Title: Experiences of people with dementia and their caregivers during the COVID-19 pandemic in India: A mixed-methods study

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Abstract

Background: The COVID-19 pandemic has unprecedented consequences for the management of chronic diseases such as dementia. However, limited evidence exists on the condition of persons with dementia and their caregivers during the pandemic in lower-middle-income countries (LMICs). The study aimed to provide insights into the experiences of persons with dementia and their families during the early phases of the pandemic in India.

Methods: This study adopted a mixed-method approach. One hundred and four persons with dementia and their caregivers were evaluated via telephone using validated instruments and a semi-structured interview guide. We used the quantitative data collected to establish a baseline, whereas qualitative data was analysed thematically.

Results: The study revealed that persons with dementia and their caregivers experienced difficulties during the pandemic, which included worsening of behaviour, problems in accessing care, disruptions in functional activities and struggles in enforcing infection prevention contributing to caregiver distress. An important finding that emerged was the unchanging reality of caregiving for families. The relative success of the public health response to the COVID-19 pandemic contrasted with the lack of awareness and formal support for dementia.

Conclusions: The COVID-19 pandemic has exposed the vulnerabilities of persons with dementia and their caregivers. This calls for a collaborative reframing of medical care and public health policies to address dementia care.

Keywords: dementia, caregiving, COVID-19, pandemic, India

Background

With a population of 1.3 billion, India has over 5.4 million COVID-19 cases confirmed in the country as of September 21st, 2020 (World Health Organization [WHO], 2020c). Dementia is found to be a major risk factor for severity of COVID-19 infection among older people (Atkins et al., 2020). Higher mortality and increased vulnerability to COVID -19 infection are reported in dementia patients (Bianchetti et al., 2020; Rajagopalan et al., 2020; Suzuki et al., 2020). In India, the elderly population contribute to approximately 50.5% of all COVID-19 deaths in the country (Ministry of Health and Family Welfare [MoHFW], 2020b). While dementia is very prevalent in India, with approximately 5.29 million people living with dementia (Alzheimer's and Related Disorders Society of India [ARDSI], 2010), there is an absence of data on the number that have been infected or died from COVID-19.

Efforts have been made in India to reduce risks of infection and protect vulnerable populations through measures such as a nationwide lockdown (from March 25th to May 31st 2020, with phased relaxations). However, certain challenges unique to the Indian context pose a threat to the containment of virus spread. These include low awareness about various aspects of COVID-19 infection (Kamath, Kamath and Salins, 2020); high urban population density and "intergenerational cohabitation" making it difficult to adopt social distancing measures (Rajagopalan and Tabarrok, 2020, pp.5); lack of access to water and basic sanitation facilities (Rajagopalan and Tabarrok, 2020); and a high prevalence of non-communicable diseases (NCDs) (Mohan, Mohan and Dutta, 2019) that are recognized risk factors for complications from COVID-19 infection (Nandy et al., 2020). These context-specific factors are hindering the measures taken to contain the pandemic.

The efforts taken to reduce virus spread in India have simultaneously impacted the management of care for dementia. Dementia care in India is characterized by a large treatment gap, which is greater than 90% in most parts of the country (Dias and Patel, 2009). Cultural norms dictate eldercare provision as a family responsibility (Gupta, 2009) and family members (Brinda et al., 2014) predominately provide long-term care in India. This informal caregiving has been found to be associated with increased caregiver burden in India (Brinda et al., 2014; Jathanna et al.,2011).

In this background of a high burden of dementia, wide socioeconomic diversity and scarcity of resources, the COVID-19 pandemic will have complex consequences on people with dementia and their families. A recent study of dementia caregivers in South India found that the COVID-19 pandemic exacerbated caregiver difficulties, with reduced access to support (Vaitheswaran et al., 2020). There is limited information on the current condition of persons with dementia, the extent of their difficulties in accessing care in India and the impact of the pandemic on their cognition and behaviour. This study aims to examine the experiences of persons with dementia and their families during the ‘cluster of cases’ transmission phase of the COVID-19 pandemic in India. This will involve: 1) Describing the cognitive and behavioural problems experienced by persons with dementia during the pandemic; 2) Exploring how the pandemic has altered the management of care for persons with dementia 3) Examining the impact of the pandemic and its resultant changes on caregivers 4) Identifying measures taken by persons with dementia and their families to adapt to their ‘new normal’.

Methods

Study design

This study adopted a mixed-methods research design. Both quantitative and qualitative approaches were employed in order to meet the study aims. Ethics approval was provided by the NIMHANS Institutional Ethics Committee and ASHA Hospital Ethics Committee, Hyderabad.

Sampling

Persons diagnosed with dementia and their caregivers were recruited from the Cognitive Disorders Clinic Registry of the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore and the Neuropsychiatric Department of ASHA Hospital, Hyderabad in partnership with the Alzheimer's and Related Disorder's Society of India (ARDSI) Hyderabad Deccan Chapter. Diagnosis of dementia was made by an experienced behavioural neurologist or a psychiatrist based on standard criteria (McKeith et al., 2017; McKhann et al., 2011; Rascovsky et al., 2011; Sachdev et al., 2014). As a part of the diagnostic protocol, all patients underwent a detailed demographic, clinical, cognitive, imaging and laboratory investigations. Addenbrooke's Cognitive Examination-III (ACE-III) adapted for Indian languages was used as a cognitive screening instrument in all cases (Mekala et al., 2020). The severity of dementia was assessed using the Clinical Dementia Rating Scale (CDR) (Juva et al., 1995).

