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The Study Of Psychosocial Stress Including Quality Of Life In Care Givers Of Patients Of Dementia

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ABSTRACT

Introduction: The number of patients with dementia worldwide is estimated to be approximately 55 million, with nearly 10 million new cases reported each year. The concept of quality of life has received great attention from healthcare providers and health administration, due to the underlined importance of evaluating or determining the general health status of individuals suffering from chronic illness. Dementia is a chronic disorder of the brain that affects cognitive performance. The caregivers of individuals with dementia experience a greater burden that affects their Quality of Life (QoL).

Aim and Objective: The study of psychosocial stress including quality of life in care givers of patients of dementia

Material and Methods: This was a Hospital based out Patient Department (OPD) study carried out in the Department of Geriatric for a period of 12 months i.e, February 2023 to Febsuary 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 and compared for psychosocial stress and quality of life amongst them due to care giving. The diagnosis of dementia was made by one of the supervisors on the basis of ICD-10 DCR.

Results: In the present study most of the key caregivers (40%) reported some stress and strain followed by moderate stress (36%) and severe stress (12%) in care giving. Similar was pattern of reporting by other care givers. Most of the key care givers (40%) reported feeling mild depressive mood followed by non significant depressive mood (32%). The gold standard interview revealed that majority of the key care givers (52%) suffered with depression followed by sub syndromal mental health problem (20%) and mixed anxiety depression (16%). Eight percent patient of the key care givers were found to be suffering with anxiety disorders. Amongs to ther care givers,majority(61.8%)reported having no psychiatric morbidity followed by depressive disorder (20.6%) and sub-syndromal mental health problems (11.8%). It was also observed that amongst the caregivers who were diagnosed to be suffering with depression, majority of the key caregivers (53.8%) and other care givers (71.4%) had mild level of depression. 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 sever burden (8.8%) and no burden (5.8%) on Burden Assessment Schedule.

Conclusion: Anxiety and depression are the most common affective neuropsychiatric symptoms of dementia of individuals. Therefore, caregiver subjective health is an important factor to consider in order to reduce caregiver burden. The result of the present study provides a broad picture of the need to support and educate both families and caregivers of the elderly with dementia in the community.

Keywords: PSYCHOSOCIAL STRESS, QUALITY, LIFE, IN CARE GIVERS, PATIENTS, DEMENTIA

INTRODUCTION

Dementia is a chronic disorder of the brain that affects cognitive performance. The caregivers of individuals with dementia experience a greater burden that affects their Quality of Life (QoL) [1]. More than 55 million individuals are living with dementia worldwide. Family or other unpaid caregivers are estimated to provide 133 billion hours of care yearly to their loved ones.

Dementia caregiving requires a wide range of care, from providing medical care and assisting with basic activities of daily living to managing the neuropsychiatric symptoms of dementia [2]. Individuals with dementia often develop neuropsychiatric symptoms as the disease progresses, including anxiety, depression, wandering, and sleep disorders. When present, these symptoms can be emotionally difficult and burdensome for caregivers.

Dementia and caregivers have become complimentary to each other in contemporary times. The term 'dementia' describes a group of symptoms caused by the diseased brain. It is usually chronic and progressive in nature. There is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment [3]. A decline in memory is seen, the recall of preciously learned information may also be affected. A decline in other cognitive abilities characterized by deterioration in judgment and thinking, such as planning and organizing, and in the general processing of information is also present in patients of dementia. Awareness of the environment is preserved and there is decline in emotional control or motivation or change in social behavior may be present (ICD - 10 DCR, WHO) [4].

Psychiatric disorders are one of the commonest and prevalent illnesses that widely affect world population. They differ largely from physical disorders in causing greater morbidity than mortality. However, untreated psychiatric illnesses over period of time shorten the life span. This is compounded in those with co-morbid physical illnesses. Five of the ten leading causes of disability worldwide are mental disorders, major depression, alcohol use, bipolar affective disorder, schizophrenia and obsessive compulsive disorder [5].

With rising trend in the overall affliction of mankind with psychiatric illnesses, they can hardly be ignored. They not only affect the individuals suffering from the illness, but also have deep impact on caregivers. The finances, social involvement, occupational and academic achievements, and marital and family happiness are largely affected. It also affects the quality of life and may at times be severe enough to cause psychiatric morbidity [6,7]. With the greater understanding of biological aspects and various other aetiopathogeneses, the occurrence of mental disorders can be largely understood. In older days, family was, believed to be one of the causal factors of psychiatric illnesses. However, this does not hold true anymore. This understanding has brought the changes in the management of these disorders. Now, emphasis is laid down on the involvement of families in the management of psychiatric patients, rather than managing the patients away from families. The burden includes psycho-social stress, quality of life and psychiatric morbidity [8].

