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SHORT RESEARCH ARTICLE

Exploring transition in epilepsy within ERN EpiCARE centers: Insights from a survey analysis

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Abstract

The transition from pediatric to adult healthcare is a critical stage for young individuals with chronic neurological disorders, particularly those with rare and complex epilepsies. This paper aims to explore the practice of transition by healthcare providers within EpiCARE. Through a comprehensive questionnaire, developed in collaboration with European Patient Advocacy Groups, this study investigates the current management of transition and identifies key barriers hindering stakeholders' needs. The questionnaire was completed by 60 EpiCARE members. Half of the respondents reported existing written transition procedures in their centers. Findings reveal significant hurdles in dedicated transition

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services, with nearly half of the respondents indicating their centers lack such pipelines. A critical gap exists in multidisciplinary team involvement, with inconsistent participation from key specialists like psychiatrists and social workers. The transition process typically begins at 16–18 years according to 70% of respondents; though 61% believe it should occur prior to the age of 17, highlighting the need for early planning to prevent gaps in care continuity. Furthermore, routinely used informal communication methods for clinical coordination underscore the need for standardized protocols and structured processes. This survey highlights the urgent need for tailored transition protocols that address the unique challenges of managing patients with rare and complex epilepsies, emphasizing the importance of integrating psychosocial support, optimizing comorbidity management, and ensuring coordination by experts in transitional care for these conditions. Fostering collaboration among healthcare providers, patients, and families is essential for refining transition strategies and ensuring comprehensive care for individuals with rare and complex epilepsies. Further initiatives are required to bridge the gaps between pediatric and adult healthcare systems, enhancing the overall quality of life for this vulnerable population.

Plain Language Summary: Moving from child to adult healthcare is a key step for young people with rare and complex epilepsies. This study surveyed EpiCARE centers to understand how transitions are managed. Only half have written procedures, and many lack dedicated services or full specialist teams. Most start the transition at ages 16–18, but many believe it should begin earlier. Communication is often informal, without clear protocols. The results highlight the urgent need for structured, personalized transition plans that include psychological support and expert coordination to ensure continuous, high-quality care into adulthood.

KEYWORDS

ERN EpiCARE, multidisciplinary, rare and complex epilepsy, tailored protocol, transition

1 | INTRODUCTION

The concept of "transition" refers to a structured, proactive process that addresses the medical, psychosocial, educational, and professional needs of young individuals and aims to prepare both patients and their families for adult healthcare. "Transfer" specifically refers to the formal shift of care from the pediatric to the adult healthcare and is especially critical for individuals with rare and complex epilepsies.[1]

Young individuals with rare and complex epilepsies, such as developmental and epileptic encephalopathies (DEEs), often exhibit diverse phenotypes characterized by heterogeneous seizure types and varying degrees of cognitive impairment, behavioral disturbances, and motor or gait impairments.[2]

Their effective management requires collaboration among specialists, including pediatric neurologists, psychiatrists, rehabilitation physicians, psychologists, geneticists, endocrinologists, orthopedic surgeons, and others.[2–4]

By the time these individuals reach the transition age, many will be receiving polytherapy necessitating expertise in pediatric epileptic syndromes treatment.[5] Many of them will exhibit significant comorbidities and disabilities requiring continuously adapted and closely monitored therapeutic strategies.[4,5]

Key points

- A survey of 60 EpiCARE centres shows gaps in transition care for rare and complex epilepsies.
- Nearly half lack formal pipelines; multidisciplinary involvement is often inconsistent.
- There is a need for early, standardized, psychosocially integrated transition protocols.

