Socio-Demographic Profile, Burden and Coping in Spouses of Patients with Schizophrenia, Bipolar Disorder and Alcohol Dependence Syndrome- A Cross Sectional Study

Jayamadhuri Mothukuri[1], Ashok Reddy Karredla[2]

[1]Department of Psychiatry, Shadan Institute of Medial Sciences, Moinabad, Hyderabad, Telangana, India.
[2]Department of Psychiatry, SVS Medial College, Mahabubnagar, Telangana, India.

ABSTRACT

BACKGROUND

Serious mental illnesses like schizophrenia, bipolar disorder, alcohol dependence syndrome lead to great burden in care givers who adopt a variety of methods to cope with their family member's illness. Burden perceived and coping styles used by spouses is quite different from other care givers given their close relationship with the patient. Little research is focused on spouses as an exclusive group for the assessment of burden & coping. The aim was to study the socio-demographic profile, the burden and coping in the spouses of patients with schizophrenia, bipolar disorder and alcohol dependence syndrome.

METHODS

This study was conducted at the Institute of Mental Health, Hyderabad, among 180 study participants including spouses (30 male & 30 female) from patient groups of the above three illnesses. After obtaining written informed consent, patient and spouse were interviewed with a semi-structured intake pro-forma to capture the socio-demographic details of spouse, illness, marital, family & treatment history. After initial assessment of patient's functional status using GAF scale; BAS, CCL, GHQ-12 instruments were administered on spouses to assess the burden of illness, coping styles and general health status. SPSS 17 was applied to the data.

RESULTS

Alcohol use and mental illness is high in families of patients with alcohol dependence reaching statistical significance. Nuclear families are high in schizophrenia group and in alcohol dependence group, substance use in spouses is high at 25 (52.1%) along with abuse of spouses at 19 (67.9%) with statistical significance. Also, means of GHQ-12 in alcohol dependence group is higher than other groups while means of BAS is higher in alcohol dependence group.

CONCLUSIONS

Burden perceived by spouses of these three patient groups is significant. The coping styles used by spouses to handle the distress due to patient's illness are many. A high global functioning score of the patient corresponds to good general health in the spouse. Proper psychosocial interventions when employed can help spouses deal better with burden and enhance coping styles.

KEY WORDS

Spouses, Burden, Coping, General Health, Schizophrenia, Bipolar Disorder, Alcohol Dependence Syndrome

Corresponding Author:
Dr. Jayamadhuri Mothukuri,
H. No. 11-24-108, Shathavahanapuri,
Desaipet Road, Warangal-506002,
Telangana, India.
E-mail: jmothukure@gmail.com

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BACKGROUND

Individuals with severe mental illness stay ill for long durations, unable to fulfil normal roles expected for their age and intellectual ability by society. Most persons with Schizophrenia are now having community care by families impacting caregivers due to the advent of deinstitutionalization.[1] The evaluation of caregiver's impact of mental illness is in the form of burden, psychological morbidity, coping, finance. Burden of care is defined as "the presence of problems, difficulties or adverse events which affect the life of the psychiatric patients' significant others".

The burden of care concept has two distinct components.[2]

1. Objective burden includes measurable effects in household disruptions, economic burden, loss of work and social activities, time spent negotiating mental health, medical and social welfare and sometimes criminal justice systems.
2. Subjective burden is the caregiver's own perception of the impact of caring consisting of negative feelings of loss, anxiety, anger, sorrow, hatred, uncertainty, guilt, shame or embarrassment, which causes significant distress and suffering.

