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Burden and Depression among the Elderly Care Givers of Patients with Schizophrenia

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Abstract: ***The family is an important support system in India, in the care of the mentally ill. Schizophrenia is a severe mental disorder, characterized by fundamental disturbances in thinking, perception and emotions, and it is the most burdensome illness worldwide. It is challenging task especially for elderly caregivers. This study was done to assess the level of burden and depression among elderly care givers of patients with schizophrenia and its relationship with severity of illness and socio-demographic variables. The study was conducted in Out Patient Department of the Department of Psychiatry, in a tertiary care center in South India. The study sample included 105 patients with a diagnosis of schizophrenia and their elderly caregivers selected by using non-probability, convenient sampling as per inclusion and exclusion criteria. Zarit Burden Interview and Geriatric Depression scale were used for the study. Results showed that 72% of them had moderate to severe burden and 46% of them had moderate to severe Depression. There was strong positive co-relation between burden and depression (r=0.534, p<0.001). There is a moderate correlation of severity of illness with burden (r=0.270, p=0.002) and also with Depression (r=0.303, p=0.002). Conclusion: These results can be used to plan interventions to reduce caregiver stressors especially older caregivers. Mental Health services must be directed to caregivers as well as patients of schizophrenia.***

Keywords: Schizophrenia, Elderly caregivers, Burden, Depression

1. Introduction

The family is an important support system in India in the care of the mentally ill. Schizophrenia is a severe mental disorder, characterized by fundamental disturbances in thinking, perception and emotions, and it is the most burdensome illness worldwide. It is challenging task for caregivers who are elderly. The caregiver burden caused by schizophrenia is evaluated in a multidimensional way. The caregivers play a major role in home care of family members with mental illness. Especially the elderly care givers experience changes in their life that can generate stress and burden. The aim of this study was to assess the level of burden and depression among the elderly care givers in patients with schizophrenia.

Caregiver is the most important person who cares for the person with schizophrenia (Clement, 1995). Caregiver usually help patient in performing their daily activities such as bathing, eating, cooking, dressing and taking medicines. However, when care is provided for longer time, particularly for patients which schizophrenia, caregiver can experience burden that leads to negative consequences such as depression, anxiety and sleep disturbances (Caqueo-Urizar, 2009). Care giving is an important aspect for both physical and mental disorders in chronic and disabling condition. The factors like spending more hours, financial burden, less time of care for themselves have been associated with high level of stress leading to disturbances in physical, emotional and social health.

The world Health Organization (WHO) states care giver burden as the "emotional, physical, financial demands and responsibilities of an individual illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system''.

There are many psychosocial factors which have been shown to be associated with depression in elderly include loneliness, poor social/family support, isolation, dependency, lack of family care, and affection, insufficient time spent with children, stressful life events, perceived poor health, lower level of spirituality, and higher use of emotion-based coping. The lifestyle and dietary factors that have been linked with depression include lack of hobby, irregular dietary habits, substance use/smoking, and lack of exercise. In general, data also suggest that presence of chronic physical illnesses increases the risk of depression (Grover & Malhotra, 2015).

Among the various mental disorders, depression accounts for the greatest burden among elderly. Depression decreases an individual's quality of life and increases dependency on others. If depression is left untreated, it can have significant clinical and social implications in the lives of the elderly (Blanchard, Waterreus, Mann, (1994). Early recognition, diagnosis, and initiation of treatment for depression in older people present opportunities for improving their quality of life, preventing suffering or premature death, and maintaining optimal levels of function and independence. Early diagnosis and effective treatment of depression in old age can also lead to significant reduction in mortality due to suicide and medical illnesses, and health care costs.

Swaroop et al., (2013) states that the emotional effect of stress on family members caring for an ill person in the family has been referred to as caregiver burden. Objective burden are negative patient symptoms, disruption of the caregiver's domestic routine social activities, and leisure, social isolation, financial and employment difficulties. The subjective burden are fear, angry, guilt, loss, stigma and rejection. Because care giving is such an emotionally draining experience, caregivers have high rates of depression when compared to the general populations.

