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## FAMILY BURDEN AMONG MALE AND FEMALE CARE GIVERS OF INDIVIDUALS SUFFERING FROM SCHIZOPHRENIA

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### ABSTRACT

**Background:** Schizophrenia is a severe disorder that typically begins in late adolescence or early adulthood and characterized by profound disruption in thinking and perception, affecting language, thought, perception and sense of self. It often includes psychotic experiences such as hearing voices or delusions. Caregivers of patient with schizophrenia faced many challenges in their life. They make balance between caring of patient with schizophrenia along with family, friends and job. Gender play important role in caring of patient with schizophrenia. This study is based on family burden among care givers of patient with schizophrenia in gender prospective.

**Aim:** The aim of the study is to assess and compare the family burden among male and female care givers of patients suffering from schizophrenia.

**Methods:** The present study was a hospital based cross sectional comparative study among the male and female caregivers of Schizophrenia. Purposive sampling technique was used. The subjects for the present study were drawn from the outpatient department (OPD) of Ranchi Institute of Neuro-Psychiatry and Allied Sciences (RINPAS), Kanke, Ranchi.

**Results:** Finding of this research study indicates that the mean and standard deviation on the family burden of male care givers of individuals with schizophrenia is  $23 \pm 7.07$  and female care givers is  $22.96 \pm 5.52$ . No significant difference was found in the overall family burden between male and female care givers of patients suffering from schizophrenia.

**Conclusion:** The research studies indicate that both care giver face difficulties in caring of patient with schizophrenia.

**KEY WORD-** Family burden, Caregivers, Schizophrenia.

### INTRODUCTION :

Schizophrenia is a chronic and severe mental illness that causes individuals to separate themselves from reality. It is a chronic, severe, and disabling brain disorder that has affected people throughout history. Schizophrenia is a one type of mental disorder and the caregivers are likely to face increasing levels of family burden. The family burden term first time used by Trendly (1946) on the family in relation to the consequences of the psychiatric illness.

Platt (1985) presented as more elaborate definitions which states that burden spheres to the presence of problem difficulties or adverse events that affect the lives of psychiatric patients. Although the entire family experiences burden of the illness the



responsibility of caring is often shouldered by the primary care giver who experiences psychological and emotional burden.

### EXTENT OF BURDEN

Mandelbrote and Folkard (1961) in a study of schizophrenic patients reported that degree to which families were restricted or disturbed by the patient's presence at home. In this study, 55% of families were rated as disturbed in some way though 2% of relatives reported severe stress.

### COMPONENTS OF BURDEN

Financial difficulties is one of the major problems reported by the families since they have to take care the patient whose disease is continuous and limit opportunity for an adequate and uninterrupted income. More over the problem will widen if the index patient is the breadwinner then the family particularly if the circumstance prevent the relative's form taking over this role (Mandelbrote and Folkard 1961; Hoening and Hamilton, 1966; Copas 1974; Pai & Kapur, 1981). Due to the illness the family's interaction with the society has drastically come down; resulting in restrictions in social and leisure activity. An equal number was affected by domestic routine, housework and shopping and about 25% by financial constraints. Similar findings have been reported in a study in India by Pai and Kapur (1981). In a third of these families, the children were affected by psychological illness. Hatfield (1979) found that severe stress in a family produced physical and emotional strain and caused anxiety guilt and depression in its members due to one person's illness. The Indian scene was reported rather interestingly that the psychological disorder may be hidden to outside world and only physical ailments are obvious on the surface, beyond the screen the effects of the families, children and adult members (Satyavathi, 1971).

### MEASUREMENT OF BURDEN

Grad J Sainbury in the early 1968's assessed the burden carried by the patient's families in two different kinds of psychiatric services (a) one hospital based (b) other oriented towards community care. In an interview with a close relative of the patient a psychiatric social worker (PSW) estimated the burden on each family by rating the effect the patient had on work, leisure income and health of the family on the children and on the family relations with their neighbor in addition the amount and type of care that the family had to provide for the patient and their ability to provide it were assessed. A family problem score was derived from these ratings and the PSW also made an overall rating of burden on the unit" each items was rated on a three point scale as "not affected by the patient "affected or "Severely affected" and defined wherever possible by objective criteria". Finally, the PSW gathered socio-economic and demographic data about the family had "recorded whether abnormalities of behavior likely to trouble families such as aggressiveness were present". Inter rater reliability was assessed and found to be adequate (Grad and Sainsbury, 1968). Hoening and Hamilton (1966) were the first to make a clear distinction between objective and subjective aspects of burden. In their view, objective burden meant identifying anything that occurs as disrupting factor in family life owing to the patients' illness. Subjective burden refers to the feelings that a burden is being carried in a subjective sense". Objective burden is subdivided in two types one consists of certain specific effects on the life of the house hold grouped in four main headings financial effects on the household, effects on the health of household member effects on children and effect on family routine. Type two objective burden is based on the occurrence of certain abnormal behaviour traits in the patient (e.g., danger to self or to others), which could be assumed to cause distress. A household any type one item was found to be present was rated as positive rating on total type two burdens was made and if any item (type 1 or 2) was found present a positive rating on "combined objective burden" followed. A positive rating on "combined objective burden" followed most items of type one objective burden appear to have been rated as "present" or absent although some 3-pint scales were also used. Type two items were rated on a 4-pont scale ("none, occasional, "periodic", "Constant "with two latter rating constituting burdens. Total or combined objective burden was either present or absent subjective burden on the order hand was assessed on one global 3-point scale "none, "Some" or "Severe"). In India two scales have been devised by the first one being Family

