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Dementia caregiver burden in family caregivers

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Abstract -Introduction – Caregiver burden is an important issue in not only managing dementia but also mental well-being of caregivers.
Aims & Objective - To assess caregiver burden in caregivers of patients with dementia.
Methods – From geriatric psychiatric OPD in psychiatric centre, eighty patients with dementia were included in the study. Diagnosis of dementia was made using DSM IV TR criteria. Caregiver burden was measured using Zarit Burden Interview (ZBI). Severity of dementia was assessed using HMSE.
Results – In all cases of dementia Alzheimer's dementia accounts 31 cases, mixed type dementia 20 and Vascular dementia 17, Lewy Body dementia 7 and Frontotemporal dementia 5 cases. Majority of the caregivers were either spouse (50%) or son/daughter (30%). Caregiver burden was significantly higher in frontotemporal dementia in comparison to other types of dementia.
Conclusions – Type of dementia also predicts caregiver giver burden.

Introduction – Indian elderly population has doubled from 1991 to 2011.(1) Dementia is mainly old age problem and characterised by progressive cognitive decline. It is estimated that in every twenty years cases for dementia will be doubled.(2) According to WHO and word bank dementia accounts 4.1% of all disability adjusted life years.(3) Dementia is chronic progressive and long-term illness. Family members of patients with dementia have to pay direct and indirect cost to care. Dementia care needs time and treatment cost, which is paid by mostly by family members. Caregivers are important part in management of dementia. Caregiver burden in dementia also increases risk of depression in caregivers.(4) Dearth of studies from India about caregiver burden in different types of dementia.

Methodology - A hospital based cross- sectional observational study was carried out on eighty eligible subjects with dementia attending geriatric psychiatry OPD at Psychiatric centre. HMSE applied to screen cases of dementia HMSE score below 25 was considered abnormal and patients were further assessed to confirm diagnosis of dementia using DSM IV TR diagnostic criteria. An informed written consent obtained from the patient and caregivers prior to participation in the study. Patients with delirium, primary diagnosis other than dementia eg. Schizophrenia, depression, bipolar etc, and dementia due to reversible cause like hypothyroidism, vitamin B12 deficiency were excluded. Patients who received the clinical diagnosis of dementia in the outpatient clinic were further divided into 5 groups: Alzheimer's-disease (AD), vascular-dementia (VD), mixed dementia type, frontotemporal (FTD) and lewy body dementia (LBD) (Lewy body & Parkinson's dementia). The diagnosis of dementia and assigning diagnosed patients to five different types based on routine clinical decision protocol that included detailed clinical, neuropsychiatric and somatic examination, laboratory tests, CT and/or MRI scans. That followed by comprehensive assessment of Dementia including recording of socio-demographic profile. This also included assessment (physical examination, mental status examination and laboratory investigations) to rule out reversible causes of dementia, rule out delirium, depression and other psychiatric illness. A caregiver defined as a person who lived with the patient and who would most likely provide care if needed burden. Caregiver burden was assessed using The Zarit Burden Interview. Severity of dementia assessed by using Hindi mental status examination (HMSE).