Canhota&Piterma2001 conducted a study to identify the prevalence of depressive symptomatology in an elderly population using a screening scale. Depression was detected more in women (59%) and being female was associated with depressive status (p=0.10) not having someone willing to listen to their problems, difficulties and worries was significantly related with depression (p=0.041). Age greater than 75 years was also associated with being depressed, as not having someone to talk (p=0.037) and from being low socio economic class (p=0.050). This study concluded that participant's characteristics such as being over 75 years of age, being female and socially isolated were related to depression.

Yusuf, 2009 study reveals that most of the caregivers were female. A high level of burden was found in 47.3% of respondents. The level of burden experiences was significantly associated with place of residence and family size.

A study done by Gupta et al., (2015) showed that psychological well-being was low in older caregivers and those with lower educational level. Also showed that a strong negative correlation was found between burden and psychological well-being, thus showing that a higher level of burden in caregivers resulted in poor psychological wellbeing.

Gupta et al., (2015) study revealed that 80 percent of the caregivers experienced moderate level of burden. The burden was higher among older (r=0.334) caregivers and spouse (p=0.0001). Psychological well-being was low in older caregivers (r=0.44). A strong negative correlation was found between burden and psychological well-being (r=-0.81).

2. Significance and Need for the Study

The needs of the elderly care givers are diverse and they need assistance in emotional support, maintaining physical health and it demands a great energy. Caregiving can be highly rewarding but it can also be burdensome and pose a high risk for depression, anxiety and sleep disruption and impaired health for the elderly caregiver.

There are only very few studies done in India on Elderly caregivers. Hence the study is designed to study the burden among elderly caregivers. There is a need to address the issue and to find out the elderly caregiver burden.

3. Objectives

1. To assess the level of burden among elderly care givers of patients with schizophrenia
2. To assess the level of depression among the elderly care givers of patients with schizophrenia
3. To determine and association between the burden and depression of elderly care givers with selected sociodemographic variables of the patient
4. To determine the correlation between the burden and depression of elderly care givers with patient's severity of illness
5. To determine the correlation between the burden and depression among the elderly care givers of patients with schizophrenia.

4. Methods

The sample size was calculated using formula n= 4pq/d2, keeping prevalence of burden as 65%, the calculated sample size was 105.

A cross sectional study design was adopted for the study. Nonprobability, convenient sampling technique was used to enroll 105 elderly care givers from the age group of 55 years and above, living with the patient for at least one year prior to the study and directly involved with the care of the patients who is on treatment for 1 to 5 years. The study was conducted in Out Patient Department of the Department of Psychiatry, in a tertiary care center in South India.

A sociodemographic Performa was developed to record details, such as age, gender, education, marital status, and residence. Clinical variables like diagnosis and duration of illness was also recorded and the caregiver demographic data were collected such as relationship with the index patient, age, gender, education, marital status, duration of stay, hours of care.

5. Data Collection Methods

The following instruments were used to collect the data:

Zarit Burden Interview – It is used to assess the stress experienced by caregivers who look after an individual or older person in need of care. This is a 22-item instrument that includes the items most frequently mentioned by caregivers as problem areas in providing care for patients with chronic mental illness. The Internal consistency reliability- Cronbach's alpha is 0.82 to 0.93.

The ZBI explores the negative physical, mental, social, and economic impacts of caregiving on the life of the caregiver. The responses are rated on a Likert scale of 0 (never) to 4 (almost always) with a total score of 0–88. Higher scores indicate higher levels of caregiver burden or distress.

Geriatric Depression Scale - A Short Form GDS consisting of 15 questions was developed in 1986. Questions from the Long Form GDS which had the highest correlation with depressive symptoms in validation studies were selected for the short version. Of the 15 items, 10 indicated the presence of depression when answered positively, while the rest (question numbers 1, 5, 7, 11, 13) indicated depression when answered negatively. This scale has 92% sensitivity and 89% specificity with a high correlation (r=0.84)

Positive And Negative Syndrome Scale (PANSS) - The PANSS, comprises of 30 items is a freely available and standardized rating scale that is specifically developed to

assess the psychopathology in patients with schizophrenia. Cronbach's score for this scale is 0.80.

