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Research Paper

Family Burden and Perceived Stigma Among Caregivers of Patients with Schizophrenia

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ABSTRACT

Family members who provide ongoing support and are committed to the welfare of patients are called caregivers. Stigma compounds the burden experienced by family members of those with a mental illness. Schizophrenia is characterized by distortions in thinking, perception, emotions, language, sense of self and behavior. The purpose of the study has to explore about the Family burden and perceived stigma among caregivers of patents with schizophrenia. Literature has been searched the both electronic databases including PubMed and manual searches for this. Caregivers with high supernatural explanations of mental illness had stigma, which evidences the need to challenge supernatural explanations of mental illness. Since caregivers' stigma can negatively affect patients' treatment-seeking, adherence, and rehabilitation process, programs giving caregivers counseling by health care providers and establishing family support groups may be helpful to tackle stigma among caregivers of people with mental illness.

Keywords: *Schizophrenia, stigma, family burden, intervention, treatment*

Family and Family burden

Family is the primary unit in which individual is a member. Family can be defined as a "group of persons united by the ties of marriage, blood or adoption, constituting a single household, interacting with each other in their respective social roles of husband and wife, mother and father, son and daughter, brother and sister and creating a common culture" [1]. It is an accepted practice today to view the family as a system organized around the support, regulation, nurturance, and socialization of its members within this framework, the family also can be viewed broadly as "a small social system made up of individuals who comprise a household or cluster of households that persists over years'. Members enter the family through birth, adoption, or marriage and leave only by death. [2] The term family

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burden can be defined as the extent of suffering experienced by the family of a psychiatric patient due to various problems encountered with regard to financial conditions, routine, family interaction, and leisure, physical and mental health of other members of the family caused by the illness of the index patients. Treudley first used the term burden on the family in relation to the consequences for those in close contact with psychiatric patient.[3] The burden can be grouped into two form: Subjective burden defined as a sense of loss, grief and guilt and anxiety due to abnormal behavior in the primary care giver. Objective burden referred to the adverse effects on finical costs, health of caregiver's intrusion and disruption of family lives etc. [4] Family members who provide ongoing support and are committed to the welfare of both child and adult patients are typically called caregivers or caretakers. The letter is denoted as functional responsibility related to task accomplishment rather than to emotional involvement. Primary Caregiver is a person who resides with patient with mental illness and is responsible for providing care to that person and includes a relative or any other person who performs this function, either for free or with remuneration.[5]

Stigma

Stigma compounds the burden experienced by family members of those with a mental illness. Self-stigma is a process of identity transformation wherein a person loses their previously held or desired identities e.g., as a partner, friend, parent, employee etc., to adopt a stigmatized view of themselves.[6] It is one of a range of personal responses to mental illness stigma. Other responses include energization, righteous anger or no observable response.[7]Self-stigma is also referred as internalized stigma.[8]

Schizophrenia

Schizophrenia is a chronic and severe mental disorder affecting 20 million people worldwide. Schizophrenia is characterized by distortions in thinking, perception, emotions, language, sense of self and behavior. Common experiences include hallucinations (hearing voices or seeing things that are not there) and delusions (fixed false beliefs). Worldwide, schizophrenia is associated with considerable disability and may affect educational and occupational performance. People with schizophrenia are 2-3 times more likely to die early than the general population. This is often due to preventable physical diseases, such as cardiovascular disease, metabolic disease and infections. Stigma, discrimination and violation of human rights of people with schizophrenia is common. Schizophrenia is treatable. Treatment with medicines and psychosocial support is effective. Facilitation of assisted living, supported housing and supported employment are effective management strategies for people with schizophrenia.[9] Bhowmick et al conducted a study having the patient of schizophrenia and found that there was a significant negative correlation between quality of life and psychosocial dysfunction also there were significant negative correlation between severity of illness and quality of life. There was significant positive correlation between severity of illness and psychosocial dysfunction.[10]

Schizophrenia, Family burden and stigma

Several mental disorders such as Schizophrenia, affective disorder and many other have an adverse impact on the lives of "caregivers" of the patient. The mental health professionals are interested in patient's caregivers not only because of their interactions with patients, but because their emotional or even physical health and mental health status which may be affected due to burden imposed by the mental illness of loved one.[11]

Mandelbrote & Folkard, in their study of schizophrenia patients found that financial difficulties is one of the major problems reported by the families, since they have to take

care of the patients, whose diseases continuous and there is limited resource for an adequate and uninterrupted income. Moreover, the problem will widen if the index patient is the bread winner. Schizophrenic patients reported that degree to which families were disturbed by the patient's presence at home. In this study, 55%of families were rated as disturbed in some way though 2% relatives reported severe stress [12]. Brown et al found that 29% schizophrenic patients admitted for the first time caused problems in the family as compared to 66% of readmitted schizophrenics. Burden refers to the presence of problems, difficulties or adverse effect on the life of significant others of psychiatrically ill patients. Measurements of burden have tended to rate only those problems which are related to patients illness and patients symptomatic behavior of the various frame of daily activities.[13]

Gopinath & Rao noted that due to the rapid industrialization and urbanization and subsequent changes in the family structure and role, care for psychiatric patients imposes a significant burden on the families in developing countries like India.[14]The stress of not only interacting with the afflicted family member, but also with the grief associated with the illness, places an incredible strain on the day-to-day functioning of that family. The impact of mental illness is felt in other areas of family life too, such as leisure, work, income, and family health, relations with relatives, friends and neighbors. Magliano et al reported that up to 83 percent of the friends and family members of people diagnosed as having Schizophrenia experience considerable financial, emotional, and practical burdens. They report time lost from work, reimbursed medical and other patient-related expenses, limited time for leisure and socializing, elevated symptoms of psychological distress, and feelings of stigmatization. In addition to its impact on caregiver quality of life, care giving strain has been associated with other adverse effects.[15]

Fernando et al found that care burden was significantly higher for schizophrenia than affective disorders. Female care givers experienced significantly higher burden than male care givers. Diagnosis, gender of care giver and stigma predicted 22% of the variance in care giver burden, with gender identified as a significant predictor. They concluded that reducing stigma related to disclosure of mental illness in care givers has the potential to reduce care giver burden.[16]

Singh et al examined stigma in patients with schizophrenia (in the form of internalized stigma, perceived stigma and social-participation-restriction stigma) and its relationship with specified demographic and clinical variables (demographic variables, clinical profile, level of psychopathology, knowledge about illness, and insight) Research findings show 81% patients experienced alienation and 45% exhibited stigma resistance. Stereotype endorsement was found in 26% patients, discrimination experience was faced by 21% patients, and only 16% patients had social withdrawal. Overall, 29% participants had internalized stigma on total Internalize Stigma in Mental Illness Scale (SMIS) score was taken into consideration. They found 67% patients experienced significant restriction, with a majority reporting moderate to mild restriction. In terms of associations between stigma and socio demographic variables, no consistent correlations emerged, except for those who were not on paid job, had higher participation restriction. On the clinical variables, level of functioning was the only consistent predictor of stigma. While better knowledge about the disorder was associated with lower level of stigma, there was no association between stigma and insight. Significant proportion of patients with schizophrenia experience stigma and stigma is associated with lower level of functioning and better knowledge about illness is associated with lower level of stigma.[17]

Doll conducted a study (to determine the prevalence and socio-demographic correlates of caregiver's burden in schizophrenia) and found that there were significant differential demographic associations with caregivers' burden. They emphasized that caregivers of schizophrenia patients experience enormous burden and are potential "high risk group" for mental disorders. Thus, they require comprehensive intervention in order to reduce the growing incidence of chronic enduring diseases including mental disorders.[18]

Sharma et al conducted research to assess the objective and subjective impact of burden in caregivers of schizophrenia and bipolar disorder patients, and measure the perceived stigma in primary caregivers. The level of burden for schizophrenic caregivers is more as compared to the caregivers of Bipolar Disorder. The caregivers of patients with schizophrenia were more stigmatized as compared to caregivers of Bipolar Disorder patients. Females were more stigmatized than males in both the groups. The caregivers of both Bipolar Disorder and schizophrenic patients used Active emotional coping to combat the situation.[19]

The family burden and stigma are the two major psychosocial aspects of any psychiatric disorders. They play a vital role in course and progress of disorder. Review of literature show nonexistence of research focused on perceived stigma and family burden among caregivers of patient with schizophrenia. The present study would be an action to fulfilling the gap of the literature and facts in the area of family burden and perceived stigma among the caregivers of patients with schizophrenia.

Munoz et al, studied the relationships between the principal variables involved in the functioning of internalized stigma (socio-demographical and clinical variables, social stigma, psychosocial functioning, recovery expectations, empowerment, and discrimination experiences). The results indicate the relationships among social stigma, discrimination experiences, recovery expectation, and internalized stigma and their role in the psychosocial and behavioral outcomes in schizophrenia spectrum disorders.[20]

Lysakar et al examined the association of stigma experiences with symptoms and social function both concurrently and prospectively. They found stigma was associated with concurrent levels of positive and emotional discomfort symptoms and degree of social contact. Greater initial stigma predicted greater emotional discomfort at follow-up. Internalized stigma is linked with social function and symptoms. Positive symptoms may make some persons with schizophrenia more vulnerable to ongoing stigma experience.[21]

Effect of stigma also reported in the treatment, and it adversely impacted on taking medicine by the patient. Fung and Chung explored the relationship between self-stigma, readiness for change and psychosocial treatment adherence among individuals with schizophrenia. Findings suggested that individuals with higher global functioning, better readiness for action, and lower level of self-stigma demonstrated better treatment participation. Individuals with lesser severity of psychiatric symptoms and female participants had better treatment attendance. The results of discriminate function analysis showed the combined score of self-stigma, stages of change, and global functioning measures correctly classified 76.2% participants into adherent/no adherent group membership. [22]

Kharb et al mentioned that rehabilitation in schizophrenia is an integrated approach that incorporates early detection and treatment of schizophrenia symptoms, collaboration between person with schizophrenia and caregivers in managing treatment, family and social supports and training in social, instrumental and coping skills has been documented to

improve the course and outcome of schizophrenia as measured by symptoms recurrence, social functioning and quality of life.[23]

CONCLUSION

It can be said that stigma had an impact on quality of life at the personal and family levels, and this was associated with overall burden. Increased awareness among service providers may decrease the impact of stigma on relatives. Being part of a well-functioning family is important for recovery in schizophrenia [24], and stigma may contribute to the family's overall burden. Experiences of stigma are common among persons with schizophrenia, which has been shown in varied geographic and cultural settings [25] Relatives of and others with close social connections to a person with schizophrenia may also experience stigma. The current global situation demands a multidimensional approach to the demands of healthcare. There needs to be a holistic model of delivery that takes care of the physical, emotional, social and spiritual wellbeing of patients as well as care givers of schizophrenia and communities into account.

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Conflict of Interest
The author(s) declared no conflict of interest.

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