



Family Caregiving in Dementia: Caregivers' Mental Health and Nature of Caregiving

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KEYWORDS

Dementia caregiver, mental health traits, stress, depression, anxiety, activities of daily living, factors of caregiving, India

ABSTRACT

Family caregivers are the main lifeline of a person with dementia. In India, research on caregivers' health is rarely attempted. Present study aims to examine the relationship between selected mental health traits of family caregivers and the duration and level of caregiving focused their care recipients. A cross-sectional empirical study was conducted in Kolkata and Howrah districts of West Bengal. 131 family caregivers of demented person participated, and data were collected using pre-tested questionnaires. Care recipients' incompetence to perform daily activities predicted the mental health condition of the caregivers. Significant association was found between anxiety and level of support provided by the caregivers. When involved in caregiving for many years and providing caregiving for 9 hours or fewer per day, caregivers are likely to experience adverse mental health condition. Caregiving is very challenging and it affects the psychological health of the caregivers. The health management of dementia caregivers should get priority in health system research.

Introduction

Dementia is characterised as a progressive loss of brain function giving rise to many cognitive malfunctions, along with physical, emotional and functional disabilities (Alzheimer's Disease International, 2009). The decline of cognitive ability along with physical disability necessitates the need for a high level of care and surveillance even during the early stage of dementia, and care recipients become fully dependent upon caregivers as dementia progresses (Alzheimer's Disease International, 2013). The burden of dementia is not only limited to persons with the condition, but also has immense social, psychological and economic consequences on their family members.

Currently, dementia is one of the major health problems of elderly people all over the world. Almost 41 million people are living with dementia around the world; it is expected that the number will reach nearly 115 million by the year 2050 (World Health Organization and Alzheimer's Disease International, 2012). In India, the number of people with dementia is increasing day by day. The prevalence of dementia in Eastern India, varies from 0.8% to 1.28%, 2.44 to 4.1% in Western India, 1.83% in Northern India and 3.6% in Southern India (Das et al. 2012). According to a report by Alzheimer's & Related Disorders Society of India (2010), it has been estimated that, in the state of West Bengal, around 20,000 to 40,000 people will be living with dementia by the year 2036. The risk

of having dementia increases with age. The chance is about 1% among individuals under the age of 65 years; but almost 40% among people aged 85 years or older. Therefore, more family members will become engaged in providing care for incapacitated relatives (Ferrara et al. 2008).

It is well documented that caring for a person with dementia creates a health burden among family caregivers, and it becomes a common challenge in both developed and developing countries (Chan et al. 2010). A study based in the UK and USA reported that the prevalence of depressive disorder is high among dementia caregivers (Gallo and Lebowitz, 1999). Gender difference in caregivers' mental health has been documented in many studies. The literature reveals that male caregivers experience lower level of burden and depression than females (Ormel et al. 1994; Harris, 1959; Garrido and Paulo, 2004). A study in Brazil found that women with higher education experienced a higher level of burden associated with caregiving (de Moraes and da Silva, 2009).

In Asian societies, the family forms the preliminary support system for someone with dementia, and this support may influence family functioning in many ways. A study found that presence of behavioural problems among people with dementia has enormous impact on caregivers' psychological health (Chi-Chan et al. 2009). A study in Taiwan emphasised that diminished psychological health may continue among caregivers even after institutionalization of the person receiving care (Lau et al. 2008).

In India, the cost of treatment as well as the dearth of specialized hospital facilities usually means that a person with dementia remains at home and receives daily care from their family members (Shaji and Reddy, 2012). The type of help or support a caregiver usually provides depends on the specific needs of a person with dementia, which often changes with the progression of the disease (Alzheimer's Disease International, 2013). For many caregivers, caregiving becomes a full time responsibility that demands much of their time and efforts (Ferrara et al. 2008). The adjustment in caregiving responsibilities may compel caregivers to reduce their other activities and to balance their role as caregiver along with other commitments (i.e. career, social relationships and many more) (Shaji and Reddy, 2012) Earlier studies reported that insufficient social interaction and limited financial resources may lead to worse psychological health among caregivers (Tomoko et al. 2003; Das et al. 2010).

Providing care to people with dementia is an extremely challenging work, and is associated with higher levels of psychological morbidity (Chi-Chan et al. 2009). It is observed that longer period of caregiving may give rise to negative health outcomes, such as stress, depression, anxiety and consequently many physical health complications (Schulz et al. 1995; Schulz and Martire, 2004).