Data collection

Persons with dementia were evaluated in the two hospitals between April 1st 2019 and March 15th , 2020 were contacted via telephone between May 15th to June 25th, 2020. This was during phased relaxations of the nationwide lockdown, which was initially introduced on March 25th , 2020 on the recognition of the serious threat the pandemic posed to the community. Information regarding the severity of dementia, the prevalence of behavioural and psychological symptoms, caregiver distress and experiences of caregivers in care provision during the COVID-19 pandemic were obtained using semi-structured telephonic interviews, validated measures and instruments. Informed verbal consent was taken from all caregivers. The interviews lasted between 45 to 60 minutes and were conducted in multiple languages: Hindi, Kannada, Telugu, Tamil and English.

Considering the dynamic nature of the COVID-19 pandemic, it was planned to conduct the study in three phases. The current observations are based on the ‘cluster of cases’ transmission phases of the pandemic (WHO, 2020a, 2020b). Follow-up telephonic re-assessments for this study cohort will be performed again after a period of three months during the next pandemic phase to identify any differences in the effect of the pandemic on dementia care and once again during the post-pandemic phase when disease activity would have reverted to the normal levels observed for seasonal influenza (WHO, 2009).

Measures

Sociodemographic questionnaire

Sociodemographic and clinical details of persons with dementia, information about the caregiver and whether their place of residence was in or nearby a COVID-19 hotspot zone (where a higher number of cases are reported (MoHFW, 2020a)) were noted.

Clinical Measures

Behavioural assessment and associated caregiver distress were conducted using the Neuropsychiatric Inventory (NPI) (Cummings, 1997). The severity of dementia was assessed using the Clinical Dementia Rating (CDR) Scale (Juva et al., 1995). The Depression, Anxiety and Stress Scale (DASS-21) was administered to assess emotional distress in caregivers (Henry and Crawford, 2005).

Semi-structured interview guide

The semi-structured interview guide was developed after an in-depth literature review and several rounds of discussion between a multidisciplinary group of experts that comprised of neurologists, psychologists, psychiatric social workers and a public health researcher. The structured questions were developed in alignment with study objectives. Specific questions covered: profile of caregivers, medical and non-pharmacological management strategies, cognitive status and behaviour of persons with dementia, caregiver stress and caregivers' understanding of COVID-19 infection. In addition, the interview guide had several open-ended questions to facilitate a more comprehensive understanding of the experience of providing dementia care during the pandemic. These questions covered five main areas: 1) Challenges experienced during the pandemic with respect to the behaviour of persons with dementia and care provision; 2) Changes in caregiver routines since the institution of the nationwide lockdown; 3) Access to medical and social support; 4) Effect of the pandemic on the caregiver; 5) Changes made to adapt to the COVID-19 pandemic. On interviewing caregivers, responses to open-ended questions revealed limited knowledge of dementia and hence an additional question on the understanding of dementia was introduced midway through the study.

Data analysis

Quantitative

All data were analysed using the Statistical Package for Social Sciences (SPSS) software version 16.0 (SPSS, Chicago, IL). The demographic variables and questionnaire assessment of each participant were expressed in the terms of Mean (SD)/Median[IQR] for continuous variables and frequency (percentage) for categorical variables. Pearson correlation /Spearman Rank correlation coefficient was used to assess the correlation between NPI Score, CDR and DASS-21 scores. All $p < 0.05$ were considered as statistically significant.

Qualitative

Participants' key verbatims and points for each of the open-ended questions were not audio-recorded, but manually noted down by the interviewers. The interviewers subsequently translated participant responses to English, which was then subjected to thematic analysis (Braun and Clarke, 2006). This process was deductive and iterative in nature. The data was coded manually and these codes were assembled to form relevant themes. Once the themes were developed, the quotes that best explained the overarching themes were identified.

Results

Quantitative results

Sociodemographic and clinical profile

Of the 152 persons with cognitive impairment evaluated during the ‘cluster of cases’ transmission phase of the pandemic (WHO, 2020a, 2020b), complete information was obtained from a family caregiver for 104 persons with dementia: 5 had expired prior to the onset of the pandemic, 32 were not reachable, 8 primary caregivers did not provide consent and 3 with mild cognitive impairment (MCI) were excluded.

Of the 104 persons with dementia and their caregivers: 18 were recruited from ASHA Hospital, Hyderabad and 86 from NIMHANS, Bangalore. None of the 104 persons with dementia or their family members had developed COVID-19 infection at the time of data collection. Eight out of 104 (7.7%) persons with dementia lived in or nearby COVID-19 hotspot zones—as demarcated between May to June 2020. The mean age of persons with dementia was 65.83 (9.79) years, 49 (47.1%) were women and the duration of illness was 36.42 (31.73) months. Sociodemographic characteristics of the persons with dementia cohort are provided in **Table 1**. Diagnoses of dementia included Alzheimer’s disease (AD) (29.8%), Frontotemporal dementia (FTD) (24.0%), Vascular dementia (VD) (14.4%) and others (31.8%). The severity of dementia ranged from questionable to severe (CDR 0.5 to 3) (**Table 2**). Data on associated co-morbidities were available for 81 persons with dementia: 33 (40.7%) had hypertension, 22 (27.2%) had diabetes mellitus, and 9 (11.1%) had hypothyroidism.

103/104 respondents were primary caregivers, all were family members and 55 (53.3%) were women. Caregivers were predominantly spouses (53.8%), children (30.7%), daughter-in-law/son-in-law (7.7%), siblings (4.8%) and parents (2.8%) of the persons with dementia. Seventy of the primary caregivers (67.3%) received support from other family members in care provision to variable extents. Of the 93 persons with dementia for whom data was available on attender support, 26 (27.95%) had paid attender support and this included untrained domestic help. Six (5.8%) persons with dementia visited daycare centres regularly and 2 (1.9%) had been enrolled in residential facilities prior to the pandemic.

