

To Study the Psychiatric Morbidity Amongst Caregivers of Patients of Dementias

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ABSTRACT

Introduction: The global burden of disease is largely caused by health issues related to ageing. Although the majority of deaths in this demographic are caused by chronic diseases, dementia and associated behavioural issues account for a large portion of the years lived with disability. The negative effects of the ongoing care needs on older persons with health issues like dementia are numerous for informal carers (ICs).

Aim and Objective: To study the psychiatric morbidity amongst caregivers of patients of dementias.

Material and Methods: This was a Hospital based out Patient Department (OPD) study carried out in the Department of Psychiatry for a period of 12 months i.e., February 2023 to February 2024 where index cases were the consecutive cases of dementia, attending to Psychiatry OPD at a tertiary care centre. Caregivers (Key and Other) of patients of Dementia were identified. These caregivers were assessed for psychosocial stress, quality of life and psychiatric morbidity amongst them due to care giving. The diagnosis of dementia was made by one of the supervisors on the basis of ICD-10 DCR. A minimum of 20 patients of dementia were.

Results: In the current study most of the key caregivers (64%) reported severe level of burden followed by moderate burden (36%). All the key care givers reported experiencing burden in care giving. On the other hand the majority of other care givers (85.4%) reported experiencing moderate burden followed by severe burden (8.8%) and no burden (5.8%) on Burden Assessment Schedule. It was also observed that in the overall family burden majority of care givers (68%) reported moderate level of burden followed by severe burden (28%). In the areas of financial, family routine activities, family leisure time, and financial interaction similar amount of burden were reported the majority (60%, 72%, 60% and 76%) reported moderate burden followed by severe burden (32%, 24%, 36% and 16%) respectively. With regard to mental health, majority reported severe level of burden (44%) followed by moderate burden (36%) and no burden (20%). In the area of physical health, majority of the key caregivers reported experiencing no burden at all (80%) followed by moderate level of burden by (20%).

Conclusion: The caregiver preparedness, increased social support and social networks, assistance in care, positive appraisal and coping, and satisfaction with healthcare services are associated with reduced depression and stress in ICs. Evidence of these effects is important to plan caregiver interventions to mediate their psychological outcomes. Clinicians should be cognizant of the risk in this group of caregivers and assess and intervene to alleviate caregivers' psychological problems.

Keywords: Psychiatric, Morbidity, Caregivers, Patients, Dementias.

INTRODUCTION

Dementia is a progressive neurodegenerative syndrome characterized by deterioration in memory, thinking, behavior, and the ability to perform everyday activities, resulting in progressive dependency on caregivers. Globally, over 55 million people live with dementia, with nearly 10 million new cases annually, and this number is projected to triple by 2050 as the population ages [1]. In India, demographic transition, enhanced healthcare services, and rising life expectancy have led to a significant increase in the elderly population, making dementia an emerging public health challenge [2]. Alzheimer's disease is the most common cause, followed by vascular dementia and other subtypes [3].

Caregiving for dementia patients is uniquely challenging due to the combination of cognitive decline, functional impairments, and behavioral disturbances. Functional deficits may include an inability to perform activities of daily living, such as dressing, bathing, or feeding, while behavioral and psychological symptoms of dementia (BPSD) — such as agitation, aggression, hallucinations, or apathy — significantly increase caregiver stress [4]. In India, most dementia patients are cared for at home by family members due to cultural norms, scarcity of institutional care facilities, and the belief that caring for elders is a family duty [5]. While these traditions offer emotional comfort, they can mask the underlying psychosocial stressors and psychiatric morbidities caregivers experience.

Caregiver burden refers to the physical, emotional, social, and financial strain associated with prolonged caregiving responsibilities. It is not determined solely by the severity of dementia but is influenced by caregivers' coping abilities, access to social support, financial security, and physical health status [6]. Multiple studies have shown that caregivers of dementia patients face higher risks of depression, anxiety disorders, sleep disturbances, and reduced quality of life [7]. The concept of the “hidden patient” has emerged to describe caregivers who, despite not being the identified patient, experience significant morbidity due to the demands of caregiving [8].

India's joint family structure has traditionally provided a strong network of support for caregivers. However, rapid urbanization, migration, and lifestyle changes have disrupted these extended family systems, often leaving a single “key caregiver” — usually a spouse or adult child — to bear the majority of the caregiving responsibilities [9]. Prolonged and intensive caregiving can disrupt employment, social interactions, and leisure activities, leading to isolation and chronic stress, which are strong predictors of psychiatric morbidity.

Assessing caregiver well-being is essential not only for the health of the caregiver but also for the patient's outcomes. Evidence suggests that caregiver distress is linked to early institutionalization of dementia patients, poor adherence to care plans, and worsening behavioral disturbances [10]. However, there is limited research in India that systematically explores psychiatric morbidity among both primary and secondary caregivers. This gap highlights the need for studies focusing on the prevalence, severity, and determinants of psychiatric conditions in dementia caregivers, with the ultimate goal of informing interventions that support caregiver resilience and improve overall quality of life.

MATERIAL AND METHODS

This was a Hospital based out Patient Department (OPD) study carried out in the Department of Psychiatry for a period of 12 months i.e, February 2023 to February 2024 where index cases were the consecutive cases of dementia, attending to Psychiatry OPD at a tertiary care centre. Caregivers (Key and Other) of patients of Dementia were identified. These caregivers were assessed for psychosocial stress, quality of life and psychiatric morbidity amongst them due to care giving. The diagnosis of dementia was made by one of the supervisors on the basis of ICD-10 DCR. A minimum of 20 patients of dementia were .

Statistical Analysis

The data have been analyzed employing percentages and Fisher's exact test of independence by using the S-PLUS software.

Fisher's exact test is a statistical significance test used in the analysis of contingency tables where sample sizes are small. It is one of a class of exact tests, So called because the significance of the deviation from a null hypothesis can be

RESULTS

The study included 59 caregivers of 25 dementia patients (25 key caregivers, 34 other caregivers). Most dementia patients were 60–70 years old, male, and married. Key caregivers were older (41–60 years) and predominantly female, while other caregivers were younger (21–40 years) and more often male. Spouses formed the largest group among key caregivers, while sons predominated among other caregivers. Key caregivers devoted significantly more time to care, with many providing over 70% of their day, compared to mostly under 30% among other caregivers.

