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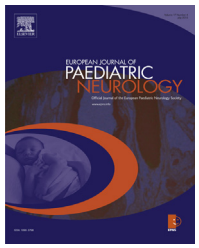

Original article

Psychological and social outcome of epilepsy in well-functioning children and adolescents. A 10-year follow-up study

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ABSTRACT

Background: From a population based study of epilepsy in Swedish children a subgroup designated well-functioning with an epilepsy diagnosis in 1997 was worked up from a medical point of view 10 years later.
Aim: To describe the psychological and social outcome in this subgroup.
Methods: Thirty-one patients aged 11–22 years and their parents/partners responded to a questionnaire according to Achenbach System of Empirically Based Assessment (ASEBA) to evaluate behavioural and emotional problems, and social competence.
Results: Active epilepsy, diagnosed in 32%, was related to attention problems, somatic complaints, and school problems. Polytherapy, used in 16%, was related to attention problems and aggressive behaviour. School problems were found in six of seven children younger than 18 years. Internalizing, externalizing, and 'other' syndromes were found in 29% of the individuals, but a grouping of these syndromes in the clinical range only in two (6.5%), a girl with generalized tonic–clonic seizures alone, and a boy with structural focal epilepsy. Both had active epilepsy and were treated with polytherapy. All ten individuals with Rolandic epilepsy were classified as normal. The answers to the ASEBA questionnaire of individuals and parents/partners were inconsistent, and parents generally stated more problems than the individuals.
Summary.: This 10-year follow-up study of psychological and social outcome in well-functioning children and adolescents with childhood onset epilepsy shows some emotional, behavioural, and social problems. Thus, early information to increase knowledge about epilepsy and associated psychological co-morbidities in order to decrease risk of low self-esteem, social anxiety, and depression later in life is of importance.

1. Introduction

Epilepsy is one of the most common neurological disorders in children having potential impact for health and well-being during adolescence and adulthood. The prognosis of childhood epilepsy depends on different conditions, most commonly with respect to seizure freedom or remission being normal mental development, no neurological dysfunction

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including co-morbidities, low seizure frequency, and early response to antiepileptic drug (AED) treatment.[1–4]

In individuals with epilepsy there is a relation to cognitive difficulties,[5–7] and in addition there is an obvious occurrence of social and psychiatric problems including behavioural/emotional problems and conduct, attention, and hyperactivity disturbances.[8–11] All these problems are associated with the underlying cause of epilepsy, seizure frequency, and AED treatment.[7,12,13] It has been reported that behavioural problems remain despite at least 5 years of seizure remission and off medication.[7,14]

In some studies, individuals with 'uncomplicated epilepsy' or 'epilepsy only' are described. Cognitive and behavioural problems have been reported, as well as symptoms of depression, inability to concentrate, tension, loneliness, fewer friends and factors related to psychological well-being and self-image.[5,15–19] In a long-term perspective these individuals will also present low level of education and high unemployment rate,[17,19] and learning difficulties are prevalent.[15,20,21] That individuals with childhood onset epilepsy experience more problems in social functioning and psychological well-being compared with healthy controls is well-known.[2,10,18,22,23] The described problems are often considered to be more handicapping than the seizure manifestations themeselves,[13,24,25] and they are also a cause of concern to parents.[14,19]

Studies on long-term prognosis of childhood onset epilepsy are of importance as social discrepancies and psychological problems persist into adulthood.[4,5,23]

In 2006 a population-based study of epilepsy in children from Uppsala County, Sweden, was published.[26] The prevalence of epilepsy was 3.5/1000 and the incidence 40/100,000. We decided that it would be of interest to follow this population, and initially all children who had epilepsy and an age-related normal psychomotor development in January 1997 were selected for a 10-year follow up in December 2006. These children were called well-functioning (see below 'definitions'). Forty-seven individuals were identified, and in the first part of the study, which reported epidemiological characteristics as family history, individual history, seizure types, electroclinical syndromes, and treatment, 45 participated, which is a response rate of 96%.[27] In the second part, the aim was to report psychological and social outcome, especially in relation to factors such as electroclinical syndromes, actual epilepsy situation, and discrepancy between questionnaire responders.

1.1. *Definitions*

Epilepsy is defined as two or more unprovoked seizures occurring at least 24 h apart.[28]

Active epilepsy is defined as having had epilepsy with at least one seizure episode in the last five years regardless of actual or earlier antiepileptic treatment.[28]

Electroclinical syndromes are classified according to the revised terminology in the 2010 ILAE report,[29,30] with some modifications.[31] As the actual study comprised patients presented in our first article,[27] we wanted to have as far as possible congruence in terminology.

Well-functioning children with epilepsy are those who at inclusion in the study had no neuroimpairment such as cerebral palsy or other neurological disorder with clinically visible signs, normal psychomotor development, and attended mainstream school.

2. Methods

2.1. *Subjects*

The 45 individuals and their families/partners were invited to participate in the present study. Written information had been provided already in connection with the first part of the study.[27] Another information letter was sent out along with questionnaires according to ASEBA (see below). To those who had not responded within two months, a reminder and a copy of the questionnaire were sent out. Those, who had still not returned the questionnaire after another two months, were contacted by telephone, and those accepting received the questionnaire again. Thirty-one answered the questionnaire, for a response rate of 69% (Table 1).

Table 1 – Patients' individual history and family history.

	Group A	Group B	Drop outs
	$N = 7$ (16%)	$N = 24$ (53%)	$N = 14$ (31%)
Electroclinical syndromes			
Rolandic epilepsy	1	9	5
Other focal epilepsies	2	9	4
ABPE	0	0	1
Panayiotopoulos syndrome	0	0	2
Gastaut syndrome	0	1	0
IPOE	1^1	0	0
Ufe	1	5^3	1
Sfe	0	3^2	0
Generalized epilepsies	3	6	4
CAE	0	2^1	2
JAE	0	1^1	0
Jeavons syndrome	1	0	0
GTC alone	2^1	1	2^1
Photo GTC	0	2^1	0
Infantile spasms	1	0	1
Treatment			
Actual			
Monotherapy	0	8	3
Polytherapy	3	2	0
Earlier			
Monotherapy	3	16	10
Polytherapy	3	5	3
Never treated	1	3	1
Febrile seizures	0	3	4
Primary headache	1	9	2
Neurodevelopmental disorder	0	3	3
Family history of			
Epilepsy	4	11	5
Febrile seizures	0	3	5
Primary headache	2	14	10

Elevated digits represent number with active epilepsy.
Abbreviations: ABPE – atypical benign partial epilepsy; Ufe – unknown focal epilepsy; Sfe – structural focal epilepsy; CAE – childhood absence epilepsy; GTC alone – epilepsy with generalized tonic–clonic seizures alone; IPOE – idiopathic photosensitive occipital lobe epilepsy; JAE – juvenile absence epilepsy; Photo GTC – epilepsy with photosensitivity and generalized tonic–clonic seizures.