Table 1. Sociodemographic characteristics of the patient cohort

		Persons with dementia N=104 Mean (SD) or N (%)
Age in years		65.83 (9.79)
Education	Professional degree	17 (16.3%)
	Graduate or postgraduate	38 (36.5%)
	Intermediate or post-high school diploma	8 (7.7%)
	High school certificate	14 (13.5%)
	Middle school certificate	6 (5.8%)
	Primary school certificate	11 (10.6%)
	Illiterate	7 (6.7%)
Gender	Male	55 (52.9%)
	Female	49 (47.1%)
Duration of illness (months)		36.42 (31.73)
Occupation	Professional (white collar)	1 (1.0%)
	Semi-professional	43 (41.3%)
	Clerical/shop-owner/farm	9 (8.7%)
	Skilled/Semi-skilled	11 (10.6%)
	Unskilled worker	7 (6.7%)
	Unemployed	29 (27.9%)
Socioeconomic status	Upper class	5 (4.8%)
	Middle class	74 (71.1%)
	Lower class	10 (9.6%)

Missing values: Education – 3; Occupation – 4; Duration of illness – 2; SES- 15

Table 2. Clinical measures

Clinical Measure		Evaluation Scores Mean (SD) or N (%)
CDR (0-3)		
	Questionable	18 (17.3%)
	Mild	24 (23.1%)
	Moderate	42 (40.4%)
	Severe	20 (19.2 %)

Neuropsychiatric profile

The median NPI total score was 6 [IQR = 15]. The most common symptoms reported were: agitation (37.2%), night-time sleep disturbances (30.9%) and irritability (29.8%) **(Table 3).**

Dementia care

Medical management

Of 104 persons with dementia, 94 (90.4%) did not experience major medical problems during the movement restrictions period. Eleven (10.3%) reported increased neuropsychiatric symptoms. Difficulties in accessing medical care during the lockdown were reported: 34 (32.6%) struggled with accessing follow-up physician appointments, and 19 (18.3%) had difficulties in obtaining medications. Fifty-one (49.0%) could contact physicians via teleconsultation.

Functional rehabilitation

73/104 (70.2%) were regularly involved in one or more indoor cognitively stimulating activities. 45/104 persons with dementia (43.4%) participated in outdoor activities such as walking, grocery shopping, visiting temples, interacting with elder groups prior to the lockdown. 60 (57.7%) persons with dementia engaged in some form of physical exercise prior to the lockdown. 53 (51.0%) persons with dementia socially interacted with their family members and/or friends and 73 (70.2%) communicated via telephone on a regular basis. After the lockdown was instituted, caregivers reported that all forms of outdoor activities were stopped. All 6 (5.8%) persons with dementia that were regularly attending day care centres stopped coming in during the COVID-19 pandemic. Two persons with dementia that were enrolled in residential care facilities were withdrawn and moved to their homes.

Table 3. Neuropsychiatric symptoms in cohort and associated caregiver distress.

	All persons with dementia				Persons with dementia showing symptoms					
	Item scores		Caregiver Distress Score		Proportion with non-zero score	Proportion with score ≥ 4	Item scores		Caregiver Distress Score	
Domains	**Median**	**IQR**	**Median**	**IQR**	**N (%)**	**N (%)**	**Mean**	**S.D**	**Mean**	**S.D**
Delusion	0	0	0	0	10 (10.6%)	8 (7.7%)	6.20	4.10	2.70	1.06
Hallucination	0	0	0	0	15 (16.0%)	11 (11.7%)	5.13	3.31	2.64	1.08
Agitation	0	2	0	2	35 (37.2%)	22 (23.4%)	4.20	2.88	2.31	0.99
Depression	0	0	0	0	20 (21.3%)	13 (13.8%)	4.60	3.62	2.50	1.25
Anxiety	0	0	0	0	22 (23.4%)	15 (16.0%)	4.36	2.52	2.05	0.74
Elation	0	0	0	0	11 (11.7%)	6 (6.4%)	4.00	2.68	1.70	0.95
Apathy	0	1	0	0	24 (25.5%)	16 (17.0%)	3.88	2.86	2.27	1.28
Disinhibition	0	0	0	0	8 (8.5%)	5 (5.3%)	5.13	3.44	2.75	0.89
Irritability	0	2	0	1	28 (29.8%)	22 (22.3%)	4.79	2.87	2.39	1.03
Aberrant Motor	0	0	0	0	12 (12.8%)	10 (10.6%)	5.17	2.69	2.67	1.07
Sleep Night-time	0	3	0	2	29 (30.9%)	23 (24.5%)	5.23	2.97	2.77	1.03
Appetite	0	0	0	0	22 (23.4%)	15 (16.0%)	4.82	3.08	2.20	0.62
NPI Total	6	15	2	6			11.99	14.04	5.19	4.64

The table structure was adapted from Aarsland et al., 2007; Missing values: 10 patients in each domain.

Caregiver distress

The median NPI-D score for caregivers was 2 (IQR = 6). The highest caregiver distress was associated with night-time sleep, disinhibition, delusion, aberrant motor and hallucinations (**Table 3**). As per DASS-21, the proportion of caregivers that experienced moderate to extremely severe depression (11.5%), anxiety (11.6%) and stress (12.5%) (**Table 4**). There was a significant positive correlation between the neuropsychiatric symptoms measured by NPI and caregiver emotional status: DASS-21 depression scores ($r = 0.394$, $p < 0.001$) (**Figure 1**), anxiety ($r = 0.281$, $p = 0.005$) (**Figure 2**), stress ($r = 0.593$, $p< 0.001$) (**Figure 3)**. A significant positive correlation was also found between severity of dementia scale CDR and DASS-21 depression ($\rho = 0.444$, $p = 0. 001$) (**Figure 4**), anxiety ($\rho = 0.222$, $p = 0.026$) (**Figure 5**) and stress ($\rho = 0.370$, $p= 0.001$) (**Figure 6**) scores.

