



Long-term effects of a multidisciplinary transition intervention from paediatric to adult care in patients with epilepsy



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ABSTRACT

Purpose: To evaluate the long-term effects of a multidisciplinary transition intervention compared to the impact of patient-related intrinsic factors on the improvement in medical and psychosocial outcome. **Methods:** All patients who visited our multidisciplinary Epilepsy Transition Clinic between March 2012 and September 2014 were invited to participate ($n = 114$). Patients were sent one questionnaire and informed consent was obtained. Questions included the patient's level of functioning on three transitional domains and a list with medical health care workers. Previously defined scores on three transitional domains and the risk profile score were re-evaluated. Past and current patient characteristics were compared using descriptive statistics. Discriminant analyses were used to determine the influence of patient-related intrinsic factors (defined as the risk factors from our previous study) and a multidisciplinary transition intervention on the improvement of medical and psychosocial outcome.

Results: Sixty-six out of 114 invited participants (57.9%) completed the questionnaire. Discriminant analyses showed that the patient-related intrinsic factors combined proved a strong predictor for improvement in medical outcome (72.7%) and relatively strong for educational/vocational outcome (51.5%). The transition interventions are a relative strong predictor of improvement in medical outcome (56.1%), educational/vocational outcome (53.0%) and improvement in the overall risk score (54.5%).

Conclusion: Based on the overall improvement of psychosocial outcome in most patients, and the influence of a transition intervention on medical, educational/vocational outcome and the overall risk score, it is likely that adolescents with epilepsy benefit from visiting a multidisciplinary epilepsy transition clinic.

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1. Introduction

Adolescence is a critical and vulnerable period in life because adolescents have to develop their own identity, autonomy, peer relationships and their own social network [1–3]. Having a chronic

illness transferring into adulthood, such as epilepsy, makes adolescence even more complex. Several studies indicated that patients with epilepsy are at risk of persistent long-term poor psychosocial outcome on several transitional domains, e.g., education and employment [1,4–7]. Therefore, age-specific issues often deserve special attention in adolescents with epilepsy. Further, adolescents with (chronic) epilepsy have to transfer from paediatric to adult medical care at a certain point in life [3,4]. If insufficient attention is given to this transition, adolescents and young adults with epilepsy may withdraw from necessary medical and psychosocial health care, and end up in a troublesome situation. To cope with these problems, epilepsy transition clinics have been set up for adolescents [8,9]. A transition clinic can

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provide help for medical, psychosocial and developmental issues during adolescence [8,10]. Although the main objective of an epilepsy transition clinic is to revise the previously made epilepsy diagnosis and treatment options, and to transfer the adolescent to an adult health care system, most transition clinics also provide special attention for the above mentioned developmental age-specific issues of patients with epilepsy [4,8,9,11].

Several different models of epilepsy transition clinic staffing have been reported, including both paediatricians and adult neurologists, or nurse specialist. Sometimes referral to a psychologist, a social worker or a career adviser is made [8,9,11–15]. Only little evidence is published about the attempts that have been made to evaluate the effectiveness of transition interventions in chronic disease [16]. Prior et al. [16] reviewed studies that described health care transition interventions in for example diabetes, kidney disease and juvenile idiopathic arthritis. However, to the best of our knowledge, no information is available about the true, i.e. long-term effects of transition interventions in patients with epilepsy. Therefore the objective of this study was to evaluate the long-term effects of a multidisciplinary transition intervention compared to patient-related intrinsic factors on the improvement in medical and psychosocial outcome.

2. Methods

2.1. Epilepsy transition clinic

An Epilepsy Transition Clinic was set up in March 2012 in Epilepsy Center Kempenhaeghe, a tertiary referral center for patients with epilepsy. Our transition clinic is staffed with a neurologist, a clinical neuropsychologist, a social worker and an educationalist/vocational counselor, all with adequate knowledge of paediatric and adolescent developmental issues, paediatric and adult medical care and of epileptology.

