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Developing from child to adult: Risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy

R.P.J. Geerlings [a,*], A.P. Aldenkamp [a,b,c,d], L.M.C. Gottmer-Welschen [a], P.H.N. de With [b], S. Zinger [b], A.L. van Staa [e,f], A.J.A. de Louw [a,b]

[a] Epilepsy Center Kempenhaeghe, Heeze, The Netherlands
[b] Faculty of Electrical Engineering, University of Technology, Eindhoven, The Netherlands
[c] Department of Neurology, Maastricht University Hospital, The Netherlands
[d] Department of Neurology, Ghent University Hospital, Belgium
[e] Institute of Health Policy & Management, Erasmus University Rotterdam, The Netherlands
[f] Research Centre Innovations in Care, Rotterdam University of Applied Sciences, The Netherlands

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ABSTRACT

Introduction: Childhood-onset epilepsy during the years of transition to adulthood may affect normal social, physical, and mental development, frequently leading to psychosocial and health-related problems in the long term.
Objective: This study aimed to describe the main characteristics of patients in transition and to identify risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy.
Methods: Patients with epilepsy, 15–25 years of age, who visited the Kempenhaeghe Epilepsy Transition Clinic from March 2012 to December 2014 were included ($n = 138$). Predefined risk scores for medical, educational/occupational status, and independence/separation/identity were obtained, along with individual risk profile scores for poor psychosocial outcome. Multivariate linear regression analysis and discriminant analysis were used to identify variables associated with an increased risk of poor long-term psychosocial outcome.
Results: Demographic, epilepsy-related, and psychosocial variables associated with a high risk of poor long-term outcome were lower intelligence, higher seizure frequency, ongoing seizures, and an unsupportive and unstable family environment. Using the aforementioned factors in combination, we were able to correctly classify the majority (55.1%) of the patients regarding their risk of poor psychosocial outcome.
Conclusion: Our analysis may allow early identification of patients at high risk of prevention, preferably at pretransition age. The combination of a chronic refractory epilepsy and an unstable family environment constitutes a higher risk of transition problems and poor outcome in adulthood. As a consequence, early interventions should be put into place to protect youth at risk of poor transition outcome.
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1. Introduction

Transition from adolescence to adulthood is a challenging period in life, especially for youth with epilepsy and for their caregivers [1]. Epilepsy and comorbidities, their treatment, and persistent social stigma have a substantial impact on the child's and their relatives' lives [1,2]. Furthermore, childhood-onset epilepsy and comorbid conditions may interfere with normal brain maturation and delay age-appropriate social, physical, and cognitive development, leading to poor psychosocial outcome and societal integration in the long term [3]. Adolescents are vulnerable to negative psychosocial consequences [4]. Sillanpää and Cross [1] and Camfield and Camfield [5] evaluated long-term psychosocial outcome of childhood-onset epilepsy among patients without obvious cognitive impairment. Adults with childhood-onset epilepsy had lower educational levels, less social interaction, and more problems in self-care and daily activities compared with healthy controls. Chin et al. [6] examined psychosocial, medical, and mental health outcomes in adults with childhood-onset epilepsy. Patients with epilepsy without intellectual disabilities or other comorbid conditions showed outcomes equal to those in healthy controls regarding medical, educational, and vocational status but experienced significantly more problems with social interaction and relationships. Furthermore, patients with epilepsy and concomitant cognitive impairment had worse psychosocial outcome compared with controls with cognitive impairment in absence

* Corresponding author at: Department of Research & Development, Epilepsy Centre Kempenhaeghe, P.O. Box: 61, NL-5590 AB Heeze, The Netherlands. Tel.: +31 40 227 9022; fax: +31 40 226 5691.
E-mail addresses: GeerlingsR@Kempenhaeghe.nl (R.P.J. Geerlings), AldenkampB@Kempenhaeghe.nl (A.P. Aldenkamp), GottmerL@Kempenhaeghe.nl (L.M.C. Gottmer-Welschen), P.H.N.de.With@tue.nl (P.H.N. de With), ZingerS@Kempenhaeghe.nl (S. Zinger), a.van.staa@hr.nl (A.L. van Staa), LouwA@Kempenhaeghe.nl (A.J.A. de Louw).

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of epilepsy. Moreover, Baker et al. [7] found that adolescents with epilepsy had an increased risk of psychopathology (e.g., depression and anxiety disorders). In a prospective cohort study by Jalava et al. [8], a statistically significantly decreased social outcome in patients with epilepsy compared with controls thirty-five years after onset of childhood epilepsy was shown. In particular, those on antiepileptic polypharmacy or having ongoing seizures reported lower health status. Again, patients had lower educational and vocational rates and lower marital status. These findings are in accordance with Geerts et al. [9], who found that self-perception of health, educational achievement, living arrangements, and socioeconomic status were less among patients with epilepsy than in the healthy population. Furthermore, remission in patients with epilepsy had a worse outcome than expected [5,9]. Therefore, seizure remission is no guarantee for better psychosocial outcome [5,6,9].

Wakamoto et al. [10] and Reeve and Lincoln [11] found more nonproductive coping strategies in adolescents with epilepsy compared with controls, especially during the process of transition, indicating inability to deal with adolescent transitional problems [10,11].