Table-I:Details of Sample Selection

1. Selection of Patients of Dementia (IndexCases)and their Key Care Givers

<ul style="list-style-type: none"> Total number of dementia patients in OPDs contacted Total number of dementia patients excluded Total number of dementia patients finally included in the study 	43 18 25
Reasons for exclusion- a.Due to patient related reasons: <ul style="list-style-type: none"> Durationof dementia lessthan one year Livingoutsidemunicipallimitsof Lucknow DementiaPatientwithfractureneckfemur Dementiapatientswithoutkeycare givers b.Due to keycare giver related reasons: <ul style="list-style-type: none"> Keycare giveraged 10 years Refused to participateinthestudyduetopaucityof time Historyof bi-polar disease in key care givers 	 03 05 01 03 } 12 01 03 02 } 06

2. Selection of Other CareGivers

■ Total number of other caregivers with 25 dementia patients: <ul style="list-style-type: none"> Total number of other care givers excluded Reasons for exclusion of othercare givers <ul style="list-style-type: none"> -The accompanying person was not the care giver -Refused to participate in the study -History of schizophrenia Total number of other care givers finally included in the study– 	37 03 01 01 01 34
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■ Caregivers finally recruited:

- Keycaregivers with 25 dementia patients 24
- Other caregivers with 25 dementia patients 34

■ Total number of caregivers finally included and studied 59

From table-I it is obvious that for 25 dementia patients, 25 key care givers and 34 other care givers were included for the study. It was decided a priory that only those dementia patients will be included who will be accompanied with key care givers. Similarly, based on availability, the other care givers (for one patient not more thantwo) were to be included. At the time of assessment, finally 34 other care givers fulfilling the inclusion, exclusion criteria were recruited and studied. Thus, two groups of care givers (key and others i.e., 25+34=59) formed the study sample.

Table—IA:Socio Demographic Profile of Included Dementia Patients

Variable	Category	NumberofPatient(s)	Percentage
Age in years	55-60	1	4
	60-70	13	52
	70-80	8	32
	80 and above	3	12
Sex	Male	16	64
	Female	9	36
Marital Status	Married	16	64
	Widowed	9	36
Educational Status	Illiterate	5	20
	BelowPrimary	2	8
	Primary&Above	5	20
	HighSchool	3	12

Intermediate	3	12
Graduate	5	20
PostGraduate	2	8

Table—I Ais about the profile of included dementia patients. Most of the patients were from age group of 60 to 70 years (52%) followed by 70 to 80 years (32%), were males (64%) married (64%; and illiterate or educated primary and above or graduates (20%) each.

Table—II: Distribution of Severity of Dementia (as per MMSE scores) and number of their Care Givers

Severity of dementia*	No. of dementia patients	No. of key caregivers	No. of other caregivers
Mild	3	3	1
Moderate	12	12	16
Severe	7	7	12
Patients could not be assessed on MMSE due to severity of dementia	3	3	5

*severity=mild:20-24; moderate:11-19;severe:0-10

Table —II is about the distribution of patients of dementia according to severity of dementia based on total MMSE scores and their key and other care givers. 3 patients of dementia could not be assessed as MMSE could not be administered due to severity of the disease.

Table III: Age wise Distribution of Care Givers

Age in Years	Key Caregiver		Other Caregiver	
	N	%	N	%
12-20	1	4	4	11.8
21-40	4	16	21	61.8
41-60	11	44	8	23.5
61-80	8	32	1	2.9
80 & above	1	4	0	0.0
Total	25	100	34	100

Fisher' Exact p-value=0.0002(significant)

Table III shows age wise distribution of the key and other care givers. The majority of key care givers (44%) were in the age group of 41-60 years followed by (32%) in age group of 61-80 years. The other care givers were younger and maximally distributed (61.8%) in the age group of 21-40 years followed by (23.5%) in the age range of 41-60 years. The proportions in different age groups of key and other care givers were statistically significantly different ($p=0.0002$). A graphic presentation of the data is shown Figure-1.

Table IV: Gender wise Distribution of Care Givers

Table III: Age wise Distribution of Care Givers

Sex	Key Caregiver		Other Caregiver	
	N	%	N	%
Male	9	36	18	52.9
Female	16	64	16	47.1
Total	25	100	34	100

Fisher' Exact p-value=0.2905(insignificant)

Table IV shows gender wise distribution of the key and other caregivers. Majority of the key caregivers (64%) were females followed by (36%) males. Amongst the other caregivers majority were males (52.9%) followed by females (47.1%). Statistically the gender difference was found to be insignificant ($p = 0.2905$)

Table V: Relationship of the key and other Caregivers with patents

Relationship with patient	Key Caregiver		Other Caregiver	
	N	%	N	%
Spouse	11	44	1	2.9
Son	5	20	13	38.2
Daughter	2	8	4	11.8
Son-in-law	5	20	7	20.6
Daughter-in-law	1	4	4	11.8
Grand-son/daughter	1	4	5	14.7
Total	25	100	34	100

Fisher'Exact p-value = 0.0003 [significant]

Table V reveals the relationships of the key and other caregivers with patients. It shows that majority of key caregivers were spouse (44%) followed by son and son-in-laws, 20% each. Only two of the key care givers were daughters and one was daughter in law. Amongst other caregivers, majority were sons (38.2%) followed by son-in-laws(20.6%) and grandchildren (14.7%). As is evident from the table daughters or daughter in laws were proportionally less (11,2%) in other care givers as well. There is dependency between the types of care givers and their relationship with the patients. That is, the proportion of spouse, son etc. are significantly different in key and other care givers ($p = 0.0003$).

Table VI; Occupation of the Key and other Caregivers

Occupation	Key Caregiver		Other Caregiver	
	N	%	N	%
Farming	1	04	0	00
Business	2	08	8	23.5
Service	4	16	11	32.4
No gain fulemployment(NGE)	3	12	3	8.8
Housewife	13	52	4	11.8
Unpaid domestic work(UDW)	1	04	0	00
Others	1	04	8	23.5
Total	25	100	34	100.0

Fisher' Exactp-value =.0002(significant)

Table VI demonstrates occupation of the key and other care givers. Majority of the key caregivers were house wives (52%) followed by in service (16%). (12%) of the key care givers did not have a gainful employment and (4 %) were unpaid domestic workers. Amongst other caregivers, majority were in service (32.4%) followed by equally distributed in business and other works (23.5 % each). A very small percentage of the other care givers were house wives(11.8%). Occupational difference between the two kinds of care givers was found to be statistically significant ($p = 0.0002$).