In view of the above, the present study aims to examine the relationship between the mental health traits of caregivers (in terms of stress, depression and anxiety) and the level of support (in terms of daily and instrumental activities, in years and hours/day) they provide to care recipients.

Materials and methods

Selection of study participants

The present study is cross sectional in nature, conducted in Kolkata and Howrah districts, West Bengal, during 2016 - 2018. Contact details of 450 family caregivers who provided daily care for person with dementia, were obtained from the Alzheimer's and Related Disorders Society of India (ARDSI)-Calcutta Chapter, Kolkata, West Bengal. Those addresses were mainly distributed in various localities of Kolkata and Howrah. The caregivers were contacted over telephone, and the purpose of

the study was explained. On the basis of telephone conversations, a list of willing participants was made. Out of 450 caregivers, 267 declined, and 183 agreed to take part in the study. The inclusion criteria were (1) he/she must be a primary family caregiver of a person with dementia; (2) he/she should be an adult, aged 20 years or above; (3) he/she should have provided care to the person with dementia for at least 1 continuous year at the time of interview. 131 primary family caregivers satisfied these conditions, and were included in the present study. Later, we visited each willing caregiver's residence as per their preferred time. Informed consent was obtained from each participant before filling out the questionnaires. Participant interviews lasted for an hour, during which we collected socio-demographic information of caregivers and care recipients, along with data on ADL, IADL, stress, depression and anxiety of caregivers.

Instruments

A questionnaire was developed to elicit the socio-demographic profile of caregivers, and designed to be filled out by the participants. It included questions about the caregiver's sex, age at the time of interview, education, occupation, marital status, relationship with care recipients, family types, and monthly house hold expenditure [in Indian Rupees (INR)]. Information on care recipient's sex, age at the time of interview, type of dementia and duration of suffering from dementia was also collected.

The Kartz Index of Independence in Activities of Daily Living Scale (ADL) (Wallace And Shelkey, 2007) and Lawton Instrumental Activities of Daily Living Scale (IADL) (Graf, 2008), Cohen's Perceived Stress Scale (PSS) (Cohen et al. 1983), Patient Health Questionnaire-9 (PHQ-9) (Kroenke, 2001), Hamilton Anxiety Rating Scale (HAM-A) (Hamilton, 1959) were also used for this study.

ADL and IADL both were filled out by caregivers, and produced information on the kind of help they provided to care recipients. ADL includes activities like bathing, proper dressing, proper toileting, ability to move independently, self-control over urination and defecation, ability to take food. IADL includes information about the care receiver, such as the ability to operate telephone, taking care of shopping needs, planning or preparing meals, performing light daily household tasks, laundry tasks, taking proper medicines on time, ability to travel independently outside home and ability to handle day to day finances. Lower ADL scores indicate higher dependency and higher scores indicate high independence. We denoted the caregiver's level of support as maximum and minimum depending upon whether when the care recipients ADL score indicated a high or low rate of dependence.

The Cohen's Perceived stress scale (PSS) has been administered to caregivers to measure perceived stress level. PSS is a multiple-choice questionnaire which has 10 sets of questions. The score of each question ranges from 0 to 4. Thus, the total score ranges between 0 and 40. A score of below 20 indicates lower level of stress and a score of 20 and above indicates higher level of stress.

The Patient Health Questionnaire-9 (PHQ-9) is the psychological instrument widely used to measure level of depression. It was used to elicit the thoughts and feelings of the caregivers during last 2 weeks prior to the date of survey. PHQ-9 consists of nine questions with four response choices. Each response ranges from 0 to 3 with total score ranges between 0 and 27. A score equal to or below 9 indicates mild depression, 10 to 14 indicates moderate depression, 15 to 19 indicates moderately severe depression and a score of 20 and above indicates severe level of depression. In the present study PHQ-9 has been used to measure the level of stress.

The Hamilton Anxiety Rating Scale (HAM-A) was used to measure level of anxiety among

caregivers in the present study. In HAM-A, 14 sets of questions were represented with five response choices. Each response ranges from 0 to 4, and the total score ranges between 0 and 56. A score equal to or below 17 indicates mild anxiety, a score of 18 to 24 indicates moderate anxiety, while a score of 25 to 30 indicates severe anxiety and a score above 30 indicates extreme level of anxiety.

Most of the participants understand Bengali and English languages. However, a Bengali version of all instruments duly translated by professional translators was kept ready for those who were not very proficient in English. In order to check validity, the same individual answered each version of the same question. The Institutional Review Board of the Indian Statistical Institute, Kolkata, checked the participant information document and the relevant informed consent form, and duly issued the certificate of ethical clearance.