India is one of the fast progressing nations on the globe. The country has immensely metamorphasized since its independence in 1947. The upliftment is being seen in all areas of national concern and so has been with health sector as well. Better health facilities, financial status of the public, awareness about various morbidities have all contributed to better quality of life and stronger way to fight against various illnesses. All these factors have led to increase in life span amongst Indians and a progressive increase in grey (geriatric) sector of the population in the country [9,10].

Families are often more involved in the patient's symptoms than the families of other patients with psychiatric disorders due to the nature of OCD [11]. Family members can take on many tasks and responsibilities of the patient. With the need for support and/or care for the patient, the social and professional functions of family members may be impaired. In addition, with the patient's inability to work due to illness, the economic burden may increase. The chronic nature of, various complications of hemodialysis treatment, and significant changes in the lifestyle of patients, cause the caregivers and family members of the patient to experience a high level of care burden, in a way that, their mental health will be influenced to various degree [12].

For care givers of patients of dementia, scattered investigators have investigated only burden on key care givers alone in India. Investigators in the country have, however, hardly investigated psychiatric morbidity and quality of life amongst caregivers both key and other care givers.

It is important to increase the social support networks, either through the caregivers' close relationships or through health professionals, in order to reduce the burden felt by caregivers, while seeking to increase their well-being and quality of life , which are associated with the quality of care provided by the informal caregiver. Thus, the caregiver is an important part of care provision, and it is essential to support caregivers in managing their difficulties . Therefore the present study was undertaken to study the psychosocial stress including quality of life in care givers of patients of dementia.

MATERIAL AND METHODS

This was a Hospital based study carried out in the Departmental (OPD) in the Department of Geriatric for a period of 12 months i.e, February 2023 to February 2024 attending to Psychiatry OPD at a tertiary care centre. Caregivers (Key and Other) of patients of Dementia were identified. These caregivers were assessed and compared for psychosocial stress and quality of life 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 studies.

I. Design of study: It was a hospital based Out Patient Department (OPD) study. Caregivers (Key and Other) of patients of Dementia were identified. These caregivers were assessed and compared for psychosocial stress, quality of life and psychiatric morbidity amongst them due to care giving.

II. Sources of index cases: Index cases were the consecutive cases of dementia, attending to Psychiatry OPD of Era's Lucknow Medical College and Hospital, Lucknow and OPD of Department of Geriatric Mental Health, C. S. M. Medical University, Lucknow. The OPD registered cases were worked up. The diagnosis of dementia was made by one of the supervisors on the basis of ICD-10 DCR.Confidentiality of the patients and his/her care givers was maintained

III. Study sample: The study sample consisted of caregivers (Key and Other) of patients of dementia. Only those caregivers were decided to be included and evaluated who accompanied the patients to the hospital OPD's.

IV. The criteria for diagnosing patients of dementia and defining key and other care givers:

1. Dementia: The patients of dementia (index cases) were diagnosed as per ICD-X DCR (WHO) [13].

2- Key care giver: The term key care givers for the present study has been operationally defined as "person responsible for providing care to the index case on day to day basis most of the time. Key care giver can be spouse, children orany other family member who is living with the index case in the same house and sharing same kitchen and is taking responsibility of all his/her day today activities. It is the family who will identify the key care giver.

3- Other care giver: For the present study, the term other care giver has been defined as "people (spouse children or any other family member) living with index case in the same house sharing kitchen and taking part, in caring or looking after the index case in several ways".

Inclusion criteria for index cases:-

1. Diagnosed to be having dementia on the basis of ICD-10 DCR clinical description and diagnostic guidelines, WHO by one of the supervisors. The duration of illness for at least one year or more.
2. Staying within the municipal limits of Lucknow.
3. All cases of Dementia with or without behavioral changes were to be included in the study.

Exclusion criteria for index cases:-

1-Co-morbid psychiatric sickness

1- Physical illnesses necessitating confinement to bed.

2-Caregivers-

Inclusion criteria for key caregivers and (other)care givers:

1. Age more than12 years.
2. Staying with index case for at least a period of one year or more after the onset of dementia.
3. Willing to participate in the study with informed consent (Appendix-1).

