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RESEARCH ARTICLE

Transition from pediatric to adult care system in patients with complex epilepsies: Necker model for transition evaluated on 70 consecutive patients

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Abstract

Objective: Complex epilepsies such as epileptic and developmental encephalopathies require multidisciplinary care throughout life. A coordinated transition program is therefore essential to provide optimal support for patients leaving pediatric for adult care. The aim of this study is to describe and evaluate our transition program for complex epilepsies, focusing on the last step in this program, that is, the multidisciplinary transition day hospital (MTDH).

Methods: We performed a retrospective observational study including patients with complex epilepsies who underwent the full steps of the transition program at Necker–Enfants Malades Hospital between May 2021 and June 2023, with a follow-up until February 2024. We described the cohort and detailed the interventions performed during the MTDH including medical, medicosocial, educational, daily life abilities, and laboratory and imaging assessments with the participation of one member of the adult team.

We evaluated two indicators of our program: (1) the "adult first clinic attendance rate," defined by the percentage of patients attending their first adult clinic; and (2) the "return rate," defined by the percentage of patients who requested a pediatric encounter after their transfer.

Results: Our cohort included 70 patients with a mean age of 19.1 years (interquartile range = 16.3–19.5). Eighty percent had an epilepsy syndrome diagnosis; 72.8% were treated with three or more antiseizure medications. All patients had their appointment at the adult clinic within 6 months of the day hospital, and only two families requested a pediatric encounter after the transfer.

Significance: The transition program is key for an optimal transfer of patients with complex epilepsies to adult care. It requires a comprehensive multidisciplinary approach and provides a complete summary of the medical record. Our

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program secures a smooth landing in adult care and is a promising model to better manage the challenging transition process, especially in patients with complex epilepsy.

KEYWORDS

adolescent, DEEs, outcome, transition, transition passport

1 | INTRODUCTION

Epilepsy is one of the most common chronic diseases in pediatric patients and often presents diagnostic and therapeutic challenges.[1] Pediatric onset epilepsies need lifelong structured care mainly for complex epilepsies such as developmental and epileptic encephalopathies (DEEs), epilepsies associated with metabolic or mitochondrial disorders, drug-resistant structural epilepsies, and epilepsies in syndromes that evolve throughout lifetime or present changes in patients' major needs such as in tuberous sclerosis complex (TSC).[2–4] For instance, DEEs last into adulthood in approximately half of cases,[2] and the transition from pediatric to adult health care system should be accurately planned and realized.

Patients with complex epilepsies and mainly DEEs often present neuropsychological and psychiatric comorbidities, motor disorders, low education achievements, low level of autonomy, and increased risk of unsafe behaviors, challenging a smooth transition.[5] This risk is also increased by the high prevalence of neurodevelopmental comorbidities such as intellectual disability (ID) and cognitive impairment, known as the most impactful negative factors affecting the transition process.[5–7]

Families should be supported in this change from a global family-centered care including the patient, especially in patients with ID, to a patient-centered care in the adult system.[1,7]

All patients' information including patient history, comorbidities, and social, educational, legal, financial, and familiar issues should be reported and transferred for the adult care coordinator, facilitating a patient-individualized approach. Different transition programs are reported in chronic diseases such as diabetes type 1 and renal transplant, with some reported improvement in outcomes.[8–13] However, models for transition generalizable for different countries or settings are lacking as well as objective outcomes accurately evaluating the effectiveness of such models.

The aim of this retrospective 3-years observational cohort study is to describe the transition process focusing on the last step, multidisciplinary transition day hospital (MTDH), and to assess with two indicators the outcome of our cohort of patients with complex epilepsies who underwent the transition program at Necker–Enfants Malades Hospital, a tertiary reference center for rare epilepsies in Paris, France.

Key points

- The transition from pediatric to adult health care systems may be challenging. It should be accurately planned, especially in patients with complex epilepsies.
- The transition program should be holistic and personalized, addressing patients' and families' multidisciplinary needs.
- Diagnosis and individual needs should be evaluated during transition until the last step before the transfer to adult care.
- The multidisciplinary transition day hospital allowed a last holistic evaluation and education of the patient, improving the transfer process.
- The transition program helped to secure smooth landing in adult care, with none lost in transition and almost no requests of return to pediatric care.

2 | MATERIALS AND METHODS

2.1 | Study setup, inclusion criteria, and data collection

We performed a retrospective observational cohort study, enrolling consecutive patients with complex epilepsies, such as DEEs, structural epilepsies, and/or epilepsies related to systemic syndromes, who underwent the full steps of the transition program at Necker–Enfants Malades Hospital in Paris, France. We included in the MTDH patients from 17 to 20 years of age, mainly presenting complex epilepsies with a need for multidisciplinary care at any time of their epilepsy history and who had their MTDH from May 2021 to June 2023. We evaluated their outcome in the adult care through a cross-sectional

study in February 2024, securing a minimum follow-up of 6 months after the date of their MTDH.

