Official Journal of the European Paediatric Neurology Society

Original Article

Evaluation of a multidisciplinary epilepsy transition clinic for adolescents

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

ARTICLE INFO

Article history:
Received 18 March 2015
Received in revised form
27 November 2015
Accepted 4 January 2016

Keywords:
Transition to adult care
Epilepsy transition clinic
Adolescence
Psychosocial

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.

* *Corresponding author*. Department of Research & Development, Epilepsy Center Kempenhaeghe, P.O. Box: 61, NL-5590 AB Heeze, The Netherlands. Tel.: +31 0 40 227 9022; fax: +31 0 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).

http://dx.doi.org/10.1016/j.ejpn.2016.01.003
1090-3798/

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.

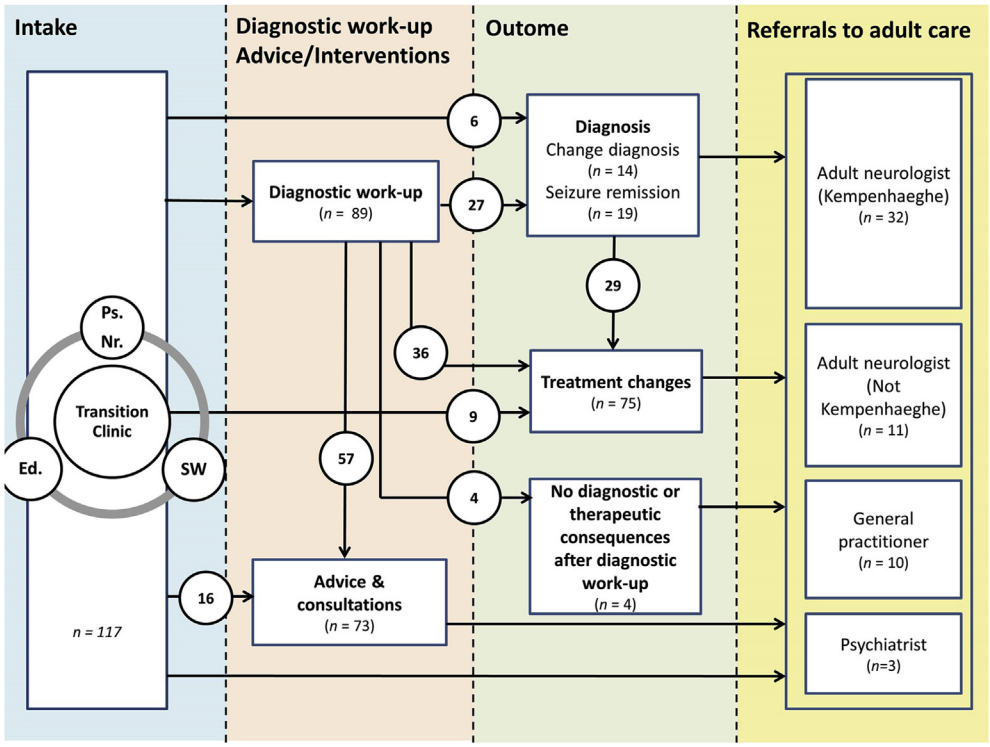

Fig. 1 – Evaluation of the epilepsy transition clinic, showing the number of diagnostic work-ups, advice and consultations, outcome and referrals after a visit at the epilepsy transition clinic. Some patients had both a diagnostic work-up and a consultation by the social worker, educationalist or clinical neuropsychologist. Ed: Educationalist; Ps: Psychologist; Nr: Neurologist; SW: Social worker.

