

Caregiver burden and associated factors among caregivers of dementia patients attending state hospital psychiatry clinics in Colombo district.

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Abstract

Objective: To determine the caregiver burden and associated factors among caregivers of dementia patients attending state hospital psychiatry clinics in Colombo district

Methods: A descriptive cross-sectional study was carried out among 65 selected, volunteered caregivers using pretested interviewer administered questionnaire. Caregiver burden was assessed using "Zarit burden interview scale."

Results: Majority of dementia patients of the study sample were aged between 71 to 80 years with a mean age of 75.43 years +/- 11.06 with a majority of females (n=50, 76.9%). However, there was no significant association between patients' age, gender and caregiver burden.

Out of the study population majority were in 46 -65 age group with a majority of females. Also, majority has received education beyond 6th Grade, with an income more than Rs.20, 000 (43.1%) and about half of the population was employed (49.2%). The majority were married (78.5%). According to this study there was no significant association between age, gender, level of education, marital status, occupation or monthly income of the caregivers' and caregiver burden. Majority of the population had mild caregiver burden 43.1%. Frequent feeling of lethargy among caregivers, caregivers' enjoyment of their routine activities had an association with the caregiver burden. Interestingly presence of other comorbidities in patients, transportation mode to the Dementia clinic, and the presence of other care receivers showed an association with caregiver burden.

Conclusion: In conclusion majority of the study population showed mild care giver burden. Interestingly sociodemographic factors of both the caregiver and patient showed no statistical significance. While caregivers' frequency of exhaustion, enjoyment of routine activities, and presence of comorbidities of the patient, transportation mode to the clinic and presence of other care receivers showed statistically significant association with caregiver burden.

Key Words: Dementia, Caregiver burden, Zarit Burden Interval Scale, psychiatry clinics

Introduction

Dementia is an acquired global impairment of intellect, memory, and personality, but without impairment of consciousness (Burns and Life, 2009). These dementia patients suffer from memory impairment, language problems, poor executive functions, visuospatial impairment, apraxia, personality change, psychiatric symptoms and behavioral problems that make them unable from attending to their occupational, social and private routines of life. This gives rise to an essential requirement of a caregiver. Caregiver is defined as a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person. But here in this research only family members are included as they are the most affected caregivers. Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Stucki & Mulvey, 2000).

Here since there's a cognitive impairment patients have a very disabling memory impairment. Also, as the disease progresses the patient can't recall even recent events and may not be able to identify their own caregiver who is mostly a family member.

Further since these patients suffer from psychiatric symptoms, they can have depression, anxiety, suspiciousness and suicidal ideation personality changes where this further adds up to the caregiver burden. Also, the patients have behavioral symptoms where they might engage themselves in socially unacceptable behaviors and sexually unacceptable behaviors where the caregiver has to address the social issues and damages that arises. So here since this disease has many impairments theirs invariably a huge long-term burden on caregivers. We are planning to assess the caregiver burden and to identify associated factors among caregivers such as patient factors, caregivers' factors and other affecting caregivers' factors and their contribution to the caregiver burden.

Specific Objectives

- To describe the sociodemographic characteristics of dementia patients and their caregivers attending state hospital psychiatry clinics in Colombo district.

- To describe caregiver burden among dementia caregivers.
- To determine the factors associated with caregiver burden.

Methodology

A Descriptive cross-sectional study was carried out in outpatient psychiatric clinics conducted in selected hospitals in Colombo District. Study population consisted of caregivers of dementia patients attending to these clinics. As our study unit we identified primary caregivers defined as 'any person who takes primary responsibility for someone who cannot care for themselves alone; most of the time, this person may be a family member who spends more hours a week in providing care, than any other caregiver who has been providing care for at least 6 months. The sample size was 65 caregivers. We used consecutive sampling by visiting clinics in relevant days and recruit the caregivers of dementia patients who fulfil the eligible criteria. Interviewer- administered questionnaires were used. The questionnaire includes sections covering socio-demographic and associated factors of caregivers and the Zarit Buren Interview Scale to assess caregiver burden. The questionnaire was available in Sinhala, Tamil, and English to ensure better social reach. Obtained ethical clearance from Faculty of Medical Sciences University of Sri Jayewardenepura, Colombo South Teaching Hospital, National Institute of Mental Health.

Obtained permission from Institution of Research and Development of Sri Lanka to use Zarit burden Interval Scale which is a validated tool to be used in Sri Lanka. Pre testing was done in order to improve the presentations of the interviewers. These data is not included in the proper data analysis.