For each patient, we collected demographic data and epilepsy history including age at onset, seizure type, etiology, and epileptic syndrome according to the International League Against Epilepsy (ILAE) criteria.[14–16] We identified the investigations performed during the MTDH (blood tests, electroencephalogram (EEG), magnetic resonance imaging [MRI], genetic tests), number and type of antiseizure medications (ASMs) or other drugs, and nonpharmacological therapies such as vagal nerve stimulation and ketogenic diet (KD). We specified whether the patient underwent epilepsy surgery. We recognized as etiology-specific syndromes entities with a defined phenotype, related to a specific etiology, such as genetic or structural epilepsies.[14] We report seizure frequency as yearly: <1/month; monthly: 1–3/month; weekly: ≥1/week; or daily: ≥1/day. Patients were considered to have a relatively "controlled" epilepsy when they had less than one seizure per year or only occasional myoclonus. In this group, we identified the patients who discontinued the ASMs.

2.2 | Transition program

We established a multidisciplinary transition program including three distinct phases (Figure 1), where professionals such as pediatric nurses, adult and pediatric social workers, psychologists, pediatric neurologists, gynecologists, and adult nurses were involved. The transition program initiated at approximately 13–14 years of age and included a continuous evaluation of the patients' and families' multidisciplinary medical needs, educational needs, economic support, and degree of autonomy according to the Katz Activities of Day Living (ADL). In the second phase, between 15 and 16 years of age, a readiness survey was administered to the patients and their caregivers, with a gynecology clinic for female patients. A third phase (patient age = 17–20 years) ended our program and consisted of the MTDH. During this transition, patients were able to attend group educational sessions and individual appointments regarding different aspects of adult life at our chronic diseases transversal dedicated program, La Suite. In this parents' free space, patients were able to have personal or group encounters with educators, sociologists, psychologists, social workers, sports trainers, makeup artists, and hairdressers to discuss their issues in entering adolescence and adulthood.

2.3 | Multidisciplinary transition day hospital

During this 1-day hospital for transition, specialized professionals including pediatric neurologists, pediatric epilepsy nurses, neuropsychologists, social workers, and adult epilepsy nurses are involved. Female patients have in addition a gynecological clinic. We target tailored reevaluation including neurological examination, epilepsy evaluation, treatment assessment, appraisals of medicosocial needs, education level, degree of autonomy, and legal and financial status. Patients, when possible,

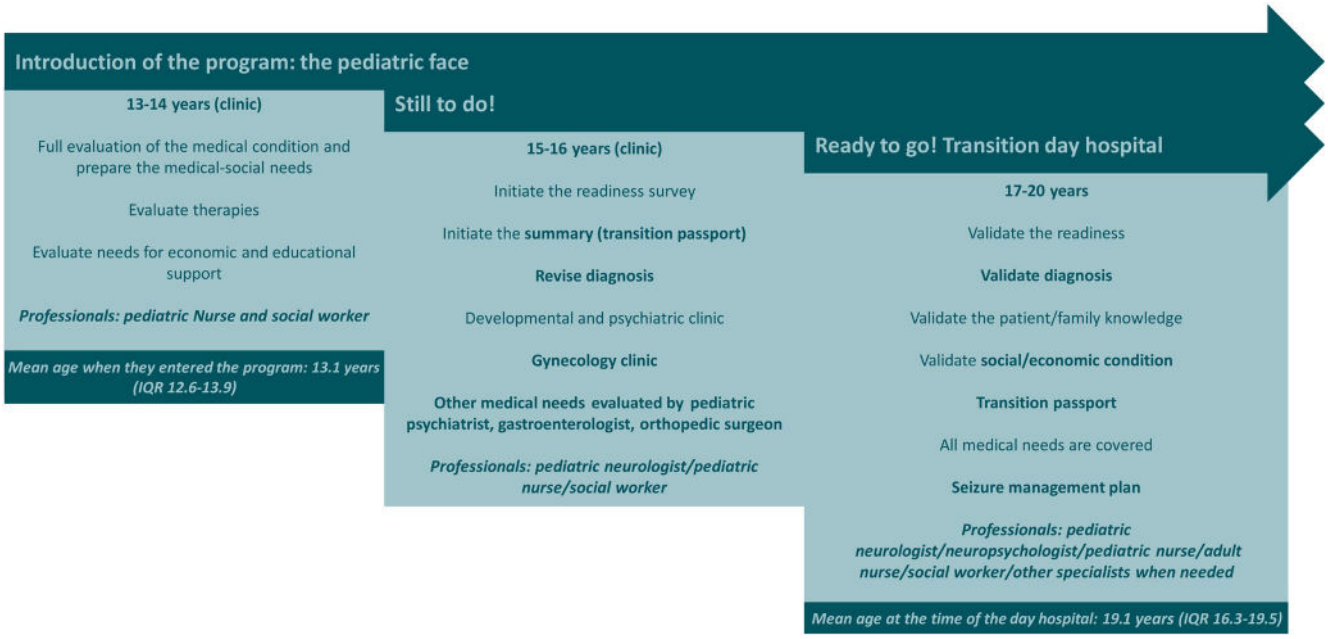

FIGURE 1 The three phases of the multidisciplinary transition program at Necker–Enfants Malades Hospital, starting at 13–14 years and ending at 17–20 years with the multidisciplinary transition day hospital (MTDH). IQR, interquartile range.

and families have a consolidation of their education program on seizure recognition, seizure diary and management, daily life adaptation, and contraception for female patients. We perform blood tests for liver and renal function, cell count, vitamin D, lipid levels, and ASM serum levels. Few patients have additional tailored examinations such as brain MRI EEG and genetic tests as well as other specialist clinics.