3.3. *Data collection*

The following medical, demographic and psychosocial data were collected from all patients who visited the Epilepsy Transition Clinic: age, gender, epilepsy syndromes classified according to International League Against Epilepsy (ILAE) 1989 classification, seizure frequency and duration of epilepsy in years, use of AEDs and self-reported medication adherence, other epilepsy treatments (KD, VNS, or epilepsy surgery), full scale intelligence quotient (FS IQ) by neuropsychological testing using the Wechsler Intelligence Scale for Children, educational and vocational status, living arrangements. Special education was defined as an educational setting (school) for patients with special needs, e.g., developmental delays, mental disabilities, learning disorders, or comorbid emotional and behavioral conditions e.g. ADHD or autism spectrum disorders. Patients were asked if they had ever been in a special education setting, either now or in the past. Having a social network was defined as having a support network of friends, or adequate social interaction with peers. Independence was evaluated by the social worker and clinical neuropsychologist and defined as patients who were in charge of making their own decisions and take care of themselves in terms of household chores and personal hygiene. The amount of family support was evaluated by the neuropsychologist and/or social worker.

To evaluate diagnostic procedures and outcomes, data about diagnostic work-up (EEG, clinical neuropsychological assessment, MRI, blood laboratory tests, and 24 h admittance to ease the diagnostic work-up) were collected. Change in AED prescriptions and change of diagnosis, applied interventions and consultations and number of referrals (to adult care) were collected. All data were recorded in an IBM SPSS database.

3.4. *Statistical analysis*

Statistical analysis was performed by IBM SPSS Version 21. We used descriptive statistics to compute percentages (%) and frequencies (*n*) of categorical variables. In case of a normal distribution pattern of continuous variables, the mean and standard deviation (SD) are shown, whereas in case of a non-normal distribution pattern the mean and interquartile range (IQR) are represented.

4. Results

4.1. *Patient characteristics*

Table 1 shows that 117 patients were included in our study (65 boys, 52 girls), with a median age of 18.3 years (IQR 3). Mean full intelligence score was 82.5 (SD 15.4), and forty-two patients had a below average IQ (36.2%) or had a mild mental retardation (19.8%). Forty-eight patients (43.6%) of the total population ever had special education, of which 12 patients with a normal intelligence. Fifty-two patients (48.1%) showed independence. Fourteen out of sixteen adult patients (aged 21–25 years) were still living at home with their parents.

Three out of these sixteen adult patients were currently unemployed and not studying. Eighty-five patients (78.7%) were considered having sufficient social participation and social support from peers. Thirty-three patients (30.0%) were considered having unsupportive family conditions.

Epilepsy-related variables are shown in Table 2. Mean duration of epilepsy was about 10.4 years (SD 5.0), and 59 patients (54.1%) had a seizure frequency of less than one seizure per year. Ninety-four patients (80.3%) were diagnosed with localization-related epilepsy. Fifty-eight (69.0%) were self-reported compliant to AEDs. Nine patients (7.6%) were not using any AEDs anymore at time of referral to the transition clinic, mostly because of seizure remission.

4.2. *Diagnostic procedures and outcome*

The number of diagnostic work-ups is shown in Fig. 1 and Table 3. In 89 patients (76.1%), a diagnostic work-up was provided. Twenty-eight patients further a diagnostic work-up was already done in the past, or a diagnostic work-up was not considered necessary during their visit at the transition clinic.

Clinical neuropsychological assessment was conducted in 61 patients (52.1%). In thirty-four patients (29.1%) also the intellectual abilities were tested. Seven patients (6.0%) were tested for autism spectrum disorder, and this diagnosis was confirmed in two patients (1.7%). In eleven patients (9.4%) the test was focused specifically on AED's potential cognitive adverse effects (such as reduced central processing speed) which were found in 4 patients (3.4%). A second clinical neuropsychological assessment was conducted in four patients to evaluate the effects of AED withdrawal; 3 out of 4 patients showed substantial improvement of their processing speed after AED switch or withdrawal; in one patient the side effects increased after switch of AED.

In 16 patients (13.7%) seizures negatively influenced the central processing speed. In 8 of the 16 patients improvement was observed after adequate reduction of seizure frequency. In 2 patients the negative effects of epilepsy persisted, even after adjustment of AEDs. Seven patients (6.0%) were specifically tested for their personality and coping strategies.

Twenty-eight MRIs (23.9%) were conducted, of which 5 were abnormal and had consequences for further treatment options: 3 patients were referred for epilepsy surgery and one patient received a VNS.

