

# Problems and expectations of caregivers of patients with dementia: a qualitative study from a tertiary care hospital

## Abstract

**Background:** Patients with dementia (PwD) are primarily cared by a family member or their relatives in India. In managing these patients they often face a number of problems during care and sometimes they do not have any knowledge or understanding of the problems, so problems remain unattended. **Objectives:** Present study aimed to find out the problems faced by caregivers of dementia patients and management strategies evolved by themselves vis a vis training needs. **Methods:** The primary caregivers to patients with dementia admitted to the Department of Geriatric Mental Health giving consent were interviewed using a semi-structured proforma. Information regarding socio-demographic details, caregiver tasks, problems in performing care giving tasks and their own management techniques vis a vis need for training in managing the patients were gathered. **Results & Discussions:** A total of 21 caregivers of patients with dementia consented to participating in the study. They reported that they often confronted with a variety of problems in managing activities of daily living (ADL), and behavioral and psychological/emotional spheres of the patients during care giving. Managing toileting, bathing, feeding and dressing were the main problem areas. Caregivers depended on the management strategies evolved by themselves for providing support and managing day to day difficulties faced during care giving. The majority of the caregivers acknowledged the need for structured skills training for managing patients with dementia.

**Keywords:** Activities of Daily Living; Caregivers; Dementia; Problems & Expectations

## Introduction

Hospital records reveal dementia as the common mental health problems of old age. Though the community studies indicate lower prevalence of dementia in India as compared to developed countries (Shaji *et al.* 2005) but the prevalence has been reported to be variable, from 1.4% to 9.1% (Chandra *et al.* 1998; Rajkumar *et al.* 1997; Vas *et al.* 2001; Shaji *et al.* 2005; Tiwari &

Pandey, 2012; Tiwari *et al.* 2013; Kumar *et al.* 2019). However, with progressing illness the patients with dementia become more dependent on caregivers for their day to day needs at home or in the hospital. Further, they become unable to perform their activities of daily living (ADL), instrumental activities of daily living (IADL) (Jekel *et al.* 2015) and might not be able to cope with family/ friend or companion as they were doing

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premorbidly. It may further increase the burden on caregivers (Hamza *et al.* 2018).

Sometimes behaviors of patients with dementia vary from their accepted role and they may not be able to behave as spouse, parent and grandparents. And therefore, providing care to a dementia patient becomes a responsibility of the family member/s as it is an irreversible disease.

Problem behaviour has been reported to be the most stressful aspect of caregiving (Coen *et al.* 1997; Payne *et al.* 1997) and contributes to the increased burden for caregivers (Janardhana *et al.* 2015). Problem behaviours can have the major impact on caregivers (Tripathi *et al.* 2020). Research and practitioners have identified a number of problem behaviours related to Alzheimer's Dementia (Srivastava *et al.* 2016). These include paranoid and delusional ideation, hallucinations, aggressiveness, affective disorders, and problems with activities of daily living (Pruchno & Resch, 1989). Studies reported regarding caregivers problem of dementia (Srivastava *et al.* 2016; Kalikaya *et al.* 2005; Mason *et al.* 2007; Livingstone *et al.* 2014), neuropsychiatric disorders, cognitive disorders and normally aging older adults (Tripathi *et al.* 2020). Livingstone *et al.* 2014 reported that two third of dementia caregivers develop clinical depression or anxiety.

After identification of the different types of problem behaviours, and strain experienced of caring them, the focus of researcher and psychogeriatrician will turn to how to manage or reduce the frequency of behaviours. Therefore, the present study is planned with objectives to identify and assess the kind of problems exactly faced by caregivers and their management strategies developed by caregivers themselves vis a vis the need for training.

## Material and Methods

**Sample :** Sample consist of 21 caregivers of dementia patients.

## Tools

Semi-structured proforma containing following items was developed.

- Socio-demographic details of the caregivers.
- Details of family members and their living arrangements.
- Source of referral of the patient and reasons of the referral.
- Details of primary health caregivers.
- Details of initial health care practitioners.
- Details of the progression of the illness.
- Main caregiving problems -activities of daily living, behavioral and psychological symptoms as well as other areas and the management strategies evolved by themselves.
- Skilled care giving knowledge in care giving and their perceived need for training and guidance for same.

