# COVID-19 and Dementia in India: Experiences of Family Caregivers

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# Dementia: The Indian Scenario

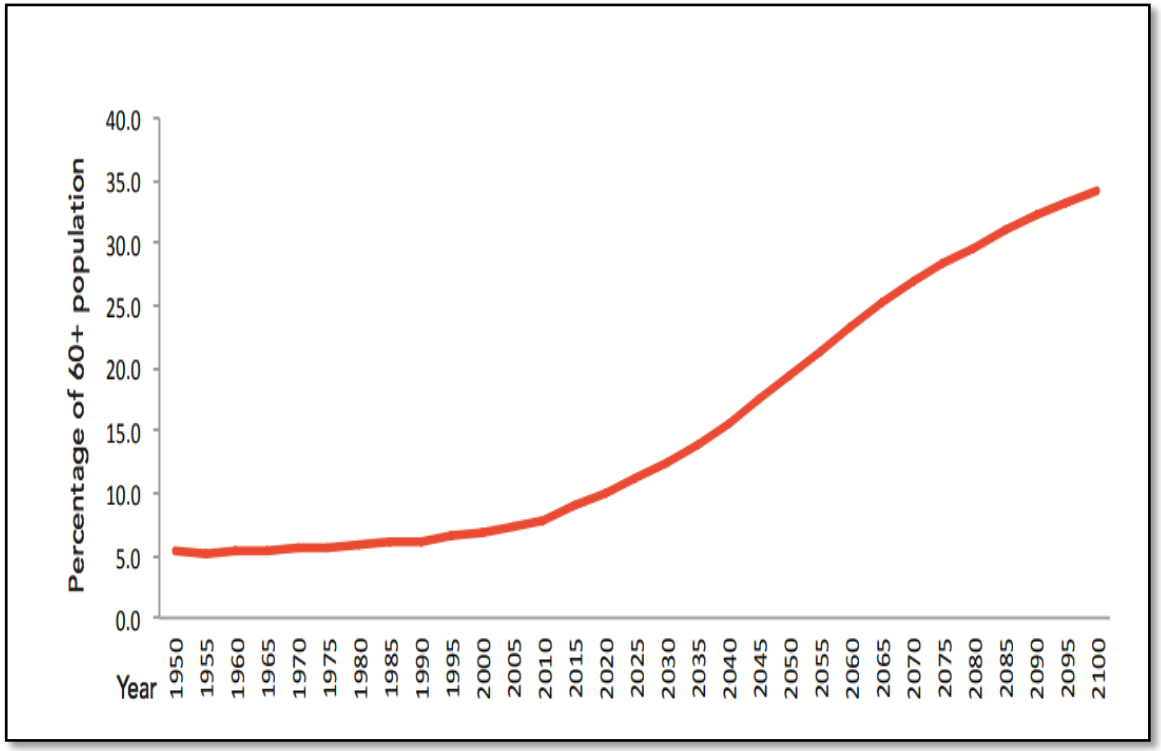


Fig 1. Percentage of people aged 60 and over in India: 1950-2100

Source: UNPF (2017)

