

ASSESSMENT OF THE CORRELATION BETWEEN FAMILY BURDEN IN PRIMARY CAREGIVERS AND DISABILITY IN PATIENTS WITH SCHIZOPHRENIA

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Abstract

Background: Schizophrenia is one of the most devastating, and a chronic, relapsing mental illness associated with increased morbidity, poor quality of life and low recovery rates. In India, families are the major providers of long-term care and they represent an important supportive, social network for patients with schizophrenia. Indian families experience significant degrees of burden in the care of their relatives with schizophrenia. Illness severity and patients' disability have a direct positive relationship with perceived family burden.

Methods: This study is a cross-sectional study, done to assess the correlation between family burden in primary caregivers and disability in patients with schizophrenia. 60 patients with schizophrenia and their primary caregivers were recruited from the outpatient and inpatient units of Department of Psychiatry, Government Rajaji Hospital, Madurai. IDEAS (Indian Disability Evaluation Assessment Scale) scale was used to assess the disability of patients with schizophrenia and BAS (Burden Assessment Schedule) of SCARF (Schizophrenia Research Foundation) was used to assess the family burden in their primary caregivers.

Results: Among the 60 primary caregivers, (48.3%) were having caregiver burden between 50 and 70%. (56.4%) of female caregivers had burden range 50- 70%. (56.5%) of caregivers delivering care for patients with illness between 15 and 20 years experienced burden >70%. Statistical analysis revealed that the correlation between caregiver burden and disability was statistically significant.

Conclusions: The severity of caregiver burden increases with increasing grades of disability and indicates that caregiver burden affects the overall outcome of schizophrenia

Keywords: Schizophrenia, Caregiver burden, Disability, Outcome

Introduction

Schizophrenia is one of the most devastating, and distressing psychiatric disorders. It is a chronic, relapsing mental illness associated with increased mortality, poor quality of life and low recovery rates. Nearly 6 – 7 million Indians suffer from this disorder variously described as the “Cancer of the mind” and the “Greatest disabler of youth”. It starts in the most productive period of life 15 – 45 years. It cuts across barriers of gender, educational and social classes.

The World Health Organization (2010) estimated that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of this illness. 20% of people with schizophrenia show unremitting symptoms and increasing disability, and around 35% of them show a mixed pattern with varying degrees of remission and exacerbations.

¹ Disabilities that may result directly include poor self-care, inability to manage the tasks of daily living, social withdrawal, poor functioning in affiliative roles and work

incapacity. These patients depend on the family for care provision. Families often serve as an extension of the mental health system. If caregivers do not have adequate knowledge and support, they might not be able to take up the responsibilities of taking care of the ill persons, thus leading to relapse or readmission. Hence the individual has many barriers or limitations to overcome for better community living.

According to the World Health Organization, a disability is “any restriction or lack (resulting from any impairment) of ability to perform an activity in the manner, or within the range considered normal for a human being”. The spectrum of disability problems that occur depends upon the interaction of the patient with his environment¹.

Deinstitutionalization of psychiatric patients was a notable movement of the 20th century, which resulted in the transfer of the care of psychiatric patients to their family members. In India, families are the major providers of long-term care

and they represent an important supportive, social network for patients with schizophrenia. Patient's interaction is mainly with his family that works as primary environment which might stimulate the persons with schizophrenia in reducing their disability. Healthy family environment with adequate support would be ideal for persons with schizophrenia in leading the life with optimal functioning. Perhaps the family environment could influence either in a positive or negative way based on the mutual reciprocations.

The catastrophe of mental illness strikes not only the individual but also the entire family, placing an undue burden on them. According to Platt 'family burden' refers to the presence of problems, difficulties or adverse events, which affect the life of the psychiatric patient's significant others.² Numerous studies have demonstrated that family caregivers of persons with severe mental illness experience significant stresses and have a high level of burden. Primary caregivers are often referred as forgotten patients. Caregivers' symptoms such as mood swings, marital and family conflicts and financial problems may be a reflection of caregivers' stress. Demands of time and resources are supposed to lead to negative physical and psychological consequences of caregiving.⁸

'Burden of care' is a complex construct that challenges simple definition, and is frequently criticized for being broad and generally negative.³ Although the entire family experiences the burden of illness, a major part of the responsibility is often shouldered by one "Primary caregiver", who is defined as the person most involved in the care of the patient at home. The primary caregiver experiences significant physical and emotional burden. This eventually poses a challenge for the care. Frequently, burden of care is more defined by its impacts and consequences on caregivers. In addition to the emotional, psychological, physical and economic impact, the concept of 'burden of care' involves subtle but distressing notions such as shame, embarrassment, feelings of guilt and self-blame. In addition, caregivers' stress increases due to communication difficulties, lack of appropriate intervention strategies for patient's symptoms, and financial problems.⁴

Having a member of the family with schizophrenia disorganizes the family dynamics. Caregivers indicate that patients do not fulfil their expectations, generating personal and familiar dissatisfaction.⁵ Care giving becomes one way where the patient only receives and is unable to give. Some of the problems associated with care giving which are experienced negatively by the relatives include strained home atmosphere; quarrels caused by the patient; guarding from patient committing dangerous acts, self-inflicted injury, and taking illegal drugs; ensuring that the patient got enough sleep; worrying about the patient's safety; urging the patient to take care of himself; urging the patient to eat enough; urging the patient to undertake activities; urging the patient to wake up in the morning; worrying about how the patient would manage financially if relative no longer helps; and worrying about patient's future and about own future⁹

In India care for other family members is an obligation. Not all caregivers perceive the same burden as it varies according to the family support, cultural beliefs, and coping strategies. Indian families experience significant degrees of burden in the care of their relatives with schizophrenia. Illness severity and patients' disability have a direct positive relationship with perceived family burden. Management of caregiver burden is crucial for a state like Tamilnadu which is in a transitional state facing a quantum jump in the number of nuclear families (74.4% according to census 2011). Hence systematically understanding the caregivers' burden is vital while providing comprehensive structured bio- psychosocial interventions to improve the outcome of schizophrenia.¹⁰ Thus the need for this study arises.

Materials and Methods

The study was a cross-sectional study, done to assess the family burden among the caregivers of patients with schizophrenia and to assess the disability of patients with schizophrenia and find the correlation between family burden in primary caregivers and disability in patients with schizophrenia. 60 patients with schizophrenia and their primary caregivers were recruited from the outpatient and inpatient units of Department of Psychiatry, Government Rajaji Medical College Hospital, Madurai.

Informed consent was obtained from all participants. Data was collected primarily from 60 patients diagnosed to have schizophrenia as per ICD – 10 criteria for at least duration of 12 months and their primary caregivers. Primary caregiver is defined as an adult (at least 18 years of age) relative living with a patient, in the same environment, for at least 12 months and was involved directly in giving care to the patient and most supportive either emotionally or financially, i.e. felt most responsible for the patient. Semi-structured case study form was used to obtain socio-demographic details, psychiatric history, family history and other details of the patients with schizophrenia and their caregivers. Socio-demographic status was assessed by using modified Kuppaswamy's socio-economic status scale.

The IDEAS, (Indian Disability Evaluation Assessment Scale) evaluates disability in four areas (termed items in the scale), namely, self care, interpersonal activities, communication and understanding, and work. Each item is scored on a 5 point scale with a range of 0-4, *i.e.* from no (0) to profound disability (4). To ease rating on each item, questions related to that area of functioning are given explicitly and a description for each score has been provided. The total disability score is obtained by summing up the ratings on each item. The global disability score is calculated by adding the 'total disability score' and Duration of Illness (DOI) score which has been operationalized for different duration of illness categories. Global disability score of 0 (*i.e.* 0%) corresponds to 'no disability', a score from 1 to 6 (*i.e.* <40%) corresponds to 'mild disability', a score of 7-13 (40 - 70%) corresponds to moderate disability, score of 14-19 (71-99%) to severe disability and a score of 20 (100%) corresponds to profound disability.⁶

BAS (Burden Assessment Schedule) of SCARF (Schizophrenia Research Foundation) was used to assess the family burden in their primary caregivers. The Burden Assessment Schedule developed at SCARF is based on an integrative framework encompassing subjective and objective components of burden. It comprises of 40 items to identify the broad domains of burden experienced by the caregivers. ⁷

Karl Pearson Correlation coefficient and other appropriate statistical methods were carried out to do the analysis of data. Confidentiality and safety of the subjects was taken care of.

Results

The socio demographic profile of the patients revealed that majority (36%) of the patients in this study fell within the age group of 30-40 years with mean age of **35.05** years (**Figure 1**). Majority of the patients were females (56%) While **66.6%** were unemployed, 23.3% were engaged in semi-skilled jobs, 10% in unskilled and 3.3% in skilled jobs

Regarding their marital status 32 were single, 16 were married, 9 were separated and 3 were widowed (**Figure 2**). The duration of illness was between 1 and 5 years in 12 patients, between 5 and 10 years in 13 patients, between 10 and 15 years in 12 patients, between 15 and 20 years in 23 patients (**Figure 3**). Majority (85%) of patients belonged to nuclear family whereas severe disability was found in 43 % (N=26) of the patients (**Figure 4**).

Among the 60 primary caregivers, majority (25%) of them fall in the age group of 50-60 years (**Figure 5**). Females (65%) outnumbered males. Among these 3 were unemployed, 9 were engaged in semi-skilled jobs, 43 in unskilled and 4 in skilled jobs and 1 in semi-profession. Among the caregivers 25 were mothers, 10 were fathers, 9 were husbands, 7 were wives, 5 were sisters, 2 were sons, 1 was daughter and 1 was grand-mother of the patients. 48.3% (N=29) were having caregiver burden between 50 and 70% (**Figure 5**). (56.4%) of female caregivers were found to have burden range 50- 70% and (52.3%) of male caregivers were found to have burden range below 50%.

(50%) of caregivers delivering care for patients with illness less than 5 years experienced burden <50%, While (61.5%, 75%) of them delivering care for patients with illness between 5 and 10 years & between 10 and 15 years respectively experienced burden of range 50-70%. majority (56.5%) of caregivers delivering care for patients with illness between 15 and 20 years experienced burden >70% (**Figure 6**).

When correlating global disability score with caregiver burden, p value is 0.003 (statistically significant) and Karl Pearson correlation coefficient is 0.587 (positive correlation) (**Table 1**).

Table 1: Association between Disability and Caregiver Burden

Caregiver Burden N=60	Caregiver Burden <50%	Caregiver Burden 50-70%	Caregiver Burden >70%	Total
Disability N=60				
Mild Disability	6 (85.7%)	1 (14.3%)	0	7 (100%)
Moderate Disability	5 (35.7%)	7 (50%)	2 (14.2%)	14 (100%)
Severe Disability	1 (3.8%)	18 (69.2%)	7 (26.9%)	26 (100%)
Profound Disability	1 (7.6%)	3 (23.1%)	9 (69.2%)	13 (100%)
TOTAL	13	29	18	60

One way ANOVA test $p=0.003^*$,

Karl Pearson correlation coefficient is **0.587**

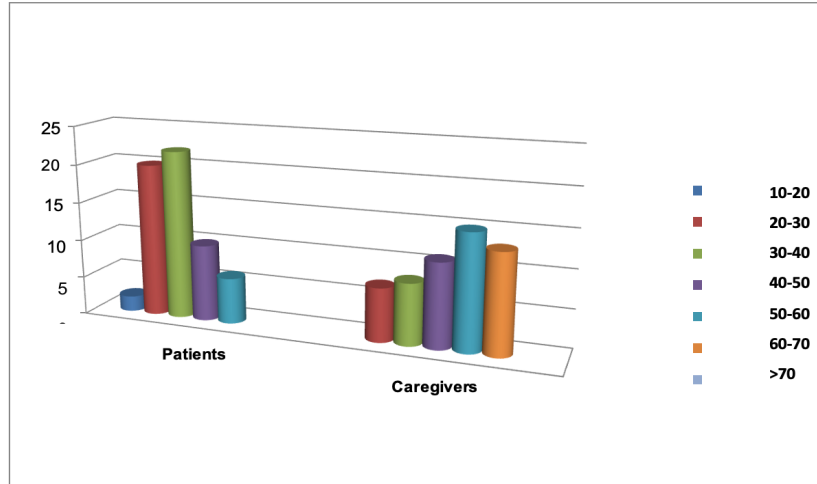


Figure 1: Distribution of Age among Patients and Caregivers

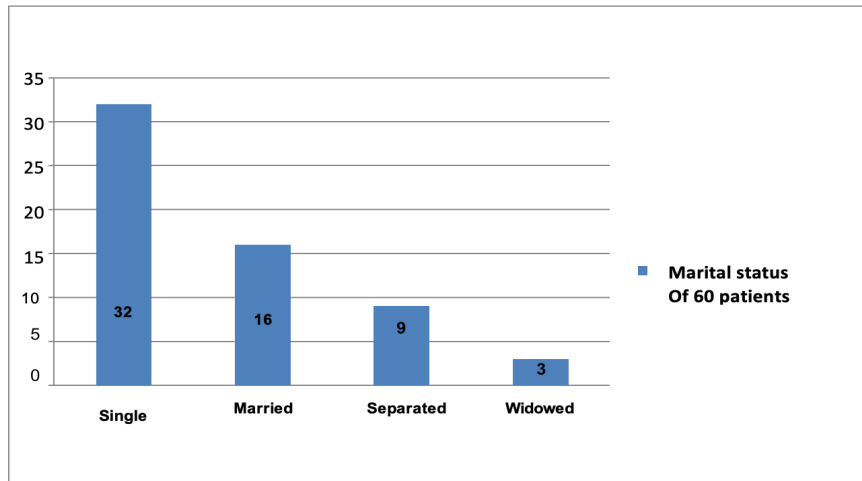


Figure 2: Marital status of 60 patients with Schizophrenia

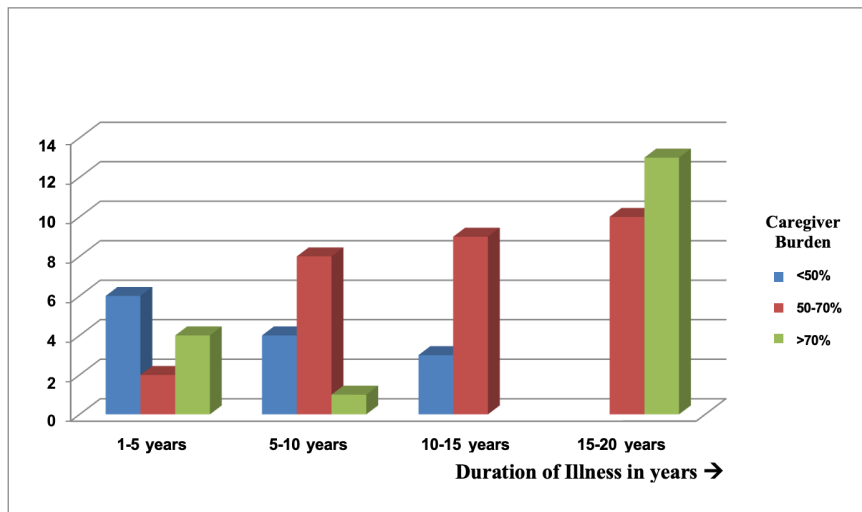


Figure 3: Relationship between Duration of Illness and Caregiver Burden

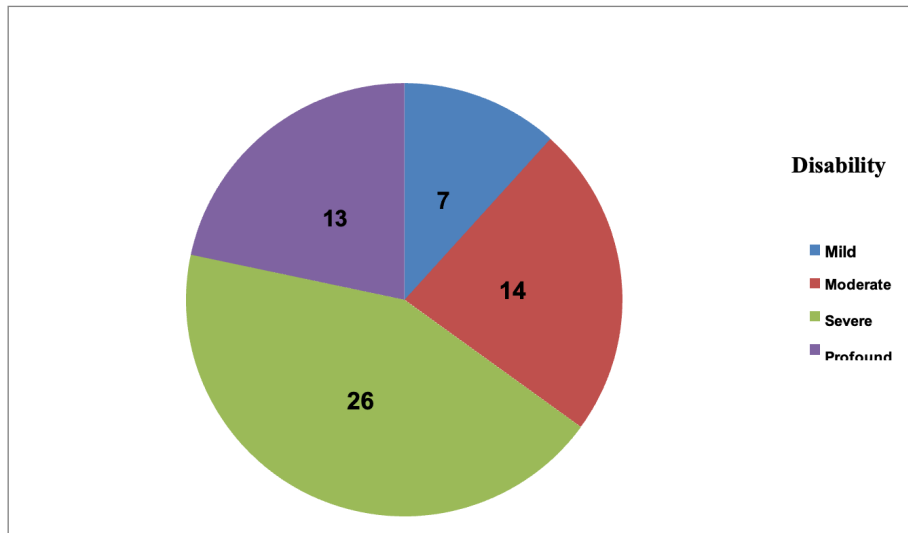


Figure 4: Distribution of Disability among 60 Patients

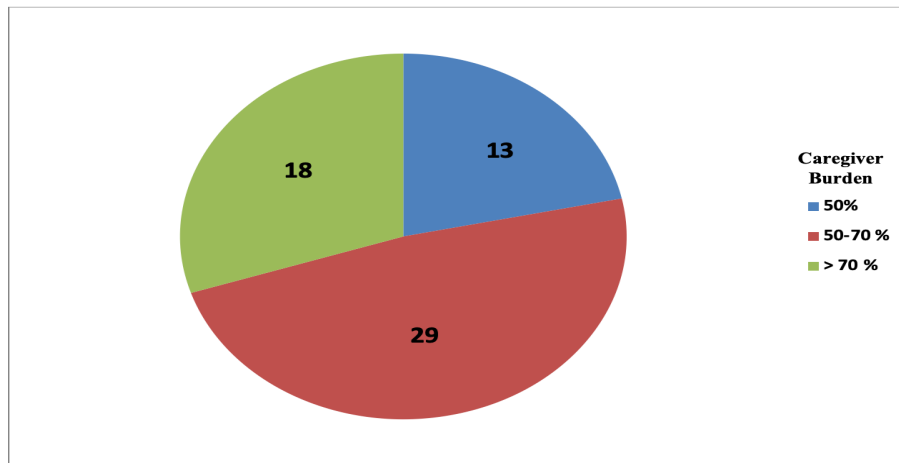


Figure 5: Distribution of Burden among 60 Caregivers

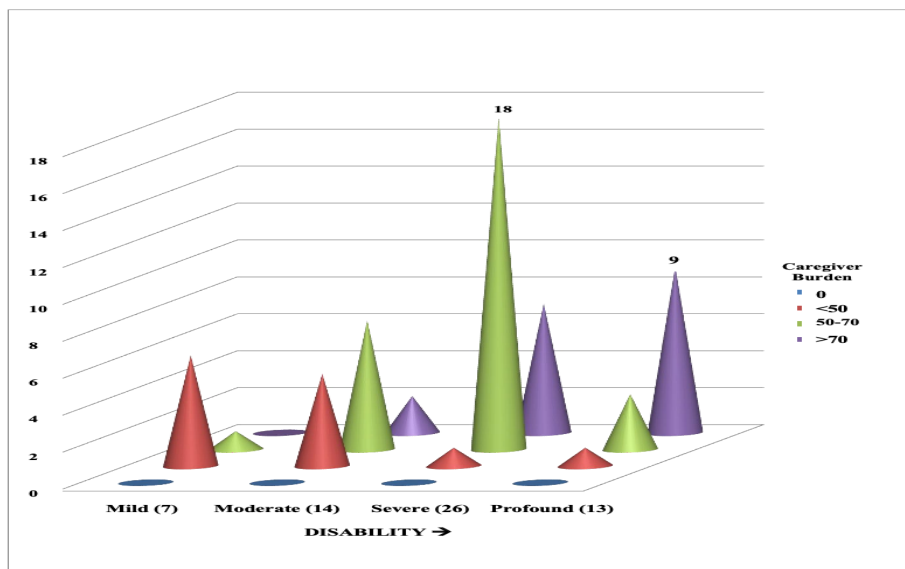


Figure 6: Relationship between Disability and Caregiver Burden

Discussion

From the socioeconomic data, it is evident that majority of patients with illness are unemployed. This may be mainly due to frequent relapses and lack of ability to carry on responsibilities. This makes the patient economically dependent on the caregiver. Similar results were obtained in the study by Marwaha *et al*, which derived that the employment rate in schizophrenia appears to decline with increase in relapses. Barriers to getting employment include stigma, discrimination, fear of loss of benefits and a lack of appropriate professional help.¹¹ Most of them remain single because of the stigma attached with mental disorders. Separation after marriage is also found to be due to the illness. Turner *et al* also support our study finding that stigma prevents the client from having marriage.¹²

Majority of them belong to nuclear family. Due to this, the entire burden is often shouldered by a single person, who according to our study, are often females. Females perceive higher levels of burden, which is attributed to their other responsibilities like child-rearing, maintenance of house-hold activities etc apart from care giving. L.Sam *et al* derived that burden in the form of rejection is more severe among males. This difference may be due to several cultural and social aspects as that study was conducted in Kerala, with higher female literacy rates compared to Tamilnadu.¹³

Majority of caregivers belong to geriatric age group (figure 1), but most are engaged in unskilled jobs, not only to compensate the economic ineffectiveness of the patient but also to earn for the extra care of the relative. This implies the financial burden of the family. Victor *et al* in their study also concluded that financial burden is significant among caregivers in a developing nation with little or no resources for the care of mentally ill. This is due to the continuing salience of family out-of-pocket expenses for the care of patients.¹⁴ As this study was also done in a developing country, the similarity of results is not unexpected.

Naughton *et al* showed that older caregivers significantly reported burden. This finding is attributable to the fact that general medical conditions are very prevalent within the older age groups. It also suggests that older caregivers are more “at risk” of mental health problems as a result of care giving.¹⁵ Our study showed that caregivers caring for patients with increased duration of illness experience more burden compared to those caring for less duration. This signifies the effect of long term illness on the socioeconomic and psychological aspects of the caregiver. Lim YM *et al*, also support this notion by accomplishing that long duration of schizophrenia could affect objective burden, including the physical deterioration of family caregivers and financial difficulties.¹⁶

As there is a positive correlation between caregiver burden and disability, burden escalates with rise in disability. If the caregiver is burdened, the care delivered by them is decreased, which would result in frequent relapses among the patients. This in turn will burden the caregiver more. On contrary there was a negative strength of association between disability and family burden in the study conducted by Ismail Shihabuddeen T.M. *et al*.^{1,17} They have concluded that disability among the patients should be intervened individually. The difference in the results may be due to cultural factors or due to economic factors, as most of participants of this study belong to low socioeconomic group where in the loss of income from the severely disabled person, would cripple the family’s economy more.^(18,19)

Long duration of severe burden will enormously deteriorate the mental and physical health of the caregiver, which will affect the function of the whole family. Increasing severity of disability causes more care-giver burden, in psychological, socioeconomic, financial and cultural aspects. In turn caregiver burden, because of negative expressed emotions, causes an increase in burden.²² Thus a vicious cycle of disability and caregiver burden continues to deteriorate the outcome. Caring for a family member with schizophrenia is an enduring stressor and causes considerable amount of burden. The Study

examined burden and coping in parents and spouses of persons with schizophrenia. Spouses reported greater emotional burden. Parents used more of denial as a coping strategy, while spouses used more of negative distraction strategies.²³ Yoga was found to be as effective as relaxation in reducing stress, anxiety and improving health status of caregivers. Yoga appears to provide a comparable improvement in stress, anxiety and health status compared to relaxation. A study suggests that yoga and meditation may be a feasible and effective intervention for family caregivers and may improve affect, coping, physical well-being, and stress management.²¹

Family interventions in schizophrenia have demonstrated the positive impact of various family interventions in improving family environment, reducing relapse and easing the burden of care.²⁷ Although the evidence of such positive impact of family interventions in schizophrenia is well documented, such interventions are neither widely used nor appropriately integrated in care plans, and are frequently underfunded. On stepwise regression analysis, patient's age, educational level, and level of functioning and caregiver's use of denial as a coping strategy emerged as significant predictors of caregiver burden. The study highlights the fact that family intervention programs need to address the specific concerns of care givers.²⁸

In achieving a balance between the patients' and caregivers' perspectives, Tailoring of treatment plans where caregivers have to be included in the care plan and adequate information and support should be extended to the family and caregivers. Only an effective caregiver with proper support and coping skills can help the patient to overcome the social, economical and psychological barriers.²⁴ Access to better treatment for patients, including medications, psychosocial interventions and rehabilitation services, are important basic elements in easing the burden on caregivers. There is also a need for continued improvement in the delivery of psychiatric services to the severely psychiatrically ill and their families.²⁵

As there is a lack of reliable cost information about the family burden of care specific to

schizophrenia, there is an urgent need to develop reliable approaches that can generate data that can inform in policy making and organization of services.³

Future studies with a larger sample size and with a prospective design giving importance to cultural aspects of burden would yield more accurate and reliable results in the field of caregiver burden with respect to disabling conditions, in this case, schizophrenia.

Conclusion

There is a positive correlation between caregiver burden and disability. The severity of caregiver burden increases with increasing grades of disability. It indicates that caregiver burden affects the overall outcome of schizophrenia. High levels of caregiver burden can be associated with negative expressed emotions which results in relapses. Rapid changes in life styles, establishment of nuclear family system and increasing financial strain, may all contribute to the caregiver burden. Therefore caregiver stress relieving strategies in the form of counselling, support groups, mindfulness-based stress reduction methods, progressive muscle relaxation techniques, yoga stress management workshops, should be adopted to support the caregivers and also to decrease the incidence of relapses among patients with schizophrenia.

On analysis of data using statistical tools like Karl Pearson Correlation coefficient and one way ANOVA test, it was found that the correlation between caregiver burden and disability is positive and is statistically significant. Therefore the severity of caregiver burden increases with increasing grades of disability.

The responsibilities of care giving can lead to feelings of isolation and abandonment. High levels of caregiver burden can be associated with negative expressed emotions which results in relapses. Apart from worsening the outcome of the patient, caregiver burden causes several adverse effects on the primary caregiver. Caregivers with poor coping skills and support experience severe burden. Support for caregivers in the form of counselling, support groups, mindfulness-based

stress reduction methods, stress management workshops, progressive muscle relaxation²⁰, yoga not only relieves the stress of the caregivers but also helps in improving the outcome of schizophrenia²¹

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Declarations

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