Burden schedule (Pai and Kapur, 1981). Six categories of objective burden (each consisting of 2-6 items) are measured in a semi structured interview schedule; which comprises of Financial effect on the family routine, effect on family leisure effect on family interaction, effect on physical health and effect on mental health. The second one Burden Assessment Schedule by Thara et al., (1998) consists of nine factors in a semi structured interview schedule. Numerous definitions of burden exist in literature and these share a common underlying frame of reference, namely the effect of the patient on the family (Goldberg and Huxley, 1980); impact of living with a psychiatric patient on the way of life and health of family members (Brown, 1967) or the difficulties felt by the family of a psychiatric patient (Pai & Kapur, 1981). Various aspects of burden on the family have been addressed, financial burden (Hoening and Hamilton, 1966 and 1968, Pai and Kapur, 1981), social discrimination (Claussen and Yarrow, 1955), restriction of social and leisure activity (Grad and Sainsbury, 1968) effect on health of others, both physical and mental (Rogler and Hollingshed, 1965, Brown et al., 1967). Pai and Kapur (1981) developed a semi structured interview schedule to assess burden on families of psychiatric patients living in the community. The schedule has 6 broad areas of assessment of burden namely, (i) financial burden, (ii) disruption of family routines, (iii) disruption of family leisure, (iv) disruption of family interaction, (v) effect on physical health of others and (vi) subjective burden on the family. These items are rated on a 3-point scale (severe burden=2; moderate burden=1, no burden=0). The study revealed that families found their sick relative burdensome in some aspects like family finances, disruption of normal family activities and production of stress symptoms in the family members. The inter-rater reliability and validity of the interview schedule was found to be high. Pai and Kapur (1981) compared two groups of patients, one availing inpatient psychiatric services and the other who received home care (927 patients each). Home care was delivered through a trained psychiatric nurse who was trained in skills and knowledge to provide such care. The results revealed that 'home based care' was better than 'hospital care' in terms of care in the reduction of burden. This finding is significant as the two group studies were comparable in their socio.

**Aim of the study:** To assess and compare the family burden among male and female care givers of individuals with schizophrenia.

**Research design:** The present study was a hospital based cross sectional comparative study among the male and female caregivers of Schizophrenia

**Sampling:** Samples were taken by using purposive sampling method, from Ranchi institute of neuro psychiatry and allied sciences (RINPAS).

#### **Inclusion and exclusion criteria:**

##### **Inclusion criteria for patients**

1. Patients attending RINPAS, who are diagnosed with schizophrenia according ICD- 10 (D.C.R)
2. Patients with schizophrenia of age between 21 to 45 years.
3. Patients who are having illness of duration not less than 1 year.
4. Patients who are not having any other physical or mental illness.

##### **Exclusion criteria for patients:**

1. Patients who are less than age of 21 years and more than the age of 45 years.
2. Patients who have duration of illness less than 1 year.
3. Patients who are having some other severe physical or mental illness.

##### **Inclusion criteria for care givers**

1. Care givers patients attending RINPAS involved in care at least for 1 year.
2. Care givers who will provide written informed consent.
3. Care givers who are educated up to 5th standard
4. Care givers who don't have any other person with mental, physical illness, neurological and mental and behavioral disorder due to use of any psychoactive substance.



**Exclusion criteria for care givers:**

1. Care givers who are having any physical, mental illness, neurological and mental and behavioral disorder due to use of any psychoactive substance
2. Care givers who are involved in caring more than one person with mental illness.
3. Care givers who are illiterate.

**Procedure of study:**

Initially permission was taken from the director and the head of the department of the psychiatric social work of the institute for conducting the present study “family burden among male and female care givers of the patients suffering from schizophrenia”. After screening according to the inclusion and exclusion criteria, samples were selected for the current study from the outpatient department of Ranchi Institute of Neuro psychiatry and Allied Sciences (RINPAS) Kanke Ranchi. The samples were selected by using purposive sampling technique and a total of 60 samples which were further divided into 30 male care givers of patients suffering from schizophrenia and 30 female care givers of patients suffering from schizophrenia. The objectives of the study were explained to the participants. After establishing the rapport and explaining the purpose of the study the details of the socio-demographic data and various scales like General health Questionnaire, burden interview schedule was administered. For the statistical analysis SPSS (statistical package for social sciences) 16.0 version was used. t test was used for the statistical analysis.

