

# Exploring Caregiver Burden and Health Condition of Dementia Patients during Lockdown due to COVID-19 Pandemic

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## Abstract

**Background:** To combat the COVID-19 pandemic, several countries imposed strict lockdown to ensure social distancing to limit the spread of the virus. This caused difficulties in the management and care of patients with various chronic disorders including dementia. **Objectives:** The objective of the study was to explore the health condition of patients with dementia and assess their caregivers' burden during the lockdown. **Methods:** A total of 57 caregivers of patients with dementia who had attended the cognitive clinic of the institute for a follow-up within 1 year preceding the lockdown were assessed through telephonic interviews. Caregivers' details were noted following an interview related to the patients' health condition during lockdown and caregiver concerns. **Results:** Findings showed a deterioration in memory in 66.7% of patients with dementia and an increase in symptoms like agitation, sleeplessness, low mood, restlessness, aggression, etc., Caregivers felt helpless and had to manage new concerns and they were not sure as to how to deal with the situation. **Conclusion:** The lockdown situation disrupted the health conditions of dementia patients and caregivers faced novel challenges while managing them.

**Keywords:** Caregiver burden, COVID-19, dementia, lockdown, pandemic

## INTRODUCTION

The pandemic caused by coronavirus disease 2019 (COVID-19) has its effects throughout the world.<sup>[1]</sup> There is an extensive mental health burden impacting individuals and their families during this pandemic.<sup>[2]</sup> It has forced several countries to go under lockdown, including India. The lockdown in India started on March 24, 2020. Social distancing, self-isolation, private, and public quarantine helps to control the mass spreading of the virus.<sup>[3]</sup> However, it has its adverse effects on patient health conditions, especially those suffering from chronic illness. Hospital visits for regular follow-up have been difficult. Social distancing can also cause a lack of motivation, loss of self-worth, and other related mental distress.<sup>[4]</sup> Moreover, pandemic causes fear and distress<sup>[5]</sup> along with a lack of certain necessary supply of goods and facilities and an overall drop in the economy.<sup>[6]</sup> The pandemic tremendously challenges the healthcare system globally, especially for the geriatric population.

The health condition of dementia patients has deteriorated during the pandemic. This is not only due to the death rates seen in patients with dementia but also due to lack of family support and for not being able to avail proper healthcare facilities for various physical and psychological problems. In a developing country like India, it is already a strain for the caregivers of patients with dementia.<sup>[7]</sup> It has become incredibly challenging for the caregivers of dementia patients to provide the necessary care, increasing the caregiver burden during the lockdown period.<sup>[8]</sup> Moreover, the pandemic situation is making the caregivers more disoriented increasing their anxiety.<sup>[9]</sup>

The aim of this study was to explore the health condition of patients with dementia and their caregivers' burden during lockdown caused by the COVID-19 pandemic.

## METHODS

This was a cross-sectional study conducted in Kolkata, India, on informal caregivers (i.e., family members) of patients suffering from dementia between June and July 2020. This was part of an ongoing research work of the department and permission was obtained from the Institutional Ethics Committee.

## Tools

1. Information Schedule (Supplementary file): Caregiver characteristics and difficulties were obtained through this form.

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2. Checklist on Patient Health Condition (Supplementary file): A structured set of questions was asked, which enquired about any change in patient's health condition, including any deterioration in memory, and a checklist pertaining to any neuropsychiatric symptoms that have worsened/set in during the lockdown phase.
3. Semistructured Interview Schedule Related to Caregiver Concerns (Supplementary file): A set of four open-ended questions was set, which enquired about caregiving concerns during the lockdown and how the caregiver is managing the situations.

Construction of the information schedule, checklist, and interview schedule: The checklist and interview schedule were constructed with the opinion of five subject-level experts. Subject-level experts were neurologists and neuropsychologists. They were asked about the probable questions and from there the common questions were noted down.

Sample: The study was conducted on caregivers of patients with dementia who had attended the cognitive clinic for a follow-up within 1 year preceding the lockdown. A list of 115 patients was prepared from the database of the Cognitive Clinic of the Institute. The patient characteristics, i.e., diagnosis, severity, age, sex, and gender were obtained from the database.

Procedure: A telephonic semistructured interview was conducted to collect the data. A psychologist (RM) conducted the telephonic interview between June and July 2020. The caregivers were called and asked for their convenience of time and availability for the telephonic interview. They were explained the purpose of the study and it was conducted on their verbal consent. Once the caregiver agreed, their responses were taken down on the datasheet. The information schedule and patient health condition were duly filled up and the semistructured interview was taken down as a transcript.

