

Original Research Article

Association between symptom profile of schizophrenia and the perceived wellbeing in their caregivers

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ABSTRACT

Background: The chronic nature of Schizophrenia has a devastating impact not only on the patients but also in their caregivers. The burden experienced by the caregivers can seriously affect the psychological wellbeing and caregivers take up multiple coping strategies to tackle the burden. This study was undertaken to find the association between symptom profile of Schizophrenia patients and the perceived wellbeing of their caregivers.

Methods: 30 patients with schizophrenia and their caregivers (parents or spouses), who were actively involved in care of the patient for at least 6 months prior to assessment, were included in the study. Patients were evaluated by socio demographic data sheet and Positive and negative syndrome scale (PANSS) while their caregivers were evaluated using Caregiver socio demographic data sheet, Burden Assessment Schedule (BAS), Coping Checklist (CCL) and Psychological Well Being Questionnaire (PWBQ). Statistical analysis was done using Chi square test and Fischer exact test for categorical variables, Pearson correlation to find correlation between data and Analysis of variance (ANOVA) to find significance of study parameters between groups. $p < 0.05$ was considered significant.

Results: Burden experienced by caregivers was more with a severe symptom profile. Moderate correlation is found between patient's positive symptom profile, negative symptom profile and burden. There was a weak correlation between patient's symptom profile and care givers coping strategies. The total PANSS scores did not influence the pattern of coping. There was no statistically significant difference in coping strategies in positive and negative symptom of schizophrenia. There was a moderate negative correlation between patient's symptom profile (positive and total PANSS score) and psychological wellbeing in caregivers. However, there was a weak correlation between patient negative symptom profile and psychological wellbeing in caregivers.

Conclusions: Burden and wellbeing of the care givers of schizophrenic patients are closely inter related. These parameters are in turn related to patient's symptoms profile namely, the overall psychopathology and more with the positive symptoms of schizophrenia. Though all care givers used different coping strategies, there did not appear to be any interrelation between strategies and the perceived burden, well-being and patient's psychopathology.

Keywords: Burden, Caregivers, Coping, Schizophrenia, Wellbeing

INTRODUCTION

A severe mental illness, like schizophrenia, has a devastating impact on the patient as well as his or her family members. This is due to chronic nature of the illness and the long term it often involves. Patient

experiences problems related to both positive symptoms such as aggressive behavior, delusions, hallucinations and negative symptoms such as poor motivation and inadequate self-care. The capacity for social relationship is often diminished, and employment opportunities are reduced.^{1,2} Patient's relatives experience a range of emotions, from loss and grief to guilt and anger. Like the

patient they also feel isolated and stigmatized. The addition of the care giving role to already existing family roles becomes stressful; physically, psychologically and economically.³

Burden has an objective and a subjective component. Objective burden refers to the disruptions in everyday life for family members such as financial costs, loss of free time and altered social relationships, while subjective burden is viewed as the emotional costs of the illness to the family.^{4,5} Coping refers to the person's constantly changing cognitive and behavioral efforts to manage an encounter appraised as stressful. Coping strategies can be problem focused or emotion focused. The former refers to strategies where the emphasis is on solution to the problem, while the latter refers to ways in which the individual regulates the emotional response to the problem situation.^{6,7} In situations of chronic stress, emotion focused coping strategies are more likely to be adopted.

Greater burden was predicted by more severe patient negative symptoms (stressor), greater anger control and blame self-coping (vulnerability), and decreased tangible social support (resource) in the caregiver.⁸ Research suggests that the negative symptoms of schizophrenia contribute more to poor functional outcomes in the patient and their care givers report high levels of burden.⁹ The problem behavior factor was significantly and positively associated with positive but not negative symptoms, whereas the reverse was true for impairment in activities of daily living, which was positively associated with negative but not positive symptoms.⁵ Caregiver burden and their psychological well-being was not only controlled by the positive and negative symptoms alone but also by the coping strategies used by the caregiver in response to the symptom profile.

Higher levels of subjective burden were related to (1) greater perceived frequency of positive and negative symptom behaviors, (2) a tendency to use problem-focused oriented coping for dealing with negative symptom behaviors and (3) a tendency not to use problem-solving oriented coping for dealing with positive symptom behaviors. Well-being was also related to lower perceived frequency of positive symptom behaviors and social support, but not to coping style.¹⁰ Positive symptoms and total PANSS score are related to lower psychological well-being. This shows that positive symptoms of patients are related to greater feelings of burden among caregivers, which is in turn related to more depressive symptoms and emotional wellbeing.¹¹

Mental health problem in India mostly remains unnoticed due to various reasons i.e. it is either not considered as a problem needing attention or sometimes it is ignored as no one in the family has time to think or discuss about the mentally challenged person and their mental ailment. The situation gets further aggravated by lack of adequate medical or health facility to treat the case right in earnest.

India with a population of more than one billion is home of one sixth of the world's mentally ill. The prevalence rate of schizophrenia as reported in India range from is 0.7-5.5/1000.¹²

Thare and Srinivasan highlight certain aspects of Schizophrenia which are unique in our culture. Marriage rates are high (almost 70%) as compared to the west.¹³ This is probably because the age of marriage is lower in India, especially in woman. Onset of illness is often after the marriage, especially in women, which leads to more broken marriages. Male patients are likely to remain single. The presence of children is often a protective factor in marriage.

Very few studies have examined the patients` symptom profile in relation to burden, coping and well-being in caregivers of schizophrenia, more so in the Indian context. On this background, the present study attempts to explore the relationship between the burden experienced by the caregivers, their psychological wellbeing and the coping methods evolved by them to handle the problems in relation to the clinical symptom profile of the illness. The aim of the study was to explore the association between symptom profile of schizophrenic patients and burden, coping styles and subjective well-being in caregivers.

METHODS

This was a prospective observational study conducted at the outpatient department of psychiatry, Government Thanjavur Medical College and Hospital, Thanjavur, Tamilnadu, India from July 2011 to December 2011. Thirty patients who were diagnosed with schizophrenia as per WHO ICD-10 and their caregivers (parents or spouses), who were actively involved in care of the patient for at least 6months prior to assessment, were included in the study. Patients who were affected by other mood affective disorders or by psychosomatic drug intake were excluded from study. Patients were evaluated by socio demographic data sheet and Positive and negative syndrome scale (PANSS) while their caregivers were evaluated using Caregiver socio demographic data sheet, Burden Assessment Schedule (BAS), Coping Checklist (CCL) and Psychological Well Being Questionnaire (PWBQ).¹⁴⁻¹⁷ Data entry and analysis were done using SPSS software version 17.0. Descriptive data were given in summary statistics while statistical analysis was done using Chi square test and Fischer exact test for categorical variables, Pearson correlation to find correlation between data and Analysis of variance (ANOVA) to find significance of study parameters between groups. $p < 0.05$ was considered significant.

RESULTS

30 consecutive patients with schizophrenia and their caregivers were evaluated to know the symptom profile

of the patient and the level of burden, coping strategies and psychological wellbeing in the caregivers.

From the socio demographic data of patients (n=30), 60% (n=18) were males, 56.7% (n=17) were younger than 30 years, 56.7% (n=17) had completed higher education (PUC and above), 66.7% (n=20) were unemployed, 46.7% (n=14) were married, 46.7% (n=14) had children, 70% (n=21) were from urban background and 50% (n=15) had duration of illness more than 5 years. From the socio demographic data of caregivers (n=30), 50% (n=15) were males, 33.3% (n=10) were younger than 40 years, 50% (n=15) had completed higher education (College education), 76.7% (n=23) were employed, 56.7% (n=17) were parents and 50% (n=15) were giving care for more than 5 years.

All patients (n=30) had more positive symptoms than negative symptoms. This was probably due to the fact that the entire sample was diagnosed to have paranoid schizophrenia.

Burden experienced by caregivers was more with a severe symptom profile (Figure 1) (Table 1). This indicates that higher the total score on PANSS, more severe was the perceived burden. Moderate correlation is found between patient's positive symptom profile, negative symptom profile and burden which was found to be statistically significant (p<0.01). This shows that the presence of positive symptoms or negative symptoms, each by themselves affected the perceived burden.

Table 1: Correlation between patient's symptom profile and care giver's burden, coping strategies and psychological well-being.

Positive and negative syndrome scale (PANSS)	Burden assessment score		Coping check list		Psychological well-being questionnaire	
	R value	P value	R value	P value	R value	P value
PANSS - positive symptoms	0.574	0.001*	0.134	0.482	-0.501	0.005*
PANSS - negative symptoms	0.472	0.008*	0.177	0.349	-0.199	0.293
PANSS - global	0.671	<0.001*	0.371	0.044*	-0.191	0.337
PANSS - total	0.715	<0.001*	0.316	0.089+	-0.322	0.023*

* p < 0.05 - Statistically significant

There was a weak correlation between patient's symptom profile and care givers coping strategies. The total

PANSS scores did not influence the pattern of coping (Table 2).

Table 2: Correlation between burden, coping strategies and psychological wellbeing in caregivers.

Variables	Correlation (r)	P value
Burden assessment score vs Coping check list	0.288	0.123
Burden assessment score vs Psychological well being questionnaire	-0.413	0.023*
Coping check list vs Psychological well being questionnaire	0.053	0.782

* p < 0.05 - Statistically significant

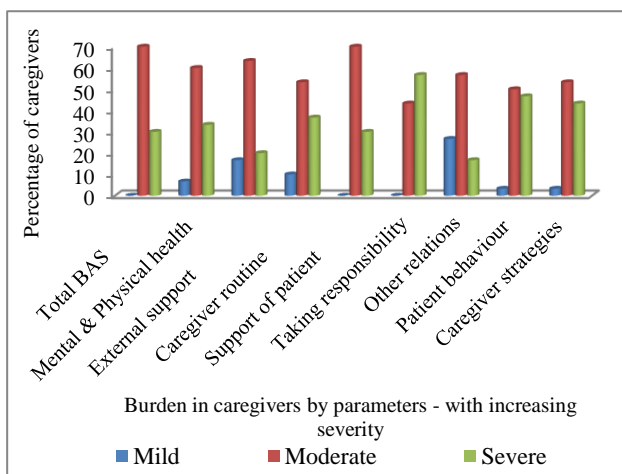


Figure 1: Assessment of burden in caregivers (mild, moderate and severe).

All the caregivers used coping strategies, irrespective of whether the symptom profile was predominantly positive or negative. There was no statistically significant difference in coping strategies in positive and negative symptom of schizophrenia. There was difference in burden perceived and the coping strategies adopted by parents and spouses of patients (Figure 2, 3).

There was a moderate negative correlation between patient's symptom profile (positive and total PANSS score) and psychological well-being in caregivers, which was statistically significant. However, there was a weak correlation between patient negative symptom profile and psychological wellbeing in caregivers and this was not statistically significant (Table 2). Higher the total PANSS score; lower was the psychological well-being. This association was also true for positive symptoms, i.e., higher the positive symptom score, lower was the well-

being of the care giver. This shows that positive symptoms of patients were related to greater feelings of burden among caregivers, which was in turn related to more depressive symptoms and poorer emotional wellbeing. There was no significant relationship between the predominance of negative symptom scores and psychological well-being of the care giver.

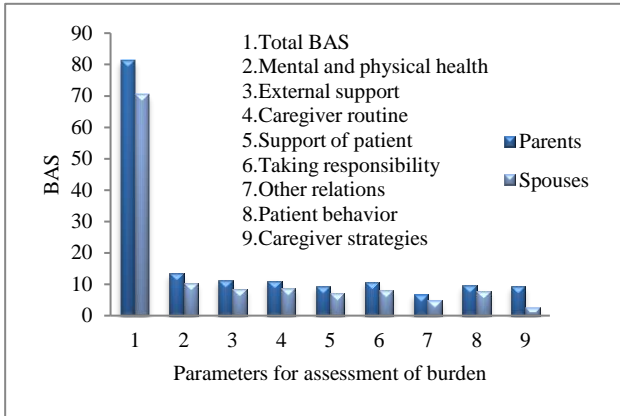


Figure 2: Differences in burden experienced by caregivers of schizophrenia (parents and spouses).

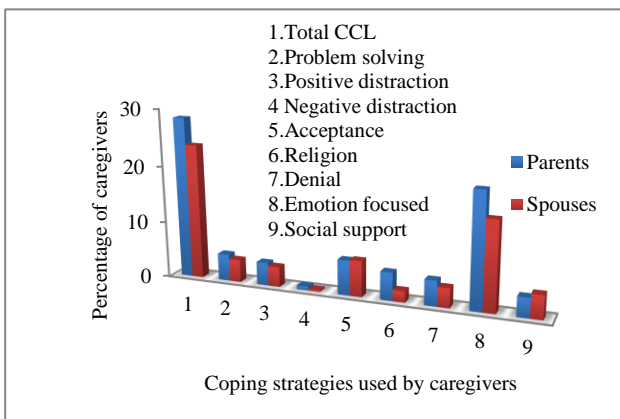


Figure 3: Distribution of coping strategies among caregivers of schizophrenia (parents and spouses).

DISCUSSION

Studies on burden and distress in families of persons with schizophrenia in India have been conducted since the past few decades. Early studies indicated that the mentally ill person was perceived as a financial liability and a source of disturbance to family life. Burden was perceived by family members mainly in the areas of finance, interpersonal relationships and physical and mental health of the care giver.¹⁸

Gautam and Nijhawan found that relatives of patients with schizophrenia experienced severe burden and that the relatives of male schizophrenics experienced increased financial burden.¹⁹ Gopinath and Chaturvedi found that inactivity, slowness, poor self-care, inability to participate in household activities were perceived as most

distressful. Interestingly, aggressive or psychotic behavior was not perceived as distressful by relatives. However, young and educated relatives reported an increased overall distress and burden. Negative symptoms of patients were associated with greater distress in care givers.²⁰

It has been found in our study that 70% of patients and their caregivers were from urban background. However, different results were found in the study by Ali and Bhatti, who found that families experienced equal burden irrespective of the residential settings.²¹ A review of 48 studies on family structure and problems found that majority of psychiatric patients came from nuclear families. Unlike in the West, the traditional joint family system in India acts as a buffer against various kinds of stresses. However, due to rapid urbanization and industrialization, the joint family system is breaking. The nuclear families are more vulnerable to stresses and are less equipped to handle mentally ill members.²²

Another study showed that burden was principally felt in the areas of family routine, family leisure, family interaction and finances. The emotional health of the family was relatively untouched and the impact on physical health of the caring relatives due to burden of care was almost negligible.²³ Despite high levels of burden, care givers experienced subjective well-being scores in the normal range, indicating that they possessed considerable coping resources.²⁴ In the study by Shankar et al., global disability was higher in females, particularly with regard to poor role functioning in terms of slowness and lack of involvement in household chores. In both sexes, negative symptoms predominated among the factors associated with global disability.²⁵

In addition to experiencing high degrees of psychiatric morbidity, spouses of persons with schizophrenia reported greater time sharing and less participation in social activities than spouses in the normal group.²⁶ In the present study, 60% of caregivers were males, 56.7% had completed higher education while 66.7% were unemployed which was in contrast to the studies by Pai et al and Moily et al in whose studies, majority of the caregivers of schizophrenic patients were female (55%), illiterate and unemployed.^{27,28} Low socio-economic status, stigma and low educational level of the caregiver were correlates of psychiatric morbidity in caregivers while this burden was significantly and positively correlated with duration of the illness in schizophrenia.²⁹

In a study on the coping styles of caregivers, 71% of the relatives used resignation strategies, 79% failed to maintain social contacts and 60% did not seek information about the illness. Only one third of the relatives ever attempted active social involvement of the patients, coercion and avoidance strategies. Resignation, as a coping strategy, had a significant and positive correlation with burden. Resignation correlated positively with the presence of negative symptoms.³⁰ In the present

study, it was found that parents and siblings of schizophrenic patients experienced more burden in comparison to spouses which was similar to the results obtained by Trivedi et al. Younger relatives experienced more burden than the middle age group relatives. Longer the duration of illness more was the burden. Gender differences were seen, with females perceiving greater burden in respect to external support, spouse related, physical and mental health areas.³¹

In the study of perceived burden and coping strategies in patients and spouses of persons with schizophrenia by Rammohan et al it was found that spouses reported greater emotional burden. Parents used more of denial as a coping strategy while spouses used more of negative distraction strategies. On stepwise regression analysis, patient's age, level of education and level of functioning and caregiver's use of denial as a coping strategy emerged as significant predictors of caregiver burden.³²

The quality of burden experienced by family members in relation to negative and positive symptoms differed in different aspects of perceived burden. In the present study, BAS score was statistically significant in all the spectrum of symptoms of schizophrenia. This was similar to the results obtained in studies by Provencher et al. and Magliano et al but Wolthaus et al had found increased burden with positive symptoms alone while Mahendru et al had found negative symptoms to be a greater source of burden.³³⁻³⁶

In a study looking at gender and burden issues, it was found that female caregivers experienced greater burden. If patient is male and lived in joint families, family stress levels are likely to be significantly higher leading to greater burden.³⁷ Research on burden and distress carried out in the Indian context have found the same trends to exist, as in the west. Patient demographic variables like age, gender and education are correlated with burden, as are illness related variables such as duration and severity. Financial difficulties and disruption of family routine are the areas where burden was felt the most. Some studies indicate that despite the presence of burden, levels of well-being are in the normal range, indicating these caregivers have resources which enabled them to cope with the stress of care giving. Few studies have examined the well-being of the caregivers of schizophrenia in India.

