

### Depression and anxiety in parents of children with epilepsy. *Are fathers involved?*

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Despite the fact that epilepsy is one of the leading neurological disorders in Saudi Arabia, the disorder has not been well accepted in society.<sup>1</sup> Although attitudes toward people with epilepsy have improved over the years, for many people with epilepsy, stigma continues to adversely impact their psychological well-being and quality of life. It is now widely acknowledged that people with epilepsy are as likely to be distressed by social and cultural problems as they are by persistent seizures.<sup>1</sup> Caring for a child with epilepsy can be particularly stressful for parents. The data related to psychiatric morbidity in families of children with epilepsy are insufficient,<sup>2</sup> and medical literature looking at specific psychiatric illness, such as depression in the parents is lacking. Mothers are most often the children's primary caregiver, and may be at greater risk for clinical depression as shown in a recent study by Ferro & Speechley.<sup>3</sup> There are only a few studies that have considered the father's experience with their children's epilepsy.<sup>3</sup> A better understanding of the fathers' role in pediatric epilepsy from a research standpoint, and a more routine inclusion of fathers in family-based interventions in pediatric epilepsy is likely to lead to more informed research and more effective treatments. Understanding anxiety and depression in parents have immense clinical relevance, especially in pediatric settings. Not only are these symptoms unhealthy for parents; research has demonstrated that parental anxiety and depression have a significant effect on health outcomes in children,<sup>2</sup> and may have a negative impact on the child's psychosocial adjustment to living with a chronic condition. The purpose of this study was to explore the presence of anxiety and depression in the parents of children with epilepsy.

A prospective observational cohort study was carried out after obtaining approval from the Institutional Review Board from July 2008 to April 2009, at the National Neuroscience Institute, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia. Parents (both

father and mother) of 16 consecutive children with epilepsy (CWE) were recruited from the pediatric neurology clinic. Following consent, parents were asked to complete the Hospital Anxiety and Depression Scale (HADS)<sup>4</sup> questionnaire, under the supervision of a psychologist. The HADS measures depression and anxiety in hospital and community settings. It contains an easy-to-use questionnaire, which allows establishing the presence and severity of both anxiety and depression simultaneously. Inclusion criteria were (1) child up to age 12 years. Exclusion criteria were (1) diagnosis of other progressive or degenerative neurological disorder (2) any major co-morbid non-neurological disorders, and (3) prior history of diagnosed psychiatric illness in the parents. In addition, details on the subject's demography, epilepsy duration and treatment, seizure frequency, and other family members with epilepsy or other chronic illness was obtained. The collected data were analyzed to obtain the frequency of depression and anxiety in parents of CWE.

Patients' characteristics are summarized in Table 1. Thirty-one parents of 16 CWE (8 male and 8 females) were recruited. Half of the children were male (50%), with average age of 77.9 months (range 8-156). The mean duration of epilepsy was 30.5 months. Seizures

**Table 1** - Patient's characteristics in children with epilepsy.

No. of patient	Age (months)	Gender	Duration of epilepsy (months)	Anti-epileptic drug side effects	Other chronic illness in household
1	64	M	18	No	No
2	156	F	12	No	No
3	16	F	10	No	No
4	50	F	46	No	Yes
5	55	F	9	Yes	No
6	8	M	2	No	No
7	126	M	84	No	Yes
8	25	F	9	No	No
9	128	M	21	No	No
10	60	M	12	No	No
11	74	M	40	No	No
12	54	F	18	No	Yes
13	84	F	48	No	No
14	51	M	15	No	Yes
15	145	M	24	Yes	No
16	150	F	120	No	No

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in all but 2 children were controlled. Mothers were the primary caregivers in all but one child. Fifty-five percent of parents (8/16 fathers and 9/15 mothers) were found to be anxious, and 38.7% (5/16 fathers and 7/15 mothers) depressed. Thirty-two percent of the parents had both anxiety and depression. No significant association was seen with the child's age and gender, or side effects of medications. We found significant involvement of fathers, though they were not the primary caregivers.

Despite advances in the management of epilepsy, living with epilepsy is not easy for a considerable number of patients and their caregivers. Besides having a seizure disorder, these children suffer from mental health problems with rates almost 3-6 times that of the general population.<sup>1</sup> The child with behavior issues often under performs in multiple psychosocial domains and has a compromised health-related quality of life.<sup>2</sup> Negative parental attitudes such as rejection and cold behavior towards the child, are identified as one of the contributing factors to psychosocial adaptation in childhood.<sup>2</sup> There are multiple reasons for this, and may include fear and concern about the child's mental health, disease prognosis, lifestyle, social stigma, and unpredictability of next seizure episode.<sup>5</sup> In a chronic condition like epilepsy, persistence of the above mentioned factors may cause psychosocial stress in the parents, who themselves may develop a variety of mental health problems such as adaptation disorders and depression that may further contribute to their pessimistic attitude. Some studies conclude that the influence of parental emotion is larger than the epilepsy itself, and this often causes the child to have a lower level of satisfaction with family relationships and often depression in adolescence.<sup>2</sup>

Chiou and Hsieh<sup>5</sup> observed higher rates of depression in the parents of CWE compared to parents of asthma patients. The study by Ferro and Speechley<sup>3</sup> also documented maternal depression, and reported that over a quarter of mothers not at risk of clinical depression when their child was diagnosed with epilepsy became at risk at 24 months.

There are very few studies looking at the fathers' attributes towards CWE. In our cohort, fathers were

found to be frequently affected even though they were not the primary caregivers. Significant involvement of fathers reflects somewhat different roles that parents might play in dealing with children's health issues.

Thus, there are a number of clear messages from this study. Depression and anxiety are frequently seen in both parents of CWE, even when the seizures are well controlled. This is of immense clinical importance to explore for the presence of these symptoms in parents during the epilepsy clinic visit. If present, these need to be addressed as a part of the management plan for the child with epilepsy, which can improve the overall well-being of the patient and their families. Results from this study were preliminary and limited due to small sample size. Further studies will need not only to have a more accurate assessment of psychiatric comorbidity in families of CWE, but also to establish whether similar associations are seen in other serious pediatric conditions.

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