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

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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.

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

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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

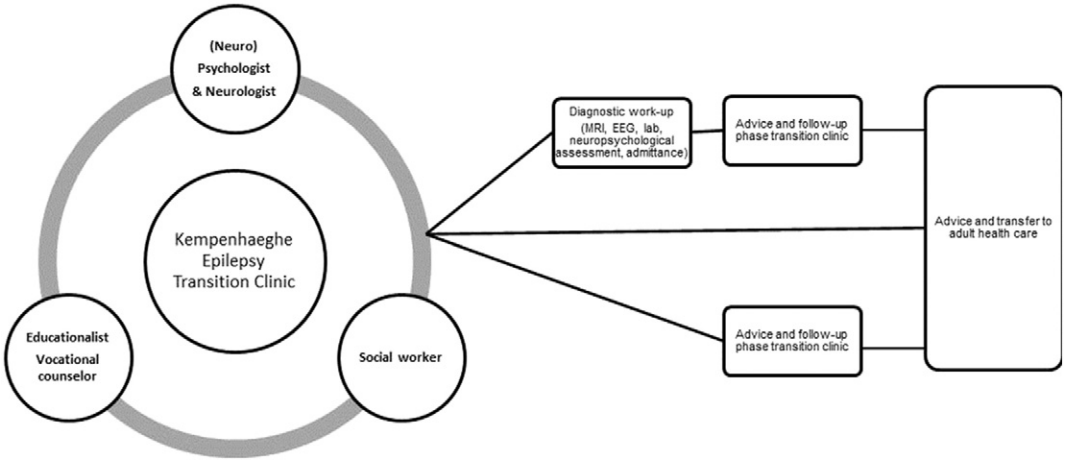

Fig. 1. Flowchart transition clinic.

independence/separation/identity domain were allocated by the transition clinic's neurologist and psychologist in a consensus model. If no agreement occurred, discussions were required until consensus. Therefore, a kappa to express the correlation of these scores by the neurologist and psychologist cannot be provided.

2.2. Inclusion and exclusion criteria

Patients who visited the transition clinic from the start in March 2012 until December 2014 were to participate in the study. The criteria for an appointment at the transition clinic (mentioned above in the Methods section) were the same as the inclusion criteria for this study. Adolescents and young adults, 15–25 years of age, with confirmed (childhood-onset) epilepsy were eligible for a visit to the transition clinic. This upper age limit was chosen because developmental milestones are often delayed in patients with epilepsy [3,16]. Patients were excluded from our analysis if they had nonepileptic seizures only or if they were diagnosed with an IQ < 50.

2.3. Data collection

Data of all patients who visited the transition clinic and met the inclusion criteria for this study were entered in an IBM SPSS database. Demographic, medical, and psychosocial data were collected, specifically gender, age at first appointment at the transition clinic, epilepsy syndromes classified according to International League Against Epilepsy (ILAE) 1989 classification, duration of epilepsy in years, frequency of seizures, use of concomitant antiepileptic drugs, and correct ingestion of the AEDs as reported by the patients themselves or other treatments (e.g., vagus nerve stimulation (VNS), ketogenic diet (KD), or epilepsy surgery), Full Scale Intelligence Quotient (IQ) by neuropsychological testing using the Wechsler Intelligence Scale for Children, substance use, psychiatric disorder diagnosed by health-care professionals (mood disorder, attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), or anxiety disorder), all DSM-IV diagnosed by a psychologist or psychiatrist, physical comorbidities (diabetes, arthritis, or other chronic diseases with childhood-onset continuing into adolescence), educational and vocational status, housing, and family history of epilepsy. Having a social network was defined as having several friends or having a romantic relationship [21,22]. Age-appropriate social independence, evaluated by the social worker, was defined as patients who were able to independently make their own decisions or take care of their own personal hygiene including minor household chores appropriate to the individual's intellectual (dis)abilities [23]. The level of family support was evaluated by the social worker and clinical neuropsychologist as '*sufficient*' or '*insufficient*' and was based on the information gathered during the consecutive consultations at the first visit to the transition clinic. A medical work-up was only conducted when considered necessary by the health-care workers and of added value for revision of the diagnosis or for further interventions and consultations. Subsequently, we evaluated the diagnostic work-up conducted after the first visit to the transition clinic; the interventions, consultations, and follow-up by the psychologist, educationalist/vocational counselor, or social worker, and data on referral to adult health-care providers.