All patients who had an appointment for a visit at the transition clinic were between 15 and 25 years of age. As described in our previous study [11], this age limit was chosen because developmental milestones are often delayed in patients with epilepsy [11,17]. In our opinion, transition is a gradual process, and should not be limited by only reaching the adult age. To get an appointment at the multidisciplinary Epilepsy Transition Clinic, patients had to have a diagnosis of epilepsy and at least one medical issue (e.g., problems with transition from paediatric to adult care), psychological issue (e.g., in the development of self-management and independence) or psychosocial issue (e.g., career advice) related to the transition phase. Not all patients had had an assessment of their Full Scale Intelligence Quotient (FSIQ) to measure their intelligence level in the past, before their first visit to the transition clinic. Patients with severe mental disabilities (FS IQ < 50) were not accepted at the transition clinic but referred to a special outpatient clinic for patients with epilepsy and mental disabilities at our epilepsy center. All patients were given appointments with the above mentioned health care workers in three consecutive consultations on the same morning (the ‘carousel’) [11]. The neurologist and clinical neuropsychologist work together in one consultation, after which all patients had appointments with the social worker, and the educationalist/vocational counselor. All professionals stimulate independence and empowerment of the adolescent. After all three consecutive appointments, the four health care professionals discuss the progress of transition on the medical, psychological, social and educational/vocational domain, in a short multidisciplinary case-meeting. Consequently a personalized advice is discussed with the patient.

The transition clinic’s advice may include a new ‘snap-shot’ for a diagnostic work-up, such as a magnetic resonance imaging (MRI), electroencephalography (EEG), a neuropsychological test and/or

laboratory tests or genetic counseling. Not all patients had a strict medical indication for a full diagnostic work-up. One or more diagnostic procedures (e.g., MRI, EEG, neuropsychological tests) were only conducted when considered necessary for revision of the medical diagnosis (e.g., EEG) or in optimizing the multidisciplinary advice during the transition process (e.g., measurements of the Full Scale Intelligence Quotient to provide adequate career advice). Other advices included support by health care workers, e.g., in finding housing, financial support, vocational training or psychosocial support. All patients visited the whole ‘carousel’ at least once. Some patients were followed by the transition clinic’s neurologist for a short period (for example because of a diagnostic work-up or after a recent change in AED prescription), others had a few follow-up visits for further support by the psychologist, social worker or educationalist/vocational counselor. Transition is a gradual process, and there was no set number of maximum visits to the transition clinic. The total number of visits at the transition clinic varied, depending on the medical or psychosocial problems of the individual, but finished after two or three visits preferably. After completing the transition clinic, the medical transition, i.e. the transfer from paediatric to adult medical care was facilitated. Patients were either referred to an adult neurologist at the tertiary referral epilepsy center, to an external adult neurologist, or, in case of seizure remission after withdrawal of AEDs, to a general practitioner.

In our previous study [11], we scored patients who visited the transition clinic on three transitional domains, namely their medical performance, educational/vocational performance and the development of their own independence/separation/identity. Scores are further defined in Table 1. As mentioned [11], no validated scoring system to assess the level of functioning on transitional domains in adolescents or young adults with epilepsy existed. Therefore, we developed our own scoring system, based on the Sydney Psychosocial Reintegration Scale Version 2 (SPRS-2), a validated scoring system for patients with traumatic brain injury. In our scoring system, scores ranged from 0 (normal), –1 (suboptimal), to –2 (poor). To cope with the wide range of intellectual abilities and the maximum levels of functioning of the individual patients, and the comorbid conditions, scores were individually allocated by the transition clinic’s neurologist and psychologist with respect to the optimal level of functioning which can be achieved by the individual.

We also developed a risk profile scoring system [11]. This risk profile score too was individually allocated by the transition clinic’s neurologist and psychologist and represented the patient’s risk for future adverse psychosocial outcome. A risk profile score of 3 indicated that the patient had poor perspectives for long-term psychosocial outcome, a score of 2 indicated a substantial increased (‘moderate’) risk for adverse psychosocial outcome, and a score of 1 indicated a low risk (‘no obvious risk’) for long-term psychosocial outcome [11].