Table 4. Frequency of Depression, Anxiety and Stress as per DASS-21

	Depression N (%)	**Anxiety N (%)**	**Stress N (%)**
Normal	84 (80.8%)	87 (83.6%)	84 (80.8 %)
Mild	4 (3.8%)	1 (1.0%)	3 (2.9%)
Moderate	7 (6.7%)	6 (5.8%)	5 (4.8 %)
Severe		3 (2.9%)	5 (4.8 %)
Extremely Severe	5 (4.8%)	3 (2.9%)	3 (2.9%)

Missing values: Depression - 4; Anxiety – 4; Stress– 4

[Insert Figure 1.]

[Insert Figure 2.]

[Insert Figure 3.]

[Insert Figure 4.]

[Insert Figure 5.]

[Insert Figure 6.]

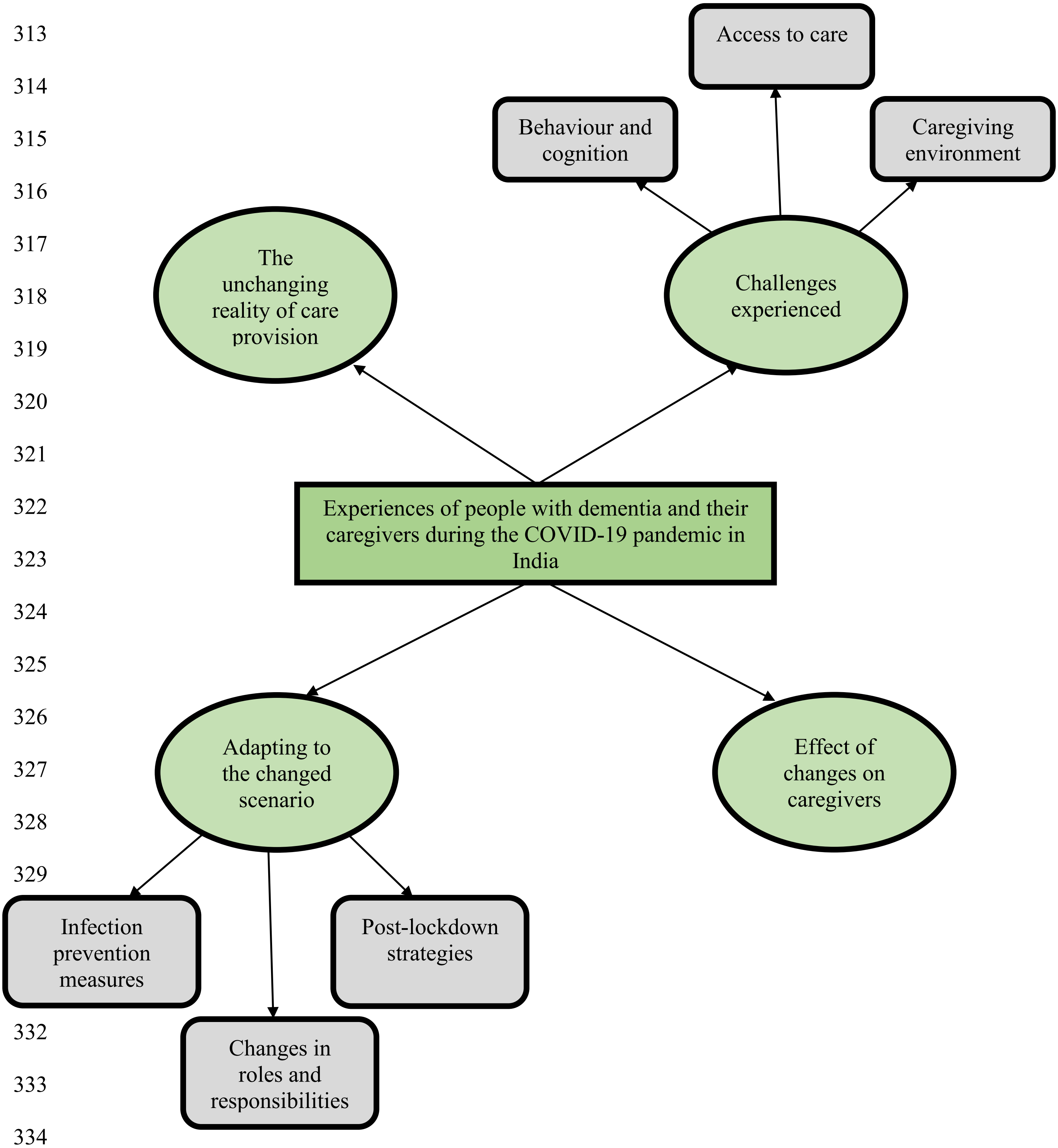
Awareness regarding COVID-19 and dementia

103/104 caregivers (99%) were aware of and following government updates on infection control for COVID-19. On the other hand, from the 48 caregivers questioned on their understanding of dementia, 34 (70.8%) caregivers were unable to describe the meaning of the term ‘dementia’ despite providing care to a relative with dementia for a fairly long period of time.

Qualitative Results

Hundred and three caregivers shared in-depth regarding their experiences with caregiving during the pandemic. 54 (52.4%) reported no major challenges and 49 (47.6%) reported one or more challenges. Four themes emerged:1) Unchanging reality of care provision; 2) Challenges experienced; 3) Effect of changes on caregivers; 4) Adaptation to the changed scenario. A thematic map (**Figure 7**) provides an overview of the themes identified from qualitative analysis.