2.4. Statistical analysis

Statistical analysis was performed by using IBM SPSS Version 21. We used descriptive statistics to compute frequencies (n) and percentages

Table 1
Definitions of medical, educational/vocational, and independence/separation/identity performance scores.

	Normal (score 0)	Suboptimal (score −1)	Poor (score −2)
Medical performance score	Low seizure frequency or seizure freedom. No comorbid conditions.	Medium seizure frequency (monthly). One mental or physical comorbid condition.	High seizure frequency (daily, weekly). Multiple mental or physical comorbid conditions.
Educational/vocational performance score	Maximum educational/vocational opportunities with respect to the patient's individual mental abilities and maximum level of functioning.	Underemployment, academic underachievement suboptimal educational/vocational opportunities with respect to the patient's mental abilities and maximum level of functioning.	Patient is currently not studying or is unemployed. Inability to keep a job. Poor educational/vocational opportunities with respect to the patient's individual mental abilities and maximum level of functioning.
Independence/separation/identity performance score	Maximum level of independence and separation from parents, or patient does not require help on daily activities, making choices, and household chores, with respect to the patient's mental abilities and maximum level of functioning.	Suboptimal level of independence and separation from parents, or patient needs any help of parents on daily activities, choices, and household chores, with respect to the patient's mental abilities and maximum level of functioning.	Poor level of independence and separation from parents, or patient needs help of parents on almost any daily activities, choices, and household chores, with respect to the patient's mental abilities and maximum level of functioning.

(%) of categorical variables. Means are presented with median, standard deviation (SD), and range.

Nonparametric correlation analysis was used to compute the correlation between the three different performance scores (independent variables) and the individual risk profile score (dependent variable) represented by Pearson's correlation coefficient (r). The threshold for significance was $p < 0.05$.

Data were categorized as demographic (age, gender, IQ, and ever having special education), medical (duration of epilepsy, IQ, number of AEDs, and seizure frequency), or social independence variables (self-reported AED adherence, seizure-free over one year, living arrangements, social participation, and unsupportive/unstable family environments and interactions). Backward multiple linear regression analysis was applied to determine demographic, medical, and social variables as independent risk factors associated with the risk profile score. The proportion of explained variance (R^2), unstandardized coefficient B, standard error B (SE B), 95% confidence interval (CI), and standardized coefficients (β) are shown. The threshold for significance was $p < 0.05$.

Because the level of intelligence was used in both demographic and medical regression models, the level of significance from this variable differs between these models. To create a uniform set of outcome variables, the correlation between variables and risk profile scores is represented Pearson's correlation coefficient (r), and the level of significance (p) in regression analysis. All variables which were significant in the regression analysis were included in a discriminant function analysis to determine the predictive value of these variables.

2.5. Ethics

The Medical Ethics Committee of Kempenhaeghe considered this as a medical audit for which general approval of patients was already provided. Patients could withdraw consent for participation upon request.

3. Results

3.1. Outcome of the epilepsy transition clinic

Between March 2012 and December 2014, a total of 148 patients visited the transition clinic at Epilepsy Centre Kempenhaeghe, a tertiary center for patients with epilepsy in The Netherlands. Ten patients were excluded from our analysis: two patients did not give consent to use their medical data for research purposes, three patients exceeded the age limitation for inclusion, three patients were not diagnosed with epilepsy at the time of their visit (two suffering from psychogenic nonepileptic seizures and one having learning disabilities without epilepsy), and two patients were excluded because severe posttraumatic stress disorder initiated their social problems, not epilepsy. A total of 138 patients were finally included in this study.

3.1.1. Patient characteristics

Demographic, epilepsy-related, and psychosocial characteristics at the initial visit to the transition clinic are shown in Table 2. A total of 78 (56.5%) men and 60 (43.5%) women visited the transition clinic, with a mean age of 18.7 years (median = 18.2, SD = 2.1). The mean IQ was 82.6 (median = 82, SD = 15.3). Sixty (43.5%) patients had ever been involved in a special education program. Seventy-three (52.9%) patients had at least one mental or psychiatric comorbidity, of which autism spectrum disorder (ASD) (14.5%) was the most common (men $n = 15$, women $n = 5$). Twenty-one (15.2%) had physical comorbidity, e.g., hearing problems ($n = 6$, 4.3%) or cerebral palsy ($n = 5$, 3.6%).