The transition passport (Figure 2), including all pivotal information of the patient history, including patient lifestyle, personal and family history, epilepsy history and current epilepsy status, seizure management protocol and therapies, last clinical examination with cognitive and psychiatric evaluation, information on rehabilitation program, investigations performed, social and societal integration including palliative care, and consolidation of the therapeutic education, is finalized and explained to the family and the patient when possible. This passport is compiled by the physician who is dedicated to the transition program with the referent pediatric neurologist. An updating and validation of the social, daily life, medical needs, and home care aspects are confirmed and validated during the MTDH stay by the multidisciplinary team.

The patient is formally referred to adult care based on the level of care needs and on the geographical proximity to the residence of the patient. This decision is prepared during the previous steps of the program with the family or the legal guardian involving the patient when possible. Specifically, patients are oriented to four levels of adult care (0–3) adapted to their needs (Figure 3). Patients with multidisciplinary needs and requiring high expertise in complex epilepsies (level 3) are transferred to the nearest neurology department member of the Reference Center for Rare Epilepsies (CReER) network. The CReER network represents the highest level of expertise in complex and rare epilepsies and is labeled by by the Ministry of Health through a criteria-based selection process within the national program on rare diseases in France. Level 2 centers are the secondary centers of expertise with expert neurologists without access to all complex interventions in epilepsy, as surgery or genetic epilepsy program. Level 1 is for neurologists with knowledge in epilepsy practicing in general hospitals, in specialized home care, or in office practice. Finally, level 0 is for general and family practitioners. For patients referred to the CReER network in the Paris region, the adult nurse is present during the MTDH and is introduced to the patient and the family.

After the day hospital, and upon family request, a final meeting between the referring pediatric neurologist, patient, and caregiver/s may be organized within 1 month of the MTDH to clarify any potential uncertainties or remaining questions. The date and place of the adult referral are confirmed during the MTDH stay, and patients and caregivers are reminded at the last pediatric clinic meeting if this final meeting has been organized.

Patients or families receive the transition passport with detailed explanation of the different information included. They are also informed that the pediatric team secures the continuity of care until the first neurologist clinic and that they can always request an appointment with their pediatric neurologist after their transfer to adult care to discuss and review any issue if needed.

An information about the MTDH is given to the families and the patients during the previous steps of the transition program with a non opposition procedure that they can use to not accept this MTDH.

2.4 | Outcome evaluation

We reviewed two indicators of short-term outcome after the transfer to adult facility care: (1) the "adult clinic attendance rate," defined by the percentage of patients attending their first adult clinic as organized by the pediatric team; and (2) the "return rate," defined by the percentage of patients who request a medical visit with their pediatric neurologist or at the pediatric center after the transfer. Both criteria were evaluated until February 2024 with a follow-up from 6 months to 3 years.

2.5 | Statistical analysis

Descriptive statistics are expressed as median and interquartile range (IQR) for continuous variables and as absolute frequency and percentage for categorical variables.

3 | RESULTS

We included 75 patients. They entered the program at the age of 13.1 years (IQR = 12.6–13.9). Five patients dropped out because their families moved to another institution closer to their residence for follow-up before the end of the program. None declared an opposition to the program. The mean age at MTDH was 19.1 years (SD = .8, median = 18.8, IQR = 16.3–19.5), with a male:female ratio of 1:.94. Seizure semiology was described according to the ILAE[14–16] and was focal (11/70, 15.7%), generalized (27/70, 38.6%), and focal and generalized seizures (32/70, 45.7%). The mean age at onset of epilepsy was 5 years (SD = 3.75, median = 4, IQR = .1–14.8). The two most frequent etiologies were genetic (28/70, 40%) and structural (17/70, 24.2%). Nineteen of 70 (27%) patients received one to two ASMs or other therapies, 28 of 70 (40%) three to

Transition passport

Date of delivery of the passport: DD/MM/YYYY _____

Name: _____ **Surname:** _____ **Date of birth:** _____

Gender (optional): _____

Current address: _____

Epilepsy type / Syndrome:

_____

Etiology: _____

Current treatment: _____

Seizure freedom: Y/N

Age of seizures' onset: _____

Referent physician at CReER[1]: name/surname/secretary phone number and email

_____

Adult neurologist for whom the patient is addressed: name/surname/secretary phone number and email

_____

General physician (family medicine): name/surname/secretary phone number and email

_____

Patient lifestyle

Education current level _____

Education/job orientation program _____

Driving licence: Y/N

Type of current residence: specify if he has a personal residence/lives with his family or in home care

_____

Status of the disability as recognised by the MDPH[2]

_____

Personal and familial history

- Family history:
  - Parental situation (married/divorced/separated/single parent…) _____
  - Consanguinity: Y/N
  - Geographical origin _____
  - Siblings: specify number/gender/age _____
  - Medical history (epilepsy/other neurological diseases/other relevant diseases): Y/N (if yes, specify)
    _____
- Pre and Perinatal history:
  - Pregnancy (normal/abnormal)
    If abnormal specify _____
  - Delivery (a term/prematurity/dysmaturity) _____
  - Birth (W/H/HC/gestational age at birth) _____
  - Neonatal distress (neonatal resuscitation, APGAR score)
    _____

