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Factors related to adverse mental health condition of demented family caregivers: A study in West Bengal, India

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ABSTRACT: Dementia caregiving is a unique and the caregivers faces extreme challenges which affect caregiver's mental health adversely. Family caregiving towards elderly individuals with dementia is becoming widespread. The study aims to evaluate the mental health status of dementia family caregivers and some related factors that affect their mental health condition.

Present cross sectional study includes a total of 134 family caregivers. Socio-demographic and caregiving related data were collected using pre-tested questionnaires. Standardized questionnaires were used to collect data on caregivers' mental health traits (measured in terms of level of stress and anxiety), level of psychosocial distress, support they provided and the care recipient's behavioural symptoms associated with dementia. Mean age of the caregivers was 61.64 years (SD 13.89) while the care recipients were above 70 years of age. Mean age of care recipients was 75.46±7.26 years. Alzheimer's type of dementia was the most common type found among them. Higher level of stress and anxiety was prevalent among the caregivers. Level of education, being a spouse, psychological distress has strong relationship with caregivers' mental health condition. Behavioural abnormalities of care recipients were also responsible for poor mental health conditions of caregivers. Family caregiving is becoming the most suitable option nowadays and it associated with caregivers' psychological distress and other health issues. Present study also revealed distressed mental health conditions of caregivers. Since care recipients remain dependent mostly on their family caregivers, it is necessary that caregivers should be fit mentally as well as physically. Therefore, proper support and management is needed for caregivers in near future.

KEY WORDS: dementia caregivers, mental health, stress, anxiety, socio-demographic factors

Introduction

Dementia is one of the most health challenging factors in this century rooted in the disability and dependency among a large number of elderly people (Cova et al. 2018). Worldwide, over 46 million people live with dementia and by the year 2050 there will be 135 million people affected by dementia (Alzheimer's Disease International 2015). In India, the affected people with dementia is increas-

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ing rapidly. The prevalence of dementia varies from 0.8% to 1.28% in Eastern India, 2.44 to 4.1% in Western India, 1.83% in Northern India and 3.6% in Southern India (Das et al. 2012). It was presumed that, around 20,000 to 40,000 people will live with dementia within the next 26 years in the state of West Bengal (Bharath and Dias 2010).

Dementia is characterised as a progressive loss of brain function giving rise to many cognitive malfunctions, along with physical, emotional and functional disabilities (World Alzheimer Report 2009). The risk of having dementia increases with age (Bharat and Dias 2010). At age 65, the chance of having dementia is about 1% and it becomes almost 40% when people aged above 85 years (Ferrara et al. 2008). Therefore, from the early stage of dementia, affected person requires increased amount of care and support (World Alzheimer Report 2009). Moreover, it is found that majority of the demented person stayed at home and completely depended on their family members for living. Family caregivers is the person who takes daily care of the care recipients. It required huge amount of time to do care recipient's daily activities (Ferrara et al. 2008). Therefore, the problem is not only restricted to the demented person, it also affects their family members (Gottlieb and Wolfe 2002; Kneebone and Martin 2003).

Family caregivers or informal caregivers are those individuals who lived with demented person, provide unpaid and uncompensated care with significant amount of time and energy for months or even years. Additionally, they perform all the required tasks which may be physically and mentally demanding (Schulz and Sherwood 2008). Study suggest that the numbers of caregivers and their informal caregiving will continue to increase during the next decade. As a consequence, health problem among caregivers will increase day by day and it warrant serious attention (Ory et al. 1999). There are number of reasons that providing care for demented person make caregivers emotionally drained and feel burden. These demented people live very long life such as 20 years after the onset of symptoms of dementia. Therefore, the duration of caregiving years remains extremely long and very challenging (Schulz et al. 2003; Aneshensel et al. 2004).

