

ORIGINAL ARTICLE

PSYCHOLOGICAL DISTRESS AMONG CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA

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Background: Schizophrenia is a devastating disorder not only for the patients but also for their caregivers. The caregivers of the patients suffer from psychological distress but receive minimum support from psychiatric services. Objectives were to assess the stress level in caregivers of patients with schizophrenia and to determine the association of stress with demographic variables of caregivers. **Methods:** It was a descriptive hospital based study carried out in Psychiatry Department of Khyber Teaching Hospital, Peshawar. Fifty caregivers were included in the study during a period of one year. Socio-demographic variables were recorded on specially designed *pro forma*. Stress level was assessed by using Self Report Questionnaire (SRQ-20) with a cut off score of 9 being taken as stressed. **Results:** Mean age of the caregivers was 45.44 ± 14.25 years. Forty-two (84%) caregivers were males and 8 (16%) were females. Twenty-eight (56%) were uneducated, 16 (32%) had Primary education, 4 (8%) were matriculates and 2 (4%) graduates. Thirty-four (68%) of the caregivers were married 8 (16%) each unmarried and widows/widowers. Thirty-two (64%) were unemployed and 18 (36%) were employed. Two (4%) had been providing care for less than 6 months, 4 (8%) for less than 12 months, 10 (20%) for less than 18 months, 2 (4%) for less than 24 months and 32 (64%) for more than 24 months. 22 (44%) were parents, 14 (28%) were siblings, 2 (4%) were children of the patients. Thirty-six (72%) caregivers were having score of more than 9 on SRQ-20. Stress showed a statistically significant association only with age (p -value < 0.004). **Conclusion:** Psychological distress is present in majority of the caregivers of patients with schizophrenia. There is statistically significant association between age of the caregiver and psychological distress, while gender, educational status, marital status, occupational status, duration of care and relation with the patient are not associated with psychological distress.

Keywords: Psychological distress, caregivers, schizophrenia, Peshawar

J Ayub Med Coll Abbottabad 2013;25(3-4):27-30

INTRODUCTION

Schizophrenia is a psychiatric diagnosis denoting a persistent, often chronic, mental illness variously affecting behaviour, thinking, and emotion.¹ It is a heterogeneous disorder defined by sustained periods of psychosis and functional deterioration in the major arenas of life, such as interpersonal relations, education, employment and self-care.² Schizophrenia ranks 6th in the league of causes of disability worldwide as measured by Years of Life lived with Disability (YLD).³ Even if schizophrenia is not a very frequent disease, it is among the most burdensome and costly illnesses worldwide. It usually starts in young adulthood and causes a high degree of disability, which accounts for 1.1% of the total disability-adjusted life years (DALYs) and 2.8% of YLDs. In the World Health Report, schizophrenia is listed as the 8th leading cause of DALYs worldwide in the age group 15-44 years.⁴

It has long been recognized as a devastating disorder for patients and their families. Although substantial progress has been achieved both in its diagnosis and treatment, and in understanding the disorder's neurobiological substrates, a full

understanding of its origins and pathogenic mechanisms remains elusive.⁵

Carers are people who "provide unpaid care by looking after an ill, frail or disabled family member, friend or partner".⁶ Deinstitutionalization has shifted much of the burden of care of patients with schizophrenia from mental institutions to the family.⁷ In Pakistan, among the patients suffering from severe psychiatric disorders, nearly 43.74% live with their parents and 40.62% with their siblings and about 15.62% with other relatives.⁸ The patients do have an impact on the psychological health of the caregivers and they experience burden and psychological distress at similar levels in all cultures.⁹ Variables like age of caregiver, relation with patient, female gender, duration of care giving, low educational level and employment status are found to be significantly associated with stress.^{9,10} Only 10% of the carers even in developed countries receive psychological support when a relative is ill. This lack of services further adds to the sufferings of the caregivers.¹¹

As a consequence of unremitting stress, multiple aspects of their lives are affected, including relationships, roles, and health. They often do not know how to cope with schizophrenia and its impact on their lives.¹²

There is a high level of behavioural disturbance associated with hallucinations and delusions, disruption of household routine, and medication non-compliance. Patients who show more disturbing behaviours exhibit significantly more stress.¹³

MATERIAL AND METHODS

It was a descriptive hospital based study carried out in Psychiatry Department of Khyber Teaching Hospital, Peshawar. Fifty caregivers were included as per convenience in the study during a period of one year. Socio-demographic variables were recorded on specially designed *pro forma*. Stress level was assessed by using Self Report Questionnaire (SRQ)-20 with a cut off score of 9 being taken as stressed. Data was analysed using SPSS-16.

RESULTS

A total of 50 caregivers who accompanied the patients with schizophrenia in Psychiatry Department of Khyber Teaching Hospital, Peshawar and satisfied the study criteria were included. Mean age of the caregivers was 45.44±14.25 years. The socio-demographic profile of the caregivers is shown in the Table-1

The stress level of the caregivers as assessed by SRQ-20 showed that 36 (72%) of them were having SRQ-20 score of more than 9 and 14 (28%) had score of less than 9. The duration of the care giving showed that 2 (4%) caregivers had been providing care for less than 06 months, 4 (8%) for less than 12 months, 10 (20%) for less than 18 months, 2 (4%) for less than 24 months and 32 (64%) for more than 24 months. In 22 (44%) of the patients caregivers were parents, 14 (28%) were siblings, 2 (4%) were children and 12 (24%) were others.