Subjective psychological distress has been found to be highly prevalent, with 29 to 60% of the caregivers suffering from diagnosable psychiatric disorders across different studies.[3] Research evidence from various countries on patients with Schizophrenia caregivers reveal the presence of inadequate help and support plus inability to cope with the caring roles and responsibilities.[4] Mental illness onset in a family member usually results in whole family's psychological and emotional disturbance.[5]

A study in Malaysia found that a relatives' mental illness compels the caregivers to cope with the stigma impact.[6] One study highlighted that the family burden and financial burden were significantly higher in persons with Schizophrenia when compared with other mental disorders.[7] Similarly, two prospective studies conducted in India have found no difference in family burden severity observed between families of patients with Schizophrenia and relatives of Bipolar disorder sufferers.[8,9]

Alcohol use has negative effects on the spouse of an alcohol user like feelings of hatred, self-pity, avoidance of social contacts, exhaustion and become physically or mentally ill. Alcohol drinking families were characterized by poorly communicating family members, less mutual warmth and affection, poor role functioning and compatibility between husband and wife leading to unpleasant, tense, cold and inhospitable environment. Greater burden is due to substance dependent person's disrupting activities and financial difficulties arising from income loss and/or funds spent on substance dependence.

Coping strategies of caregivers have been distinguished into two broad groups. Problem-focused strategies refer to constructive coping efforts which modify difficult situations such as problem solving, seeking information, or using positive methods of communication. Emotion-focused strategies like avoiding or resigning themselves to the situation are less adaptive attempts at modulating the caregiver's stress-related emotional response. Caregiver-burden, patient's social functioning, and expressed emotions of caregivers and social support available are the most consistent correlates of coping. High levels of burden, dysfunction, and expressed emotions together with low levels of available support are associated with maladaptive emotion-focused styles such as avoidance, resignation, coercion, etc.

Problem focused coping strategies were more frequent among young relatives and relatives of younger patients. Relatives who lived longer with the patient and having poor social support frequently adapted emotion-focused strategies.[10] The coping behaviour of wives of persons with alcohol dependent are emotional, tolerant, inactive, controlling, confronting and supporting the user.[11] The perception of needs study of the patients of Schizophrenia by themselves and their family members revealed that the number of needs as perceived by the caregivers & patients was similar. Most of the needs are met in the West, however in India more than two third needs of Schizophrenia patients were unmet, especially welfare benefits.[12]

When an experience of illness onset in spouses of schizophrenic patients was investigated, the finding was first episode of a schizophrenic disorder leads to severe distress in the spouse of the patient that is often viewed as an existential threat to marriage and family life. If spouses feel that neither their information about the disease nor their supportive resources are sufficient, emotions of fear, despair and loss of control are especially pronounced. Supportive services for these spouses should be offered very closely to the onset of Schizophrenia, as it is very burdensome in this period. Interventions should meet the particular needs of spouses giving information about the illness and coping strategies plus considering issues relevant for partnership and parenting roles.[13,14]

Burden and coping in caregiver parents and spouses of patients of Schizophrenia when studied, greater emotional burden found in spouses and denial was most used coping strategy by parents, with negative distraction strategies used more b spouses. 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 on stepwise regression analysis.[15,16] A review of burden of Schizophrenia in caregivers examining the role of gender reveals that relatives of male patients frequently experience more social dysfunction and disabilities than those of female patients. An extensive literature also demonstrated the positive impact of various family interventions in improving family environment, reducing relapse and easing the burden of care. Access to better treatment for patients, including medications, psychosocial interventions and rehabilitation services, are important basic elements in easing the burden on caregivers.[17]

In a review of the factors that influence experienced burden, coping and needs for support of caregivers for patients with a Bipolar disorder, both objective and subjective burden is high and subjective burden being extremely influenced by illness beliefs. High burden is associated more with severity of symptoms, difficulties in the relationship with patient, lack of support and stigma. Coping is influenced by appraisal and burden with different phases in care giving requiring different coping mechanisms. It's recommended to increase support for these caregivers.[18,19] A study of family burden among relatives of patients with

Bipolar affective disorder concluded that almost all the family members experienced severe burden initially and even when symptoms subsided, family members continued to experience burden specifically related to finances.[20]

