

Assessment of burden of care amongst caregivers of students with epilepsy: A study from Eastern India

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Objective: Epilepsy with its multifaceted psychosocial dimensions has an important bearing on caregivers. This study was undertaken to assess the burden of caregivers of students with epilepsy and to evaluate the factors influencing them.

Methods: This cross-sectional study was conducted at the Neurology Clinic of Students' Health Home, a voluntary organisation. One hundred consecutive caregivers, who took an active interest in the management of students with epilepsy were included. Patients with mental retardation or gross neurodeficit were excluded. Socio-demographic data were collected by using structured proforma. Seizure variables such as age of onset, duration, frequency, type of seizure, drug treatment, CT, MRI, EEG findings were noted. Burden of care was assessed by a comprehensive 40 item Burden Assessment Scale (BAS) and relationship of different seizure variables with burden were noted.

Results: The duration of seizures varied from 2-20 years. Generalised tonic-clonic seizures were the commonest (42%) followed by complex partial seizures (30%). Forty-four percent of patients were on more than one drug. Statistical analysis showed an overall increase in the burden amongst caregivers of students with epilepsy (mean BAS score 78.9, SD 12.6) compared to the control group. A lesser burden was experienced by caregivers with a higher income (mean BAS 65.1, SD 8.6) and from a non-nuclear family (mean BAS 63.8, SD 11.2). Some impairment of physical and mental health as well as significant concern about unpredictable behaviour of the patient contributed to the burden of the caregivers. The level of burden did not differ with regard to the patient's age at first visit, gender, age of onset, duration, type and frequency of seizure.

Conclusion: This study showed that caregivers of students with epilepsy experienced a burden involving diverse areas of functioning. We suggest that more efforts should be made for addressing this important psychosocial aspect while treating patients with epilepsy.