Data Collection Procedure

The primary care givers of patients who attend the outpatient department were recruited for the study. After introducing and explaining the purpose of the study, a written consent was obtained from the subjects. The instruments were administered by the investigator in either of the two languages, English and Tamil according to the relative's preferences. Each interview was conducted for 30 minutes in a separate room.

This study was conducted after getting approval from the College of Nursing Research Committee. Written informed consent was obtained from the subject prior to the data collection. The data was kept confidential.

Statistical Methods: The data entry and analysis was done using SPSS 16.0 software. Descriptive statistics methods mean and SD was used to assess the care giver burden and level of depression. The categories of burden and depression levels were presented as frequencies and percentages. Pearson correlation coefficient was used to find out the relationship between severity and level of burden / level of depression**.** Chi-square test was used to find the association of burden/depression with clinical variables and demographics. Significance is assessed at 5% level of significance.

The study was approved by Research Committee of the College of Nursing and permission was obtained from the Nursing and Medical Heads of Department of Psychiatry. Informed consent was taken from the caregiver.

6. Results

Table 1: Sociodemographic characteristic of elderly caregivers N=105

Variables	No	Percentage
Age in years	62.88±7 (Mean±SD)	
Sex		
Male	38	36
Female	67	64
Marital Status		
Single	5	4.8
Married	100	95.2
Educational status		
Illiterate	26	24.8
Primary	20	19.0
Secondary	55	52.4
Higher secondary	0	0
Graduate	4	3.9
Occupation		
Unemployed	36	34.3
Unskilled	43	41.0
Skilled	12	11.4
Professionals	8	7.8
Others	6	5.7
Type of family		
Joint	48	45.7
Nuclear	42	40.0
Extended	15	14.3
Income		
0 – 2000	29	27.6
2001 – 4000	35	33.3
4001 – 6000	24	22.9
6001 & above	17	16.2
Duration of stay		
1 – 3 years	12	11.4
3 – 6 years	7	6.7
6 years & above	86	81.9
No of hours of care		
0 – 12	76	72.6
13 and above	29	27.4
Relationship to the patient		
Mother	61	58.1
Father	25	26.7
Spouse	9	8.6
others	7	6.7
Relatives staying together		
Yes	88	83.8
No	17	16.2

Table 1 shows that majority of the care givers are female (64%), most of the care givers are married (95.2%), graduates are about 3.9%, 41% care givers are unskilled workers, 45.7% care givers are from Joint family, 27.6% earning below 2000 Rupees, 81.9% care givers are staying with patient for 6 years and above, 72.6% patients requires 0 – 12 hours of care givers care and majority of the care givers (58.1%) are mother and 83.8% of care givers are staying with patients.

Table 2: Demographic characteristic of patients N=105

Variables	No	Percentage	Mean	SD
Age in years			31.7	8.3
Sex				
Male	54	51.4		
Female	51	48.6		
Marital Status				
Single	53	50.5		
Married	45	42.9		
Divorced	7	6.7		
Educational status				
Illiterate	7	6.7		
Primary	36	34.3		
Secondary	20	19.0		
Higher secondary	20	19.0		
Graduate	22	21		
Occupation				
Unemployed	59	56.2		
Unskilled	24	22.9		
Skilled	9	8.6		
Professionals	7	6.7		
Others	6	5.7		
Income				
Rs. 0 – 2000	29	27.6		
Rs. 2001 – 4000	23	21.9		
Rs. 4001 – 6000	23	21.9		
Rs. 6001 & above	30	28.6		
Religion				
Hindu	91	86.7		
Christian	12	11.4		
Muslim	1	1		
others	1	1		
House ownership				
Own house	82	78.1		
Rented house	23	21.9		
Family debt				
Yes	49	46.7		
No	56	53.3		

Table 2 shows that mean age of the patient is 31.7 years, most of the patients are male (51.4%), 50.5% of patients are unmarried, 21% patients are graduates, 56.2% patients are unemployed, 41% of patients are from joint and nuclear family, 27.6% patients are earning below 2000 rupees, majority of them are Hindu in religion (86.7), majority of the patient required care from the care givers below 12 hours of care and 27.4% patients required care about 13 and above hours of care. 78.1% patients are staying in their own house.