Family caregiving defined as a stressful work, contributing to the development of physical and psychological illness and even increasing morbidity and mortality among family caregivers (Kiecolt-Glaser et al. 2003; Vitaliano et al. 2004). The personal, social and health impacts of dementia caregiving have been well documented. Studies reported that through the course of caregiving process they experienced enormous burden (Akpınar et al. 2011; Laks et al. 2016). A study found that caregivers experienced less self-efficiency and worse health conditions compared to non-caregivers (Pinquart and Sorensen 2003). Mental health problem such as anxiety disorder and symptoms may be the most common problem found among dementia caregivers (Mahoney et al. 2005). They experienced more symptoms of anxiety, depression than non-caregivers (Garcia-Alberca and Berthier 2011; Joling et al. 2015) and frequently reported stress, burden, and sleep disturbances (Chiu et al. 2014; Contador et al. 2012). Many investigators reported that high level of stress can give rise to negative effects on caregivers, such as depression, social isolation and increase risk of other health problems (Andrieu et al., 2003; Pinquart and Sorensen, 2006; Waite, et al., 2005). Caregivers' age, gender, duration of caregiving (in years and hours/ day) can lead to adverse outcomes (Algase et al. 2004). Studies have also found that abnormal behavioural characteristics of a person with dementia acts as the source of poor mental health condition of the caregivers. Depression, unruly behaviours, memory related problems of demented persons help increase distress and psychological morbidity among caregivers. A study in Canada, found that caregiver's burden was associated with higher level of behavioural problem among demented person (Teri 1997; Gallicchio et al. 2002). Another study in Japan, reported that main factors of mental fatigue among caregivers was related with care recipient's cognitive impairment, unexpected behaviour and activity of daily living status (Nagatomo et al. 1999). Similarly, a Taiwan study revealed that physical and psychological demands of caregiving could well predict caregivers burden (Chou et al. 1999).

In India, because of escalating cost of institutional care and dearth of specialized hospital facilities, person affected with dementia mainly stayed at home with full dependence upon their family members (Shaji and Reddy 2012). According to the World Alzheimer Report 2013, with the progression of dementia, the type of support caregivers provide change with specific need of the person. In the course of caregiving, caregivers may require to reduce their other duties (Shaji and Reddy 2012) and continue caregiving along with other responsibilities i.e. career, social relationship and many more. Insufficient social interaction, financial resources may lead to worse psychological health among caregivers (Tomoko et al. 2003; Das et al. 2010).

The aim of the present study was to evaluate (i) the level of stress, anxiety and presence of psychological distress among dementia caregivers and (ii) how good demographic characteristics, caregiving related factors and psychological distress can predict the occurrence of level of stress and anxiety among caregivers.

Material and Methods

Study participants

The study was conducted among 134 family caregivers who provided daily care for their demented relatives, from Kolkata and Howrah district of West Bengal. Contact details of those caregivers were obtained from an organization, namely Alzheimer's and Related Disorder Society in India (ARDSI)-Calcutta Chapter, Kolkata, West Bengal. At first we contacted the caregivers over phone. After that a list of willing participants was made. Later, we visited each and every willing caregivers' residence following their convenience. All participants were fully informed about the purpose of the study and informed consent was obtained from each participant before filling up of questionnaires. At the time of interview, socio-demographic information of both caregivers and care recipients were collected. Additionally, we collected data on caregiver's level of stress, anxiety and general health along with care recipient's activities of daily living and symptoms of dementia.

Instruments

Demographic information was collected using pre-tested socio demographic questionnaire. It includes questions like caregiver's gender, 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 of care recipient such as gender, age at the time of interview, type of dementia and duration of suffering from dementia were also collected.

Cohen's Perceived stress scale (PSS) (Cohen et al. 1983) has been administrated on caregivers to measure their level of stress. Multiple-choice questionnaire made up with 10 questions were used. The score of each question ranges from 0 to 4. Thus, the total score varies between 0 and 40. Score ≤20 indicates lower level of stress and >20 and above indicates higher level of stress. For the assessment of level of anxiety among caregivers, Hamilton Anxiety Rating Scale (HAM-A) (Hamilton, 1959) was used with 14 sets of questions with five response choices. Each response ranges from 0 to 4 and the total score ranges between 0 and 56. Score ≤17 indicates mild anxiety, a score of 18–24 indicates moderate anxiety, while a score of 25–30 indicates severe anxiety and score >30 indicates extreme level of anxiety. General Health Questionnaire-28 (Goldberg and Hillier, 1979) was used to understand the psychological distress among caregivers. This questionnaire consists of 28 questions. Each question has response ranges from 0 to 3. A total score23/24 is the threshold for the presence of psychological distress.