Sixty-one EEG (52.1%) registrations included 22 one-hour EEG registrations (18.8%) and 39 24-h ambulatory EEG registrations (33.3%). Thirty-three EEGs were abnormal.

Forty-one patients (35.0%) were shortly admitted (approximately 24 h) to facilitate the diagnostic work-up.

Following diagnostic work-up, epilepsy diagnoses were changed in 14 patients (12.0%), out of which 3 patients (2.6%) were diagnosed with non-epileptic seizures.

Nineteen patients (16.2%) had complete seizure remission (for at least one year).

Antiepileptic drugs were changed in 64 patients (54.7%). In 20 patients (17.1%) AEDs were completely withdrawn, and dosage was adjusted (either increased or decreased) in 24 patients (20.5%). The main reason for changing AED treatment was seizure remission, or side effects in 16 patients (13.7%). Valproate was completely withdrawn in 9 out of 10 girls, because of potential teratogenic effects in women in the child bearing age.

Table 1 – Demographic and psychosocial variables of adolescents visiting the epilepsy transition clinic.

Gender ($n = 117$)	
Men	65 (55.6%)
Women	52 (44.4%)
Age at first visit in years ($n = 117$)	18.3 (IQR 3)
Younger than 18 years	51 (43.6%)
Full scale intelligence (FS IQ) ($n = 99$)	82.5 (SD 15.4)
Cognitive abilities ($n = 116$)	
Below average IQ (70–90)	42 (36.2%)
Mild mental retardation (50–70)	23 (19.8%)
Moderate mental retardation (35–50)	1 (0.9%)
Mental retardation, severity unknown	1 (0.9%)
No mental retardation	49 (42.2%)
Special education program	
In the past/ever ($n = 110$)	48 (43.6%)
Currently ($n = 117$)	34 (29.1%)
Living arrangements ($n = 115$)	
At home with parents	106 (92.2%)
Independently	4 (3.5%)
Supported accommodation	5 (4.3%)
Social participation ($n = 108$)	85 (78.7%)
Self-efficacy/independency ($n = 108$)	52 (48.1%)
Unsupportive/unstable family environment ($n = 110$)	33 (30.0%)
Employment ($n = 115$)	
Yes	53 (46.1%)
No	16 (13.9%)
Internship	19 (16.5%)
Student without a job	27 (23.5%)

Data are presented as means (SD; standard deviation), *n* (%) or median (interquartile range (IQR)), in case of a skewed distribution.

Table 2 – Adolescent's epilepsy-related variables at their first visit at the epilepsy transition clinic.

Age at diagnosis epilepsy in years ($n = 112$)	7.6 (IQR 7.8)
Duration of epilepsy (years) ($n = 112$)	10.4 (SD 5.0)
Type of epilepsy ($n = 117$)	
Localization-related epilepsy	94 (80.3%)
Idiopathic	5 (4.3%)
Symptomatic	26 (22.2%)
Cryptogenic	63 (53.8%)
Generalized epilepsy	19 (16.2%)
Idiopathic	14 (12.0%)
Symptomatic	5 (4.3%)
Cryptogenic	0 (0%)
Not classified yet	4 (3.5%)
Seizure frequency ($n = 109$)	
Daily	10 (9.2%)
Weekly	13 (11.9%)
Monthly	19 (17.4%)
Yearly	8 (7.3%)
Less than 1/year	59 (54.1%)
Number of AEDs ($n = 117$)	
No current AED treatment	9 (7.6%)
Monotherapy	54 (46.2%)
Polytherapy (2–4 AEDs)	54 (46.2%)
AED adherence ($n = 84$)	58 (69.0%)
Previous therapies ($n = 117$)	
Epilepsy surgery	5 (4.3%)
Vagal nerve stimulator	2 (1.7%)
Ketogenic diet	2 (1.7%)

Table 3 – Results of the Epilepsy Transition Clinic: referrals, diagnostic procedures and outcomes.