Analysis: Frequencies and percentages of patient and caregiver characteristics along with difficulty areas of caregivers were calculated. Percentages of reported difficulties about patient health condition during lockdown were also calculated.

Interviews were interpreted following the thematic analysis method. The transcripts of the semistructured interview about caregiver concerns were read, coded, and themes were picked up from them and analyzed accordingly.

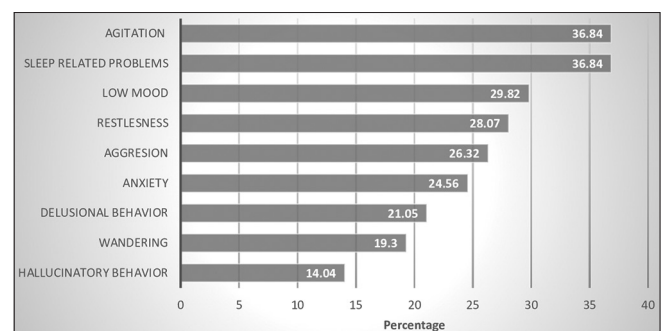
## RESULTS

Out of 115 caregivers of patients, 12 reported the death of their patients, 45 contact numbers were either invalid or unreachable, and one caregiver refused to take part. Thus, a total of 57 caregivers completed the telephonic questionnaire (including checklist) and semistructured interview. None of the patients or caregivers were reported to be COVID-19 positive. The demographic characteristics of patients are given in Table 1. Almost 58% of our patients were male and, 70% of our patients were  $\geq 60$  years of age. Majority (58%) had mild dementia, and 52.6% were suffering

from Alzheimer's disease. [Table 1]. Thirty-eight caregivers responded in the structured interview about having difficulties in caregiving during the lockdown. A total of 35.1% caregivers reported difficulties in managing cognitive and/or neuropsychiatric symptoms during the lockdown [Table 2], whereas 66.7% reported a deterioration in memory of their patients during the lockdown and 73.7% reported increase/onset of neuropsychiatric symptoms (as obtained from the structured questionnaire). The data obtained from the patient health checklist also showed an increase in neuropsychiatric symptoms like agitation, sleep-related problems, low mood, restlessness, aggression, anxiety, delusional behavior, wandering, and hallucinatory behavior. Sleep-related problems and agitation had the highest increase in percentage (36.84% for each) [Figure 1].

**Table 1: Patient characteristics**

Characteristics	n (%)
Gender	
Male	33 (57.9)
Female	24 (42.11)
Age	
$\geq 60$ years	40 (70.18)
$< 60$ years	17 (29.82)
Education	
Graduate and above	17 (29.82)
Below graduation	40 (70.18)
Occupation	
Working	8 (14.04)
Nonworking	49 (85.96)
Severity of Dementia	
Mild	33 (57.9)
Moderate	12 (21.05)
Severe	12 (21.05)
Types of Dementia	
Alzheimer's disease	30 (52.6%)
Frontotemporal dementia	9 (15.8%)
Vascular dementia	6 (10.5%)
Mixed dementia	4 (7%)
Parkinson's disease with dementia	6 (10.5%)
Corticobasal degeneration	1 (1.7%)
Dementia with Lewy bodies	1 (1.7%)



**Figure 1: Patient's health condition pertaining to neuropsychiatric symptoms that have increased/have set in during lockdown**

**Table 2: Caregiver characteristics and difficulties**

Characteristics	n (%)
Gender	
Male	20 (35.1)
Female	37 (64.9)
Age	
≥60 years	17 (29.8)
<60 years	40 (70.2)
Education	
Graduate and above	32 (56.1)
Below graduation	25 (43.9)
Number of caregivers	
Sole caregiver	15 (26.3)
Multiple caregivers	42 (73.7)
Occupation	
Working	20 (35.1)
Nonworking	37 (64.9)
Relation with patient	
Spouse	37 (64.9)
Children	20 (35.1)
Caregivers' difficulties in patient's care related to lockdown (n=38 [66.7%])	
Cognitive/behavioral issues difficult to manage	20 (35.1)
No one to support in family	7 (12.3)
Professional caregiver not available	3 (5.3)
Difficult to consult doctor regarding dementia	26 (45.6)
Stoppage of dementia medication	11 (19.3)

The caregiver concerns (as obtained from the semistructured interview) gave rise to a total of 6 themes from the 57 interviews conducted. The themes may be classified under the following headings.

#### Theme 1: *Difficulties in making patients understand the COVID-19 protocol*

Caregivers reported that it was difficult for them to make the patients understand the COVID-19 protocols. Very often the patients took off their masks and did not put them back. They did not sanitize their hands properly or at regular intervals and the caregivers had to help or instruct them repeatedly. Also, the patients quite often forgot about the lockdown and asked why they were not visiting places.

