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RELATIONSHIP BETWEEN FAMILY INTERACTION, FAMILY BURDEN AND QUALITY OF LIFE AMONG CAREGIVERS OF PATIENTS WITH EPILEPSY



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ABSTRACT

Living with epilepsy imposes great challenges on both patients and their family caregivers but most researchers only explored the impact on patients, with less attention given to family caregivers. Our study intended to explore the needs and problems of epilepsy family caregivers of epilepsy patients encountered during the caregiving process. The present study was an attempt to assess the relationship between Family interaction pattern, family burden schedule and Quality of life of the caregivers of individuals with epilepsy. This study was conducted at the Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi. It was a cross sectional study and purposive sampling was used. The present study was conducted among 60 caregivers of epilepsy, those who were willing to participate and those who have satisfied with inclusion and exclusion criteria have been included in the study. The socio demographic data sheet had been used for collecting socio demographic details of the caregivers of individuals with epilepsy. Family interaction pattern scale, family burden interview schedule and WHO Quality of life scale were applied on the caregivers of individuals with epilepsy. Statistical analysis was performed by using the SPSS programme 16.0 version. The result found that family interaction pattern has effect on family burden and quality of life. Likewise family burden has greater impact on quality of life. The study highlights the need for family interventional programs to address the specific issues related to family interaction, burden and quality of life of caregivers.

Keywords:

Family interaction pattern, Family burden, Quality of life, Caregivers, Epilepsy.

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1. INTRODUCTION

Epilepsy is the most common serious brain disorder and a global problem affecting all ages, races, social classes and countries. It imposes enormous physical, psychological, social, and economic burdens on patients as well as family members. Epilepsy can affect the lives of other family members besides the persons with epilepsy. The caregivers of persons with epilepsy undergo severe physical, psychosocial, emotional, coping, adjustment within marital relationship, issues surrounding children, employment, economic burden and stigma about the disease. Family caregivers also face enormous problem of caring who is having epilepsy is an enduring stressor and causes considerable amount of burden. A study conducted in India by Kumar Jaya et al (2002) to assess the burden of care giving among the caregivers of persons with epilepsy. In the study it was found that caregivers of persons experienced a greater degree of burden. A study done by Ray et al (2004) reports an overall increase in the burden amongst caregivers with epilepsy compared to the control group. Researchers has found that caregivers of patients with epilepsy have high levels of strains, fears and concern about what will happen to patients in future when the caregiver will not be available to take care (Anderson, 1990 & Thomson, 1992). In an Indian study recently conducted on association between quality of life, depression and caregiver burden in epileptic patients it was found that significant positive correlation was found between Beck depression inventory and Zarit burden interview. Duration of disease was not significantly correlated with Quality of life and Beck depression inventory and Zarit burden interview. It was also found that that emotional well being is most affected domain in quality of life (Shiva Sirari, 2014). Analysis of family interaction pattern, family burden and Quality of life of family members of patients with epilepsy provide for a real world clinical decision, application of research finding, and generation of counseling strategies, all geared to promote holistic caring. The ultimate goal of mental health care professional is to maintain and enhance client and family quality of life irrespective of nature of illness.

2. METHODOLOGY

The present study consisted of 60 caregivers of patients with epilepsy. Purposive sampling techniques were used and data collected from outpatient and inpatient department of Ranchi institute of Neuro Psychiatry and Allied Sciences (RINPAS), Ranchi. Patients were selected as per ICD -10 DCR criteria. The following tools were used for the current study: Socio-demographic data, GHQ-12, Family interaction pattern scale, Family burden interview schedule and WHO Quality of life scale.

3. RESULTS

Table 1: Correlation among Family Interaction Pattern Scale and Family burden Scale of Caregivers of patients with epilepsy

	Family Burden Scale					
	Financial burden	Disruption of routine family Activities	Disruption of family leisure	Disruption of family interaction	Effect on physical health of others	Effect on mental health of others

Family interaction pattern scale	Reinforcement	-.328*	-.261*	-.182	-.062	-.172	-.065
	Social support system	-.295*	-.265*	-.208	-.141	-.316*	-.314*
	Role	-.081	.216	-.344**	-.338**	-.055	-.302*
	Communication	-.260*	-.278*	-.055	.161	-.088	-.263*
	Cohesion	-.289*	-.062	-.091	-.117	-.076	-.154
	Leadership	-.175	-.096	-.026	-.269	-.239	-.200

*Significant p < .05, **Significant p < .01.