Statistical analysis

Descriptive statistics were used to analyse the socio-demographic profiles of the caregivers and care recipients. A Chi-square test was applied to show the association of caregiver's mental health traits (in terms of stress, depression, anxiety) with duration of caregiving (in terms of hours/day and in years) along with level of support (in terms of ADL scores) provided to care recipients. Because almost every care recipient was found to be dependent upon their caregiver in many ways, no statistical analysis was not applied to IADL data. A correlation matrix was used to identify links between socio demographical variables and mental health traits, based on Pearson's correlation coefficients for significance. A p-value of ≤ 0.05 was considered statistically significant. Data were analysed using Power of Advanced Statistical Analysis version 18.0 (IBM Corporation, 2009).

Results

Table 1 presents socio-demographic information about the study participants (i.e. the family caregivers). The number of female participants (74.8%) was greater than males (25.2%). The mean age of caregivers was 61.11 years (SD 14.034). More than half of the participants (51.9%) had education up to graduate level. It was observed that more than 67% of the participants were unemployed and over 80% of the caregivers were married. Most commonly (54%), caregivers were the spouses of care recipients. More than 60% of the caregivers lived in nuclear families. It was observed that 71 % of the caregivers had an average monthly household expenditure of about Rs. 50,000. Additionally, it was found that 53% of the caregivers were engaged in caregiving for about 9 hrs per day, and 45% of the caregivers had provided care for more than 5 years. There were more female care recipients (50.4%) than males (49.6%). It was found that about 76% of the care recipients were older than 70 years of age. Only 3.1% of care recipients were aged below 60 years. More than 50% of the care recipients had suffered from dementia for about 5 years. Alzheimer's type of dementia (above 76%) was the most common type found among care recipients followed by vascular dementia (above 15%) and frontotemporal dementia (above 4%).

Table 1: General information about caregivers and care recipients

❖ Caregivers [N=131]			
Variables	Category	n	%
<i>1. Demographic Characteristics</i>			
Sex	Male	33	25.2
	Female	98	74.8
Age group (in years)	<30	4	3.1

	30-59	47	35.8
	60+	80	61.1
	Mean age (yrs±sd)	61.11±14.034	
Marital status	Single	23	17.6
	Married	108	82.4
Education	Up to secondary	24	18.3
	Graduate	68	51.9
	Post graduate and beyond	39	29.8
Occupation	Employed	42	32.1
	Unemployed	89	67.9
Relationship With Care-recipient	Spouse	72	54.0
	Daughter/Son	34	25.9
	Others*	25	19.1
Family type	Joint	49	37.4
	Nuclear	82	62.4
Monthly Household expenditure	≤26,000	35	26.7
	26,001-50,000	71	54.2
	50,000 and beyond	25	19.1
<i>2. Caregiving related</i>			
Duration of Caregiving (hrs/day)	≤ 9	70	53.4
	>9	61	46.6
Duration of Caregiving (years)	≤ 5	71	54.2
	>5	60	45.8
<i>3. Mental health status</i>			
Stress	Lower	68	51.9
	Higher	63	48.1
Depression	Mild	78	59.5
	Moderate	31	23.7
	Mod. severe	18	13.7
	Severe	4	3.1
Anxiety	Mild	59	45.0
	Moderate	42	32.1
	Severe	16	12.2
	Extreme	14	10.7
❖ Care recipients [N=131]			
Sex	Male	65	49.6
	Female	66	50.4
Age group (in years)	≤ 60	4	3.1
	61-70	27	20.6
	71-80	64	48.9
	>80	36	27.4
	Mean age (yrs ± sd)	75.74±7.960	45.8
Duration of Suffering (in years)	≤ 5	71	54.2
	> 5	60	45.8
Types of dementia	Alzheimer's	100	76.3
	Vascular dementia	21	16.0
	Lewy body dementia	2	1.5
	Fronto-temporal dementia	6	4.7
	Others	2	1.5

*Others: sister, brother, daughter-in-law and son-in-law.