All scores were allocated by the transition clinic’s neurologist and psychologist. If no agreement occurred, discussions were required until consensus.

Last, the interventions that took place during the transition clinic were recorded and categorized in three groups according to the interventions, namely: (a) transition clinic only; (b) transition clinic in combination with a single intervention; either medical (by the neurologist/neuropsychologist), or social (by the social worker or educationalist/vocational counselor); (c) transition clinic in combination with a multidisciplinary approach (both medical and the social worker or educationalist).

2.2. Study population and study procedure

All patients in this follow-up study were recruited from the study population of our previous study [11]. The minimum

Table 1

Definitions of previously defined 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.	No study or unemployment. 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.

This table was published before in *Epilepsy & Behavior* [11].

duration between the initial visit at the transition clinic and the invitation for the study was six months, the maximum duration was three years. Because patients were transitioned from paediatric to adult medical care, and were no longer in follow-up at the transition clinic or at our tertiary referral center, a questionnaire was sent to every patient who visited our Epilepsy Transition Clinic from March 2012 until September 2014. The questionnaires contained questions regarding the patient's medical, educational/vocational status, and independence. To be more specific: we asked patients to report their seizure frequency by filling out a number and additionally choosing the option daily/weekly/monthly/yearly. Data about their current and past treatment options, their neurologist and number of visits per year, and the number of hospital admittances due to epilepsy were collected with the questionnaire. Furthermore, we asked to report their current education or employment status, their financial income and, if applicable, financial guardianship, relationships, housing, level of independence by completing several household tasks. Finally, a list of medical and societal health care workers, e.g., the number and frequency of different (health) care providers the patient was in contact with at the moment, was assessed.

Based on the patient reported outcome, previously collected baseline statistics were compared to the current outcome. The above mentioned performance scores and the risk profile score were re-evaluated and re-allocated (Table 2) according to the definitions in Table 1.

Data of all patients who gave written informed consent, and fully completed the questionnaire, were entered in an IBM SPSS database.

2.3. Statistical analysis

All statistical analyses were performed by IBM SPSS Version 21. We used descriptive statistics to compute frequencies (n) and percentages (%) of categorical variables and to give an overview of baseline and current statistics. Means are presented with standard deviation (SD) and range.

First, patients were grouped according to their past and current risk profile scores. Patients with improvement of their risk profile score, or patients with a persistent low risk profile score, were grouped in group 1; patients with a moderate risk profile score were grouped in group 2; patients with a deterioration of risk profile score or persistent high risk profile score were grouped in group 3. Further information about the grouping of patients is provided in Table 2. After grouping of patients, patient's demographic, medical and social characteristics were compared using the aforementioned criteria for continuous or dichotomous variables. The involved medical and societal health care workers were classified in two ways. In our first analysis they were classified as dichotomous variables (yes/no) and compared between groups using the Chi-Square Test. In our second analysis, the frequency of the involved health care workers was classified as a continuous variable and compared using the Independent-Samples T Test. The threshold for significance was $p < 0.05$ in both analyses.

Second, we performed a two-tailed Paired-Samples T Test to evaluate the difference in patient characteristics (the continuous variables), the performance scores, and risk profile score over time between baseline and at follow-up. A p -value < 0.05 was considered statistically significant.

Third, we conducted descriptive discriminant analyses to determine the predictive values of patient-related intrinsic factors (defined as the risk factors found in our previous study [11]) and transition interventions for final outcome. We used the difference (delta) in the three transitional performance scores and the difference in risk profile scores as dependent variables. We used two types of independent variables: first, the characteristics of the transition intervention (interventions during transition (as categorized in Section 2 above), duration of time since first visit at the transition clinic, and age at first visit at the transition clinic); second, the risk factors we found in our previous study [11] (intelligence level, seizure frequency, and an unstable and unsupportive family environment). However, to compare the impact of transition interventions to the impact of patient-related factors, and to avoid any confusion in the analyses, we chose to name the previously found risk factors as 'patient-related intrinsic factors' throughout this manuscript. The patient-related intrinsic factors and the interventions were entered in two separate discriminant analyses for each dependent variable.