Table (1) shows the Correlation among Family Interaction Pattern Scale and Family burden Scale of the caregivers of patients with epilepsy. Significant negative correlation exists between family interaction patterns scales domain reinforcement with financial burden and disruption of routine family activities of family burden Scale (p < .05). Significant negative correlation exist between family interaction patterns scales domain social support system with financial burden, disruption of routine family activities, effect on physical health of others and effect on mental health of others of family burden Scale (p < .05). Significant negative correlation exist between family interaction patterns scales domain role with disruption of routine family leisure, disruption of routine family interaction and effect on mental health of others of family burden Scale (p < .05, p < .01). Significant negative correlation exists between family interaction patterns scales domain communication with financial burden and disruption of routine family activities of family burden Scale (p < .05). Significant negative correlation exists between family interaction patterns scales domain cohesion with financial burden of family burden Scale (p < .05).

Table 2: Correlation among score of Family burden Scale and WHO QOL of caregivers of epilepsy Patients

		WHO QOL			
		Physical health	Psychological health	Social relationships	Environment
Family Burden Scale	Financial burden	-.312*	-.312**	-.252	.151
	Disruption of routine family Activities	-.062	-.365**	-.105	.093
	Disruption of family leisure	-.539**	-.463**	-.104	-.119
	Disruption of family interaction	-.232	-.044	-.275*	.042
	Effect on physical health of others	-.310*	-.251	-.124*	.089
	Effect on mental health of others	-.341**	-.340**	-.212	-.031

*Significant p < .05, **Significant p < .01.

Table (2) shows the Correlation among scores of Family burden Scale and WHO QOL of the caregivers of patients with epilepsy. This indicates that significant negative correlation exist between Family burden Scale domain financial burden, disruption of family leisure and effect on

mental health of others with physical health and psychological health of WHO QOL scale ($p < .05$ & $p < .01$). Significant negative correlation exists between financial burden Scale domain disruption of routine family activities with psychological health of WHO QOL scale ($p < .01$). Significant negative correlation exists between financial burden Scale domain disruption of routine family interaction with social relationship of WHO QOL scale ($p < .05$). Significant negative correlation exists between financial burden Scale domain effect on physical health of others with physical health and social relationship of WHO QOL scale ($p < .05$).

Table 3: Correlation among score of Family Interaction Pattern Scale and WHO QOL of caregivers of epilepsy patients

		WHO QOL			
		Physical health	Psychological health	Social relationships	Environment
Family interaction pattern scale	Reinforcement	.263*	.300*	.163	.060
	Social support system	.256*	.358**	.129	.081
	Role	.546**	.324*	.295*	.063
	Communication	.273*	.327*	.013	.115
	Cohesion	.307*	.463**	.338**	.051
	Leadership	.369**	.332**	.173	.084

*Significant $p < .05$, **Significant $p < .01$.

Table (3) shows the Correlation among scores of Family Interaction pattern scale and WHO QOL of the caregivers of patients with epilepsy. Significant positive correlation exists between domains Family Interaction Pattern Scale domain reinforcement, social support system, communication and leadership with physical health and psychological health of WHO QOL scale ($p < .05$ & $p < .01$). Significant positive correlation exists between domains Family Interaction Pattern Scale domain role and cohesion with physical health and psychological health and social relationship of WHO QOL scale ($p < .05$ & $p < .01$).

4. DISCUSSION

DISCUSSION OF SOCIODEMOGRAPHIC VARIABLES

The aim of the study was to assess the relationship between family interaction pattern, family burden and Quality of life among caregivers of patients with epilepsy. This study was conducted at the Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi. It was a cross sectional study and purposive sampling was used. The present study was conducted among 60 caregivers of patients with epilepsy, those who were willing to participate in the study and those who have satisfied with inclusion and exclusion criteria have been included in the study. The socio demographic data sheet had been used for collecting socio demographic details of the caregivers of individuals with epilepsy. Family interaction pattern scale, family burden interview schedule and WHO Quality of life scale were applied on the caregivers of individuals with epilepsy.

RELATIONSHIP BETWEEN FAMILY INTERACTION PATTERN, FAMILY BURDEN AND QUALITY OF LIFE IN CAREGIVERS OF PATIENTS WITH EPILEPSY:

The present study found that reinforcement shows its negative correlation with financial burden and disruption of routine family activities of family burden of caregivers of patients with epilepsy. This means that with improvement in reinforcement, there is a corresponding degrade in the financial burden and disruption of routine family activities and in the areas of work capacity, mobility, activities of daily living, financial resources, security, social care, opportunity for recreation etc.