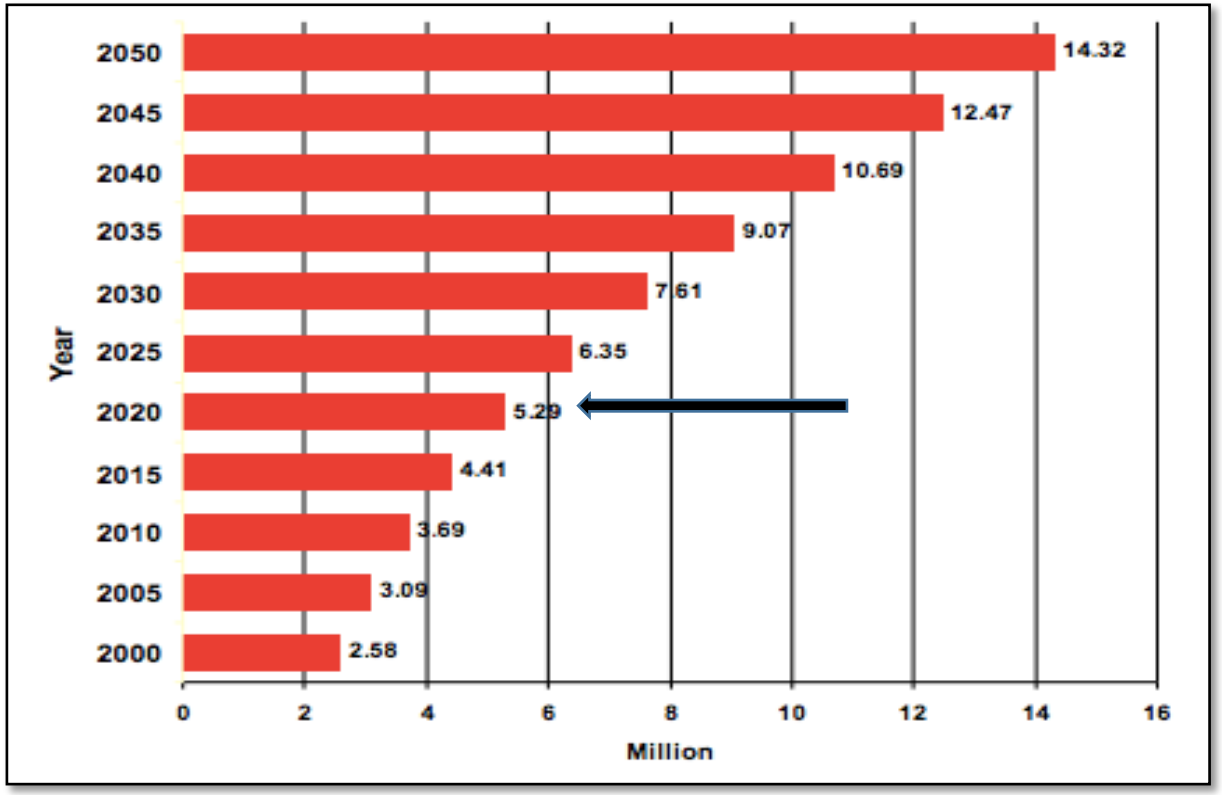


Fig 2. Projections on the number of people living with dementia in India

Source: ARDSI (2010)

