Burden and Perceptions Associated with Epilepsy: Caregivers' Perspectives

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ABSTRACT

Background: Neuropsychiatric diseases which are mental, neurological and behavioural are growing causes of morbidity, and epilepsy is prominent among them. Epilepsy is a disease of uncertainty and disappointment and is the most common disorder of brain. It has neurobiological, cognitive, psychological and social consequences. With its increasing disease burden in all societies, the role of caregiver has been increasingly recognized as an important one, both functionally and economically. The stress associated with unsupported care for chronically ill family members may result in a condition commonly referred to as caregiver syndrome which is the emotional, physical and financial demands and responsibilities of an individual's illness that are placed on family members, friends or other individuals involved with the individual outside the health care system. Objectives: Present study attempts at exploration of caregiver burden and associated psychosocial perceptions of primary caregivers of patients with epilepsy. Sample: 30 participants who were primary caregivers of patients with epilepsy were selected from Child guidance clinic and neurology OPD, IHBAS-Delhi. Design: Present study was an exploratory study which aimed to elicit quantitative and qualitative data on caregiver burden in primary caregivers of patients with epilepsy and their perceptions about epileptic illness. Tool: The data was collected with the help of Zarit Burden inventory and a semi structured interview schedule. Results: Study indicates moderate to severe levels of caregiving burden and various stigma, anxieties and misconceptions about epileptic illness. Conclusion: Present study strongly indicated the need for comprehensive and integrative health care system focusing psychoeducation, support group and awareness initiatives designed for public to reduce the stigma and anxieties associated with this illness. It also stresses the need for shift from medical model to biosyposchosocial model of

Keywords: Caregivers, Caregiver Burden, Epilepsy, Perception about Epilepsy, Social Stigma, Psychoedcuation

Introduction

Neuropsychiatric diseases which are mental, neurological and behavioural are growing causes of morbidity and epilepsy is prominent among them. It's a disease of uncertainty and disappointment and is the most common disorder of brain. It means the same thing as "seizure disorders". Epilepsy is characterized by unpredictable seizures and can cause other health problems. Epilepsy is a spectrum condition with a wide range of seizure types and it varies from person-to-person. One of every ten people has at least one epileptic seizure during a normal life span and about one third of these develop epilepsy. According to WHO epilepsy is contributing to 1% of the global burden and 50 million people are suffering from epilepsy worldwide. Incidence and prevalence of epilepsy is more in developing nations than in developed countries.

ILAE (International League Against Epilepsy) has recently defined the epileptic seizure as "a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain." It has also redefined epilepsy as "A chronic condition of the brain characterized by an enduring propensity to generate epileptic seizures, and there is neurobiological, cognitive, psychological and social consequences of this condition." Studies have been reported on the epilepsy covering different aspects like screening of the community people, wherein it is found that about 10 million people are suffering from epilepsy in our country (Gourie Devi et al., 2003).

In rural areas 452465 people have been screens and 2435 cases of epilepsy have been observed with an average rate of 5.38 persons in rural areas with an overall rate of 5.32 persons per 1000 (Sridharan, 2002). This estimate is based on the total projected population of India in 2001 which says that the estimated number of people with epilepsy is about 55,00,000. Considering rural population which constitutes about 74% of the Indian population, the number of people with epilepsy in rural areas will be close to 41,00,000. The prevalence of epilepsy is about one percent but this varies widely across populations. There is a significant level of under-reporting because of the stigma associated with seizures.

It involves diagnosis of epilepsy by differentiating other mimicking conditions like pseudo-seizures and assessment of different domains i.e. physical, psychological, cognitive, behavioural as well as social on an individual basis. Assessment and intervention can be optimal only when the multiple medical, psychological, social and environmental factors that contribute to epilepsy are addressed. Indeed the battle between prejudice and acceptance, ignorance and knowledge, myths and science and charlatanism and rational therapy has been long and difficult and even today it has not yet been fully won.