#### Theme 2: *Difficulties with financial situation*

Caregivers faced financial constraints during the lockdown. They were stressed between their caregiving job and how to sustain themselves financially. Caregivers who were also the bread earner of the family were distressed about how to meet both ends.

#### Theme 3: *Difficulties accessing necessary things*

Since there was a total lockdown, caregivers found it difficult to go out for any necessary purchases and/or activities. They were stressed as no one was available to help for even a brief period.

#### Theme 4: *Concern about own health and caregiving*

Caregivers were also concerned about their own health. They reported that they were tensed about the fact that if they had any health issues, who would look after their patients.

#### Theme 5: *Physically stressed due to caregiving*

Too much household work, without any break, made caregivers physically exhausted and they felt burdened. Caregivers were also burdened because they had to stay at home all the time and no alteration in the routine was possible.

#### Theme 6: *Deterioration in caregiver's physical and mental health*

Caregivers reported that they themselves faced deterioration in their health. They felt physically exhausted from doing all household chores and looking after their patients at the same time. They sometimes missed their medication and other health-related routines. Adhering to the COVID-19 protocol demanded an increase in the amount of household chores, which included extra importance to hygiene maintenance. Also, there was a feeling of helplessness as they were not sure what to do regarding any sudden crisis in patient's health condition.

The findings from the structured questionnaire and semistructured interview revealed the change in health conditions of the patients and concerns faced by their caregivers during the lockdown due to COVID-19 pandemic.

## DISCUSSION

COVID-19 pandemic has caused a disruption of patients with dementia on the daily way of living during the lockdown. Previous studies have also shown a rise in the caregivers' burden and an increased requirement in the number of caregivers for demented patients during the worldwide pandemic.<sup>[8,10]</sup>

As reported by the caregivers, there was deterioration of health condition of patients with dementia. A total of 66.7% of patients were reported to have a deterioration in memory functioning. Increased neuropsychiatric symptoms like agitation, restlessness, and aggression along with sleep-related problems, dysphoria, and tension in demented patients were also reported during the lockdown. Hallucinatory and delusional behaviors were also reported. Disturbances and deferments to healthcare facilities, alterations in routines, restrictions in social interactions, and a prolonged period of social isolation may have contributed to a decline in patient health conditions and an increase in their disruptive behaviors. Previous findings show that caregivers of patients with dementia who reported a higher level of caregiver burden also reported a lower quality of patient's health condition.<sup>[11]</sup>

It is challenging for caregivers to provide proper care to the patients during lockdown caused by the pandemic.<sup>[12]</sup> In our study, overall, 66.7% of caregivers have reported difficulties in providing care to their patients during the lockdown, mostly

due to increased cognitive (memory) and neuropsychiatric symptom-related difficulties. Problems were reported in availing healthcare facilities due to complete lockdown across the state. Stoppage of medicines and unavailability of help from others also accelerated the difficulties. In addition, 26.3% reported to be the sole caregivers in the family and perceived a higher burden due to lack of support. The absence of helping hands during lockdown increased the difficulties and the sole caregivers faced a challenge as they had to do all household work along with caregiving. According to Reinhard *et al.*,<sup>[13]</sup> multiple caregivers and family support are particularly important for handling patients as helping the primary caregivers provide them with more confidence and competence to engage in the caregiving process along with their well-being.

The themes overall represent a helpless condition in the caregivers which evolved all of a sudden and they were not sure as to how to deal with the situation. They faced new caregiving challenges that were not there before. Caregivers felt stuck in the situation and were not sure about what to do and whom to seek help from. Also, caregiving and adhering to the COVID-19 protocol increased their physical exhaustion and told upon their physical and mental health conditions. Findings from other studies show that social distancing and isolation practiced during lockdown led to a disconnection from relatives and friends along with a decrease in social activities,<sup>[14]</sup> leading to increased mental distress and loneliness.<sup>[15]</sup> The prolonged stretch of the COVID-19-related lockdown, social distancing, and isolation not only created uncertainty but also constant distress among the caregivers.

## CONCLUSION

The lockdown due to COVID-19 pandemic caused disruption in the lifestyle and daily functioning of patients with dementia and their caregivers. Disruption of patient health conditions in terms of cognitive and/or neuropsychiatric symptoms was seen. New challenges were also faced by the caregivers during the lockdown.

## Limitations

The study was conducted on limited sample size. Also, the findings lack generalizability as no statistical analysis was done.

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## Conflicts of interest

There are no conflicts of interest.

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