Effect of the COVID-19 Pandemic on the Self-Perceived Change of Caregivers' Burden in Providing Care for People With Dementia

Apichaya Wongmek, MD[1], Titima Wongviriyawong, MD[1], Sutisa Pitiyarn, APN, MNS, RN[3], Pitiporn Siritipakorn, MNS, RN[3], Harisd Phannarus, MD[2] (iD), and Weerasak Muangpaisan, MD[2],

Abstract

Objectives: To explore how the COVID-19 pandemic affects caregiver (CG) burden, the quality of care provided to people with dementia (PwD) and their perceived changes between before and during the pandemic. **Methods:** A cross-sectional study surveyed primary CGs about burden and self-perceived change in multidimensional domains and compared these before and during the pandemic. **Results:** About 135 primary CGs of PwD were enrolled at Siriraj Hospital's Geriatric Clinic in Thailand and assessed using various online platforms. About 13.8% of CGs had a "mild to moderate" burden. The NPI-Q score and level of functional capacity of the PwD declined during the COVID-19 pandemic (*p*-value .001 and .001, respectively). The CG-associated factors that related to a higher CG burden were younger age (mean age of 54.2 years old), female (76.3%), and high educational level (80.7%). Conflict between CG and PwD was associated with an increase in CG burden (*p*-value .004; 95% CI [1.19, 6.12]). Regarding the COVID-19-related factors, there was no association between CG burden and the PwD's characteristics or COVID-19-related concerns. **Conclusions:** The COVID-19 pandemic was associated with a higher CG burden. Identifying the related factors in an unusual situation may help reduce the CG burden and improve the care of PwD.

Introduction

A caregiver (CG) is a person who provides physical and mental care to individuals with a range of problems, including supporting their health and ability to do daily living activities. The term "CG burden" (Wade et al., 1986; Zarit et al., 1980) refers to the impact of the patient care on the emotional, physical, social, and financial domains of the caregiver. Included among the features of CG burden are depression, the deterioration of physical ability, and other stresses that negatively impact the quality of life of CGs (Chuakhamfoo et al., 2020; Lethin et al., 2020). Previous studies have reported three factors related to people with dementia (PwD) that might contribute to the CG burden: (1) the characteristics of the PwD, the stage and type of dementia, functional ability, and the severity of the Behavioral and Psychological Symptoms of Dementia (BPSD); (2) the demographic data of the CGs, including their gender, age, socioeconomic status,

relationship with the PwD, personality, duration of care, coping skills, and learned resourcefulness (Chen et al., 2015; Gaugler et al., 2005; M. Pinyopornpanish et al., 2021; Yaffe et al., 2002); and (3) the support systems (Muangpaisan et al., 2010), including CG training programs, healthcare accessibilities and networks, respite care, public services, and community support.

[1]Department of Medicine, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok, Thailand
[2]Department of Preventive and Social Medicine, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok, Thailand
[3]Department of Nursing, Siriraj Hospital, Mahidol University, Bangkok, Thailand

Corresponding Author:
Harisd Phannarus, Department of Preventive and Social Medicine, Faculty of Medicine Siriraj Hospital, Mahidol University, 2 Siriraj Hospital, Bangkok Noi, Bangkok 10700, Thailand.
Email: harisd.pha@mahidol.edu

COVID-19 emerged in 2020 and rapidly spread worldwide, causing a global pandemic that affected societies and economies. COVID-19 symptoms range from asymptomatic to severe respiratory failure, possibly occurring with a higher mortality rate in older people (Guan et al., 2020). Therefore, there are several recommended COVID-19 prevention protocols, including social distancing, masking, travel restrictions, and quarantine, to reduce viral transmission (The Government Public Relations Department, Thailand, 2021). The COVID-19 pandemic had negative physical and mental effects on PwD and CGs, either in terms of access to medical care or quality of life. As a result, the rate of disability and death among PwD increased, while the quality of life for CGs declined (Caratozzolo et al., 2020; Czeisler et al., 2021). Moreover, there are also concerns that the social restrictions during the pandemic may have had an adverse effect on CGs' psychological health, manifesting as stress, irritability, depression, confusion, and insomnia (Brooks et al., 2020).

In Thailand, previous studies before the pandemic showed the characteristic of CG of PwD in Thai rural area. Most of them (86%) were informal caregivers and 63.2% of CGs were the PwD's child. Informal CGs had regular work outside the home and had either minimal supporting system or other CGs to help (Chuakhamfoo et al., 2020; Sittironnarit et al., 2020). Two recent studies demonstrated that for PwD, COVID-19 prevention policies worsened their cognitive function (53.4%–55.1%), neuropsychiatric symptoms (NPS) (48.3%–51.9%), increased the incidence of new-onset NPS (25.9%), and caused functional decline (34.5%) (Borelli et al., 2021; Rainero et al., 2021). Previous research found that the incidence of stress in CGs increased from 9% to 22% of CGs before and during the COVID-19 pandemic (Nikolaidou et al., 2022). However, few global and local studies have focused on the effects of COVID-19 on the mental health, well-being, and health-related concerns of CGs (Cohen et al., 2020; Losada et al., 2022; Park, 2020). Consequently, the present study aimed to explore the impact of the pandemic on CG burden and examine the association of potential factors such as patients' factors (functional change, neuropsychiatric symptoms, stage and severity of dementia) and CG's factors (depression, CG characteristics, and support).

Materials and Methods

Study Design

This was a cross-sectional study using an electronic-based questionnaire administered to the primary CGs of PwD (Bédard et al., 2001; Hemrunrojn, 2011; Kaufer et al., 2000; Lotrakul et al., 2008; Mahoney & Barthel, 1965; Pinyopornpanish et al., 2020; Silpakit et al., 2015; Yi et al., 2020). This study was conducted between September 2021 and January 2022. Ethical approval was provided by the Research Ethics Committee (protocol number 621/2564).

Participants

The study participants were enrolled at the Geriatric Clinic at Siriraj Hospital, which is a tertiary hospital in Bangkok, Thailand, and via an online survey process. The 166 participants were recruited and their eligibility for participation in the study was determined by using screening questions. The inclusion criteria were as follows: (1) primary CGs of PwD who were diagnosed in any stage of dementia by geriatricians or neurologists and who were currently under treatment follow-up; (2) primary CGs who provided care to PwDs for at least 4 hours per day without remuneration; (3) primary CGs who had no communication problems; and (4) in case of visual or hearing impairment or unable to access the electronic questionnaire, availability of a family member or researcher who could fill in the questionnaire on their behalf. The primary CGs of PwD who were institutionalized 3 months before enrollment were excluded. The final eligible participants consisted of 135 primary CGs, who were recruited in the study and their data were included in the analysis. All the participants gave informed online consent prior to participating in the study.

Data Collection and Measures

Data collection was performed through an electronic questionnaire using a QR code generated by the researchers. The survey was completed by the primary CG or one of the researchers in the case that the CG had a visual or hearing impairment or was unfamiliar with the technology and needed assistance filling in the questionnaire. The questionnaire was composed of items related to both the CG and the PwD, including the demographics, burden, depression, and concerns of CGs and the NPS and functional capacity of PwD. In addition, the researcher inquired about the situation before and during the pandemic, as well as the individual's responses to the questionnaire.

CG Burden

The Thai version of the Zarit Burden Interview (ZBI-12) was used to assess CG burden. Each item was rated for the frequency of symptoms on a 4-point Likert scale, from 0 (never) to 4 (almost always). The total scores ranged from 0 to 48, with a high score indicating a higher burden. The burden score of 0 to 10 was defined as "no to mild burden," 11 to 20 as "mild to moderate burden," and 21 to 48 as "severe burden" (Bédard et al., 2001; Pinyopornpanish et al., 2020; Silpakit et al., 2015).

Depression

The Thai version of the Patient Health Questionnaire (PHQ-9), which consists of nine items, was used to examine the depressive symptoms of the CGs. The total

number of possible scores ranged from 0 to 27. The scores of 0 to 6 was defined as "no depression," 7 to 12 as "mild," 13 to 18 as "moderate," and 19 to 27 as "severe" (Lotrakul et al., 2008).

NPS

The Neuropsychiatric Inventory Questionnaire (NPI-Q), which consists of 12 NPS, was used to measure the BPSD. These 12 NPS are: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, sleep/nighttime behavioral disturbances, and appetite/eating abnormalities. The questionnaire focused on the severity and distress of each symptom. The total NPI-Q distress scores ranged from 0 to 60 (Hemrunrojn, 2011; Kaufer et al., 2000), which was rated by the primary CG.

Functional Independence of the PwD

Barthel's Index (BI) was used to measure the functional independence of the PwD. Each of the 10 items was scored based on their functional performance as: inability, need for help, and independence. The total scores ranged from 0 to 100, with a lower score indicating a decreased functional ability. Functional ability was divided into five levels, with scores of 80 to 100 as "independent," 60 to 79 as "minimally dependent," 40 to 59 as "partially dependent," 20 to 39 as "very dependent," and 0 to 19 as "totally dependent" (Mahoney & Barthel, 1965; Yi et al., 2020).

CGs' Concerns

Based on previous studies, the authors developed the questionnaire to assess the CGs' concerns about the COVID-19 pandemic (Borelli et al., 2021; Mahoney & Barthel, 1965; Yi et al., 2020). The questionnaire asked questions regarding the CGs' daily lives, their access to healthcare services, their COVID vaccination status, and their self-care throughout the pandemic.

Socio-Demographic Characteristics of the CGs and PwD

Details on the socio-demographics of both the CGs and PwDs were gathered, including age, gender, marital status, education, comorbidities, relationship with PwD, occupations, self-perceived income, duration of caregiving, care experience, and care training. In this study, the stage of dementia was determined based on the functional independence of the PwD using BI, in which PwD who could perform all indices without help, or who needed help in some indices, or who needed help in all indices were classed as having mild, moderate, or severe dependence, respectively.

The primary outcomes were CG burden and the CGs' self-perceived change in CG burden and depression, comparing between before and during the COVID-19 pandemic. The secondary outcomes were the factors associated with the CG burden, depression, CGs' concerns about COVID-19, NPS, and functional independence of the PwD.