Table VII: Marital Status of Caregivers

Marital Status	Key Caregiver		Other Caregiver	
	N	%	N	%
Unmarried	4	16	12	35.3
Married	20	80	21	61.8
Widowed	1	4	0	0.0
Separated	0	0	0	0.0
Divorced	0	0	1	2.9
Total	25	100	34	100

Fisher' Exact p-value0.1373(insignificant)

As is evident from table VII, majority of the caregivers were married -key care givers (80%); other caregivers (61.8 %) followed by unmarried (16% key caregivers; 35.3% other care givers). Amongst key care givers one individual was widowed whereas in other care givers one was divorcee. Statistically the difference of marital status amongst the care givers was found to be insignificant ($p=0.1373$).

Table VIII: Education of Care Givers

Education Status	Key Caregiver		Other Caregiver	
	N	%	N	%
Illiterate	1	4	1	2.9
Up to High School	4	16	1	2.9
Intermediate	6	24	4	11.8
Graduate	12	48	18	52.9
Post Graduate	2	8	10	29.4
Total	25	100	34	100

Fisher' Exact p-value = 0.0851 (insignificant)

Table VIII gives the details of educational status of the key and other caregivers. The majority of the key caregivers were graduates (48%) followed by intermediate (24%), education up to high School (16%), postgraduates (8%) and one of them was illiterate. In other caregivers, majority were graduates (52.9%) followed by postgraduates(29.4%) and inter mediates(11.8%). Only one of the other care givers was illiterate and one was educated up to high school. However, the educational status was independent of type of caregivers i.e, the proportions of type of caregivers was insignificantly different in different classes of educational status ($p=0.0851$).

Table IX: Time Given for Care Giving in 24 Hours

Total Time Given for Care Giving	Key Caregivers		Other Caregivers	
	N	%	N	%
0-8hours (up to 30%)	3	12	27	79.4
8-16 hours (31-70%)	12	48	6	17.7
16-24hours (71-100%)	10	40	1	2.9
Total	25	100	34	100

Fisher' Exactp-value=0.000(significant)

Table VIX reveals subjective reports of the caregivers about the time given by them to the patients for care giving. The majority of the key care givers(48%)reported that they give 31 -70% of their time to the patients, whereas (40%) reported that they could give 71-100% of their time for care giving. Amongst the other caregivers, majority (79.4%) were giving only up to 30 % of their total time followed by (17.7 %) who were giving 31-70% of their total time for care giving. Only one other care giver gave >70% of time to care giving. Statistically the time duration and type of caregivers were dependent to each other ($p=0.000$)

Table X: Subjective Feeling of Satisfaction Amongst Care Givers in Care Giving

Feeling of satisfaction	Key Caregiver		Other Caregivers	
	N	%	N	%
Highly dissatisfied	0	0	0	0
Dissatisfied	4	16	7	20.6
Neutral	3	12	8	23.5
Satisfied	15	60	18	52.9

Highly satisfied	3	12	1	2.9
Total	25	100	34	99.9

Fisher' Exact p-value=0.4386(insignificant)

Subjective feeling of satisfaction amongst care givers in providing care to the patients is given in Table X. The majority of the key caregivers felt satisfied (60%) in providing care, followed by dissatisfied ones (16%), equally placed neutral and highly satisfied (12% each) caregivers. Amongst the other caregivers majority were satisfied (52.9%) followed by neutral (23.5%) and dissatisfied (20.6%) care givers. Statistically the proportions of different caregivers in different categories of feeling of satisfaction was found to be statistically insignificant (p =0.4386). A graphical presentation of the data is shown in Figure-1

Figure -1

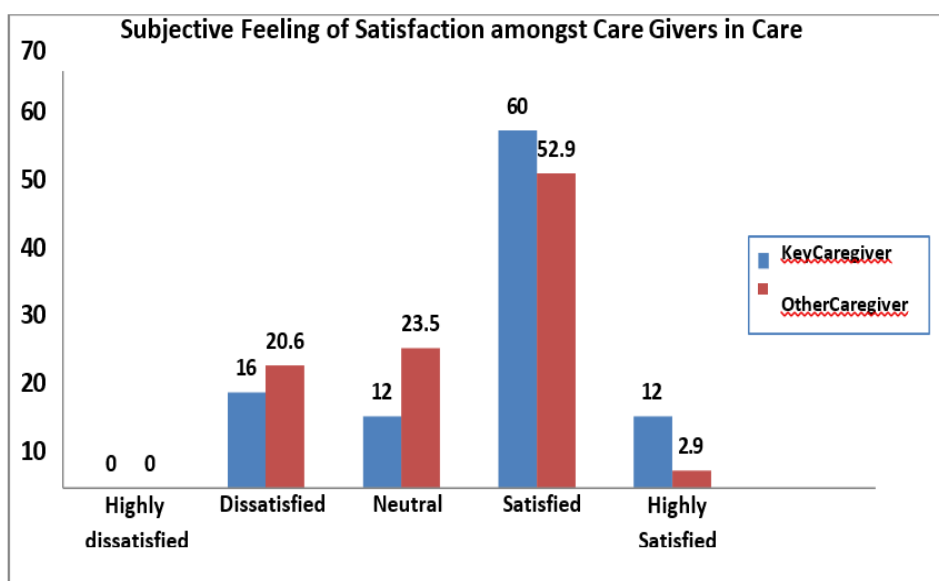


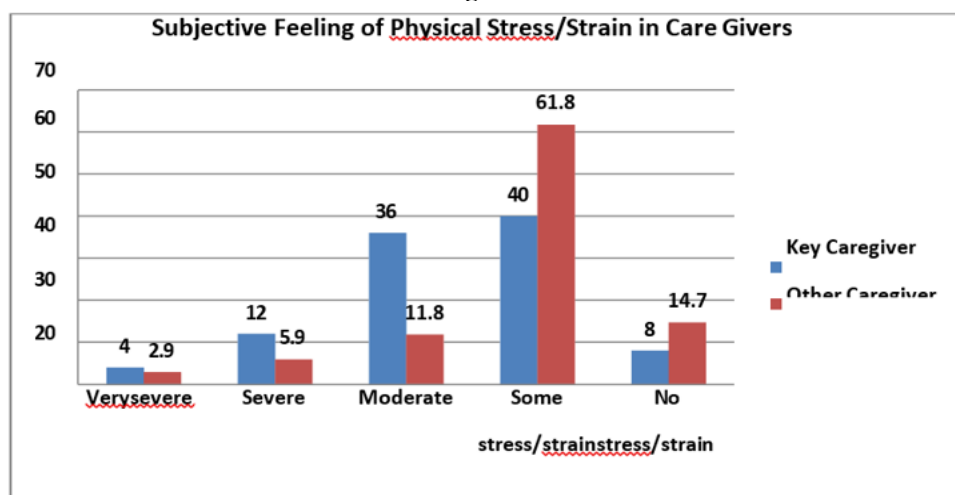
Table XI: Subjective Feeling of Physical Stress/Strain in Care Givers

