

## **Burden among Caregivers of Person with Schizophrenia and Schizoaffective Disorder: A Comparative Study**

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### **ABSTRACT**

This is a cross-sectional comparative study with the aim to compare two patient groups of schizophrenia and schizoaffective disorder and their respective caregivers with the objectives to quantify and compare the burden in caregivers of person with schizophrenia and schizoaffective disorder and to study the relationship between them. In this study, 40 patients schizophrenia, 40 patients of schizoaffective disorder, along with their 80 respective caregivers were taken on the basis of inclusion and exclusion criteria. Subjects were assessed using Socio-demographic and clinical sheet & BAS. Appropriate statistics such as mean, standard deviation, chi-square test, unpaired t test, Pearson's correlation were applied to analyze the data. The results of the study revealed considerable burden of care in families of the patients and a significantly greater burden of care in caregivers of patients with schizoaffective especially in the following domains: spouse related, caregivers' routine, physical and mental health, taking responsibility, patient's behaviour and caregiver's strategy. Some of the demographic variables like age and education etc. were also found to have significant correlation with burden of care.

**Keywords:** *Burden, Schizophrenia, Schizoaffective Disorder*

*"Mental illness is nothing to be ashamed of, but stigma and bias shame us all"*

- **BILL CLINTON**

**M**ental illness is an age old problem of mankind as recorded in the literature of the oldest civilizations world over. A chronic mental illness such as schizophrenia is a challenging task for caregivers especially in the current era of de-institutionalization. After the de-institutionalization of psychiatric hospital, many families become primary care givers for seriously mentally ill individuals. Deinstitutionalization has highlighted the role of family members as the primary source of care giving to persons with chronic mental disorder. It extols a significant burden on the caregiver as a result of the shift of burden of care from hospital to families, and on society at large in terms of significant direct and indirect costs that include frequent hospitalizations and

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the need for long-term psychosocial and economic support, as well as life-time lost productivity. A noteworthy finding by Weidmann et al was that despite the downfall of traditional family structure from joint families to nuclear families more than 60% of persons with long term schizophrenia live with at least one significant other i.e. primary caregiver who is responsible for fulfilling most of the needs of patient and care for significant period of time. Mental health and illness are not polar opposite, but instead can be viewed as points on a continuum, which changes from day to day. We live in a society that bombards us with stressful situation continuously. It is natural for an individual to ebb and flow emotionally daily in response to the stress they are experiencing. Mentally healthy person can deal with their stress.<sup>1</sup> Psycho educational family programmes, in combination with medication, management have been shown to make a substantial contribution to preventing relapse among psychotic patients, particularly among those with chronic schizophrenia (Mathew Samuel & Murali Thyloth)

The World Health Organization (WHO) states caregiver burden as the “the emotional, physical, financial demands and responsibilities of an individual’s illness that are placed on the family members, friends or other individuals involved with the individual outside the health care system. A study was conducted by WHO in 2003 concluded that there are about 40 million mentally ill persons in India. The presence of a mentally ill patient in a family cause stressful experience to the care givers especially in physical, emotional, social and financial areas. More the patient behaviour and functional disability put the primary care givers in a great risk as the care giving to a mentally ill patient is a very complex process as most of the mentally illness occur with a change in the behavioural pattern of the patient .These factors may act as a burden to the care givers and can affect even the quality of life of the primary care giver too; as a health professional the mental health nurse has a main responsibility in identifying these levels of burden, coping and quality of life among the care givers specially the primary care givers of the mentally ill patients. Globally 450 million people suffer from mental disorder. WHO 2002 showed that out of 450 million people, 154 million people suffer from depression and 25 million people from schizophrenia. Schizophrenia affects about seven per thousands of the adult population mostly in the age group of 15-35 years. Though the incidence is low (3-10,000), the prevalence is high due to chronicity.<sup>3</sup>In India 9.1% of the population suffer from depressive disorders. The estimation of schizophrenia incidence was 0.38/ 1000 in urban and 0.44/1000 in rural part of Chandigarh.