Figure 7. A thematic map



Unchanging reality of care provision

Many caregivers felt that care provision during the pandemic was reflective of the consistently increasing caregiving stressors that they have been encountering

> *'It [caregiving] has not really changed [during the pandemic]. It had become difficult for the last 4-5 months, and it is just increasing day by day.' – CG 66*

Therefore, caregivers felt that their care provision role had an unchanging reality to it. Caregiving for persons with dementia was always difficult, and these challenges continued to increase, with the pandemic as the latest stressor.

Challenges experienced

Behaviour and cognition: The most commonly reported behaviour and cognition related changes that raised concerns among caregivers were: increased memory loss, poor spatial and temporal orientation, restlessness, confusion, irritation, anger, sadness, and reduced eating. Few of these changes were precipitated by alterations in the routines of their relatives with dementia due to restrictions on various outdoor-related activities that were a part of the daily routine for many persons with dementia. This change was identified by some caregivers to increase frustration among persons with dementia.

> *'Yes, he was a person who used to enjoy going outside the most, but now [current pandemic situation] convincing and negotiating with him for staying at home has been difficult and has also affected him.' – CG 59*

One caregiver reported that their relative with dementia filled gaps in their memory with confabulations about COVID-19.

> *"My father is making false stories during routine conversations that a doctor whom he met last week had developed COVID19 and died. This is not true."- CG 72*

Access to care: Caregivers reported difficulties in accessing essential medications or getting consultations with health professionals for follow-ups or check-ups.

> *'It has been difficult to go to the hospital with the monthly check-ups being stopped, and general check-up is impossible in the current situation.' – CG 70*

Other problems included accessing long-term care support services, including home-based physiotherapy services. Those caregivers that relied on day care facilities for much-needed respite time, were struggling to find new ways to engage the person with dementia due to the suspension of such facilities during the lockdown period.

Caregiving environment: The sudden lockdown announcement left a few caregivers and persons with dementia unable to travel back to their hometowns, which posed many difficulties.

> *'We [person with dementia and caregiver] went to Orissa prior to lockdown and were stuck there. We cannot come to Bengaluru [hometown] because of the lockdown' – CG 74*

Effect of changes on caregivers

While many acknowledged that the process of caregiving itself is distressing, the changes in care arrangements and routines as a result of the lockdown were reported to have exacerbated an already difficult situation for a few caregivers. Caregivers expressed many negative emotions associated with care provision. The terms or phrases most often used by caregivers to describe their situation were: “stressed”, “distressed”, “irritated” and “feeling lost”. One stated:

> ‘*I feel a sense of isolation and lack of support and honestly, I think I am out of words to even explain my situation’ – CG 66*

The lack of socialization during lockdown further heightened feelings of loneliness and isolation.

> *‘Previously guests used to visit, but due to the lockdown, they are not coming.’*
> *– CG 75*

Few caregivers also reported feelings of stress caused by loss of employment or consistent income due to the lockdown.

Adaptation to the changed scenario

Behavioural changes to reduce risks of infection and protect patients: The majority of caregivers had adopted COVID-19 infection prevention measures. Caregivers mentioned that they had taken a number of steps to educate and remind the person with dementia to socially distance. Some caregivers mentioned that it was difficult to enforce these measures as their relative with dementia was unable to comprehend or remember their instructions.

> *'We showed her news on TV and educated her along with my father [her husband] and my child. She learns from them and practises the same. They see each other, tell each other, and hence it becomes easier to practise.' – CG 51*

A few caregivers reported that they did not see the need to practice social distancing at all.

> *'We are inside the house, and he doesn't really go outside hence [social distancing] is not required.' – CG 16*

Changes in roles and responsibilities in care provision: A few caregivers reported that they spent more time with their relative with dementia for their activities of daily living (ADL) compared to prior to the lockdown. They also had to try and to balance their new work-from-home situation with their care provision responsibilities. However, one caregiver stated that one family member took complete responsibility for care provision.

> *'No difficulty due to the lockdown, my wife takes care of everything, from food to dressing, she takes total care.' – CG 67*

Post-lockdown strategies: While a large proportion of caregivers mentioned no plans of adopting majors changes post-lockdown, a number of them did report that they would continue to adapt to their 'new normal' by maintaining infection prevention measures. There was also eagerness among some caregivers to resume outdoor activities such as visiting relatives/temples/parks, resuming day care, going walking etc.

Discussion

This is the first study to use a large cohort of persons with dementia and their caregivers to explore their condition during the COVID-19 pandemic in India. The qualitative data revealed that behavioural symptoms in some persons with dementia worsened during the pandemic. While no persons with dementia or caregivers developed COVID-19 infection during this early phase of the pandemic, there were difficulties in accessing consultations and long-term care support services. Functional rehabilitation activities such as outdoor physical exercises and social interactions were majorly disrupted due to movement restrictions that were introduced to contain the pandemic. These restrictions, in addition to fears of infection, led to shifts in caregiving responsibilities. With high levels of awareness regarding COVID-19, many caregivers sought to implement infection prevention measures in their households, but these measures were difficult to enforce on persons with dementia. In a situation of decreased access to support, these new responsibilities increased caregiver stress. However, for many caregivers, the process of care provision was perceived to be unchanging due to the consistent stressors associated with caregiving that existed prior to and continued through the pandemic.

This study was conducted during the early stages of the 'cluster of cases' phase of the COVID-19 pandemic (WHO, 2020a, 2020b). As a result, much of the experiences shared are in response to the lockdown and restrictions in movement that were a part of government regulations at the time. Family caregivers highlighted the unrelenting stresses associated with care provision, which was prevalent even prior to the emergence of the COVID-19 pandemic. The significant positive correlation found between caregiver distress and greater severity of dementia is consistent with previous studies (Prince et al., 2012).