Table 2

Grouping and distribution pattern of patients' past and current risk profile scores.

	Total number of patients ($n=66$)
<i>Group 1: Improvement of risk profile score or persistent low risk profile score</i>	
Past score: 3 → current score: 1 (–2)	2
Past score: 3 → current score: 2 (–1)	7
Past score: 2 → current score: 1 (–1)	14
1 = 1	11
Total	34 (52%)
<i>Group 2: Stable moderate risk profile score</i>	
2 = 2	6 (9%)
<i>Group 3: Deterioration of risk profile score or persistent high risk profile score</i>	
Past score: 1 → current score: 2 (+1)	1
Past score: 1 → current score: 3 (+2)	3
Past score: 2 → current score: 3 (+1)	7
3 = 3	15
Total	26 (39%)

2.4. Ethics

This study was approved by the Medical Ethics Committee of Kempenhaeghe. Patients could participate voluntarily. Written informed consent was obtained from all participants.

3. Results

3.1. Responder characteristics

3.1.1. Responder versus non-responder analysis

A total of 114 patients were assessed at baseline and were invited to participate in this study. In total, completed questionnaires were obtained from 66 patients (57.9%); 48 patients (42.1%) were non-responding. The presence of an unsupportive/unstable family environment was significantly different between responders and non-responders (21.2% vs. 39.6%, $p = 0.04$). Non-responders also had a significantly lower (=worse) performance score in the past for their level of independence/separation/identity (-1.12 vs. -1.48 , $p = 0.02$), and a significantly higher (=worse) risk profile score (2.14 vs. 2.44, $p = 0.04$). Among the other characteristics no statistically significant differences were found between responders and non-responders.

3.1.2. Patient characteristics

Patient characteristics at baseline and at follow-up are shown in Table 3. In total, 35 men (53.0%) and 31 women (47.0%) participated in this study. Their mean age was 18.9 years at baseline (median = 18.6, SD = 2.2) and 20.8 years at follow-up (median = 20.7, SD = 2.3). The mean Full Scale Intelligence Quotient was 83 (median = 81, SD = 16.9). The mean age at diagnosis of epilepsy was 8.1 years (median = 8.1, SD = 5.0), with a mean duration of epilepsy of 10.6 years at baseline (median = 9.5, SD = 5.3) and 12.6 years at follow-up (median = 11.9, SD = 5.4). Fifty-two patients (78.8%) had a localization-related epilepsy, of which the cryptogenic type was most common (35 patients, 53.0%). At baseline, 39 out of 66 patients (59.1%) were seizure-free for one year, compared to 38 out of 66 patients (57.6%) at follow-up. (The difference in seizure frequency over time had a p -value of 0.81). Less patients were using polytherapy at follow-up (29 patients (43.9%) vs. 32 previously (48.5%), $p = 0.27$), and nine patients (13.6%) were not using AEDs anymore, compared to 7 patients (10.6%) at baseline. Their self-reported AED adherence was higher at follow-up (80.3% vs. 57.6%). Compared to the baseline characteristics, more patients were independent from their parents at follow-up (42 vs. 30, 63.6% vs. 45.5% respectively), and more patients were socially participating at follow-up (50 vs. 47, 75.8% vs. 71.2% respectively). Eight patients (12.1%) were living either independently or in a supported accommodation compared to 4 patients (6.1%) at baseline. More patients were employed at follow-up (31 vs. 42, 47.0% vs. 63.6%), and less patients were studying (13 vs. 6, 19.7% vs. 9.1%) or in an internship during their study (13 vs. 1, 19.7% vs. 1.5%). Finally, more patients were not studying anymore and had not found a job afterwards compared to baseline (unemployment 7 vs. 17, 10.6% vs. 25.8%). Thirty-six patients (54.5%) had a salary out of a job or internship, whereas 29 patients (43.9%) were on some kind of governmental financial support.