Referral by ($n = 117$)	
Neurologist of the Epilepsy Transition Clinic	54 (54.5%)
Other neurologist within the epilepsy center	45 (45.5%)
Referral from external neurologists	10 (8.5%)
General practitioner	4 (3.4%)
Paediatrician	4 (3.4%)
Diagnostic work-up ($n = 117$)	89 (76.1%)
EEG	61 (52.1%)
24 h ambulatory EEG registration	39 (33.3%)
1 h EEG registration	22 (18.8%)
MRI	28 (23.9%)
Laboratory	31 (26.5%)
Admittance for diagnostic work-up	41 (35.0%)
Clinical neuropsychological assessment	61 (52.1%)
Specific reason clinical neuropsychological assessment	
Intellectual abilities	34 (29.1%)
Mental slowing as a side effect of AED treatment	11 (9.4%)
Personality and coping strategies	7 (6.0%)
Autism spectrum disorder	7 (6.0%)
Attention and concentration	2 (1.7%)
Outcome initial/first clinical neuropsychological assessment	28 (23.9%)
Growing into deficit	2 (1.7%)
Diagnosis other than epilepsy	3 (2.6%)
Negative effects of epilepsy on central processing speed	8 (6.8%)
Mental slowing as a side effect of AED treatment	4 (3.4%)
Autism spectrum disorder	2 (1.7%)
Behavioral disorder	1 (0.9%)
Negative coping strategies	4 (3.4%)
Outcome follow-up/second clinical neuropsychological assessment	
Increase central processing speed after optimizing epilepsy treatment	8 (6.8%)
Negative effects of epilepsy on central processing speed	2 (1.7%)
Improvement central processing speed after AED withdrawal/switch	3 (2.6%)
Increase side effects after switch AED	1 (0.9%)
No obvious difference	4 (3.4%)
AED change ($n = 117$)	64 (54.7%)
Withdrawal of AED	20 (17.1%)
Start additional AED	9 (7.7%)
Switch AED	11 (9.4%)
Increase dose AED	8 (6.8%)
Decrease dose AED	16 (13.7%)
Main reasons AED change	
Complete epilepsy remission > 1 year	19 (16.2%)
Side effects	16 (13.7%)
Women in child bearing age (Withdrawal of Valproate)	9 (7.7%)
Change diagnosis ($n = 117$)	14 (12.0%)
Other type of epilepsy syndrome	11 (9.4%)
No epilepsy	3 (2.6%)
Epilepsy surgery ($n = 117$)	8 (6.8%)
Ketogenic diet ($n = 117$)	1 (0.9%)
Vagus nerve stimulator ($n = 117$)	2 (1.7%)

Table 4 – Results of the Epilepsy Transition Clinic: interventions and consultations.

Advice/interventions (some patients had >1 intervention/advice) ($n = 117$)	73 (62.4%)
Social worker	54 (46.2%)
Housing assistance	31 (26.5%)
Reason financial advice	12 (10.3%)
Reason improving family support	9 (7.7%)
Reason improving separation/ individualization	9 (7.7%)
Reason increasing social interaction and support	4 (3.4%)
Reason planning daily activities	2 (1.7%)
Reason addiction	1 (0.9%)
Educationalist/vocational counselor	39 (33.3%)
Educational assistance	25 (21.4%)
Vocational assistance	11 (9.4%)
Vocational training	11 (9.4%)
Psychological treatment	17 (14.5%)

After a diagnostic work-up, eight patients (6.8%) were referred for a pre-surgical assessment for epilepsy surgery. One patient started a ketogenic diet, and two patients were referred for a vagus nerve stimulator.

4.3. *Consultations and interventions*

Consultations and interventions are shown in Fig. 1 and Table 4. Thirty-one patients (26.5%) required assistance by the social worker to apply for suitable housing or supported living accommodations. Improving separation from parents, financial assistance or guardianship, or help to improve the adolescent's social interaction with peers were provided in 9 patients (7.7%), 12 patients (10.3%), and 4 patients (3.4%), respectively. In nine patients (7.7%), a social worker was involved to improve family interactions and support.