In the study of the costs and consequences of caring for a relative or friend with Bipolar disorder, caregivers were evaluated within 1 month after patient's admission. High burden caregivers reported more physical health problems; depressive symptoms, health risk behaviour and health service use, and less social support than less burden caregivers. Psychosocial interventions targeting the strains of care giving for a patient with Bipolar disorder are needed.[21,22] In an investigation of the caregivers of Bipolar disorder, approximately 30% reported distress. Male caregivers used more avoiding coping style and sort activities to provide diversion. Less active approach and less social support was sought by female caregivers. So the symptoms of caregiver distress have to be assessed and when noticed, efforts should be undertaken to support the caregiver and teach them skills to cope effectively.[23]

An assessment of burden borne by the family caregivers of men with alcohol and opioid dependence showed that more often the alcohol dependence group was older, married, currently working, having a higher income and with the wife as a caregiver. Family burden was associated with low income and rural location. It was concluded that almost all caregivers reported a moderate or severe burden, which indicates the gravity of the situation and the need for further work in this area.[24] A study of Psychological distress among female spouses of male at-risk drinkers from a Quebec community health survey confirmed high level of psychological distress in such female spouses.[25] Caregivers of bipolar patients adapted problem-focused coping strategies more while caregivers of schizophrenic patients used emotion-focused strategies which appears to be linked to differences in caregiver-burden and appraisal between the two groups. Reducing burden on caregivers and enhancing their awareness of illness could lead to adoption of more adaptive coping styles.[26] There is a clear need for studies on spouses exclusively as caregiver group and the amount of perceived burden and coping styles in them.

This study was to assess the socio-demographic profile, burden and coping in spouses of patients with schizophrenia, bipolar disorder and alcohol dependence syndrome.

METHODS

This cross sectional study was conducted at Institute of Mental Health, Hyderabad with 180 subjects, 60 each are Spouses of patients with Schizophrenia, Bipolar affective disorder and alcohol dependence diagnosed as per ICD-10, and age between 18 to 60 years, both genders (30 male & 30 female), primary caregiver for more than 2 years were included with exclusion of age below 18 or above 60 years, cognitive impairment, mental retardation, other psychiatric illnesses. The sample size was taken based on the convenience of the study. The study for approved by IEC and informed consent was obtained. After a valid written informed consent from the patient and spouse, they were interviewed with the semi-structured intake pro-forma to capture the socio-demographic data and details of spouse, illness, marital history, family history & treatment history. Initially, functional status of patient was assessed using Global assessment of functioning (GAF) scale. Subsequently, Burden assessment schedule (BAS) (Thara et al),[27] Coping checklist (CCL) (Rao K., Subbakrishna and Prabhu, 1989),[28] General health questionnaire (GHQ-12) was administered on spouses to assess the burden of illness, coping styles and general health status

Statistical Analysis

The data collected was subjected to descriptive statistics namely measures of central tendency & dispersion and inferential tests namely T-test, chi-square & ANOVA using SPSS software 17 version.

RESULTS

Variable	Schizophrenia N=60(%)	Bipolar Disorder N=60 (%)	Alcohol Dependence Syndrome N=60(%)	Total	Test (chi Square)	Sig (2-Tailed)
Religion of patient						
Hindu	48(36.6)	50(38.2)	33(25.2)	131	17.93	0.006*
Muslim	8(28.6)	5(17.9)	15(53.6)	28		
Christian	4(22.2)	5(27.8)	9(50)	18		
Others	0	0	3(100)	3		
Education of patient						
Nil	20(34.5)	19(32.8)	19(32.8)	58	11.78	0.3
Primary	21(41.2)	13(25.5)	17(33.3)	51		
SSC	13(33.3)	13(33.3)	13(33.3)	39		
Intermediate	4(18.2)	11(50)	7(31.8)	22		
Degree	1(16.7)	1(16.7)	4(66.6)	6		
Postgraduate	1(25)	3(75)	0	4		
Domicile of patient						
Rural	43(35.8)	40(33.3)	37(30.8)	120	1.35	0.509
Urban	17(28.3)	20(33.3)	23(38.3)	60		
Employment status of patient						
Unemployed	1(16.7)	4(66.7)	1(16.7)	6	16.54	0.168
Housewife	17(45.90	11(29.7)	9(24.3)	37		
Farmer	11(33.3)	13(39.4)	9(27.3)	33		
Laborer	15(30.6)	15(30.6)	19(38.8)	49		
Business	6(46.2)	2(15.4)	5(38.5)	13		
Job	6(18.8)	10(1.2)	16(50)	32		
Others	4(40)	5(50)	1(10)	10		
SES in patient						
Low	44(31.9)	47(34.1)	47(34.1)	138	0.559	0.756
Middle	13(31.0)	16(38.1)	13(31)	42		
Upper	0	0	0	0		
Nature of marriage in patient						
Arranged	57(35)	57(35)	49(30.1)	163	8.315	0.016*
Love	3(17.6)	3(17.6)	11(64.7)	17		

Table 1. Socio-Demographic Profile of Patients across the Three Groups

* Reaching statistical significance; % calculated within variables across groups

Table 3 shows means in alcohol dependence group is higher than Schizophrenia & Bipolar disorder. Table 4 shows means of BAS is high in alcohol dependence group than Schizophrenia &Bipolar disorder. Table 5 shows that there is no statistically significant difference between the groups.

Variable	Schizophrenia	Bipolar Disorder	Alcohol Dependence	Total	Test (Chi-Square)	Sig (2-Tailed)
Education of spouse						
Nil	28(46.7)	14(23.3)	18(30)	60	12.42	.13
Primary	19(30.6)	22(35.5)	21(33.9)	62		
SSC	10(25.6)	13(33.3)	16(41)	39		
Intermediate	2(18.2)	6(54.5)	3(27.3)	11		
Degree	1(12.5)	5(62.5)	2(25)	8		
Employment of spouse						
Unemployed	0	0	1(100)	1	12.5	.253
Homemaker	12(31.6)	13(34.2)	13(34.2)	38		
Farmer	9(24.7)	15(42.9)	11(31.4)	35		
Labourer	20(34)	16(27)	23(39)	59		
Job	11(32.4)	11(32.4)	12(35.5)	34		
Others	8(61.5)	5(38.5)	0	13		
Type of family						
Joint	28(26.2)	39(36.4)	40(37.4)	107	6.13	.04*
Nuclear	32(43.8)	21(28.8)	20(27.4)	73		
Financial dependence on patient						
Yes	26(36.6)	19(26.8)	26(36.6)	71	2.279	.32
No	34(31.2)	41(37.6)	34(31.2)	109		
Mental illness in spouse						
Yes	9(37.5)	11(45.8)	4(16.7)	24	3.75	.15
No	51(32.7)	49(31.4)	56(35.9)	156		
H/o substance abuse in spouse						
Yes	10(20.8)	13(27.1)	25(52.1)	48	10.73	0.005*
No	50(37.9)	47(35.6)	35(26.5)	132		
H/o of abuse in spouse						
Yes	3(10.7)	6(21.4)	19(67.9)	28	18.35	.00*
No	57(37.5)	54(35.5)	41(27)	152		

Table 2. Socio-Demographic Profile of Spouses across the Three Groups

Variable	Schizophrenia Mean (SD)	Bipolar Disorder Mean (SD)	Alcohol Dependence Mean (SD)	One-Way ANOVA F-Value	p
GHQ-12	18(1.95)	18.58(2.51)	19.43(3.36)	4.354	.014*

Table 3. Mean Scores of GHQ-12 across the Three Groups

Variable	Schizophrenia Mean (SD)	Bipolar Disorder Mean (SD)	Alcohol Dependence Mean (SD)	One-Way ANOVA F-Value	p
BAS	79.68(5.41)	81.4(4.41)	83.6(6.95)	7.261	.001*

Table 4. Mean Scores of Burden Assessment Schedule across the Three Groups

Variable	Schizophrenia Mean (SD)	Bipolar Disorder Mean (SD)	Alcohol Dependence Mean (SD)	One-Way ANOVA F-Value	p
CCL-problem focused	1.41(.61)	1.4(.64)	1.38(.62)	.294	.764
CCL-positive distraction	1.01(.59)	.95(.62)	.833(.64)	1.34	.264
CCL-acceptance	1.85(.77)	1.88(.76)	1.78(.73)	.27	.764
CCL-religion	2.20(.97)	2.35(.89)	2.11(1.07)	.866	.422
CCL-denial	1.0(.58)	.967(.609)	1.05(.565)	.307	.736
CCL-social support	1.88(.99)	1.55(.99)	1.66(.96)	.176	.175

Table 5. Coping Styles across the Groups Using Coping Check List

Variable	Schizophrenia Mean (SD)	Bipolar Disorder Mean (SD)	Alcohol Dependence Mean (SD)	One-Way ANOVA F-Value	p
GAF	64.08(61.5)	59.88(10.01)	55.28(12.3)	.862	.424

Table 6. Global Assessment of Functioning in Patients across the Three Groups

DISCUSSION

Although available literature studied burden of care and coping styles in caregivers broadly, studies on spouses are less in whom the impact and perception of illness is different to other care givers in family. The present study aims to assess the socio-demographic profile, burden and coping exclusively in spouses of patients with Schizophrenia, Bipolar disorder and alcohol dependence syndrome. The significant findings are discussed.

The distribution of religion across the three groups is statistically significant. In alcohol dependence group, love marriages are high along with mental illness. Also, alcohol use is high in families of patients of alcohol dependence. Nuclear families are high in schizophrenia group. In alcohol dependence group, substance use in spouses and spousal abuse is high reaching statistical significance. Mental illness in families of spouse is found to be high in alcohol dependence group along with alcohol use reaching statistical significance. Prior studies found no difference in burden between alcohol dependence group and BPAD group. In contrast, this study reveals that means of burden in alcohol dependence are higher than other two groups reaching statistical significance.

A study revealed that emotion-focused coping strategy is found in most of the Schizophrenic relatives.[29] Fatalism and problem-solving contributed 26.4% and 27.4% of the coping effort of caregivers respectively, followed by passivity, expressive-action and escape-avoidance inference that relatives use a broad range of coping styles.[30] The present study also points not one but multitude of coping styles being employed by spouses of mentally ill persons. No difference in coping is reported between the caretakers of Schizophrenia and bipolar disorder.[9] the present study also show no statistical significant difference between coping styles in spouses of patients.

It is found that problem-focused coping strategies were more common in caregivers of Bipolar disorder patients and emotion-focused strategies in caregivers of Schizophrenia patients [26] whereas in the present study we could not find any statistically significant difference in coping styles. It is found that the common coping style in spouses with mental illness is negative distraction [16] but in the present study no particular coping style is commonly seen in spouses of mentally ill persons.

Limitations

The current study was conducted at a tertiary care centre that may not represent the general population and study population was mostly from the lower socioeconomic group hence results cannot be projected for middle and higher economic groups. Other factors that influence experience and reporting of burden like social support and expressed emotions were not taken into account.

CONCLUSIONS

Burden perceived by spouses of schizophrenia, bipolar disorder and alcohol dependence patients is significant and almost similar. Coping styles used by spouses to handle the distress are many. Severity of illness in the patient and general health of the spouse are strongly associated with each other. Measures to improve the treatment effectiveness may lead to reduction of perceived burden in the spouses. Psychotherapeutic techniques like psycho education, family and couple therapy may help in better coping of spouses of

mentally ill persons. Group therapy can help spouses in sharing their views and understanding of various coping methods employed by others.

In view of perceived burden in the spouses of mentally ill persons, there is a need to develop family intervention programs focusing on psycho education and skill building. Society should ensure access to better rehabilitation and psycho social services. Self-help groups for spouses should be encouraged where they can share & seek mutual support. Periodic screening of spouses is required given their vulnerability for psychological problems. Financial incentives from the government agencies can help in reducing the burden of spouse.

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