The overall incidence of schizophrenia was 0.35/1000. The prevalence is 2.5/1000(urban and rural) - Ganguli 2007. <sup>3</sup>The initial Global Burden OF Disease study found that depression was the fourth leading cause of disease burden, accounting for 3.7% of total disability adjusted life years ( DALYS) in the world in 1990.Mental disorders cause clinically significant distress or impairment in social, occupational, and/or other important areas of functioning. This impairment is chronic and consequences of psychopathology have long lasting constraints on the level of functioning, preventing patients from recovering to their pre-morbid state resulting in chronic

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invalidity. So impaired functioning continues even after discharge of patient from hospital to home which leads to stress in the caregivers.

## **EPIDEMIOLOGY OF SCHIZOPHRENIA**

According to DSM-TR, the annual incidence of schizophrenia ranges from 0.5 to 5.0 per 10,000 with some geographical region. Schizophrenia is a relatively common illness affecting approximately 0.7% of the world's population prevalence estimates from 188 studies from 46 countries life time prevalence was found to be 4.0 per 1000. Among epidemiological studies conducted in India, largest has been the longitudinal study of functional psychosis in an urban community (SOFPUC) in Chennai carried out by SCARF (schizophrenia research foundation) and department of psychiatry, Madras Medical College. First episode schizophrenia patients from a predominantly urban background were followed up and age corrected prevalence rate of Schizophrenia was estimated to be 3.87/1000. The incidence rate in same study was 0.35/1000.

## **EPIDEMIOLOGY OF SCHIZOAFFECTIVE DISORDER**

Schizoaffective disorder is a psychiatric disorder that affects about 0.5 to 0.8 percent of the population. It is characterized by disordered thought processes and abnormal emotional responses. Common symptoms include delusions, hallucinations, disorganized speech, and bizarre behaviours, as well as mood problems. Schizoaffective disorder appears to be about one-third as common as schizophrenia. Lifetime prevalence of schizoaffective disorder is uncertain, but probably less than 1 percent, in the range of 0.5 to 0.8 percent. The incidence of the disorder is higher in females than in males, mainly due to an increased incidence of the depressive type among females. The typical age at onset of schizoaffective disorder is early adulthood, although onset can occur anywhere from adolescence to late in life.

## **OPERATIONAL DEFINITIONS:**

### **1. Primary Care givers:**

A person who involved in direct care of a mentally ill patient and spent most of their time for caring the patient. This is usually the family member. Depending on culture there may be other members of the family engaged in care. Such as (Father, Mother or Husband, wife or Brother, Sister)-who are providing care for the mentally ill patients.

### **2. Chronic Mentally ill patient:**

Goldman et al. (1981) defined the chronically mentally ill as “ persons who suffer certain mental or emotional disorder(organic Brain syndrome, schizophrenia, Recurrent depressive and Manic depressive disorder, paranoid and other psychosis) plus other disorders that may become chronic that erode or prevent the development of their functional capacities in relation to three or more primary aspect of daily life-personal, hygiene and self-care, self-care

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direction, interpersonal relationship, social transaction, learning and recreation and that erode or prevent development of their economic self-sufficiency”.

**3. Caregiver burden:**

Caregiver burden Refers to the negative feelings and subsequent strain experienced as a result of caring for a chronically sick person. Caregiver burden associated with mental illnesses refers to negative responses that occur when caregivers assume an unpaid and unanticipated responsibility for the person for whom they are caring who has disabling mental health problems.

**Objective burdens** are defined as readily verifiable behavioural phenomena, e.g. negative patient symptoms; disruption of the caregiver’s domestic routine social activities and leisure; social isolation; and financial and employment difficulties.

**Subjective burdens** comprise of emotional strain on caregivers, e.g. fear, sadness, anger, guilt, loss, stigma and rejection. The shift towards community care for patients with mental illness has resulted in transferring responsibility for day-to-day care of patients to their family members, which has led to profound psychosocial, physical and financial burdens on patients’ families.

**Statement of the Problem-**When a member of the family suffers from a chronic illness, the family dynamic may drastically change. A chronic illness has a monumental impact not only on the development of the individual suffering from it, but also on the individual's family members and relationships. Based on this fact, it is imperative for people working in the helping profession to gain a more comprehensive understanding of how a chronic illness continuously affects the individual and the family structure as a whole.

**RATIONALE FOR THE PRESENT STUDY**

Caregiver burden have been studied in patients with Schizophrenia but literature is less regarding with other chronic mental illness (schizoaffective disorder, Alcohol dependence syndrome). There are few studies on schizoaffective disorder. But less attention is given to the assessment of burden on caregivers of schizoaffective disorder. In this background, the present study will plan to assess and compare the burden in caregivers of schizophrenia and schizoaffective disorder.