Table 3: Frequency distribution of patients based on clinical variables

N=105

Variables	No	Percentage	Mean	Median	SD	QD
Age of onset of illness			26.30		7.826	
Duration of illness in months				48		30
No of hours of care						
0 – 12	76	72.6				
13 and above	29	27.4				
Patient compliance to medication						
Compliance with medication	62	59				
Noncompliance with medication	43	41				
Number of psychotic episodes						
0	5	4.8				
1	37	35		2		
2-4	52	50				
5 & above	11	10				
Number of hospitalization						
0	22	21		1		

1 2-5 6 & above	61 19 3	58.1 18.2 2.9				
Severity of Illness (PANSS SCORE) Mildly Ill (31 - 74) Moderately ill (75 – 119) Severely ill (120 and above)	 7 75 23	 6.7 71.4 21.9		108	23	

Table 3, shows that the age of onset of illness mean is 26.30 with the standard deviation of 7.826. The median of duration of illness in month is 48. About 72.6% of patients needed below 12 hours of care, and 41% of them were non-compliance to medication. The severity of illness PANSS score shows that 71.4% had moderately ill.

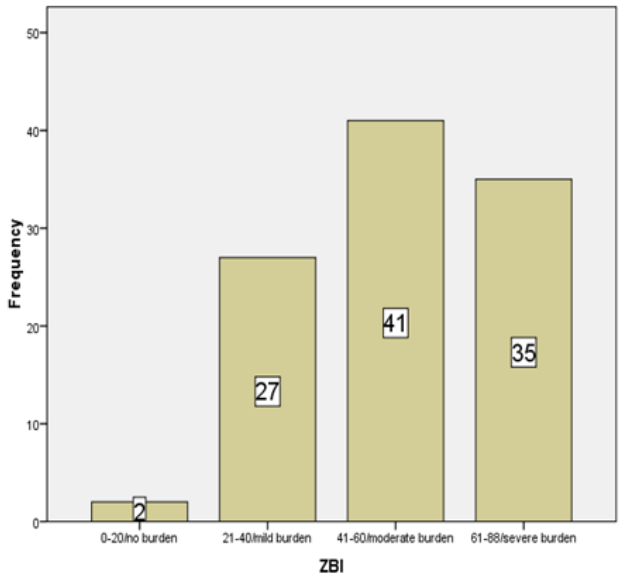

Figure 1: Distribution of level of burden of elderly care givers
(ZBI – Zarit Burden Interview)

Figure 1 shows that 2 (2%) them are not having burden, 27 (26%) of them are showing mild burden majority of the care givers 76 (72%) are with moderate to severe burden.

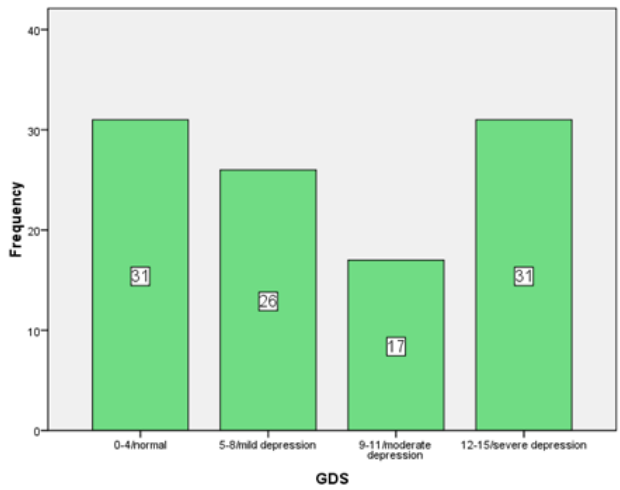

Figure 2: The distribution of Level of Depression among elderly care givers of schizophrenia
(GDS – Geriatric Depression Scale)

Figure 2 shows that 31 (30%) has no depression, 26 (25%) are having mild depression, and 48 (46%) care givers having moderate to severe depression.