It has been reported that despite high levels of burden associated with schizophrenia, caregivers in India display subjective well-being within the normal range, suggesting considerable degree of resilience.³⁸ In the present study, psychological wellbeing in caregivers was inversely correlated to positive symptoms PANSS score and overall PANSS score and this was statistically significant. Higher the total PANSS score lower was the psychological well-being. This association was also true for positive symptoms, i.e., higher the positive symptom score, lower was the well-being of the care giver. This was similar to the study done by Sandy M. Magana.³⁹

Rammohan found that higher levels of wellbeing were reported by caregivers of female schizophrenic patients with shorter duration of illness. Higher levels of well-being were also associated with the use of problem solving coping strategies rather than denial.⁴⁰

CONCLUSION

Thus, burden and well-being of the care givers of schizophrenic patients are closely inter related. These parameters are in turn related to patient's symptoms profile namely, the overall psychopathology and more with the positive symptoms of schizophrenia. Though all care givers used different coping strategies, there did not appear to be any interrelation between strategies and the perceived burden, well-being and patient's psychopathology. The above finding would help in planning interventions for the care givers of schizophrenic patients, which reduce their burden, improve positive coping skills and enhance their psychological well-being. This would in turn improve the quality of care given to the schizophrenic individuals.

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REFERENCES

1. Lefley HP. Family Burden and Family Stigma in major mental illness. *American Psychologist.* 1989;44(3):556-60.
2. van Wijngaarden B, Schene AH. Caregiving Consequences in The Netherlands and Other European Countries: The Development and Use of the Family. *Family Interventions in mental illness: International perspectives.* 2002:145.
3. Robin E. Clark. Family costs associated with severe mental illness and substance abuse. *Hospital Community Psychiatry.* 1994;45(8):808-13.
4. Cohler BJ, Pickett SA, Cook JA. The psychiatric patient grows older: Issues in family care. Springer. 1991:82-110.
5. Hoenig J, Hamilton MW. The schizophrenic patient in the community and his effect on the household. *Inter J social Psychiatry.* 1966;12(3):165-76.
6. Folkman S, Lazarus RS. An analysis of coping in a middle-aged community sample. *J Health Social Behavior.* 1980;21:219-39.
7. Lazarus RS. From psychological stress to the emotions; A history of changing outlooks. *Annual Review of Psychology.* 1993;44:1-21.
8. Dyck DG, Short R, Vitaliano PP. Predictors of burden and infectious illness in schizophrenia caregivers. *Psychosomatic Medicine.* 1999;61(4):411-9.
9. Lysaker PH, Lancaster RS, Nees MA, Davis LW. Attributional style and symptoms as predictors of social function in schizophrenia. *J Rehabilitation Research Development.* 2004;41(2):225-32.
10. Velligan DI, Mahurin RK, Diamond PL, Hazleton BC, Eckert SL, Miller AL. The functional significance of

