the caregiver lives with the PWD

	Caregivers mental health Scales							
	Mini Zarit <sup>1</sup>		GAD 7 <sup>2</sup>		CES-D <sup>3</sup>		Self-reported stress <sup>4</sup>	
	OR (CI)	p	OR (CI)	p	OR (CI)	p	OR (CI)	p
Evolution of relationship with PWD (more difficult) <sup>a</sup>	4.22 (2.48–7.18)	<0.0001	3.27 (2.012–5.33)	<0.0001	2.91 (1.73–4.90)	<0.0001	2.09 (1.30–3.35)	0.002
Caregiver helps PWD more <sup>b</sup>	2.28 (1.24–4.18)	0.008	2.09 (1.21–3.62)	0.008	1.39 (0.78–2.46)	0.25	2.65 (1.54–4.54)	<0.0001
Caregiver feels more isolated <sup>c</sup>	7.34 (3.49–15.45)	<0.0001	2.41 (1.39–4.15)	0.002	4.17 (2.39–7.27)	<0.0001	2.18 (1.31–3.64)	0.003
Difficulties maintaining a good sleep / awake cycle (yes/no)	4.54 (2.23–9.23)	<0.0001	3.27 (1.6–6.69)	<0.0001	2.78 (1.23–6.28)	0.01	1.95 (0.95–3.98)	0.06
Difficulties to feel well-rested (yes/no)	3.32 (1.97–5.61)	<0.0001	3.34 (2.45–5.06)	<0.0001	5.63 (3.25–9.74)	<0.0001	3.84 (2.32–6.32)	<0.0001
Difficulty getting enough physical activity (yes/no)	2.29 (1.4–3.74)	0.001	2.25 (1.39–3.63)	0.001	3.86 (2.17–6.86)	<0.0001	3.49 (2.1–5.81)	0.0001

<sup>1</sup>Mini-Zarit  $\geq 5.5$  versus  $< 5.5$ ; <sup>2</sup>GAD 7  $\geq 10$  versus  $< 10$ ; <sup>3</sup>CES-D  $\geq 20$  versus  $< 20$ ; <sup>4</sup> self-rated stress scale  $\geq 6$  versus  $< 6$ . <sup>a</sup>This variable derives from the following question: 'During lockdown, relations with my family member became: easier or Unchanged / More difficult'. <sup>b</sup>This variable derives from the following question: 'Since the beginning of lockdown, I have been helping my family member even more: Yes /No'. <sup>c</sup>This variable derives from the following question: 'Did you feel more isolated by accompanying your family member? Yes/No'.

reported 22% of major depressive disorder in such a population [17]. Few studies have addressed caregivers' mental health during COVID-19 lockdown. Previous findings [18] reported a similar level of anxiety (46%) but a lower depression rate (18%) than our study. However, these authors did not use standardized scales to evaluate mood disorders, the caregivers were only asked if they felt anxious, depressed, isolated or helpless [18]. Using self-administered questionnaires, another study asked 210 caregivers living with PWD if they felt an increase in their psychological or physical burden; possible answers were "not at all", "some" and "a lot". In this latter study, 35% of caregivers declared that their psychological burden increased "a lot" while 45% answered "some".

Another finding needs to be underlined: similar PMH rates were observed in HC and NHC. These results suggest that increased material tasks may explain only a small part of caregivers' distress. Generally, caregivers report difficulty coping with separation after PWD placement. In addition, visiting restrictions during lockdown may have increased such difficulties. A previous study during COVID 19 pandemic assessed the psychological impact of visiting restrictions on caregivers of PWD living in nursing-homes. A large proportion of respondents reported recent low well-being as well as feeling lonely and isolated: 44% reported well-being scores below 50%; furthermore, 17% of the caregivers reported a poor support from nursing-homes staff [6]. In our study, almost half of the NHC reported difficulties or impossibility to get information about PWD's health status from the nursing-home staff, certainly contributing to worsen their psychological distress.

#### *Factors associated with caregivers' poor mental health*

Regarding HC group, our results highlighted that providing more help to PWD, living with PWD and feeling isolated were linked to increased anxiety-depressive symptomatology and subjective stress and burden. The reduction of the support provided by professional caregivers during lockdown may contribute to increase caregivers' PMH. Additionally, the lockdown period probably negatively impacted caregivers' daily life by decreasing intimacy and social life, while increasing a feeling of loss of control, all of this causing emotional burden.

Sleep disorders and difficulties to feel well-rested were associated with a higher level of stress, anxiety

and depression. Lockdown, by modifying daily activities and life routines, can bring significant disturbances in biological rhythms and sleep, which can in turn exert detrimental effects on mental health. An Italian study [19] reported that 42.2% of respondents exhibited sleep disorders during lockdown. In addition, reduced physical activity seems to be linked to anxiety-depressive symptoms, stress and burden, as revealed from our results.

In line with previous reports [20], female gender can be identified as a risk factor for higher caregivers' anxiety, depression, stress or burden. In contrast, caregivers' age did not contribute to explain PMH risk.