FIGURE 2 The transition passport. This document summarizes all pivotal information of the patient as listed. APGAR, Adaptability, Partnership, Growth, Affective, and Resolve; ASM, antiseizure medication; CreER, Reference Center for Rare Epilepsies; CT, computed tomography; EEG, electroencephalography; KD, ketogenic diet; MRI, magnetic resonance imaging; PET, positron emission tomography; SEEG, stereo-EEG; SPECT, single photon emission computed tomography; VitD, vitamin D; VNS, vagus nerve stimulation; HC: head circumference, ALD: French acronym for chronic disease recognition (Affection Longue Durée), MDPH: French acronym for the disability evaluation and recognition by the French authorities (Maison Departementale des Personnes Handicapées).

five ASMs, and 23 of 70 (33%) had more than five ASMs during their pediatric follow-up. Additionally, 26 individuals received nonpharmacological treatments, including KD (16/70, 23%) and vagus nerve stimulation (9/70, 13%), and one had epilepsy surgery. One patient with TSC underwent surgery for subependymal giant cell astrocytoma (1/70, 1%; Table 1).

According to the ILAE criteria,[14] 56 of 70 (80%) patients presented a defined epilepsy syndrome; among those, 27 of 56 patients (48.3%) had a diagnosis of DEE: Lennox–Gastaut syndrome (8/27, 30%), early infantile developmental and epileptic encephalopathy (7/27, 26%), Dravet syndrome (6/27, 22%), progressive myoclonic epilepsy (3/27, 11%), developmental and/or

- Family history of epilepsy or other neurological/relevant diseases: Y/N
  If yes, specify: _____
- Other chronic/acute disorders: Y/N
- If yes, specify:

_____

Epilepsy history

- **First seizure:** _____
  - Febrile seizure history: Y/N
    If yes specify: _____
  - Age at onset: _____
  - Seizure type: _____
  - Triggering factor: Y/N
    If yes, specify which _____
  - Duration: _____
  - Pre-existent neurodevelopmental disorder: Y/N
    If yes specify: _____
- **Seizures over the course of the illness:**
  - Seizures description (specify per seizure types: frequency/duration/precipitating factors/**inducing falls or trauma**/time period/…)

    _____
  - Seizure free episodes: date and treatments _____
  - Episodes of status epilepticus: Y/N (if yes, specify number of episodes/types/triggers/dates or time periods/previous treatments successes and failures)

    _____
  - History of clusters of seizures: Y/N (if yes, explain seizure type/duration/rescue medication)

    _____
- **Treatments over the course of the illness:**
  - **Anti-seizure medications:**
    i. Current ASMs (specify date of introduction, current dose and last dose modification, adverse events) _____
    ii. ASMs tried previously (dates and reasons for discontinuation)

    _____
  - **Nonpharmacological and nonsurgical therapies:**
    i. Ketogenic diet: Y/N, if yes specify:
- Date of KD onset _____
- Ongoing Y/N (if no, precise date of KD end and the reason) _____
  i. Other medications/therapeutics used regularly:
    a. Vitamin(s) (specify) _____
    b. Others _____
  - **Surgical therapies:**
    i. Epilepsy surgery: Y/N
    If yes specify _____

a. SEEG performed: Y/N
   If yes, specify:

   _____
b. Date of surgery _____
c. Institution _____
d. Type of surgery _____
e. Pathology report _____

- Seizure control 1 year after surgery: Y/N
  Current seizure control: Y/N (specify if ASM full withdrawal or not)

  _____
  i. Neuro-modulation: Y/N
  If yes specify _____
- VNS/others implanted at the age of _____
- Battery replaced: Y/N, if yes specify the reason and the date

  _____
- Seizure control after VNS implantation: Y/N

FIGURE 2 (Continued)

epileptic encephalopathy with spike-and-wave activation in sleep (2/27, 7%), and infantile epileptic spasms syndrome (1/27, 4%). This last patient had severe ID with autism spectrum disorder and rare focal seizures at the time of MTDH. Genetic generalized epilepsy was diagnosed in 16 of 56 children with an epileptic syndrome (28.6%), whereas eight of 56 (14.2%) presented an etiology-specific syndrome, including tuberous sclerosis complex (TSC) (5/8, 62%), PCDH19 clustering epilepsy (2/8, 25%), and Sturge–Weber syndrome (1/8, 12%). A few patients with self-limited epilepsies were included in the program, four of 56 (7.1%) and one of 56 (1.8%) patients, respectively (Table 2). Thirty-four of 70 individuals (49%) presented refractory seizures with one seizure per year or more, and among those, eight of 34 (23%) experienced daily seizures (one or more per day). One patient (1/34, 3%) had a treatment adjustment, and another one (1/34, 3%) had a discontinuation of KD. Thirty-six patients (36/70, 51%) exhibited a controlled epilepsy, with fewer than one seizure per year (30/70, 43%) or only occasional myoclonus (6/70, 16%); eight of 36 (22%) of them had stopped treatment. Thirty-four patients (34/70, 49%) had uncontrolled epilepsy. Of these, five of 34 (14%) had yearly seizures, 11 of 34 (32%) monthly, 10 of 34 (29%) weekly, and eight of 34 (23%) daily. The most frequent ASMs administered at the time