Moreover, the shift from pediatric to adult care presents unique challenges stemming from the differing paradigms of these systems. Transition should be a gradual process that empowers young individuals, their families, and their support systems to navigate and understand the changes associated with adult services. Pediatric care typically adopts a holistic, family-centered approach, while adult care prioritizes disease management and related disabilities. Although the evolution from dependency to autonomy is generally a natural progression, it poses relevant risks to the continuity of care, especially for individuals with chronic and complex conditions, including intellectual disabilities, behavioral and psychiatric disorders, and motor impairments.[5]

Despite the existence of various models and recommendations for transitioning young patients with childhood-onset neurological disorders, there remains a notable gap in the literature specifically addressing models of transition for patients with rare and complex epilepsies.[4,6,7]

The primary objective of the transition process is to mitigate the risks of symptoms' exacerbation, treatment non-adherence, and loss of follow-up that may profoundly affect the quality of life of patients and families. The European Reference Networks (ERNs) were established by the European Union Board of Member States in 2017 to enhance access to specialized healthcare centers and improve the diagnosis and management of patients with rare diseases.[8] Within this framework, ERN EpiCARE focuses on rare and complex epilepsies, ensuring that patients receive tailored, comprehensive care throughout their lives. Addressing the unmet needs and challenges of transition is part of EpiCARE's objectives, and a special interest group (SIG) on this topic was created. This group is dedicated to developing a coordinated and comprehensive transition model that addresses the complexities and multidisciplinary nature of care required for individuals with early-onset rare and complex epilepsies.

In line with this scope, the present survey marks an initial step toward understanding the experience of healthcare providers (HCPs) within EpiCARE. By emphasizing the barriers that hinder effective management of the transition process, our final goal is to identify and address the diverse unmet needs of patients and their families approaching adulthood, ultimately striving for a seamless and supportive transition process that enhances their health outcomes and quality of life.

2 | METHODS

2.1 | The questionnaire

The EpiCARE Transition SIG consists of 12 EpiCARE members from Italy, Croatia, France, and Denmark, including 7 child neurologists, 2 adult neurologists, and 3 European Patient Advocacy Groups (ePAGs) representatives. The SIG has discussed and identified transition-related challenges through online meetings and in-person group discussions. As a result, a questionnaire was developed to explore these issues and potential solutions.

The questionnaire was created on the EpiCARE survey platform and comprised 37 items—28 closed-ended, 6 multiple-choice, and 3 ranking questions— divided into five key areas:

- General information: About the HCP and the respondent (Questions 1–3)
- Clinical care organization: HCP structure and organization (Questions 4–6)
- Child–Adult transition practices: Current practices regarding the transition (Questions 7–23)
- Challenges encountered and ways of improvement: Major issues faced in the health care center and propositions to improve the transition process (Questions 24–37)

The questionnaire was finalized in April 2024 and distributed via e-mail to all the representatives of 50 HCPs within the EpiCARE network. We requested a separate answer to the survey from pediatric and adult HCPs with a preference for those involved in the transition and transfer from pediatric to adult care.

The survey was available for 4 months between April and July 2024 with two reminders.

2.2 | Data analyses

Numeric data were analyzed and reported as a percentage of respondents or a numeric range. Answers represented by qualitative multiple-choice were summarized into major categories and reported as a percentage. When a ranking was asked, the ranking of key challenges and proposed solutions was derived from the frequency and emphasis of responses provided by the participating centers in the survey. An ordinal scale was used to scale responses (1 = necessary; 2 = very important; 3 = important; 4 = not important).

3 | RESULTS

The survey responses are outlined in detail in Tables 1 and 2.

The questionnaire was completed by 60 EpiCARE members across 42 HCPs in 21 European countries out of

TABLE 1 Clinical care organization and child–adult transition practices.

	Total responders		Child neurologists		Adult neurologists	
Survey questions	***N***	**%**	***N***	**%**	***N***	**%**
General informations and clinical care organization						
The specialty of the person answering this questionnaire						
Adult neurologist	23	/	/	/	23	40.35
Child neurologist	34	/	34	59.65	/	/
What is the status of your HCP?						
Adult HCP only	7	12.28	/	/	/	/
Pediatric HCP only	15	26.32	/	/	/	/
Both	35	61.4	/	/	/	/
What is the mean waiting time for an appointment at a specialist outpatient clinic?						
<1 month	4	7.02	3	6.98	1	7.14
1–3 months	29	50.88	20	46.51	9	64.29
3–6 months	7	12.28	5	11.63	2	14.29
6–12 months	2	3.51	2	4.65	0	0
>12 months	0	0	0	0	0	0
Do not know/not applicable	9	15.79	9	20.93	0	0
other	6	10.53	4	9.3	2	14.29
Up to what age do you care for adolescents in the pediatric department?						
14 years	/	/	1	1.75	/	/
16 years	/	/	5	8.78	/	/
18 years	/	/	42	73.68	/	/
other	/	/	9	15.79	/	/
How old are the oldest patients with epilepsy you follow?						
16 years	/	/	1	2.94	/	/
18 years	/	/	9	26.47	/	/
20–25 years	/	/	14	41.18	/	/
25–30 years	/	/	3	8.82	/	/
30–40 years	/	/	0	0	/	/
>40 years	/	/	7	20.59	/	/
N/A (adult neurologist)	/	/	0	0	/	/
Other	/	/	0	0	/	/
How many patients do you refer to the adult neurological specialist clinic per year?						
<10/year	/	/	6	17.65	/	/
10–20/year	/	/	14	41.18	/	/
20-30/year	/	/	5	14.71	/	/
30–50/year	/	/	6	17.65	/	/
50–75/year	/	/	1	2.94	/	/
75–100/year	/	/	0	0	/	/
>100/year	/	/	0	0	/	/
N/A (adult neurologist)	/	/	0	0	/	/
Other	/	/	2	5.88	/	/
Child–adult transition practices						
Is there a written or approved procedure for transition in your HCP?						
Yes	27	47.37	/	/	/	/
No	28	49.12	/	/	/	/
I don't know	2	3.51	/	/	/	/

TABLE 1 (Continued)

	Total responders		Child neurologists		Adult neurologists	
Survey questions	***N***	**%**	***N***	**%**	***N***	**%**
If yes, have relevant patient organizations been involved in the development?						
Yes	5	8.77	/	/	/	/
No	32	56.14	/	/	/	/
I don't know	6	10.53	/	/	/	/
Other	14	24.56	/	/	/	/
Is there a transition program in your HCP?						
Yes, with dedicated personnel and space	7	12.28	/	/	/	/
Yes, with dedicated personnel but no space	13	22.81	/	/	/	/
No	28	49.12	/	/	/	/
Other	9	15.79	/	/	/	/
If there is a transition program, where is it located?						
In the pediatric department, the same HCP	12	21.05	/	/	/	/
In the adult department, the same HCP	8	14.04	/	/	/	/
In the pediatric hospital other than HCP	1	1.75	/	/	/	/
In the adult hospital other than HCP	1	1.75	/	/	/	/
We do not have a transition clinic	27	47.37	/	/	/	/
Other	8	14.04	/	/	/	/
What is the mean waiting time for an appointment at the transition clinic?						
<1 month	2	3.51	/	/	/	/
1–3 months	13	22.8	/	/	/	/
3–6 months	6	10.53	/	/	/	/
6–12 months	5	8.77	/	/	/	/
>12 months	0	0	/	/	/	/
>24 months	0	0	/	/	/	/
N/A (if there is not a transition clinic)	27	47.37	/	/	/	/
Other	4	7.02	/	/	/	/
Who benefits from transition clinic compensation?						
Adult neurology department	4	7.02	/	/	/	/
Child neurology department	4	7.02	/	/	/	/
Both	5	8.77	/	/	/	/
Independent budget	3	5.26	/	/	/	/
Don't know	14	24.56	/	/	/	/
Other	27	47.37	/	/	/	/
Does your HCP provide any additional financial support for transition clinics?						
Yes	0	0	/	/	/	/
No	42	73.69	/	/	/	/
I don't know	3	5.26	/	/	/	/
Other	12	21.05	/	/	/	/
At what age do patients usually do the transition process?						
14–15 years	3	5.27	/	/	/	/
16–17 years	21	36.84	/	/	/	/
18 years	19	33.33	/	/	/	/
Highly variable	5	8.77	/	/	/	/
Other	9	15.79	/	/	/	/

(Continues)

TABLE 1 (Continued)