Severity of physical stress and strain	Key Caregiver		Other Caregivers	
	N	%	N	%
Very severe	1	4	1	2.9
Severe	3	12	2	5.9
Moderate	9	36	4	11.8
Some stress/strain	10	40	21	61.8
Nostress/strainatall	2	8	5	14.7
Total	25	100	34	99.9

Fisher'Exact p-value=0.1462(insignificant)

Table XI relates to subjective feelings about physical stress and strain amongst key and other caregivers in providing care. The majority of the key caregivers (40%) reported some stress & strain followed by reports of moderate stress and strain by (36%). The (12%) of the key care givers reported severe stress and strain in care giving. Amongst the other caregivers, majority (61.8%) reported some stress and strain, followed by no stress and strain at all (14.7%) and moderate stress and strain (11.8%). The proportions of type of caregivers in different levels of feeling of Physical Stress/Strain was found to be insignificant (p =0.1462). A graphical presentation of the data is shown in Figure-2

Figure -2



TableXII: Psychological Status and Subjective Well Being amongst Caregivers (PGWB Schedule)
(Percentages are given in parentheses)

Groups	Key Caregiver					Total	Other Caregiver					Total
	NS	Mild	Mod	Severe	Pro		NS	Mild	Mod	Severe	Pro	
Anxiety	18 (72)	05 (20)	02 (08)	00 (0.0)	00 (0.0)	25	30 (88.2)	03 (8.9)	01 (2.9)	00 (0.0)	00 (0.0)	34
Depressive mood	08 (32)	10 (40)	05 (20)	01 (04)	01 (04)	25	24 (70.5)	07 (20.5)	03 (8.9)	00 (0.0)	00 (0.0)	34
Groups	Very good	Good	Normal/ average	Poor	Very poor		Very good	Good	Normal/ average	Poor	Very poor	
Positive well-being	03 (12)	03 (12)	05 (20)	09 (36)	05 (20)	25	15 (44.2)	09 (26.5)	07 (20.5)	01 (2.9)	02 (5.9)	34
SelfControl	09 (36)	07 (28)	05 (20)	03 (12)	01 (4)	25	21 (61.8)	09 (26.4)	03 (8.8)	00 (0.0)	01 (2.9)	34
General Health	02 (8)	11 (44)	08 (32)	04 (16)	00 (0.0)	25	10 (29.4)	19 (55.9)	05 (14.7)	00 (0.0)	00 (0.0)	34
Vitality	03 (12)	05 (20)	06 (24)	10 (40)	01 (4)	25	8 (23.5)	13 (38.2)	12 (35.2)	01 (2.9)	00 (0.0)	34

Psychological General Well Being Schedule was administered to assess domains as shown in table XII. PGWB schedule is a twenty two item schedule, each item having six questions. Each question has a rating from five to zero or zero to five depending upon the nature of the item. In case of items of anxiety and depressed mood, lowest score indicate maximum anxiety and depression and vice versa. In case of positive wellbeing, self control, general health and vitality, lowest score indicate minimum of these and vice versa. With this background, severity of item was arbitrarily categorized into non significant, mild, moderate, severe and profound. Description of individual domains is being provided in following tables and text.

Table XHa: Anxiety amongst Caregivers

Severity of problem	Keycaregivers		Other caregivers	
	N	%	N	%
NonSignificant	18	72	30	
Mild	05	20	03	8.9
Moderate	02	08	01	2.9
Severe	00	00	00	0.0
Profound	00	00	00	0.0

Fisher'Exact p-value = 0.2806 (insignificant)

Amongst the individual domains, the level of experienced anxiety in key and other caregivers is shown in table Xlla. The majority of the key caregivers (72%) felt non significant severity of anxiety, followed by mild (20%) and moderate anxiety (08%). Similarly, in the group of other caregivers, majority (91.2%) reported non significant anxiety, followed by mild (8.9%) and moderate (2.9 %). Statistically there was no significant association between type of caregivers and their anxiety levels. Figure -10a shows feeling of anxiety in the form of bar diagram.

Table XII b: Depression amongst Caregivers

Severity of problem	Keycare givers		Other caregivers	
	N	%	N	%
Non Significant	08	32	24	70.5
Mild	10	40	07	20.5
Moderate	05	20	03	8.9
Severe	01	04	00	00
Profound	01	04	00	00

Fisher'sExactp-value=0.0208(significant)

Table XII.b deals with the domain of feelings of depression as per PGWB schedule amongst key and other caregivers. Majority of the key caregivers (40%) reported mild, followed by moderate (20%), severe and profound (04% each) depression. 32% key caregivers reported non significant depression. On the contrary, in the group of other care givers majority reported experiencing non significant (70.5%), followed by mild (20.5%) and moderate (8.9%) depression. Statistically there was an association between the type of caregivers and their depressive mood i.e, the proportions of different caregivers in different levels of depression were significantly different (p=0.0208). The graphical presentation of the data is shown in Figure-10b.

Table XIIc: Positive Well Being amongst Caregivers

Positivewellbeing	Key care givers		Othercaregivers	
	N	%	N	%
Verygood	3	12	15	44.2
Good	3	12	09	26.5
Normal/Average	5	20	07	20.5
Poor	9	36	1	2.9
Verypoor	5	20	2	5.9

Fisher'sExactp-value=0.0008(significant)

Table XIIc reveal feelings of positive well being amongst key and other caregivers. Majority of the key caregivers had poor level of positive well being (36%), followed by very poor and average (20% each). Three key care givers reported good positive well being and three very good. In other caregivers, majority had very good positive well being (44.2%) followed by good (26.5%) and average (20.5%). Only one other care giver reported poor positive well being and two very poor. Statistically, there was an association between type of caregivers and positive well being i.e, the proportions of different caregivers in different levels of positive well being were significantly different (p=0.0008).