Care recipient's daily activity level was administrated by Kartz Index of Independence in Activities of Daily Living Scale (ADL) (Wallace and Shelkey 2008). It includes activities like bathing, proper dressing, proper toileting, ability to move independently, self-control over urination and defecation, ability to take own food. Lower scores indicate higher dependency and higher score indicate less dependency on the caregivers. Additionally, Neuropsychiatric Inventory (NPI) (Cummings 1997) was used to measure the behavioural problems among demented person. It assesses 12 neuropsychiatric symptoms common in dementia. These are delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, night-time behavior disturbances, appetite and eating abnormalities. Each domain is scored for frequency and severity. Each symptom, using scores from 0 to 4 for frequency, and scores from 0 to 3 for severity. The total score for each domain is calculated by multiplying the frequency by the severity. A total score is calculated by adding all the domain scores together. The total NPI scores thus obtained ranged from 0 to 144. Severity of dementia was obtained by quartile division of the total value and categories as mild, moderate and severe.

Since Bengali is a vernacular language of the study participants, we developed the Bengali version of all instruments duly translated by professional translators. The ethical permission was obtained by IRB of ISI, Kolkata.

Statistical analysis

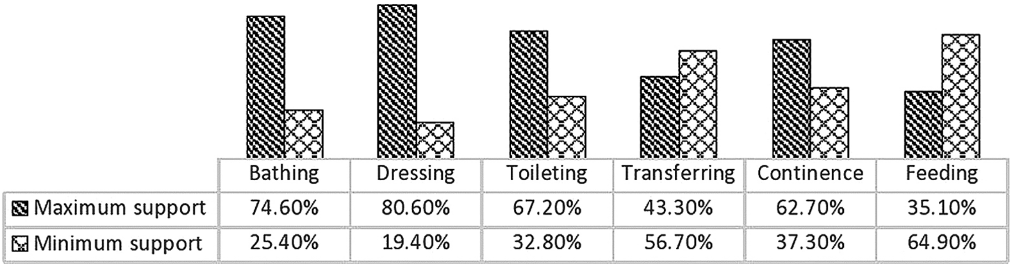
Data were analysed using the statistical software package IBM SPSS, version 18. Descriptive statistics were shown to represent the trends in socio-demographic profile of the caregivers and care recipients. ETA (η) test of association was applied to show the degree of association between caregiver's mental health (in terms of stress and anxiety) condition and caregiver's along with care recipient's demographic characteristics and factors related to caregiving (nominal and categorical variable). The variables which showed association at least level of 30% considered in hierarchical regression analysis. A 3-level hierarchical regression analysis was conducted to identify the impact of caregiver's and care recipient's characteristics to caregiver's mental health condition. Demographic features (for caregivers these are age, education, being a spouse and for care recipient it is age) were entered in level 1, followed by the severity of care recipient's level of dementia and daily activity level in level 2, and caregiver's psychological morbidity and caregiving related factors (caregiving in years and hours/day) in level 3. In both ETA and hierarchical regression analysis, stress and anxiety were denoted as quantitative and dependent variable and all the other variables were categorical and independent.

Results

Table 1 describes some general information about the study participants. In the present study female (73.9%) caregivers were more in numbers than males (26.1%). The mean age of caregivers was 61.64 years (SD 13.89). More than 50% of the participants had education up to graduate level and above 68% of them were unemployed. Husband-wife relationship (57.4%) was the most common type of relationship observed between caregivers and care recipients. It was observed that 30% of the caregivers had an average monthly household expenditure below Rs.30,000/-. It was found that 50% of the caregivers are engaged in caregiving for about 9 hours per day and 45% of the caregivers providing care for more than 5 years. Additionally, above 50% of the caregivers experienced higher level of stress and more than 26% of the caregivers reported severe to extreme level of anxiety. Furthermore, 70% of the caregivers showed signs of psychological distress.

Table 2 describes general information about the care recipients. Interestingly, number of male and female care recipients (50%) were same in numbers. It was found that about 60% of the care recipients were aged between 60 to 80 years. Only few (2.2%) of them were aged below 60 years. More than 67% of the care recipients suffered from dementia for about 10 years. Alzheimer's type of dementia (above 73%) was the most common type found among care recipients followed by vascular dementia (above 17%) and frontotemporal dementia (above 4%).

Fig. 1 describes level of support provided by caregivers towards care recipi-



	Bathing	Dressing	Toileting	Transferring	Continence	Feeding
▨ Maximum support	74.60%	80.60%	67.20%	43.30%	62.70%	35.10%
▩ Minimum support	25.40%	19.40%	32.80%	56.70%	37.30%	64.90%

Fig. 1. Level of support provided towards care recipients for performing daily activities

ents to perform daily activities. In the present study all the care recipients required assistance from their caregivers. Daily activities include 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. On the other hand, above 70% of the care recipients required help for bathing and dressing.