In this background of high carer burden, the emergence of the COVID-19 pandemic has presented unique challenges for caregivers of persons with dementia. Older people and people with co-morbidities comprise a significant proportion of case fatalities in India (MoHFW, 2020b). Considering that the mean age of our study cohort is 65.8 years and over half reported comorbidities, our study cohort is at a high risk of mortality from COVID-19 infection. However, none of the persons with dementia or their caregivers reported infection with COVID-19 during the study period. This could be because the data was collected during the early stages of the ‘cluster of cases’ transmission phase, wherein the total confirmed cases were substantially lower in the country. It is also plausible that the family-based model of home care has had a protective effect in this phase of the pandemic. In comparison, developed countries, where institutional care is well established, have been reporting high mortality rates in their care homes (Comas-Herrera et al., 2020) during the local transmission and community transmission phases of the pandemic. However, the study cohort continues to remain highly vulnerable as the pandemic continues to evolve in India.

The indirect impacts of the pandemic on persons with dementia were also examined. The most common behavioural symptoms persons with dementia presented with were agitation, night-time sleep disturbances and irritability. The qualitative data indicates that such symptoms in some persons with dementia may partially be attributed to alterations in their routines that occurred as a result of movement restrictions. This is corroborated by a previous study examining neuropsychiatric symptoms in AD during the confinement period of the pandemic (Boutoleau-Bretonnière et al., 2020). Furthermore, an interesting finding that emerged was the presence of COVID-19 related confabulations in a person with dementia. Confabulations are false memories encountered in dementia and contain overlearned information that is known to emerge under stressful situations (Johnson, Connor and Cantor, 1997; Van Damme et al., 2017). We hypothesize that repeated information in the media about the COVID-19 pandemic and continuous reminders at home may have contributed to the COVID-19 content in this person’s confabulations.

Nearly one-third of the cohort reported challenges in accessing physicians, and almost one-fifth had difficulties in obtaining medications. The suspension of non-emergency services and disruption in the supply of medications disproportionately affects the care for people with chronic diseases, who require frequent monitoring and a stable supply of medications (Brown et al., 2020). While teleconsultations were started in the early stages of the pandemic by participating hospitals, this may be viewed as inadequate, due to difficulties in performing neurological and cognitive tests via virtual platforms (Brown et al., 2020).

The pandemic was found to have a larger impact on the functional rehabilitation of dementia. Studies (Spector et al., 2003; Vreugdenhil et al., 2012) have indicated the importance of non-pharmacological management in delaying functional decline of persons with chronic neurological conditions. Prior to the lockdown, more than half the study cohort was involved in some form of physical exercise, and approximately 43.4% were involved in outdoor activities. These outdoor physical activities along with daycare visits, physiotherapist home visits and in-person socialization outside the household were completely stopped due to movement restrictions. This may have contributed towards deterioration in certain persons with dementia. While this association could not be established due to the constraints accompanying the COVID-19 situation, a clinical follow-up of persons with dementia could provide insights into the consequences of discontinuing cognitively and physically stimulating activities (Ruthirakuhan et al., 2012).

Management of care for dementia was identified by caregivers to be overwhelming and stressful. Behavioural disturbances were found to be significantly associated with caregiver distress. This correlation may partly be attributed to the pandemic, as a few caregivers communicated changes in behaviours that emerged due to movement restrictions. Caregivers had to find new ways to engage their relative, manage changes in their environment and address behavioural problems with limited access to support due to the suspension of day care facilities, the inability of paid attenders to come in and restrictions on in-person socializing. These findings are in line with another study conducted in South India

(Vaitheswaran et al., 2020). It is important to note that these pandemic associated changes are likely to have exacerbated the caregiver distress that is reflective of providing care for persons with progressive disease. The latter association is confirmed by the significant positive correlation between caregiver distress and dementia severity and also behavioural symptoms and caregiver distress. The caregiving responsibilities fell primarily on women, as indicated by the large proportion of women that were informal primary caregivers in this study, consistent with earlier reports (ARDSI, 2020; Brinda et al., 2014).

Caregivers made multiple efforts to adapt to their changed scenario. The most significant change was introducing infection prevention measures. This was difficult to enforce due to the inability of persons with dementia to understand the need for such measures. This finding is similar to observations made by Suzuki et al., 2020, who noted the difficulties faced by persons with dementia in adopting infection prevention measures during the COVID-19 outbreak in Japan. However, a small proportion could partially understand and carry out such measures, highlighting that persons with dementia can be trained to perform certain tasks. Moreover, it is interesting to note that almost all caregivers were familiar with the term ‘COVID’ and the importance of infection prevention measures, while over half of those interviewed were unable to describe the term ‘dementia’ despite caring for a relative with the disease for a fairly long period. This emphasizes a paradox, wherein caregivers had insufficient awareness about dementia, but relatively high awareness regarding the recent and ongoing COVID-19 pandemic. This novel finding highlights the strength of the public health response to the pandemic, as almost all caregivers irrespective of socioeconomic status, were acutely aware of the pandemic.

We acknowledge a few limitations to this study. Participants were recruited through purposive sampling via a hospital registry and database. Therefore, all persons with dementia were diagnosed and had access to medical services, which prevents the generalizability of findings. Furthermore, due to the lack of prior quantitative data to facilitate comparisons, the data collected via the NPI, CDR and DASS scales serve as a baseline for the next phase of data collection and analysis. We were also unable to formally assess cognition during the pandemic and as a result, could not attribute cognitive deterioration to the pandemic. In addition, caregiver distress is likely to be underreported as the DASS was administered via telephone rather than by self-administration, which may have given rise to social desirability bias (Krumpal et al., 2013).