Statistical Analyses

SPSS version 18.0 (SPSS Inc., PASW Statistics for Windows, Chicago, IL, USA) was used for the statistical analysis. Descriptive analysis results were reported as the mean, median, and standard deviation (SD), and categorical data were reported as frequency and percentages. The independent *t*-test, Pearson correlation, non-parametric test, Mann–Whitney *U*-test, and Wilcoxon Signed Ranks test were used to analyze the continuous data depending on the distribution of the data. The Chi-square test was used for the categorical data. The researchers performed multivariate linear regression analysis to evaluate the associations between the CG burden and related variables. A *p*-value $<.05$ indicated statistical significance.

Results

The characteristics of the primary CGs and PwD are shown in Table 1. Regarding the CGs, 103 (76.3%) were women, and the mean (SD) age was 54.2 (10.7) years old. In 72 cases (53.3%), the CGs were unmarried; 79.3% were the patients' children; and 80.7% had a bachelor's degree or above in education. Also, 91 CGs (67.4%) perceived that they had enough income. In terms of health, 42% of CGs had no underlying diseases. However, the most common underlying diseases among CGs were hypertension (18.5%), hyperlipidemia (17.8%), and knee osteoarthritis (11.9%). Sixty CGs (44.4%) spent at least 12 hours per day caring for the PwD, and 72 CGS (53.3%) had looked after the PwD for at least 48 months. Regarding the previous experience with PwD care, most CGs (88.9%) had no experience, and 80.3% had never attended a CG training program. In terms of the PwD, 100 PwD (74%) were women with a mean (SD) age of 81.7 (7.9) years old. About 69 PwD (51.1%) were married, and 62 (45.9%) had graduated from primary school. In 73 cases (54.1%), the duration of the dementia diagnosis ranged from 1 to 5 years, and the majority of dementia stages were moderate in 67 cases (49.6%).

The mean (SD) ZBI-12 score was 14.9 (8.7) during the COVID-19 pandemic. About 52 CGs (38.5%) were defined as having a mild to moderate burden, and 36.3% CGs had none or a mild burden. The mean (*SD*) of the PHQ-9 score was 4.87 (4.8), while 95 CGs (70.4%) had no depression and 27 CGs (20%) had mild depression. When comparing the self-perceived changes between

Table 1. Demographic Characteristics of the CGs and PwD (*n* = 135).

CGs' characteristics	*N* (%)	PwD's characteristics	*N* (%)
Age (year), mean ± *SD*	54.2 ± 10.7	Age (year), mean ± *SD*	81.7 ± 7.9
Women	103 (76.3)	Women	100 (74.1)
Marital status		Marital status	
Single/widowed/separated	78 (59.3)	Single/widowed/separated	66 (48.9)
Married	55 (40.7)	Married	69 (51.1)
Education		Education	
≤Secondary school	26 (19.3)	≤Primary school	76 (56.3)
≥Bachelor's degree	109 (80.7)	≥Secondary school	59 (43.7)
Relationship with PwD		Stage of dementia	
Child	107 (79.3)	Mild	38 (28.1)
Spouse	13 (9.6)	Moderate	67 (49.6)
Grandchild	9 (6.7)	Severe	30 (22.2)
Occupation		Duration of dementia diagnosis (years)	
Retired/unemployed	48 (35.6)	<1	12 (8.9)
Government officer	23 (17)	1–5	73 (54.1)
Self-perception with income		>5–10	42 (31.1)
Not enough	26 (19.3)	>10	8 (5.9)
Enough	109 (80.7)		
Conflict with PwD, yes	63 (46.7)		
Underlying disease			
None	57 (42.2)		
Hypertension	25 (18.5)		
Hyperlipidemia	24 (17.8)		
Depression	8 (5.9)		
Duration of care for PwD (months)			
6–12	7 (5.2)		
>12–48	55 (40.7)		
>48	72 (53.3)		
Caregiving hours per day			
4–8	55 (40.7)		
>8–12	20 (14.8)		
>12	60 (44.4)		
Care experience (none)	120 (88.9)		
Caregiving training attendance (none)	115 (85.2)		
Care assistance			
None	25 (18.5)		
Family members	91 (67.4)		
Formal CG	19 (14.1)		

Note. CG = caregiver; PwD = people with dementia; *N* = number; *SD* = standard deviation.

before and during the COVID-19 pandemic, the majority of CGs reported an increased CG burden and depression with 48 CGs (35.6%) experiencing "increased burden," 25 (18.5%) "strongly increased burden," 57 (42.2%) "increased depression," and 56 (41.5%) "strongly increased depression."

Prior to the pandemic, the mean (*SD*) of the NPI-Q total score to evaluate 12 symptoms for the PwD was 12.4 (12.6), with severity of the symptoms at 6.6 (5.5), and distress of the symptoms at 6.2 (7.3). There was an increase in the mean (*SD*) total score of NPI-Q during the pandemic at 15.6 (15.7), with severity of the symptoms of 7.5 (6.9), and distress of the symptoms of 8.2 (9.0).

Regarding the functional abilities of the PwD, the mean (*SD*) scores of the Barthel's Index declined from before the COVID-19 pandemic compared to during the pandemic by 5 (11) (95% CI [−0.27, 0.91]). About 50.4% of CGs perceived that PwD had independent functional status before COVID-19, whereas 20.7% perceived they had minimal functional independence. As shown in Table 2, the scores for the PwD's dependent status increased, and their functional ability decreased during COVID-19. Furthermore, as shown in Table 3, the change in the PwD's NPS and functional ability before and during the COVID-19 pandemic demonstrated statistical significance.