Results

Description of study sample: Majority of the dementia patients were more than 60 years of age (n=62, 95.4%). Majority of the dementia patients were female (n=50, 76.9%). Age of the caregivers in the study sample ranged from 25 to 76 years, with a mean age of 52 years (SD= 11.36). Majority of the caregivers were females (n=53, 81.5%). Majority of the caregivers in the study population were married (n=51, 78.5%). Most of caregivers had studied up to or more than G.C.E Advanced Level (n=40, 61.5%) in this population. Nearly half of the selected population are unemployed (50.8%). Most of the caregiver's monthly income is between Rs.20, 000 to Rs.50, 000 in this study population (n=28, 43.1%). *Caregiver burden among dementia caregivers:* Most of the caregivers were under mild burden (n=28,43.1%) in this study population. However, 21 of them (32.3%) were under low/no burden, 14 of them (21.5%) were under moderate burden and 2 of them (3.1%) were under severe burden in this study population.

Table 1: Frequency distribution of categorized caregiver burden in the study sample

<i>Categorized burden.</i>	<i>Frequency</i>	<i>Percentage (%)</i>
<i>Low/No</i>	21	32.3
<i>Mild</i>	28	43.1
<i>Moderate</i>	14	21.5
<i>Severe</i>	2	3.1
<i>Total</i>	65	100

Factors associated with Caregiver Burden

Table 2: caregiver burden and associated factors

		Caregiver burden		Total	Chi Squared test Df P value
		Low/Mild	Moderate/High		
Age of patient (In completed years as at 31.12.2019)	<i>Less than 75 years</i>	17 (70.8%)	7 (29.2%)	24 (100.0%)	X ² = 0.425 Df = 1 P = 0.515
	<i>More than 75 years</i>	32(78.0%)	9 (22.0%)	41 (100.0%)	
	<i>Total</i>				
Sex of the patient	<i>Female</i>	40 (80.0%)	10 (20.0%)	50 (100%)	Fisher's test value = 0.17
	<i>Male</i>	32(78.0%)	9 (22.0%)	15 (100%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100%)	
Age of caregiver	<i>Less than 50 years</i>	22 (84.6%)	4 (15.4%)	26 (100.0%)	X ² = 1.990 Df = 1 P = 0.158
	<i>More than 50 years</i>	27 (69.2%)	12 (30.8%)	39 (100.0%)	
	<i>Total</i>				
Sex of caregiver	<i>Female</i>	41 (77.4%)	12 (22.6%)	51 (100%)	Fisher's test value = 0.470
	<i>Male</i>	8 (66.7%)	4 (33.3%)	14 (100%)	
	<i>Total</i>				
	<i>Unmarried</i>	32(78.0%)	9 (22.0%)	12 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Educational level of caregiver	<i>Up to O/L</i>	12 (60.0%)	8 (40.0%)	20 (100.0%)	Fisher's test value = 0.068
	<i>More than O/L</i>	37 (82.2%)	8 (17.8%)	45 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Marital status of caregiver	<i>Married</i>	40 (75.5%)	13 (24.5%)	53 (100.0%)	Fisher's test value = 1.000
	<i>Unmarried</i>	9 (75.0%)	3 (25.0%)	12 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Current employment of caregiver	<i>Yes</i>	27 (84.4%)	5 (15.6%)	32 (100%)	X ² = 2.745 df = 1 p = 0.098
	<i>No</i>	22 (66.7%)	11 (33.3%)	33 (100%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100%)	
Monthly Income of caregiver	<i>Less than Rs. 50 000</i>	30 (81.1%)	7 (18.9%)	37 (100.0%)	
	<i>More than Rs. 50 000</i>	19 (67.9%)	9 (32.1%)	28 (100.0%)	
	<i>Total</i>	49 (75.3%)	16 (24.6%)	65 (100%)	

Comorbidities of caregiver	<i>Yes</i>	22 (68.8%)	10 (31.3%)	32 (100.0%)	X ² = 1.495
	<i>No</i>	27 (81.8%)	6 (18.2%)	33 (100.0%)	df = 1
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	p = 0.221
Duration of sleep of caregiver	<i>More than 6 hours</i>	23 (85.2%)	4 (14.8%)	27 (100.0%)	X ² = 2.391
	<i>Less than 6 hours</i>	26 (68.4%)	12 (31.6%)	38 (100.0%)	df = 1
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	p = 0.122
Frequency of exhaustion	<i>Yes</i>	18 (60.0%)	12 (40.0%)	30 (100.0%)	X ² = 7.106
	<i>No</i>	31 (88.6%)	4 (11.4%)	35 (100.0%)	df = 1
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	p = 0.008
Enjoy routine activities.	<i>Yes</i>	41 (82%)	9 (18.0%)	50 (100.0%)	Fisher's test Value = 0.039
	<i>No</i>	8 (53.3%)	7 (46.7%)	15 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Capability of decision making of caregiver	<i>Yes</i>	38 (76.0%)	12 (24.0%)	50 (100.0%)	Fisher's test Value = 1.000
	<i>No</i>	11 (73.3%)	4 (26.7%)	15 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Availability of leisure time to caregiver	<i>Yes</i>	29 (85.3%)	5 (14.7%)	34 (100.0%)	X ² = 3.773
	<i>No</i>	20 (64.5%)	11 (35.5%)	31 (100.0%)	df = 1
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	p = 0.052
Caregivers' knowledge on Dementia	<i>Yes</i>	39 (78.0%)	11 (22.0%)	50 (100.0%)	Fisher's test Value = 0.495
	<i>No</i>	10 (66.7%)	5 (33.3%)	15 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Severity of illness	<i>Mild</i>	16 (88.9%)	2 (11.1%)	18 (100.0%)	Fisher's test value = 0.198
	<i>Moderate to severe</i>	33 (70.2%)	14 (29.8%)	47 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Comorbidities of patient	<i>Yes</i>	23 (62.2%)	14 (37.8%)	37 (100.0%)	X ² = 8.093
	<i>No</i>	26 (92.9%)	2 (7.1%)	28 (100.0%)	df = 1
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	p = 0.004

<i>Relationship to the patient</i>	<i>First degree</i>	34 (82.9%)	7 (17.1%)	41 (100.0%)	X ² = 3.404 df = 1 p = 0.065
	<i>Other</i>	15 (62.5%)	9 (37.5%)	24 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
<i>Caregiver's description about patients' insight</i>	<i>Yes</i>	16 (88.9%)	2 (11.1%)	18 (100.0%)	Fisher's test value = 0.198
	<i>No</i>	33 (70.2%)	14(29.8%)	47 (100.0%)	
	<i>Total</i>	49 (100.0%)	16 (100.0%)	65 (100.0%)	
<i>Dependents of caregiver</i>	<i>Less than 03</i>	29 (78.4%)	8 (21.6%)	37 (100%)	X ² = 0.415 df = 1 p = 0.520
	<i>More than 03</i>	20 (71.4%)	8 (28.6%)	28 (100%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100%)	
<i>Supportive personal of caregiver</i>	<i>Yes</i>	34 (81.0%)	8 (19.0%)	42 (100%)	X ² = 1.983 df = 1 p = 0.159
	<i>No</i>	15 (65.2%)	8 (34.8%)	23 (100%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100%)	
<i>Transportation mode to the dementia clinic</i>	<i>Public</i>	7 (50.0%)	7 (50.0%)	14 (100.0%)	Fisher's test Value = 0.031
	<i>Private</i>	42 (82.4%)	9 (17.6%)	51 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	
Presence of other care receivers (Children, grandchildren, handicapped)	<i>Yes</i>	20 (62.5%)	12 (37.5%)	32 (100.0%)	X ² = 5.639 df = 1 p = 0.018
	<i>No</i>	29 (87.9%)	4 (12.1%)	33 (100.0%)	
	<i>Total</i>	49 (75.4%)	16 (24.6%)	65 (100.0%)	

As above it shows no significant association between patients 'age, gender with regard to dementia caregiver burden. And Age, gender, level of education, marital status, occupation or monthly income of the caregivers' shows no association with caregiver burden. Majority of the population had mild caregiver burden 43.1%. Frequent feeling of lethargy among caregivers, caregivers' enjoyment of their routine activities had an association with the caregiver burden. But presence of other comorbidities in patients, transportation mode to the Dementia clinic, and the presence of other care receivers showed an association with caregiver burden.

Discussion

Demographic Characteristics

In the sample population majority of the patients were between 71 to 80 years and the mean age of the population was 75.4 (SD 11.06) years. In a study done in South Korea the mean age of the study population was 75.8 (SD 8.4) which was similar to

this study (Lee SM, 2019).