The association of stress with gender, age, relationship, education, marital, employment status and duration of care giving was assessed and a *p*-value of less than 0.05 was considered significant. Apart from age of the caregiver, no other variables were significantly associated with stress.

Table-1: The socio-demographic profile of the caregivers

Characteristics	No.(%)	
Gender	Male	42 (84%)
	Female	8 (16%)
Educational Status	Uneducated	28 (56%)
	Primary	16 (32%)
	Matriculate	4 (8%)
	Graduate	4 (8%)
Marital Status	Married	34 (68%)
	Un married	8 (16%)
	Widow/widower	8 (16%)
Employment status	Unemployed	32 (64%)
	Employed	18 (36%)

DISCUSSION

Schizophrenia has long been recognized as a devastating disorder for patients and their families.⁵ Majority of patients with psychiatric disorders remain in close contact with their families⁸ and families are the main caregivers for patients suffering from psychiatric illnesses⁷.

As a result of the consistent support to these patients and continuous care for years at the end, the family members are at risk of developing psychological distress, anxiety and depression.^{10,13-15} In comparison of the distress in caregivers of patients with schizophrenia and eating disorders higher rates of distress are found in the caregivers of patients with schizophrenia.¹⁶⁻¹⁸

Psychological distress in caregivers is reported in all cultures.⁹ Along with other factors, stress in caregivers is also related to lack of support from psychiatric services.¹¹

Nearly 83% of the caregivers have psychological distress^{16,19} whereas burden is reported by 45% of the caregivers.²⁰ In Pakistan 40% caregivers are at risk of developing depression and anxiety.¹⁸ Similar findings were observed in a follow-up study where depression was present in 40% of the caregivers.²¹

In this study the results were consistent with previous studies in Pakistan and other countries. Majority of the caregivers (72%) were found to have a score of 9 or more on SRQ-20 and were found to be distressed. This higher psychological distress might be because of the study design (hospital based), inclusion of only those caregivers who were living with the patient or might had been because the patients coming to hospital are more disturbed than those in the community. It needs further evaluation whether this higher prevalence is due to higher prevalence of distress in the community in the province of Khyber Pakhtunkhwa (KPK)²² or is independent of it.

The subjective, objective and economic consequences of care giving and their relationship with distress in the caregivers are established facts for long.²³ In the recent years there have been concerns about the correlation of caregivers' psychosocial resources and socio-demographic variables with family burden and stress.²⁴

The socio-demographic variables include age, gender, marital status, education, employment, relationship with the patient and duration of care giving. Family burden is associated with patients' symptoms, male gender, unemployment, marital status, patient's contact and being a patient's parent.²⁵ In a local study the commonest reasons of depression in caregivers were the effect of sex, socio-economic

status, marital status, family size, education and relationship with the patient.¹⁷ Among the caregivers of the patients with cancer it was found that association of stress was significant with female gender, age more than 41 years, being parent as caregiver and caring for a patients with illness duration more than one year.¹⁰ Some studies have emphasized over only one or more of these demographic variables to be more related to psychological distress and depression while others have included many.

It is also reported that the younger caregivers are more distressed than the older ones and is the result of more responsibilities and roles a younger person has to carry out. Here the sample consisted of mothers and spouses and the mean age of the caregivers was 55 years and the majority of participants had less than 9 years of education.⁹ Similar correlations with age were also found in other studies.²¹ In our study mean age of the caregivers was 45.44. The difference could be because we did not include caregivers above the age of 65 years in our study while the other studies included all age groups. In our study there was significant association of distress with age which is consistent with other studies. The findings of our study were found consistent with study in Bali, Indonesia, where mean age of the key caregivers was 45.6 ± 14.7 years.²⁶

Some studies reported relationship of depression with female gender and duration of care giving more than 18 months.¹⁸ The effect of gender may be highlighted more as depression is generally more prevalent in females in Pakistan.¹⁷

In our study though 100% of the females scored more than 9 on SRQ-20 but this did not yield any significance as the female sample size was only 8 which was not representative of the female population.

The effect of lower education is thought to be more related to psychological distress.²⁶ In the context of caring for an adult with schizophrenia, low levels of education are related to lower socioeconomic status and it results in fewer resources available to caregivers.⁹ In our study the majority of the caregivers were uneducated or if educated had been having lower levels of education. Though no association with distress was reported by educational levels in our study, it could have contributed an additive effect to overall higher level of distress. Duration of care is reported to be related to the psychological distress and depression.^{10,18}

Majority of our subjects in this study were males, parents or siblings, unemployed and had been caring for more than 24 months. Though no association was found with psychological distress individually with these variables, yet these could

have contributed to additive effects in overall higher rates of distress. Majority of patients were accompanied by male caregivers and this might have had a cultural reason. Other important considerations are the hospital based study and the studied sample not been true representative of the community.

CONCLUSION

Psychological distress is present in majority of the caregivers of patients with schizophrenia. There is significant association between age of the caregiver and psychological distress, while gender, educational status, marital status, occupational status, duration of care and relation with the patient are not associated with psychological distress.

The high rates of caregivers' psychological distress found in our study suggest that interventions with family caregivers of a relative with schizophrenia should include attention to the mental health of family caregivers in addition to recovery of the patient.

Our findings also suggest that current interventions that work with caregivers to help reduce psychiatric symptoms of their relative may indeed have an impact on lowering the stress of caregivers.

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