- **Rescue therapy protocol:** type of rescue medication/date of the last prescription

Clinical examination

Weight _____ **Height** _____**Head circumference** _____**Right-handed/left-handed** _____

- General health status _____
- Allergies _____
- Neurological examination:
  - Language: normal/abnormal (if abnormal spec fy abnormal findings detected)
  - Physical examination: normal/abnormal (if abnormal specify abnormal findings detected)
- Eye examination: normal/abnormal (if abnormal specify abnormal findings detected)
- Abdomen: normal/abnormal (if abnormal specify abnormal findings detected)
- Swallowing: normal/abnormal (if abnormal specify abnormal findings detected)
- Dental observation: normal/abnormal (if abnormal specify abnormal findings detected)
- Orthopedic findings and therapies _____
- Other organs (skin/kidneys/heart…) _____
- Gynecological follow-up (female patient): performed/not performed if performed specify:
  - Contraception at the time of transition: Y/N (if yes, specify type)

Cognitive and psychiatric evaluation:

- Intellectual disability: Y/N (if yes specify):
- Level of intellectual disability (mild /moderate/severe/profound/specific disabilities)
- Type of cognitive evaluation (clinical/specific scales)
- Psychiatric comorbidities: Y/N (if yes specify the type and the professional who confirmed the psychiatric diagnosis and the treatment) _____
- Behaviour disorders: type and treatment _____
- Sleep disorders: type and treatment _____

Rehabilitation:

- Past rehabilitation program: type and years
- Current rehabilitation program types/frequency

Investigations:

- EEG:
  - Seizures recording (Y/N), If yes specify date and result of most recent
  - Significant EEG performed over the years, specify date and result of most recent
- Imaging:
  Contraindication for MRI: Y/N (if yes specify) _____

FIGURE 2 (Continued)

of the MTDH were valproate (VPA; 24/70, 34%), levetiracetam (17/70, 24%), and lamotrigine (LTG; 15/70, 21%; detailed information is listed in Table 3). At the time of the MTDH, 10 of 70 (14.2%) patients had no ASM, 38 of 70 (54.2%) had one or two, and 22 of 70 (31.6%) had three to five.

Almost all patients or families (65/70, 93%) had an interview with both the social worker and the neuropsychologist to assess the patient/family awareness of the disease, psychosocial status, level of disability, autonomy, and adequacy of social, legal, and financial support. In this regard, 44 of 70 patients (63%) exhibited a good level of autonomy in everyday functions, according to the Katz ADL scale (level 6), whereas 13 of 70 (18%) presented severe dependence (Katz scale <3). Thirty of 70 patients (43%) were trained for employment, thirteen of 70 (18%) for sheltered employment. Eighteen of 70 patients (26%) lived in assisted home care. Finally, nine of 70 (13%) individuals lived with their families at the legal guardians' request having sporadic assistance without any planned home care at the time of the transfer to the adult care. During the MTDH, patients underwent distinct examinations depending on their needs. Specifically, EEG was performed in 24 of 70 (34%) patients; four patients had

- Morphological imaging CT/MRI (specify major results and dates)

  _____

- Functional imaging:
  i. SPECT: performed/not performed (if performed please specify dates and attach results)

  _____

  ii. PET: performed/not performed (if performed please specify dates and attach results)

  _____

- Others: if yes specify _____

- Metabolic testing: performed/not performed (if performed please specify dates and attach all test results [positives and negatives])

  _____

- Genetic testing: performed/not performed/ongoing
  (if performed please specify dates and attach all test results validating a copy for the patient/family)

  _____

- Results of blood tests performed during the transition day hospital: liver function/renal function/VitD/ASM serum levels

_____

Social and societal integration

- **Daily autonomy evaluation**: normal/abnormal, if abnormal specify abnormal findings and scales used

  _____

- **Societal integration**:
  - Leisure _____
  - Education and professional history and current level

    _____
  - Professional project

    _____

- **Social support** Y/N If yes specify:
  - Long-term disease (ALD) – taking charge request (if performed specify date/validity reporting expiry date) _____
  - Departmental Home for Disabled Persons (MDPH) request (if performed specify date/validity reporting expiry date) _____
  - Legal protection procedure _____
  - Juridical protection: present/absent. If present , specify

    _____

Consolidation of the therapeutic education and information:

- Seizure recognition, seizures' diary and management
- Understanding and managing daily life constraints (professional, leisure and driving)
- Genetic counselling in case of genetic aetiology
- Pregnancy and contraception for women

FIGURE 2 (Continued)