Transition clinic interventions are shown in Table 4. The mean duration of follow-up between the transition interventions and the current study was 23.7 months (median = 24.1, SD = 10.4). After their first visit at the epilepsy transition clinic, a diagnostic work-up was done in 56 patients (84.8%), involving 35 (53.0%) clinical neuropsychological assessments and EEG recording. Furthermore, 17 MRIs (25.8%) and 22 laboratory tests (33.3%) were performed. Twenty-two patients (33.3%) were briefly admitted (<24 h) to

complete the diagnostic work-up. Forty-two patients (63.6%) underwent a change in AED prescription based on the evaluations of the multidisciplinary transition clinic, of which 3 patients (4.5%) were women in child-bearing age using valproate. After visiting the transition clinic, two patients (3.0%) were referred for the implantation of a vagal nerve stimulator.

The social worker was consulted in 26 patients (39.4%), e.g., to provide help with housing assistance (15 patients, 22.7%), for advice about financial guardianship (6 patients, 9.1%) or to assist in the separation from parents (4 patients, 6.1%). The educationalist/vocational counselor provided educational assistance in 18 patients (27.3%), vocational assistance (6 patients, 9.1%) or vocational training (4 patients, 6.1%). Psychosocial assistance was indicated in 10 patients (15.2%).

In 43 patients (65.2%) a medical transition was facilitated to an adult neurologist at our tertiary referral epilepsy center, and sixteen patients (24.2%) were referred to an external adult neurologist for further epilepsy care. Seven patients (10.6%) with seizure remission after AED withdrawal no longer needed specialized epilepsy care and were referred to their general practitioner.

Summarized, 12 patients (18.2%) had only one visit at the transition clinic without further consultation, diagnostic procedure or follow-up in the transition outpatient clinic; 20 patients (30.3%) visited the transition clinic and had either a diagnostic follow-up or a follow-up consultation with the psychologist or the social worker and educationalist; 34 patients (51.5%) visited the transition clinic and had a multidisciplinary follow-up including a medical intervention (either diagnostic work-up or change in AED prescription) in combination with a consultation at the psychologist, social worker or educationalist.

As shown in Table 5, the risk profile score improved, but not statistically significant (2.14 at baseline vs. 1.97 at follow-up, $p = 0.12$). The medical performance score improved from baseline mean -1.09 , SD = 0.87 to a mean -0.60 , SD = 0.90 ($p < 0.001$), the educational/vocational performance score improved from -1.06 , SD = 0.86 to mean -0.82 , SD 0.89 ($p = 0.01$); the independence/separation/identity performance score improved from -1.12 , SD = 0.80 to -0.94 , SD = 0.88 ($p = 0.04$).

3.2. Medical and societal health care workers

A beneficial outcome was not significantly correlated with the involvement of medical and societal health care workers both in terms of type of health care worker and quantity of support, except for the intervention by a psychologist (23.5% compared to 3.1%, $p = 0.02$).

3.3. Descriptive discriminant analyses

We used the interventions and the patient-related intrinsic factors [11] as predictive variables in a discriminant analyses to evaluate the relative impact of the variables on the delta in risk profile score and performance scores. As mentioned above in Section 3, all scores improved at follow-up. The results of the discriminant analysis are shown in Table 6.

3.3.1. Improvement in medical outcome

The interventions combined showed a sensitivity of 56.5% and a specificity of 52.6% on improvement of medical outcome. The interventions combined could predict 56.1% of the classification of medical improvement.

The patient-related intrinsic factors showed a sensitivity of 80.4% and a specificity of 52.6%. In total 72.7% of the improvement in medical outcome can be predicted when combining the patient-related intrinsic factors.