Cognitive problems with epilepsy are mostly concerned with memory, speech and attention difficulties along with behavioural and psychological symptoms of epilepsy are major causes of stress to family and kinsmen providing care to people with epilepsy. The magnitude and burden is very huge and is affecting more than 450 million people in the world. It is mentioned that 33 percent of years lived with disability and 13 percent of disability
adjusted life years (DALYs) are due to neurological and psychiatric disorders, which account for four out of the six leading causes of years lived with disability (Mathers et al., 2003). Epilepsy is neurological disease causing the social suffering to the family and community adding to an irreparable loss. The burden caused by this disease remains largely unrecognized in developing countries. Such chronic neuropsychiatric disease are devastating the poor population living in our country. They cause serious social suffering and social handicap by making people unproductive. It can manifest in loss of job or being unable to work, loss of family income, burden on family for caring with further potential loss of wages, the cost of medications and the need for other medical services which can be expected to be particularly devastating especially among those with limited resources. Besides these, they are also frequent victims of human rights violations, stigmatization, and discrimination and hence it puts limits to patients' access to treatment. Therefore these diseases require special attention in developing countries including ours.

Caregivers and associated burden

Caregiver syndrome which is the emotional, physical and financial demands and responsibilities of an individual's illness that are placed on family members, friends or other individuals involved with the individual outside the health care system. Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness. For example, a person caring for someone with a chronic illness may experience such stressors as financial strain, managing the person's symptoms, dealing with crises, the loss of friends, or the loss of intimacy. 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, feelings of guilt and self-blame.

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. Family caregivers have been described as forgotten patients and it was suggested that caregiver's symptoms such as mood swings, 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. There is abundance of literature available depicting burden on caregivers affecting their physical, psychological, financial, social lives thus affecting their well-being and quality of life (Datta, 2005). Grad & Sainsbury (1963a, 1968) and Smith (2003) found that age and sex are important determinants of caregiver burden. There is more burden associated with male patients and increased age. Brown et al. (1966) found that more burden is linked with female caregivers, low education, singlehood, chronic and severe illness and greater disability. Pratt et al. (1985) have found emotion focused and combination strategies for coping with stress related to caregiving. Many of the patients' emotional difficulties about disorder originate from the way family perceive and formulate the disorder and feel the burden in different domains. Also presence of expressed emotions and the way it mediates and moderates the exacerbations of patients' problems indicate the need for such studies especially in the Indian set up.

Research in the area of counselling and mental health services is needed to assist caregivers in dealing with manifestations of burden is needed. Health care should be readily available to the entire populace affected with epilepsy at affordable prices.

Methodology

Sample:

30 participants (both males and females between age ranges of 25-55 years) who were primary caregivers of patients with epilepsy were taken from Child guidance clinic and neurology OPD, IHBAS-Delhi using purposive sampling.

Inclusion criteria

- Primary caregivers of patients having epileptic seizures since more than one year duration.

Exclusion criteria

- Those with diagnosed medical or psychiatric conditions, alcohol or other substance abuse and subnormal intelligence
Design:

Present study was an exploratory study which aimed to elicit quantitative and qualitative data on caregiver burden in primary caregivers of patients with epilepsy and their perceptions about epileptic illness.

Tools:

- **Basic identification Sheet**: It comprised details regarding age, gender, education, religion, socio-economic condition and domicile of the caregivers.

- **Zarit Burden Inventory (Zarit et al., 1980)**: It is a 22 items inventory to measure caregiver burden on which responses are taken on a 5 point rating scale. The internal consistency i.e. Cronbach's alpha is 0.89 and test-retest reliability is 0.71 for this inventory. The test items were translated in Hindi and reliability between Hindi and English version was established by back to back translation.

- **Semi-structured Interview Schedule**: Based on pilot study with primary caregivers of patients with epilepsy, clinical observations and experts' suggestions a semi-structured Interview Schedule was prepared to know about caregivers' perceptions and associated issues with epileptic illness (e.g. possible nature, duration, reasons and future course of illness, possibilities of treatment, existing and available treatment modalities, possible outcomes, their ideas, views and association with this illness and how it has impacted their lives).