Majority of the patients were females (76.9%) which was similar to a study conducted by University of Kelaniya regarding the dementia prevalence in semi urban populations in Sri Lanka. According to that study 61% of the population was female and they have presented female gender being a factor associated with high prevalence of dementia (De Silva HA, 2003).

In the current study majority of the caregivers were between 46 to 56 years. The mean age of the population was 51.95(SD 11.36). In a similar study conducted in South Korea which is an Asian country the mean age of the caregivers was 57.1(SD 12.9) (Lee SM, 2019).

When considering the gender of the caregivers in the current study majority were females. It was 81.5% (n=53) from the total population. Similarly, in a study conducted in South Korea where they have recruited 454 participants the majority 72.9 (n = 331) were females (Lee SM, 2019). Majority (43.1%) of the caregiver's monthly

income was between Rs.20, 000 to Rs.50, 000 in this study population. According to household Income and Expenditure Survey –2016, median income of Sri Lankan income receiver was Rs. 23,260, which is similar to this study (2016, p11). Frequencies were approximately similar between employed (49.2%) and unemployed (50.8%) caregivers in this study, although study on Brazil majority are unemployed caregivers (75%)

Majority of the caregivers in the study population were married (78.5%) followed by never-married (16.9%), widow (1.5%), separated (1.5%), divorced (1.5%). A Brazilian study shows 57.6% married, 16.9% never married, 13.6% divorced, and 10.2% widowed caregivers (FM- UFMG, 2016). The percentage difference of married caregivers can be due to increase divorce rates in western countries compared to Asian countries due to difference in socio-cultural backgrounds.

Caregiver Burden among Dementia Caregivers: Most of the caregivers in this study population were under mild burden category (n=28, 43.1%). However, 21 of them (32.3%) were under low/no burden, 14 of them (21.5%) were under moderate burden and 2 of them (3.1%) were under severe burden category.

According to the study done in Japan, the mean total ZBI score was 28.6 (SD 15.3). In this study caregiver burden was evaluated with the Japanese version of Zarit Caregiver burden Interview. The mean total ZBI score of our study was 29.29 (SD 15.76) which was similar to this Study. (Hirono N, 1998) According to the descriptive study done in Greek (2018), more; 44). The mean value of ZBI was 43.42 (SD 46.42) in this (Mougias AA, 2018). However according to our study only 3.07% of the caregivers had severe caregiver burden ZBI (cut off > 44), and the mean value of ZBI was 29.29 (SD 15.76). This can be due to the difference in sociocultural background in the two countries.

Factors associated with Caregiver Burden: According to a study conducted on South Korea, they have stated that general caregiver burden was higher when looking after younger patients (Lee SM, 2019). However, in our study there was no significant association with the caregiver burden (p =0.515). According to the study majority of patients were female but there is no significant association between sex of patient and caregiver burden (Fisher's Test value = 0.170).

A study done in Australia suggested that there is a negative correlation between the caregiver burden and caregivers age (Ransmayr G, 2018). However, in a study done in Greece, lower care giver age has an independent association with caregiver burden (Mougias AA, 2015). However, in the current study there was no statistically significant association (p=0.158) with caregiver burden. This can be due to the smaller in sample size in the current study.

A previous study done on South Korea suggested that the general burden was higher amongst female

caregivers (Lee SM, 2019). But in our study, there was no significant association with the caregiver burden with female sex. (Fisher's Test value = 0.470).

According to a study done in United States of America, the caregivers - socio demographic factors and psychological factors were the two primary factors affecting the caregiver burden (Petrovsky DV, 2019).

Also, research done in Greek have concluded that CB is a complex issue that is associated with several patients and caregivers' factors (Mougias AA, 2015).

According to our study there was a significant association between frequent feeling of lethargicness of the caregiver and caregiver burden. (p=0.008).

Though there were no direct study evaluating the relationship between the above factors and caregiver burden a study done in Colombia, South America it was revealed that caregiver role limitations due to physical problems, and pain were uniquely associated with burden (Perrin PB, 2014).

According to a previous study done in USA, aiming to determine whether burden is associated with sleep disturbance have found out that poor sleep was associated with a greater burden in dementia caregivers (Beaudreau S, 2008).

Though our study shows no significant association with the caregiver burden (p=0.122). This can be due to the smaller sample size of our study.