Table 3 describes types of support offered towards care recipients by the caregivers along with their mental health trait profile. Generally, (about 50%) higher level of stress and anxiety was observed

Table 1. General characteristic of the study caregivers

Variable	Category	n	%
Sex	Male	35	26.1
	Female	99	73.9
Age groups (in years)	<30	4	3.0
	30–59	44	32.8
	60+	86	64.2
	Mean±SD (years)	1.64±13.89	
Marital status	Single	22	16.4
	Married	112	83.6
Education	Up to secondary	24	17.9
	Graduate	70	52.2
	Post graduate and beyond	40	29.9
Occupation	Employed	42	31.4
	Unemployed	92	68.6
Relationship with care-recipient	Spouse	77	57.4
	Daughter/Son	32	23.8
	Others*	25	18.6
Family type	Joint	49	36.6
	Nuclear	85	63.4
Monthly household expenditure	≤26,000	38	28.5
	26,001–50,000	71	53.0
	50,000 and beyond	25	18.7
Duration of caregiving (hours/day)	≤ 9	67	50.0
	>9	67	50.0
Duration of caregiving (years)	≤ 5	73	54.5
	>5	61	45.5
Level of stress	Lower	66	49.3
	Higher	68	50.7
Level of anxiety	Mild	58	43.3
	Moderate	40	29.9
	Severe	19	14.2
	Extreme	17	12.7
Psychological distress	Absence	39	29.1
	Presence	95	70.9

Number of caregivers N=134; *Others: sister, brother, daughter-in-law and son-in-law.

among the caregivers regardless of their support. Among them above 38% provide maximum support and above 12% of them provide minimum support. On the other hand, similar trend was found for level of anxiety also. Above 55% of the caregivers experienced moderate to extreme level of anxiety. Almost 40% of them who provide maximum support towards their care recipients showed higher level of anxiety than those who provide minimum support. Association between caregiver's types of support towards care recipients and their health (in terms of stress and anxiety) was shown using chi-square test. Significant association was not found in case of level of anxiety and anxiety with caregiver's types of support offered towards care recipients.

Fig. 2 and Table 4 describes the symptoms of dementia and its severity. Overall, 12 symptoms have been reported in

Table 4. Severity of dementia based on behavioural symptoms

Level of dementia severity	No of care recipients =128 n (%)
Mild severity	6 (6.5)
Moderate severity	36 (26.9)
Severe severity	92 (68.7)

Table 2. General characteristic of the study care recipients

Variable	Category	n	%
Sex	Male	67	50.0
	Female	67	50.0
Age groups (in years)	≤ 60	3	2.2
	61–70	31	23.1
	71–80	65	48.1
	>80	35	26.6
	Mean±SD (years)	75.46±7.26	
Duration of suffering (in years)	≤ 3	34	25.4
	4–10	90	67.5
	>10	10	7.1
Types of dementia	Alzheimer's	99	73.9
	Vascular dementia	24	17.9
	Lewy body dementia	2	1.5
	Fronto–temporal dementia	6	4.5
	Others	3	2.2

Number of care recipients N=134; *Others: Mixed dementia, Parkinson's dementia.

Table 3. Association between caregiver's mental health status and level of support provided towards care recipients daily activities

Variable	Category	Minimum support	Maximum support	χ^2-value	*p*-value
Stress	Lower	13 (9.70)	53 (39.55)	0.542	0.462
	Higher	17 (12.69)	51 (38.06)		
Anxiety	Mild	14 (10.45)	44 (32.84)	1.192	0.774[a]
	Moderate	8 (5.98)	32 (23.87)		
	Severe	3 (2.24)	16 (11.94)		
	Extreme	5 (3.73)	12 (8.95)		

[a] Fisher's exact test.

dementia i.e. delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behaviour, night-time behaviour disturbances, appetite and eating abnormalities. In the present study above 84% of the care recipients' experienced apathy followed by symptoms like anxiety (72.4%) and motor disturbances (69.4%). Apart from that hallucination (67.2%), disinhibition (64.9%) and night behaviour (64.2%) were also common, and 68.7% of care recipients were suffering from severe level of dementia.