Table 2. Comparison of the Functional Ability of the PwD Reported by CGs Between Before and During the COVID-19 Pandemic.

Reported functional ability	Before COVID-19 (%)	During COVID-19 (%)	*p*-Value
Totally dependent	7.4	9.6	.002
Very dependent	7.4	9.6	
Partially dependent	14.1	17.8	
Minimally dependent	20.7	20.7	
Independent	50.4	42.2	

Note. CG = caregiver; PwD = people with dementia.

Table 3. Comparison of the PwD's NPI-Q Score and Functional Ability Between Before and During the COVID-19 Pandemic (*n* = 135).

Clinical features of the PwD	Before COVID-19	During COVID-19	*p*-Value
NPI-Q (12 symptoms), mean ± SD (min, max)			
Total score	12.4 ± 12.6 (0, 69)	15.6 ± 15.7 (0, 67)	<.001
Symptom score	6.2 ± 5.5 (0, 30)	7.5 ± 6.8 (0, 300)	<.001
Distress score	6.2 ± 7.3 (0, 41)	8.2 ± 9.0 (0, 37)	<.001
Functional ability			
Barthel's Index, mean ± SD	70.7 ± 28.2	65.7 ± 29.5	<.001

Note. CG = caregiver; PwD = people with dementia; SD = standard deviation; NPI-Q = neuropsychiatric inventory questionnaire.

Table 4. COVID-19-Related Concerns Variables (*n* = 135).

COVID-19-related CGs' concerns	*N* (%)	Factor-related healthcare accessibility	*N* (%)	COVID-19-related impact on CGs	*N* (%)
PPE		Follow-up difficulties		Personal care purchase	
Good standard	117 (86.7)	None	65 (48.1)	None	81 (60)
Substandard	10 (7.4)	PwD mobility problems	34 (25.2)	Some difficulties	50 (37)
Not enough	8 (5.9)	Long distance transportation	20 (14.8)		
Information literacy		Follow-up method		Food purchase	
Adequate	107 (79.3)	Onsite service	56 (41.5)	None	87 (64.4)
		Telemedicine	79 (58.5)	Some difficulties	46 (34.1)
Frequency of concerning				Loneliness	
Sometimes	101 (74.8)			Yes	36 (26.7)
Always	18 (13.3)			No	99 (73.3)
Investigation- and treatment-related				Social restriction on PwD	
Never	30 (22.2)			Yes	82 (60.7)
Sometimes	77 (57)			No	26 (19.3)
Always	28 (20.7)			Previously yes	27 (20)

Note. CG = caregiver; N = number; PPE = personal protective equipment; PwD = people with dementia.

In term of the COVID-19-related aspects of CGs, self-concern, healthcare accessibility, routine daily lives, and concern about COVID vaccination, are shown in Table 4. It can be seen that 86.7% of CGs reported they had enough self-care protection facilities, and 79.3% reported receiving adequate COVID-19 information updates, while the most common concerns among the CGs were the high infection rate and the treatment if the CGs or PwD were infected. In terms of healthcare accessibility factors, more than half of the CGs (51.9%) experienced difficulties receiving routine follow-up care with multiple causes, including PwD immobility (25.2%) and a long distance between their residence and

hospital (14.8%). Furthermore, approximately two-thirds of PwD used telemedicine services during the pandemic. Only 26.7% of CGs reported loneliness during the COVID-19 outbreak, although more than 60% of CGs were living under the policy of social restriction. Also, 70 CGs (51.9%) had registered for the COVID vaccine using mobile applications, while 21.5% did so at healthcare units. A minority of the CGs had rejected the COVID vaccine due to concerns about the potential side effects of the vaccine.

As shown in Table 5, the multiple logistic regression analysis showed that a high CG burden was significantly associated with having a higher level of education

Table 5. Multiple Linear Regression Analysis of the CG-Burden-Related Factors in the CGs of PwD During the COVID-19 Pandemic (*n* = 135).

Variables	β	*SE*	*T*	Sig.	95% CI
CGs' characteristics					
Age (years)	.005	0.06	.08	.939	[−0.12, 0.13]
Women	−.28	1.43	−.19	.846	[−3.11, 2.56]
≥Bachelor's degree	3.74	1.59	2.35	.020*	[0.59,6.89]
No experience PwD care	2.26	1.89	1.19	.236	[−1.49, 6.01]
Had conflict with PwD	3.65	1.25	2.93	.004*	[1.19, 6.12]
PHQ-9 score	.62	0.15	4.15	<.001*	[0.32, 0.91]
PwD's characteristics					
Marital status (single/widowed/separated)	−1.61	1.21	−1.34	.184	[−4.00, 0.78]
The difference of Barthel's Index before- and during COVID-19	.32	0.30	1.08	.283	[−0.27, 0.91]
NPI-Q, symptom score during COVID-19	.31	0.10	3.11	.002*	[0.11, 0.51]
COVID-19-related concerns					
Follow-up care difficulties	.04	0.40	.09	.930	[−0.75, 0.82]
Personal care purchase difficulties	.89	1.16	.77	.445	[−1.41, 3.19]
Loneliness	−1.38	1.32	−1.04	.301	[−4.02, 1.25]
Social restriction of PwD	.78	0.62	1.27	.207	[−0.44, 2.00]

Note. CG = caregiver; PwD = people with dementia; *SE* = standard error; CI = confidence interval; PHQ-9 = 9-item Patient Health Questionnaire NPI-Q = Neuropsychiatric Inventory Questionnaire.
*p < .05.

(*p* = .020), the incidence of family conflict (*p* = .004), depression (PHQ-9) (*p* < .001), and a high score in the NPS (NPI-Q) (*p* = .002) during the COVID-19 pandemic. There was no significant association between CG burden and COVID-19-related concerns.

Discussion

This cross-sectional study evaluated the impact of the COVID-19 pandemic on PwD and their CGs in multiple dimensions, including CG burden and depression, PwD's NPS and functional ability, and COVID-19-related concerns. The results of this study revealed a high CG burden, a high prevalence of depression in CGs, the development of NPS and functional dependency in PwD, and the CG-burden-related factors during the COVID-19 outbreak. The findings are in accordance with previous reports of a rising CG burden and worsening NPS during the pandemic (Borelli et al., 2021; Cohen et al., 2020; Tsapanou et al., 2021; Yuan et al., 2022). In this study, the authors showed the association between CG burden and related factors, including CG depression, a high level of CG education, conflict between the CGs and the PwD, and a high score for NPS. The level of education in this study corresponded with the average education year in Thai population in Bangkok, where the study was conducted (National Statistical Office, Thailand, 2021; Sittironnarit et al., 2020). The CGs' background characteristics revealed a high level of education and the common presence of family conflict, which were reported in association with the CG's burden. The high educational level of CGs was significantly associated with the CG burden, probably because CGs with higher education

usually had more demanding jobs, which could be more burdensome when combined with caring for the PwD (Rosdinom et al., 2013). CGs' perceptions of their burden and mental health were influenced by their relationship with the PwD through family conflict (Strawbridge & Wallhagen, 1991). A previous study reported a high incidence of depression in CGs during the COVID-19 outbreak, which might be a result of the intensity of caregiving, the feeling of loneliness, and the level of the burden they felt and experienced (Otobe et al., 2022). There was no association found between loneliness and depression in this study, which might differ from other studies (Sepúlveda-Loyola et al., 2020). This may be due to the fact that depression has a variety of etiologies, including increasing household responsibilities, financial problems (Ibáñez et al., 2021), personal health concerns, their perspective on depression, their capability to handle the situation (Messina et al., 2022), and social support (Losada-Baltar et al., 2022; Messina et al., 2022). The Ministry of Public Health takes mental health very seriously and their policy related to the mental health support system for primary healthcare in Thailand was for village health volunteers to survey and develop initial protocols to support people in their community in order to reduce the rate of depression during COVID-19 (Institute for Population and Social Research, Thailand, 2022).

The author surveyed the PwD-related factors, showing there was a high functional dependency and high prevalence of NPS. Previous studies found a correlation between PwD-related factors and CG burden (Borelli et al., 2021; Manini et al., 2021; Soysal et al., 2022). There are many causes related to NPS, such as a lack of

social interactions, physical activities, and the closing of outpatient programs. Therefore, functional dependency and NPS affected CGs throughout the prolonged lockdown period; however, some studies revealed that CG burden may have had an impact on the CGs' NPS reporting. The authors found that PwD tended to have a more dependent functional status, which could make them lose their ability to take care of themselves, resulting in higher physical resistance requirements and consequently an increased CG burden (Tsapanou et al., 2021).

The support systems, including family, community, social support, public utilities, government assistance, the healthcare system, and caregiver knowledge training might be associated with CG burden. A previous study revealed that social restriction policies decreased social interaction, limited non-pharmacological support, and restricted physical activities, which reduced the quality of care and increased stress in primary CGs (Borelli et al., 2021). Several research studies have found that a comprehensive family support programs and social support systems can reduce caregiver burden (Cravello et al., 2021; Institute for Population and Social Research, Thailand, 2022; Lai et al., 2020). National policies supported a campaign to establish a social support system and telemedicine to improve the resilience and well-being of both care recipients and CGs at home under the context of the need for social distancing caused by the pandemic. Consequently, this is why CG burden may not have been associated with support system factors in this study.

This study has several strengths to highlight. Beginning with this study, CG burden-related factors were established in a multidimensional survey, including physical, mental, and social aspects. The authors also assessed health literacy about the COVID-19 pandemic and factors influencing healthcare accessibility during the COVID-19 outbreak. Because all the PwD were identified by specialists, their characteristics were also highly reliable. Finally, there was no missing data due to the use of a well-organized online and face-to-face questionnaire.

There are also some limitations of the study to note, including the relatively small sample size. Also, the study was a cross-sectional study, which means that there was a risk of recall bias, which might have affected some questions that compared situations prior to and during the pandemic. However, the researchers emphasized that before beginning the questionnaire, the study participants should recall their situations in the pre-epidemic period as opposed to their current situation with the highest epidemic. Moreover, there was no causal relationship between the COVID-19 outbreak and CG burden-related factors. Also, some notable characteristics of CGs might not be generalizable, such as a high level of education and good financial status. Additionally, there was the possibility of selection bias because COVID-19 resulted in certain participants not being invited to participate in the study. Thus, the researchers extended the data collection time to gather more data from participants who were not able to visit the hospital at the time.

Conclusions

The study reveals the worsening mental health and increasing burden in CG, as well as the functional deterioration and higher NPS in PwD during the COVID-19 pandemic. This is important knowledge in order to initiate a further intervention aimed at reducing the incidence of CG burden during the COVID-19 outbreak or in the event of a future healthcare crisis. Modifiable factors should be identified in order to reduce the burden and improve the quality of care for PwD. Our results showed that caregivers are already grappling with rising stress levels caused by the pandemic. Additionally, the authors suggest providing social intervention and healthcare services, such as telemedicine and family interventions, and evaluating their effectiveness in preventing the adverse effects on PwD and CGs in particularly unusual situations.

ORCID iD

Harisd Phannarus ⓘD https://orcid.org/0000-0001-9030-7310

References

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit burden interview: A new short version and screening version. *The Gerontologist*, *41*(5), 652–657. https://doi.org/10.1093/geront/41.5.652

Borelli, W. V., Augustin, M. C., de Oliveira, P. B. F., Reggiani, L. C., Bandeira-de-Mello, R. G., Schumacher-Schuh, A. F., Chaves, M. L. F., & Castilhos, R. M. (2021). Neuropsychiatric symptoms in patients with dementia associated with increased psychological distress in caregivers during the COVID-19 pandemic. *Journal of Alzheimer's disease: JAD*, *80*(4), 1705–1712. https://doi.org/10.3233/JAD-201513

Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenberg, N., & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: Rapid review of the evidence. *Lancet*, *395*(10227), 912–920. https://doi.org/10.1016/S0140-6736(20)30460-8

Caratozzolo, S., Zucchelli, A., Turla, M., Cotelli, M. S., Fascendini, S., Zanni, M., Bianchetti, A., Psy, M. P., Rozzini, R., Boffelli, S., Cappuccio, M., Psy, F. G., Psy, C. V., Bellandi, D., Caminati, C., Gentile, S., Psy, E. L., Di Fazio, I., Psy, M. Z., . . . Padovani, A. (2020). The impact of COVID-19 on health status of home-dwelling elderly patients with dementia in East Lombardy, Italy: Results from COVIDEM network. *Aging Clinical and Experimental Research*, *32*(10), 2133–2140. https://doi.org/10.1007/s40520-020-01676-z

Chen, H. M., Huang, M. F., Yeh, Y. C., Huang, W. H., & Chen, C. S. (2015). Effectiveness of coping strategies intervention on caregiver burden among caregivers of elderly patients with dementia. *Psychogeriatrics*, *15*(1), 20–25. https://doi.org/10.1111/psyg.12071

Chuakhamfoo, N. N., Phanthunane, P., Chansirikarn, S., & Pannarunothai, S. (2020). Health and long-term care of the elderly with dementia in rural Thailand: A cross-sectional survey through their caregivers. *BMJ Open*, *10*(3), e032637. https://doi.org/10.1136/bmjopen-2019-032637

Cohen, G., Russo, M. J., Campos, J. A., & Allegri, R. F. (2020). Living with dementia: Increased level of caregiver stress in times of COVID-19. *International Psychogeriatrics*, *32*(11), 1377–1381. https://doi.org/10.1017/S1041610220001593

Cravello, L., Martini, E., Viti, N., Campanello, C., Assogna, F., & Perotta, D. (2021). Effectiveness of a family support intervention on caregiving burden in family of elderly patients with cognitive decline after the COVID-19 lockdown. *Frontiers in Psychiatry*, *12*, 590104.

Czeisler, M. É., Kennedy, J. L., Wiley, J. F., Facer-Childs, E. R., Robbins, R., Barger, L. K., Czeisler, C. A., Rajaratnam, S. M. W., & Howard, M. E. (2021). Delay or avoidance of routine, urgent and emergency medical care due to concerns about COVID-19 in a region with low COVID-19 prevalence: Victoria, Australia. *Respirology*, *26*(7), 707–712. https://doi.org/10.1111/resp.1409410.1111/resp.14094

Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). Unmet care needs and key outcomes in dementia. *Journal of the American Geriatrics Society*, *53*(12), 2098–2105. https://doi.org/10.1111/j.1532-5415.2005.00495.x

Guan, W. J., Ni, Z. Y., Hu, Y., Liang, W. H., Ou, C. Q., He, J. X., Liu, L., Shan, H., Lei, C. L., Hui, D. S. C., Du, B., Li, L. J., Zeng, G., Yuen, K. Y., Chen, R. C., Tang, C. L., Wang, T., Chen, P. Y., Xiang, J., … Zhong, N. S.; China Medical Treatment Expert Group for Covid-19. (2020). Clinical characteristics of coronavirus disease 2019 in China. *New England Journal of Medicine*, *382*(18), 1708–1720. https://doi.org/10.1056/nejmoa2002032

Hemrunrojn, S. (2011). *Neuropsychiatric inventory questionnaire Thai version (NPIQ Thai)* [Paper presentation]. The Annual Meeting of the Royal College of Psychiatrists of Thailand, Bangkok, Thailand.

Ibáñez, A., Pina-Escudero, S. D., Possin, K. L., Quiroz, Y. T., Peres, F. A., Slachevsky, A., Sosa, A. L., Brucki, S. M., & Miller, B. L.; On behalf of the Multi-Partner Consortium to Expand Dementia Research in Latin America. (2021). Dementia caregiving across Latin America and the Caribbean and brain health diplomacy. *The Lancet: Healthy Longevity*, *2*(4), e222–e231. https://doi.org/10.1016/s2666-7568(21)00031-3

Institute for Population and Social Research, Thailand. (2022). *Situation of the Thai Elderly 2021*. https://ipsr.mahidol.ac.th/post_research/situation-of-the-thai-older-person

Kaufer, D. I., Cummings, J. L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., Lopez, O. L., & DeKosky, S. T. (2000). Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *12*(2), 233–239. https://doi.org/10.1176/jnp.12.2.233

Lai, F. H., Yan, E. W., Yu, K. K., Tsui, W. S., Chan, D. T., & Yee, B. K. (2020). The protective impact of telemedicine on persons with dementia and their caregivers during the COVID-19 pandemic. *The American Journal of Geriatric Psychiatry: Official Journal of the American Association for Geriatric Psychiatry*, *28*(11), 1175–1184. https://doi.org/10.1016/j.jagp.2020.07.019

Lethin, C., Leino-Kilpi, H., Bleijlevens, M. H., Stephan, A., Martin, M. S., Nilsson, K., Nilsson, C., Zabalegui, A., & Karlsson, S. (2020). Predicting caregiver burden in informal caregivers caring for persons with dementia living at home - A follow-up cohort study. *Dementia (London, England)*, *19*(3), 640–660. https://doi.org/10.1177/1471301218782502

Losada, A., Vara-García, C., Romero-Moreno, R., Barrera-Caballero, S., Pedroso-Chaparro, M. D. S., Jiménez-Gonzalo, L., Fernandes-Pires, J., Cabrera, I., Gallego-Alberto, L., Huertas-Domingo, C., Mérida-Herrera, L., Olazarán-Rodríguez, J., & Márquez-González, M. (2022). Caring for relatives with dementia in times of COVID-19: Impact on caregivers and care-recipients. *Clinical Gerontologist*, *45*(1), 71–85. https://doi.org/10.1080/07317115.2021.1928356

Losada-Baltar, A., Martínez-Huertas, J. Á., Jiménez-Gonzalo, L., Pedroso-Chaparro, M. D. S., Gallego-Alberto, L., Fernandes-Pires, J., & Márquez-González, M. (2022). Longitudinal correlates of loneliness and psychological distress during the lockdown situation due to COVID-19. Effects of age and self-perceptions of aging. *The Journals of Gerontology: Series B, Psychological Sciences and Social Sciences*, *77*(4), 652–660. https://doi.org/10.1093/geronb/gbab012

Lotrakul, M., Sumrithe, S., & Saipanish, R. (2008). Reliability and validity of the Thai version of the PHQ-9. *BMC Psychiatry*, *8*, 46. https://doi.org/10.1186/1471-244X-8-46

Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel index. *Maryland State Medical Journal*, *14*, 61–65.

Manini, A., Brambilla, M., Maggiore, L., Pomati, S., & Pantoni, L. (2021). The impact of lockdown during SARS-CoV-2 outbreak on behavioral and psychological symptoms of dementia. *Neurological Sciences*, *42*(3), 825–833. https://doi.org/10.1007/s10072-020-05035-8

Messina, A., Lattanzi, M., Albanese, E., & Fiordelli, M. (2022). Caregivers of people with dementia and mental health during COVID-19: Findings from a cross-sectional study. *BMC Geriatrics*, *22*(1), 56. https://doi.org/10.1186/s12877-022-02752-x

Muangpaisan, W., Praditsuwan, R., Assanasen, J., Srinonprasert, V., Assantachai, P., Intalapaporn, S.,

Chatthanawaree, W., Dajpratham, P., Kuptniratsaikul, V., & Pisansalakij, D. (2010). Caregiver burden and needs of dementia caregivers in Thailand: A cross-sectional study. *Journal of the Medical Association of Thailand = Chotmaihet thangphaet*, *93*(5), 601–607.

National Statistical Office, Thailand. (2021). *Average years of schooling of population by age group and sex: Academic 2012–2021*. http://statbbi.nso.go.th/staticreport/page/sector/th/03.aspx

Nikolaidou, E., Tsatali, M., Eleftheriou, M., Wang, H., Karagiozi, K., Margaritidou, P., & Tsolaki, M. (2022). Emotional function, negative thoughts about the pandemic, and adaptability skills among dementia caregivers during the COVID-19 pandemic. *Brain Sciences*, *12*(4), 459. https://doi.org/10.3390/brainsci12040459

Otobe, Y., Kimura, Y., Suzuki, M., Koyama, S., Kojima, I., & Yamada, M. (2022). Factors associated with increased caregiver burden of informal caregivers during the COVID-19 pandemic in Japan. *The Journal of Nutrition Health & Aging*, *26*(2), 157–160. https://doi.org/10.1007/s12603-022-1730-y

Park, S. S. (2020). Caregivers' mental health and somatic symptoms during COVID-19. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *76*(4), gbaa121–e240. https://doi.org/10.1093/geronb/gbaa121

Pinyopornpanish, K., Pinyopornpanish, M., Wongpakaran, N., Wongpakaran, T., Soontornpun, A., & Kuntawong, P. (2020). Investigating psychometric properties of the Thai version of the Zarit burden interview using Rasch model and confirmatory factor analysis. *BMC Research Notes*, *13*(1), 120. https://doi.org/10.1186/s13104-020-04967-w

Pinyopornpanish, M., Pinyopornpanish, K., Soontornpun, A., Tanprawate, S., Nadsasarn, A., Wongpakaran, N., & Wongpakaran, T. (2021). Perceived stress and depressive symptoms not neuropsychiatric symptoms predict caregiver burden in Alzheimer's disease: A cross-sectional study. *BMC Geriatrics*, *21*(1), 180. https://doi.org/10.1186/s12877-021-02136-7

Rainero, I., Bruni, A. C., Marra, C., Cagnin, A., Bonanni, L., Cupidi, C., Laganà, V., Rubino, E., Vacca, A., Di Lorenzo, R., Provero, P., Isella, V., Vanacore, N., Agosta, F., Appollonio, I., Caffarra, P., Bussè, C., Sambati, R., Quaranta, D., … Ferrarese, C.; the SINdem COVID-19 Study Group. (2021). The impact of COVID-19 quarantine on patients with dementia and family caregivers: A nation-wide survey. *Frontiers in Aging Neuroscience*, *12*, 625781. https://doi.org/10.3389/fnagi.2020.625781

Rosdinom, R., Zarina, M. Z., Zanariah, M. S., Marhani, M., & Suzaily, W. (2013). Behavioural and psychological symptoms of dementia, cognitive impairment and caregiver burden in patients with dementia. *Preventive Medicine, 57*(Suppl), S67–S69. https://doi.org/10.1016/j.ypmed.2012.12.025

Sepúlveda-Loyola, W., Rodríguez-Sánchez, I., Pérez-Rodríguez, P., Ganz, F., Torralba, R., Oliveira, D. V., & Rodríguez-Mañas, L. (2020). Impact of social isolation due to COVID-19 on health in older people: Mental and physical effects and recommendations. *The Journal of Nutrition Health & Aging*, *24*(9), 938–947. https://doi.org/10.1007/s12603-020-1500-7

Silpakit, O., Silpakit, C., & Chomchuen, R. (2015). Psychometric study of the Thai version of Zarit burden interview.

Sittironnarit, G., Emprasertsuk, W., & Wannasewok, K. (2020). Quality of life and subjective burden of primary dementia caregivers in Bangkok, Thailand. *Asian Journal of Psychiatry*, *48*, 101913. https://doi.org/10.1016/j.ajp.2019.101913

Soysal, P., Smith, L., Trott, M., Alexopoulos, P., Barbagallo, M., Tan, S. G., Koyanagi, A., Shenkin, S., & Veronese, N.; European Society of Geriatric Medicine Special Interest Group in Dementia and Systematic Reviews and Meta-Analyses. (2022). The effects of COVID-19 lockdown on neuropsychiatric symptoms in patients with dementia or mild cognitive impairment: A systematic review and meta-analysis. *Psychogeriatrics*, *22*(3), 402–412. https://doi.org/10.1111/psyg.12810

Strawbridge, W. J., & Wallhagen, M. I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist*, *31*(6), 770–777. https://doi.org/10.1093/geront/31.6.770

The Government Public Relations Department, Thailand. (2021, April 17). *Royal Thai Government Gazette announcement*. https://www.prd.go.th/th/content/category/detail/id/37/iid/14920

Tsapanou, A., Zoi, P., Kalligerou, F., Blekou, P., & Sakka, P. (2021). The effect of prolonged lockdown due to COVID-19 on Greek demented patients of different stages and on their caregivers. *Journal of Alzheimer's Disease: JAD*, *83*(2), 907–913. https://doi.org/10.3233/JAD-210702

Wade, D. T., Legh-Smith, J., & Hewer, R. L. (1986). Effects of living with and looking after survivors of a stroke. *British Medical Journal (Clinical Research Ed*, *293*(6544), 418–420. https://doi.org/10.1136/bmj.293.6544.418

Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., & Covinsky, K. E. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *The Journal of the American Medical Association*, *287*(16), 2090–2097. https://doi.org/10.1001/jama.287.16.2090

Yi, Y., Ding, L., Wen, H., Wu, J., Makimoto, K., & Liao, X. (2020). Is Barthel index suitable for assessing activities of daily living in patients with dementia? *Frontiers in Psychiatry*, *11*, 282. https://doi.org/10.3389/fpsyt.2020.00282

Yuan, S., Zhang, W., Yao, Q., Lü, W., Yu, W., Zhong, F., Wang, Y., Xing, D., Wang, X., Song, J., Huang, H., Chen, C., Liu, J., Yu, W., & Lü, Y. (2022). The neuropsychiatric changes after COVID-19 quarantine in patients with cognitive impairment and their caregivers in Chongqing, China: A cohort study. *Frontiers in Aging Neuroscience*, *13*, 762907. https://doi.org/10.3389/fnagi.2021.762907

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649–655. https://doi.org/10.1093/geront/20.6.649