Table XII d: Self Control Amongst Caregivers

Self control	Key care givers		Othercare givers	
	N	%	N	%
Very good	9	36	21	61.8
Good	7	28	9	26.5

Normal/average	5	20	3	8.8
Poor	3	12	0	0.0
Very poor	1	4	1	2.9

Fisher'sExact p-value=.0917(insignificant)

Assessment of one of the parameters of PGWB schedule, self control is presented in table XIId. Majority of the key caregivers (36%) had very good self control followed by good (28%), average (20%) and poor (12%) self control; only one of the key care giver reported very poor self control. Amongst the other caregivers, majority had very good (61.8%) followed by good (26.5%) and average (8.8%) self control. Only one other care giver reported very poor self control. Statistically there was no association between type of caregivers and their self control level i.e, the proportions of different caregivers in different levels of Self Control were insignificantly different (p=0.0917).

Table XIe: General Health amongst Caregivers

Severity of problem	Keycaregivers		Other caregivers	
	N	%	N	%
Verygood	2	8	10	29.4
Good	11	44	19	55.9
Normal/Average	8	32	5	14.7
Poor	4	16	0	0.0
Verypoor	0	0	0	0.0

Fisher'sExactp-value=0.0093(significant)

Table XIe shows distribution of general health parameters of PGWB schedule amongst key and other caregivers. The majority of the key caregivers had good (44%) followed by average (32%), and poor (16%) level of general health. Amongst, other caregivers majority had good (55.9%), followed by very good (29.4%) and average (14.7%) level of general health. Statistically, there was an association between type of caregivers and their general health level i.e, the proportions of different caregivers in different levels of general health were significantly different (p=0.0093).

Table XIIf: Vitality amongst Caregivers

Severityof problem	Key care givers		Other care givers	
	N	%	N	%
Very good	3	12	8	23.5
Good	5	20	13	38.2
Normal/Average	6	24	12	35.3
Poor	10	40	1	2.9
Very poor	1	4	0	0.0

Fisher'sExactp-value=0.0026 (significant)

Table XIIf gives the details of vitality according to PGWB schedule amongst key and other caregivers. The majority of the key caregivers had poor (40%), followed by average (24%) and good (20%) level of vitality. Amongst the other caregivers majority had good (38.2%), followed by average (35.3%) and very good (23.5%) level of vitality. Statistically, there was a dependency between type of caregivers and their vitality level i.e, the proportions of different caregivers in different levels of vitality were significantly different(p=0.0026).

Table XIII: Psychiatric Morbidity amongst Caregivers(Gold standard interview)

Descriptions	Key Caregiver		Other Caregivers	
	N	%	N	%
No problem at all	0	0	21	61.8
Sub-syndromal problems	5	20	4	11.8
Depressive Disorders	13	52	7	20.6
Anxiety Disorders	2	8	1	2.9
Mixed Anxiety Depression	4	16	0	0
Reaction to severe stress & adjustment disorders	1	4	1	2.9
Total	25	100	34	100

Fisher's Exact p-value=0.000 (significant)

Table XIII shows the distribution of psychiatric morbidity amongst key and other caregivers. Majority of the key caregivers were diagnosed as suffering from depression (52%) followed by sub syndromal problems (20%) and Mixed Anxiety Depression (16%). Amongst the other caregivers majority had no problem at all (61.8%) followed by Depressive Disorders (20.6%) and sub syndromal problems (11.8 %). Statistically there was an association between type of caregivers and their anxiety level i.e, the proportions of different caregivers in different levels of anxiety were significantly different (p=0.000).

Table XIV: Severity of Depression(asper HAM-D) amongst Caregivers

Hamilton Scale for Depression	Key Caregiver (N=25)		Other Caregiver (N=34)	
	N	%	N	%
Mild	7	53.8	5	71.4
Moderate	4	30.8	2	28.6
Severe	2	15.4	0	00

Fisher's Exact p-value=0.8084 (insignificant)

Table XIV shows distribution of severity of depression [HAM-D] amongst key and other caregivers. The majority of the key caregivers had mild (53.8%) followed by moderate (30.8%) level of depression. Only two (15.4%) of the key care givers had severe level of depression. Amongst the other caregivers (71.4%) had mild and (28.6%) had moderate level of depression. Statistically there was independency between type of caregivers and their severity of depression i.e, the proportions of different caregivers in different levels of anxiety were insignificantly different (p=0.8084).

Two instruments were used to evaluate burden on caregivers and their families. The Burden Assessment Schedule was used to evaluate overall burden on individual caregivers, while Family Burden Assessment Schedule was used to assess overall burden on the families and burden in specific domains.

Table XV: Burden evaluated by Burden Assessment Schedule amongst Caregivers

Burden Assessment Schedule	Key Caregivers		Other Caregiver	
	N	%	N	%
No Burden	00	00	02	5.8
Moderate Burden	09	36	29	85.4
Severe Burden	16	64	03	8.8
Total	25	100	34	100

Fisher's Exact p-value=0.000(significant)

Table XV shows distribution of overall burden (psychosocial stress) as per Burden Assessment Schedule amongst key and other caregivers. The majority of the key caregivers reported experiencing severe level of burden (64%) followed by moderate level of burden (36%). Amongst the other care givers, majority reported moderate level of burden (85.4%) followed by severe burden (8.8%). Two (5.8%) of the other care givers reported experiencing no burden. Statistically there was dependency between type of caregivers and their burden evaluated by Burden Assessment Schedule i.e, the proportions of different caregivers in different levels of anxiety were significantly different ($p=.0000$).

For studying overall burden on the families and burden in specific domains, only care givers were interviewed on Family Burden Assessment Schedule. The observations have been presented in Table XV.