Table 5 describes the association between demographic and caregiving related factors with level of mental health. ETA (η)value measures the perfection of the impact of dependent variable. ETA-square (η^2) can be explained as the proportion of variance in the dependent variables. η ranges from 0 to 1, where value 0 indicates no association and 1 indicates perfect association. Independent variables like caregiver's age, psychological distress, care recipient's severity level of dementia were strongly associated with caregiver's level of stress and anxiety. Caregiver's level of education has strong association with level of stress but mild association with level of anxiety.

Table 6 describes the findings regarding the contribution of caregiver's and care recipient's few demographic characteristics, caregiver's psychological distress and factors related to caregiving on their mental health status (i.e. stress and anxiety). Caregiver's level of stress and anxiety was considered as dependent variable whereas caregiver's demographic characteristics, care recipient's age, caregiver's psychometric features and caregiving factors was considered as independent variables. The results of regression analysis showed that caregiver's demographic, caregiving related factors, and care recipient's age was not significantly related to caregiver's level of stress. However, caregiver's psychological morbidity was found to be significantly and positively ($p<0.01$ and $\beta=0.679$) related to their level of stress. In case of anxiety, caregiver's demographic characteristics (education $\beta=-0.152$, $p<0.05$); being a spouse ($\beta=-0.197$, $p<0.05$,), severity of dementia ($\beta=0.190$, $p<0.05$,) and presence of psychometric features ($\beta=0.552$, $p<0.01$,) was significantly related with

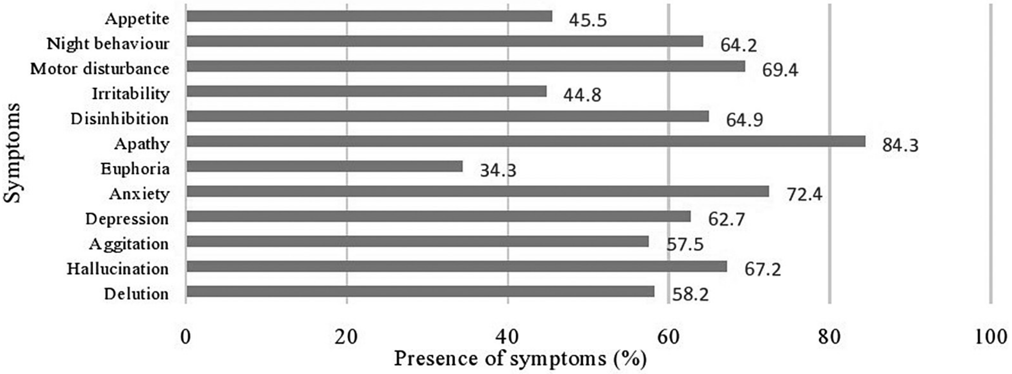


Fig. 2. Dementia symptoms present among care recipients

caregiver's level of anxiety. In explaining the regression model of stress, it was found that in Model I, demographic variables (i.e. caregiver's age, gender, education, relationship with care recipients and care recipient's age) did not significantly contribute to the caregiver's level of stress (adjusted $R^2=0.036$; $F=2.23$; $p=0.069$). With the inclusion of severity level of dementia and daily activity level of care recipients in Model II and presence of psychological morbidity and factors related to caregiving in Model III resulted in a significant increase in R^2 ($\Delta R^2=0.398$, $\Delta F=11.215$, $p<0.01$) wherein, the model could explain 49.5% of the stress variance ($R^2=.495$, adjusted $R^2=0.458$, $F=13.498$, $p<0.01$) taking into account all the independent variables. Alternatively, in regression model of anxiety, it was found that demographic variables of caregivers and care recipients significantly contribute to the level of anxiety among caregivers ($R^2=0.195$, adjusted $R^2=0.170$; $F=7.82$; $p<0.01$). With the inclusion of severity level of dementia and daily activity level of care recipients in Model II and presence of psychological morbidity and factors related to caregiving in Model III resulted in a significant increase in R^2 ($\Delta R^2=0.256$, $\Delta F=6.285$, $p<0.01$) where the model could explain 48.5% of the anxiety variance ($R^2=0.485$, adjusted $R^2=0.448$, $F=12.99$, $p<0.01$) taking into account all the independent variables.

