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RESEARCH ARTICLE

CAREGIVER'S STRESS AND ITS PREDICTORS WHILE CARING DEMENTIA PATIENTS DURING COVID-19 PANDEMIC

Madhu Bala¹, Sunita Sharma², Renu Sharma² and Aseem Mehra³

1. M.Sc. Nursing, National Institute of Nursing Education, Post Graduate Institute of Medical Education and Research, Chandigarh.
2. Department of Nursing, National Institute of Nursing Education, Post Graduate Institute of Medical Education and Research, Chandigarh.
3. Department of Psychiatry, Post Graduate Institute of Medical Education and Research, Chandigarh.

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Abstract

Background: The COVID-19 pandemic had a great impact on dementia patients as well as on their caregivers. The caregivers of such patients face great difficulties and marked level of stress in dealing with their patients during COVID-19. The roles and responsibilities of the caregivers also increased and messed up with daily routines due to sudden changes in the environmental situation because of COVID.

Aim: To assess the level of stress among the caregivers of patients with dementia during COVID pandemic.

Methods: A cross sectional research design in which purposive samples of 31 caregivers of patients with dementia were selected for the study. The caregivers who were stayed with the patients for at least one year and were fulfilled the eligibility criteria were participated in the study. The data was collected by using a telephonic interview on one to one basis. Perceived stress scale (PSS-10) was used to assess level of stress among the caregivers.

Results: The findings of the study have shown that the majority of the caregivers of patients with dementia 90.3% had moderate stress level.

Conclusion: The roles and responsibilities of caregivers of patients with dementia become challenging during COVID which affect their mental health also. The emphasis is on the stress management strategies for the caregivers and shared responsibilities of caring their patients.

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Introduction:-

World Health Organization (WHO) announced the Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) as pandemic on 11th March 2020. ^[1]The COVID-19 pandemic has affected general population globally with marked consequences. The total cases of COVID-19 reaches upto 3,07,52,950 including 4,05,939 deaths till now in India. ^[2]The ongoing Coronavirus disease is having profound impact on the vulnerable population like older people, children, pregnant women, etc. ^[3]Among them, people with dementia has been adversely affected during COVID times. ^[4]About 50 million of people have dementia worldwide. It is the 7th leading cause of death among people of all ages. ^[5]The impact of the COVID pandemic is creating a lot of physical and psychological stress in persons with dementia, their families and especially caregivers. ^[6]As many preventive strategies like imposing periods of

Corresponding Author:- Madhu Bala

Address:- M.Sc. Nursing, National Institute of Nursing Education, Post Graduate Institute of Medical Education and Research, Chandigarh.

lockdown; mass quarantines, restrictions on activities;etc. have been implemented to control the situation. These restrictions augmented difficulties in dealing with the daily needs of persons with dementia, accessing health services and social support.^[7] Under such circumstances, the caregivers of the persons with dementia reported high distress.^[3] It has not only affected the physical health of the caregivers but also leads to high level of stress.^[8] During the pandemic, the caregivers of persons with dementia are providing continuous long term care without assistance of the others family members or other formal health care services which increasing the level of stress among them.^[3] As the cognitive functions decline during the illness so it is very difficult to understand the situation and unable to follow the instructions of maintaining COVID safeguard measures.^[9] Because of this, the fear of getting an infection also increase and it exacerbates the caregiver's stress and worry.^[7] The caregiver's stress included the psychological manifestations like distress, worry, anxiety, frustration, social isolation, disruption in personal and professional life. So, it is very challenging for the caregivers of persons with dementia to handle them during COVID pandemic.^[10] The study focuses on the caregivers of patients with dementia. Therefore, the present study aimed to assess the stress level of the caregiver's of patients with dementia.

Methods:-

A cross-sectional study was conducted in PGIMER, Chandigarh. A purposive sampling technique was used to collect the data telephonically of caregivers of patients with dementia that have registered in Psychiatry department, PGIMER, Chandigarh. The caregivers who stayed with the patients for at least one year and who were fulfilled the inclusion criteria participated in the study. Finally, 31 caregivers who were willing to participate in the study and fulfill the criteria participated in the study. A total of 75 patients and their caregivers were approached before the recruitment. Permission was obtained from Head, Department of Psychiatry. Ethical clearance was obtained from Institute Ethics Committee (IEC), PGIMER, Chandigarh. Informed consent was obtained from the caregivers before the recruitment. The data was collected telephonically with the help of interview schedule. The socio-demographic and clinical details were taken from the patient's records. If any information was missing, gathered through telephonically with the help of interview schedule. In addition, caregivers were also assessed on the Perceived Stress Scale (PSS 10-item).

Perceived Stress Scale

PSS-10 is a 10 item scale that widely used to assess the perception of the stress. It is a measure of the degree to which situations in one's life are appraised as stressful. The scale consisted of 10 questions about current levels of experienced stress (Cohen et al., 1983). The items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. The questions are of general nature and hence are relatively free of content specific to any subpopulation group. The questions in the perceived stress scale (PSS) ask about feelings and thoughts during the last month. It has adequate psychometric properties (Lee et al., 2012).

Statistical Analysis

The collected data was analyzed in SPSS 20.0 version by using descriptive statistics (mean, standard deviation). Pearson correlation coefficient and Spearman's correlation coefficient were used to find the association between different variables. Stress as the dependent variable and age of caregivers; number of family members; sex of caregivers; marital status; duration of illness and clinical course as the independent variables were entered in multivariate regression.

Results:-

Table 1 depicts that total number of the caregivers participated in the study were 31. The caregiver's age ranged from 24-82 years with the mean age of 47 ± 15.64 years. Majority of the caregivers 90.3% were married. About half of the caregivers 45.2% were having Upper Lower (IV) socioeconomic status. The clinical course of the illness among majority of the patients with dementia 93.5% was continuous. The mean hours of daily time spent for caregiving were 11.84 ± 6.07 hours/day.

Table 1:- Socio-demographic characteristics of the caregivers of patients with dementia.

Variables	n (%) Mean± S.D
Age (in years)	
20-40 years	11(35.5%)
41-60 years	11(35.5%)
61-80 years	8(25.8%)

>80 years Mean± S.D (Range)	1(3.2%) 47.61±15.64 (24-82)
Sex Male Female	25(80.6%) 6(19.4%)
Marital Status Single Married	3(9.7%) 28(90.3%)
No. of hours/day spent for caregiving 0-8 9-16 17-24 Mean± S.D (Range)	15(48.4%) 8(25.8%) 8(25.8%) 11.84±6.07 (4-22)
Socioeconomic Class (Modified Kuppaswamy Socioeconomic Scale) Upper (I) Upper Middle (II) Lower Middle (III) Upper Lower (IV) Lower (V)	4(12.9%) 5(16.1%) 7(22.6%) 14(45.2%) 1(3.2%)

Table 2 summarizes that majority of patients 80.6% had a total duration of illness of 1-5 years. Majority of the patient's 93.5% clinical course of illness was continuous. Only 6.5% of dementia patients had a history of the previous hospitalization due to psychiatric illness. Half of the patients with dementia 51.6% had more than 1 medical illnesses and the number of medical illnesses ranged from 0-4 with the mean number was 1.55± 1.21.

Table 2:- Clinical profile of patients with dementia.

Variables	n (%)
Total duration of illness (in years) 1-5 years 6-11 years >11 years Median (Q₃-Q₁)	25(80.6%) 4(12.9%) 2(6.5%) 4 (5-3)
Clinical course Continuous Fluctuating	29(93.5%) 2(6.5%)
Previous Hospitalization Yes No	2(6.5%) 29(93.5%)
No. of medical illnesses 1 >1 Mean± S.D (Range)	8(25.8%) 16(51.6%) 1.55±1.21 (0-4)

Majority of the caregivers of patients with dementia 90.3% were having moderate level of stress and only 9.7% were having low stress with the mean score of 19.26± 4.81 as shown in Table 3.

Table 3:- Stress of caregivers of patients with dementia.

Variables	Never n (%)	Almost never n (%)	Sometimes n (%)	Fairly often n (%)	Very often n (%)
1. Felt upset because of something that happened unexpectedly	1(3.2)	6(19.4)	10(32.3)	13(41.9)	1(3.2)
2. Felt that you were unable to control the important things in your life	2(6.5)	7(22.6)	11(35.5)	9(29)	2(6.5)

3. Felt nervous and “stressed”	3(9.7)	2(6.5)	11(35.5)	14(45.2)	1(3.2)
4. Felt confident about your ability to handle your personal problem	2(6.5)	9(29)	16(51.6)	3(9.7)	1(3.2)
5. Felt that things were going your way	2(6.5)	6(19.4)	20(64.5)	3(9.7)	-
6. Found that you could not cope with all the things that you had to do	3(9.7)	7(22.6)	18(58.1)	3(9.7)	-
7. Have been able to control irritations in your life	-	10(32.3)	14(45.2)	6(19.4)	1(3.2)
8. Felt that you were on top of things	1(3.2)	7(22.6)	20(64.5)	3(9.7)	-
9. Have been angered because of things that were outside of your control	1(3.2)	5(16.1)	13(41.9)	12(38.7)	-
10. Felt difficulties were piling up so high that you could not overcome them	2(6.5)	16(51.6)	7(22.6)	6(19.4)	-
Stress Level					
Low stress (0-13)	3(9.7)				
Moderate stress (14-26)	28(90.3)				
High perceived stress (27-40)	-				
Mean± S.D (Range)	19.26± 4.81 (6-26)				

According to Pearson’s correlation coefficient, there was a significant negative relationship of the caregiver’s stress score with their socioeconomic status ($r = -0.339$, $P = 0.036$) i.e., low the socioeconomic status of the caregivers, then stress level will be more in the caregivers as shown in Figure 1. But there were no significant relationship between stress score of the caregivers within the age of the caregivers ($r = 0.159$, $P = 0.39$), duration of illness of patients with dementia ($r = -0.377$, $P = 0.48$) and no. of hours spent for caregiving ($r = 0.236$, $p = 0.201$).

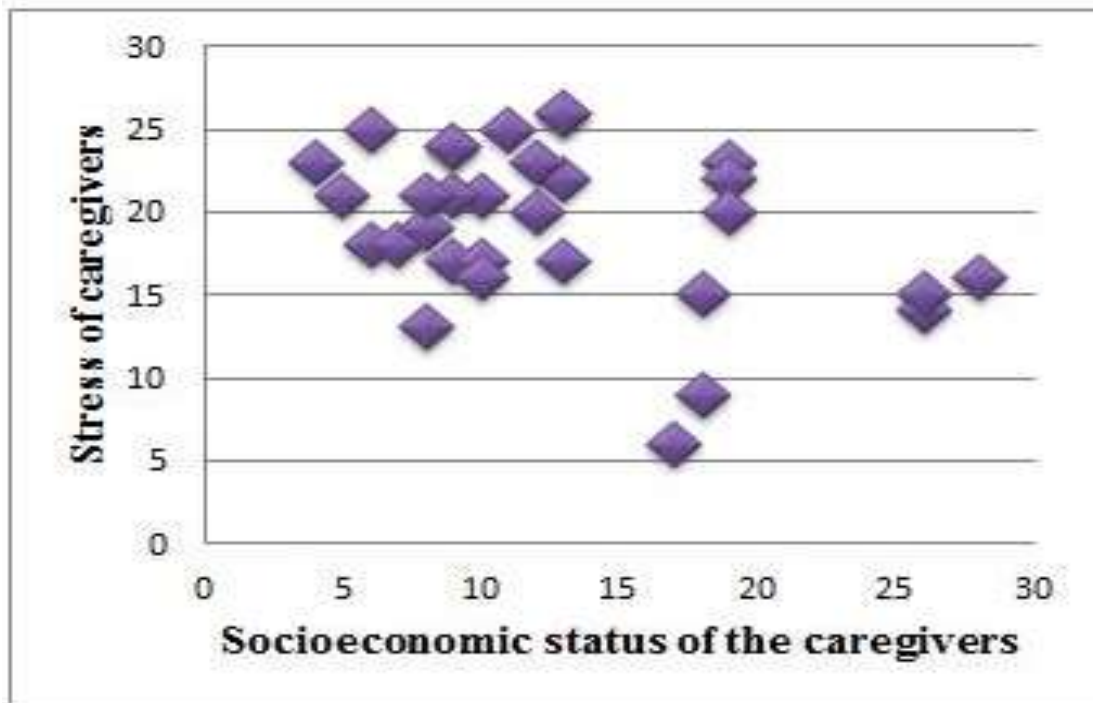


Fig 1:- Correlation between socioeconomic status and stress among the caregivers of patients with dementia.

The multivariate linear regression analysis showed that, the significant relationship with the stress score, number of the family members, marital status of caregivers, duration of illness of the patient with dementia and clinical progress of the illness of the patients with dementia were stronger predictors of stress score and the rest of the variables were not significant predictors of the stress score in the presence of these four variables as shown in Table 3.

Table 4:- Multivariate linear regression model to predict stress score based on different variables.

Variables	Raw coefficients	Standardized coefficients	p
Age of caregivers	2.243	0.379	0.076
No. of family members	-4.116	-0.482	0.008
Sex of caregivers	-1.292	-0.108	0.572
Marital status of caregivers	8.344	0.521	0.010
Duration of illness among patient	4.282	0.512	0.024
Clinical progress	2.620	0.510	0.017

*P-value is significant at the level of <0.05.

Discussion:-

The impact of COVID on the caregivers of patients with dementia was found significant. The social isolation, boredom, restrictions, limited resources, lack of support, disturbed daily routines played an important role in increasing the caregiver's stress. In literature, the rise in clinical presentation of the illness, progression of dementia and increased functional dependence of the patients with dementia was observed due to pandemic. It exacerbates the stress of the caregivers of patients with dementia. ^[11]The present study was aimed to determine the level of stress among the caregivers of the patients with dementia. In the present study, less than half of the caregivers of patients with dementia 35.5% were in the age group of 20-40 years and similarly 35.5% in 41-60 years respectively. Majority of the caregivers 90.3% were married. Kenneth E. et al. (2003) conducted a study on "patient and caregiver characteristics associated with depression in caregivers of patients with dementia" which shown that 49% of the caregivers were in the age group less than 65 years and majority of the caregivers (81.1%) were married. ^[12]In the present study, in nearly half of the caregivers of patients with dementia 48.4%, spent no. of hours for caregiving ranged from 0-8 hours per day. A similar study conducted by Borges-Machado F et al. (2029) found that less than half of the caregivers 36.1% providing care to their patients that ranged from 4-7 hours per day. ^[13]In the present study, majority of patients 80.6% had a total duration of illness of 1-5 years. Cagnin A. et al. (2020) conducted a study which shown that the average duration of disease among the patients with dementia was 4.5 ± 3.1 . ^[14]Majority of the patient's clinical course of illness was continuous (93.5%). Only 6.5% of dementia patients had a history of the previous hospitalization due to psychiatric illness. Half of the patients with dementia 51.6% had more than 1 medical illnesses and the number of medical illnesses ranged from 0-4. About 45.1% of the caregivers were fallen in upper lower and lower socioeconomic status respectively which were having moderate stress. A similar study conducted by Zahed S. et al. (2019) evidenced that the mean stress score obtained in the study was 25.4 ± 10.9 and classified as moderate stress. ^[15]In the current study, the number of the family members, marital status of caregivers, duration of illness of the patient with dementia and clinical progress of the illness of the patients with dementia were stronger predictors of stress score. The literature assumed that less education consequently leads to low socioeconomic status that is contributing to perceived stress of the caregivers. ^[7]The current study showed the moderate level of stress among the caregivers which was significantly correlated with socioeconomic status of the caregivers. The attention is given on the perceived stress of the caregivers which increased during COVID-19.

Limitations

The limitation of the study was small sample size. It was a cross sectional study, not able to tell the casual relationship. The interviews were conducted over telephone, which has its own limitation. Hence, the findings of the study were not generalized into general settings. There were other factors which could influence the findings of the present study were not taken into account. The study did not account any interventions for the stress management. The study needs the large sample size with interventional strategies to deal with the increased stress during COVID pandemic.

Conclusion:-

The present study, majority of the caregivers have moderate stress during the pandemic which is directly related to the concern of their patients with dementia. Thus, stress is a barrier in the positive mental health outcomes of the caregivers of patients with dementia. The stress level was significantly higher in the caregivers who were married and had upper lower socioeconomic status. These findings demonstrated that there is need of promoting of positive mental health and providing formal health services and family support to the caregivers in coping with the stress.

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Conflicts of interest

There is no conflict of interest.

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