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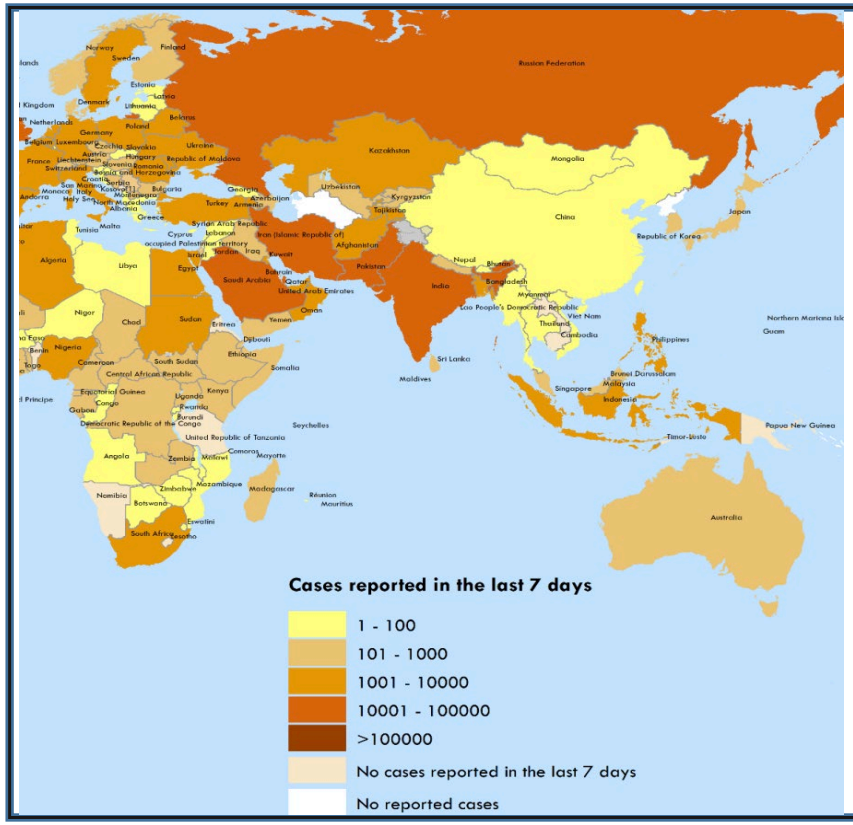
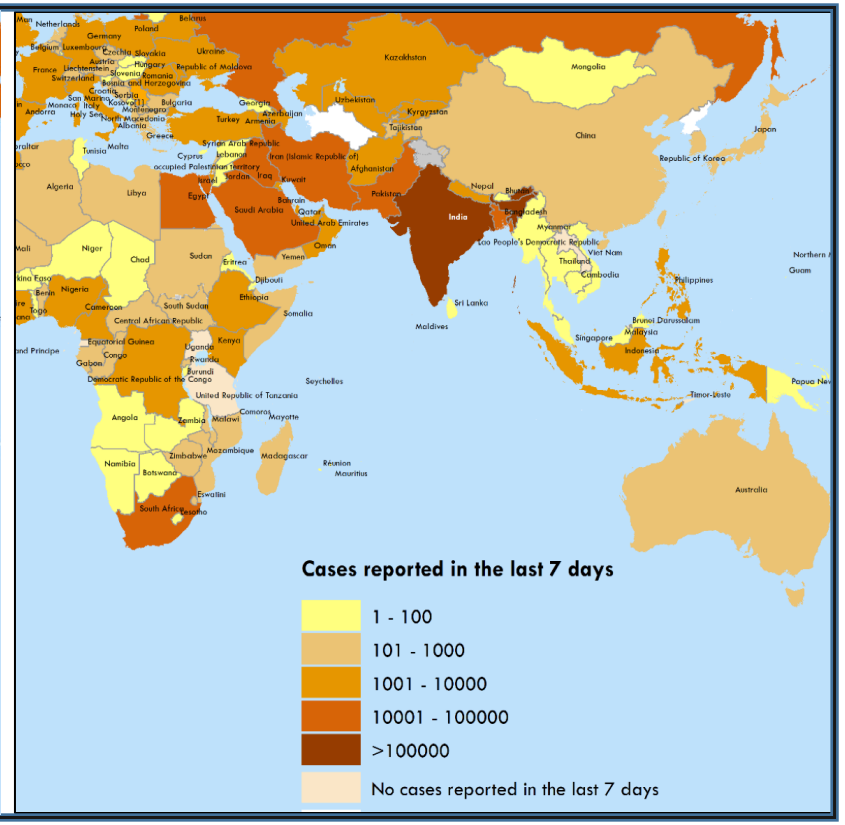
# COVID-19 situation during data collection: Phase 1 and 2