Table 5. Degree of association between demographic and caregiving related factors with level of mental health

Characteristics of caregivers and care recipients (categorical, independent variable)	Level of mental health (quantitative, dependent variable)			
	Stress		Anxiety	
	ETA(η)	ETA-square(η²)	ETA(η)	ETA-square(η²)
Demographic characteristics				
Caregivers				
Age	0.586	0.343	0.619	0.383
Gender	0.122	0.015	0.043	0.002
Education	0.504	0.254	0.338	0.114
Being a spouse	0.481	0.231	0.365	0.133
Care recipients				
Age	0.441	0.194	0.432	0.187
Gender	0.124	0.015	0.156	0.024
Education	0.297	0.088	0.292	0.085
Severity of dementia and care recipient's activity				
NPI	0.703	0.494	0.695	0.483
ADL	0.307	0.094	0.237	0.056
Caregiver's psychometric feature and caregiving character				
Psychological morbidity (GHQ-28),Yes	0.831	0.690	0.791	0.626
Caring hours/day	0.405	0.164	0.362	0.131
Duration of caregiving (years)	0.317	0.101	0.297	0.088

Note: NPI – Neuropsychiatric Inventory; ADL – Activities of Daily Living; GHQ – General Health Questionnaire-28.

Table 6. Hierarchical linear regression analysis: factors predicting caregivers' mental health status

Independent Variables (categorical)	Level of mental health					
	Stress Models			Anxiety Models		
	I	II	III	I	II	III
Level 1						
Demographic characteristics						
Caregiver						
Age	−0.078	−0.091	−0.121	0.189	0.170	0.145
Education	−0.172	−0.179*	−0.036	−0.254*	0.268*	−0.152*
Being a spouse	−0.094	−0.109	0.003	−0.268*	−0.280*	−0.197*
Care recipient						
Age	−0.008	−0.003	−0.011	−0.038	−0.050	−0.071
Level 2						
Severity of dementia and care recipient's activity						
NPI		0.150	−0.027		0.190*	0.065
ADL		−0.138	−0.051		−0.040	0.044
Level 3						
Caregiver's psychometric feature and caregiving characters						
Psychological morbidity (GHQ-28), Yes			0.679**			0.552**
Caring hours/day			0.049			0.020
Duration of caregiving (years)			0.046			0.102
F value	2.230	2.283*	13.498**	7.816**	6.285**	12.988**
R	0.254	0.312	0.703	0.442	0.478	0.697
R^2	0.065	0.097	0.495	0.195	0.229	0.485
Adjusted R^2	0.036	0.055	0.458	0.170	0.193	0.448
ΔF		0.053	11.215**		−1.53	6.285**
ΔR^2		0.033	0.398		−0.034	0.256

Note: NPI – Neuropsychiatric inventory; ADL – Activities of Daily Living; Model I,II,III represent standardised β coefficients; F value represents the model significance; R and R2 correspondence to models explaining the variance of the dependent variable; ΔF = increase of F-value; ΔR2 = increase of R2 value; *$p<0.05$, **$p<0.01$.

Discussion

In this cross-sectional study, we try to investigate the mental health condition of family caregivers in respect to demographic characteristics and factors related to caregiving. Mental health conditions were measured in terms of level of stress, anxiety and presence of psychological distress. It was attempted to evaluate the degree of association between caregiver's mental health condition with socio-demographic characteristics, care recipient's behavioural problems and caregiving related factors. In addition, it tried to find out the relationship between caregiver's level of stress and anxiety with demographic and caregiving related factors. The study findings suggest that caregiver's education, psychological distress, severity level of dementia of the care recipients was strongly associated with caregiver's mental health conditions. Furthermore, the study reveals that lower level of education, being a spouse, presence of psychological distress, severe behaviour problems of the care recipients are also responsible for adverse mental health conditions of the caregivers.

Caregivers may experience a variety of challenges when a family member or a loved one experiences dementia. To make adjustment with the overall varied problems developed by care recipients and providing support towards their daily activities is a demanding task (Carretero et al. 2009; Etters et al. 2008). Study revealed that caregiving for a person with dementia leads to worse mental and psychological conditions i.e. stress, anxiety and other health problems (Brodaty et al. 2002; Molyneux et al. 2008). Our study findings also portrait the similar result. It was found that more than 50% of the caregivers experienced higher level of stress and moderate to severe level of anxiety. Additionally, it was also observed that above 70% of the caregivers reported presence of psychological distress. The impact of stress in caregiver's health has been studied. Emotional exhaustion, anxiety are some such psychiatric symptoms experienced by caregivers. These symptoms affect their quality of life in a greater way. This study depicted that caregiver's age was not a predictor to determine caregiver's mental health conditions and it corroborates the finding by Kim and colleagues (2011). The study though revealed that caregiver's age may be the indirect indicators of poor mental health conditions of caregivers as older caregiver's experiences age related physical vulnerability. There are few more studies which showed just the opposite result (Rinaldi et al. 2005; Serrano-Aguilar et al. 2006). Most importantly our study found that level of education and being a spouse, it may be husband or wife, has significant effect on caregiver's level of anxiety. Like other studies, it was observed that spousal relationship was most common relationship found between caregivers and care recipients (Schulz and Martire 2004; Campbell et al. 2008).

