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A COMPARATIVE STUDY OF CAREGIVER BURDEN AND ADHERENCE TO TREATMENT IN PATIENTS OF VERY LATE ONSET SCHIZOPHRENIA LIKE PSYCHOSIS (VLOSLP) AND DEMENTIA

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ABSTRACT

BACKGROUND: VLOSLP and dementia caused more lost quality of life, lost productivity and chronic and debilitating course of both disorders make it difficult for the family members and care givers to continue care and treatment.

METHODOLOGY: Thirty-three patients of VLOSLP and dementia and their caregiver were selected after taking informed consent and screened with the entire inclusion and exclusion criteria. Socio-demographic profile of all patients and caregiver were recorded and Zarit Caregiver Burden Interview (ZBI) questionnaire and Drug Adherence inventory (DAI) applied to both groups.

RESULTS AND CONCLUSION: Mean ZBI of VLOSLP was 41.85 ±13.28 and DAI was .94 ±3.784 (P. coeff. = -.682, p= .0001). Mean ZBI of dementia was 49.45 ±15.51 and DAI was -1.85 ±3.78 (P coeff. = -.935, p= .0001) indicated that the caregiver burden was more in patients of dementia and drug adherence was less then VLOSLP. There is a strong negative association between caregiver burden and compliance to the treatment.

KEYWORDS : Caregiver, VLOSLP, Dementia

INTRODUCTION

There are unique diagnostic and therapeutic considerations in the management of older adults with mental illness. They face the dual stigma of mental illness and aging. These problems are further compounded by therapeutic pessimism fostered by rampant societal as well as professional ageism. The incidence and prevalence of Dementia increases with age in geriatric population and so is the burden on family and care giver. A looming public health crisis is the rising number of people with dementia, doubling every 20 years, due to global aging. Currently, there are approximately 47 million people with dementia in the world (1), the great majority of whom are cared for by family members in the community (2). A meta-analysis found dementia family caregivers to be significantly more stressed than nondementia caregivers and to suffer more serious depressive symptoms and physical problems [3].

Historically, schizophrenia has been considered a disease of younger adulthood. However, literature suggests that approximately 23% of patients with schizophrenia have an onset of illness after 40 years of age with 3-4% being older than 60 years at the time of onset of the illness or the patients who presented later after the time of onset of illness.(4,5)The onset of psychotic symptoms after age 60 years, generally not schizophrenia, but is best labeled as very late- onset schizophrenia like psychosis(VLOSLP). International Classification of Diseases-10 (ICD-10) nor DSM-IV-TR contain separate diagnoses for very late-onset schizophrenia like psychosis (VLOSLP). Community prevalence estimates for schizophrenia in individuals over the age of 65, ranges from only 0.1% to 0.5% (5). India, with its growing geriatric population warrants a clearer perspective on the concepts of LOS and VLOSLP (4).

The chronic and debilitating course of both diseases makes it difficult for the family members and care givers to continue care and treatment. Caregivers often report feeling of stress by various aspects of caring for the patient; this is termed as 'caregiver burden'. In India, mostly family members care for the patients. The institutional care is considered as the last resort. The caregivers themselves have a high risk of emotional dysregulation (6). Mostly, the burden of care is more defined by its impacts and consequences on caregivers. Other than the emotional, psychological, physical and economic impact, the concept of 'burden of care' involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame(7).

This study examines whether the burden of caregiving has a relationship with non-adherence of medications, in very late onset schizophrenia like psychosis (VLOSLP) and dementia. Adherence is "the extent to which a patient's behaviour coincides with medical or prescribed health advice" (8). Non-adherence, is a widespread major obstacle to the treatment effectiveness, patient quality of life and a demand on the health care system. The family and health professionals need to understand and address the dynamics of adherence (9). Theoretical models which are concerned with medication adherence take the issue that are based on social, personal and cognitive factors, with influences the duration of the illness and its medication /treatment regime, the patient himself/herself, and the interactions between the doctor and the patient (9,10). Dealing with these factor increases medication adherence according to some studies (9,11,12).

AIMS

To study, quantify and co-relate care giver burden and adherence to treatment in very late onset schizophrenia like psychosis (VLOSLP) and dementia in geriatric population, at a tertiary care center.

OBJECTIVES

1) To study care giver burden and adherence to treatment in patients of VLOSLP and dementia .
2) To corelate and quantify the effect of care giver burden and adherence to treatment in patient with VLOSLP and dementia.

MATERIAL AND METHOD

STUDY DESIGN:

This is a cross-sectional and descriptive study conducted at department of Psychiatry, **S.M.S. Medical College & Hospitals, Jaipur**. We collected a sample from the period of 1st January 2019 to 31st December 2019. Thirty-three patients (N=33) of VLOSLP and dementia and their caregiver were selected after taking informed consent and screened with a specially designed performa which encompassed the entire inclusion and exclusion criteria. Socio-demographic profile of all patients and caregiver were recorded and Zarit Caregiver Burden Interview (ZBI) questionnaire and Drug Adherence inventory (DAI) applied to both groups. The permission to conduct the study was taken from the ethical committee of the above mentioned institute.