Table XVI: Burden as evaluated by Family Burden Assessment Schedule (Percentages are Given in Parentheses)

Family Burden	Overall Burden	Financial	Family Routine Activities	Family Leisure Time	Family Interaction	Mental Health	Physical Health
No Burden	01 (04)	02 (08)	01 (04)	01 (04)	02 (08)	05 (20)	20 (80)
Moderate Burden	17 (68)	15 (60)	18 (72)	15 (60)	19 (76)	09 (36)	05 (20)
Severe Burden	07 (28)	08 (32)	06 (24)	09 (36)	04 (16)	11 (44)	00 (00)
Total	25 (100)	25 (100)	25 (100)	25 (100)	25 (100)	25 (100)	25 (100)

It is evident from table XVI that majority of the families of dementia patients reported overall moderately burdened (68%), followed by severely burdened (28%). Only one (04%) of the care givers reported that his family is not at all burdened. In different domains of life majority felt moderate level of burden followed by severe level of burden. Majority felt severe level of burden in the areas of mental health followed by family leisure time (36%), financial (32%), family routine activities (24%) and family interaction (16%). None of the key care giver reported severe level of burden in physical health. Extensive moderate level of burden was reported in the areas of family interaction (76%) followed by family routine activities (72%), financial and family leisure time (60% each), mental (36%) and physical (20%) health.

Figure -2

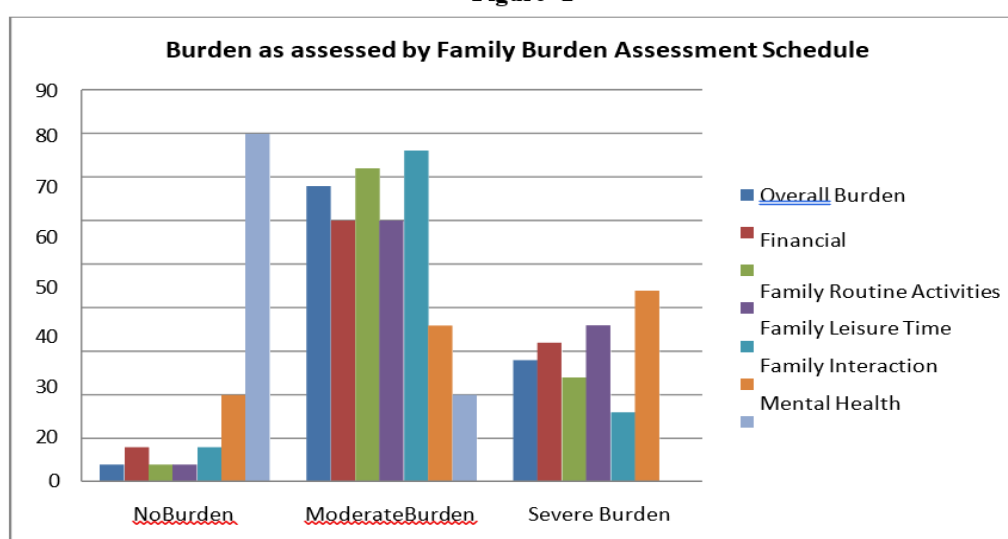


Table XVII: Quality of Life of Care Givers(WHOQOL-BREF)

Domains			Quality of life					Fisher's Exactp-values
			Very Poor	Poor	Average	Good	Very Good	
Physical Health	Key caregiver	Number	0	2	13	10	0	0.0005 (significant)
		Percentages	0	8	52	40	0	
	Other caregivers	Number	0	2	5	24	3	
		Percentages	0	5.9	14.7	70.6	8.8	
Psychological health	Key caregiver	Number	0	2	14	8	1	0.0001 (significant)
		Percentages	0	8	56	32	4	
	Other caregivers	Number	0	0	4	26	4	
		Percentages	0	0	11.8	76.4	11.8	
Social relationship	Key caregiver	Number	1	6	12	5	1	0.175 (insignificant)
		Percentages	4	24	48	20	4	
	Other caregivers	Number	0	2	19	11	2	
		Percentages	0	5.9	55.9	32.3	5.9	
Environment	Key caregiver	Number	0	0	13	12	0	0.0282 (significant)
		Percentages	0	0	52	48	0	
	Other caregivers	Number	0	1	7	24	2	
		Percentages	0	2.9	20.6	70.6	5.9	

Table XVII gives the overall view about quality of life of key and other caregivers in relation to different domains of WHOQOL-BREF scale i.e.- physical health, psychological health, social relationship and environment. In the domain of physical health majority of key caregivers reported average quality of physical health (52%) followed by good quality of physical health (40%). On the contrary, amongst other caregivers majority reported good physical health (70.6%) followed by average (14.7%) quality of physical health. Statistically there was an association between type of caregivers and domains namely physical health, psychological health, environment i.e, the proportions of different caregivers in different levels of said domains were significantly different ($p=0.0005, p=0.0001, p=0.0282$ respectively) while there was independency between type of caregivers and environment factor i.e, the proportions of different caregivers in different levels of environment factor were insignificantly different ($p=0.175$). A graphical presentation of the data is shown in Figure -15. a below.

Table XVII further reveals that the majority of key care givers had average psychological health (56%) followed by good (32%). Amongst the other care givers majority had good (76.4%) psychological health followed by average and very good (11.8%) each. Statistically psychological health difference is significant ($p= 0.0001$)

The distribution of social relationships [WHOQOL-BREF] amongst key and other caregivers is also seen in table XVII. The majority of the key caregivers had average social relationships (48%) followed by poor (24%) and good (20%). Amongst the other caregivers majority had average (55.9%) followed by good (32.3%) social relationship. Statistically social relationship difference is insignificant ($p= 0.175$)

Table XVII also reveals the distribution of perception about overall environment (external milieu) (WHOQOL-BREF) amongst key and other caregivers. The majority of key caregivers had average (52%) followed by good (48%) perception of environment. Amongst the other caregivers majority had good (70.6%) followed by average (20.6%) perception of the environment. Statistically the difference is insignificant ($p= 0.0282$).

Caregivers	Psychiatric problems	Severity of dementia			Fisher's Exact p-values
		Mild	Moderate	Severe	
Key Caregivers	No Problem	0 (0.0)	0 (0.0)	0 (0.0)	0.8123 (insignificant)
	SubSyndromal problem	1 (04)	2 (08)	1 (04)	
	Depressive disorder	1 (04)	7 (28)	5	
	Anxiety	0	1 (04)	1 (04)	
	Mixed anxiety	1 (04)	1 (04)	0 (0.0)	
	Reaction to severe stress and adjustment Disorder	0 (0.0)	1 (04)	0 (0.0)	
Other Caregivers	No Problem	1 (2.9)	15 (44.2)	2 (5.8)	0.000 (significant)
	SubSyndromal problem	0 (0.0)	1 (2.9)	3 (8.9)	
	Depressive disorder	0 (0.0)	0 (0.0)	6 (17.6)	
	Reaction to severe stress and adjustment Disorder	0 (0.0)	0 (0.0)	1 (2.9)	

Table —XVIII is about the relationship between severity of dementia and psychiatric morbidity between key and other caregivers. From the above it is concluded that there is no relationship between key caregiver and severity of dementia while there was no relationship between other caregivers and severity of dementia in patients.