Survey questions	Total responders		Child neurologists		Adult neurologists	
	N	%	*N*	%	*N*	%
At what age do you think patients should start the transition process?						
14–15 years	11	19.3	7	21.21	4	16.67
16–17 years	24	42.11	14	42.42	10	41.67
18 years	3	5.26	1	3.03	2	8.33
It depends from patient to patient	15	26.32	8	24.24	7	29.16
Other	4	7.02	3	9.1	1	4.17
Do you have a designated Transition Coordinator?						
Yes, child neurology	8	14.04	/	/	/	/
Yes, nurse	13	22.81	/	/	/	/
Yes, social worker	0	0	/	/	/	/
Yes, psychologist	1	1.75	/	/	/	/
Yes, secretary	2	3.51	/	/	/	/
No/other	33	57.89	/	/	/	/
How much of your working time does the transition process preparation involve?						
0–4.99%	23	40.35	13	38.24	10	43.48
5–9.99%	23	40.35	15	44.12	8	34.78
10–19.99%	5	8.77	1	2.94	4	17.39
30%–50%	0	0	0	0	0	0
>50%	0	0	0	0	0	0
Other	6	10.53	5	14.71	1	4.35
Does the pediatric team share a current medical summary, transition passport, letter and/or emergency care plan?						
Yes	47	82.46	/	/	/	/
No	7	12.28	/	/	/	/
Other	3	5.26	/	/	/	/
How does the preparatory activity for the transition process take place?						
Multiple answers allowed						
E-mail communications from different specialists	23	40.35	/	/	/	/
Phone call communications from different specialists	16	28.07	/	/	/	/
Dedicated in-person meetings	27	47.37	/	/	/	/
Dedicated online meetings	13	22.81	/	/	/	/
Dedicated hybrid meetings	5	8.77	/	/	/	/
Other	13	22.81	/	/	/	/
Does the transition visit take place in the presence of several specialists?						
Multiple answers allowed						
Child neurologist	40	70.18	/	/	/	/
Adult neurologist	40	70.18	/	/	/	/
Pedopsychiatrist	1	1.75	/	/	/	/
Psychiatrist	0	0	/	/	/	/
Residents	9	15.79	/	/	/	/
Nurse	11	19.3	/	/	/	/
Social worker	4	7.02	/	/	/	/
Psychologist	3	5.26	/	/	/	/

TABLE 1 (Continued)

Survey questions	Total responders		Child neurologists		Adult neurologists	
	N	%	*N*	%	*N*	%
Neuropsychologist	7	12.28	/	/	/	/
Other	20	35.09	/	/	/	/
Do you have any ongoing research activity/ study regarding the transition program in your HCP?						
Yes	19	33.33	/	/	/	/
No	36	63.16	/	/	/	/
Other	2	3.51	/	/	/	/
Do you use standardized questionnaires in transition visits to assess readiness/ patients' needs?						
No	40	70.18	/	/	/	/
I don't know	0	0	/	/	/	/
Yes	17	29.82	/	/	/	/
Do you have a priority track for specific patients?						
Yes, we do give priority to patients with complex clinical situations	24	42.11	/	/	/	/
Yes, we give priority to patients with specific urgent issues	20	35.09	/	/	/	/
No, we do not have a priority track	10	17.54	/	/	/	/
Other	3	5.26	/	/	/	/

50 HCPs (Figure 1). Respondents included 60% child and 40% adult neurologists, with 62% reporting HCPs providing both pediatric and adult care.

Child neurologists follow adolescents until 18 years (74%) but may extend care to age 40 (71%). The majority of responders (59%) reported a range of 1–20 patients referred annually to the adult care system.

Half of respondents (47%) reported existing written transition procedures in their centers; however, ePAGs were involved in only 9% of cases. Waiting times for transition clinics are 1–6 months (37%). Dedicated personnel and space exist in only 12%. Merely 3% of responders declared a transition service outside their HCP. The transition process typically begins at 16–18 years (70%), though 61% believe it should occur prior to the age of 17 or be personalized to the patients' and families' needs.

Medical summaries are shared in 83% of cases, and transition coordinators, often epilepsy nurses, coordinate the programs in 42%. Transition clinics include child and adult neurologists (70%), followed by nurses (19%), residents (16%), and neuropsychologists (12%). Transition activities account for less than 10% of overall working time for 80% of respondents.

While 47% of responders consider that a structured transition process is necessary for all epilepsies, the great majority of responders (84%) agree that a dedicated transition protocol is essential in DEEs.

Key challenges for an effective transition include, in order of ranking, lack of dedicated time, personnel, protocols, space, and funding. Solutions for improvement include dedicated staff, case coordinators, integrated protocols, and transition spaces.

