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

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Under review
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)
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

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease (AD)</td>
<td>29.8%</td>
</tr>
<tr>
<td>Frontotemporal dementia (FTD)</td>
<td>24.0%</td>
</tr>
<tr>
<td>Vascular dementia (VD)</td>
<td>14.4%</td>
</tr>
<tr>
<td>Others</td>
<td>31.8%</td>
</tr>
</tbody>
</table>

Table 2: Caregiver relationship to patient

<table>
<thead>
<tr>
<th>Relationship with the patient</th>
<th>Caregiver (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>53.8%</td>
</tr>
<tr>
<td>Children</td>
<td>30.7%</td>
</tr>
<tr>
<td>Son/Daughter in laws</td>
<td>7.7%</td>
</tr>
<tr>
<td>Siblings</td>
<td>4.8%</td>
</tr>
<tr>
<td>Parents</td>
<td>2.8%</td>
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</table>
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."
Challenges Experienced

- **Behaviours**
  - NPI Phase 1
  - Agitation (37.2%), night-time sleep disturbances (30.9%) and irritability (29.8%)

- **Access to Care**

  “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 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.”

  “He was not able to go to day care, he doesn’t want to do any activities at home.”

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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."

DASS 21
PHASE 1

Moderate to severe depression, anxiety and stress was reported in 11.5%, 11.6% and 12.5% at baseline.

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Adapting to the Changed Scenario

- Infection Prevention Measures
- Changes in roles and responsibilities
- Post-lockdown strategies

Under review
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.
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References: