



FAMILY BURDEN OF CARE GIVER IN CHRONIC SCHIZOPHRENIA: A CASE STUDY

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Abstract

Background: Family caregiver bears the burden and responsibilities of providing the treatment and the rehabilitation of schizophrenic patient with the society. This disorder gives severe distress to the patient and his family members.

Method: The study was to assess the insight of the patient and family burden of care giver of the patient with chronic schizophrenia, and to measure the effect of the intervention on insight and family burden of the care giver of the patient at before, after and follow-up assessments.

Results: The salient highlights were that the patient underwent the pharmacological and psychological intervention (PPI) was benefited mostly since he had high insight into his illness and to arrest his symptoms mostly and did routine work usually. It is interesting to observe that the symptoms associated with schizophrenia were reduced in the patient. Burden was defined as a negative impact of caring for the impaired person experienced by caregiver. The burden of impact on wellbeing, appreciation of caring, impact on relationship with others, and perceived society of the disease were reduced in the present study.

Conclusion: It could be inferred that patient who had schizophrenia was mostly benefited with the intervention in reducing the severity of symptoms. The patient had insight more than 85% and maintained well and the burden of care giver was reduced tremendously. Therapist could teach various skills to the patient and his family member in bringing about change in his quality of life and caregiver's burdens.

Keywords: *Insight, Burden, Caregiver, PPI Intervention.*

INTRODUCTION

Schizophrenia is a disabling, chronic and severe mental illness. Care giver of the family is often frustrated and such frustrations are enhanced by an acute care model that lacks a longitudinal perspective and this sets a relatively low value on maintenance of treatment and rehabilitation of the patient with chronic schizophrenia. In India, the asylum based treatment is withdrawn by the Government of India and the burden of treatment and management has been shifted to families. The estimate of the overall financial burden to these families is increasing enormously and the patients may have no place to live, may be forced to live in circumstances of isolation and hopelessness, or may end up in jail. Severity of the illness affects the patient, his family and society.

The primary caregiver and the family have to bear the burden of providing the treatment at an initial stage of schizophrenic patients for the rehabilitation. This is a long and tedious course in most of the cases and the family members have to face burden during the whole process. The patients may experience impairment in thought process which influences their behaviors. The behaviors are odd and sometimes harmful for themselves, such as committing suicide (Pompili et al, 2009) or violence to others (Vivera et al, 2005). Besides, the disease may relapse during treatment and recovery (Bostrom & Boyd, 2005).

The patients with schizophrenia are frequently hospitalized and usually need long term care and treatment in order to reduce negative impacts. The caregiver is the most important person who cares for the person with schizophrenia. The caregiver takes care of approximately 60 to 85% of the disabled or impaired people (Clement, Gerber, & McGuire, 1995). He usually helps patient in performing their daily activities such as, bathing, eating, cooking, dressing, taking drug, and checking up. However when care is provided for longer time, particularly for patients with schizophrenia, caregiver can experience burden that leads to negative consequences (Caqueo-Urizar & Gutierrez-Maldonado, 2006; Grandon, Jenaro, & Lemos, 2008; Roick et al, 2006; Shu-Ying et al, 2008).

Burden negatively affects caregiver's physical, emotional, and economic status (Caqueo-Urizar, & Gutierrez-Maldonado, 2009). Furthermore, their negative quality of life has impacted on poor caring, mistreatment or behaving violently to the patients which can cause patients relapse (Bostrom & Boyd, 2005; Havens, 1999). Burden of caregivers also causes family conflict and financial problem in individual, family, and health care system. So it is obvious that the family has got an important role to play in the overall management, both pharmacological and psychological, of chronic schizophrenic patient. But this important area has never been examined systematically in this part of the country. This study tries to explore the

various aspects of this particular subject in relation to our sociocultural setup. The most important is how the caregiver is able to use coping technique and utilize the social support (Roick et al, 2007). Coping strategies and receiving more practical support from their family members have proved a reduction of family burden over time (Magliano et al, 2000).

OBJECTIVES

The objectives were as below

1. To assess the insight and family burden of the patient before administering the pharmacological and psychosocial intervention
2. To assess the after effect of pharmacological and psychosocial intervention to the patient suffering from chronic schizophrenia.

METHODOLOGY

Design: Pre-post design was used in the study to assess the efficacy of pharmacological and psychosocial intervention.

Sample: Schizophrenic patient, Mr. N who admitted in the psychiatric ward, Chennai, for getting treated for his mental disturbances served as sample for the study. Care giver counseling for taking drugs and psychosocial intervention were given to the caregiver. The caregiver of the patient consented to participate in the study.

Demographic Information

The male patient who had pharmacological and psychosocial intervention was primarily in the age of 23. He belonged to Hindu religion had education of diploma in computer and had no sibling. Experience of schizophrenia and its impact on functioning was more than 9 years. The patient stated that he was unaware of what he was talking or doing and upsetting her family members who recognized the symptoms and were trying to help him.

Materials

- a. ICD-10 diagnostic criteria –was used to do diagnosis the disorder of schizophrenia.
- b. At baseline level, Beck insight scale (Beck et al, 2004) was administered which comprised 15 items ranging from 0- do not agree at all, to 3- agree completely. He scored 7% in insight at before assessment and after assessment he had insight 85%. Perhaps he might improve still more insight at follow-up assessment.
- c. The Burden Assessment Schedule (BAS) developed by Sell et al, (1998) was used to assess the impact on wellbeing, marital relationship, appreciation of caring, impact on relationship with others, and perceived society of the disease. Marital relationship was omitted as per the manual as he did not marry a girl. It comprised 20 item ranging from 0- not at all, 2 some extend, and 3 very much.

PHARMACOLOGICAL AND PSYCHOSOCIAL INTERVENTION (PPI)

The patient was subjected to detailed physical and neurological examination to exclude organic causes and the patient was diagnosed the disorder of schizophrenia. He was admitted in the psychiatric ward for treatment. He was put under medications by the psychiatrist, and the intervention was done by the psychologist for weekly twice for a period of six months. ECTs were given at two different periods for seven times in the first episode, followed by the relapse of second time, where ten ECTs were given by a different psychiatrist. The antipsychotic, and antidepressant drugs, injection Serenace and Lopez were given by the psychiatrist to the patient. They were instructed to continue take the prescribed antipsychotic drugs. The patient's caregiver, his aunt, was given adequate information about the illness and guidelines on its management were provided. The main goals in this discussion were acceptance and understanding of the reality of the illness, identification of precipitating factors for present episode and future, within and outside of the family, elucidation of family interactions, planning strategies for managing stresses and acceptance of the need for continued treatment after the discharge.

The caregiver could play a very important role in detecting subtle fluctuating behavior of the patient and could act therapeutically. It may be as promising as other psychosocial interventions in improving therapeutic outcomes, because she (caregiver) involves the patient's immediate world. It might be an important means of helping the task of better dealing with the illness and its consequences. It was administered for six months in 45 minute session - psycho education, communication enhancement training and problem-solving skills. The therapy focus was directed to clinically relevant dimensions of daily functioning as problem solving, communication, involvement and behavior control. This therapy relied on a core set of therapeutic principles tailored to the individual's problems. The therapy was performed through a progressive series of stages - assessment, contracting, treatment and termination.

Results

Table – 1, Shows the burden assessments of the patient with schizophrenia

S.No	Burden assessment schedule	Assessments		
		Before	After(6months)	Follow-up
1	Impact on wellbeing	12	6	6
2	Appreciation of caring	12	7	5
3	Impact on relationship with others	12	8	7
4	Perceived society of the disease	12	9	8
	Total score	48	30	24

The above table showed a remarkable decrease of burden schedule at after and follow up (2 months) assessments.

Care Giver Report

He faced the following hardships which were reduced after the treatment. The hardships were the symptoms such as delusion, hallucination, disordered (confused) thinking and no speech, bizarre or disorganized behavior such as not drinking water, not taking food from home, self-neglect, and inappropriate emotions.

The patient expressed that he had less symptoms of schizophrenia and less problem behaviors. He constrained on social and leisure activities and had change in coping skills to carry out their daily activities. He wanted to continue to work with his caregiver who worried about the cost of drugs and spent Rs. 1.5 lakh for the medicines and treatment for long duration. Neither the patient nor his caregiver was aware of the side effects of the antipsychotic drugs. His mother also had similar mental illness. The caregiver worried about patient's health and her own future, safety and financial position and she had unresolved grief. She also developed depression.

The patient did not have the symptoms of hallucination but he had no disability related to study and work. He took self-care and had moderate level of satisfaction with mental health services, and social relationships. He worried about complete recovery of symptoms, having a long beard and reading materials related Christianity. Few residual symptoms were pain in head but gained the weight of 92 kg. He had compliance with the medications. He relieved from the symptoms of schizophrenia, and carried the social stigma.

DISCUSSION

This study provides insight into the problems faced by the sufferer of schizophrenia and the intervention determining insight and burden. The main finding to emerge from this study is that the medications had impact on their family due to the reduction of symptoms. The medications had a range of side effects including pain/ heaviness in head, fatigability, and headache, drowsiness, confusion, and weight gain. The caregiver was not given sufficient information regarding mechanisms by which the medication would work and the possible side effects previously. Personal suffering, frequent hospitalizations and the need for long-term psychosocial and economic support, as well as life-time lost productivity are not uncommon in schizophrenia. Further caregivers are challenged with financial responsibilities, disturbance of domestic routines, constraints on social and leisure activities, and reduced attention to other family members. Often family members forego work outside the home to provide care for the patients and have an unresolved grief due to the severe mental illness. Burden in caregivers of the patient can be disability related to work and satisfaction with mental health services, nuisances, worries about the patient's health, and his own future, and safety. The patient had high insight and few burdens in the caregiver after the intervention and the caregiver got sufficient information. The present research supports the earlier findings of the Stanley & Shwetha, (2006); Solomon & Draine, (1995); Surajit Kumar, & Kamal (2011).