Table-XIX: Relationship between Overall Burden(Tharaetal,1998)in care givers and severity of dementia (percentages in parenthesis)

Caregivers	Overall burden on individual caregivers	Severity of dementia			Fisher's Exact p-value
		Mild	Moderate	Severe	
Key Caregivers	No burden	0 (0.0)	0 (0.0)	0 (0.0)	0.5068 (insignificant)
	Moderate burden	2 (08)	5 (20)	2 (08)	
	Severe burden	1 (04)	7 (28)	5 (20)	
Other Caregivers	No burden	0 (0.0)	0 (0.0)	0 (0.0)	0.6059 (insignificant)
	Moderate burden	1 (2.9)	15 (44.2)	10 (29)	
	Severe burden	0 (0.0)	1 (2.9)	2 (5.8)	

Table -XX : Relationship between Overall Family Burden (Pai and Kapur , 1981) and severity of dementia (percentages in parenthesis)

Caregivers	Overall	Severity of Dementia			Fisher's Exact p-value
		Mild	Moderate	Severe	
Key Caregivers	NoBurden	0 (0.0)	0 (0.0)	1 (04)	0.4943 (insignificant)
	MildBurden	2 (08)	10 (40)	4 (16)	
	SevereBurden	1 (04)	2 (08)	2 (08)	

Table —XX reports relationship between overall family burden and severity of dementia. Statistically it was found to be insignificant (p=0.4943).

Table-XXI: Relation between Physical Health of caregivers(WHOQOL-BREF) and Severity of Dementia (percentages in parenthesis)

Caregivers	Physical Health	Severity of Dementia			Fisher's Exact p-value
		Mild	Moderate	Severe	
Key Caregivers	Poor	0 (0.0)	1 (04)	1 (04)	0.805 (insignificant)
	Average	1 (04)	7 (28)	3 (12)	
	Good	2 (08)	4 (16)	3 (12)	
Other Caregivers	Poor	0 (0.0)	1 (2.9)	1 (2.9)	0.4591 (insignificant)
	Average	0 (0.0)	3 (8.8)	0 (0.0)	
	Good	1 (2.9)	11 (32.3)	11 (32.3)	
	Very Good	0 (0.0)	1 (2.9)	0 (0.0)	

Table-XXII: Relation between Psychological Health of caregivers(WHOQOL- BREF) and Severity of dementia (percentages in parenthesis)

Caregivers	Psychological Health	Severity of Dementia			Fisher's Exact p- value
		Mild	Moderate	Severe	
Key Caregivers	Poor	0 (0.0)	0 (0.0)	1 (04)	0.4451 (insignificant)
	Average	1 (04)	8 (32)	3 (12)	
	Good	2 (08)	4 (16)	2 (08)	
	<u>VeryGood</u>	0 (0.0)	0 (0.0)	1 (04)	
Other Caregivers	Average	0 (0.0)	2 (5.8)	1(2.9)	0.1524 (insignificant)
	Good	0 (0.0)	13 (38.2)	11 (32.3)	
	<u>VeryGood</u>	1 (2.9)	1 (2.9)	0 (0.0)	

Table—XXIII: Relation between Social Relationship of caregivers(WHOQOL- BREF) and Severity of dementia (percentages in parenthesis)

Caregivers	Social Relationship	Severity of Dementia			Fisher's Exact p-value
		mild	moderate	severe	
Key Caregivers	Very poor	0 (0.0)	1 (04)	0 (0.0)	0.1268 (insignificant)
	Poor	1 (04)	3 (12)	0 (0.0)	
	Average	0 (0.0)	7 (28)	4 (16)	
	Good	2 (08)	1 (04)	2 (08)	
	Very Good	0 (0.0)	0 (0.0)	1 (04)	
Other Caregivers	Poor	0 (0.0)	1 (2.9)	1 (2.9)	0.6799 (insignificant)
	Average	0 (0.0)	11 (32.3)	7 (20.5)	
	Good	1 (2.9)	3 (8.9)	3 (8.9)	
	Very Good	0 (0.0)	1 (2.9)	1 (2.9)	

Table-XXIV: Relation between Environment of caregivers(WHOQOL-BREF) and severity of dementia (percentages in parenthesis)

Caregivers	Environment	Severity of Dementia			Fisher's Exact p-value
		mild	moderate	severe	
Key Caregivers	Poor	1 (04)	6 (24)	4 (16)	1.0 (insignificant)
	Average	2 (08)	6 (24)	3 (12)	
Other Caregivers	Poor	0 (0.0)	1 (2.9)	0 (0.0)	0.8601 (insignificant)
	Average	0 (0.0)	3 (8.9)	4 (11.7)	
	Good	1 (2.9)	12 (35.2)	8 (23.5)	

On the Burden Assessment Schedule, 64% of key caregivers had severe burden versus 85.4% of other caregivers with moderate burden. Family burden was mostly moderate, particularly affecting mental health, family interaction, leisure time, and finances. PGWB scores showed key caregivers had poorer positive well-being, vitality, and general health, and more depressive mood ($p < 0.05$), while anxiety levels were similar. Psychiatric morbidity was higher in key caregivers, with 52% having depressive disorders compared to 20.6% in others. HAM-D scores indicated mild to moderate depression in both groups.

WHOQOL-BREF scores revealed significantly lower physical and psychological health in key caregivers, though social relationships did not differ. There was no significant association between dementia severity and caregiver psychiatric morbidity, burden, or quality-of-life domains. Overall, key caregivers bore a greater psychological, physical, and time-related burden than other caregivers, with higher depression rates and lower quality of life.

DISCUSSION

In this study, caregivers of dementia patients—particularly key caregivers—demonstrated significantly elevated levels of burden, psychiatric morbidity, and compromised quality of life compared to other caregivers.