Social support system shows its negative correlation with financial burden, disruption of routine family activities, effect on physical health of others, and effect on mental health of others of family burden of caregivers of patients with epilepsy. Role shows its negative correlation with disruption of routine family leisure, disruption of routine family interaction and effect on mental health of others of family burden of caregivers of patients with epilepsy. Communication shows its negative correlation with financial burden and disruption of routine family activities and effect on mental health of others of family burden of caregivers of patients with epilepsy. Cohesion shows its negative correlation with financial burden of family burden of caregivers of patients with epilepsy. Epilepsy had an impact on caregivers' QOL and imposed a mild to moderate burden as a consequence of caregiving (Ana, 2007). Epilepsy becomes an identity and the focus of the caregivers' lives. The stress of having epilepsy impacts mental health and psychological well-being not only of individuals with the condition, but also of their families (Thompson & Upton, 1992).

The correlation of the domains of BAS was done with perceived social support. Physical and mental health and external support, support of patient, caregivers' taking responsibility, other relation, and caregivers' strategy domains of BAS has a significant negative correlation with perceived social support. The presence of social support is beneficial for parental well-being, adjustment, and care giving. Social support on different dimensions of parenting and care giving affects the various domains of caregivers' burden. Nevertheless, it has been demonstrated that social support directly affects burden to the caregivers. Social support serves as a resource that reduces parenting stress and burden; subsequently, exerts beneficial effects on care giving. It is evident that social support was poor for the families who had been studied. External services are lacking and social support from families and external setups is poor in the society. The burden experienced by caregivers may be the cumulative effect of the disease over the years. Frequent relapses and repeated seizure attacks challenge the coping and problem-solving ability of the caregiver. This also involves frequent hospital visits, using high doses of psychotropic drugs which are expensive, close monitoring of persons at home. Thus, prolonged attacks and relapses, and stigmatisation - all add to caregiver burden, and inadequate inputs in social services and facilities are an indication for social support. In a study conducted Joannis et al (2014) found that, higher number of antiepileptic drugs, poorer patient neuropsychological performance, lower patient quality of life (QOL) score, and lower caregiver education level were associated with higher care burden. This study examines the association between family interaction pattern, family burden and WHO Quality of life in caregivers of patients with epilepsy.

In the present it was found that financial burden, disruption of routine family leisure and Effect on mental health of others shows significant negative correlation with physical health and psychological health of WHO QOL scale. According to Baronet (1999), burden in mental illness is determined by the presence of the disease and the result of the activities of caregiving mediated by physical and psychological aspects and the resources of the environment. Disruption of routine family activities shows significant negative correlation with psychological health of WHO QOL scale. Disruption of routine family interaction shows significant negative correlation with social relationship of WHO QOL scale. Effect on physical health of others shows significant negative correlation with physical health and social relationship of WHO QOL scale. Reinforcement, Social support system, Communication and Leadership shows significant positive correlation with physical health and psychological health of WHO QOL scale. Role and Cohesion shows significant positive correlation with physical health, psychological health and social relationship of WHO QOL scale. Marital and family conflicts may contribute to the poor quality of life and increase of burden on caregivers of persons with chronic diseases (Chou, 2000). This study finding matches with Ana, 2007 Negative effects on caregivers in relation to physical and mental health, reflecting areas of concern such as health, personal and social life, emotional status, personal relationships, and economic resources. The main limitation of the study was the size of the sample; the other variables like family home environment, family coping and problem-solving skill should be taken for study in order to understand the true burden of caregivers. In fact, Kumar et al. (2013) studied the subjective well-being and coping among people with schizophrenia and epilepsy.

5. CONCLUSION

The result found that family interaction pattern has effect on family burden and quality of life. Likewise family burden has greater impact on quality of life. Knowledge about burden perception and enhancement of family interaction pattern goes a long way in improving the quality of life of patients and their families and also towards management of epilepsy. Caring for patients with epilepsy is really challenging and it is associated with enormous burden. Various inputs in the psychosocial area can be planned based on knowledge gained. This study would be useful to enlighten us about various facets i.e family interaction, family burden and quality of life of caregiving of patients with epilepsy. Caregiving holds a key position in the treatment and rehabilitation of these patients. Success of treatments and rehabilitations are largely depending on the caregiving. If caregiving is found to be inadequate or improperly done then success of the intervention would likely be doubtful. This study was carried out on small samples so in future such kind of study can be done on large samples in order to get more generalized conclusion in this regard.

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