Factors that may accelerate transition include pregnancy programs (26%), driving license projects (18%), and uncontrolled epilepsy (17%). Delays in transition program implementation may occur due to strong attachment to pediatric neurologists (37%), intellectual disability (27%), adult services' lack of resources (25%), and psychiatric comorbidities (15%). Communication between pediatric and adult teams is considered poor by 28%, mainly due to a lack of time (43% of them).

4 | DISCUSSION

For many years now, there has been an increasing awareness that the need for effective transition is a priority in almost all European healthcare systems; yet we are still lacking a universal strategy.[9] Whether it is due to the lack of defined and measurable outcomes or to the diversity in healthcare systems, this remains open for debate.[2,7]

European models and transition protocols vary and are often developed in specific HCPs[4,6,10] reflecting a clear need for assessment of current transition status, especially in EpiCARE centers.

The present survey sheds light on the limitations and challenges that EpiCARE centers face in the transition

TABLE 2 Challenges encountered and vision for improvement.

	Total responders		Child neurologists		Adult neurologists	
Survey questions	***N***	**%**	***N***	**%**	***N***	**%**
Challenges encountered						
Which are the major difficulties encountered in your hospital for the child–adult transitions?						
Ranking required						
Lack of time	1st.	/	1st.	/	1st.	/
Lack of dedicated personnel	2nd.	/	2nd.	/	2nd.	/
Lack of dedicated protocol	3rd.	/	3rd.	/	4th.	/
Lack of spaces	4th.	/	4th.	/	3rd.	/
Lack of funds	5th.	/	5th.	/	5th.	/
Lack of knowledge	6th.	/	6th.	/	6th.	/
Poor communication between pediatric and adult departments	7th.	/	7th.	/	7th.	/
Other	8th.	/	8th.	/	8th.	/
Which are the main factors that might delay the transition in your experience?						
Multiple answers allowed						
Attachment of patients/caregivers to the child neurologist	37	33.64	23	28.75	14	32.56
Intellectual disability	27	24.55	18	22.5	9	20.93
Adult service's lack of resources	25	22.73	16	20	9	20.93
Other	2	1.82	2	2.5	0	0
Other medical comorbidities	10	9.09	6	7.5	4	9.3
Psychiatric comorbidities	15	13.64	11	13.75	4	9.3
Uncontrolled epilepsy	7	6.36	4	5	3	6.98
How would you describe the communication/relationship between pediatricians and the adult team at your HCP?						
Very good	30	52.63	18	54.55	12	50
Good	16	28.07	10	30.3	6	25
Sufficient	3	5.26	1	3.03	2	8.33
Poor	3	5.26	2	6.06	1	4.17
Other	5	8.77	2	6.06	3	12.5
How would you describe the communication/relationship between pediatricians and the adult team when the transition process happens outside of your HCP?						
Poor	16	28.07	10	28.13	6	25
Good	15	26.32	10	31.25	5	20.83
Sufficient	9	15.79	5	15.63	4	16.67
Very good	7	12.28	3	9.38	4	16.67
I don't know	8	14.04	4	12.5	4	16.67
Other	2	3.51	1	3.13	1	4.17
If you choose poor in the last question, what is the reason for that?						
Lack of time	7	43.75	4	40	3	50
Lack of interest	3	18.75	1	10	2	33.33
Lack of knowledge	0	0	0	0	0	0
Lack of spaces where to meet	0	0	0	0	0	0
Lack of a dedicated referring neurologist	3	18.75	2	20	1	16.67
Other	3	18.75	3	30	0	0
Which are the main unmet needs in the transition process according to your experience?						
Multiple answers allowed						
Coping with comorbidities	37	64.91	25	30.12	12	38.75
Availability of a multidisciplinary team	37	64.91	17	20.48	15	48.39
Support in achieving autonomies	22	38.6	15	18.07	6	19.35
Patients and caregiver assistance	13	22.81	11	13.25	2	6.45
Counseling regarding financial support	13	22.81	7	8.43	6	19.35
Transition readiness evaluation	7	12.28	5	6.02	2	6.45
Possibility to conduct a comprehensive diagnostic evaluation	4	7.02	3	3.61	1	3.23
Vision for improvement						
Would you consider that it is important to have a dedicated protocol for child–adult transition?						
Necessary	23	40.35	15	44.12	8	34.78
Very important	22	38.6	12	35.29	10	43.48
Important, but not necessary	10	17.54	6	17.65	4	17.39
Not important, it is part of clinical practice	2	3.51	1	2.94	1	4.35
Who do you think are the figures who should be involved?						
Ranking required						
Child neurologist	1st.	/	1st.	/	1st.	/
Adult neurologist	2nd.	/	2nd.	/	2nd.	/
Neurologist dedicated to transition process	3rd.	/	3rd.	/	3rd.	/
Pedopsychiatrist	4th.	/	6th.	/	4th.	/
Adult psychiatrist	5th.	/	5th.	/	5th.	/
Neurosurgeon	6th.	/	9th.	/	6th.	/
Geneticist	7th.	/	8th.	/	7th.	/