Educational ($n = 25$, 21.4%) or vocational assistance or Vocational Training (both $n = 11$; 9.4%), appropriate for the individual's capacity, were provided by the educationalist/occupational counselor. In 17 patients (14.5%) psychological consultations and follow-up for psychosocial problems was provided.

4.4. *Transition from paediatric to adult care*

As shown in Table 3, 99 patients were referred by a neurologist of our epilepsy center, of which 54 (54.5%) by the transition clinic's neurologist. Ten patients (8.5%) were referred by an external neurologist, 4 (3.4%) by their general practitioner, and 3 (3.4%) by a paediatrician.

At time of referral to the transition clinic, 66 patients (56.4%) were 18 years or older. In total, 43 patients (36.8%) were referred from a paediatrician or paediatric neurologist to an adult neurologist. Three patients (2.6%) were referred to a psychiatrist for further follow-up because of the impact of their psychiatric comorbid conditions. At the time of analysis, 57 patients (48.7%) were still in follow-up at the transition clinic's neurologist for the following reasons: sixteen patients (13.7%) preferred to remain under long-term medical epilepsy

care with regular visits at the transition clinic's neurologist after transition to adult care ('transition to adult medical care'), or under temporary follow-up because of recent changes in epilepsy treatment ($n = 34$, 29.1%), or awaiting the results of a diagnostic work-up ($n = 7$, 6.0%). However, not all epilepsy patients are in need of epilepsy care at a specialized tertiary referral hospital, and 11 patients (9.4%) were referred to an external neurologist at a general hospital for further epilepsy care. Ten patients (8.5%) no longer required follow-up of specialized epilepsy care because of complete seizure remission (8 out of 10) or adequate seizure control for at least one year, and were referred back to their general practitioner. The number of referrals are shown in Fig. 1 and Table 5.

5. Discussion

Our epilepsy transition clinic uses a combined approach of a neurologist/epileptologist, neuropsychologist, an educationalist/occupational counselor and a social worker. This multidisciplinary approach allows us to re-evaluate specific medical and psychosocial developmental issues that arise during transition from adolescence to adult and provide both fine-tuned diagnostic work-up and treatment interventions.

Several transition clinics for adolescents with epilepsy have been described, but only limited data on the process and outcomes of transitional care in clinical practice are available. There is no consensus for its setting, staffing or the necessary procedures, and there is still no proof which model is the best.[4,14–17] Transition clinics are held within the paediatric or adult setting.[15] Joint consultation of adult and paediatric neurologists with or without support of epilepsy nurses is the most reported organization form. This staffing is sometimes complemented with career advisers, social workers and psychologists.[15,16,18–20] The presence of a familiar (paediatric) health care worker can provide continuity of care.[3,4,7,13–15] A collaboration between paediatric and adult health care workers is sometimes recommended, as medical and psychosocial issues can be evaluated from both perspectives.[3,13] However, Lewis et al.[21] state that adolescents with epilepsy still experience insufficient psychosocial care during transition to adult health care.

Table 5 – Results of the Epilepsy Transition Clinic: referrals and main reasons to remain under (temporary) follow-up.

Referral to ($n = 117$)	
Adult neurologist within the epilepsy center	32 (27.4%)
External referral to adult neurologists	11 (9.4%)
General practitioner	10 (8.5%)
Psychiatrist	3 (2.6%)
Lost-to-follow-up	6 (5.1%)
Main reasons for follow-up at the transition	
Clinic's neurologist ($n = 57$)	
Long-term epilepsy care ('Transition to adult care')	16 (13.7%)
After recent treatment changes (e.g. AED prescription)	34 (29.1%)
Awaiting the results of a diagnostic work-up	7 (6.0%)

A neuropsychologic revaluation of cognitive, behavioral and attention problems during transition to adulthood is highly recommendable, because behavioral problems and cognitive impairments and even cognitive deterioration require medical or psychoeducational interventions.[2,12] In addition, unrecognized conditions with major consequences for adolescents with epilepsy must be diagnosed. Moreover, a clinical neuropsychologic assessment can provide specific data about the patient's intellectual abilities, or cognitive adverse events of the AED's (e.g., central processing speed). These data can be usefull for further follow-up, e.g., to monitor treatment effects or for an educationalist to determine the patient's academic expectations.[12]