Procedure:

Sample was collected from outpatient setting as per the inclusion and exclusion criteria and informed consent was taken from them. Interviewing and assessment was done keeping in mind the linguistic background, level of motivation and degree of cooperation of the subjects which was preceded by adequate rapport formation. Data obtained was analyzed quantitatively using appropriate descriptive statistics while themes associated with caregivers' perceptions and their subjective accounts were analyzed qualitatively using content and thematic analyses. After information gathering basic psychoeducation about epilepsy was provided to all the caregivers by the author in individual setting that included seizure counselling, nature of treatment, possible outcomes and impact on various domains of patients' lives and their family members. Issues related to epilepsy and their well being were also discussed at length and their doubts were clarified by the therapist.

Ethical Considerations:

Permission and Ethical Clearance was taken from the institute.

Written informed consent was taken from the participants. Purpose and nature of study was explained to participants. Participants had the right to withdraw from the study at any point of time and it was ensured that it would not affect the course of ongoing treatment of their wards in any manner. Confidentiality was ensured.

Results

I. Socio-demographic profiles of the caregivers

Figure 1: Pie chart showing Gender composition of the sample

Figure 2: Pie chart showing caregiver burden

II. Brief personal accounts of the participants and common themes during interview and assessment:

During interview, assessment and intervention few recurrent and common themes appeared which included negative beliefs about the origin and cause of the epilepsy, associated severe level of stigma in our society, apprehensions of family members because of uncertainty about future seizure attacks, feelings of shame, guilt, fear, over concerns and worries about their patients' future like what would happen to them after their caregivers' death, feelings of physical burden as their wards need more care and supervision along with financial burden incurred on the families due to difficult accessibility, availability and affordability of good treatment. Present study has shown that caregivers of patients with epilepsy have high levels of strains, fears that the illness may cause severe injuries or deaths to patients. They were also concerned about what will happen to patients in future when the caregiver will not be available to cater for patients and who will marry these patients. Some of the male caregivers of married
patients expressed the need for divorce due to uncertain nature of illness and increasing familial and social stigma associated with it. In addition, it was also found that caregivers were mostly experiencing very high caregiving burden. They also reported that caring for these patients was really challenging and it was associated with enormous burden. Caregivers reported increasingly high burden with gradual increase in duration of epilepsy, poor seizure control and living far away from treatment centres. Another thing for which they appeared perturbed was the question of “Why me? Or Why this has happened to my family?” and they mostly believed that God is punishing them for their bad “Karmas” (wrong deeds of earlier lives or this life). Their expectations from the health professionals were also very high. Caregivers stressed that it was the duty of the professionals to cure their patients while providing care was the role they assigned to themselves. It is suggested that while this perception may be linked with tolerance and acceptance, it also promotes a climate of passive caring. Caregivers also felt sad about not having proper awareness about the disorder and they mostly attributed it to the works of ‘Upri chakkar’ (evil forces or supernatural forces of bad natures) while very few considered it of neurophysiologic origin. Rural caregivers also expressed the need of proper medical facilities in their nearby areas for early detection and timely prevention. They also told the interviewer that if there had been good health care facilities they would not have sought things like faith healing earlier. They also reported that nobody entertained their illness related queries regarding possible causes, nature and course of illness, possible treatment duration and outcomes, precautions to be taken by patients and their family members, how their wards can get affected beyond its physical manifestations and if there can be any long lasting damage to patients’ brains and bodies. Few educated caregivers also asked about the possible side effects of anti-epileptic medications. They also talked about the discriminations faced by their wards at places like schools, work places, neighbourhoods, play grounds etc. Caregivers also reported about poor social support from extended family members, relatives and neighbours. When asked about their own physical and psychological health if had been affected since their ward's illness, they expressed depressive feelings, helplessness, general weakness, frequent headaches, irritability and anger out bursts and poor quality of life. They also reported state of unrest, agitation, inability to manage their own emotional upheavals leading to despair, loss of confidence in one's abilities, lack of hope to achieve something substantial for self which was further leading to dejection and despair as reflected through various physical and psychological symptoms. Many of them were taking medicines by their own for sleep disturbances, headaches, low mood and anxiety without any proper medical consultations. Sample had a preponderance of females over male which could be an indicator that females are more responsible and concerned for caregiving when the family members are not well and thus females might be at the increased risk for experiencing high caregiving burden. 20% caregivers felt severe level of burden, 37% felt moderate to severe burden, 33% of them felt mild to moderate burden while only 10% felt little or no burden of caregiving. Thus majority of the participants were facing high levels of burden thereby caregivers are at increased risk of developing various physical and psychological problems.