The mean age at diagnosis of epilepsy was 8.1 years (median = 8.0, SD = 4.9), with a mean duration of epilepsy of 10.5 years (median =9.7, SD =] 5.1). The most common type of epilepsy syndrome was localization-related epilepsy ($n = 109$, 79.0%). On average, patients were seizure-free for 1.5 years (median 0.3, SD 2.9). Sixty-four (46.4%) patients were seizure-free for more than one year. One hundred and twenty-seven (92.0%) patients were currently using AEDs, of which 67 (48.6%) patients were on monotherapy. One hundred and nine (79.0%) patients showed self-reported AED adherence. Three patients

Table 2
Demographic, epilepsy-related, and psychosocial variables.
Legend with definitions is provided below this table.

		Median	SD	Range
Gender				
Men	78 (56.5%)			
Women	60 (43.5%)			
Mean age at first visit	18.7	18.2	2.1	15–25
Younger than 18 years of age	62 (44.9%)			
Mean Full Scale Intelligence Quotient (FSIQ)	82.6	82	15.3	51–113
IQ = >100	15 (10.9%)			
IQ = 90–100	23 (16.7%)			
IQ = 70–90	49 (35.5%)			
IQ = 50–70	25 (18.1%)			
Not assessed	26 (18.8%)			
Mean age at diagnosis of epilepsy	8.1	8.0	4.9	0.1–21.5
Mean duration of epilepsy (years)	10.5	9.7	5.1	0.33–21.32
Type of epilepsy				
Localization-related epilepsy	109 (79.0%)			
Idiopathic	6 (4.3%)			
Symptomatic	27 (19.6%)			
Cryptogenic	76 (55.1%)			
Generalized epilepsy	24 (17.4%)			
Idiopathic	19 (13.8%)			
Symptomatic	5 (3.6%)			
Cryptogenic	0 (0%)			
Landau–Kleffner syndrome	1 (0.7%)			
Not classified yet	4 (2.9%)			
Seizure frequency				
Daily	16 (11.6%)			
Last week	16 (11.6%)			
Last month	26 (18.8%)			
Last year	8 (5.8%)			
Seizure-free > 1 year	64 (46.4%)			
Unknown	8 (5.8%)			
Mean number of seizure-free years	1.5	0.3	2.9	0–21.3
Number of AEDs				
No current AED treatment	11 (8.0%)			
Monotherapy	67 (48.6%)			
Polytherapy (2 to 4 AEDs)	60 (43.5%)			
Self-reported AED adherence				
Yes/most likely yes	109 (79.0%)			
No	18 (13.0%)			
No current AED treatment	11 (8.0%)			
Previous therapies				
Epileptic surgery	6 (4.3%)			
Vagal nerve stimulator	3 (2.2%)			
Ketogenic diet	2 (1.4%)			
Special education program				
In the past/ever	60 (43.5%)			
Current	42 (30.4%)			
Living arrangements				
At home with parents	127 (92.0%)			
Independent	4 (2.9%)			
Supported accommodation	5 (3.6%)			
Unknown	2 (1.4%)			
Social participation	98 (71.0%)			
Independence	63 (45.7%)			
Unsupportive/unstable family environment	40 (29.0%)			
Employment				
Yes	59 (42.8 %)			
No	18 (13.0%)			
Internship	21 (15.2%)			
Student without a job	38 (27.5%)			
Unknown	2 (1.4%)			

Data are presented as number (n, %). Means are presented with median, standard deviation (SD), and range.

had a VNS (2.2%), two were on a KD (1.4%) and six had had epilepsy surgery in the past (4.3%).

In the total study population, 127 (92.0%) patients were still living at home with their parents compared with 15 (88.2%) out of 17 patients 21–25 years of age. Four (23.5%) out of seventeen patients 21–25 years of age were unemployed and not studying. Forty (29.0%) patients were living in an unsupportive and unstable family environment. Ninety-eight (71.0%) patients were considered to have their own sufficient social network. Based on the data collection, 63 (45.7%) patients were considered independent.

3.1.2. Transitional care

A supplementary diagnostic work-up was considered necessary in 100 (72.5%) patients and involved a neuropsychologic test ($n = 73$, 52.9%), an EEG ($n = 70$, 50.7%), MRI ($n = 29$, 21.0%), or laboratory tests ($n = 48$, 34.8%). Forty-five (32.6%) patients were briefly (for a maximum of 24 h) admitted to facilitate the diagnostic work-up.