Continuity of psychosocial and medical care is required to prevent these adolescents and young adults from having negative long-term consequences of epilepsy and to improve societal integration [6]. On approaching adulthood, adolescents should, at some point, transition from the family-centered pediatric care to the individual-centered adult care. However, recent literature often describes the outcome of this transition, which is often a direct transfer to adult care instead of a comprehensive transition process, as problematic [12–14]. Suddenly, the adolescent is expected to manage his own medical condition along with arising challenging life situations such as their career and relationships. Several transition clinics for adolescents with epilepsy have been set up to cope with this problem [15–18]. Up to now, different designs of transition clinics have been used. Joint consultation of an adult and a pediatric neurologist with or without support of epilepsy nurse specialists is mentioned most [15–18].

Transition to adulthood is a gradual process starting in early adolescence and continuing into young adulthood. The objective of specialized transition clinics is to identify and intervene in current issues and concerns of adolescents and mark the start of transition from pediatric to adult care. Recognition of patients at risk of poor psychosocial outcome can lead to detection of problems and application of interventions [1].

The main objective of this study was to analyze risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy who visited a newly set up transition clinic at the tertiary Epilepsy Centre Kempenhaeghe, The Netherlands.

2. Methods

2.1. Transition clinic

A transition clinic for adolescents and young adults with epilepsy was set up at Epilepsy Centre Kempenhaeghe in March 2012. Patients were referred to the transition clinic in case at least one medical, psychological, or psychosocial issue was present at the moment of referral, e.g., problems with transition from pediatric to adult care, revision of epilepsy diagnosis, optimization of treatment options, learning problems or career advice. Not all patients had had a neuropsychological assessment to measure their intelligence level before their first visit to the transition clinic, but patients with probable severe mental disabilities (presumed IQ < 50) were not accepted at the transition clinic, since mental retardation might interfere with normal transitional issues and developmental opportunities. These patients were referred to a specific outpatient clinic for patients with both epilepsy and mental retardation at our tertiary referral center.

The epilepsy transition clinic resides in a tertiary referral center for children and adults with epilepsy. It is staffed by a multidisciplinary team consisting of an adult neurologist with adequate knowledge of both pediatric care and adult care, a psychologist, a social worker, and an educationalist/occupational counselor.

Every patient (and caregiver) is scheduled for three consecutive consultations during one morning, in which they are seen by all four abovementioned health-care professionals. The procedure of the transition clinic is shown in Fig. 1.

All consultations focus on independence and empowerment of the adolescent. Subsequently, the health-care professionals discuss four domains of transition (medical, psychological, social, and educational/vocational) in a multidisciplinary meeting in which tailored advice is formulated. This advice is then discussed with the adolescent (and caregiver) directly afterwards, with the adolescent being in charge of his own decisions.

This advice can be focused on one or several of the four domains leading to a new diagnostic work-up, interventions, or further follow-up by a psychologist, an educationalist/vocational counselor, or a social worker. A diagnostic work-up, including magnetic resonance imaging (MRI), electroencephalography (EEG), a neuropsychologic test, and/or laboratory tests (serum antiepileptic drug (AED) levels, monitoring, for example, renal and/or liver failure, or genetic counseling), provides a new 'snapshot' of the current medical and psychosocial status before the final intervention or advice is provided. The final intervention or advice depends on the individual's problems and may consist of antiepileptic drug alterations, job training or coaching, help with finding suitable housing, support from social work or psychological support. There may be a follow-up period of appointments with the neurologist, psychologist, social worker, or educationist. The goal of the transition clinic is finding tailor-made solutions for transition problems before transferring the patient to adult care. The number of total visits depends on the medical, vocational/educational, or psychosocial problems of the individual patient. Some patients visited the transition clinic only once before they were referred to adult medical care. Others, for example, patients who underwent a diagnostic work-up or a change in AED prescription, were followed by the transition clinic's neurologist for a time until they were ready for transition to adult medical care.

No relevant validated scoring systems for adolescents or young adults with epilepsy exist. There is a validated scoring system for patients with traumatic brain injury, namely, the Sydney Psychosocial Reintegration Scale Version 2 (SPRS-2) [19]. The SPRS-2 scores the level of functioning on three different domains: occupational activity for work and leisure, independent living, and relationships. The SPRS-2 is also used in other neurologic conditions, e.g., stroke, primary brain tumor, and spinal cord injury, and is reported in multiple studies. Our scoring system is roughly based on the SPRS-2 for patients with traumatic brain injury but with respect to specific transitional problems. Scores for the current level of functioning on the medical domain, educational/occupational domain, and independence/separation/identity domain were allocated by the transition clinic's neurologist and psychologist. Scores range from 0 (normal), −1 (suboptimal), to −2 (poor) in our scoring system compared with scores of 0 ('extreme') to 4 ('not at all') in the SPRS-2. To cope with the wide range of intellectual abilities of the included patients, we individually allocated scores with respect to the optimal level of functioning which can be achieved by an individual. An overview of the classification of our scoring system is provided in Table 1.

Another score, namely the risk profile score, was individually determined by the transition clinic's neurologist and psychologist according to the patient's risk of future decline in psychosocial outcome. Risk profile scores for good, moderate, or poor social outcome ranged from 1 to 3, as previously defined by Camfield and Camfield [20], and were also allocated with respect to the patient's intellectual capacity and related maximum level of functioning. A score of 3 indicated that the patient already had poor perspectives for transitional outcome, a score of 2 indicated that the patient had a substantial risk of negative outcome (moderate), and a score of 1 indicated a low risk (no obvious risk) for poor psychosocial outcome. Scores for the current level of functioning on the medical domain, educational/occupational domain, and

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