The rising numbers of elderly affected with dementia is increasing with time and it becomes one of the most conspicuous health problems worldwide (Das et al. 2010). Many people with dementia lose capability to live life independently. Therefore, majority of these people live with their family and get constant assistance from their family members (Arno et al. 1999; Covinsky et.al. 2001; Manton et al. 1993; Fried and Guralnik 1997). Another study reported that from the initial stage of dementia, care recipients required support to do their daily activities (Arango-Lasprilla et al. 2010). Present study corroborates with these findings. Our study also found that majority of the care recipients were dependent on their caregivers to do their basic daily activities. It was reported that above 70% of the care recipients received assistance for taking bath and for proper dressing. Apart from that more than 60% of the care recipients need help for activities like get into the proper toileting area, having control over bladder and bowels and so on.

Basis of support given for daily activities, we divided caregivers into two groups i.e. one who provided maximum support and the other provided minimum support. It was found that above 38% of the caregivers who provided maximum support experienced higher level of stress and moderate to severe level of anxiety. A strong correlation with caregiver's level of stress and care recipient's incompetence for daily activities has been reported widely. It was also reported that moderate to severe disability of care recipients resulted in higher level of burden among caregivers (Folstein et al. 1975; Katz et al. 1963). Another study revealed that difficulty of providing care for recipient's daily activities may develop mental fatigue for the caregivers (Nagatomo et al. 1999). Similarly, a study in Taiwan reported that caregivers' burden is being determined by physical and psychological demand of caregivers (Chou et al. 1999). It may be the reason that involvement in caregiving work itself affect the health related quality of life among caregivers.

In dementia behavioural problems are most common and inevitable phenomenon. Yet, lack of information on how to deal with the problems increase the risk of caregiver's burden (Rymer et al. 2002). Other studies reported that deterioration in behavioural problems affects caregiver burden more than deterioration in cognitive states (Boutoleau-Bretonnière et al. 2008; Mioshi et al. 2009). Dealing with behavioural problems like hallucination (false vision or voice), delusion (false beliefs), agitation (resistive to take help from others) etc. for a long time are very tough to handle. Another most common behavioural problem of demented person is apathy, that is lack of interest in doing their usual activities. A study informed that most frequently observed symptoms for dementia is apathy (Küçükgüçlü et al. 2017). Current study corroborates with the previous study in that it also showed care recipients experienced symptoms like apathy most. In our study, severe behaviour problem of care recipient's results into poor mental health condition of caregivers. Large numbers of care recipients (68%) showed severe behavioural problems which are raised in nature. Hence, dealing with usual behavioural problems of a demented person may increase the level of stress among caregivers (Pearlin et al. 1990; Gaugler et al. 2000; Leggett et al. 2011). This finding resembles the findings of the present study.

Our findings have some limitations though. The study being a cross sectional one; it fails to documents the change of caregivers' mental health traits over time. Another limitation is our study population was from a particular urban ethnic group (Bengali) which limits generalization of our findings and sample size was small. However, in Indian context, this type of research has not been attempted frequently. We suggest future research should focus on longitudinal follow-up for better understanding the situations of caregivers.

Conclusion

Summing up it can be said that caregiving is a tedious and unrewarded job, which may lead to many psychological problems. The findings suggest that caregiving can increase the level of stress and anxiety among caregivers. Enormous dependency for daily activities increase the risk to experience to poor mental health condition. As care recipients are mostly dependent among their family caregivers, it is necessary that caregivers should be fit mentally as well as physically. Therefore, proper support and management is needed for caregivers in near future. Despite some limitations, the study contributes to understand the factors related to caregivers worse mental health condition.

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Authors' contributions

IB carried out the data collection, dataset tabulation, analysis of the data and draft the manuscript; SM designed the study and help to draft the manuscript.

Conflict of interest

Authors declare no conflict of interest. The authors are solely responsible for the content and writing of the manuscript.

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