Table 3
Demographic, epilepsy-related and psychosocial variables at baseline and at follow-up.

	Baseline characteristics			At follow-up			p-value		
	Median	SD	Range	Median	SD	Range			
Gender									
Men	35 (53.0%)								
Women	31 (47.0%)								
Mean age	18.9	18.6	2.2	15–25	20.8	20.7	2.3	16–26	
Younger than 18 years of age	27 (40.9%)				6 (9.1)				
Mean Full scale Intelligence (FS IQ)	83	81	16.9	51–113					
IQ ≥100	31 (47.0%)								
IQ 90–100	19 (28.8%)								
IQ 70–90	15 (22.7%)								
Not assessed	1 (1.5%)								
Mean duration of epilepsy (years)	10.6	9.5	5.3	0.4–19.6	12.6	11.9	5.4	1.2–22.1	
Mean age at diagnosis of epilepsy (years)	8.1	8.1	5.0	(0.1–17.4)					
Type of epilepsy									
Localization-related epilepsy	52 (78.8%)								
Idiopathic	2 (3.0%)								
Symptomatic	15 (22.7%)								
Cryptogenic	35 (53.0%)								
Generalized epilepsy	13 (21.2%)								
Idiopathic	10 (15.2%)								
Symptomatic	3 (4.5%)								
Cryptogenic	0 (0%)								
Not classified yet	1 (1.5%)								
Seizure frequency								0.81	
Daily	3 (4.5%)				6 (9.1%)				
Last week	7 (10.6%)				5 (7.6%)				
Last month	10 (15.2%)				7 (10.6%)				
Last year	3 (4.5%)				9 (13.6%)				
Seizure free > 1 year	39 (59.1%)				38 (57.6%)				
Unknown	5 (7.6%)				1 (1.5%)				
Mean number of AEDs	1.56	1.0	0.95	0–4	1.45	1.0	0.98	0–4	0.27
No current AED treatment	7 (10.6%)				9 (13.6%)				
Monotherapy	27 (40.9%)				27 (40.9%)				
Polytherapy (2–4 AEDs)	32 (48.5%)				29 (43.9%)				
Self-reported AED adherence									
Yes/most likely yes	38 (57.6%)				53 (80.3%)				
No	7 (10.6%)				4 (6.1%)				
No current AED treatment	7 (10.6%)				9 (13.6%)				
Unknown	14 (21.2%)				0 (0%)				
Previous therapies									
Epileptic surgery	4 (6.1%)				4 (6.1%)				
Vagal Nerve Stimulator	2 (3.0%)				4 (6.1%)				
Ketogenic diet	1 (1.5%)				1 (1.5%)				
Special education program									
In the past/ever	28 (42.4%)								
Current	15 (22.7%)				6 (9.1%)				
Living arrangements									
At home with parents	61 (92.4%)				58 (87.9%)				
Independently	2 (3.0%)				3 (4.5%)				
Supported accommodation	2 (3.0%)				5 (7.6%)				
Unknown	1 (1.5%)				0 (0%)				
Social participation	47 (71.2%)				50 (75.8%)				
Independence	30 (45.5%)				42 (63.6%)				
Unsupportive/unstable family environment	15 (22.7%)								
Employment									
Yes	31 (47.0%)				42 (63.6%)				
No	7 (10.6%)				17 (25.8%)				
Internship	13 (19.7%)				1 (1.5%)				
Student without a job	13 (19.7%)				6 (9.1%)				
Unknown	2 (3.0%)				0 (0%)				
Financial income (some patients had >1 income)									
Job/salary/internship					36 (54.5%)				
Governmental support					29 (43.9%)				
Parents					6 (9.1%)				

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

3.3.2. Improvement in independence/separation/identity

The interventions combined showed a sensitivity of 38.7% and a specificity of 54.2% on the improvement of independence/separation/identity outcome. In combination the interventions

could predict 43.9% of the improvement of independence outcome.