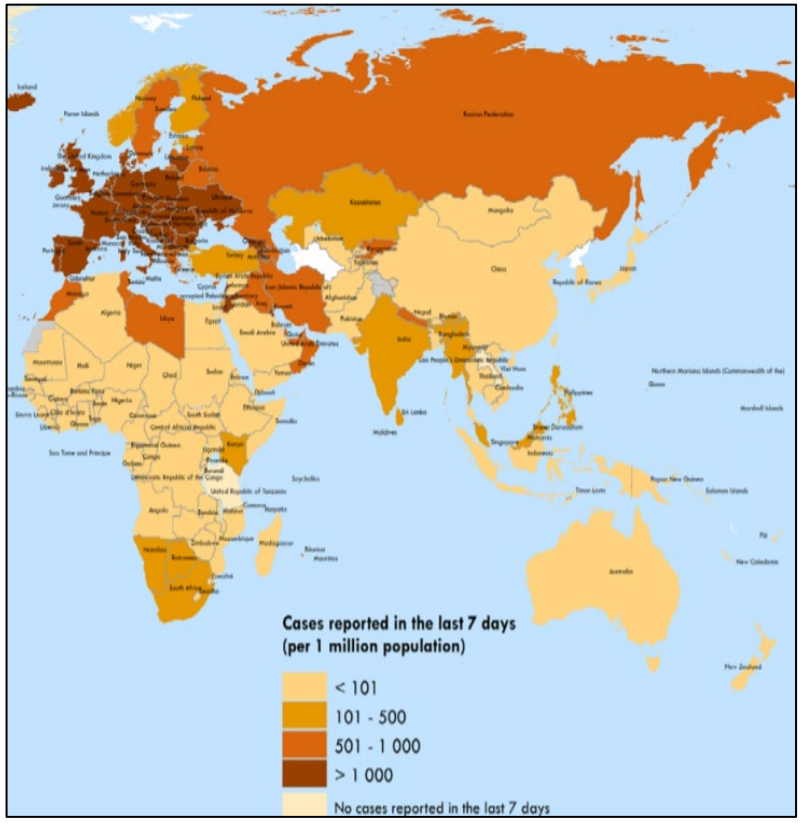

Confirmed cases in India between 15th to 21st May 2020

Source: WHO (2020a)




Confirmed cases in India between 19th to 25th June, 2020

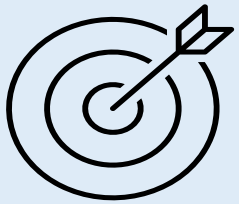
Source: WHO (2020b)




Confirmed cases in India between 26th to 1st November, 2020

Source: WHO (2020c)

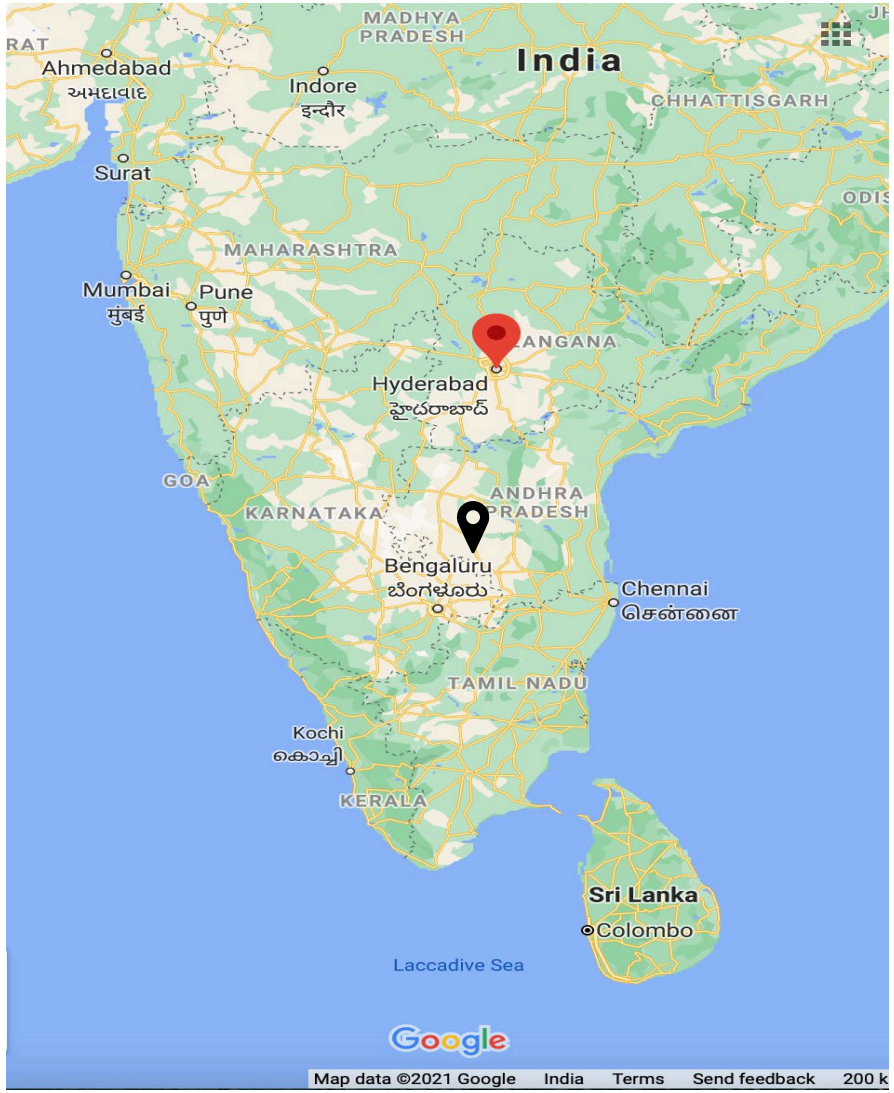
# Aim



- To explore the impact of the COVID-19 pandemic on persons with dementia and their family caregivers in India.

# Methods

- **Phase 1:**
  - 104 caregivers of persons with dementia completed the study.
  - Semi-structured interviews via telephone.
  - Questionnaire, Clinical Dementia Rating Scale (CDR), Neuropsychiatry Inventory (NPI) and Depression, Anxiety and Stress Scale (DASS-21).
  - SPSS, Thematic Analysis

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# Participant Characteristics: Phase 1

- Middle Socioeconomic Class [71.1%]
- Mean duration of illness: 3 years
- The majority of caregivers were women [53.3%]

Table 1: Clinical diagnosis of patient

| Diagnosis | Frequency (%) |
|---|---|
| **Alzheimer's disease (AD)** | 29.8 % |
| **Frontotemporal dementia (FTD)** | 24.0% |
| **Vascular dementia (VD)** | 14.4% |
| **Others** | 31.8% |

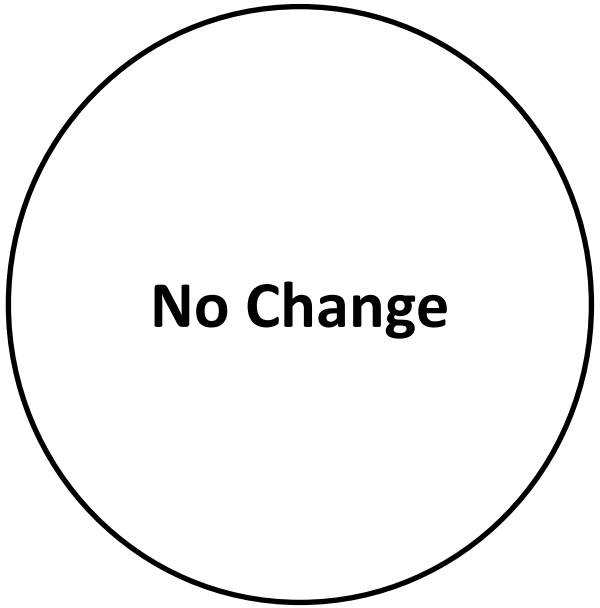
Table 2: Caregiver relationship to patient

| Relationship with the patient | Caregiver (%) |
|---|---|
| **Spouse** | 53.8% |
| **Children** | 30.7% |
| **Son/Daughter in laws** | 7.7% |
| **Siblings** | 4.8% |
| **Parents** | 2.8% |

# Emergent Themes

- Unchanging reality of caregiving
- Challenges experienced
- Effect of changes on caregivers’
- Adapting to the changed scenario

# Unchanging Reality of Caregiving




*“From the time the diagnosis was made, I have forgotten that I have a life…. I am now running the house and also working.”*

*"Not really much of an effect , was not going well before and is not going well now either."*

