Editorial

Quality of Life in children with epilepsy

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Abstract

Care of children with epilepsy (CWE) in developing resource limited nations like India includes major emphasis on seizure control with minimal possible side effects of anti-epileptic drugs. Evaluation of QOL of CWE and steps to improve it is unfortunately not considered as an important issue.

Keywords: QOL, symptoms of anxiety, CWE, Epilepsy stigma

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Epilepsy, being a chronic condition with associated co-morbidities, is usually associated with poor quality of life (QOL). Children with epilepsy have to deal with various restraints in daily activities, adventure sports in addition to effect of epilepsy and side effects of anti-epileptic drugs on scholastic performance, thus adversely impairing their quality of life. Even in the twenty first century, epilepsy is considered as a social stigma!

Care of children with epilepsy (CWE) in developing resource limited nations like India includes major emphasis on seizure control with minimal possible side effects of anti-epileptic drugs. Evaluation of QOL of CWE and steps to improve it is unfortunately not considered as an important issue.

In a study by Nadkarni J et al, Quality of Life in Childhood Epilepsy (QOLCE) questionnaire was administered to 102 CWE aged 5-15 years. The results from this cross-sectional study revealed that overall QOL was affected more in older children, those living in rural areas, those with lower socio-economic status and in mothers with lower literacy levels. QOL was also reported to be affected by disease characteristics, with a poorer QOL in children with higher seizure frequency, those receiving polytherapy, having partial seizures and longer duration of treatment [1]. A similar study by Devinsky et al also reported that older adolescents, independent of epilepsy severity, reported worse overall Health Related Quality of Life (HRQOL) than did their younger counterparts. They suggested that older adolescents are more likely to perceive a greater negative impact on life and general health and thus have more negative attitudes toward epilepsy [2]. Tests of language, intelligence, achievement, and structured psychiatric interviews were administered to 182 epilepsy youth, aged 6.3-8.1, 9.1-11.7, and 13.0-15.2 years, as well as to 102 age- and gender-matched normal children by Caplan R et al. The results from this study documented that older compared to the younger epilepsy groups had more language impairment and a wider range of linguistic deficits [3].

The most significant differences in functioning of epileptic, drug-resistant patients and those with controlled seizures were observed in areas of cognitive processes and social activity in a study on CWE using QOLCE questionnaire by Talarska et al [4]. Even parents of CWE have been reported to have symptoms of anxiety more commonly than parents of healthy controls [5]. In the current issue Akpan MU et al report their findings on HRQOL of CWE based on child self-report and parent-proxy report questionnaires (Pediatrics Quality of Life inventory version 4.0) administered to 60 children and their mothers. They concluded that children with seizure disorder had mean total score and mean score in the subscales that was significantly lower than that of the controls and that good quality of life was associated with good seizure control [6].

In addition to the physical and psychological effects of epilepsy, the social stigma associated with epilepsy too affects QOL in CWE. Epilepsy stigma has three different levels; internalized, interpersonal, and institutional [7]. All these need to be addressed concurrently in addition to collaborative comprehensive efforts to evaluate and upgrade the QOL of children with epilepsy and also tackle the social stigma associated with it.

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