Results –

Table 1 : Socio -Demographic Profile of Patients

Demographic characteristic		All cases of Dementia	AD	VD	FTD	LBD (DLB+PD)	MIX TYPE	P value
Total no of Cases		80 (100%)	31 (38.8%)	17 (21.3%)	5 (6.3%)	7 (8.6%)	20 (25%)	
Age of patients (yrs)		72.68±7.23	72.52±7.8	73.6±6.34	73.2±11.39	70.86±4.4	73.5±6.2	0.86
Gender	Male	51 (63.75%)	20 (64.5%)	9 (52.9%)	5 (100%)	7 (100%)	16 (80%)	0.54
	Female	29 (36.25%)	11 (35.5%)	8 (47.1%)	00	00	4 (20%)	
EDU. STATUS	Illiterate	51 (63.75%)	24 (77.4%)	14 (82.4%)	00	5 (71.4%)	12 (60%)	0.076
	Primary	12 (15%)	6 (19.4%)	1 (5.9%)	00	00	5 (25%)	
	Secondary	7 (8.75%)	00	2 (11.8%)	00	1 (14.3%)	00	
	High School	10 (12.5%)	1 (3.2%)	00	5 (100%)	1 (14.3%)	3 (15%)	
	Above High Scholl	00	00	00	00	00	00	
RESIDENCE	Rural	54 (67.5%)	24 (77.4%)	10 (58.8%)	2 (40%)	5 (71.4%)	13 (65%)	0.28
	Urban	26 (32.5%)	7 (22.6)	7 (41.2%)	3 (60%)	2 (28.6%)	7 (35%)	
TYPES OF FAMILY	Nuclear & Extended nuclear	12 (15%)	00	5 (29.4%)	00	00	7 (35%)	0.061
	Joint	68 (85%)	31(100%)	12 (70.6%)	5 (100%)	7 (100%)	13 (65%)	
RELIGION	Hindu	55 (68.75%)	22(71%)	13 (76.5%)	5 (100%)	4 (57.1%)	11 (55%)	0.40
	Muslim	25 (31.25%)	9(29%)	4 (23.5%)	00	3 (42.9%)	19 (45%)	
	Others	00	00	00	00	00	00	
FAMILY INCOME	Up To5000	10 (12.5%)	4(12.9%)	1 (5.9%)	1 (20%)	1 (14.3%)	3 (15%)	0.21
	5001 – 15000	38 (47.5%)	15 (48.4%)	12 (70.6%)	3 (60%)	3 (42.9%)	5 (25%)	
	>15000	32 (40%)	12 (38.7%)	4 (23.5%)	1 (20%)	3 (42.9%)	12 (60%)	
Duration of illness (yrs)		4.8±2.2	6.03 ±2.1	4.1 ±1.1	2 ±1	3 ±1	5.12±2.2	0.04

AD- Alzheimer's Dementia, VD- Vascular Dementia, FTD- Fronto temporal dementia, LBD – Lewy body dementia (Parkinson disease dmentia+Dementia with lewy body), Mix type – Patients who fulfil criteria of both AD and VD.

In all eighty cases of dementia there were 31 (39%) had Alzheimer's dementia, 20 (25%) had Mixed type dementia, 17 (21%) had Vascular Dementia, 7(9%) had Lewy Body dementia (Dementia with Lewy body and Parkinson disease dementia) and 5(6%) had Frontotemporal Dementia. The mean age of all cases was 72.68±7.23 years, the mean age of VD and FTD variant were higher (73.6±6.34) than other type of dementia but no statistical difference found between different types of dementia. In all cases of dementia duration of illness was 4.8 years (mean) and duration of illness was significantly higher in Alzheimer's while lower in FTD.

Table 2: Socio-demographic Profile of Caregivers

Demographic characteristic		Frequency	Percentage
GENDER	MALE	20	25%
	FEMALE	60	75%
Age (yrs)	18 - 20	5	6.25%
	21 – 30	8	10%
	31 - 40	32	40.75%
	41- 50	15	18.75%
	>51	20	25%
RESIDENCE	RURAL	54	67.5%
	URBAN	26	32.5%
MARITAL STATUS	SINGLE	12	15%
	MARRIED	68	85%
RELATION OF CARE GIVERS	SPOUSE	20	25%
	SON	8	10 %
	DAUGHTER	15	18.75 %
	DAUGHTER IN LAW	32	40 %
	OTHER (Grandchild etc.)	5	6.25 %

Table 3: Caregivers age and Zarit burden interview score in Different Types Of dementia

Clinical Characteristic	All	AD	VD	FTD	LBD	MIX	P value
Mean age of caregiver (Years)	40.3± 12.0	41.2±13.1	39.8±11.4	42.7±14.3	40.9±7.5	39.6±9.8	**0.12**
ZBI Mean score	55.3±11.1	54±11.13	51.6±11.31	68.8±4.2	59.7±1.3	52.6±12.31	**0.008**

Table 4: Caregiver burden severity in different types of dementia

Clinical Characteristic	All	AD	VD	FTD	LBD	MIX
ZBI Mild (21-40)	11(13.75%)	3 (9.7%)	3(17.6%)	00	00	5 (25%)
Moderate(41-60)	42(52.5%)	18(58.1%)	10(58.8)	00	4(57.1)	5 (25%)
Severe (61-88)	27(33.75%)	10 (32.3%)	4(23.5%)	5(100%)	3(42.9%)	10 (50%)

Mean age of caregiver was 40.38 ± 12.0 years and no statistical difference in mean age of caregivers in different types of dementia. Caregiver burden was significant higher in FTD in compare to other types of dementia (p-0.008). In most of cases of Alzheimer's,

vascular and LBD there was moderate caregiver burden (58.1%, 58.8% & 57.1% respectively) while all cases (100%) of FTD have severe burden on Zarit burden interview score.