INCLUSION CRITERIA:

- Patients age above 60 years
- Patients with diagnosis Very late onset schizophrenia like psychosis (VLOSLP) and Dementia (according to ICD 10 criteria)
- Caregivers with age more than 18 years, belonging to both the sexes.
- Patients and care givers who agreed and signed the informed consent.

EXCLUSION CRITERIA:

1. Patients with other psychiatric diagnosis.
2. Patient suffering or on treatment for any other chronic medical /surgical illness.

3. Patients/caregivers who were not willing to give written consent.

TOOLS OF STUDY

1. Socio demographic and clinical profile sheet.
2. Informed consent form.

3. ZARIT CAREGIVER BURDEN INTERVIEW (ZBI) QUESTIONNAIRE[13]:

The ZBI is the most extensively used measure in researching caregiver burden. This 22-item questionnaire has five possible responses to each question, with a possible score of 0–4. The ZBI was administered as a self-reporting questionnaire in English to those caregivers who could understand it; to others, it was administered by an interview technique in which the interviewer translated the questionnaire into the vernacular language understood by both the caregiver and the interviewer.

4. DRUG ATTITUDE INVENTORY(DAI)[14]:

The DAI-30 contains 15 items that a patient who is fully adherent to their prescribed medication (and so would be expected to have a 'positive' subjective response to medication) would answer as 'True', and 15 items such a patient would answer as 'False'. To calculate the score from a set of answers, each 'positive' answer is given a score of plus one, and each 'negative' answer is given a score of minus one. The total score for each patient is calculated as the sum of the positive scores, minus the negative scores. A positive total score indicates a positive subjective response (adherent) and a negative total score indicates a negative subjective response (non-adherent).

STATISTICAL ANALYSIS

Statistical analysis was done by using the Statistical Package for Social Scientists, version twenty-three (SPSS-23). Discrete variables were computed as frequency and percentage. Mean and standard deviation was calculated for all the continuous variables. Pearson's correlation was calculated for computing the correlations of parametric variables. Significance was compared using two tailed values. The significance level was set at <0.01.

OBSERVATION AND RESULTS

In this study, we evaluated thirty three patients (N=33) diagnosed VLOSLP and dementia for caregiver burden and adherence to treatment. In our study 60.60% for VLOSLP and 48.48% for dementia care givers were male. Caregiver of Patients of VLOSLP were younger (mean age 45.24±12.19), the majority were married (87.87%), and 54.54% were living in rural area. Thirteen (39.39%) caregiver of patients of VLOSLP were their spouse and 15(45.45%) were patient's children. Caregiver of patients of dementia (mean age 50.97±14.74), who were mainly married (81.81%)) and 57.57% lived in urban area. fourteen (42.42%) caregiver of patients of dementia were their spouse and 16(48.48%) were their children. Other than mean age of caregiver (x^2=-1.72, df=64, p=0.09), all socio- demographic variable did not show any statistical differences between the groups (table-1).

TABLE 1: Socio -demographic profile of caregivers of Very late onset Schizophrenia like psychosis (VLOSLP) and Dementia

variable	Very late onset Schizophrenia like psychosis (VLOSLP) n=33	Dementia n=33	Chi-square value, df, P- value
Age ± SD (Years)	45.24±12.19	50.97±14.74	-1.72, df=64 P=0.09
Gender Male (%) Female (%)	20 (60.60%) 13 (39.39%)	16(48.48%) 17(51.51%)	0.978, df=1 p=0.323
Locality Urban Rural	15(45.45%) 18(54.54%)	19(57.57%) 14(42.42%)	0.971, df=1 P=0.325
Marital status Married Unmarried	29(87.87%) 4(12.12%)	27((81.81%) 6(18.18%)	0.471, df=1 p=0.492
Relationship Spouse Child other	13(39.39%) 15(45.45%) 5(15.15%)	14(42.42%) 16(48.48%) 3(9.09%)	.569 df=2 P=0.752

Significant at 0.01 level (2-tailed)

Mean ZBI of VLOSLP was 41.85 ±13.28 and mean DAI of VLOSLP was .94 ±3.784 (Pearson co-relation coefficient= -.682, p=.0001). Mean ZBI of dementia was 49.45 ±15.51 and mean DAI of dementia was -1.85 ±3.78(Pearson co-relation coefficient = -.935, p=.0001) indicates that the caregiver burden was more in dementia (table 2 and 3).