The epilepsy diagnosis was changed in 16 (11.6%) patients following their diagnostic work-up, from which thirteen were diagnosed with a different epilepsy syndrome and three were diagnosed with a nonepileptic disorder (e.g., nonepileptic seizures). To be more specific, in eight patients, the diagnosis of cryptogenic localization-related epilepsy was changed: four patients were diagnosed with either idiopathic generalized epilepsy or cryptogenic generalized epilepsy; in one patient, the diagnosis was specified as juvenile absence epilepsy (JAE); one patient was diagnosed with idiopathic localization-related epilepsy; in one patient, the diagnosis was not yet specified but certainly not cryptogenic localization-related epilepsy; and one patient was diagnosed with nonepileptic seizures.

In four patients, the diagnosis of idiopathic generalized epilepsy was changed: in two patients, the diagnosis was specified as juvenile myoclonic epilepsy; one patient was diagnosed with cryptogenic localization-related epilepsy; and one patient was diagnosed with nonepileptic seizures.

Two patients with symptomatic localization-related epilepsy were diagnosed with another major cause than epilepsy for their transition problems, namely, a visual agnosia due to a developmental malformation of the occipital lobes or another cause of their symptomatic localization-related seizures than previously diagnosed.

One patient with idiopathic localization-related seizures was diagnosed with symptomatic localization-related seizures.

One patient with symptomatic generalized seizures was diagnosed with idiopathic generalized seizures.

Antiepileptic drugs were changed in 75 (54.3%) patients, for example, because of remission of epilepsy ($n = 22$, 15.9%) or side effects ($n = 16$, 11.6%). In ten (90.9%) out of eleven women using valproate, this AED was withdrawn because of reaching the child-bearing age. In addition, eleven (8.0%) patients were referred to an assessment team to explore epilepsy surgery as a treatment option. Two (1.4%) patients were referred for a VNS, and one patient was referred to start with a KD.

A social worker was involved in guidance and follow-up of 63 (45.7%) patients, and exploration of living arrangements was carried out in 36 (26.1%) patients. The educationalist/vocational counselor provided 47 (34.1%) patients with advice and follow-up. Some patients had more than one follow-up consultation or intervention. Follow-up and interventions are shown in Table 3. Because transition is a gradual process instead of a single handing over, the number of visits to the transition clinic ranged from 1 to 9 (average = 2.95, median = 2), with a maximum total duration of 30.95 months (average = 8.6 months, median = 4.4) from the time of referral to the transition clinic until the time of referral to adult care. At the time of statistical analysis of this manuscript, 71 (51.4%) patients were still in follow-up of epilepsy care by the neurologist of the transition clinic. The main reasons for remaining under temporary follow-up were as follows: (1) changes in AED prescription ($n = 36$, 50.7%) and (2) waiting for the results of a diagnostic work-up ($n = 16$, 22.5%). Nineteen (36.8%) out of these 71 patients in follow-up decided to continue their long-term epilepsy care with regular visits to the transition clinic's adult neurologist and, thus, were 'referred to adult care'.

Eventually, 46 (33.3%) patients were transferred to an adult neurologist, of which 35 were sent to a neurologist in a tertiary referral center and 11 to a neurologist in a general hospital. Eleven (8.0%) patients were referred to a general practitioner, and three (2.2%) to a psychiatrist for further follow-up. Fourteen (10.1%) patients had seizure remission. Three out of these 14 patients had a low total performance score over the three domains, indicating current poor level of functioning, combined with a high risk profile score. These three patients were referred to the social worker and/or psychologist for further care and follow-up

Table 3
Transition clinic variables.