- symptomatology and cognitive function in schizophrenia. *Schizophrenia research.* 1997;25(1):21-31.
11. Magaña SM, Ramírez García JI, Hernández MG, Cortez R. Psychological distress among latino family caregivers of adults with schizophrenia: the roles of burden and stigma. *Psychiatric services (Washington, DC).* 2007;58(3):378-84.
 12. Reddy VM, Chandrashekar CR. Prevalence of mental and behavioural disorders in india: a meta-analysis. *Ind J Psychiatry.* 1998;40(2):149-57.
 13. Thara R, Srinivasan TN. The outcome of marriage in schizophrenia. *Social Psychiatry Psychiatric Epidemiology.* 1997;32:416-20.
 14. Kay SR, Fiszbein A, Opler LA. The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin.* 1987;13(2):261-76.
 15. Thara R, Padmavati R, Kumar S, Srinivasan L. Burden assessment schedule instrument to assess burden on caregivers of chronic mentally ill. *Ind J Psychiatry.* 1998;40(1):21-9.
 16. Rao K, Subbakrishna DK, Prabhu GG. Development of a coping checklist-a preliminary report. *Ind J Psychiatry.* 1989;31(2):128-33.
 17. Bhogle S, Jaiprakash I. Development of the Psychological well-being (PWB) Questionnaire. *J Personality Clinical Studies.* 1995;11(1-2):5-9.
 18. Muralidhar D, Shariff IA. Obstacles in the way of readjustment of mental patients in the family. *J Rehabilitation Asia.* 1981;21(4):37-41.
 19. Gautam S, Nijhawan M. Burden on families of schizophrenic and chronic lung disease patients. *Ind J Psychiatry.* 1984;26:156-9.
 20. Gopinath, PS, Chaturvedi, SK. Distressing behavior of schizophrenics at home. *Acta Psychiatrica Scandinavica.* 1992;86:185-8.
 21. Ali M, Bhatti RS. Social support system and family burden due to chronic schizophrenia in rural and urban background. *Ind J Psychiatry.* 1988;30(4):349-53.
 22. Bharat S. Research on family structure and problems: Review, implications and suggestions. *Research on families with problems in India.* 1991;1:33-67.
 23. Chakrabarti S, Raj L, Kulhara P, Avasthi A, Verma SK. Comparison of the extent and pattern of family burden in affective disorders and schizophrenia. *Ind J Psychiatry.* 1995;37(3):105-12.
 24. Pai S, Kapur RL. Evaluation of home care treatment for schizophrenia patients. *Acta Psychiatrica Scandinavica.* 1983;67(2):80-8.
 25. Shankar R, Kamath S, Joseph AA. Gender differences in disability: A comparison of married patients with schizophrenia. *Schizophr Res.* 1995;16:17-23.
 26. Mahendru RK, Singh V, Sachan SN. A study of psychiatric morbidity in the spouses of schizophrenic patients. *Ind J Psychiatry.* 1997;39:48.
 27. Pai S, Kapur RL. The burden on the family of a psychiatric patient: Development of an interview schedule. *Brit J Psychiatry.* 1981;138:332-5.
 28. Moily S, Murthy RS, Nagarajaiah B, Sekar K, Puttamma M, Kumar KV, et al. Burden in families with schizophrenic patients in a rural community. *Indian J. Psychiatry.* 1997;39:48.
 29. Vohra AK, Garg S, Gaur DR. A study of burden on families of schizophrenia and depressive disorder. Abstracts of the scientific papers presented at the 54-annual national conference of Indian Psychiatric Society. *Ind J Psychiatry.* 2000;42:33.
 30. Chandrasekaran R, Sivaprakash B, Jayestri SR. Coping Strategies of the Relatives of Schizophrenic Patients. *Ind J Psychiatry.* 2002;44(1):9-13.
 31. Trivedi JK, Dalal PK, Kalra H. Family burden and coping strategy in relatives of schizophrenic patients. *Ind J Psychiatry, Supplement.* 2003;106.
 32. Rammohan A, Rao K, Subbakrishna DK. Burden and Coping in Caregivers of Persons with Schizophrenia. *Ind J Psychiatry.* 2002;44(3):220-7.
 33. Provencher HL, Mueser KT. Positive and negative symptom behaviors and caregiver burden in the relatives of persons with schizophrenia. *Schizophrenia Research.* 1997;26(1):71-80.
 34. Magliano L, Marasco C, Fiorillo A, Malangone C, Guarneri M, Maj M. The impact of professional and social network support on the burden of families of patients with schizophrenia in Italy. *Acta Psychiatrica Scandinavica.* 2002;106(4):291-8.
 35. Wolthaus JE, Dingemans PM, Schene AH, Linszen DH, Wiersma D, Van Den Bosch RJ, et al. Caregiver burden in recent-onset schizophrenia and spectrum disorders: the influence of symptoms and personality traits. *J Nervous Mental Dis.* 2002;190(4):241-7.
 36. Mahendru, R.K. Mental morbidity and personality pattern in the spouses of schizophrenic patients. *Ind J Psychiatry.* 1996;38:14-5.
 37. Kumar S, Mohanty S. Spousal burden of care in schizophrenia. *J Ind Academy Applied Psychol.* 2007;33(2):189-94.
 38. Roychaudhuri J, Mondal D, Boral A, Bhattacharya D. Family burden among long term psychiatric patients. *Ind J Psychiatry.* 1995;37(2):81-5.
 39. Magaña SM, Ramírez García JI, Hernández MG, Cortez R. Psychological distress among latino family caregivers of adults with schizophrenia: the roles of burden and stigma. *Psychiatric services (Washington, DC).* 2007;58(3):378-84.
 40. Rammohan A, Rao K, Subbakrishna DK. Religious coping and psychological well-being in carers of relatives with schizophrenia. *Acta Psychiatrica Scandinavica.* 2002;105(5):356-62.

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