#Others: Mixed Dementia, Parkinson's Dementia

Table 2 describes level of support provided by caregivers towards care recipients in terms of daily and instrumental activities, including the ability to operate telephone, planning for shopping or preparing meals, performing daily household tasks, taking proper medicines on time, the ability to travel independently, and the ability to handle day to day finance. Daily and instrumental activities were organized into two categories (independent and dependent). “Independent” indicates no or minimal levels of supervision, direction or personal assistance while “dependent” indicates supervision, direction and personal assistance from others. In other words, the care recipients who were categorised as “independent” needed minimum assistance whereas care recipients who were categorised as “dependent” required more assistance from their caregivers. In the present study however, each care recipient required substantial assistance in daily activities like bathing, dressing, toileting, transferring, continence and feeding. It was found that more than 50% of the care recipients required maximum level of support for toileting, transferring and continence, and more than 80% of the care recipients required help for bathing and dressing. It was found that almost 90% of the care recipients required assistance from their caregivers in the performance of instrumental activities.

Table 2: Level of support provided towards care recipients (in terms of daily activities and instrumental activities)

Activity	Level of support provided towards care recipients	
	Maximum support n (%)	Minimum support n (%)
<i>1. Daily activity</i>		
Bathing	99 (75.57)	32 (24.43)
Dressing	106 (80.92)	25 (19.08)
Toileting	89 (67.94)	42 (32.06)
Transferring	61 (46.56)	70 (53.44)
Continence	82 (62.60)	49 (37.40)
Feeding	49 (37.40)	82 (62.60)
<i>2. Instrumental activity</i>		
Using telephone	97 (74.05)	34 (25.95)
Shopping	131 (100.0)	0 (0.0)
Food preparation	129 (98.47)	2 (1.53)
House keeping	124 (94.66)	7 (5.34)
Laundry	127 (96.95)	4 (3.05)
Mode of transport	129 (98.47)	2 (1.53)
Taking own medicine	130 (99.24)	1 (0.76)
Ability to handle finance	131 (100.0)	0 (0.0)

Table 3 describes types of support caregivers offered to care recipients relative to the level of caregiver stress, depression and anxiety. Approximately 18% of caregivers provided maximum support and about 29% provided minimum support. Caregivers who provided maximum support showed moderate-to-severe levels of depression (25.95%), compared to those who provided minimum level of support (14.51%). Over all, about 40% of the caregivers showed moderate-to-severe levels of depression. The level of anxiety among caregivers also varied with the level of support they provided to care recipients. Chi-square tests indicate that the level of support was significantly associated only with the level of anxiety.

Table 3: Association between caregivers' mental health status and level of daily activity support provided to care recipients

Category	Level	Minimum Support	Maximum Support	X ² - value	p-value
Stress	Lower	28 (21.37)	40 (30.53)	0.252	0.616
	Higher	39 (29.77)	24 (18.33)		
Depression	Mild	33 (25.19)	45 (34.35)	0.934	0.817
	Moderate	11 (8.40)	20 (15.27)		
	Mod. Severe	6 (4.58)	12 (9.15)		
	Severe	2 (1.53)	2 (1.53)		
Anxiety	Mild	26 (19.85)	33 (25.19)	9.229	0.026*
	Moderate	15 (11.45)	27 (20.61)		
	Severe	2 (1.53)	14 (10.68)		
	Extreme	9 (6.87)	5 (3.82)		

*p<0.05

Table 4 describes the association between duration of caregiving (in terms of hours/day and years) and the mental health status of caregivers. The level of stress reported by longer and shorter term caregivers was about evenly divided between higher and lower levels of stress. Likewise, most caregivers reported mild-to-moderate levels of depression and mild-to-moderate levels of anxiety, regardless of whether they provided longer or shorter period of care giving. No significant association was found between mental health and duration of caregiving, either in terms of years or hours of the day.

Table 4: Association between mental health and duration of caregiving (in years and hrs/day)

Variable	Category	Duration of caregiving (in hrs/day)		p-value	Duration of caregiving (in yrs)		p-value
		Short term (≤9)	Long term (≥9)		Short term (≤5)	Long term (≥5)	
Stress	Lower	37 (28.24)	30 (22.90)	.675	36 (27.48)	31 (23.66)	.913
	Higher	33 (25.19)	31 (23.67)		35 (26.72)	29 (22.14)	
Depression	Mild	41 (31.29)	37 (28.25)	.921a	42 (32.06)	36 (27.48)	.333a
	Moderate	16 (12.21)	15 (11.43)		14 (10.69)	17 (12.98)	
	Mod. severe	11 (8.39)	7 (5.37)		13 (9.92)	5 (3.81)	
	Severe	2 (1.53)	2 (1.53)		2 (1.53)	2 (1.53)	
Anxiety	Mild	33 (25.19)	26 (19.84)	.619	36 (27.48)	23 (17.55)	.453
	Moderate	19 (14.51)	23 (17.55)		19 (14.51)	23 (17.55)	
	Severe	10 (7.64)	6 (4.58)		8 (6.11)	8 (6.11)	
	Extreme	8 (6.11)	6 (4.58)		8 (6.11)	6 (4.58)	