		Median	Range
Visits to the transition clinic	2.95	2	1–9
Duration of follow-up at the transition clinic (months)	8.6	4.4	0–30.95
Diagnostic work-up after first visit to the transition clinic	100 (72.5%)		
Clinical neuropsychological assessment	73 (52.9%)		
EEG	70 (50.7%)		
MRI	29 (21.0%)		
Admittance for diagnostic work-up	45 (32.6%)		
Laboratory	48 (34.8%)		
Serum blood levels	47 (34.1%)		
AED levels	37 (26.8%)		
Genetic counseling	9 (6.5%)		
AED change	75 (54.3%)		
Reason for AED change			
Epilepsy remission	22 (15.9%)		
Side effects	16 (11.6%)		
Switch of AED	8 (5.8%)		
Addition of AED	8 (5.8%)		
Increase dose of AED	7 (5.1%)		
Decrease dose of AED	4 (2.9%)		
Woman in child-bearing age	10 (7.2%)		
Change of diagnosis	16 (11.6%)		
Other types of epilepsy syndrome	13 (9.4%)		
No epilepsy diagnosis	3 (2.2%)		
Consultation transition clinic (some patients had >1 intervention/consultation)			
Social worker	63 (45.7%)		
Housing assistance	36 (26.1%)		
Reason - improving family support	10 (7.2%)		
Reason - improving separation/individualization	13 (9.4%)		
Reason - financial advice	14 (10.1%)		
Reason - increasing social interaction and support	5 (3.6%)		
Reason - for addiction	1 (0.7%)		
Reason - planning daily activities	2 (1.4%)		
Educationalist/vocational counselor	47 (34.1%)		
Educational assistance	30 (21.7%)		
Vocational assistance	14 (10.1%)		
Vocational training	11 (8.0%)		
Psychological assistance	19 (13.8%)		
Epilepsy surgery	11 (8.0%)		
Vagal nerve stimulator	2 (1.4%)		
Ketogenic diet	1 (0.7%)		
Referral to			
Transition clinic's neurologist (see below)	71 (51.4%)		
Adult neurologist within the epilepsy center	35 (25.4%)		
External referral to adult neurologist	11 (8.0%)		
General practitioner	11 (8.0%)		
Psychiatrist	3 (2.2%)		
Pediatric neurologist (patient < 18 years of age)	1 (0.7%)		
Lost to follow-up	6 (4.3%)		
Main reasons for follow-up with the transition clinic's neurologist			
Long-term epilepsy care ('transition to adult care')	19 (26.8%)		
After recent changes in AED prescription	36 (50.7%)		
Awaiting the results of a diagnostic work-up	16 (22.5%)		

Data are presented as number (*n*, %). Means are presented with median and range.

of their psychosocial problems, but medical care was no longer required because of their seizure freedom.

3.2. Correlations of performance scores with risk profile scores

According to the risk profile scores, 47.8% were scored as high-risk patients, and about 31.9% were at mild risk of poor outcome in the long term.

Performance scores for medical, educational/occupational status, and independence/separation/identity showed a significant correlation with the risk profile scores. Scores for independence/separation/identity were strongly related ($r = 0.823$, $p < 0.001$), followed by educational/occupational scores ($r = 0.731$, $p < 0.001$) and medical status ($r = 0.575$, $p < 0.001$) (Table 4).

3.3. Multivariate linear regression analysis of demographic, medical, and psychosocial variables with risk profile scores

Demographic, medical (epilepsy-related), and psychosocial variables were entered in three separate multivariate linear regression analyses to predict risk profile scores. The prediction models for all three individual linear regression analyses were statistically significant for demographic variables $F(4, 133) = 5.648$, $p < 0.001$, explaining 14.5% of the variance ($R^2 = 0.145$), for epilepsy-related variables $F(4, 133) = 8.735$, $p < 0.001$, accounting for 20.8% of the variance ($R^2 = 0.208$), and for psychosocial variables $F(5, 132) = 7.127$, $p < 0.001$ explaining approximately 21.3% of the variance ($R^2 = 0.213$) of risk profile scores. There were no signs of multicollinearity in all of the three models, with a VIF-value ranging between 1.013 and 1.198.

Significant variables in predicting risk profile scores were unsupportive family environment ($r = 0.363$, $p < 0.001$), lower intelligence (in both demographic and medical analyses, $r = -0.334$ and $p < 0.000$ and $p = 0.005$, respectively), higher seizure frequency ($r = 0.311$, $p = 0.001$), and ongoing seizures (seizure remission was negatively correlated with a high risk) ($r = -0.257$, $p = 0.045$). The strongest weight belonged to unsupportive family environment ($\beta = 0.315$), followed by IQ (in the demographic analysis, $\beta = -0.310$ and $\beta = -0.224$ in the medical analysis), seizure frequency ($\beta = 0.273$), and, to a lesser extent, to ongoing seizures ($\beta = 0.166$). An overview of the results of the regression analyses is shown in Table 5 and in Fig. 2.

Table 4
Medical, educational/vocational and independence performance scores and personal risk profile scores. Nonparametric correlations between performance scores and risk profile scores are shown.

Risk profile scores	
Low (1)	28 (20.3%)
Increased (2)	44 (31.9%)
High (3)	66 (47.8%)
Medical performance score	
Spearman's rho = 0.58, $p < 0.001$	
Normal	48 (34.8%)
Suboptimal	33 (23.9%)
Poor	57 (41.3%)
Educational/vocational performance score	
Spearman's rho = 0.73, $p < 0.001$	
Normal	72 (26.8%)
Suboptimal	41 (29.7%)
Poor	60 (43.5%)
Independence/separation/identity performance score	
Spearman's rho = 0.82, $p < 0.001$	
Normal	29 (21.0%)
Suboptimal	43 (31.2%)
Poor	66 (47.8%)

Data are presented as number (*n*, %).

3.4. Discriminant analysis

The results of the regression analysis were tested in a discriminant function analysis to control for the predictive power of the identified risk factors for poor transitional outcome. Intelligence, frequency of seizures and seizure freedom over one year, and unsupportive family interactions were used as predictor variables. The discriminant analysis significantly differentiated groups (Wilks' lambda = 0.718, $chi^2(4) = 30.612$, $p < 0.001$). Studying the structure matrix table revealed that unsupportive family interactions (0.708) and low intelligence (−0.657) were strong predictors, whereas seizure frequency (0.093) and ongoing seizures (0.050) were poor predictors. The cross-validated classification showed that with the predictors in combination, 55.1% of the patients were correctly classified. Patients at high risk were better classified (positive predictive value of 57.6%) compared with patients without obvious risk (negative predictive value 46.4%) for poor transitional outcome.

4. Discussion

In our study, we described four risk factors for poor psychosocial outcome in adolescents and young adults with epilepsy. In both regression and discriminant analyses, impaired, unsupportive, and unstable family dynamics was the strongest predictor for long-term poor psychosocial outcome in adolescents and young adults with epilepsy. Intelligence level and seizure remission were negatively correlated variables for poor transitional outcome in the long term. Furthermore, a high seizure frequency was found to be significant (Table 5, Fig. 2).

This study identified risk factors during the years of transition and took into account multidomain specific transitional problems. Previous studies have focused on risk factors in either children or adults, while adolescence and approaching adulthood are characterized by a specific developmental period not comparable with other age groups [24–28]. Specific age-related developmental milestones, e.g., medication adherence, and living arrangements as a part of developing independence are not yet relevant for a cared-for childhood population. However, most childhood studies are based on parent-reported instead of patient-reported quality-of-life or psychosocial outcome measures [25,29]. Outcomes reported by parents or health-care workers do not necessarily correlate with patient-reported outcomes [30]. Studies including adolescents and young adults were not conducted in an epilepsy transition clinic and predominantly measured health-related quality-of-life (HRQOL), without examining age-specific transition-related psychosocial and medical issues, e.g., development of independence and living arrangements [26]. Because designs and population of these studies differ substantially from our study, it is difficult to compare the results.

Only a few studies mentioned the detrimental effects of unsupportive family environments and lack of social and societal support as profound risk factors for poor psychosocial outcome in patients with epilepsy [2,28,31–33]. Fastenau et al. [32] found that children (8–15 years) with epilepsy and intellectual disabilities were at risk of poor academic outcome, especially those with a disruptive or unstable family environment. Jayalakshmi et al. [34] found that patients with juvenile myoclonic epilepsy (15–40 years of age) without proper family support had lower AED adherence, resulting in reduced seizure control, a higher incidence of psychiatric disorders, and lower educational and vocational levels. Furthermore, patients experiencing societal or family support have improved coping mechanisms, higher socioeconomic status, and, thus, an increased self-reported quality of life (QoL) [2,33]. Further, higher QoL is associated with fewer outpatient or hospital visits and admissions [2].