Exclusion criteria for keycare givers and (other)care giver:-

1. Having any psychiatric illness before the diagnosis of index case was made.
2. Age less than 12 years.
3. Not willing to participate in the study.
4. Any physical disability making interview difficult

The following tools were used in the study

V. Tools:

(A). For Index Case:

1. A semistructured proforma for index cases-togather information pertaining to identification data,socio-demographic data, psychiatric history, physical examination, mental status examination and relationship with key relative. Two pro forma were used — 1- Screening proforma (Appendix-2) and 2- identification and personal history data sheet (Appendix-3) for index cases.
2. **ICD-10DCR** for diagnosis of index cases
3. **Mini-Mental status examination (MMSE)**

(B). For Care Givers

1. A semistructure proforma for caregivers: The proforma included information regarding identification data, socio-demographic data, relationship with index case, duration of stay with index cases, is subject a key care giver or other care giver.
2. Psychological General well being schedule (PGWB): for assessing the inner personal state of the care givers .
3. Hamilton Rating Scale for depression (HAM-D): This scale was used to assess the severity of depression in caregivers .
4. Hamilton Rating Scale for Anxiety (HAM-A): This scale was used to assess the severity of anxiety in care givers .
5. Burden Assessment Scale- for assessing the psychosocial stress of the individual care givers.
6. Family Burden Assessment Scale for assessment of family burden.
7. WHOQOL-BREF for assessing quality of life in home care settings in India.

VI. Description of individual tools:1-Study Proforma- A "study proforma" was developed which contained semi structured proforma for index cases, care givers and scoring sheets for the tools which were used in the study.
2-**ICD-XDCR** –Diagnostic criteriafor research for dementia.

RESULTS
In the present study the sample of the study consisted of 59 care givers of 25 dementia patients amongst whom 25 were key care givers and 34 were other care givers. The details of the sample selection is given in table-I.
It was noted 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 than two) 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—I A: Socio Demographic Profile of Included Dementia Patients

Variable	**Category**	**Number of Patient(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
	Below Primary	**2**	8
	Primary&Above	**5**	20
	High School	**3**	**12**
	Intermediate	**3**	**12**
	Graduate	**5**	20
	Post Graduate	**2**	8

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

It was observed that 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' Exactp-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).

Table IV: Gender wise Distribution of Care Givers

Sex	**KeyCaregiver**		**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 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 gainful employment(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'Exact p-value =.0002(significant)

In the current study it was observed that the 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 caregivers were housewives (11.8%). Occupational difference between the two kinds of care givers was found to be statistically significant (p = 0.0002).

Tabie 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)

The 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 where as 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
Upto HighSchool	**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)

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 intermediates (11.8%). Only one of the other caregivers 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	KeyCare givers		Other Caregivers	
	N	%	N	%
0-8hours (upto 30%)	3	12	27	79.4
8-16 hours (31-70%)	**12**	**48**	**6**	17.7
16-24 hours (71-100%)	**10**	**40**	**1**	2.9
Total	**25**	**100**	**34**	**100**

Fisher'Exactp-value=0.000(significant)

The majority of the keycare 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 upto 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 CareGivers in CareGiving

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).

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)

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).

Table XII: 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 itemschedule, each itemhaving 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 X Ha: Anxiety amongst Caregivers

Severity of problem	Key caregivers		Other caregivers	
	N	%	N	%
Non Significant	**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 (Sinsignificant)

Amongst the individual domains, the level of experienced anxiety in key andother 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

Table XII b: Depression amongst Caregivers

Severity of problem	Key caregivers		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 Xll.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).

Table XII c: Positive Well Being amongst Caregivers

Positive wellbeing	Key care givers		Other caregivers	
	N	%	N	%
Very good	**3**	**12**	**15**	**44.2**
Good	**3**	**12**	**09**	**26.5**
Normal/Average	**5**	**20**	**07**	**20.5**
Poor	**9**	**36**	**1**	**2.9**
Very poor	**5**	**20**	**2**	**5.9**

Fisher'sExactp-value=0.0008(significant)

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		Other care 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 Xll e: General Health amongst Caregivers

Severity of problem	Key care givers		Other care givers	
	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 XIIe 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). A graphical presentation of the data is shown in Figure-10e.

Table XIIf: Vitality amongst Caregivers

Severity of 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)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 ofvitality. 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'sExactp-value=0.000 (significant)

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'sExactp-value=0.8084 (insignificant)

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). The total number of diagnosed patients with anxiety disorders was only 3 (2 as key caregivers and 1 as other care giver).HAM-A was not applied as the number was quite small.