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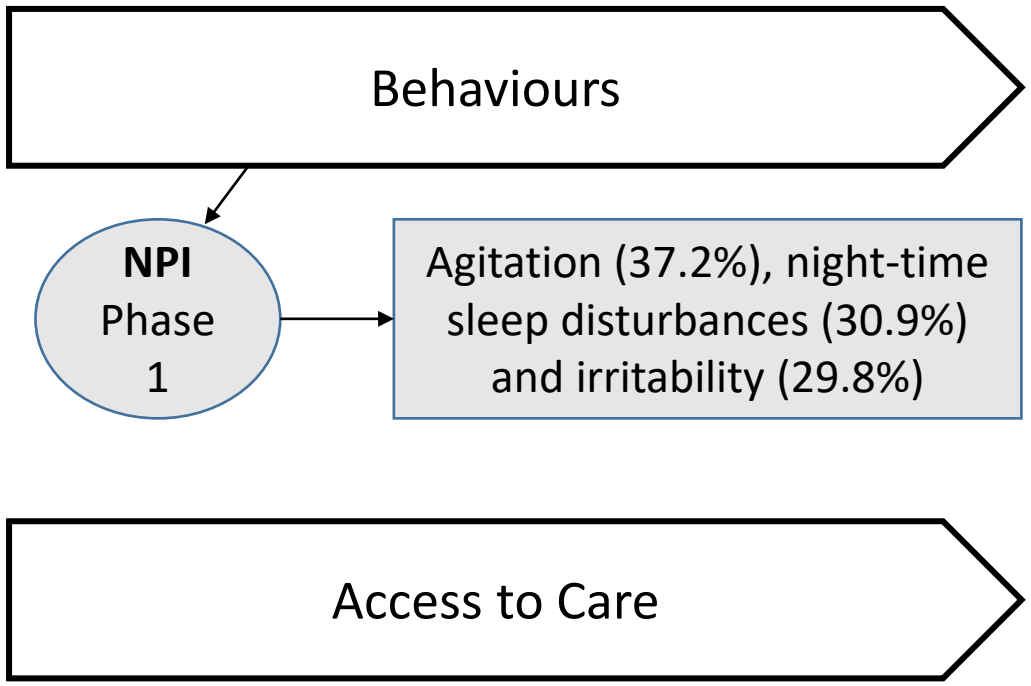
# Challenges Experienced




*"He is predominantly an outgoing person and suddenly asking him to stay in the house and not go outside was very difficult. He was irritated and would constantly fight to go outside."*

*"It has been difficult to go to hospital with the monthly check-ups being stopped and general check-up is impossible in the current situation."*

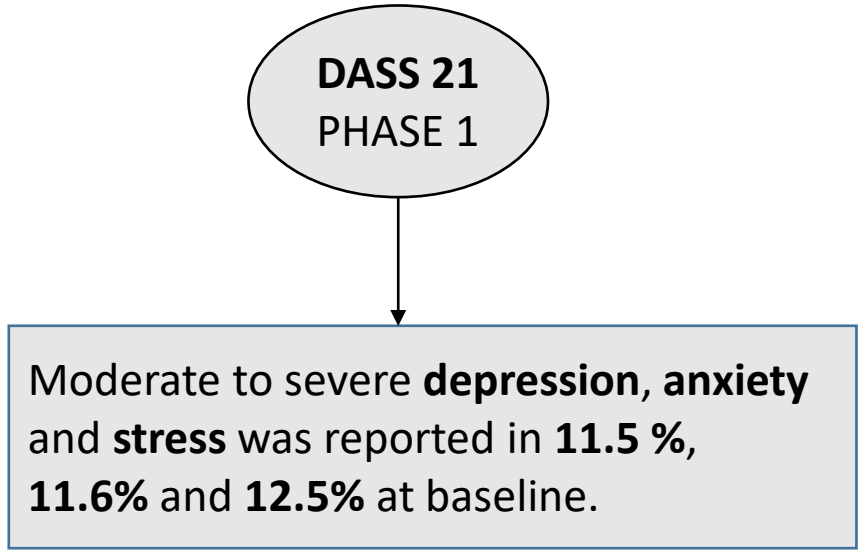
*"He was not able to go to day care, he doesn't want to do any activities at home."*

# Effect of Changes on Caregivers

Exacerbation of an already difficult situation for some caregivers.

"*I feel sense of isolation and lack of support and honestly I think I am out of words to even explain my situation*"

*"Previously guests used to visit, but due to the lockdown, they are not coming."*

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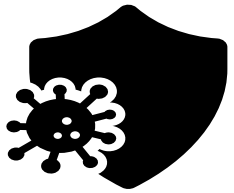
# Adapting to the Changed Scenario



Infection Prevention Measures

Changes in roles and responsibilities

Post-lockdown strategies

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# Key Takeaways

- Caring for persons with dementia is complex even during ’normal periods’.
- A global public health emergency such as the COVID-19 pandemic has exacerbated difficulties for some caregivers and  further highlighted gaps in the health and social care system.
- A multidisciplinary approach is required to address these gaps and meet caregiver needs.

# Thank you

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