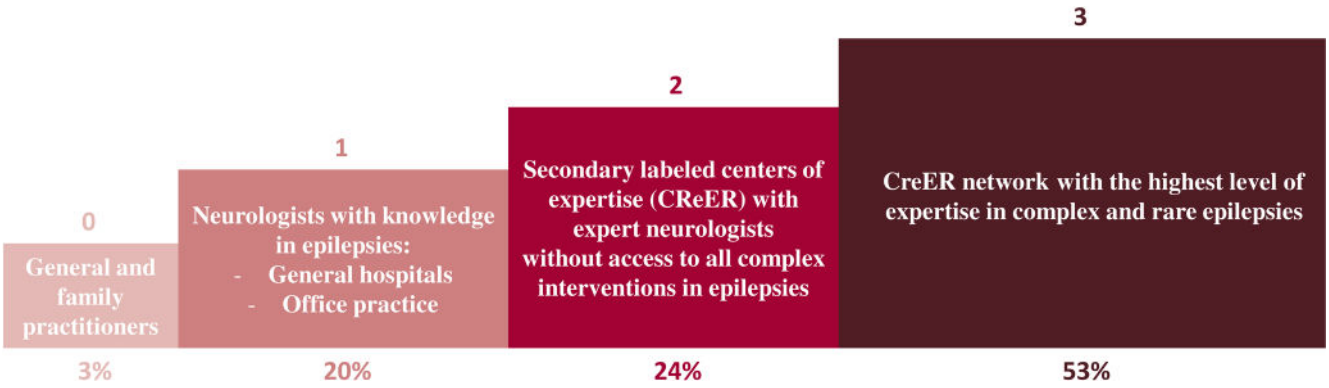

FIGURE 3 The referral institutions, centers, or physicians after the finalization of the transition process. The four levels of adult care are based on patient needs, on the institutions' or physicians' expertise, and on the geographical proximity of the adult facility to the residence of the patient as an adult. CReER, Reference Center for Rare Epilepsies.

repeated genetic testing and MRIs. Three of them had an unrevealed etiology (two genetic) and one a structural etiology (polymicrogyria).

Among the 34 female patients, 30 of 34 (88%) received a gynecological consultation; nine of 30 (30%) had already had medical contraception through our previous program steps, and five of 30 (17%) had the prescription during the MTDH. None of those receiving hormonal contraception experienced a seizure worsening potentially related to ASM–contraceptive medication interactions. Hormonal contraception was proposed for various reasons: painful and abundant periodic menstruation, contraception, and in only one patient, exacerbation of seizures during periodic menstruation.

TABLE 1 Demographic and clinical characteristics of the included patients ($N = 70$).

Characteristics	Value
Age at transition, years	
Mean (IQR)	19.1 (16.3–19.5)
Min–max	16–25
Female/male, ***n*** (%)	34 (49)/36 (51)
Age at epilepsy onset, years	
Mean (IQR)	5 (.1–14.8)
Min–max	.1–15
Seizure type, *n* (%)	
Generalized	27 (38.6)
Focal	11 (15.7)
Generalized and focal	32 (45.7)
Etiology, *n* (%)	
Genetic	28 (40)
Structural	17 (24.2)
Metabolic	1 (1.4)
Infectious	1 (1.4)
Unknown	23 (33)
Identified syndrome, *n* (%)	56 (80)
Pharmacological therapies, *n* (%)	
1–2	19 (27)
3–5	28 (40)
>5	23 (33)
Nonpharmacological therapies, *n* (%)	
Ketogenic diet	16 (23)
Surgery	1 (1)
Vagus nerve stimulation	9 (13)

Abbreviation: IQR, interquartile range.

TABLE 2 List of patients with identified syndromes (56 patients).

Syndrome	*n* (%)
Genetic generalized epilepsies	16 (28.6)
Idiopathic generalized epilepsies	
Epilepsy with generalized tonic–clonic seizure alone	5
Juvenile absence epilepsy	4
Juvenile myoclonic epilepsy	2
Childhood absence epilepsy	1
Nonidiopathic generalized epilepsies	
Epilepsy with myoclonic–atonic seizures	2
Epilepsy with eyelid myoclonia	1
Myoclonic epilepsy in infancy	1
Developmental and/or epileptic encephalopathy	27 (48.3)
Lennox–Gastaut syndrome	8
Early infantile developmental and epileptic encephalopathy	7
Dravet syndrome	6
Progressive myoclonic epilepsy	3
Epileptic encephalopathy with spike-and-wave activation in sleep	1
Developmental and epileptic encephalopathy with spike-and-wave activation in sleep	1
Infantile epileptic spasms syndrome	1
Self-limited epilepsies	4 (7.1)
Genetic epilepsy with febrile seizures plus	3
Photosensitive occipital lobe epilepsy	1
Etiology-specific epilepsies	8 (14.2)
Tuberous sclerosis complex	5
PCDH19 clustering epilepsy	2
Sturge–Weber syndrome	1
Focal epilepsy syndromes	1 (1.8)
Mesial temporal lobe epilepsy with hippocampal sclerosis	1

After the finalization of the transition process, 37 of 70 patients (53%) were referred to a level 3 center, whereas 17 of 70 patients (24%) were referred to a level 2 center, 14 of 70 individuals (20%) to a level 1 center, and the last two of 70 (3%) to their general practitioner (level 0; Figure 3).

The adult nurse of two of the regional reference centers of the CReER network were present during the MTDH for half of the patients addressed to level 3 care and were introduced to the families and the patients. They were able to introduce their institution and prepare the adult neurologist encounter.

All patients and families had their transition passport delivered and their education consolidated on seizure recognition, seizure diary, and seizure management plan and on the management of possible daily life constraints (professional, leisure, and driving). The gynecologist delivered information on pregnancy and contraception, and genetic counseling was proposed. Finally, all patients received their first appointment date in the adult care system.

When the adult neurologist receives the transition passport, he may also request the complete patient file.

We evaluated the outcome criteria in February 2024 with a follow-up from 6 months to 3 years. The "adult clinic attendance rate" defined by the percentage of patients attending their first adult clinic encounter as organized by the pediatric team was 100% (68/68), excluding the two patients who did not need any organized follow-up. The

TABLE 3 Medications administered in our patient cohort, ranked in decreasing order of use, and related retention rate.

	Current treatment, *n*			Current and previous, *n*			Retention rate, %
Medication	**Female**	**Male**	**Total**	**Female**	**Male**	**Total**	**Total**
Valproate	12	12	24	26	30	56	43
Levetiracetam	10	7	17	23	20	43	40
Lamotrigine	7	8	15	19	15	34	44
Clobazam	7	5	12	14	13	27	44
Carbamazepine	3	6	9	8	17	25	36
Topiramate	6	2	8	16	8	24	33
Perampanel	5	4	9	10	8	18	50
Cannabidiol	5	5	10	8	6	14	71
Rufinamide	1	3	4	5	6	11	36
Oxcarbazepine	1	1	2	4	6	10	20
Zonisamide	1	0	1	8	2	10	10
Corticosteroids	0	0	0	4	5	9	0
Lacosamide	1	2	3	5	3	8	38
Vigabatrin	1	0	1	4	3	7	14
Stiripentol	3	2	5	5	2	7	71
Ethosuximide	1	0	1	3	3	6	17
Felbamate	2	0	2	4	1	5	40
Gardenal	0	0	0	3	1	4	0
Phenytoin	1	1	2	2	2	4	50
Sulthiame	0	0	0	0	4	4	0
Fenfluramine	1	0	1	1	0	1	100

"return rate" was two of 70 (2.8%) and consisted of a request for a pediatric clinic in each case. The first family asked for a medical "return clinic" to discuss the neurologist proposal of withdrawal of an ASM in a patient with polytherapy and almost controlled epilepsy. The adult neurologist discussed this point as a possible future action. The second "return clinic" was in the context of seizure exacerbation, and the family wanted to discuss the adult neurologist proposal of therapy changes with their pediatric neurologist.

4 | DISCUSSION

Pediatric epilepsies are frequently complex disorders, where patients experience distinct clinical features and comorbidities making the transition from adolescence to adulthood challenging.[7] Over the years, we witness the elergence of a growing necessity of coordinated and organized transition programs from the pediatric to adult care system to face multiple issues. This is crucial for exclusive pediatric institutions such as ours, where the transfer to adult care is mandatory because the pediatric hospital facilities such as emergency room and intensive care unit do not accept young adults, leading to catastrophic transfer to adult units. In addition, the adult epilepsy care system is rarely trained to manage complex pediatric onset epilepsies with neurodevelopmental comorbidities, some specific therapies, and many complex beyond the seizures needs.[17] In this regard, DEEs and other complex epileptic disorders are always associated with multisystem involvement and present a high need for multidisciplinary care.[1,17–20] Furthermore, patients frequently present refractory seizures managed with complex treatments, including polytherapies, Ketogenic diet, and ASMs, that are less frequently used in adults and are therefore unfamiliar to neurologists. Notably, 31% of our patients tried more than two ASMs during the transition program, with 54% remaining on one or two ASMs.

Females of childbearing age with a previous epilepsy diagnosis present an increased risk of unplanned pregnancy compared to healthy controls.[1,21–24] Interaction between many ASMs and hormonal contraceptives may be relevant, as enzyme-inducing ASMs could lead to a contraceptive failure.[25–27] Furthermore, it was also observed that some combined oral contraceptives reduced LTG serum concentrations by nearly 50% through an

enzyme mechanism, potentially impairing seizure control.[25,28,29] Importantly, the exposure to some ASMs during pregnancy, such as VPA, and less frequently, phenobarbital, phenytoin, carbamazepine, and topiramate, has been associated with fetal major congenital malformations, and VPA has also been related to significantly lower intelligence quotient, behavioral impairment, and autism spectrum disorders.[30–37] The need for contraception is not well evaluated in the females with ID. In our cohort, 88% of women had a gynecological consultation during MTDH, with 30% already having contraception prescribed during the transition program and an additional receiving contraception during the MTDH. Notably, none of the female patients enrolled had an unplanned pregnancy. One patient had a treatment adjustment, and none experienced seizure worsening potentially related to ASM–contraceptive drug to drug interactions.

Frequently, entering legal adult age has been associated with stressful issues that caregivers have to face, such as legal considerations, support services access, and financial, community, and occupational matters.[1] Moreover, they might not be entirely informed regarding the patient's disease, or might not be prepared for the transfer, and the psychological status of both the patient and the caregivers might, in this setting, impair the transition and transfer process. The disease awareness, the psychosocial status, and the level of patient disability were reassessed in 93% of our patients to ensure that the planned support was currently suitable or should be adjusted to avoid missed situations. Of note, at 1-year follow-up, only two patients (3%) lived at their family home without any home care facility plan.

The transfer represents a key moment in young adults' lives. It should be accurately planned, aiming at supplying a continuity of care. The transition passport is a tool to accurately summarize the history of the patient and his current needs. This passport contains all pivotal information such as seizure management protocol, psychosocial screening, legal, financial, community status, rehabilitation, and palliative care in addition to the disease history and main characteristics. It allows an accurate overview of the disease and the patient status for the neurologist receiving him in adult care. This passport gave the possibility also for the patient and the family to have this summary available and to have a final consolidation about their knowledge of the disease, the etiology, the therapies, the seizure management, and possible needs for adaptation of their daily activities.