The collaboration with the educationalist/occupational counselor is especially important, as learning disorders, underemployment and unemployment are common in adolescents with epilepsy.[22] Even patients with epilepsy with a normal intelligence suffer academic underachievement, and frequently fail to complete higher education.[12]

Sixty percent of the patients with epilepsy worry about future education and employment.[4] An educationalist/occupational counselor helps patients to make appropriate future career choices in line with the characteristics of their epilepsy and their individual capacities, based on the outcome of a clinical neuropsychological assessment. Furthermore, the educationalist/occupational counselor has the ability to contact the patient's teacher or school staff members to provide further information about the individual's wishes and capacities with an individual education plan.

Among our population, we found that 13.7% of the patients ($n = 16$) were unemployed and currently not studying, compared to 20.5% of the youth aged 15–27 years in the Dutch population (Statistics Netherlands). However, the mean age at first visit was just above 18 years old in our transition clinic, and 77.8% ($n = 91$) of our population was still in school, which might be a reasonable explanation for the differences found with the Dutch reference population which has supposedly a higher average age. Causes for unemployment among adolescents with epilepsy include seizure frequency and severity, transportation or driving restrictions, and stigma by employers and society. Predictors for employment are seizure control, level of intelligence, adaptive coping styles and vocational training.[22]

One of the most important contributions from the social worker was to optimize and arrange future living arrangements for adult patients without seizure remission. Ninety-two percent of the adolescent study population was still living at home with their parents, of which 88.2% (15 out of 17) of the adolescents aged 21–25 years. This percentage is extremely high, compared to the normal population in which 50% of the girls and 65% of the boys at age 21, and 15% and 30% at the age of 25 live with their parents (Statistics Netherlands).

A social worker has extensive knowledge about resource facilitations, community support, and the consequences of the child's illness on complex family relations and family support.[12,20] Literature suggests one of the most important reasons for relatives to seek help from a social worker is to increase the patient's independence and self-responsibility.[12] In our study, we found that 9 patients needed support from a

social worker to increase their independence and self-efficacy. Although we have no comparative numbers, the clinical experience in our patient group shows many adolescents develop a passive role in daily functioning and gaining independence, leading to so called 'learned helplessness'.[23]

Independence and social participation were evaluated by the social worker and clinical neuropsychologist, but it would be better to use standarised measures for these variables. One example of a validated tool to measure social participation during transition to adulthood (validated for youth with cerebral palsy and normal intelligence) is the Rotterdam Transition Profile.[24] This tool distinguishes three developmental phases of transition to adulthood, namely the dependent childhood phase, the transition phase, and the independent adulthood phase. In total, six domains of social participation and three healthcare domains are evaluated in order to determine the adolescent's level of functioning.[24]

Based on the outcomes of our epilepsy transition clinic, re-evaluation of medical and psychosocial issues during the years of transition to adulthood is of utmost importance. After a diagnostic work-up, the diagnosis was changed in 14 patients (12.0%), compared to 15% found by Appleton et al.[4] In the study of Smith et al.,[17] 30 out of 207 patients (14.5%) were diagnosed with a non-epileptic diagnosis, and 4 out of these 207 patients (1.9%) with a single seizure. Most of the patients consulted by Smith et al.[17] were referred by general practitioners, paediatric neurologist, general paediatricians, namely 94 patients, 59 patients and 41 patients respectively.

The relatively low number of altered diagnosis in our study compared to Appleton et al.[4] and Smith et al.[17] is not surprising, since most of the patients were referred by a specialized neurologists/epileptologist from our specialized epilepsy hospital, and a probable diagnosis of epilepsy had been made before.

