



Impact of Coronavirus Disease Pandemic on Persons with Dementia and Their Caregivers: An Audit Study

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To the editor:

The ongoing coronavirus disease (COVID-19) pandemic has disproportionately affected persons with dementia (PWD). A diagnosis of dementia is an important risk factor for mortality in patients with COVID-19.¹⁾ Not surprisingly, many countries have implemented strict public health measures to protect vulnerable groups such as PWD from the deleterious physical effects of COVID-19. The profound impact of the secondary consequences of the pandemic, such as reduced access to healthcare services, disruption of social support networks, and increased social isolation and loneliness,^{2,3)} on PWD and their caregivers is being increasingly appreciated, prompting the need for a balanced approach to pandemic control.

A recent study highlighted that the duration of home confinement was significantly correlated with both the severity of neuropsychiatric symptoms and the distress experienced by caregivers of PWD.⁴⁾ Effective non-pharmacological interventions for behavioral and psychological symptoms of dementia (BPSD) involve social and physical contact,⁵⁾ which would be compromised by social distancing measures. The sudden discontinuation of community services, such as the operation of dementia daycare centers (DDC) and domiciliary services, would further increase the caregiver burden.

The Singapore government implemented a set of safe distancing measures from April 7 to June 1, 2020, locally known as the “circuit breaker (CB) period,” to curb the local transmission of COVID-19.⁶⁾ During the CB period, only essential services remained available. DDC were temporarily closed, with limited designated centers remaining open for individuals with inadequate family support. In addition, caregiver support services run by the Alzheimer’s Disease Association (ADA), such as Eldersit Respite Care service, person-centered home-based interventions, and caregiver support group sessions, were also affected.

The above-mentioned measures provided the impetus for this

clinical audit to evaluate the impact of COVID-19 on community-dwelling PWD and their caregivers who attended our clinic services. We wanted to ascertain whether the measures implemented during the CB period, such as the suspension of DDC, resulted in increased rates of BPSD and caregiver stress. Understanding the impact of COVID-19 on PWD and their caregivers would help local policymakers, institutions, healthcare workers, and service providers to make decisions related to care needs. Our experience may also be pertinent to PWD and caregivers in other countries who are similarly affected by the secondary effects of pandemic control measures.

We retrospectively reviewed the electronic records of patients who attended clinic consultations between January 23 and June 1, 2020, at the Centre of Geriatric Medicine, Tan Tock Seng Hospital, Singapore. The start date of the audit coincided with the date of detection of the first COVID-19 case in Singapore. The end date was the last day of the CB period. We included patients with a known diagnosis of dementia followed up at the Memory Clinic, Geriatric Assessment Clinic, or general geriatric medicine clinics. We excluded patients who were institutionalized as we wanted to understand the impact of COVID-19 on community-dwelling PWD and informal caregivers. For patients meeting the inclusion criteria, relevant data were extracted by reviewing the electronic documentation of clinic visits by doctors and nurses as well as that of telephone correspondence between doctors, nurses, or clinical assistants and the patients or their caregivers.

The data collected included data on patient demographics and social characteristics, severity of dementia (based on the Clinical Dementia Rating Scale), presence and nature of baseline BPSD (reported symptoms based on the Neuropsychiatric Inventory Questionnaire), baseline usage of psychotropic medication and cognitive enhancers, use of home- or community-based services, presence of recent behavioral changes and their relation to the COVID-19 pandemic (as indicated in the doctors’ notes), and subjective changes in

stress levels reported by caregivers. Statistical analyses were performed using IBM SPSS Statistics version 26.0 (IBM Corporation, Armonk, NY, USA). All statistical tests were two-tailed, and a p-value < 0.05 was considered statistically significant.

Among 883 patients who visited the clinic during the study period, 634 (71%) met the inclusion criteria: 444 (70%) visited the clinic before and 190 (30%) visited the clinic during the CB peri-

od. Comparisons between these two groups (Table 1) showed a significantly increased proportion of PWD with behavioral changes, mainly agitation, sleep disturbance, and irritability, during the CB period compared to that before the CB period (37% vs. 23%; $p < 0.001$). In total, 44.4% of behavioral changes encountered during the CB period were attributable to the COVID-19 pandemic, compared to 8% of changes encountered before the CB pe-

Table 1. Comparison between patients who visited the clinic before and during the “circuit-breaker” period