These findings resonate with existing literature, which highlights that caregiver burden often encompasses emotional, physical, and financial domains, frequently leading to anxiety, depression, and burnout. Family caregivers, who typically provide care in home-based settings, are known to experience significant emotional and physical challenges, sometimes neglecting their own health and facing social isolation [11]. The mental health impact on caregivers is particularly concerning, as increased caregiver stress has been linked to adverse outcomes for the patients under their care [12]. Studies employing instruments like the Zarit Burden Interview and Self-Reporting Questionnaire have similarly documented high rates of caregiver distress and psychiatric symptoms [13]. Research from Singapore also found that caregiver burden and distress correlate with increased healthcare utilization in persons with dementia, suggesting that caregiver well-being directly affects care trajectories [14]. Moreover, burden severity is influenced by both objective factors—such as patient neuropsychiatric symptoms and caregiving duration—and subjective factors including caregiver coping capacity, relationship stress, and perceived social support [15]. Interventions that combine psychoeducational strategies, support networks, and empowerment initiatives have shown promise in reducing burden and improving mental health outcomes [16]. Emerging technological solutions and AI-supported tools offer potential avenues for delivering scalable, personalized support to caregivers, particularly those navigating prolonged caregiving journeys [17]. Broader public health data indicate that caregivers—especially in midlife—face worse health outcomes, including higher rates of mental distress, chronic conditions, and reduced self-care practices [18]. Given that unpaid caregiving has broader societal and economic consequences—sometimes delaying caregivers' retirement and impacting financial health—policymakers must consider the holistic value of caregiving and support needed to sustain it [19]. Furthermore, preparing caregivers through early training, respite services, and accessible interventions can preserve caregiver well-being and reduce associated morbidity [20].

CONCLUSION

In conclusion, this study highlights that key caregivers of dementia patients bear a substantially higher psychological, physical, and time-related burden than other caregivers, with significantly greater rates of depressive disorders, poorer quality of life, and reduced well-being. While both groups experience varying levels of stress and disruption to family life, key caregivers—often spouses or immediate family members—are more vulnerable to psychiatric morbidity and diminished vitality due to the intensive and prolonged nature of care provision. These findings underscore the urgent need for targeted interventions, including psychosocial support, caregiver training, respite services, and mental health screening, to mitigate the adverse effects of caregiving and enhance both caregiver and patient outcomes.

DECLARATIONS:

Conflicts of interest: There is no any conflict of interest associated with this study

Consent to participate: There is consent to participate.

Consent for publication: There is consent for the publication of this paper.

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REFERENCES

1. World Health Organization. Global status report on the public health response to dementia. Geneva: World Health Organization; 2023. 97 p.
2. Alzheimer's Disease International. Dementia in low- and middle-income countries: 2024 update. London: Alzheimer's Disease International; 2024. 54 p.
3. Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. Dementia prevention, intervention, and care: 2024 report of the Lancet Commission. *Lancet*. 2024;403(10430):1235-90.

4. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. *Front Neurol*. 2024;15:1356724. doi:10.3389/fneur.2024.1356724.
5. Shaji KS, Jotheeswaran AT, Girish N, Srikala B. Caregiving for dementia: The Indian perspective. *Indian J Psychiatry*. 2024;66(1):15-26. doi:10.4103/indianjpsychiatry.indianjpsychiatry_426_23.
6. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: A review of the literature. *J Am Assoc Nurse Pract*. 2024;36(4):187-95. doi:10.1097/JXX.0000000000000875.
7. Ma M, Li W, Tang C, Sun Y, Zhang Y, Chen L, et al. Mental health outcomes in informal dementia caregivers: A meta-analysis. *J Affect Disord*. 2025;370:59-70. doi:10.1016/j.jad.2024.12.067.
8. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull*. 2024;150(2):215-46. doi:10.1037/bul0000408.
9. Banerjee S, Dutta A, Mukherjee D. Impact of caregiving on quality of life and psychiatric morbidity in dementia caregivers in India. *Int Psychogeriatr*. 2024;36(5):421-30. doi:10.1017/S1041610223001855.
10. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2024;26(2):123-35. doi:10.31887/DCNS.2024.26.2/hbrodaty
11. Shi JM, Yoo DW, Wang K, Rodriguez VJ, Karkar R, Saha K. Mapping Caregiver Needs to AI Chatbot Design: Strengths and Gaps in Mental Health Support for Alzheimer's and Dementia Caregivers. *arXiv [Internet]*. 2025 Jun 18; preprint. Available from: arXiv:2506.15047
12. Lau JH, Abdin E, Jeyagurunathan A, Seow E, Ng LL, Vaingankar JA, Chong SA, Subramaniam M. The association between caregiver burden, distress, psychiatric morbidity and healthcare utilization among persons with dementia in Singapore. *BMC Geriatr*. 2021;21:67.
13. Scientific Archives. Much is Known about Caregiver Burden in Dementia: What Is Next? *Sci Arch [Internet]*. [cited 2025]. Available from: <https://www.scientificarchives.com/article/much-is-known-about-caregiver-burden-in-dementia-what-is-next-the-role-of-comorb-idities-and-future-perspectives>
14. Centers for Disease Control and Prevention (CDC). Changes in Health Indicators Among Caregivers — United States, 2015–2016 to 2021–2022. *MMWR Morb Mortal Wkly Rep*. 2024;73(34):741–746.
15. MarketWatch. Unpaid caregiving can delay your retirement by as much as 21 years. *MarketWatch [Internet]*. 2024 [cited 2025]. Available from: <https://www.marketwatch.com/story/unpaid-caregiving-can-delay-your-retirement-by-as-much-as-21-years-7af97796>
16. Nature. Empowering Alzheimer's caregivers with conversational AI. *Nat Aging*. 2024;4(8):830–832.
17. Verywell Mind. Everything You Need to Know About Alzheimer's Disease as a Caregiver, According to Experts. *Verywell Mind [Internet]*. 2025 Feb 21 [cited 2025]. Available from: <https://www.verywellmind.com/what-you-need-to-know-about-alzheimers-disease-as-a-caregiver-8783366>
18. ScienceDirect. Caregiver burden—A critical discussion. *J Psychosom Res*. 2013;74(2):300–306. (Stress theory and role theory as frameworks.)
19. Health.com. More People Will Become 'Sandwich Carers' in the Coming Years—And It Could Take a Toll on Their Health. *Health.com [Internet]*. 2025 [cited 2025]. Available from: <https://www.health.com/sandwich-carer-mental-physical-health-effects-8772305>
20. Scientific Archives (as already in #3). For full distinct 10-source listing, we can also include Dementia Caregiver Burden Research Update, an older but comprehensive review: