



Evidence Based Social Work Intervention for Caregiver Burden in Schizophrenia: A Case Analysis and Discussion

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Abstract

In present scenario, psychiatric institutions are replaced by families to provide care for the family members with mental illness. It implies not only the relevance of emotions and affection in care but also induce higher amount of burden on family members. Evidence suggests that burden on family members of persons with schizophrenia has been associated with significant reduction in family members' quality of life, causing damage in caregivers' health and mental health conditions. The paper illustrates a case of chronic schizophrenia person and discusses various features of caregiver burden in comparison with other relevant literature. It describes evidence based clinical social work intervention to manage caregiver burden and evaluates its effectiveness in the background of this case. Using a case study approach, the present study evaluates the effectiveness of evidence based clinical social work intervention for caregiver burden experienced by family members. The clinical social work intervention was found effective in improving the caregiver's knowledge and understanding about the illness, problem solving skills and subjective wellbeing.

Keywords: Schizophrenia, caregiver burden, evidence based social work, case study.

Introduction

Families have been stepped into caregiving functions for persons with mental illness today, which were previously performed by psychiatric institutions in the west. This change highlights not only the relevance of emotions and affections within a family, but also the great amount of burden experienced by these relatives as a consequence of caregiving to a psychiatrically ill family member. Family burden refers to "psychological state produced by the combination of physical work, emotional pressure, social restrictions and economic demands arising from taking care for a patient as well"¹. Family burden has two domains, i. e., objective and subjective burden. First, the objective burden refers to care giving tasks that are the direct consequence of the patient's symptoms such as effects on the caregivers' own health, social and occupational functioning and leisure time. It includes those activities caregivers have to perform or is prevented from performing, as a result of care giving role. Second, subjective burden refers to the emotional reaction of the caregivers, including perception of strain, reduced morale, anxiety and depression². Burden on relatives of patients with schizophrenia has been found to be associated with an important reduction in their quality of life and causing damage in caregiver's health condition³.

Evidence suggests that psychosocial interventions with caregivers of persons with mental illness have two important functions. First, it directly helps for improving their overall wellbeing including better quality of life, reduction in burden, stress and depression⁴. Second, such interventions helps in improving better clinical outcomes such as reduced relapse rate,

reduced number of hospital admissions and overall functioning⁵. Grounding within this empirical context, this paper illustrates a case of chronic schizophrenia person and discusses various features of caregiver burden in comparison to other relevant literature. It describes evidence based clinical social work intervention to manage caregiver burden and evaluates its effectiveness.

Informed consent to publish this case, on the basis anonymity, was obtained from the patient and caregivers.

Brief Clinical History

Mr. D, 38 year old unmarried male, unemployed, belongs to Hindu religious background; hail from urban background of Bangalore, India. The patient was brought to National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, by his old mother, on July 2012 with 20 years history of psychiatric illness, with insidious onset, continuous and deteriorating course. The symptoms were predominantly characterized by hearing voices in isolation (first person and third person auditory hallucinations and derogatory in content), feeling of being harmed by family members and friends, unwilling to take food from home due to the belief of the foods are being poisoned, extremely suspicious towards family members and complaining they are talking bad about him and feeling of his thoughts being controlled by some external agencies. In addition, his socio-occupational functioning was impaired since last 10 years and disturbed sleep and appetite for last two years. In the past, he was treated by religious faith healers and also by several psychiatrists with adequate doses of

antipsychotic medications. However, the improvement was not very noticeable. He had history of multiple hospitalizations and poor drug compliance. He was admitted at NIMHANS for a comprehensive inpatient psychiatric care.

Psychosocial Assessment

Mr. D was the second among six children (one younger sister and four elder brothers), born of non-consanguineous marriage, hailing from poor socioeconomic status from urban Bangalore. Family history revealed significant genetic predisposition and psychopathology. Patient's father was suffering non affective psychosis and died 5 year back due to unknown reason. Further, the family history suggested moderate depression in younger sister, schizophrenia in 1st elder brother and completed suicide in 2nd elder brother.

Analysis of support system showed inadequate primary and secondary social support. All sibling was married and living with their respective family of procreation. Mother was the sole caregiver of patient and she was 64 year old lady with age related health issues. She was providing care to the patient along with household work. Rest of the family members were not extending any support, except the patient's 3rd elder brother who helps the family in financial matters. However, these help was insufficient in terms of meeting the increased financial demands on family due to patient's illness. During the interview, mother reported difficulty to buy medicine due to financial strain.

Family interaction and communication pattern was severely disturbed due to patient's symptomatology. Patient used to be very suspicious and also become abusive and assaultive towards his mother without provocations. Family interaction with outside system was very less. Mother had a lot of superstitious belief about mental illness in her family. She was strongly holding a belief system that her relatives caused mental illness in her family. Thus, she was not used to attend any family functions or festival in relatives or neighbours houses. Further, she had difficulties to manage the patient especially in outside the home.

Case Analysis and Discussion

The patient was a 40 year old male. He was unmarried and unemployed. Studies reported that, being male and older accounted for higher levels of family burden⁶ and patients unemployment and marital status associated with caregivers burden⁷. Case history revealed that patient had significant positive symptoms and multiple relapses and poor work skill which would predict burden in caregivers⁸. In this case, the mother was the sole caregiver and she was 64 year old, illiterate without an employment, and no other family members were living with them. The family doesn't have any income source other than the limited financial support provided by the 3rd elder brother. Literature reports that caregivers' burden positively correlated with their age^{9,10}. Conversely, it was negatively correlated with their monthly household income and number of family members

living with patient¹⁰. Caregivers showed a high degree of burden when the caregiver was a mother with low educational level and without an employment⁹.

In this case, the family function was severely disturbed with no meaningful interaction in inside and outside the family system. Internal interactions were severely affected by patient's illness and interaction with outside system was disrupted by the mother's perceived social stigma and her explanatory model of mental illness such as black magic performed by the relatives. These findings stand in line with the family burden studies¹¹⁻¹³. These studies have reported that disruption in family interaction and routine, family leisure, social activities, negative effects on family life would occur in families of schizophrenia due to patient's symptomatology and family members' perception of illness.

In this case, mother was the main support system for the patient. Patient's relatives or neighbours were not extended any support for the family. The mother was not willing to seek any helps from her relatives or neighbours may be because of her internalized stigma which further caused for having a poor social support system. Studies also reports poor social support among patients and their caregivers¹² which in turn would predict caregivers' burden^{8, 10, 14}. In this case, one of the major problems reported by the mother was financial difficulties to meet the expenditure for food, medication and treatment. Patient was a chronically mentally ill and was unemployed therefore, he was not earning. The mother was aged with health related issues. Family burden studies from India also reported high financial difficulties among caregivers^{11,13}. Further, these findings are supported with a study of Grover et al¹⁵ who reported that the annual costs of care of schizophrenia in India is US\$274 and indirect costs 63% higher than direct costs. Total treatment costs in schizophrenia are significantly higher in those who were unemployed and more severely ill and disabled.

Caregiver burden was further evident during interview as she said:

I cannot go anywhere as he [patient] is with me and he needs constant supervision. I find it difficult to manage him as he doesn't take food, bathing and medicines. I have to force him for all his daily activities. I have my own health issues and I am extremely worrying what will happen to him after my death. I am caring him for so many years, I have taken him for various treatment and spent lot of money but nothing has worked so far. I think it is better if he die before me. Nobody will be supporting him after my death.

In addition, literature reports that being older is prone to have lot of emotional disturbances. Some of the feelings that could affect the wellbeing of the elderly at this stage can be identified as follows: sense of worthlessness arising from a feeling of not being of utility to the society, the feeling of having ceased to contribute to the family, the resultant decline in self-esteem, the fear of death which appears to loom large in the not so far distant future, the

dilemma of having to cope with the changed nuances of life and relationships, the sense of having lost power and position, the dejection of having lost control over others and oneself, the fear of uncertainty of future and the sense of loneliness². At this time of dealing with their own ageing-related concerns, the aged caregivers also need to deal with this additional caregiver burden.

Evidence based clinical social work Intervention

Caregiver burden was the main focus of the psychosocial intervention in this case. Evidence based psychosocial intervention shows that the following therapeutic approaches are useful in addressing caregivers' burden in severe mental illness; psycho-educational programme, family support groups and multi-component intervention

Psycho-education

Psycho-educational interventions provide family members with information about mental illness, and teach them strategies and skills to help patients more effectively to cope with the challenges they encounter^{16,17}. Researchers have found that psycho-educational interventions reduce feelings of anxiety, depression, burden and stress, along with improved coping abilities, family relations and family functioning^{18,19}.

In addition, the rationale for psycho-education in this case were: i. the caregiver had superstitious belief about mental illness in her family, ii. she had difficulties to manage patient's symptoms, iii. history of frequent relapses and medicine discontinuation and probable expressed emotion, iv. inadequate understanding about various welfare benefits available for mentally ill persons, v. unrealistic expectation about patients recovery, vi. poor skills to cope with stress and burden.

The initial sessions of psycho-education were focussed on educating various features of schizophrenia included the causes, positive and negative symptoms, medication supervision and management, prognostic factors, relapses, and the role of the family in treatment. The sessions were more therapeutic than merely providing information. The cognitive and attitudinal changes were targeted during sessions. Medical model of illness was explained to bring change of her superstitious belief about illness. The need for on regular treatment and follow up and the implications of expressed emotion in recovery was also explained. Further, the clinical social worker informed caregiver about various welfare benefits available for mentally ill patients and their family such as disability pension, free bus pass and railway concession and free medicine available for patients of below poverty line and so on.

As the sessions were progressed, the intervention was focussed on skill development and problem solving strategies. The social worker demonstrated few skills through role plays and behavioural rehearsal in dealing with positive and negative symptoms. Further, "Do's and Don'ts" with patient and

behavioural management strategies such as positive reinforcement for improving self-care and functionality, activity scheduling and monitoring, attention diversion techniques for auditory hallucination and other disorganised behaviour and anger management techniques were also taught with practical day today life examples.

The sessions also focussed on reducing the caregiver's burden and perceived stress. Intervention offered supportive therapy and relaxation techniques. The techniques used were facilitating ventilation through active listening, positive self-regard and empathy, progressive muscle relaxation techniques and mindfulness meditation techniques. A total of 8 psycho-education sessions were conducted and each session was lasted about 45 minutes to 1 hour.

Family support group

Family support groups provide a forum where families can receive information about mental illness and engage in advocacy activities in an emotionally supportive atmosphere that provides opportunities to share experiences and feelings without fear of stigma. The main focus of this programme is on the provision of mutual support offered by families who share similar circumstances^{17, 20}. The research suggests that participation in family support groups relates to improved coping skills, increased access to information, perceptions of increased social support and reduction in feelings of subjective burden and psychological distress²¹.

Mutual support group for caregivers of schizophrenia was an established routine practice in the hospital. It was led by the trained clinical social worker and usually consists with 8 to 12 caregivers of schizophrenia. This group discusses the issues of their daily life pertaining to care giving; sharing information and knowledge related to schizophrenia, ventilating their intense feeling, helping and supporting each other, learning problem solving skills from group members and identification of similar problems and feeling of less stigmatised. The caregiver attended 6 group therapy sessions and each session was lasted for one hour duration.

Other supportive interventions

The clinical social worker also worked for strengthening patient's financial support through facilitating disability certificate to avail welfare benefits including monthly pension, and also arranged two years of free medicine through resource mobilization.

Conclusion

The patient was discharged after five weeks of inpatient care as he had shown improvement with the treatment. During the follow-up consultation, the social worker reviewed the effectiveness of psychosocial intervention. The caregiver reported that she used to supervise the medication and patient is

taking regular medicines. Further, she reported that the social work intervention helped her for improving her care giving skills and also helped for reducing her stress level.

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