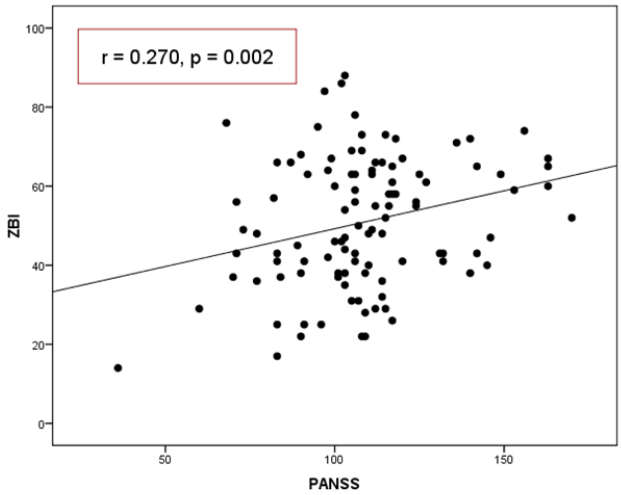

Figure 3: Correlation between Burden and Patients Psychopathology and Care Giver Burden
(PANSS- Positive and Negative Syndrome Scale)

Figure 3 shows the scatter plot shows that there is moderate positive correlation between the patient's psychopathology and the elderly care givers burden scores with 'r' value 0.270, and *'p'* value0.002 which is statistically significant.

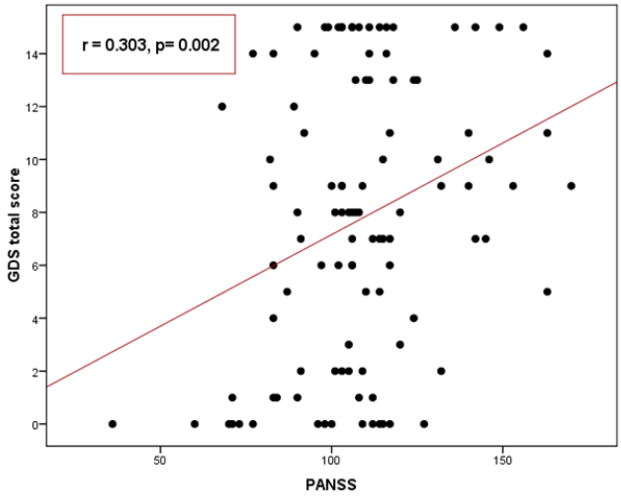

Figure 4: Correlation among Patient's Psychopathology and Depression among Elderly Care Givers

Figure 4 the scatter plot shows that there is moderate positive correlation between the patient's psychopathology and elderly care givers depression level with 'r' value 0.303 and *'p'* value 0.002 which is significant.

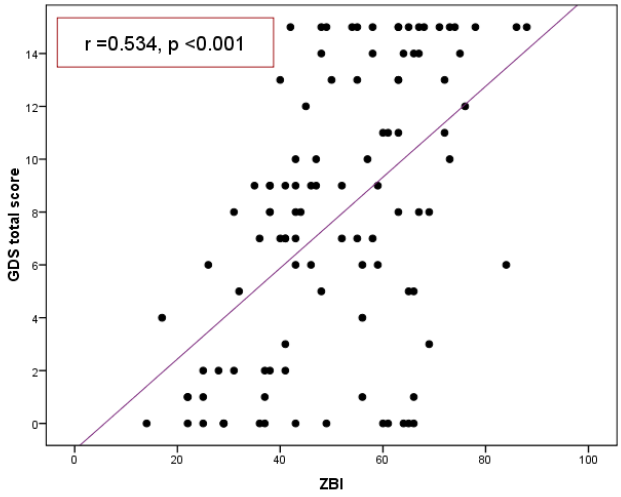

Figure 5: Correlation of burden with depression among elderly care givers

Figure 5 - The scatter plot shows that there is Strong positive correlation which statistically significant with 'r' value of 0.534, and the p value of p=<0.001.