In nineteen patients with seizure remission for at least one year, AEDs were reduced and finally withdrawn. Eight patients with seizure remission were referred to their general practitioner, one patient was referred to adult care for further follow-up, and six remained temporarily under the care of a neurologist in our centre pending withdrawal of their AED. In 16 patients AEDs were causing side effects (e.g., mental slowing), and in 9 women in the child bearing age Valproate was withdrawn. In total, an AED change was applied in 64 patients (54.7%). Furthermore, a total of eleven referrals for epilepsy surgery, a VNS or a ketogenic diet were made. These numbers indicate that many patients were on an inappropriate antiepileptic drug treatment, or had suboptimal antiepileptic therapy and therefore side effects or inadequate seizure control.

In Appleton's clinic,[4] 22% of the patients underwent a change in AED prescription, but dose alterations were excluded from their analysis. Prescriptions were changed in 20% of the teenagers in the clinic of Smith et al.[17] Remarkably, patients with a diagnosis of 'epilepsy or probable epilepsy' were referred to the transition clinic of Smith et al.,[17] and 14% finally obtained a diagnosis of non-epileptic disorders.

Forty-three patients with ongoing seizures were referred to adult care, after a multidisciplinary evaluation of their medical, educational/vocational, and psychosocial status in order to optimize not only seizure control but also their independence, and future perspective for a suitable job and living arrangements.

Transition from child to adulthood is a process, and development to independence is not captured within strict age limits.[3] The age limitation of our transition clinic had a minimum of 15 years, but had an upper limit of 25 years, since developmental milestones are often delayed in patients with epilepsy.[14,25] This explains why patients in our transition clinic were approximately two years older compared to other studies.[14,16,17] Although the optimal age for transition to adult care remains unknown, experts advise to prepare patients with a chronic disease for the medical transition process at a young age (e.g., 12 years old).[13–15,18] We recommend to start the preparation for transition to adult medical care as early as possible, preferably at the pretransitional age when children are still in paediatric care. The Transition Readiness Assessment Questionnaire (TRAQ) can be used to assess the adolescent's readiness for transition to adult care. The TRAQ is a validated tool for adolescents with special health care needs to objective the adolescent's readiness for transition from paediatric to adult care by measuring their self-management skills and self-advocacy.[26] Furthermore, this tool can be used to determine the need for additional educational support and interventions.

To further improve transition from paediatric to adult care, multidisciplinary transitional services should be integrated within the traditional paediatric and adult epilepsy health care services. The number of transition clinics for adolescents and young adults with epilepsy should be increased, and their setting should finally be extended to local referral hospitals too, instead of tertiary referral epilepsy centers only.[15]

6. Conclusion

This study describes a transition clinic in a tertiary epilepsy center, staffed by a neurologist/epileptologist, neuropsychologist, a social worker and an educationalist/occupational counselor. A diagnostic work-up and evaluation of medical, psychosocial and educational/vocational status during adolescence and early adulthood are strongly recommended in order to optimize seizure control and long-term psychosocial outcome for patients with persistent seizures, before transition from paediatric to adult care.

Conflict of interest

The authors have no conflicts of interest to declare.

Acknowledgments

The authors would like to thank R. Dabekaussen-Spiering, and J. van de Corput for their support in the Kempenhaeghe Epilepsy Transition Clinic.

This research was funded by the province of Noord-Brabant ('*Leefbaarheid@Brabant*'), The Netherlands, with grant number C2134073.