Proposed study will an attempt to bridge the gap by addressing the issues with integrated framework whereby concept of burden, problems and solution, factor associated with burden, status of support and relationship with sociodemographic variable.

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## **OBJECTIVES OF THE STUDY**

The present study will aim at exploring and comparing the burden of care in caregivers of chronic mentally ill patient. The broad objective of this study is to critically examine the families of person with chronic mental illness and the challenges they face in living with the person and Following specific objectives were formulated:

1. To explore the impact of burden in caregivers of person with chronic mental illness (Schizophrenia, schizoaffective).
2. To explore the impact of burden and their association with demographic factors like age, gender etc.
3. To quantify and compare the burden in caregivers of person with schizophrenia and schizoaffective disorder.

## **RESEARCH METHODOLOGY;**

**Study Setting:** The study was conducted in selected Psychiatric Hospital at Lucknow (Uttar Pradesh).

**Research design:**

This was a hospital-based, cross sectional and comparative study.

**Population:**

The population of the present study will include primary care givers of patients who are diagnosed as schizophrenia, schizoaffective disorder, on the basis of ICD-10 in a selected psychiatric hospital at Lucknow.

**Sample Size:**

Total subjects in caregiver group 80 (40 caregivers of person with schizophrenia, and 40 caregiver's person with schizoaffective disorder respectively were taken up for study).

**Sampling Plan:**

Purposive sampling technique was used to select the samples for the study.

**Sampling Criteria-**

**Inclusion Criteria for chronic Mentally Ill Patients**

- ✓ Age group ranging from 18-60 years
- ✓ Patients diagnosed as schizophrenia, schizoaffective disorder according to ICD-10
- ✓ Duration of illness at least 2 years recruited to the study

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**Exclusion Criteria for Chronic Mentally Ill Patients**

- ✓ Neurological disorders such as seizures, movement disorders, cerebral palsy
- ✓ Recent or current medical illness
- ✓ Co morbidity with any other psychiatric disorder.
- ✓ Use of any pharmacological intervention other than psychotropic drugs.
- ✓ Life time history of head injury associated with loss of consciousness, seizures, neurological deficits, or surgical intervention.

**Inclusion Criteria for Caregivers**

- ✓ Primary caregivers (Parents/Spouse/Sibling/Children) who are staying with the patient since the onset of illness are included.
- ✓ Age group above 21 years
- ✓ Living with the patient for at least last 1 year
- ✓ Those who gave informed consent to participate in the study

**Exclusion Criteria for Caregivers**

- ✓ Caregivers with psychiatric conditions, organic syndromes, mental retardation, substance dependence or chronic physical illness.
- ✓ Those who did not give consent

**Data collection procedures**

**Tools Used**

The following tools were used for the present study:

**A. SOCIODEMOGRAPHIC AND CLINICAL SHEET**

A semi-structured proforma will design to collect demographic information like age, sex, duration of marriage, etc. about the patients and their caregivers along with the clinical information like the age of onset, duration of illness, number of hospitalizations, etc. regarding the patient.

**B. BURDEN ASSESSMENT SCHEDULE (BAS) OF SCARF (SCHIZOPHRENIA RESEARCH FOUNDATION)**

It was developed by Thara et al based on 'stepwise ethnographic exploration' described by Sell and Nagpal in 1992. It is a semi-quantitative instrument with 40 items measuring 9 different areas of subjective and objective caregiver burden on caregiver of chronic psychotic person. 4 items are specifically pertaining to spouse. Each item is rated on a 3 point scale with 1 not at all, 2 to some extent and 3 very much. Total scores range from 40-120. Internal consistency of scale is 0.8 as measured by alpha coefficient.

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*Factor analysis has identified nine factors based on the items:-*

- a) Spouse related,
- b) Physical & mental health,
- c) External support
- d) Caregiver's routine,
- e) Taking responsibility,
- f) Other relationship,
- g) Patient behaviour,
- h) Caregiver's strategy

It is a comprehensive scale and gives special emphasis to spouse caregivers (has separate 4 questions for them), its reliability and validity is high and has been earlier used extensively in Indian population.

**Procedure**

The study was approved by the hospitals ethics committee, and all subjects gave written informed consent to participate. Person with Schizophrenia, person with schizoaffective disorder patients and their caregivers were selected by purposive sampling on the basis of inclusion and exclusion criteria from out patients of the hospitals. Detailed data was collected on the socio-demographic and clinical data sheet designed for the purpose. Subjects were assessed Burden Assessment Schedule (BAS) by Thara et al.

**RESULTS**

**Table 1: Sociodemographic Characteristics of caregivers of person with Schizophrenia (N=40) and Schizoaffective Disorder (N=40)**

Characteristics		Caregivers Schizophrenia N (%)	Caregivers Schizoaffective N (%)	df	CHI SQUARE	P value
<b>Gender</b>	Male	60%	57.4%	1,1	0.052	NS
	Female	42.3%	40%			
<b>Marital Status</b>	Married	14%	11%	1,1	0.457	NS
	Unmarried	83%	92%			
<b>Occupation</b>	Employed	41.3%	48.7%	2,1	0.202	NS
	Unemployed	55.5%	54.5%			
<b>Education</b>	Above Matric	51%	66.5%	1,1	0.464	NS
	Below Matric	43%	39.5%			

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The study sample consisted of caregivers of 40 people with schizophrenic and 40 people with schizoaffective disorder. Table 1 shows the comparison of socio-demographic variables among caregiver groups. There were no significant differences with respect to Gender ( $X^2=0.052$ ), marital status ( $X^2=0.457$ ), Education ( $X^2=0.202$ ) as well as Occupational status ( $X^2=0.464$ ) among the two groups. Most caregivers had studied below high school .48% of caregivers of Person with schizoaffective were employed compared to 41.3% of caregivers of person with schizophrenia.

**Table 2: Comparison of Burden in Two Groups of Caregivers (Schizophrenic and Schizoaffective)**

Section Of Burden	Group	N	Mean	SD	t Value	P Value
BAS TOTAL	schizophrenia	40	76.4000	12.345	2.55	0.05
	schizoaffective	40	82.8230	8.7761		
CAREGIVER DAILY LIFE	schizophrenia	40	8.17500	1.8241	2.37	0.01
	schizoaffective	40	9.0000	1.7974		
PHYSICAL&MENTAL HEALTH	schizophrenia	40	12.4500	2.9434	3	NS
	schizoaffective	40	14.1500	2.0450		
EXTERNAL SUPPORT	schizophrenia	40	9.9500	1.8529	0.67	NS
	schizoaffective	40	9.6750	1.8171		
SUPPORT OF PATIENT	schizophrenia	40	6.6750	1.2276	1.74	0.01
	schizoaffective	40	6.2500	.9268		
TAKING RESPONSIBILITY	schizophrenia	40	9.5250	2.2186	2.86	NS
	schizoaffective	40	10.700	1.3435		
OTHER RELATION	schizophrenia	40	6.2250	1.4409	1.732	NS
	schizoaffective	40	6.7000	.96609		
PATIENT BEHAVIOUR	schizophrenia	40	8.1000	1.8508	2.835	0.01
	schizoaffective	40	9.1250	1.3433		
CAREGIVER STRATEGY	schizophrenia	40	8.9250	1,8877	2.554	0.05
	schizoaffective	40	9.8750	.930600		
SPOUSE RELATED	schizophrenia	16	9.7500	2.90965	2.917	0.01
	schizoaffective	14	12.1427	1.02711		

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Table 2: shows comparison of caregiver burden in the caregivers groups as reflected in Burden assessment schedule scores. Student t test was applied to compare the mean scores in the two groups. There was a significantly higher total burden with mean value of 82.82 (SD=8.77) in caregivers of person with Schizoaffective disorder compared to schizophrenia with mean value of 76.7 (SD=12.34). Similarly t test was applied to compare means of nine factors of burden assessment schedule. Significantly higher burden was noted in care givers of schizophrenia on ‘caregivers’ routine” (t=2.037),” physical and mental health” (t=3), “taking responsibility” (t=2.865), “patient behaviour” (t=2.835) and “caregiver strategy” (t=2.554). Spouse related burden could be assessed only where caregivers were spouses of patients. There were 16 spouses of person with schizophrenia and 16 spouses of person with schizoaffective disorder among the caregiver groups. Higher spouse related burden subscale (t=2.917) score was noted in schizoaffective disorder (12.14) compared to schizophrenia (mean=9.75).

**TABLE 3: Correlation (R) Of Caregiver Burden with Sociodemographic Variables Of The Caregivers In Study Population**

	<b>Age of caregiver</b>	<b>Gender of caregiver</b>	<b>Marital status of caregiver</b>	<b>Education of caregiver</b>	<b>Occupation of caregiver</b>
<b>Bas total</b>	.276	.024	.118	.238	.134
<b>Spouse related</b>	.528	-.457	-.123	.286	.023
<b>Caregiver routine</b>	.227	.369	.100	.389	.217
<b>Physical and mental health</b>	.247	.195	.187	.189	.069
<b>External support</b>	.253	-.152	-.019	.100	.115
<b>Support to patient</b>	.185	-.146	-.083	.109	.089
<b>Taking responsibility</b>	.289	.059	.222	.357	.111
<b>Other relations</b>	.077	.014	.081	.114	.201
<b>Patient behaviour</b>	.167	-.231	.071	.031	-.033
<b>Caregiver strategy</b>	.255	-.303	.050	.055	-.003

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Pearson correlation of sociodemographic variables of caregivers of the patients and burden assessment schedule scores is calculated in Table 3. Higher the age of the caregivers more was the burden ( $r=0.276$ ). Age also being correlated with caregiver's routine ( $r=0.227$ ), health ( $0.247$ ), external support ( $0.253$ ), taking responsibility ( $r=0.289$ ) and caregiver strategy ( $r=0.255$ ). Male caregivers reported more burden in spouse related ( $r=0.457$ ), patient behaviour ( $r=0.231$ ), care giver strategy ( $0.303$ ) and reported decreased burden in affecting daily routines ( $0.369$ ). Education of care givers correlated ( $0.238$ ) positively with the burden perceived by the care givers, especially by affecting the caregiver routine ( $0.389$ ) and problems in "taking responsibilities" ( $r=0.357$ ). Married caregivers faced more difficulty in Responsibility taking ( $0.222$ ); whereas occupation of caregivers did not show any much significant relation with burden.

### **DISCUSSION**

This study was conducted on person with schizophrenia and schizoaffective disorder and their caregivers.

### **DISCUSSION OF METHODOLOGY**

The sample size in the present study was 80 caregivers of person with schizophrenia and schizoaffective disorder. To examine the sufficiency of the sample, previous related studies were reviewed. However, there were lesser studies on the caregivers' burden. Burden Assessment Schedule (BAS) by Tharaet. BAS is a comprehensive and widely used tool for assessment of caregivers' burden. It has been used extensively in Indian population. Socio-demographic variables such as sex, marital status, residence were compared using chi square. There were no significant differences in the socio demographic profile of caregivers in both groups. Hence, the groups were comparable.

In the present study the burden perceived by caregivers of schizoaffective was significantly more than in schizophrenia. Further analysis of the areas of burden further revealed that burden was significantly more in caregivers of schizoaffective group in the following areas of BAS – spouse related, caregivers routine, physical and mental health, taking responsibility, patients behaviour and caregivers strategy. The role of demographic variables in burden of care was also examined in the present study. A positive correlation between age of caregivers and burden was observed suggesting that with the advancing age of caregivers there is an increment in the magnitude of the perceived burden. The older caregivers had significantly more burden in spouse related domain, physical and mental health, caregivers routine, external support, taking responsibility, and caregiver strategy. This inconsistent with findings of earlier studies. When caregivers were older they were more worried about future of their ill family member that who will take care of them in future and also that they can't provide care well to the ill member of the family . This study also found that more educated caregivers perceived more burdens. Married and more educated caregivers perceived more burdens in the domain of taking responsibility in this study.

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This was consistent with findings by Thara et al. Both schizophrenia and schizoaffective disorder are major psychiatric disorders which invariably produce burden on caregivers. The relative magnitude of the burden was compared in the present study which is higher in the caregivers of schizoaffective. The quantum of burden present in the caregivers, points out to the need for addressing the burden and related issues of the family members as well.

## **CONCLUSIONS**

The primary aim of the study was to estimate and compare the burden of care in caregivers of the patients with schizophrenia and schizoaffective disorder. The results of the study revealed considerable burden of care in families of the patients and a significantly greater burden of care in caregivers of person with schizoaffective. Additional studies would be required to further delineate the factors associated with both burden of care and expressed emotion in the caregivers.

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**Webs**

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