Table 4: Association of Level of burden of elderly care givers with selected demographic variables of the patient
N=105

Variables	Normal 0-20		Mild to Moderate Burden 41 - 60		Severe Burden 61 - 88		P value
Age	**No**	**%**	**No**	**%**	**No**	**%**	
18-25	5	20.0	9	36.0	11	44.0	**0.039***
26-40	16	23.9	30	44.8	21	31.3	
>40	8	61.5	2	15.4	3	23.1	
Sex							
Male	15	26.4	23	42.6	16	29.6	0.665
Female	14	27.5	18	35.3	19	37.3	
Marital Status							
Unmarried	14	26.4	20	37.7	19	35.8	0.314
Married	15	33.3	16	35.6	14	31.1	
Divorced /separated	0		5	71.4	2	28.6	
Habitat							
Urban	18	33.3	21	38.9	15	27.8	0.310
Rural	11	21.6	20	39.2	20	39.2	
Income							
Rs. 0 – 2000	3	10.3	14	48.3	12	41.4	
Rs. 2001 – 4000	4	17.4	9	39.1	10	43.5	**0.021***
Rs. 4001 – 6000	9	39.1	11	47.8	3	13	
Rs. 6000 & above	13	43.3	7	23.3	10	33.3	
Religion							
Hindu	24	26.4	37	40.7	30	33.0	
Christian	5	41.7	3	25.0	4	33.3	0.526
Muslim	0	0	1	100	0	0	
Others	0	0	0	0	1	100	
Age of onset							
<25	7	15.6	17	37.8	21	46.7	**0.015***
>25	22	36.7	24	40.0	14	23.3	
Duration of illness							
<5 years	21	30.0	25	35.7	24	34.3	0.275
5 – 10 years	7	29.2	12	50.0	5	20.8	
>10 years	1	9.1	4	36.4	6	54.5	
Compliance with medication	25	40.3	20	32.3	17	27.4	**0.002***
Non - compliance with medication	4	9.3	21	48.8	18	41.9	
Number of hours of care							
< 6 hours	11	50.0	6	27.3	5	22.7	**0.070***
6 – 12 hours	12	22.2	25	46.3	17	31.5	
>12 hours	6	20.7	10	34.5	13	44.8	
***p value<0.05**							

Table 4 shows that there is an association between the age of the patients (p=0.039), the income of the patient (p=0.021), with age of onset of the patient (p=0.015), compliance with medication (p=0.002) and with the number of hours of care (p=0.070) with the care giver burden.

Table 5: Association of Level of depression of elderly care givers with selected demographic variables of the patient
N=105

Variables	Normal 0 -4		5-8 /Mild depression		9-11 Moderate depression		12 -15 Severe depression		P value
Age	**No**	**%**	**No**	**%**	**No**	**%**	**No**	**%**	
18-25	6	24	5	20	5	20	9	36	**0.031***
26-40	16	23.9	21	31.3	11	16.4	19	28.4	
>40	9	69.2	0	0	1	7.7	3	23.1	
Sex									
Male	13	24.1	16	29.6	8	14.8	17	31.5	0.483
Female	18	35.3	10	19.6	9	17.6	14	27.5	
Marital Status									
Unmarried	14	26.4	16	30.2	9	17.0	14	26.4	0.876
Married	15	33.3	9	20.0	7	15.6	14	31.1	
Divorced /separated	2	28.6	1	14.3	1	14.3	3	42.9	
Habitat									
Urban	21	38.9	16	29.6	6	11.1	11	20.4	**0.026***

Rural	10	19.6	10	19.6	11	21.6	20	39.2	
Income									
Rs. 0 – 2000	6	20.7	4	13.8	7	24.1	12	41.4	
Rs. 2001 – 4000	6	26.1	6	26.1	5	21.7	6	26.1	
Rs. 4001 – 6000	9	39.1	8	34.8	2	8.7	4	17.4	0.365
Rs. 6000 & above	10	33.3	8	26.7	3	10	9	30	
Age of onset									
<25	10	22.2	11	24.4	9	20.0	15	33.3	0.472
>25	21	35.0	15	25.0	8	13.3	16	26.7	
Duration of illness									
<5 years	24	34.3	14	20.0	11	15.7	21	30.0	
5 – 10 years	4	16.7	9	37.5	5	20.8	6	25.0	0.523
>10 years	3	27.3	3	27.3	1	9.1	4	36.4	
compliance with medication									
Non - compliance with medication	24	38.7	16	25.8	7	11.3	15	24.2	
	7	16.3	10	23.3	10	23.3	16	37.2	**0.044***
Number of hours of care									
< 6 hours	11	50	3	13.6	3	13.6	5	22.7	
6 – 12 hours	14	25.9	15	27.8	9	16.7	16	29.6	0.399
>12 hours	6	20.7	8	27.6	5	17.2	10	34.5	

p value<0.05

Table 5 shows that there is significant association between the age (p=0.031), habitat (p=0.026), compliance with medication (p=0.044) of the patient with depression of the care givers.