**Procedure:** The study was conducted on caregivers of indoor diagnosed dementia patients according to ICD-10 criteria at the Department of Geriatric Mental Health, King George's Medical University UP, Lucknow. Caregivers to all the identified cases of moderate to severe dementia were explained the procedure of the study and after obtaining the informed consent they were recruited. To get the detailed information above mentioned semi-structured proforma was administered on all the caregivers of dementia patients.

## Results

**Statistical analyses:** Obtained data was analysed using percentages, and graph. Qualitative analysis of the data was also done to draw meaningful results and conclusion.

A total of 21 caregivers gave their consent to participate in the study and all of them were from the urban background and were permanently residing

with the patients. Socio-demographic profile and their relation with patients are shown in table 1:

**Table 1**  
**Socio-demographic details of Caregivers**

Description		Details of of Dementia patients		
		Male (%) N=12 (57.1)	Female (%) N=9 (42.8)	Total (%) (N=21)
Age Group	31-40 yrs	4 (19.0)	3 (14.3)	7 (33.3)
	41-50 yrs	3 (14.3)	1 (4.7)	4 (19.0)
	51-60 yrs	2 (9.5)	3 (14.3)	5 (23.8)
	61 & >	3 (14.3)	2(9.5)	5 (23.8)
Marital Status	Unmarried	1(4.7)	0	1 (4.7)
	Married	9 (42.8)	6 (28.6)	15 (71.4)
	Widowed	2 (9.5)	3 (14.3)	5 (23.8)
Educational Status	Nil	0	7 (33.3)	07 (33.3)
	Up to 8 <sup>th</sup>	1 (4.7)	1 (4.7)	02 (9.5)
	Up to 12 <sup>th</sup>	3 (14.3)	1 (4.7)	04 (19.0)
	Graduate	5 (23.8)	0	05 (23.8)
	Post gr aduate	3 (14.3)	0	03 (14.3)
Occupation	Farming	3 (14.3)	0	03 (14.3)
	Business	2 (9.5)	0	02 (9.5)
	Service	4 (19.0)	0	04 (19.0)
	No gainful employment (NGE)	3 (14.3)	0	05 (23.8)
	House wife/ household work	0	9 (42.8)	09 (42.8)
Relationship with patient	Spouse	5 (23.8)	4 (19.0)	09 (42.8)
	Son/ Daughter	7 (33.3)	2 (9.5)	09 (42.8)
	Son-in-law/ Daughter -in-law	0	3 (14.3)	03 (14.3)

Table 1 shows that males outnumbered female caregivers (M=57.1% F=42.8%). The majority of the caregivers aged between 31-40 years (33.3%), followed by 51-60 and 61 years and above (23.8% in both age groups) and 41-50 years (19.0%). 71.45 % of the caregivers were married, 23.8% widowed and only one of the caregivers was unmarried. Amongst the males, no one was illiterate whereas among the female majority were illiterate (33.3%), the majority

of males were graduate (23.4%), followed by postgraduates and intermediate (both 14.3%). All the female caregivers were housewives. 42.6% of caregivers were spouse followed by son (33.3%), daughter in law (14.3%) and daughter (9.5%).

Symptoms in the patients, which forced the caregivers to seek health care services and its phenomenology are depicted in table 2.

**Table 2**  
**Frequency of Complaints as Reported by the Caregivers of dementia patients**

<b>Symptoms which made the care provider conscious to consult the specialist</b>
<b>Frequently reported symptoms (up to 70% of complaints)</b> Decreased memory; Not recognizing things; Wandering; Forgetting names of near and dear as well as usual/ common things
<b>Occasionally reported symptoms (up to 35-70% of complaints)</b> Decreased sleep; Increased Restlessness; Increased irritability; Increased sociability; frequent demands for food; Using abusive languages
<b>Rarely reported symptoms (up to 0- 35% of complaints)</b> Decreased bladder/ bowel control; unable to perform day to day activities; replication of talk; increased suspiciousness; unable to use appliances; increased anxiety; irrelevant talk.