a Fisher exact test

Table 5 presents the correlation analysis for the impact of caregiver's socio-demographical factors on their mental health status. There was a mild-to-moderate relationship between caregiver's socio-

demographical factors and their mental health traits. Caregivers who were male, older, married and serving their spouse experienced poorer mental health conditions than those who were female, young, unmarried and providing care for someone other than a spouse. Caregivers who had lower educational qualifications, who lived in nuclear families and had lower monthly household expenditures showed higher levels of depression. A significant relationship with the level of anxiety was found only in case of marital status ($r = .172$, $p < 0.05$).

Table 5: Pearson's correlation for the impact of caregivers' demographical and caregiving-related factors on caregivers' mental health status

	Stress	Depression	Anxiety	1	2	3	4	5	6	7	8
1. Gender	-.027	-.115	-.078	-							
2. Age	.039	.039	.069	-.295**	-						
3. Marital Status	-.006	.069	.172*	-.055	.218*	-					
4. Education	-.086	-.003	.149	-.109	-.137	.068	-				
5. Occupation	.011	-.057	-.091	.110	.318**	.146	-.345**	-			
6. Relationship	-.051	-.010	-.009	-.092	-.570**	-.047	.307**	-.351**	-		
7. Monthly Expenditure	.022	-.040	.029	-.149	-.063	.678	.471**	-.120	.075	-	
8. Family type	-.032	.024	.006	.024	.128	.005	.176*	.006	-.192*	.033	-

* $p < 0.05$; ** $p < 0.01$

Discussion

The present cross-sectional study attempted to examine mental health traits (in terms of stress, depression and anxiety) of a group of caregivers related to factors involved in caregiving. It also attempted to evaluate the relationship between the mental health traits of caregivers and factors that influenced caregiving. The study findings suggest that, overall, more than half of the caregivers suffered from higher level of stress, depression and anxiety. The caregivers who provided maximum level of support (in terms of daily and instrumental activities) towards their care recipients showed higher level of stress, depression and anxiety compared to those who provided less support. Another striking finding was that the caregivers who engaged in caregiving less than or equal to 9 hours/day showed higher level of stress, depression and anxiety compared to those who provided care for more than 9 hours per day. Similarly, the caregivers who were involved in caregiving less than 5 years experienced worse mental health condition.

The number of elderly living with dementia is increasing gradually and it has become one of the leading health problems worldwide. In future, persons with dementia also will create a growing burden for family members (Das et al. 2010). Studies have revealed that persons with dementia need assistance to do their basic activities such as bathing, dressing, feeding, taking own medicine, managing finance etc. (Arango-Lasprilla et al. 2010; Basu et al. 2019). Our study, also revealed that care recipients remain mostly dependent on their caregivers to carry out basic minimum daily activities. Dressing and bathing were the two most common activities that required the assistance of caregivers. They also need help performing other daily activities, such as those associated with toileting. The findings of the present study corroborates the observation that providing continuous assistance for a considerable period of time gives rise to excessive mental pressure, which leads to poor mental health (Arango-

Lasprilla et al. 2010; Basu et al. 2019).

The present study provides data on the level of stress, depression and anxiety of the caregivers. Mental health comparisons were made between two groups of caregivers, on the basis of the level of support they offered to the daily activities of care recipients. It was found that about 40% of the caregivers showed higher level of stress. Among caregivers, 18% showed that their stress level increases with their increasing level of support to the care recipients. More than 40% of the caregivers reported moderate-to-severe levels of depression irrespective of the level of support they offered. Although the caregivers who provided maximum level of support showed somewhat higher levels of depression compared to those who provided minimal levels of support, differences were not statistically significant. A significant association was found between level of anxiety and level of support caregivers provided towards care recipients. More than 50% of the caregivers reported experiencing moderate-to-extreme level of anxiety; and these caregivers were observed also to provide maximum level of support. Thus, results from the present study corroborates the study by Leggett et al. (2011).