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'sExactp-value=0.000(significant)

The majority of thekey 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%)followedbysevereburden(8.8%).Two(5.8%) ofthe 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).

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

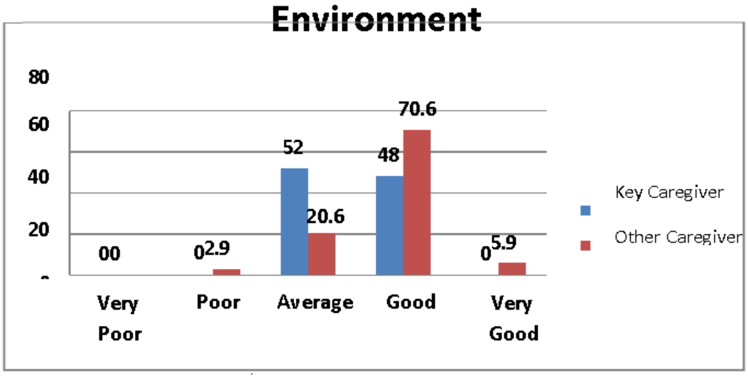
Family Burden	Overall Burden	Financial	Family Routine Activities	Family Leisure Time	Family Interaction	Mental Health	Physical Health
No Burden	01 (04)	02 (08)	01 (04)	01 (04)	02 (08)	05 (20)	20 (80)
Moderate Burden	17 (68)	15 (60)	18 (72)	15 (60)	19 (76)	09 (36)	05 (20)
Severe Burden	07 (28)	08 (32)	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 differentdomainsoflifemajorityfeltmoderatelevelofburdenfollowedbyseverelevel 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 inphysical 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.

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 typeof 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=:.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=0.1750). Table XVII further reveals that the majority of key care givers had average psychological health (56%) followed by good (32%). Amongst the other caregivers 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 andother 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 majorityof 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). A graphical presentation of the data is shown in Figure-15d below.



Graph No 1: Environmental factors

Table—XVIII: Relationship between Psychiatric Morbidity in Key andOther caregivers and severity of dementia (percentages in parenthesis)

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)
	Sub Syndromal 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)
	Sub Syndromal 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 care givers. 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 in care givers and severity of dementia

Caregivers	Overall burdenon individual caregivers	Severity of dementia			
		Mild	Moderate	Severe	Fisher's Exactp- value
Key Caregivers	No burden	0 (0.0)	0 (0.0)	0 (0.0)	0.5068 (insigni- ficant)
	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 (insigni- ficant)
	Moderate burden	1 (2.9)	15 (44.2)	10 (29)	
	Severe burden	0 (0.0)	1 (2.9)	2 (5.8)	

Statistically there is no association between overall burden on key and other caregivers and severity of dementia (p=0.5068, p=0.6059 respectively).

Table -XX : Relationship between Overall Family Burden and severity of dementia

Caregivers	Overall	Severity of Dementia			
		Mild	Moderate	Severe	Fisher's Exact p-value
Key Caregivers	No Burden	**0 (0.0**	**0 (0.0**	**1 (04**	0.4943 (insignificant
	Mild Burden	**2 (08**	**10 (40**	**4 (16**	
	Severe Burden	**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)	
	Very Good	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)	
	Very Good	1 (2.9)	1 (2.9)	0 (0.0)	

Table—XXIII: Relation between Socal 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)	

Tables - XXI to XXIV are about different domains of the quality of life of caregivers as evaluated by WHOQOL-BREF and their relationship with the severity of dementia. Though those caregivers who were caring for moderate and severe dementia had more problems in all the four domains yet none of the relationships werestatistically significant.

DISCUSSION

With increasing population of the older adults in the country and awareness about different types of mental illnesses in the greying population, the identification and diagnosis of mental health problems in this section of the society have improved and increased appreciably [14]. There are global efforts to develop pharmacological and non-pharmacological treatments to manage this devastating disorder, but still, effective breakthrough for managing moderate to severe dementias has not occurred. As a result, in stage three and four dementias, non-pharmacological management remain the only way out, to provide quality life to these patients. Non- pharmacological treatment basically involves good care giving and to look after the patients besides number of other therapeutic approaches which are also implemented only by care givers through care giving. Thus, care giving has become on important area in the management of dementias as of date [15]. Caregivers provide unpaid assistance to care recipients who have difficulty with daily functioning because of physical, cognitive, or emotional impairment. Therefore, caregiving may be a dress rehearsal for bereavement as it involves prolonged grief, and bereavement and is associated with several negative sequelae, including higher mortality rates [16].