CONCLUSION

The symptoms associated with the schizophrenia were mostly reduced except appearance of one or two symptoms on and off. The pharmacological and psychosocial intervention (PPI) could allow patient to achieve better symptomatic and functional recovery, though they had residual symptom of a strange sensation on spine. The PPI could make him more insight and few burdens in all the four areas.

It can be inferred that patients who had schizophrenia are mostly relieved. However the method of intervention takes care of physical and mental health and also effort to change in his distress and his caregiver's burden.

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REFERENCES

1. Beck, A.T., Baruch, E., Batten, J.M., Steer, R.A., & Warman, D.M. (2004). A new instrument for measuring insight: The Beck Cognitive Insight Scale, *Schizophr Res*, 1, 68(2-3), 319-329.
2. Bostrom, A. C., & Boyd, M. A. (2005). Schizophrenia. In M. A. Boyd (Ed.), *Psychiatric nursing: Contemporary practice*, Philadelphia, New York: Lippincot William & Wilkins.
3. Caqueo-Urizar, A., & Gutierrez-Maldonado, J. (2006). Burden of care in families of patients with schizophrenia, *Quality of Life Research*, 15, 719-724.
4. Caqueo-Urizar, A., Gutierrez-Maldonado, J., & Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: A literature review. *Health and Quality of Life Outcomes*, 7(84), 1-5.
5. Clement, S., Gerber, D., & McGuire, S. L. (1995). *Comprehensive community health nursing: Family aggregate and community practice*. St. Louis, MO: Mosby.
6. Completed suicide in schizophrenia: Evidence from a case-control study, Grandon, P., Jenaro, C., & Lemos, S. (2008). Primary caregivers of schizophrenia, outpatients: burden and predictor variables, *Psychiatry Research*, 158, 335-343.
7. Havens, B. (1999). *Home based and long term care*. Geneva: World Health Organization.
8. Magliano, L., Fadden, G., Economou, M., Held, T., Xavier, M., Guarneri, Malangone, C., Marasco, C. & Maj, M. (2000). Family burden and coping strategies in schizophrenia: 1 year follow up data from the BIOMED I study, *Social Psychiatry and Psychiatric Epidemiology*, 35, 109-115.
9. Pompili, M., Lester, D., Grispini, A., Innamorati, M., Calandro, F., Iliceto, P. et al. (2009). Completed suicide in schizophrenia: Evidence from a case-control study. *Life Outcomes*, 7(84), 1-5.
10. Roick, C., Heider, D., Toumi, M., & Angermeyer, M. C. (2006). The impact of caregiver's characteristics, patient's conditions and regional differences on family burden in schizophrenia: A longitudinal analysis, *Acta Psychiatrica Scandinavica*, 114, 363-374.
11. Roick, C., Heider, D., Bebbinton, P. E., Angermeyer, M. C., Azorin, J. M., Brugha, T. S., et al. (2007). Burden on caregivers of people with schizophrenia: comparison between Germany and Britain, *British Journal of Psychiatry*, 190, 333-338.
12. Sell, H., Thara, R., Padmavathi, R., & Kumar, S. (1998). *The Burden Assessment Schedule*, World Health Organization, New Delhi: Regional office South-East Asia.
13. Shu-Ying, H., Chiao-Li, K. K., Yi-Ching, S., For-Wey, L., & Chun Jen, H. (2008). Exploring the burden of the primary family caregivers of schizophrenia patients in Taiwan, *Psychiatry and Clinical Neurosciences*, 62, 508-514.
14. Solomon, P., & Draine, J. (1995). Subjective burden among family members of mentally ill adults: relation to stress, coping, and adaptation, *American Journal of Orthopsychiatry*, 65(3), 419-427.
15. Stanley S. & Shwetha, S. (2006). Integrated Psychosocial Intervention in Schizophrenia: Implications for Patients and Caregivers, *International Journal of Psychosocial Rehabilitation*, 10 (2), 113-128.
16. Surajit Kumar, S, & Kamal, N. (2011). Burden on family care giver caring for patient with chronic schizophrenia, *Nurse Media Journal of Nursing*, 1, 29 - 41.
17. Vivera, J., Hubbard, A., Vesely, A., & Papezova, H. (2005). Violent behavior in schizophrenia, *British Journal of Psychiatry*, 187, 426-430.