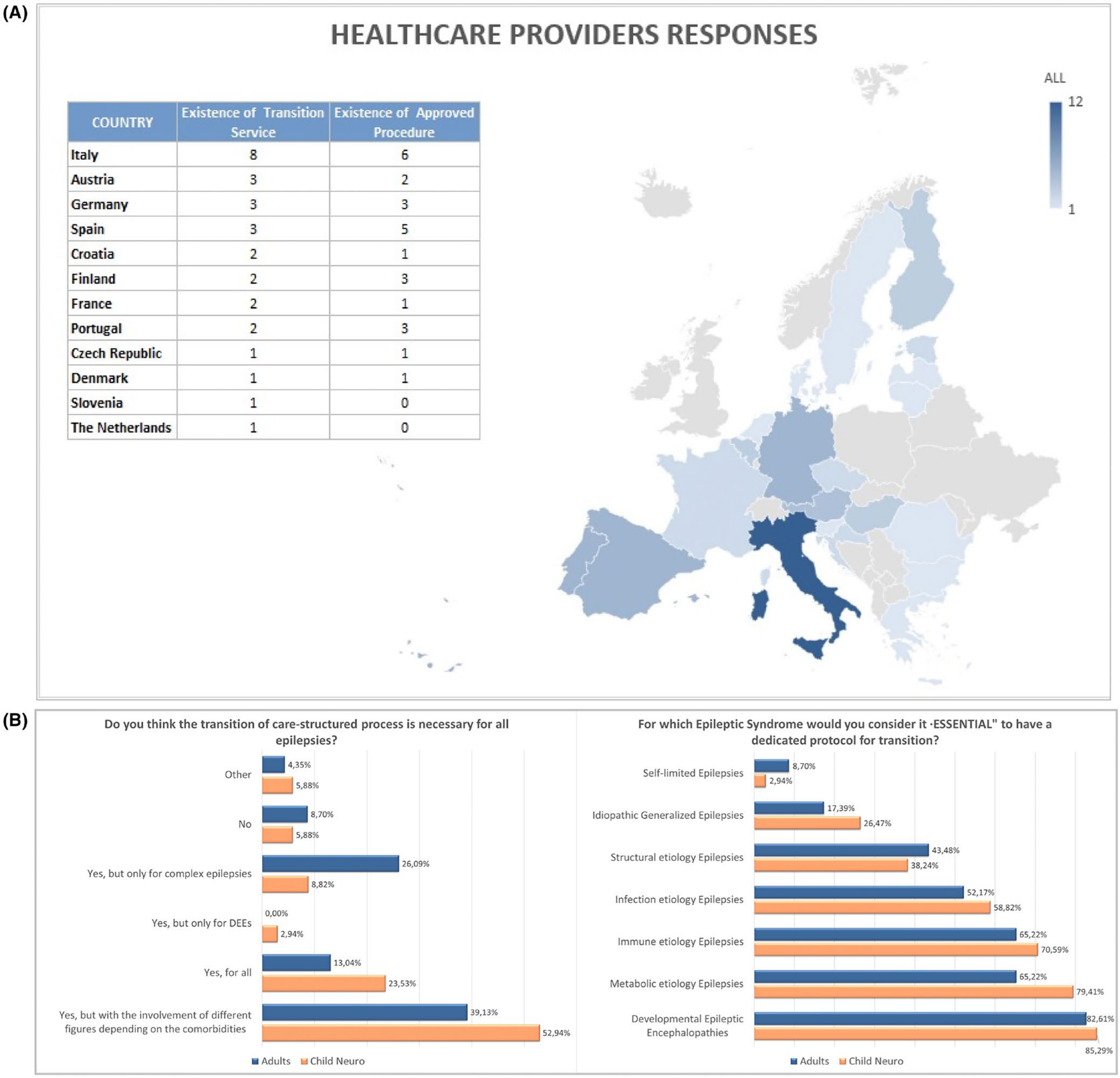
TABLE 2 (Continued)