**Observations and difficulties faced by the interviewer**

With few of the participants there was the difficulty in establishing trust which was overcome by explaining about the study in detail. At times they tended to sway in their emotions while talking, but one could see that their participation gave them a chance to went out many of their emotions. Many a times researchers was also intrigued upon the observation of the pliability and courage that some of the participants showed, despite the most exasperating times in process of caring for their family members. This level of personal torment and pain was new to the researcher but feelings of meagreness became immaterial in the face of the courage shown by the caregivers. All the participants were a little hesitant to undergo therapy when it was offered keeping their psychological conditions however they felt the need for psychological help, but they also had a doubt about what others in the family would think of them. And whether it was right to go for such sessions when they have brought their family members for their treatment.

**Limitations**

Present study was a small exploratory work which allowed exploring about some of the psychosocial aspects only. Study was carried out on a small sample of caregivers, taken from a single hospital set up and not from the community so the results cannot be generalized safely to all disorders and all caregivers. Other important clinical variables such as types of epilepsy, side effects of antiepileptic medications, frequency and seizure severity etc. have not been taken into account which could have possibly influence caregivers’ perceptions as these were beyond the scope of this study. It did not take much account of the differences due to age, gender, severity of symptoms, level of education and other psychosocial and demographic variables of caregivers.

**Future directions**

Present study needs to be replicated on a larger sample and different disorders to help patients as well as their caregivers. Similar but more controlled and rigorous study can be conducted on large sample from community and different hospital set up keeping the limitations of this study in the mind. Using this research as a small direction further therapeutic works can be done with caregivers.

**Discussion, implications and conclusion**

In present study we find that risk factors for caregiver burden
include female sex, low educational attainment, rural residence with the care recipient, higher number of hours spent in caregiving, depression, social isolation, financial stress and lack of choice in being a caregiver. Increasing risk of psychosocial problems in caregivers indicates the importance of a lifelong psychosocial support for prevention of mental health issues. Mental health professionals have a responsibility to recognize caregiver burden. Caregiver assessment and intervention should be tailored to the individual circumstances and contexts in which caregiver burden occurs. So the support groups to psychoeducate caregivers about illnesses are very important in this regard. Such studies also highlight the need for comprehensive care system addressing caregivers' health which would help in better follow ups of patients at clinics and care giving as well. It also indicates that not only patients but their caregivers should essentially be helped in maintaining a positive self-image and not feeling negative emotions about having the illness in the family. It is also implicated from this study that adopting policies and putting system in place to support and assist caregivers who are experiencing high degree of burden and are at greater risk for developing physical and psychological problems. Family movement in India would see families changing from passive carers to informed carers, from receiving services to proactive participation from suffering social stigma to fighting stigma. This is also the responsibility of the mental health care system to facilitate this journey of caregivers from burden to empowerment.

References


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How to cite this article: Singh, N. (2015). Burden and Perceptions associated with Epilepsy: Caregivers' Perspectives. *Journal of Disability Management and Rehabilitation*, 1 (1) 7-11