**Table 3**  
**Problems reported by the Caregivers in Activities of Daily living (ADL), Behavioral and Psychological Areas**

Activities of Daily living	No. (%)	Behavioral	No. (%)	Psychological/ Cognitive	No. (%)
Incontinence	17 (80.9)	Verbal/ physical aggression	13 (61.9)	Memory disturbances	21(100)
Bathing	15 (71.4)	Wandering	14 (66.7)	Orientation problems	17(80.9)
Feeding	14 (66.7)	Agitation	17 (80.9)	Anxiety	7 (33.3)
Dressing	17 (80.9)	Sleep disturbance	19 (90.5)	Fear of being left alone	5 (23.8)
Brushing teeth	13 (61.9)	Purposeless activity	12 (57.1)	Anxiety regarding upcoming events (Godot syndrome)	3 (14.3)
Physical Ambulation	4 (19.0)	Inappropriate activity	8 (38.1)	Depression	8 (38.1)
-	-	Demanding behaviour	12(57.1)	Hallucinations	4 (19.0)
-	-	-	-	Delusions	2 (9.5)
-	-	-	-	Communication difficulties	8(38.1)

Table 3 reveals that maximum caregivers reported problems in incontinence (80%) and dressing (80%), sleep disturbance (90.5), memory disturbance (100%) among patients with dementia.

Figure 1: Problems perceived by the caregivers, distressing and too serious to require medical attention

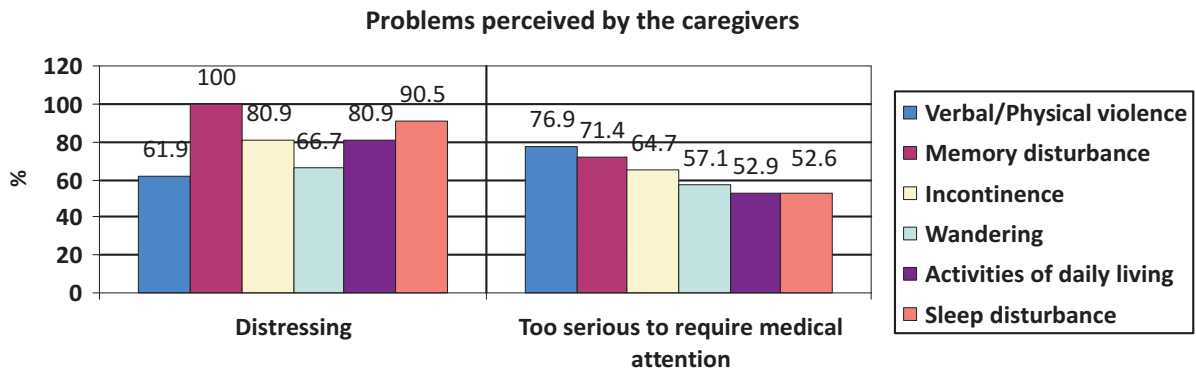


Figure 1 shows that memory, disturbances of the patient with dementia is distressing as perceived by the all caregivers, but 76.9% reported verbal/physical aggression required medical attention.

Table 4  
Supportive strategies adopted by caregivers while managing problems of day to day activities and behavioral/psychological spheres are shown

<p><b>Toileting</b></p> <ul style="list-style-type: none"> <li>• Providing help in going toilet by giving help of <b>one's own shoulder or hand, stick, washing hands, towel.</b></li> <li>• Providing diapers.</li> <li>• Cleaning of bed sheets, assuring cleanliness of clothes, providing a hygienic environment etc.</li> </ul>	<p><b>Bathing</b></p> <ul style="list-style-type: none"> <li>• Providing water bucket and mugs, keeping chair for comfortable bath, pouring water and applying soap for taking a bath (as at times patients don't want to take a bath).</li> <li>• Arranging bathe in the living rooms of the patients itself.</li> <li>• Providing towel, sponging, etc.</li> </ul>	<p><b>Dressing</b></p> <ul style="list-style-type: none"> <li>• Giving clothes, supporting in tying buttons, supporting wearing clothes.</li> </ul>
<p><b>Feeding</b></p> <ul style="list-style-type: none"> <li>• Serving meals, assisting in taking meals, coxing/insisting for taking meals etc.</li> </ul>	<p><b>Brushing teeth</b></p> <ul style="list-style-type: none"> <li>• Giving toothpaste, brush, assisting in cleaning teeth etc.</li> </ul>	<p><b>Physical Ambulation</b></p> <ul style="list-style-type: none"> <li>• Supporting walk by providing stick, hand or walker, taking in lap for going out etc.</li> </ul>
<p><b>Verbal/ physical Aggression, Agitation</b></p> <ul style="list-style-type: none"> <li>• Trying to avoid handling of injurious instruments, locking patient in a room.</li> </ul>	<p><b>Sleep disturbance</b></p> <ul style="list-style-type: none"> <li>• Consulting doctor, giving medication.</li> </ul>	<p><b>Purposeless activity, Inappropriate activity</b></p> <ul style="list-style-type: none"> <li>▪ Trying to stay away from the patient and avoid his activities.</li> </ul>
<p><b>Anxiety, Fear of being left alone</b></p> <ul style="list-style-type: none"> <li>▪ Discussing and trying to find out reasons for anxiety or fear.</li> </ul>	<p><b>Wandering, anxiety regarding upcoming events (Godot syndrome), Depression, Hallucinations, Delusions</b></p> <ul style="list-style-type: none"> <li>• Wandering managed by locking the demented patient in a room.</li> </ul>	-