	Total responders		Child neurologists		Adult neurologists	
Survey questions	***N***	**%**	***N***	**%**	***N***	**%**
Physical and rehabilitation specialist	8th.	/	10th.	/	8th.	/
Psychologist	9th.	/	11th.	/	9th.	/
Neuropsychologist	10th.	/	7th.	/	10th.	/
Pharmacists	11th.	/	12th.	/	11th.	/
Nutritionist	12th.	/	13th.	/	12th.	/
Palliative care specialist	13th.	/	14th.	/	13th.	/
Nurse	14th.	/	4th.	/	14th.	/
Social worker	15th.	/	15th.	/	15th.	/
School educator	16th.	/	16th.	/	16th.	/
Other	17th.	/	17th.	/	17th.	/
Do you think the transition of care-structured process is necessary for all epilepsies?						
Yes, for all	11	19.3	8	23.53	3	13.04
Yes, but with the involvement of different figures depending on the comorbidities	27	47.37	18	52.94	9	39.13
Yes, but only for DEEs	1	1.75	1	2.94	0	0
Yes, but only for surgically treated patients	1	1.75	0	0	1	4.35
Yes, but only for complex epilepsies	9	15.79	3	8.82	6	26.09
Yes, but only for patients with epilepsy without major comorbidities	0	0	0	0	0	0
No	4	7.02	2	5.88	2	8.7
I don't know	1	1.75	0	0	1	4.35
Other	3	5.26	2	5.88	1	4.35
For which Epileptic Syndrome would you consider it ESSENTIAL to have a dedicated protocol for transition?						
Multiple answers allowed						
Self-limited epilepsies	3	5.26	1	2.94	2	8.7
Structural etiology epilepsies	23	40.35	13	38.24	10	43.48
Idiopathic generalized epilepsies	13	22.81	9	26.47	4	17.39
Developmental epileptic encephalopathies	48	84.21	29	85.29	19	82.61
Immune etiology epilepsies	39	68.42	24	70.59	15	65.22
Infection etiology epilepsies	32	56.14	20	58.82	12	52.17
Metabolic etiology epilepsies	42	73.68	27	79.41	15	65.22

TABLE 2 (Continued)

	Total responders		Child neurologists		Adult neurologists	
Survey questions	***N***	**%**	***N***	**%**	***N***	**%**
Are there specific epileptic syndromes, clinical conditions or therapeutic procedures that are not involved in the transition process and therefore the pediatric neurologist continues to follow the patient life-long?						
No	39	68.42	21	67.74	18	69.23
I don't know	7	12.28	5	16.13	2	7.69
Yes	11	19.3	5	16.13	6	23.08
Which is the best age to begin transition preparation?						
14–15 years	13	22.81	11	32.35	2	8.7
16–17 ears	31	54.38	16	47.06	15	65.22
18 years	2	3.51	1	2.94	1	4.35
It depends from patient to patient	8	14.04	4	11.76	4	17.39
Other	3	5.26	2	5.88	1	4.35
What would be needed in your hospital for a successful transition?						
Ranking required						
More staff specifically dedicated to transition	1st.	/	1st.	/	1st.	/
A dedicated coordinator responsible for the transition	2nd.	/	2nd.	/	2nd.	/
A physical space to have a transition clinic	3rd.	/	3rd.	/	3rd.	/
A specific training for dedicated personnel	4th.	/	4th.	/	4th.	/
A transition protocol	5th.	/	5th.	/	5th.	/
Other	6th.	/	6th.	/	6th.	/
Which are the main factors that might accelerate the transition in your experience?						
Multiple answers allowed						
Driving license project	20	18.18	13	21.67	7	14
Intellectual disability	10	9.09	3	5	7	14
Other medical comorbidities	14	12.73	7	11.67	7	14
Pregnancy program	29	26.36	17	28.33	12	24
Psychiatric comorbidities	12	10.91	5	8.33	7	14
Uncontrolled epilepsy	19	17.27	11	18.33	8	16
Other	6	5.45	4	6.67	2	4