**The following tools were used in the study:**

**1.Socio demo graphic data sheet:** It is a semi structured, self prepared Performa especially created for the study. It contains information about the socio demographic variables like age, sex, religion, education, marital status, occupation and domicile.

**2.General health questionnaire- 12 (GHQ-12)(Goldberg, 1978):** Goldberg and William developed the General Health Questionnaire-12. It is used to screen any psychiatric morbidity in healthy persons. General Health Questionnaire-12 is the short version of the original General Health Questionnaire containing 60 items for the detection of the psychiatric illness. Internal consistency of GHQ - 12 has been excellent. A high degree of internal consistency was observed for each of the 12 items with Cronbach's alpha value of 0.37-0.79, while total score was 0.79 in the population study. Test-retest correlation coefficients for the 12 items score were highly significant.

**Results:** Table 1 shows the comparison of two groups i.e. male and female care givers of individuals suffering from schizophrenia in relation to their socio demographic parameters. No significant difference was found between the two groups.

**Tables-1: Socio-demographic variables between male and female caregivers of patients suffering from schizophrenia.**

Variables		Group		Df	x <sup>2</sup>
		Male	Female		
<b>Education</b>	Under metric	12 (40.0%)	24 (60.0%)	3	12.733NS
	Intermediate	7 (23.3%)	5 (16.7%)		
	Graduation	9 (30.0%)	1 (3.3%)		
	Others	2 (6.7%)	0 (0.0%)		
<b>Marital status</b>	Married	21 (70.0%)	25 (83.3%)	1	1.491NS
	Unmarried	9 (30.0%)	5 (16.7%)		
<b>Religion</b>	Hindu	24 (80.0%)	29 (96.7%)	3	4.272NS
	Islam	4 (13.3%)	1 (3.3%)		
	Christianity	1 (3.3%)	0 (0.0%)		
	Others	1 (3.3%)	0 (0.0%)		

<b>Domicile</b>	Rural	22 (73.3%)	26 (86.7%)	1	1.667NS
	Urban	8 (26.7%)	4 (13.3%)		
<b>Occupation</b>	Student	5 (16.7%)	4 (13.3%)	2	6.425NS
	Professional	12 (40%)	4 (13.3%)		
	Others	13 (43.3%)	22 (73.3%)		
<b>Socio economic status</b>	Lower	23 (76.7%)	29 (96.7%)	1	5.192NS
	Middle	7 (23.3%)	1 (3.3%)		

Table 2 Comparison of family burden between male and female care givers of patients suffering from schizophrenia

Table 2 shows the comparison of family burden between male and female care givers of individuals suffering from schizophrenia. No significant difference was found between the two groups.

Variables	Group		t	df	p
	Male (N=30) Mean±SD	Female (N=30) Mean±SD			
<b>Financial burden</b>	6.30± 3.07	6.10±2.17	0.291	58	.772
<b>Disruption of routine family activities</b>	5.80±2.17	5.73±1.81	0.129	58	.898
<b>Disruption of family leisure</b>	2.96±1.42	3.46±0.97	1.586	58	.118
<b>Disruption of family interaction</b>	5.73±2.16	5.83±1.57	0.204	58	.839
<b>Effect on physical health others</b>	1.70±1.05	1.60±.89	0.396	58	.694
<b>Effect on mental health of others</b>	0.23±1.09	0.63±1.09	1.733	58	.088
<b>Total burden</b>	23.13±7.07	22.96±5.52	.102	58	.919

\*=Significant at 0.05 Level.

\*\* Significant at 0.01 Level

**DISCUSSION:**

Overall family burden the mean and standard deviation of male care givers of individuals with schizophrenia is 23±7.07 and female care givers is 22.96±5.52. No significant difference was found in the overall family burden between male and female care givers of patients suffering from schizophrenia. The result is also in context with the study conducted by kumara et al., (2008) who conducted the study as “subjective burden on the spouses of schizophrenia”, her findings also suggest that no significant difference was found between male and female spouses of schizophrenia. Creer & Wing (1975) found that family members could tolerate a surprisingly high level of mental symptoms but this tolerance was at the expense of a great deal of internal burden i.e. financial and they also found distress i.e. physical and emotional that commonest behaviour problems reported by family members of Schizophrenics patients were those associated with social withdrawal, such as little interaction, slowness, lack of conversation, few leisure interests and self neglect.

**LIMITATIONS:**

Being time bound study sample size was small and hence the results could not be generalized. Comparison with some other disorder could have been done. The study needed to be carried out on a large sample with comparable representations of the both groups.

**FUTURE DIRECTIONS:**

The future study must be attempted to include some other psycho-social aspect of the care givers which is being experienced by the care givers.

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