Conclusions

This study provides critical evidence from a lower- middle-income country (LMIC) regarding the condition of persons with dementia and their caregivers during the COVID-19 pandemic. It has demonstrated that persons with dementia and their caregivers experienced difficulties during the pandemic, which were attributed to multiple factors including pandemic related changes, disease progression and the stressful nature of care provision in the Indian context. These findings highlight the complex needs of persons with dementia and their caregivers that require immediate recognition. Efforts taken by the government such as advisories for older people (MoHFW, 2020c) and guidelines for the protection of persons with disabilities (Ministry of Social Justice and Empowerment [MSJE], 2020) while useful, need to further address the underlying gaps in the health and social care system that have been aggravated by the pandemic. Therefore, it is essential for a multidisciplinary approach to be adopted to address the needs of persons with dementia and their caregivers. The successful convergence of medical, public health and policy spheres in response to the pandemic should be emulated for dementia care in India (Rajagopalan et al., 2020). Collaboration between these spheres (Rajagopalan et al., 2020) will aid in reframing existing models of dementia care services in the country. This is critical in order to protect and support persons with dementia and their families, who remain highly vulnerable during periods of crisis and uncertainty.

Abbreviations

Addenbrooke’s Cognitive Examination-III (ACE-III)
Alzheimer’s disease (AD)
Alzheimer’s and Related Disorder’s Society of India (ARDSI)
Clinical Dementia Rating Scale (CDR)
Depression, Anxiety and Stress Scale-21 (DASS-21)
Frontotemporal dementia (FTD)
Lower- middle-income countries (LMICs)
National Institute of Mental Health and Neurosciences (NIMHANS)
Neuropsychiatric Inventory (NPI)
Vascular dementia (VaD)

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Declarations of conflicting interests

The Authors declare that there is no conflict of interest

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Figure 1. Scatter plot diagram of correlation between DASS-21 depression subscale and NPI. Note. DASS= Depression, Anxiety and Stress Scale.

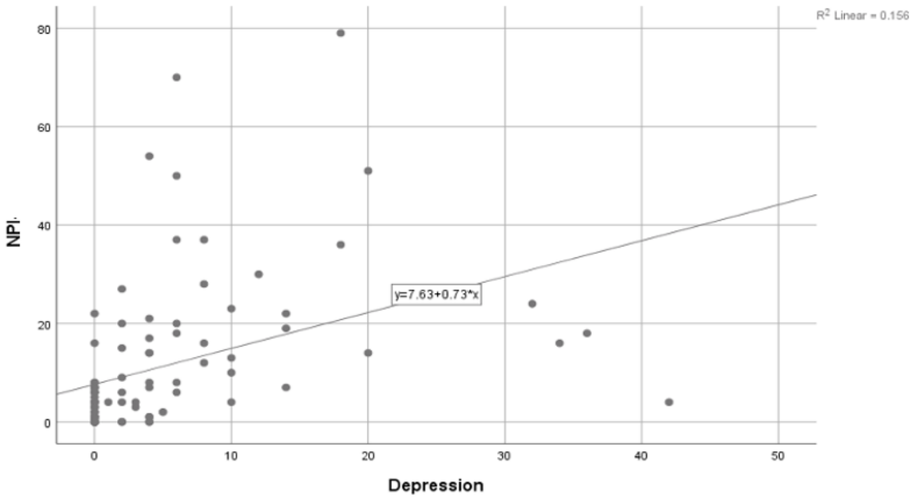

Figure 2. Scatter plot diagram of the correlation between DASS-21 anxiety subscale and NPI Note. DASS = Depression, Anxiety and Stress Scale.

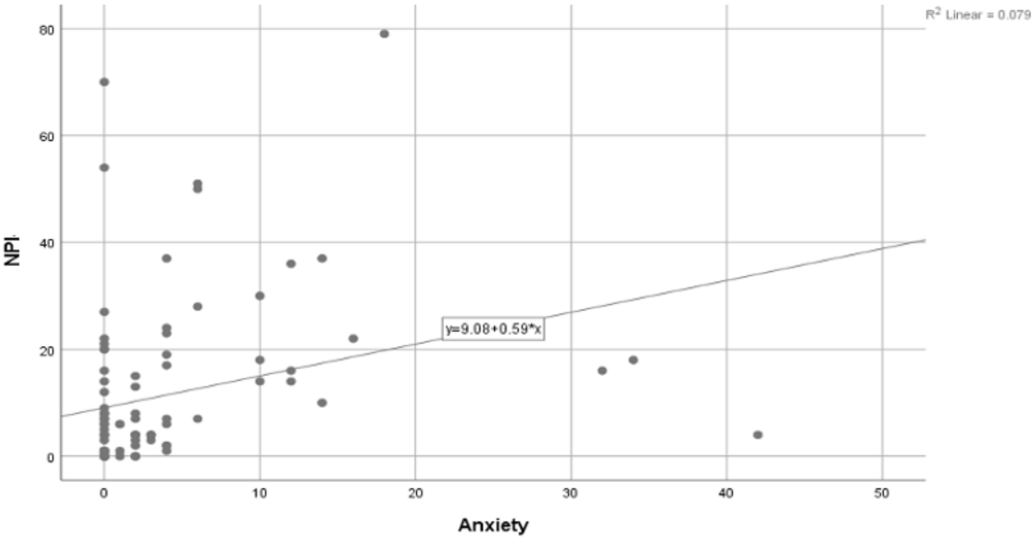

Figure 3. Scatter plot diagram of the correlation between DASS-21 stress subscale and NPI. Note. DASS = Depression, Anxiety and Stress Scale.