Discussion - In this study Alzheimer's dementia was the most common type of dementia which accounts for 39% cases followed by Mixed type Dementia 25% and Vascular Dementia 21%, other types like Lewy Body Dementia accounts for 9% of cases and Frontotemporal Dementia accounts for 6% cases. This was quite similar from other studies done in different parts of India. In a clinic-based study done in South India in 2011, Alladi et al. found AD in 38.3%, VD in 25.4%, frontotemporal dementia (FTD) in 18.7%, diffuse Lewy body disease (DLB) in 8.9%, and mixed dementia in 8.6% of the patients (5). The distribution of our dementia diagnoses is similar to other reports by Egerhazi et. al, Salka S et. Al. and Mathuranath P S et. al. from India (6,7,8). Duration of illness while consulting psychiatrist was significantly lower in FTD in comparison to other cases of dementia which indicate the early onset of behavioral and psychological symptoms in FTD presenting early in mental health care centre. Caring for a dementia patient itself being a demanding task, makes it understandable that coping with the additional burden of behavioral and psychological symptoms leads to significant distress for caregivers. In our study, most caregiver were either daughter in law, daughter or spouse and seventy five percent caregivers were females. Similarly, Leena Mary Emmatty et al, in cross sectional study conducted on dementia caregivers found that majority of the caregivers were either spouse (50%) or son/daughter (30%) and number of female caregivers (70%) was more than the number of male caregivers (30%). In our study, most cases (67%) belonged to rural background (9) and higher health care barriers are faced in rural areas. Overall caregiver burden was significantly higher in frontotemporal dementia in comparison to other types of dementia. Not only behavioural and psychological symptoms but also other factors like activity of daily living of patient with dementia, caregiver's support, availability of heath care facility, interpersonal relationship between caregiver and patient also affects caregiver burden. Among all cases of dementia, most of cases had moderate to severe cognitive impairment. Cognitive impairment was significantly higher in Alzheimer's dementia in comparison to other types of dementia. Significant correlation was found between cognitive impairment and duration of illness, which indicates cognition declines with progression of dementia. Significant positive correlation was also found between duration of illness and caregiver burden, which means with the progression of illness caregiver burden also increases. Increase in severity and magnitude of cognitive impairment may be the possible reason of higher caregiver burden with progression of illness. In our study we also found that more severe the stage of dementia greater the caregiver burden. These results are consistent with those of Fuh et al. (1999) (10). The literature suggests that certain caregiver demographics, such as younger age (Brody et al., 1995; Levesque et al., 1999), (11,12) lower educational level (Fuh et al., 1999; Levesque et al., 1999),(10,12) female gender (Gallicchio et al., 2002),(13) and spousal relationship to the patient (Fuh et al., 1999) (10), are associated with higher caregiver burden. In our study, however, no statistically significant correlation was found between caregiver burden and caregiver's age, education, gender or relationship to the patient, although female and spousal caregivers were found to have an increased caregiver burden that did not reach statistical significance. On the other hand, we found that married caregivers had a significantly higher care-giving burden than non-married caregivers. This result differs from that of Brody et al. (1995), who found no relationship between marital status and care giving burden (11). Significant negative correlation between the duration of illness and the HMSE score (rho= -0.087, p=0.026) which means when duration of illness progresses the HMSE score decreases, means the severity of the dementia increased. Previous studies done by Selbaekg et al and Santos MOA et al also suggest similar findings (14,15), Aalten et al and Engedal et al suggests it decreases with time, (16,17) and Berg et al and Serra L et al suggest it remain stable over time. (18.19) The results found are consistent with an aging population, especially considering cerebral and systemic vascular disease consequences. Caring for a dementia patient itself being a demanding task, it is understandable that coping with the additional burden of neuropsychiatric symptoms leads to significant distress for caregivers.

Conclusions - In this study, Alzheimer's dementia was

most common type of dementia among all cases of dementia. In Indian scenario most dementia caregiver are family members, as we found in our study. In most cases daughter in law and spouse were primary caregiver. Identification of caregiver distress is important while treating the patients with dementia. FTD predicts higher caregiver burden.

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