Original Research Article

Impact of Psychoeducation to reduce the burden in primary caregiver of patients with schizophrenia

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ABSTRACT

Background: Schizophrenia is a chronic and inarguably one of the most debilitating psychiatric syndromes. Primary care giver faces burden in different domains, few of the domains having significant correlation with a schizophrenia patient. The evidence has suggested that effective Psychoeducation will lead to reduced relapse rate, enhanced recovery and better family well-being at a lesser cost. The current study was aimed to explore burden of the family members and impact of Psychoeducation to reduce the burden in primary caregiver of patients with schizophrenia.
Methodology: A prospective and interventional study was conducted from October 2016 to September 2017 among primary caregivers of the patient with schizophrenia. Caregivers were interviewed and assessed by application tools like Burden Assessment Schedule (BAS). After assessment, education program was conducted every week for five weeks. One month after completion of all the sessions, post test was conducted.
Results: Total 32 primary caregivers of schizophrenia patients participated in the study. Eight caregivers did not complete the follow-up regularly as per the schedule. So, they were excluded from further study and only 24 caregivers were taken into account. Spouse as caregiver and participants with age less than 45 years felt more burden. Statistically significant reduction of burden in physical and mental health, external support, caregiver's routine, patient's behaviour related factors and total burden assessment schedule score was observed, which was denoted by paired t test. While, no statistical reduction was observed in other factors.
Conclusions: Psychoeducation is effective in reducing the burden and creates more awareness about illness. It also improves coping strategy during different stages of illness. It also deals with communication skills and expressed emotions.

Keywords: Schizophrenia, Psychoeducation, Burden, caregiver.

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INTRODUCTION

Schizophrenia is a chronic and inarguably one of the most debilitating psychiatric syndromes [1]. It is characterized by psychotic symptoms like delusions and hallucinations, disorganized speech or behavior and negative symptoms. Also, the age of onset is 15 to 25 years. This is the age when a person is preparing to be responsible for self, family, and the society [2].

Although with the introduction of antipsychotic medications, outcome of the illness has improved, it still has a long-term treatment, issues related to compliance, frequent relapses and sometimes requires hospital admission. Family also faces emotional, financial, and social crisis. All these things lead to stress and burden to the family members as well as the care giver of the patient. Stigma of mental illness further hampers the outcome of the disorder. Burden refers to adverse events or difficulties affecting a person's life. Burden can be objective, physical burden of care consequent to behavioral disturbance of an individual patient and social effect on the caregiver's daily life; and subjective, emotional reactions of the caregiver including perception of strain, reduced morale, anxiety, and depression [3].

It is also found that primary care giver faces burden in different domains like spouse related, physical and mental, external support, caregiver's routine, support of the patient, about taking responsibility, managing other relations, patient's behaviour and caregiver's strategy [3]. Few of the domains have a significant correlation with patient of schizophrenia [4]. In Indian context, most of the patients are living in nuclear or joint family. So, families extend emotional, social and economic support to their members [5]. Sometimes high and negative expressed emotions in the family members lead to relapse. We have numerous data where negative expressed emotions in a family had detrimental effect on patients already diagnosed with schizophrenia [6]. In schizophrenia with such family settings, relatives' experiences significant stress in coping with patients. Primary caregiver has a feeling of loss and grief [7]. Like the patient, they feel stigmatized and socially isolated [8].

Psychoeducation reduces the patient/caregiver's burden. There are other types of family interventions also. This is a set of systemic interventional approach with emphasis on patient and family needs [8]. The family is an important factor which affects the patient's well-being and outcome. Psychoeducation should be conducted in multiple sessions with individual or multiple family groups [9]. Evidence has suggested that effective Psychoeducation will lead to reduced relapse rates, enhanced recovery, and better family well-being at least of the cost [10]. The current study was aimed to explore burden of the family members and impact of Psychoeducation to reduce the burden in primary caregiver of patients with schizophrenia attending the psychiatric department at a tertiary care hospital.

METHODOLOGY

A prospective and interventional study was conducted from October 2016 to September 2017 among primary caregivers of the patient with schizophrenia after explanation of the procedure and purpose of study. Primary caregiver with at least one year duration of the patient suffering from schizophrenia and those who consented were included in the study. While, caregivers of other major psychiatric disorders like mood disorder, substance use disorder and mental disorder, and those who denied for participation in the study were excluded. Caregivers were interviewed and assessed by application tools like Burden Assessment Schedule (BAS) by one examiner. After assessment, the other examiner conducted education program every week for five consecutive weeks. The schedule consisted of five sessions in total, 45 to 60 minutes each. Each session included a small group of two to three caregivers. Session one included: brief education about schizophrenia and prevalence, myths related to schizophrenia, etiological factors and impact of disease over social, occupational and personal life. Session two included: myths related to treatment and medication, antipsychotics, electroconvulsive therapy, maintenance, relapse and prognostic factors. Session three included: role of environment and social factors in illness and relapse, concept of token economy and reinforcement, and social skill training education. Session four included: education about expressed emotions, positive and negative emotions, impact of expressed emotions and psychological issues of the family due to illness. Session five included: education about stress reduction methods: importance of stress management in family, development of hobbies, regular exercise and breathing exercise. One month after completion of all the sessions, post test was conducted.

Tools used:

Demographic details: A semi-structured proforma was designed that contains demographic details about the patient and primary caregiver participating in the study.

Burden Assessment Schedule (BAS): This 38 item scale was used to assess the subjective burden as perceived by caregivers of chronic mentally ill patients. Broad domains of subjective burden were covered in nine factors; spouse related, physical and mental health, external support, caregiver's routine, support to patients, taking responsibilities, other relationship, patient behaviour and caregiver's strategies. Each item was quantified on linear scale from 1 (not much affected) to 3 (severely affected). This scale had good reliability and validity, with Cronbach's alpha that ranged from 0.71 to 0.82.

STATISTICAL ANALYSIS

Data entry and analysis was done using Microsoft excel and Epi Info software. The socio-demographic profiles of participants have been expressed in terms of frequency and percentage. Independent t test was applied to find out relation of gender, domicile, age group of caregiver, family type and duration of illness with Burden Assessment Schedule scale score. While ANOVA test was used to find relation of Burden Assessment Schedule scale score with caregiver relation. Effect of education on different Burden Assessment Schedule factors was assessed using Independent t test.

RESULTS

Total 32 primary caregivers of schizophrenia patients participated in the study. Out of the 32 patients, 18(56.25%) were males and 14(43.75%) were females. Majority of the participants, 25(78.13%) were Hindu and only seven (21.87%) were Muslim. Total 18 (56.25%) patients were from urban and 14(43.75%) from rural areas. Out of the 32 participants, 19(59.38%) were between 15-35 years and 13(40.62%) were 36 or more years of age. Out of total 32 participants, eight caregivers did not complete the follow-up regularly as per the schedule. So, they were excluded from further study and only 24 caregivers were taken into account.

Table 1: Association of different variables with Burden Assessment schedule score

Variables		No of participants (n=32)	Burden Assessment schedule score Mean ± SD	P value
Gender	Female	19	56.18 ±7.00	0.655
	Male	13	58.38 ±9.33	
Domicile	Urban	18	53.89 ±10.7	0.225
	Rural	14	59.47 ±11.2	
Age of caregiver	≥ 45 years	19	61.92 ±13.46	0.038#
	Less than 45 years	13	53.47 ±11.11	
Family type	Nuclear	19	59.79± 8.05	0.084
	Joint	13	52.69 ±7.05	
Relation of caregiver	Spouse	05	51. 89 ±9.03	0.035#
	Parents	18	57.81 ±8.03	
	Others	09	60.72 ±9.53	
Duration of illness	≥ 6 years	17	57.74 ±8.00	0.568
	Less than six years	10	54.78 ±6.89	

#*Statistically significant*

Table 1 shows that spouse as caregiver and participants with age less than 45 years had statistically significant lower mean Burden Assessment schedule score with p value 0.035 and 0.038 respectively, as denoted by ANOVA test and independent t test respectively. This means spouse and participants with age less than 45 years felt more burden as caregiver. No statistically significant difference was observed in burden according to gender , domicile, family type and duration of illness of the patient, as shown in table 1 and was denoted by independent t test.

Table 2: Effect of education on different Burden Assessment Schedule factors (n=24)

Factors	Maximum score	Burden Assessment Schedule Mean ± SD		P value
		Before education	After education	
Spouse related (factor-1)	15	9.75±3.59	8.75±3.10	0.182
Physical and mental health related (factor-2)	18	12.0 ±3.10	10.0±2.07	0.001#
External support related (factor-3)	15	7.96±3.02	7.08±3.00	0.019#
Caregiver's routine related (factor-4)	12	6.63±2.3	5.04±1.43	0.02#
Support of patient related (factor-5)	9	4.5±1.86	4.5±1.81	1.00
Taking responsibility related (factor-6)	12	6.92±1.99	6.54±2.00	0.11
Other relations related (factor-7)	9	5.17±1.73	4.91±1.55	0.10
Patient's behavior related (factor-8)	12	6.58±2.083	5.13±1.54	0.01#
Caregiver's strategy related (factor-9)	12	6.00±2.28	5.79±2.10	0.13
Total BAS score	114	57.38±11.71	50.5±10.46	0.001#

#*Statistically significant ($p<0.05$)*

Table 2 shows statistically significant reduction of burden in physical and mental health, external support, caregiver's routine, patient's behaviour related factors and total burden assessment schedule score, which was denoted by paired t test. While, no statistical reduction was observed in other factors.

DISCUSSION

This was a prospective psycho-educational intervention study. The current study observed that each caregiver does perceive burden on Burden Assessment Schedule (BAS) irrespective of age group. However, total score related to burden was perceived more in the less than 45 year age group. Srivastava and others observed that age group less than 30 years was associated with more burden [4]. Gupta and others noted that older caregivers do perceive more burden [11]. While, Mandal did not find any significant difference in relation to the age of caregivers; this may be due to only urban and high income population sample [12]. As younger caregivers are generally sole earning members of the family, extra burden of care leads to financial difficulties on them as well as the family. This further leads to increase in feelings of exhaustion, frustration and isolation.

The current study did not observe any differences in burden according to participant's gender. Mandal and others found that male caregivers perceived more burden than their female counter parts [12]. In Eastern countries like India where female gender generally accepts the responsibility of care giving, the role reversal can make the males more vulnerable to burden. But in our study, the gender of the caregiver or the caregiver of a particular gender patient did not show any influence on the feelings of burden. The difference of results in the current study may be due to a small sample size.

The current study did not observe any differences in burden according to participant's domicile. Mubarak and others [13] compared rural and urban community of caregivers of chronic schizophrenic patients and found that irrespective of the domicile of caregiver, they perceived burden equally which is same as the finding of our study. Another study [4] found that caregiver of the domicile of Agra perceived more burden in factor-4, factor-7 (other relations related) and factor-8 (patient's behavior related) as compared to rural population.

In current study did not observe differences in burden according to family type (nuclear or joint). Being member of a joint and extended family helps in sharing the responsibility, while I nuclear family only two members, the patient and the caregiver, present in the family to shoulder the more burden. So, it is reasonable assumption that such caregivers would feel more lonely, frustrated and depressed.

The current study observed that the spouse being a caregiver felt more burdens as compared to others. Gupta also found that the most burden was perceived by spouses followed by parents [11]. The burden increases more as neither relatives nor friends appreciate effort of the caregiver or support them. All these made the spouses more vulnerable to feeling burdened. However, researchers did not find any correlation of the relationship of caregiver with patient [4,12].

The current study found that psycho-education strengthened caregiver's physical and mental wellbeing which is seen as a reduction of factor-2 score (p=0.001). Their doubts and myths related to the illness were resolved. Symptoms of insomnia, anxiety and depression in caregiver were addressed by stress relaxation methods. Caregivers were able to look after their health, routine and relax by sharing responsibilities. All of this led to overall impact on burden improvement. Similar response has been recorded by Kannappan and others [14] by comparing only pharmacotherapy with combination of psycho-educational method and had shown less strained relationship, economic dependency, unresolved grief in families and hope was generated, so was the capacity to problem solving.

Similar findings like family orientation to the patient's symptoms and behaviour, coping skills and effective ways of expressing emotions were noted by Sharif et al (2012) in Iran [8]. Good therapeutic relationship, empathy, stimulation of hope, feeling of being special, solidity and support from social group and role as an expert of caregiver were supported by Pitschel-Walz and others [15].

In India, Sovani and others showed effectiveness of one day psycho-education over stress [16]. Thara and others [17] also showed a decrease in burden and more satisfaction of the caregiver in a flexible program as it was according to their needs and gave more enthusiastic and meaningful response. Such flexibility was also provided in our program. Chatterjee and others [18] found that in moderate to severe illness, community based educative treatment program is more useful to reduce stigma, discrimination and stress. Sunanda and others [19] and Kulhara and others [20] have also reported improvement in psychopathology, disability, and caregiver's support and satisfaction .

The current study did not find any significant reduction in factor-1 (spouse related) (p=0.182), factor-6 (taking responsibility related) (p=0.11), factor-7 (other relations related) (p=0.10) and factor-9 (caregiver's strategy related) (p=0.13). Mainly, problems related to the financial issues were not resolved as most of the patients were unemployed and caregiver had to take care of every requirement of the patient. The feeling of helplessness was so extreme that sometimes caregiver does seek isolation and wants to go away from the patient. Even after the psycho-education program, this type of feelings were persistent (factor-9, p=0.13). These four factors were reduced to some extent but factor-5 (support of patient) (p=1.0) did not show any improvement. Factors related to the caregiver and subjective burden were influenced by psycho-education, but not the objective burden.

CONCLUSION

Schizophrenia is a chronic and long lasting illness which leads to significant burden and affects the life of the primary caregiver. They feel isolated, less supported and separated. Expressed emotions also cause more burdens and worsening of symptoms. They require psychological and emotional support. True knowledge about symptoms, signs, etiology and treatment of illness, communication skills and expressed emotions has to be provided through psycho-education.

Psycho-education is effective in reducing the burden and creates more awareness about illness. It also improves coping strategy during different stages of illness. It also deals with communication skills and expressed emotions. It is one of the most cost effective approach and can be applied to very large settings also. For a physician, it is recommended to see as a better augmenting treatment option.

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