According to previous research done to assess leisure time activities and mental health in informal dementia caregivers, concluded that dementia caregivers benefit from satisfying leisure activities (Schüz, B., 2015). Although this study shows no significant association with the caregiver burden (p=0.052).

This research showed that capability of decision making by caregiver shows no significant association with the caregiver burden (Fisher's test value=1.000).

According to our study there was no significant association between caregiver's knowledge on dementia and caregiver burden (Fisher's test value=0.495). However, in a study conducted in Hai district of Kilimanjaro, Tanzania they have stated that since dementia adds significant burden to family caregivers need more education on early recognition of symptoms and cost-effective management of dementia at family level (Mushi D, 2014). Also, in a study conducted by few universities in USA they have claimed that education about the disease will be beneficial in reducing the caregiver burden (Petrovsky DV, 2019). Another Iranian study suggested the need for interventional and/or educational programs that aim at decreasing the overall imposed burden of caregiver by increasing positive aspects of caregiving (Abdollahpour I, 2018)

A research done in China have suggested negative impact of patients' comorbidities on

caregiver burden. Also higher burden associated with higher scores on the Charlson comorbidity index (Liu H, 2019). In this study also there is statistically significant association with the caregiver burden and patient comorbidities ($p=0.004$). Research published by Cambridge University Press stated that cognitive decline (MMSE) did not affect change in caregiver burden. (Reed C, 2019) such as in the study which there was no significant association between severity of illness and caregiver burden (Fisher's Test value = 0.198).

American review of the literatures states many factors influence the impact of the caregiving experience such as relationship to the patient, although as in our study there is no significant association with the caregiver burden ($p = 0.065$) (Etters, L., 2008). No previous research data was found about caregiver burden association with caregivers' description of patient's insight on the disease. However, our study shows no significant association with the caregiver burden with patient's insight on dementia (Fisher's test value =0.198).

As per previous literature done in Japan, it has been suggested that informal social support (family members and friends) was significantly associated with lower caregiver burden. Compared to caregivers without informal support, those who had one support and two or more supports had significantly lower burden. (Shiba K, 2016)

According to a research done in Singapore showed that the majority of informal caregivers of dementia patients received support/help from a paid helper which lowered the level of caregiver burden. (Vaingankar J.A, 2016). But there was no statistically significant association between availability of supportive personal to the caregiver and caregiver burden which was incoherent with previous literature. That could be due to small size of study sample. ($p=0.159$ ($p>0.05$))

Conclusion

Regarding the socio-demographic characteristics of the dementia patient the age ranged from 32 to 95 years, with a mean age of 75.43 years (SD= 11.06). Regarding the socio-demographic characteristics of the recruited caregivers the age ranged from 25 to 76 years, with a mean age of 51.95 years (SD= 11.36). The study included 81.5% female and 18.5% of male caregivers. Majority of the caregivers in the study population were married (78.5%). Most of caregivers (87.7%) was educated up to or more than G.C.E Ordinary Level in this population. Nearly half (49.2%) of the selected population were employed while most of the caregivers (43.1%) monthly income were between Rs.20, 000 to Rs.50, 000.

Regarding caregiver burden among dementia caregivers majority were under mild burden (43.1%) in this study population. However, 32.3% had low or no burden, 21.5% had moderate burden while 3.1% were under severe burden.

Several factors are associated with caregiver burden. When considering physical factors frequency of exhaustion ($p = 0.008$), enjoyment of routine activities (Fisher's Test value = 0.039) comorbidities of patient ($P = 0.004$) transportation mode to Dementia clinic (Fisher's Test Value =0.031 ($p<0.05$), presence of other care receivers such as children, grandchildren, and handicapped ($p=0.018$ ($p < 0.05$)) shows a statistically significant association.

Recommendations

We can further improve the research result of caregiver burden and the association between patient' severity, caregiver's comorbidity and patient's comorbidity while using mini mental state examination to assess patient severity of the illness and valid comorbidity scale to assess the comorbidity of the caregivers and patients.

Health education for caregivers should be performed to improve their knowledge about dementia including behavioral changes, stages and progression of disease as well as self care of the care giver. Long term follow up should be undertaken for caregivers to minimize and to identify the caregiver burden. Reassurance and introduction of screening programs to assess caregiver depression and other psychiatric illnesses would be helpful. Organization of therapy circles among dementia caregivers as they can share and learn through each other's experiences.

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Conflicts of interest

The authors declare no conflict of interest

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