In our study, a lower intelligence level was the second strongest risk factor for long-term poor psychosocial outcome. Intellectual disabilities and associated learning disorders affect approximately 26% to 33% of the patients with epilepsy, respectively [1,2,35–37]. Several studies

Table 5
Correlations of risk profile scores and demographic, epilepsy-related, and psychosocial variables.

	r	B (CI)	SE B	β	*p*
Demographic variables $R^2 = 0.145$					
Age at first visit	0.087	0.046 (−0.015–0.107)	0.031	0.121	0.137
Gender	0.028	0.084 (−0.171–0.339)	0.129	0.054	0.515
IQ	−0.344	−0.018 (−0.027 to −0.008)	0.005	−0.310	<**0.001**
Special education	0.210	0.203 (−0.073–0.479)	0.139	0.127	0.148
Epilepsy-related variables $R^2 = 0.208$					
Duration of epilepsy	0.247	0.025 (−0.001–0.050)	0.013	0.159	0.058
IQ	−0.344	−0.014 (−0.023 to −0.004)	0.005	−0.224	**0.005**
Number of AEDs	0.088	−0.002 (−0.148–0.145)	0.074	−0.002	0.981
Seizure frequency	0.311	0.148 (0.064–0.232)	0.043	0.273	**0.001**
Psychosocial variables $R^2 = 0.213$					
Adherence	−0.209	−0.237 (−0.511–0.037)	0.139	−0.138	0.090
Seizure-free > 1 year	−0.257	−0.274 (−0.542 to −0.006)	0.136	−0.166	**0.045**
Living arrangements	0.034	0.076 (−0.242–0.395)	0.161	0.037	0.637
Social participation	−0.181	−0.270 (−0.566–0.026)	0.150	−0.141	0.073
Unsupportive family environment	0.363	0.550 (0.277–0.823)	0.149	0.315	<**0.001**

identified intelligence or education level as predictors of psychosocial problems during adolescence and early adulthood [10,20,25–28,38,39]. However, these results have some limitations, as some psychosocial items in the HRQOL outcome measurement are irrelevant to children with an intellectual disability [25]. In our current study, scores on the three different domains were allocated with respect to the patient's maximum intellectual abilities (see Table 1 for further details).

Evidence is conflicting, as one study [40] and a meta-analysis [29] found that intelligence and level of education were not significantly associated with poor outcome. Remarkably, most of the studies evaluated in the meta-analysis excluded children with a cognitive disability.

Epilepsy-specific factors are among the most commonly analyzed predictors for long-term psychosocial outcome in patients with epilepsy [25,26,29,31,39–45]. Seizure frequency and the consequences of ongoing seizures are the most predominant epilepsy-related determinants of physical and mental well-being and social participation [26,29,40,42–47].

However, Eom et al. [41] and Miller et al. [25] found seizure frequency to not significantly influence any aspect of psychosocial function, and according to Kokkonen et al. [39], having epilepsy itself did not significantly influence the psychosocial outcome. The aforementioned heterogeneity among study populations and designs might be a reasonable explanation for the contradictory evidence. Poor psychosocial outcome is predicted not only by seizure frequency alone but also by seizure type and seizure severity [46]. Unfortunately, both variables were not studied separately in our study.

Several studies indicated that patients with seizure remission have a persistent increased risk of adverse social outcome in the long term. Sillanpää et al. [48] showed that patients with normal intelligence and epilepsy in remission were less often in a relationship and less often employed compared with controls after long-term follow-up. Geerts et al. [9] found that both patients with ongoing seizures and patients with seizure remission had a worse outcome than expected compared with the Dutch control group after 15 years of follow-up. Camfield and Camfield [20] found that adults with childhood Rolandic epilepsy had a better psychosocial outcome compared with patients with juvenile myoclonic epilepsy, epilepsy with generalized tonic–clonic seizures only, epilepsies characterized by complex partial seizures, and