REFERENCES

1. Mu PF. Transition experience of parents caring of children with epilepsy: a phenomenological study. *Int J Nurs Stud* 2008;**45**:543–51.
2. Lewis SA, Noyes J. Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adult services. *BMC Pediatr* 2013;**13**:169.
3. Khan A, Baheerathan A, Hussain N, Whitehouse W. Transition of children with epilepsies to adult care. *Acta Paediatr* 2013;**102**:216–21.
4. Appleton RE, Chadwick D, Sweeney A. Managing the teenager with epilepsy: paediatric to adult care. *Seizure* 1997;**6**:27–30.
5. Baker GA, Spector S, McGrath Y, Soteriou H. Impact of epilepsy in adolescence: a UK controlled study. *Epilepsy Behav* 2005;**6**:556–62.
6. Asato MR, Manjunath R, Sheth RD, et al. Adolescent and caregiver experiences with epilepsy. *J Child Neurol* 2009;**24**:562–71.
7. Camfield P, Camfield C, Pohlmann-Eden B. Transition from pediatric to adult epilepsy care: a difficult process marked by medical and social crisis. *Epilepsy Curr* 2012;**12**:13–21.
8. Sillanpaa M, Helen Cross J. The psychosocial impact of epilepsy in childhood. *Epilepsy Behav* 2009;**15** (Suppl. 1):S5–10.
9. Chin RF, Cumberland PM, Pujar SS, Peckham C, Ross EM, Scott RC. Outcomes of childhood epilepsy at age 33 years: a population-based birth-cohort study. *Epilepsia* 2011;**52**:1513–21.
10. Jalava M, Sillanpaa M, Camfield C, Camfield P. Social adjustment and competence 35 years after onset of childhood epilepsy: a prospective controlled study. *Epilepsia* 1997;**38**:708–15.
11. Geerts A, Brouwer O, van Donselaar C, et al. Health perception and socioeconomic status following childhood-onset epilepsy: the Dutch study of epilepsy in childhood. *Epilepsia* 2011;**52**:2192–202.
12. Goldstein J, Plioplys S, Zelko F, et al. Multidisciplinary approach to childhood epilepsy: exploring the scientific rationale and practical aspects of implementation. *J Child Neurol* 2004;**19**:362–78.
13. Camfield PR, Gibson PA, Douglass LM. Strategies for transitioning to adult care for youth with Lennox-Gastaut syndrome and related disorders. *Epilepsia* 2011;**52**(Suppl. 5):21–7.
14. Jurasek L, Ray L, Quigley D. Development and implementation of an adolescent epilepsy transition clinic. *J Neurosci Nurs* 2010;**42**:181–9.
15. Carrizosa J, An I, Appleton R, Camfield P, Von Moers A. Models for transition clinics. *Epilepsia* 2014;**55**(Suppl. 3):46–51.
16. Iyer A, Appleton R. Transitional services for adolescents with epilepsy in the U.K.: a survey. *Seizure* 2013;**22**:433–7.
17. Smith PE, Myson V, Gibbon F. A teenager epilepsy clinic: observational study. *Eur J Neurol* 2002;**9**:373–6.
18. Kuchenbuch M, Chemaly N, Chiron C, Dulac O, Nabbout R. Transition and transfer from pediatric to adult health care in epilepsy: a families' survey on Dravet syndrome. *Epilepsy Behav* 2013;**29**:161–5.
19. Reeve DK, Lincoln NB. Coping with the challenge of transition in older adolescents with epilepsy. *Seizure* 2002;**11**:33–9.
20. Shanske S, Arnold J, Carvalho M, Rein J. Social workers as transition brokers: facilitating the transition from pediatric to adult medical care. *Soc Work Health Care* 2012;**51**:279–95.
21. Lewis SA, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: mixed-method systematic review. *BMC Pediatr* 2010;**10**:103.
22. Bautista RE, Shapovalov D, Saada F, Pizzi MA. The societal integration of individuals with epilepsy: perspectives for the 21st century. *Epilepsy Behav* 2014;**35**:42–9.
23. Seligman ME. Learned helplessness. *Annu Rev Med* 1972;**23**:407–12.
24. Donkervoort M, Wiegerink DJ, van Meeteren J, Stam HJ, Roebroeck ME. Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Dev Med Child Neurol* 2009;**51**:53–62.
25. Colver A, Longwell S. New understanding of adolescent brain development: relevance to transitional healthcare for young people with long term conditions. *Arch Dis Child* 2013;**98**:902–7.
26. Sawicki GS, Lukens-Bull K, Yin X, et al. Measuring the transition readiness of youth with special healthcare needs: validation of the TRAQ–Transition Readiness Assessment Questionnaire. *J Pediatr Psychol* 2011;**36**:160–71.