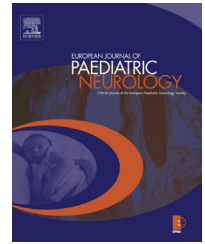




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Original article

Evaluation of a multidisciplinary epilepsy transition clinic for adolescents

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ABSTRACT

Introduction: The main goal of the transition clinic is to explore and optimize medical issues during transition from adolescence to adulthood, and to ease the transition into adult care. However, only limited data on the process and outcomes of transitional care in clinical practice are available.

Objective: To describe the process and outcomes of an Epilepsy Transition Clinic in a tertiary referral center in The Netherlands.

Methods: Data were collected from patients with epilepsy (aged 15–25 years), who visited the transition clinic between March 2012 and September 2014.

Results: The Epilepsy Transition Clinic is staffed with a multidisciplinary team including a neurologist/epileptologist, clinical neuropsychologist, a social worker and an educationalist/occupational counselor, all with knowledge of paediatric and adult medical and developmental issues. In total, 117 patients with epilepsy were included in the analysis. After consultation, 89 patients received a diagnostic work-up (76.1%), change in AED prescription ($n = 64$, 54.7%), or consultation/tailored advice ($n = 73$, 62.4%). In fourteen patients (12.0%) the epilepsy diagnosis was changed. Nineteen patients (16.2%) had complete epilepsy remission for over one year. Forty-three patients (36.8%) were referred to adult care. **Conclusion:** This study describes a multidisciplinary epilepsy transition clinic staffed by a neurologist/epileptologist, neuropsychologist, a social worker and an educationalist/occupational counselor. Diagnostic work-up and evaluation of psychosocial and educational/vocational status during adolescence are strongly recommended.

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1. Introduction

Transition is defined as the process of moving from one state to another.¹ In this manuscript we describe two types of transition, namely the transition from childhood to adulthood, and the transition from paediatric to adult care.

Adolescence can be seen as a phase during transition from childhood to adulthood. Adolescence is characterized by the development of autonomy and independence, by increasing social interaction with peers, and future choices in education, employment, and living arrangements.^{2–5} Adolescents with epilepsy have to deal with additional lifestyle implications, e.g., driving regulations, occupational restrictions and medication adherence.^{2–6} Furthermore, epilepsy and comorbid conditions can substantially delay physical, cognitive and social development during childhood, affecting the transition to adulthood, and thereby risking lowered psychosocial outcome.^{3,4,6,7} Previous studies found indeed that patients with (childhood-onset) epilepsy, with or without comorbid intellectual disabilities, had a lower educational and vocational outcome and subsequently a lower socioeconomic status. In addition, these patients experienced more social isolation and higher depression rates, and had more problems with self-care and daily activities compared with healthy controls.^{5,8–11}

Epilepsy and comorbid conditions can either persist or remit in adolescence and emerging adulthood, with major consequences for the patient's life, e.g., for choice of treatment, career opportunities, daily activities, or living arrangements.³ Therefore, re-evaluation of medical and psychosocial problems during adolescence and early adulthood is essential.¹² At a certain point, the adolescent with ongoing seizures has to transition from a family-centered paediatric care to the individual-centered adult care.¹³ Epilepsy transition clinics have been set up to optimize seizure control, to initiate early interventions for psychosocial problems, and to lessen the fear of moving to adult care.^{3,14}

To evaluate medical, familial, educational/occupational and psychosocial developmental issues during transition from adolescence to adulthood, and to guide the transition into adult care, a multidisciplinary Epilepsy Transition Clinic was set up at our tertiary Epilepsy Center in 2012.

2. Objectives

The objectives of this study are to describe the process and outcomes of our multidisciplinary Epilepsy Transition Clinic at the tertiary Epilepsy Center Kempenhaeghe.

3. Methods

3.1. The epilepsy transition clinic

The Epilepsy Transition Clinic was set up in March 2012 as part of outpatient care of a tertiary epilepsy center. The transition clinic is staffed by a neurologist/epileptologist, clinical neuropsychologist, an educationalist/occupational

counselor and a social worker, all with knowledge of and experience in paediatric and adult medical and developmental issues in patients with epilepsy.

Patients (and their caregiver(s)) are seen in three consecutive 30 min consultations ('the carousel') planned in one morning with the above mentioned health care professionals, as is shown in Fig. 1. The neurologist and clinical neuropsychologist work together in a combined consultation because of the interaction between the two fields of expertise. All three consultations focus on exploring the adolescent's developmental stage (e.g., individualization and schooling/work), as well as obtaining information on relevant age-related issues such as driving, the use of antiepileptic drugs (AEDs) with potential teratogenic effects, and the use of alcohol/drugs. The potential risk of inheritance of epilepsy was discussed with young women in child bearing age. If applicable, the interactions between AEDs and oral contraceptives was discussed by the neurologist. Also the future perspectives of the adolescent and his/her parents are assessed. In a consecutive multidisciplinary meeting, functioning and development in the four transitional domains (medical, neuropsychological, social, educational/vocational) is reviewed, after which a tailored advice is provided to the patient. This advice can cover one or several of the domains and is discussed with the patient (and caregiver(s)) directly after the multidisciplinary meeting. Most importantly, the advice is focused on autonomy, with the patient actively involved and in charge of his own decisions. All health professionals incorporate empowerment in their communication during the consultations.

Following this consultation carousel, a diagnostic work-up can be provided, including magnetic resonance imaging (MRI), neuropsychological assessment, electroencephalography (EEG), or collection of blood samples. Treatment changes in the current AEDs can be advised or the patient can be offered alternative treatment options, such as a ketogenic diet (KD), vagus nerve stimulator (VNS), or epilepsy surgery. Tailored advices from the health care professionals can include for example a vocational training, or support from a (neuro)psychologist or from a social worker (e.g., in organizing living arrangements or financial guidance). Preferably, after two to three visits, the patient is referred to an adult neurologist (if preferred by the patient, the transition clinic's neurologist or another adult neurologist working at our tertiary referral center can provide long-term medical epilepsy care with regular visits at the transition clinic's neurologist after transition to adult care), or, in case of seizure remission without AEDs, to a general practitioner. The procedure of the Epilepsy Transition Clinic is shown in Fig. 1.

3.2. Inclusion and exclusion criteria

Adolescents and young adults who visited the transition clinic between March 2012 and September 2014, with a confirmed diagnosis or highly probable diagnosis of (childhood-onset) epilepsy were included in the study. The age limits for referral to the transition clinic were 15–25 years. Patients diagnosed with non-epileptic seizures only, or those with severe mental retardation (IQ < 35) were excluded.

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