Surprisingly, while old people are known to be at risk of severe forms of the disease, a moderate proportion of caregivers exhibited a high perceived risk of severe form of COVID-19: one fourth for themselves, and half of them for PWDs. These results are in contrast with a previous study reporting that 75% of the caregivers felt that the COVID-19 pandemic was a threat for their own health, whereas 82.1% reported that it was a health threat for PWD [7]. The difference between results may be due to methodological diversity in study design and/or scale to evaluate caregivers' feeling. Notably, fear of severe infection was not related to caregivers' PMH in our results (with the exception of anxiety and fear for the PWD). Finally, no association was observed between time since lockdown onset and caregivers' PMH, both in HC and NHC. These results are in contrast with previous findings, highlighting a positive link between time of isolation and anxiety or depression risk in caregivers [21]. However, our participants' enrollment began after the first month of lockdown, although the consequences of lockdown on mental health were shown to rapidly worsen after a few days only in previous reports [21, 22]. This may explain such discrepancies.

#### *Strengths*

The present study has several strengths. Our study was the first to explore the psychological impact of lockdown on a large sample of caregivers supporting PWD living at home or in nursing-home, using standardized scales. Secondly, while most of the previous studies assessing the impact of lockdown on caregivers' mental health solely focused on the relationship between BPSD and caregivers' burden or stress, our study explored the consequences of lockdown on specific caregiver's mental health symptoms such as depression or anxiety. In this regard, the use

of validated scales and clinical cutoffs gives clinical significance to our results. Finally, the inclusion of a large number of potential confounding factors in the multivariate analyses (caregivers' sex, living or not with PWD and dementia duration) may be highlighted as another strength.

### *Weaknesses*

Our findings also have limitations, some of which are inherent to survey methodology. Indeed, since participants completed the survey on a voluntary basis, only caregivers interested and motivated by the subject of the study responded, which reduces the representativeness of our sample. In addition, no direct measure of PWD cognitive status was available in our study. However, the symptoms duration was used as an indirect measure of dementia evolution. While educational level has been shown to be a protective factor for psychosocial outcome during lockdown in PWD's caregivers [5], this variable was not collected in our study. Another limitation is the missing information on the severity of dementia, which could influence the mental health of caregivers. The time of onset of symptoms was collected, but it is only partially related to the severity of the disease.

In addition, due to the cross-sectional design, no evidence of a temporal relationship can be established between the patient's medical information and the current lockdown. Lastly, it would have been interesting to explore caregivers' mental health before lockdown and its evolution during and after this period. However, the survey methodology (anonymous online questionnaire, cross-sectional design) did not allow us to collect this data.

### *Clinical implications and recommendations for the future*

Our findings have clinical implications. In the present study, half of our population presented with current anxiety/depressive disorders. While this is a matter of concern, the persistence of the virus and the current new lockdown is likely to worsen the health status of the caregiver population already weakened by the first lockdown. According to our findings, we should pay attention to both caregivers of patients at home and in nursing homes. In case of new lockdowns, it seems therefore essential to 1) identify caregivers with symptoms of anxiety, depression or severe burden. In this regard, a systematic evaluation should be carried out in memory centers and in other

structures receiving PWD and their caregivers, e.g., with rapid screening scales. This identification should pay particular attention to women and caregivers living with their relatives because they are more at risk to develop anxiety and depression, 2) promote access to a comprehensive assessment carried out by psychologists or psychiatrists to specify the disorders in the identified caregivers, 3) refer caregivers to structures dedicated to them or to liberal professionals (e.g., psychologists) for therapeutic follow-up. Interventions and support to caregivers should be reinforced or at least maintained during the lockdown, face to face if possible or by video if necessary.

Furthermore, specific measures should be adopted to prevent occurrence or worsening of mood symptoms among caregivers during future lockdowns. For HC, it is important to maintain professional helps already in place while respecting the barrier measures. This would avoid disrupting the PWD's routine. In addition, caregivers would feel less isolated and would not have to increase the time they spend helping PWD. Access to respite solutions should be facilitated in cases of heavy burden, for example with the intervention of paid home caregivers, as group care should be avoided. Access to parks or forests should be allowed, in order to prevent patients from feeling cramped in their homes. For NHC, it would be important to authorize visits by developing appropriate health protocols. In addition, contact with family through video or telephone should be encouraged. In this regard, the development of technologies adapted to the elderly may be relevant and their use thereafter should be encouraged.

The new measures taken by the French government in the second lockdown period are consistent with some of these points, in particular regarding visits in nursing-homes. In the future, it will be necessary to pay attention to these people after the crisis in order to estimate the longer-term impact on their mental health.

## **CONCLUSION**

Our study identified factors independently linked to a higher risk of caregivers' PMH, allowing us to target a population at risk and that may benefit from specific attention. Some modifiable factors could be taken in consideration to relieve caregivers. Such measures should be provided as soon as the first anxio-depressive symptoms appear. Longitudinal studies are needed to better identify the predictors of caregivers' mental health worsening.

## DISCLOSURE STATEMENT

Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/21-0079r3>).

## SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <https://dx.doi.org/10.3233/JAD-210079>.

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