TABLE 2: Co-relation of caregiver burden and drug adherence in patients of Very late onset Schizophrenia like psychosis (VLOSLP)

Mean of ZBI (caregiver burden) ± SD	Mean of DAI (adherence) ± SD	Pearson Correlation coefficient	P- value
41.85 ±13.28	.94 ±3.784	-.682	.0001

TABLE3: Co-relation of caregiver burden and drug adherence in patients of dementia

Mean of ZBI (caregiver burden) ± SD	Mean of DAI (adherence) ± SD	Pearson Correlation coefficient	P- value
49.45 ±15.51	-1.85 ±3.78	-.935	0.0001

In our study on comparing mean ZBI of both group ,caregiver burden was significantly higher in dementia(t=-2.139,df=64,p-value=0.036).On comparing mean DAI of both group, adherence to drug was more in VLOSLP compared to dementia (t=3.057, df=64, p-value=0.003) (table-4).

TABLE 4: Comparison of means Very late onset Schizophrenia like psychosis (VLOSLP) and Dementia

	Mean ± SD in VLOSLP	Mean ± SD in Dementia	t- value	df	p-value
ZBI	41.85±13.28	49.45±15.51	-2.139	64	.036
DAI	.94±3.62	-1.85±3.78	3.057	64	0.003

DISCUSSION

This study emphasised the importance of adherence to treatment with caregiver burden in patients of VLOSLP and dementia. This study found the direct and significant correlation between caregiver burden and adherence to treatment. In our study, care giver burden in VLOSLP was less and drug adherence was better than patients of dementia. The comparison between correlation coefficients (VLOSLP **= -.682,** dementia= **-.935**) indicates that the effect of ensuring better adherence to treatment leads to reduction in caregiver burden. Ohaeri JU et al. stated that disturbed behaviour is a greater determinant of severity of burden in late onset psychosis [15]. Moreover, in these patients, there was no long-term deterioration of personality while hallucinations and delusions were experienced in clear consciousness without bothersome sequelae [16]. VLOSLP may be difficult to diagnose clinically because its clinical picture can be confused with other conditions such as dementia, delirium, and psychosis due to underlying medical illness. The patients with VLOSLP were distinguished by higher rates of marriage, higher education levels, well adjusted premorbid personality better responses to treatment[17,18] . A study by Mazeh et al. suggested that patients with VLOSLP may have somewhat more stable cognitive and everyday functioning than do chronically institutionalized elderly patients with schizophrenia [19] .

In our study care giver burden in patients of dementia was more and drug adherence was less in comparison to patients of VLOSLP. Caregiver of dementia 48.48% were theirs children and 42.42% were their spouse. This observed care giver burden might be due to factors such as closer relationship of spouses [20], co-residence with care recipients, and concomitant health and physical ailments, leading to a greater degree of perceived stress when providing long-term care [21]. Our study was supported by Sinha P et al. revealed that dementia carries a greater caregiver burden when compared with elderly patients with psychosis . Caregiver burden in dementia was positively correlated with cognitive impairment and inability to carry out activities of daily living. Presence of psychological distress in caregivers was also an indicator for greater caregiver burden in dementia[22]. Khin Khin Win et al. observed in their study adult children (85.9%) as opposed to spouses (5.3%) as caregiver, Care giver of dementia also had higher ZBI total score and experienced greater overall burden, increased demands, and lack of control over situation[23] . The caregivers of dementia in oldest-old were mainly older adult children who experienced significant role and independent of disease severity while caring for their family member with more impaired cognitive and physical function. Caregivers of dementia in oldest-old

were expected to be older in age and are likely burdened with more concerns such as health issues, family commitments and financial constraint . Furthermore, persons with dementia were likely to require higher care needs, such that the caregiving role can have deleterious impact on one's physical and psychological well-being [24]. Neuropsychiatric symptoms are most predictive of caregiver burden regardless of dementia diagnosis, but the effects appear to be driven primarily by disruptive behaviours (e.g., agitation, aggression, disinhibition). Disruptive behaviours are more disturbing partly because of the adverse impact on the emotional connection between the caregiver and the patient and partly because they exacerbate difficulties in caring for activities of daily living[25].

CONCLUSIONS

Our study care giver burden in patients of dementia was more and drug adherence was less in comparison to patients of VLOSLP and there was a strong negative association between caregiver burden and adherence to the treatment in both groups. The effect of ensuring better adherence to treatment leads to reduction in caregiver burden. The most important part of management of VLOSLP and dementia is to psycho-education about nature of illness, course and prognosis, role of drug compliance and strengthen bond between patient and care giver. The creation of intervention strategies targeting the informal caregiver, since they suffer the consequences of the psychiatric disorder and the caregiving role on a daily basis.

LIMITATION

The study having limited number of sample. The study was cross sectional design in hospital setting, so implication can not be generalized to community at large.

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