The revision of the diagnosis and the care scheme was not a major issue in our series, as this was done regularly as practice of care. However, a few patients had their etiology unrevealed repeating an old generation genetic and imaging testing. This has a major impact on the families' and siblings' "why" question and can support genetic counseling and treatment adjustments.

Patients were transferred in relation to their needs and the geographical location of their personal residence or home care. The network of the French national centers for rare epilepsies established in 2005 helped us by providing regional corresponding centers. Home care physicians' expertise allowed some of them to be considered as level 1, with the availability of a neurologist trained in epilepsy and the possibility to perform EEG recordings.

Finally, the presence of the adult epilepsy nurse for almost half of the patients requiring a continuity of care at a level 3 epilepsy expertise center allowed us to decrease partially the "new faces–new places" that patients and families are anxious about when the transfer is to another institution and not only different physicians as in our pediatric institution case. This participation was not constant and might be improved further in our program; it may involve any active member of the adult team, allowing a rotation of the adult team members and not keeping this exclusively based on the nurses' team.

Our program evaluation was based on the "adult clinic attendance rate" and the "return rate." This might seem simplistic, but evaluating the transition program is complex and there are no accepted monitoring criteria.[38] The first was 100% (68/68) after excluding the two patients who did not need any structured follow-up, and the second showed only in two families a request for a return appointment at the pediatric clinic. We selected these two simple items because they might reflect at short term the alliance of the patients and families with a 100% attendance of the first clinic in the adult care system. These criteria also encompass the validation of the first step of the continuity of care and the organization of this clinic within acceptable delay by our adult neurologists' colleagues. This first encounter with the adult team with "new places and new faces" was a condition sine qua non of the acceptance of the transfer and of the avoidance of early "lost in transition." The two families that requested a pediatric clinic after the adult first encounter were anxious about ASM withdrawal in one case and ASM changes in the other due to seizure exacerbation. The frequent need for polytherapy in many patients with complex epilepsies as DEEs in childhood and the relative decrease of seizure frequency after pediatric age may be better addressed and prepared for by the pediatric neurologist during transition.[39–44] This issue should be clearly explained to the families. In some instances, initiating a rational decrease of the polytherapy in the last years of pediatric care may be helpful during transition and before the transfer. These two outcome criteria cannot account for later lack of compliance or

deterioration of the patient's condition but can show that in the short term, the transfer happened successfully and safely and was accepted by the patients and the family. Indicators of the transition programs based on quality of life, disease outcome, and social integration may be important to develop.

Finally, the point that should be further discussed and evaluated may be the cost of such a program. We dedicated at our institution, where health care is fully covered for complex and chronic diseases by our national health system, protected times for the following professionals: a half-time pediatric neurologist fully dedicated to the program and assisting the pediatric neurologists of our team, a dedicated time for the interventions by the pediatric epilepsy nurse and the adult epilepsy nurse, a neuropsychologist, and a social worker in addition to a gynecologist for the female patients. Much of this time is dedicated to the preparation of the transition passport, communication with the adult team, preparation of the first adult encounter appointment, and MTDH organization and realization.

This study has some limitations. The major limitation may be the indicators for the program evaluation. However, the evaluation of the transition is complex.[38] One should also be aware that our population is not aligned with the epilepsy population, as there were more complex epilepsies because of recruitment at our reference center. Therefore, such a program may be more adapted for complex epilepsy cases. In addition, the satisfaction of our adult colleagues, expressed often during our common meetings, was not objectively assessed for the families' and patients' satisfaction. Finally, we did not evaluate the sustainability of such a program.

5 | CONCLUSIONS

Our study sheds light on a potentially promising transition model for complex epilepsies. We were able to accompany all the patients and families until their first clinic in adult care, and only two families requested a return appointment at the pediatric clinic. A structured multidisciplinary and coordinated program should benefit the patients and the family and enable a smooth transfer to the adult care with the various needs identified. However, the cost of such a program may support its application as proposed in patients with complex epilepsies without leaving behind patients that should benefit from the main lines of this process. Further studies should focus on some unsolved issues such as defining an operational set for transition, possibly adaptable in different countries and settings, and identifying objective outcomes to methodically appraise transition benefits and enable the sustainability of such programs.

AUTHOR CONTRIBUTIONS

Rima Nabbout designed the transition program and the paper, supervised the results interpretation and the writing, and critically revised the final version of the paper. Agathe Molimard performed the data acquisition and participated in the data analysis and interpretation and the drafting of the paper. Giovanna Scorrano participated in the data analysis and interpretation, the drafting of the paper, and the creation of the tables and figures. Melodie Aubart participated in the data collection and the revision of the paper. Delphine Breuillard and Morgane Delaune participated in the data acquisition and the interpretation of the results. Giulia Barcia reviewed the cohort genetic testing results and organized during the MTDH the updated testings. She participated in the data interpretration and revision of the manuscript. Marie-Anne Barthez participated in the data acquisition and interpretation and in the revision of the final version. Nicole Chemaly and Isabelle Desguerre participated in the data interpretation and commented on the final version. All authors approved the final version to be published.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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