**Table 5**

**Challenges of caregiving and training needs are summarized**

Challenges of Caregiving	Training Needs
<ul style="list-style-type: none"> <li>• Feel stressed and burdened with managing toileting, bathing, feeding, etc. personal care related activities.</li> <li>• Looking at the situation of patient sometimes feels fear.</li> <li>• Disturbance in daily routine.</li> <li>• Financial burden and constraints.</li> <li>• Constant feeling of fatigue and sleep disruption (specially spouse)</li> <li>• Emotional disturbance.</li> </ul>	<ul style="list-style-type: none"> <li>▪ To minimize the workload.</li> <li>• Better management strategies and reduce care giving stress.</li> </ul>

**Discussion**

This study reports the difficulties faced by caregivers of dementia patients, the management strategies evolved by themselves and perceived training needs in caregiving.

Caregivers of dementia patients were reported problems related with activities of daily living, behavioural, psychological and cognitive areas as reported in previous studies (Srivastava *et al.* 2016; Tripathi *et al.* 2020; Kalikaya, 2005). Problems in memory were reported by all of the caregivers of patients with dementia, which were distressing to them. As memory disturbances in dementia is quite common and patients are at risk to be lost. They cannot recognize family members and friends. Hence, become suspicious towards family members. They keep things and forget that where it is. They thought that somebody stolen his things. And later psychopathology of delusion of theft developed. These all conditions related to dementia patients are a major source of caregiver distress. Similarly disturbance in sleep may lead to reversal of sleep-wake-cycle and later they fall into delirium. Incontinence and inability to dress properly are other problems related to dementia patients, which reported by most of the caregivers in our study. Jekel *et al.* 2015 also reported difficulty related to activities of daily living of dementia patients.

Supportive strategies adopted by caregivers while managing problems of day to day activities and behavioral/psychological spheres are shown in table 4 on the basis of the study. Challenges of caregiving of patients with dementia and training needs for caregivers are summarized in table 5.

The findings of this study reveal that a large range of caregiving task is managed by the caregivers but 76.9% reported verbal/physical aggression required medical attention.

Though they have evolved some handling and coping strategies, but still they require guidance and training in this regard.

- Providing care to an older adult with dementia is a tough task as it requires physical, emotional and financial involvement of the care giver.
- Managing various ADL and psychological and behavioral problems by the caregivers is often stressful.
- The caregivers need support and directions from professionals to manage their patients at home.
- Almost all caregivers had shown their interest in receiving training to learn caregiving skills to perform the care giving task more effectively.
- Raising awareness and disseminating knowledge for better care of dementia patients and developing interventional modules to overcome caregivers stress and strain are the need of the hour.

**Conclusions**

Caregivers of dementia patients were reported problems related with activities of daily living, behavioural, psychological and cognitive areas while caring to dementia patients. The majority of the caregivers acknowledged the need for structured

skills training for managing and caring patients with dementia.