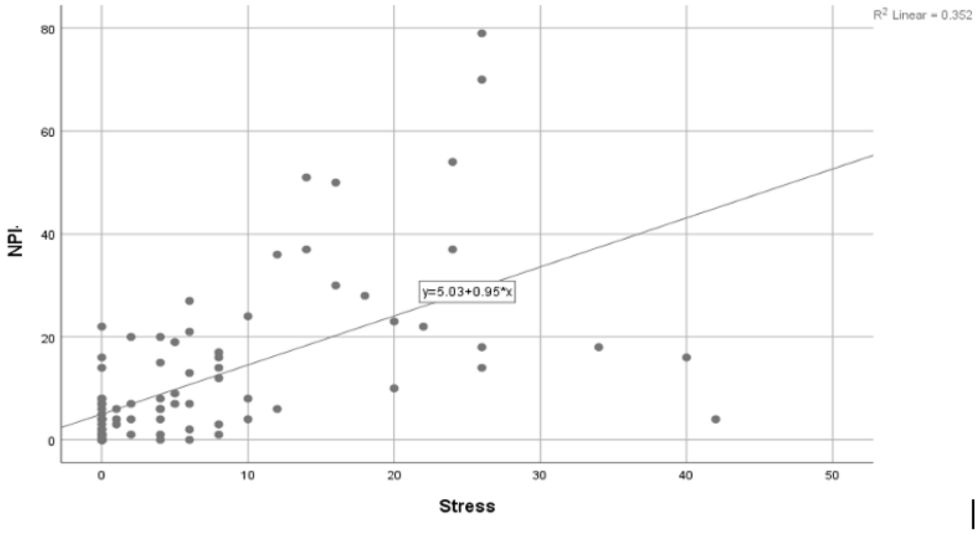

Figure 4. Scatter plot diagram of the correlation between DASS-21 depression subscale and CDR. Note. DASS = Depression, Anxiety and Stress Scale; CDR = Clinical Dementia Rating Scale.

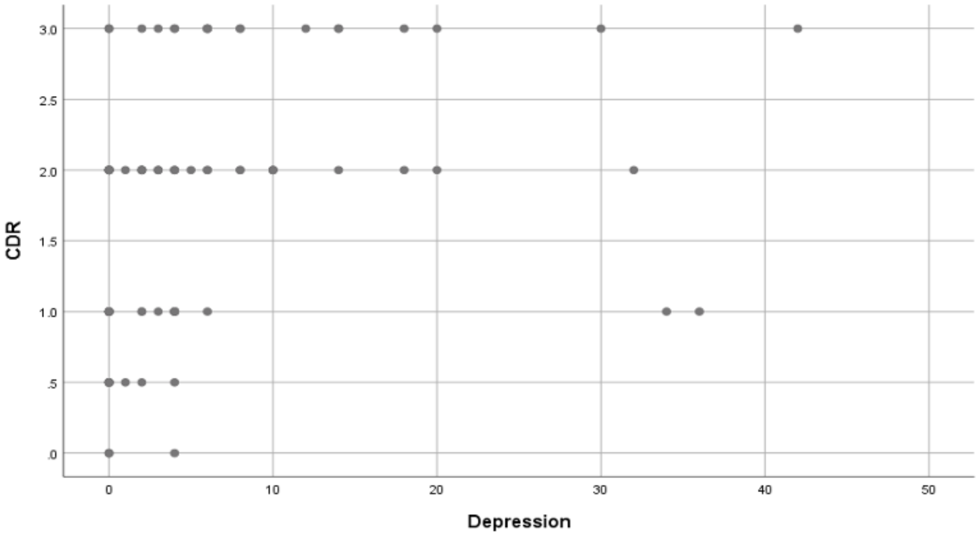

Figure 5. Scatter plot diagram of the correlation between DASS-21 anxiety subscale and CDR. Note. DASS = Depression, Anxiety and Stress Scale; CDR = Clinical Dementia Rating Scale.

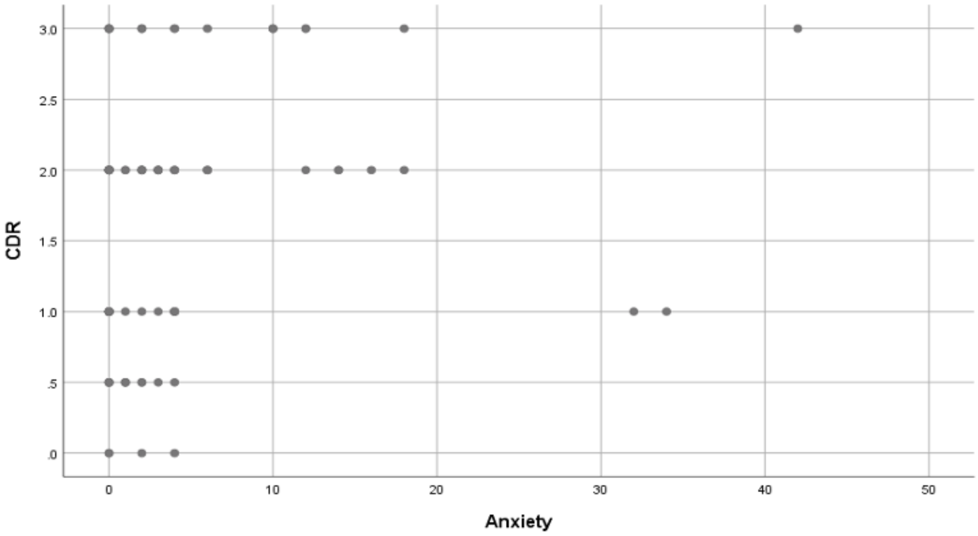

Figure 6. Scatter plot diagram of the correlation between DASS-21 stress subscale and CDR. Note. DASS = Depression, Anxiety and Stress Scale; CDR = Clinical Dementia Rating Scale.