Studies have revealed that caregiving is a challenging job that demands considerable time, energy and financial support, which leads to adverse mental health conditions (Hughes et al. 1999). In our study, a comparison was made between two groups of caregivers, based on the time (in hours/day and in years) they spend with the care recipients. More than half of the caregivers who engaged in caregiving for 9 or fewer hours/day reported experiencing some level of stress, depression and anxiety compared to less than half of those who were engaged with caregiving for more than 9 hours per day. However, association between mental health status and duration (in hours/day) of caregiving was not statistically significant. Nevertheless, the study findings do suggest that caregivers who were engaged in caregiving for fewer hours per day may have engaged in other family responsibilities which demanded additional time and labour along with caregiving. But other studies have found that adverse caregiver mental health was associated with more hours committed to caregiving (Serrano-Aguilar et al. 2006; Kim et al. 2012; Alfakhri et al. 2018). Another interesting finding of the present study is that about 54% of the caregivers who were engaged in caregiving for 5 or fewer years experienced higher level of stress and depression compared to those who had engaged in caregiving for more than 5 years. Possibly, during the early stage of dementia, symptoms are newer to caregivers; but over time they might become more accustomed to dealing with the adverse situation. Additionally, they might consider it to be their moral responsibility to provide care for their relatives with dementia.

Some studies have reported that caring for a person with dementia is an important and additional source of stress on the part of caregivers (Annerstedt et al. 2000; Papastavrou et al. 2007). It is well documented that symptoms of dementia are associated with the progressive decline of memory and other cognitive abilities, including orientation. Wandering is the most problematic and perilous symptom of people with dementia. It was found that fear of being lost may lead to other psychological problems among people with dementia like anxiety, delusions and agitation. One of the most common behavioural problems is a lack of interest in doing their usual activities. The prolonged uneasiness in dealing with usual behavioural problems of a person with dementia may increase the level of stress among caregivers (Pearlin et al. 1990; Gaugler et al. 2000; Leggett et al. 2011; Basu and Mukhopadhyay, 2019).

Some studies found that insufficient social interaction, the inability to pursue activities of interest and the inability to remain socially active are significantly associated with higher levels of depression among caregivers (Coen et al. 1997; Cummings et al. 2004; Mohamed et al. 2010). Our results are consistent with the results of these studies. At times, in order to pursue an independent life, the younger members of a household live separately, leaving the responsibilities of caring on the shoulders of senior

family members. Those members suffer from loneliness and thereby develop depression of various levels. A few studies have also reported that high anxiety level is a common mental state found among dementia caregivers (Schulz et al. 1995; Mahoney et al. 2005). This finding is also corroborated by the present study. One of the most striking findings of the present study was the significant association between caregivers' level of anxiety and level of support provided towards care recipients.

Other than caregiving related factors, several studies reported that with increasing age (Serrano-Aguilar et al. 2006), female caregivers experience a greater burden than those male and young (Papastavrou et al. 2007). The type of relationship between caregivers and care recipients also has been studied. It was found that a greater level of stress occurred when the caregiver was a spouse of the recipient. In our study it was found that older, spousal caregivers experienced poorer mental health than younger, non-spousal caregivers. But, male caregivers experienced more adverse mental health conditions than females. A significant relationship was found between marital status and level of anxiety. The married caregivers showed higher levels of anxiety and depression compared to unmarried caregivers.

Limitations

The present study has certain limitations as well. Data were collected from a particular urban ethnic group (Bengali) thus information of other ethnic groups remain under represented. Moreover, the study was cross sectional in nature, and therefore fails to document the change of caregivers' mental health traits over time. However, this type of research is not very common in the Indian context; so the findings may lead to develop several other research issues in future in other areas of India.

Conclusion

The job of caregiving is very demanding and it affects psychological health of the caregivers. It is evident from our present study that providing care for person with dementia is extremely onerous and may lead to adverse psychological morbidity (i.e. stress, depression, anxiety) among the caregivers. The major reason is the increased dependency of care recipients on caregivers for daily living activities. The caregivers who started caregiving recently showed poor mental health conditions. In India, studies about caregivers of people with dementia are very rare. The increasing cost of institutional and formal care compels family members to arrange for home based care for their affected family member, and the situation will be more challenging in the coming days. Our findings suggest that, in India, proper support and care management should be adopted for caregivers in view of the increasing trend of the disabilities.

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Author contributions *IB designed the study, carried out the data collection, dataset tabulation, analysis of the data, and drafted the manuscript; SM designed the study and helped to draft the manuscript and NM as Secretary of ARDSI Calcutta Chapter helped to contact family caregivers.*

Conflicts of interest *The authors declare no conflict of interest.*

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