**Limitations of the study:** This is a qualitative study based on small sample size. Only caregivers of admitted dementia patients were studied. Caregivers of diagnosed dementia patients were considered, but other clinical variables of dementia patients were not assessed. Amount of caregiver distress at home and at hospital setup may be fluctuate. Recall bias may be present. Mental health status of the caregivers was not assessed. But the findings of the study through some light on the need of the training to the caregivers of the dementia patients to reduce the distress and burden

## References

- Chandra, V., Ganguli, M., Pandav, R., Johnston, J., Belle, S., DeKosky, S.T. (1998). Prevalence of Alzheimer's disease and other dementias in rural India: the Indo-US study. *Neurology*, 51(4), 1000–1008.
- Coen, R.F., Swanwick, G.R., O'Boyle, C.A., Coakley, D. (1997). Behavioral disturbance and other predictors of caregivers burden in Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 12, 331–336.
- Hamza, S.A., Mahmoud, H.F., Rafaat, V.A., Mohamed, A.A.A. (2018). The Level of Function of Dementia Patients has an Impact on the Caregiver Burden. *Hamza et al., J Gerontol Geriatr Res*, 7:2 DOI: 10.4172/2167-7182.1000464.
- Janardhana, N., Raghunandan, S., Naidu, D.M., Saraswathi, L., Seshan, V. (2015). Care giving of people with severe mental illness: An Indian experience. *Indian J Psychol Med*, 37:184–94.
- Jekel, K., Damian, M., Wattmo, C., Hausner, L., Bullock, R. *et al.* (2015). Mild cognitive impairment and deficits in instrumental activities of daily living: a systematic review *Alzheimer's Research & Therapy*, 7:17 <https://doi.org/10.1186/s13195-015-0099-0>
- Kalikaya, G., Yukse, G., Varlibas, F., Tireli, H. (2005). Caregiver burden in dementia: A study in the Turkish population. *The Internet Journal of Neurology*, 4 (2).ISSN: 1531-295X.
- Kumar, C.T.S., Shaji, K.S., Varghese, M., Nair, M.K.C. (Eds) (2019). *Dementia in India 2020*. Cochin: Alzheimer's and Related Disorders Society of India (ARDSI), Cochin Chapter. <https://dementiacarenotes.in/dcnfiles/Dementia-in-India-2020.pdf> accessed on 09/02/2021.
- Livingstone, G., Barber, J., Rapaport, P., Knapp, M., Griffin, M., King, D., Romeo, R., Livingston, D., Mummery, C., Walker, Z., Hoe, J., Cooper, C. (2014). Long term clinical and cost effectiveness of psychological intervention for family carers of people with dementia: a single-blind, randomized, controlled trial. *Lancet Psychiatry*, 1, 539–48.
- Mason, A. *et al.* (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technol Assess*, 11(15).
- Payne, K.A., Caro, J.J. (1997). Behavioural disturbances in dementia as a factor in institutionalization. *Biological Psychiatry*, 42:210S.
- Pruchno, R.A., Resch, N.L. (1989). Aberrant behaviors and Alzheimer's disease: mental effects on spouse caregivers. *Journal of Gerontology*, 44, 5177–5182.
- Rajkumar, S., Kumar, S., Thara, R. (1997). Prevalence of dementia in a rural setting: a report from India. *Int J Geriatr Psychiatry*, 12(7), 702–707.
- Shaji, S., Bose, S., Verghese, A. (2005). Prevalence of dementia in an urban population in Kerala, India. *Br J Psychiatry*, 186, 136–140.
- Srivastava, G., Tripathi, R.K., Tiwari, S.C., Singh, B., Tripathi, S.M. (2016). Caregiver burden and quality of life of key caregivers of patients with dementia. *Indian J Psychol Med*, 2016, 38, 133–136.
- Tiwari, S.C., Pandey, N.M. (2012). Status and requirements of geriatric mental health services in India: An evidence-based commentary. *Indian J Psychiatry*, 54, 8–14.
- Tiwari, S.C., Srivastava, G., Tripathi, R.K., Pandey, N.M., Agarwal, G.G., Pandey, S. (2013). Prevalence of psychiatric morbidity amongst the community dwelling rural older adults in Northern India. *Indian J Med Res*, 138, 504–14.
- Tripathi, R., K., Tripathi, S.M., Pandey, N.M., Singh, B., Tiwari, S.C. (2020). Problems and strain of caregivers of urban older adults: An exploration. *Journal of Geriatric Mental Health*, 7, 1, 38–44. [https://doi.org/10.4103/jgmh\\_38\\_19](https://doi.org/10.4103/jgmh_38_19)
- Vas, C.J., Pinto, C., Panikker, D., Noronha, S., Deshpande, N., Kulkarni, L. *et al.* (2001). Prevalence of dementia in an urban Indian population. *Int Psychogeriatr*, 13(4), 439–450.