The patient-related intrinsic factors showed a sensitivity of 41.9% and a specificity of 29.2%. In total 42.4% of the improvement

Table 4
Transition clinic interventions.

		Median	SD	Range
Duration of follow-up at the transition clinic (months)	23.7	24.1	10.4	6.6–40.3
Diagnostic work-up after first visit at the transition clinic (some patients had >1 type of diagnostic intervention)	56 (84.8%)			
Clinical neuropsychological assessment	35 (53.0%)			
EEG	17 (25.8%)			
MRI	22 (33.3%)			
Admittance for diagnostic work-up	22 (33.3%)			
Laboratory				
AED change after evaluation at the transition clinic	42 (63.6%)			
Reason AED change				
Epilepsy remission	12 (18.2%)			
Side effects	10 (15.2%)			
Switch AED	5 (7.6%)			
Adding AED	5 (7.6%)			
Increase dose AED	4 (6.1%)			
Decrease dose AED	3 (4.5%)			
Women in child bearing age	3 (4.5%)			
Consultations transition clinic (some patients had >1 type of intervention/consultation)				
Social worker	26 (39.4%)			
Housing assistance	15 (22.7%)			
Reason improving family support	5 (7.6%)			
Reason improving separation/individualization	4 (6.1%)			
Reason financial advice	6 (9.1%)			
Reason increasing social interaction and support	1 (1.5%)			
Reason planning daily activities	1 (1.5%)			
Educationalist/vocational counselor	25 (37.9%)			
Educational assistance	18 (27.3%)			
Vocational assistance	6 (9.1%)			
Vocational training	4 (6.1%)			
Psychological assistance	10 (15.2%)			
Referral to				
Adult neurologist within the epilepsy center	43 (65.2%)			
External referral to adult neurologist	16 (24.2%)			
General practitioner	7 (10.6%)			
Type of interventions summarized				
Transition clinic only	12 (18.2%)			
Transition clinic + monodisciplinary intervention	20 (30.3%)			
Transition clinic + multidisciplinary intervention	34 (51.5%)			

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

Table 5
Medical, educational/vocational and independence/separation/identity performance scores and risk profile score at baseline and at follow-up.

	Baseline	Follow-up	<i>p</i> -value
Medical performance score	−1.09 (0.87)	−0.60 (0.90)	<0.001
Educational/vocational performance score	−1.06 (0.86)	−0.82 (0.89)	0.01
Independence/separation/identity performance score	−1.12 (0.80)	−0.94 (0.88)	0.04
Risk profile scores	2.14 (0.76)	1.97 (0.89)	0.12

Data are presented as mean scores with standard deviation (SD).

in independence can be predicted when combining the patient-related intrinsic factors.

3.3.3. Improvement in educational/vocational outcome

The interventions combined showed a sensitivity of 57.5% and a specificity of 45.5% on the improvement of education/vocational outcome. In combination the interventions could predict 53.0% of the improvement of educational outcome.

The patient-related intrinsic factors showed a sensitivity of 45.0% and a specificity of 59.1%. In total 51.5% of the improvement in educational/vocational outcome can be predicted when combining the patient-related intrinsic factors.

Table 6
Sensitivity and specificity of interventions and patient-related intrinsic factors in relation to improvement of psychosocial or medical outcome.

Delta score		Sensitivity	Specificity	Correctly classified
Medical performance score	Interventions	56.5%	52.6%	56.1%
	Patient-related intrinsic factors	80.4%	52.6%	72.7%
Independence/separation/identity performance score	Interventions	38.7%	54.2%	43.9%
	Patient-related intrinsic factors	41.9%	29.2%	42.4%
Educational/vocational performance score	Interventions	57.5%	45.5%	53.0%
	Patient-related intrinsic factors	45.0%	59.1%	51.5%
Risk profile score	Interventions	46.2%	58.8%	54.5%
	Patient-related intrinsic factors	23.1%	61.8%	45.5%

3.3.4. Improvement in risk profile score

The interventions combined showed a relative modest sensitivity of 46.2% and specificity of 58.8% in classifying the groups. In total the type of interventions could predict classification of risk improvement in 54.5%.