7. Discussion

The present study was undertaken to assess the burden and depression among the elderly care givers of patients with schizophrenia in the Out Patient Department of tertiary care center in South India.

The demographic variable showed that majority of the elderly care givers were female caregivers (64%) and the mother's were58.1% which is high. The possible reason could be in Indian culture caregiving is entrusted mainly on the female members of the family, which might be the reason for the higher score in female caregivers. Overall burden scores of elderly caregivers revealed that nearly 27 (26%) of them are showing mild burden and majority 76 (72%) of them are having moderate to severe burden. The possible reason could be, as most of the caregivers expressed that they suffer from arthritis, asthma and also the longer duration of patient's illness. It is supported by the study done by Pun, He & Wang, 2014 revealed that care giver experienced mild (36.7%) to moderate (46.9%) burden. This result is supported by Adeosum, 2013 revealed that older caregivers had significantly higher burden scores and also longer duration of illness correlated with higher scores.

The Depression score of the elderly caregiver showed that 26 (25%) of them are having mild depression and 48 (46%) of them are having moderate to severe depression. The reason could be the patients' behavior and their cognitive and functional ability conferred greater risk of caregiver depression and also the longer duration of patient's illness. The analysis was done for association between burden and with selected socio demographic variables and clinical variables of patient using chi-square test. The result showed that there are significant associations with age, compliance with medication, family income and age of onset and the number of hours of care. Association between depression and with selected socio demographic variables and clinical variables of patient showed that there are significant associations with age, habitat and compliance with medication. A statistically significant positive correlation between the age of caregivers and the level of burden implies that the level of burden increases with the age of caregivers. Pearson correlation coefficient was used to find out the relationship between severity of illness of patient with caregiver level of burden, and the result shows that there is significant moderate positive correlation ('r' value 0.270 and 'value 0.002). And also there is moderate positive correlation between the severity of illness with depression ('r' value 0.303 and 'p' value 0.002). Patients with worse symptom profile may have greater impairment in functioning. An Indian study by Rammohan et al. when caregiver becomes older, they are worried about who will take care of their ill family members in the future. Older caregiver also cannot provide good care to the ill member.

The current study showed that Pearson correlation coefficient was used to find out the relationship between burden and depression showed that strong positive correlation r= 0.534, p=<0.001, which is statistically significant which means when the burden level increases the depression level also increases. This result is supported by the study done by (El-Tantawy, 2010) revealed that Depressive disorders were higher among caregivers (18.33%). The reason could be due to depressive symptoms were associated with increased number of hours of care per week for providing care, older age of the caregivers and duration of care giving. The longer the duration of illness, the higher the burden scores. The reason could be due to as caregivers come to terms with

the chronic nature of schizophrenia and the reality that their caregiving role may last a lifetime, they may become more worried about the future. Older caregivers may be particularly concerned about who will step into their caregiving roles when they are no longer alive. Also revealed that higher PANSS scores predicted higher caregiver burden scores.

8. Conclusion

Relatives of patients with schizophrenia face enormous burdens, with financial and negative patient behavior. Caregivers for schizophrenic patients reported high levels of depressive symptom. The strongest and most consistent predictors of Depressive Disorders were caregiver burden due to mental disorder and poor quality of life. Depressive symptoms were associated with increased number of hours per week for providing care, old age of the caregiver and duration of care giving. These results can be used to plan interventions to reduce caregiver stressors. This study contributed to improving knowledge concerning symptoms arising from burden and depression experienced by the elderly caregiver individuals. Analyzing the characteristics of the family caregivers with burden we observed that most were adult female caregivers. Further studies are needed to confirm these findings and to develop interventions for the elderly caregivers of patients with schizophrenia. Finally, this study reinforces the value of establishing ways to improve the coping skills of the caregiver, as well as of developing interventions to help the caregiver manage the patient's disturbing behaviors and functional limitations.

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