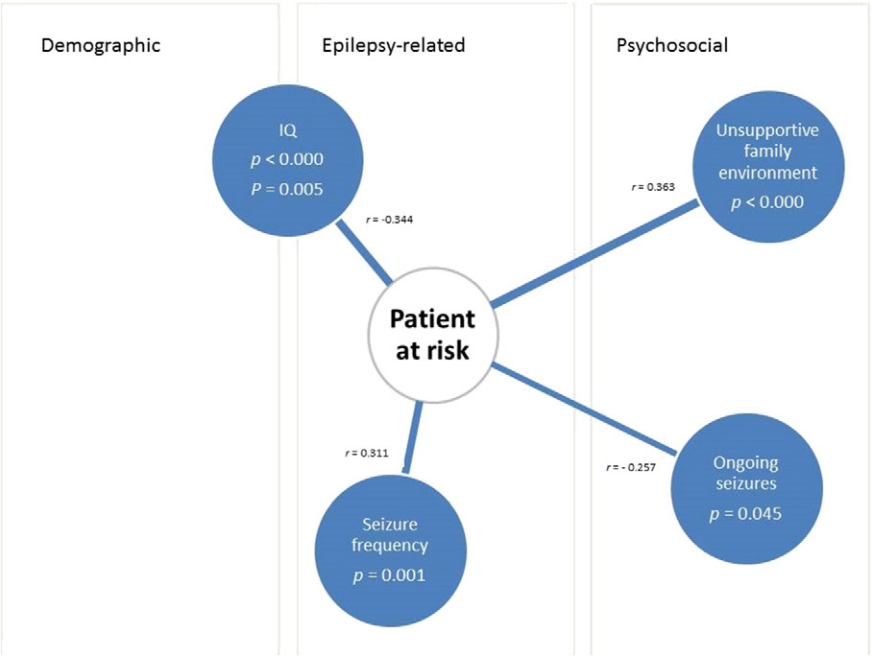

Fig. 2. Significant demographic, epilepsy-related, and psychosocial variables and their correlation coefficient (r).

epilepsies characterized by only focal seizures with secondary generalization. However, even in patients with seizure remission, adverse psychosocial outcomes were found [20]. In another study, Camfield et al. [22] stated that patients with benign epilepsy with centrotemporal spikes (BECTSs) do not need any care or further follow-up because psychosocial outcomes are similar to those in the population in contrast to patients with nonlesional focal epilepsy in otherwise normal children (NLFN), childhood absence epilepsy (CAE), and juvenile myoclonic epilepsy (JME).

Ideally, early identification of patients at risk of poor psychosocial outcome could lead to preventive measures. Besides, it would be beneficial to prepare youth with chronic epilepsy for transition to adulthood, for example, by increasing and supporting their independence. Furthermore, preparation for transition to adult care can be improved at an early stage, although the optimum age limit for preparation and transition remains unknown [49–51].

4.1. Strengths and limitations

This study has several limitations. Firstly, demographic, epilepsy-related, and psychosocial characteristics account for 14.5%, 20.8%, and 21.3% of the explained variance, respectively. With the predictors in combination, 55.1% of the patients were correctly classified, indicating that the outcome score is determined by more variables than we included in the current analysis. In general, 55.1% is a high score, though as in clinical practice, many factors cannot be controlled.

Secondly, children with other comorbid physical conditions were entered in the analysis. This could introduce confounders, as other chronic childhood-onset diseases might also affect psychosocial and medical outcomes.

Thirdly, several social variables in our analysis were ('objectively') scored by the health-care professionals of the transition clinic, e.g., age-appropriate social independence was scored by the social worker. It remains unclear whether these scores correspond with the patient's ('subjective') perception. A study by van Hedel et al. [30] showed only moderate correlations between patient-reported and investigator-reported scores for independency up to one year after patients' spinal cord injury. Different physical, psychological, and cultural factors can influence patient-reported outcome, and differences exist between physical and emotional scores reported by patients and investigators [30,52]. Hence, it would be of added value to measure patient-reported outcomes on physical and emotional domains as well, along with their preferences for transitional care [25,29,50].

Unfortunately, we were unable to collect a valid group of matched control patients within our hospital because, in our tertiary referral epilepsy center, only patients with epilepsy are treated.

Fourth, Borlot et al. [53] recently found that patients primary referred to a tertiary center like Kempenhaeghe might have more severe epileptic syndromes.

It was unfortunately impossible to prove the efficacy of interventions within this study. In order to identify positive interventions and therapies, we suggest that future studies should focus on positive or negative psychosocial outcome as a result of previous interventions.

5. Conclusion

We identified four risk factors for poor psychosocial outcome in the long term in adolescents and young adults with epilepsy, namely, poor family support, ongoing seizures (chronic refractory epilepsy) and a high seizure frequency, and a low intelligence level. Identification of risk factors can lead to early recognition of those at risk for and thereby to an early adequate therapeutic approach and tailored interventions. This study stressed the importance of revision of epilepsy diagnosis and its treatment, psychosocial issues that arise during adolescence and early adulthood, and transitional care.

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Disclosure

The authors have no conflicts of interest to declare.

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