The patient-related intrinsic factors combined had a sensitivity of 23.1% on an improvement on the risk profile score, with a specificity of 61.8%. The patient-related intrinsic factors combined could predict correct classification of risk improvement in 45.5% of the patients.

4. Discussion

This study compared changes in transition characteristics from baseline to a follow-up on average two years later in 66 patients with a mean age of 18.9 years and a mean Full Scale Intelligence Quotient of 83. On average they had a mean duration of epilepsy of 12.6 years at follow-up. This is therefore a group with chronic (mostly cryptogenic localization-related) epilepsy that transits with epilepsy from childhood to adulthood. No relevant changes were found for seizure frequency, but with respect to treatment, less patients were on polytherapy, in more patients all AEDs were withdrawn and AED adherence had improved. In terms of transition outcomes, more patients were living independently from their parents, more were socially participating, and more patients were employed at follow-up.

The results of the performance scores improved, which is in line with the aforementioned descriptive results: the risk profile score improved, but this was not statistically significant.

The main objective of this study was to evaluate the long-term effects of a multidisciplinary transition intervention compared to the impact of patient-related intrinsic factors on the improvement in medical and psychosocial outcome. Thus, the contribution of transition interventions on the positive delta (difference) in performance scores. The discriminant analyses combined indicated that the patient-related intrinsic factors combined are a strong predictor of improvement in medical outcome (72.7%). Our interpretation is that the patient-related intrinsic factors are inherent characteristics of the patients, e.g., the fact that the majority of the patients had a chronic epilepsy, and define a relatively stable situation.

The transition interventions on the other hand are an equally strong predictor as patient-related factors for improvement in educational/vocational outcome, independence, and the improvement in the overall risk score. Here transition interventions can have more influence than the patient-related intrinsic factors on improvement of the educational/vocational outcome.

In predicting a favorable overall risk, the sensitivity of type of intervention is much higher than the patient-related intrinsic factors, with equal specificity. This again illustrates the impact of transition interventions for the overall positive result. Thus, the type of transition intervention contributed more to an improvement of the risk profile score than the patient-related intrinsic factors, which is understandable given the type of patient-related intrinsic factors (i.e., relative stable factors that all will have a similar influence at follow-up compared to baseline).

The improvement in psychosocial outcome cannot be explained by the involvement of individual health care workers or the frequency of appointments with health care workers.

No comparative studies can be found in literature, since this is the first study showing the effects of a multidisciplinary transition intervention after long-term follow-up.

4.1.1. Strengths and limitations

This study has some methodological limitations. The first limitation is the use of questionnaires to obtain more information at follow-up. Since we are following patients through the transition process, most patients were no longer in follow-up at our transition clinic or at our tertiary referral hospital. In the pilot-phase of our study, many patients indicated that they would not participate in the study when they had to come over to our center for an interview because of the long distance to our tertiary epilepsy center. Therefore, we have to rely on the self-reported data.

Also, we were unable to re-evaluate the most significant variable in our previous study, namely an unsupportive family environment. This variable was significantly worse among non-responders. Further, non-responders had a significantly worse psychosocial outcome at baseline, indicating that the responders to our questionnaires probably have a better chance for a beneficial long-term psychosocial outcome at baseline. Therefore, results of this study might not be generalizable to the adolescent and young adult population with epilepsy.

Last, the 'patient-related intrinsic factor' is based on the results of previously found risk factors. Multiple variables were not tested.

5. Conclusion

Based on the overall improvement of psychosocial outcome in most patients, and the influence of a transition intervention on medical, educational/vocational outcome and the overall risk score, it is likely that adolescents with epilepsy benefit from visiting a multidisciplinary epilepsy transition clinic.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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