

Association between Socio-Demographic Characteristics and Family Burden among Caregivers of Patients with Epilepsy

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ABSTRACT

The present study was an attempt to assess the relationship between Socio-demographic characteristics and family burden of the 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 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 and family burden interview schedule were applied on the caregivers of patients with epilepsy. The data obtained was analyzed statistically. The current study result found that patient education significantly negatively correlated with financial burden. And patient occupation negatively correlated with disruption of family interaction. Regarding the correlation of caregivers of patient with epilepsy the study shows that education of caregivers of patient with epilepsy negatively correlated with disruption of routine family activities and disruption of family leisure. And also occupation of caregivers of patient with epilepsy negatively correlated with disruption of family leisure and effect on physical health of others. The study highlights the need for family interventional programs to address the specific issues related to family burden of caregivers of patients with epilepsy.

Keywords: Epilepsy, Family burden, Caregivers, Socio-demographic

Epilepsy is a neurological disease causing seizures that result from an excessive electrical discharge in the brain, they are sudden, involuntary and time limited alteration in behavior, including change in consciousness, motor activity, autonomic functioning or sensation for a limited period of time (Intisar and Mehabe, 2007). As a consequence, people with epilepsy and their families may be faced with a lack of social support from extended family members; feelings of parental guilt; social isolation, embarrassment, and fear; and discrimination. Although efforts are being made to correct these misconceptions and to better inform people

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about the epilepsies, doing so remains a challenge (Mary et al., 2012). Reports of studies carried out in various parts of the world have indicated that caring for patients with epilepsy is associated with emotional distress, burden, impaired quality of life in caregivers and poor outcome of the disease in both patients and caregivers (Li, 2008). These can be alleviated with provision of psycho-education, accessible and affordable modern health care facilities to both patients with epilepsy and caregivers (Westphal, 2007). Burden of care is a multi-factorial construct which includes emotional, psychological, physical and economic impact as well as related distressing feelings such as shame, embarrassment, anger, feeling of guilt and self-blame (Awad, 2008). It is customary to describe burden as objective or subjective. Objective burden refers to changes in household routine, family or social relations, work, leisure and physical health; while subjective burden consists of subjective distress among relatives, including impact on mental health (Rein, 2003). Family caregivers have been described as forgotten patients and it was suggested that caregiver's symptoms such as mood swing, fatigue, headaches, joint and muscle pains, marital and family conflicts, and financial problems may be a reflection of caregiver stress in looking after a sick relative (Medalie, 1994). Studies have shown that caregivers of patients with epilepsy have high levels of strains, fears that the illness may cause injury or death as well as concern about what will happen to patients in future when the caregiver will not be available to cater for patients (Anderson, 1990). In addition, it has been shown that relatives who care for patients with epilepsy have higher burden of care than control groups (Thompson, 1998) and that depression and patient's functioning separate from seizure control (Thompson, 1998) and low income (Ray, 2004) are predictors of burden in caregivers. However there is paucity of literature on the burden experienced by caregivers looking after patients with epilepsy especially in India and with this background we studied caregivers of epileptic patients to assess their level of burden in caring for their patients. This study was an attempt to identify the magnitude and factors associated with burden among care givers of patients with epilepsy. In view of the dearth of literature or studies focused on caregivers of patients with epilepsy, this study also provided an insight into the problems face by caregivers in the context of socio-demographic and burden of care.

Need For the Study

The presence of individual with epilepsy in the family affects various aspect of family life such as leisure time activities, family and social relationship and finances. Prolonged epilepsy attack can become a threat to the socio-occupational repertoire of the family members. Family's all functioning be the necessary or secondary, can become inadequate or inappropriate due to this problem. Family's important functioning like interpersonal relationship; general family atmosphere may become pathological because of this problem. Hence the present study will help us in formulating family intervention, to improve the family functioning, to reduce the care givers burden.

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METHODOLOGY

The present study was an attempt to assess the relationship between Socio-demographic characteristics, and family burden schedule of the 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 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 and family burden interview schedule were applied on the caregivers of patients with epilepsy.

RESULTS

Table-1: Correlation of Family burden Scale, Socio demographic and clinical Variables of the Patient with epilepsy

Scales		Age of Patient	Patient education	Patient occupation	Age of Onset	Duration of illness
Family Burden Scale	Financial burden	-.041	-.404**	-.102	-.008	-.045
	Disruption of routine family activities	-.005	-.147	-.209	-.066	.122
	Disruption of family leisure	.054	-.061	-.326	.017	.047
	Disruption of family interaction	.078	.047	-.312*	.051	.038
	Effect on physical health of others	-.068	-.082	-.069	-.016	-.052
	Effect on mental health of others	.215	-.008	-.133	.172	-.021

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

Table (1) shows the Correlation among Family burden Scale, and the Socio demographic and Clinical Variables of the Patient with epilepsy. There was a significant negative correlation found between patient education and financial burden ($p < .01$). And also significant negative correlation was seen between patient occupation and family interaction ($p < .05$).