In the present study the key caregivers and other caregivers (allied) of patients of dementia were identified, using a predefined criteria. Various issues, related to the profile of caregivers and care giving, were studied. Initially 43 diagnosed cases of dementia were identified and at the level of screening 18 were excluded due to patient and key care giver related issues. Thus 25 patients of dementia were finally included in the study along with their 25 key care givers. There were 37 other care givers with 25 dementia patients. Out of these, three other care givers were excluded for reasons as shown in table-I and finally 34 other care givers were included in the study. The majority of dementia patients were between 60 to 80 years of age (84%), male (64%) and married (64%). The severity of dementia was assessed using MMSE and it was found that of 25 patient of dementia majority of patients (48%) were in the moderate category (MMSE score : 11-19), followed by 7 in severe (28%) category (MMSEscore:0-10)andmild(12%)category(MMSEscore:20-24).

In the present study it was observed that amongst the key givers majority were in the age range of 41-60 years (44%) followed by the age range of 61-80 and 21-40 years. There was only one key care giver each in the age rage of 12-20 and 80 and above. From the results it is clear that key care givers were found to be older (41-80years =19) than other care givers (21-60 years =29). There was another study which was in support to the current study where the study finds that the mean age of the caregiver is 55.6 ± 10.01 years and that of patient is 69.81± 0.71 years. The mean BAS score is 68.3 ± 11.77 [17].

With regard to gender, females were about three and half times more in the category of key care givers whereas males out numbered as other care givers than females. This study was in support with the study by other researcher Raghuwanshi et al., in 2024 where the majority of caregivers were female 41 (68.3%), married 56 (93.33%), and graduate 22 (36.8%). Most caregivers were skilled 25 (41.6%) belongs to lower middle class 19 (31.6%), and urban locality 33 (55%) [17].

There was significant association between the duration of time spent for care giving in 24 hours and key and other care givers 48% of key care givers spent 31 to70% and 40% spent 71 to 100% of their time care giving.

Amongst other care givers only 28.4% reported mild to moderate depressive mood and none of them reported severe or profound depressive mood. A study conducted by Tzeng *et al* [18] demonstrated the results. It is observed that as the caregiver spent more time with the patient, their own mental and physical health gets equally affected, they often spent less time socially, and their work life gets hampered. In the current study Gold standard interviews and assessments of care givers were carried out by the supervisors to find out psychiatric morbidity, if any, amongst care givers.The findings reveal that amongst key care givers depressive disorders were the commonest diagnosis (52%), followed by sub- syndromal problems (20%) and mixed anxiety depression (16%). Amongst other care givers, majority (61.8%) reported no problem et al followed by depressive disorder (20.6%) and sub-syndromal problems (11.8%). These observations are statistically significant. In relation to quality of life of care givers as assessed by WHOQOL-BREF, majority of the key care givers in the domains of physical health (52%), psychological health (56%), social relationship (48%) and environment (52%) reported average quality of life followed by good quality of life (40%, 32%, 20% and 48% respectively).

Study conducted in the Indian context like Pattanayak *et al.* [19] have found a moderate degree of burden and burden increased with cognitive impairment. On comparing the mean BAS score of dementia caregivers with those of schizophrenia, it was found to be same (mean BAS score in dementia caregiver was 68.3 while in schizophrenia was 68.75) while mean BAS score in bipolar disorder was found to be higher (mean BAS score in dementia caregiver was 68.3 while in bipolar disorder was 64.45).

It is important to increase the social support networks, either through the caregivers' close relationships or through health professionals, in order to reduce the burden felt by caregivers, while seeking to increase their well-being and quality of life , which are associated with the quality of care provided by the informal caregiver. Thus, the caregiver is an important part of care provision, and it is essential to support caregivers in managing their difficulties [20,21].

CONCLUSION

Care giving involves sacrifice by the care giver, which is unusually carried out happily in the initial stages, but later on, it often becomes a burden to caregiver. The result is stress to the caregivers and development of number of psychological, physical, social, financial and other kind of problems. Consequently, care giver and care giving, in the case of chronic illnesses, like dementia have become an important area of interest and research for the treating psycho-geriatrician. The result of the present study provides a broad picture of the need to support and educate both families and caregivers of the elderly with dementia in the community.

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.

Authors' contributions: Author equally contributed the work.

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