	Before the “circuit-breaker” period (n = 444)	During the “circuit-breaker” period (n = 190)	p-value
Sex, female	287 (64)	126 (66)	0.690
Age (y)	82 ± 6.9	81 ± 6.3	0.230
Presence of a dedicated carer			0.111
Yes	360 (81)	151 (79)	
No	65 (15)	36 (19)	
Unknown	19 (4)	3 (2)	
Relationship between the carer and the patient			-
Helper	262	99	
Spouse	54	20	
Children/children-in-law	41	29	
Grandchild	0	1	
Relative	2	1	
Unknown	1	1	
Prior use of home- or center-based services			0.001
Dementia daycare	83 (19)	50 (26)	
Senior activity center	6 (1)	4 (2)	
Social daycare	9 (2)	3 (2)	
Day rehabilitation center	12 (3)	8 (4)	
Home care	6 (1)	5 (3)	
Home-based intervention	3 (0.7)	4 (2)	
Integrated home-based care and daycare	1 (0.2)	1 (0.5)	
Severity of dementia			0.167
Mild	129 (29)	54 (28)	
Mild-moderate	43 (9)	31 (16)	
Moderate	173 (39)	75 (39)	
Moderate-severe	36 (8)	11 (5)	
Severe	36 (8)	11 (5)	
Unknown	27 (6)	8 (4)	
Baseline behavioral and psychological symptoms of dementia			0.650
Yes	285 (64)	115 (60)	
No	155 (35)	73 (38)	
Unknown	4 (1)	2 (1)	
Baseline use of psychotropic medication			0.940
Yes	248 (56)	105 (55)	
No	196 (44)	84 (45)	
Baseline use of cognitive enhancers			0.320
Yes	245 (55)	113 (59)	
No	199 (45)	77 (41)	

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Table 1. Continued

	Before the “circuit-breaker” period (n = 444)	During the “circuit-breaker” period (n = 190)	p-value
Presence of recent behavioral changes			< 0.001
Yes	100 (23)	72 (37)	
No	344 (77)	118 (63)	
Behavioral changes related to the COVID-19 pandemic			< 0.001
Yes	8 (8)	32 (44.4)	
No	92 (92)	39 (54.2)	
Unknown	0 (0)	1 (1.4)	
Nature of the behavioral change			
Delusions	10 (10)	11 (15.3)	0.029
Hallucinations	8 (8)	7 (9.7)	0.162
Agitation/aggression	57 (57)	45 (62.5)	0.001
Depression/dysphoria	10 (10)	14 (19.4)	0.005
Anxiety	7 (7)	5 (6.9)	0.357
Elation/euphoria	1 (1)	0 (0)	1.000
Apathy/indifference	7 (7)	4 (5.6)	0.741
Disinhibition	4 (4)	5 (6.9)	0.136
Irritability/mood lability	20 (20)	26 (36.1)	< 0.001
Motor disturbance	9 (9)	9 (12.5)	0.070
Sleep disturbance	43 (43)	34 (47.2)	0.005
Appetite disorder	9 (9)	4 (5.6)	1.000
Change in the level of carer stress			< 0.001
Unknown	161 (36)	46 (24)	
Increase	39 (9)	42 (22)	
No change	84 (19)	36 (19)	
Decrease	30 (7)	7 (4)	
Need for adjustment of psychotropic medications			< 0.001
Yes	118 (27)	73 (38)	
No	142 (32)	69 (36)	
Not applicable	184 (41)	48 (25)	

Values are presented as number (%) or mean±standard deviation. COVID-19, coronavirus disease.

riod ($p < 0.001$). We also observed a significant increase in the level of stress reported by caregivers (22% vs. 9%; $p < 0.001$) and the need for adjustment of psychotropic medications (38% vs. 27%; $p < 0.001$) during the CB period. In addition, clients of DDC were more likely to exhibit BPSD exacerbation (39.1% vs. 24.3%, $p = 0.002$).

Our results highlight the challenges faced by PWD and their caregivers during the pandemic. PWD may face difficulties in adapting to public health measures, including mask-wearing and safe distancing in public places.⁷⁾ Furthermore, the disruption of usual routines, closure of DDC, and prolonged periods spent at home can aggravate BPSD and increase caregiver stress.²⁾ The closure of DDC also translated to longer hours of caregiving, leading to an increased burden as caregivers often have to juggle multiple tasks, such as working from home and childcare, in addition to car-

ing for PWD.⁸⁾ This is especially salient in the Asian context, wherein the aging-in-place of PWD is heavily dependent on care provision by the family unit.⁹⁾

Since caregiver burnout is a known and eminently modifiable risk factor for negative outcomes in PWD,¹⁰⁾ it is paramount to help caregivers to cope with the increase in caregiving demands and their own social isolation in the form of emotional, informational, and peer support from other caregivers facing similar challenges.⁴⁾ This can be done via telephone or other digital media platforms. Locally, the ADA has started online programs like “#Stayhome fun with ADA” comprising exercises, bingo, karaoke, and cooking; “Memories Cafe” comprising virtual sing-along sessions, and online caregiver support group sessions.¹¹⁾

While there is a large array of technology-based activities, the lack of access to technology, digital illiteracy, and sensory impair-

ment limit the success of technology-based solutions. Hence, a pragmatic approach to keep DDC open is required. The re-opening of DDC would greatly benefit PWD and their caregivers as DDC provide both respite and support services.¹²⁾ However, viable strategies to prevent a catastrophic outbreak of COVID-19 in DDC need to be in place.¹³⁾ Alternatively, there is some evidence that non-technology home-based interventions for PWD have positive outcomes in maintaining or improving cognition and mood, reducing behavioral symptoms, and improving the quality of the caregiving relationship. These home-based interventions include reminiscence, music, art, and cognitive stimulation therapy.¹⁴⁾ Caregivers can be trained to engage PWD in such personally meaningful activities at home.

One limitation of our audit was that the clinical documentation was not standardized. Therefore, not all patients experiencing behavioral changes due to the COVID-19 pandemic may have been detected unless there was explicit documentation. Moreover, the precipitants for the observed behavioral changes may be multi-factorial, and the changes may not be solely attributable to the pandemic. Hence, prospective research studies are required to assess the impact of COVID-19 on BPSD. Currently, evidence on the efficacy of home-based interventions delivered by caregivers is limited.¹⁴⁾ Further research on the efficacy of such interventions is urgently needed to prepare for and mitigate the impact of pandemic control measures on the provision of community services.

Given the severe impact of pandemic measures on PWD and their caregivers, it is imperative to plan for the well-being of such vulnerable populations in future public health emergencies. Improving preparedness for and the response to public health emergencies will require the combined efforts of many people and organizations,¹⁵⁾ including dementia experts, to effectively tackle the challenges faced.

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CONFLICT OF INTEREST

The authors claim no conflicts of interest.

AUTHOR CONTRIBUTIONS

Conceptualization, KZY, FL, JC, NA, LWS; Data curation, KZY, FL; Writing-original draft, KZY, FL; Writing-review & editing, JC, NA, LWS.

REFERENCES

1. Bianchetti A, Rozzini R, Guerini F, Boffelli S, Ranieri P, Minelli G, et al. Clinical presentation of COVID19 in dementia patients. *J Nutr Health Aging* 2020;24:560-2.
2. Lim WS, Liang CK, Assantachai P, Auyeung TW, Kang L, Lee WJ, et al. COVID-19 and older people in Asia: Asian Working Group for Sarcopenia calls to actions. *Geriatr Gerontol Int* 2020;20:547-58.
3. Bianchetti A, Bellelli G, Guerini F, Marengoni A, Padovani A, Rozzini R, et al. Improving the care of older patients during the COVID-19 pandemic. *Aging Clin Exp Res* 2020;32:1883-8.
4. Boutoleau-Bretonniere C, Pouclet-Courtemanche H, Gillet A, Bernard A, Deruet AL, Gouraud I, et al. The effects of confinement on neuropsychiatric symptoms in Alzheimer's disease during the COVID-19 crisis. *J Alzheimers Dis* 2020;76:41-7.
5. Brown EE, Kumar S, Rajji TK, Pollock BG, Mulsant BH. Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer's disease and related dementias. *Am J Geriatr Psychiatry* 2020;28:712-21.
6. Ministry of Health. Updates on COVID-19 (coronavirus disease 2019) local situation [Internet]. Singapore: Ministry of Health; c2020 [cited 2020 Oct 20]. Available from: <https://www.moh.gov.sg/covid-19>.
7. Wang H, Li T, Barbarino P, Gauthier S, Brodaty H, Molinuevo JL, et al. Dementia care during COVID-19. *Lancet* 2020; 395:1190-1.
8. Mohan M. 'It can be a lot for a person to bear': dealing with dementia during the circuit breaker [Internet]. Singapore: Channel News Asia; 2020 [cited 2020 Oct 20]. Available from: <https://www.channelnewsasia.com/news/singapore/covid-19-coronavirus-dementia-circuitbreaker-caregivers-12721144>.
9. Cheah WK, Han HC, Chong MS, Anthony PV, Lim WS. Multi-dimensionality of the Zarit Burden Interview across the severity spectrum of cognitive impairment: an Asian perspective. *Int Psychogeriatr* 2012;24:1846-54.
10. Lwi SJ, Ford BQ, Casey JJ, Miller BL, Levenson RW. Poor caregiver mental health predicts mortality of patients with neurodegenerative disease. *Proc Natl Acad Sci U S A* 2017;114:7319-24.
11. Alzheimer's Disease Association [Internet]. Singapore: Alzheimer's Disease Association; 2020 [cited 2020 Oct 20]. Available from: <https://alz.org.sg/>.

12. Tretteteig S, Vatne S, Rokstad AM. The influence of day care centres designed for people with dementia on family caregivers: a qualitative study. *BMC Geriatr* 2017;17:5.
13. Huang HT, Chen TC, Liu TY, Chiu CF, Hsieh WC, Yang CJ, et al. How to prevent outbreak of a hospital-affiliated dementia day-care facility in the pandemic COVID-19 infection in Taiwan. *J Microbiol Immunol Infect* 2020;53:394-5.
14. Center for Evidence-Based Medicine. Activities delivered at home by family carers to maintain cognitive function in people with dementia socially isolating during COVID-19: Evidence for Non-technology based activities/interventions [Internet]. Oxford, UK: Center for Evidence-Based Medicine; 2020 [cited 2020 Oct 20]. Available from: <https://www.cebm.net/covid-19/activities-delivered-at-home-by-family-carers-to-maintain-cognitive-function-in-people-with-dementia-socially-isolating-during-covid-19-evidence-for-non-technology-based-activities-inte>.
15. Wingate MS, Perry EC, Campbell PH, David P, Weist EM. Identifying and protecting vulnerable populations in public health emergencies: addressing gaps in education and training. *Public Health Rep* 2007;122:422-6.

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