Table-2: Correlation of Family burden Scale and the Socio demographic Variables of the Caregivers of patient with epilepsy

Scales		Age of Caregivers	Caregivers education	Caregivers occupation	religion	Residence
Family Burden Scale	Financial burden	-.156	-.103	.145	.089	-.023
	Disruption of routine family activities	-.055	-.263*	-.253	-.039	-.058
	Disruption of family leisure	-.137	-.330*	-.309*	.025	-.212

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Scales		Age of Caregivers	Caregivers education	Caregivers occupation	religion	Residence
	Disruption of family interaction	.011	-.236	-.238	-.026	-.220
	Effect on physical health of others	.254	-.135	-.284*	.158	-.099
	Effect on mental health of others	-.043	.093	-.196	.012	-.006

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

Table (2) shows the Correlation among score of Family burden Scale and the Socio demographic variables of the caregivers of Patient with epilepsy. There was a significant negative correlation observed between caregiver’s education and in the domain of Disruption of routine family activities ($p < .05$). This result also shows that there was significant negative correlation between caregiver’s occupation and caregiver education and in the domain of Disruption of family leisure ($p < .05$). And also it was found that significant negative correlation exist between caregiver’s occupation and in the domain of Effect on physical health of others ($p < .05$).

DISCUSSION

Discussion of Methodology

This study was conducted at the Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi. It was a cross sectional study about the socio-demographic and its relation with family burden in the caregivers of patients with epilepsy. The aim of the study was to assess the socio-demographic and its relation with family burden in the caregivers of patients with epilepsy. The present study was conducted of 60 caregivers of individuals with epilepsy, those who are willing to participate in the study and inclusion and exclusion criteria have been included in the study. The socio demographic data sheet had been used for collecting socio demographic details and family burden interview schedule were applied on the caregivers of patients with epilepsy.

DISCUSSION

The current study result found that Patient education significantly negatively correlated with financial burden. And Patient occupation negatively correlated with disruption of family interaction. Regarding the correlation of caregivers of Patient with epilepsy the study shows that education of caregivers of Patient with epilepsy negatively correlated with disruption of routine family activities and disruption of family leisure. And also occupation of caregivers of Patient with epilepsy negatively correlated with disruption of family leisure and effect on physical health of others and this result was matched with previous study conducted by Folorunsho (2010) on burden experienced by family caregivers of patients with epilepsy attending the government psychiatric hospital, Kaduna, Nigeria. In this study unemployment was found to be associated with high burden. In patients who have had the illness for a long time, the burden experienced by caregivers may be the cumulative effects of the disease over

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the years. And also the result found that Caregivers of patients with epilepsy experience significant burden while caring for their relatives and this was mainly associated with patient's factors and location of residence. In another study done by Narendra et al (2011) on Perceived Burden and Social Support of Caregivers in Early onset Psychosis & Epilepsy, found that in psychosis group, education of caregiver showed significant negative correlation with two areas of burden, e.g. subjective burden and financial burden. It might be because of educated caregivers could understand the actual nature of illness of patient, their awareness in more efficient manner than less or uneducated caregivers. At the same time educated caregivers can solve the financial problems more skillfully than uneducated or lesser educated caregivers since educated caregivers are employed in jobs which are more lucrative or profitable in terms of remunerations than uneducated or less educated caregivers. From these findings we could say that education can have a moderating effect on caregivers' burden. And also the current study finding regarding education of caregivers' and burden of care is consistent with the finding of Gutiérrez- Maldonado et al study (Gutiérrez- Maldonado, 2005). The authors had conducted a study on sixty-five caregivers of patients with schizophrenia in Arica, Chile and they found that burden tended to be very high, particularly for mothers, caregivers with lesser level of education, caregivers of younger patients and patients with the history of more hospitalizations in the past 3 years.

CONCLUSION

The result of this study shows that Socio-demographic characteristics have some significant correlation with some of the domains of family burden. Caring for patients with epilepsy is really challenging and it is associated with enormous burden. It urges the mental health professional to provide psychological support for the family caregivers to help them to reduce the burden and to improve their quality of life.

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