process. Even though the advantage of a transition service was well described decades ago,[11,12] our survey stresses its absence in nearly half of the responding HCPs. Sometimes a transition procedure is implemented in clinical practice



COUNTRY	Existence of Transition Service	Existence of Approved Procedure
Italy	8	6
Austria	3	2
Germany	3	3
Spain	3	5
Croatia	2	1
Finland	2	3
France	2	1
Portugal	2	3
Czech Republic	1	1
Denmark	1	1
Slovenia	1	0
The Netherlands	1	0

FIGURE 1 (A) European distribution of existing transition services and existing protocols; (B) Comparison between child and adult neurologists' opinions.

without a transition service, and a transition service might exist without a written procedure (Figure 1A). These discouraging data imply the need for more education on transition from the scientific societies and more support in organizing transition services from national healthcare authorities.

Highlighted barriers in centers with dedicated programs were the lack of a designated physical space, financial support, and personnel specifically dedicated to transition which are in line with previous publications.[13–16]

The continuous reliance on informal communication methods between pediatric and adult care teams (emails, phone communication) highlights the need for implementing structured protocols and formalized coordination mechanisms.[4,7,17]

Another critical issue is the inconsistent involvement of multidisciplinary teams. While neurologists, both pediatric and adult, are consistently present during transition, other key specialists, such as psychiatrists, rehabilitation physicians, psychologists, social workers, and geneticists, are less frequently included, limiting the ability to address the needs of patients with significant comorbidities and psychosocial challenges. Some of the benefits of a multidisciplinary epilepsy transition clinic include optimization of seizure control and long-term psychosocial outcomes for patients with complex epilepsies[18,19] such as those in EpiCARE centers.

The allocation of specific times for all professionals involved in the transition process may be one of the solutions that may allow the involvement of all actors.[4] Indeed, lack of time followed by lack of dedicated personnel was stated as a major difficulty encountered during the transition process.

A strength of this survey is the involvement of ePAGs in the context of defining questions, demonstrating positive results from the engagement of patient organizations in transition protocols. Indeed, even where written transition procedures are in place, the involvement of ePAGs remains rare. We propose here the implementation of patient and caregiver perspectives into the transition process to better address the unique challenges they face.

The survey highlights differences between pediatric and adult care paradigms and the challenges these differences create during the transition process (Figure 1). While pediatric care often adopts a holistic, family-centered approach, adult care focuses more on individual autonomy and disease management.[20,21] This information is relevant as some guidelines incorporate holistic life skills training as key elements.[22]

Although most respondents emphasized the necessity of initiating transition planning before the age of 17, practices remain variable across institutions, with transition timelines often influenced by individual patient needs and epilepsy characteristics rather than standardized criteria.

This is supported by a recent review[23] where the transfer to adult care range was from 13 to 32 years, underscoring the adaptive nature of the process, mostly taking place around or after the age of 18 years. Even though the caregivers would prefer transition services at an early age (12–16 years),[10] it is important to keep in mind that the transition age of young people with epilepsy may be seen as artificial since chronological age might significantly differ from developmental and emotional age.[24] However, for legal reasons, this transfer to adult care is accompanied by different social changes.

Factors recognized in our survey as delaying transfer are attachment and lack of adaptation, while pregnancy, driving license, and uncontrollable epilepsy accelerate the process. The observed discordances between pediatric and adult epileptologists reflect local trends and healthcare policies that undoubtedly create transition gaps even in tertiary centers.[15,25]

FIGURE 2 Successful transition smart figure. To effectively address the challenges of transition, future initiatives should focus on developing tailored and structured protocols. These protocols should integrate multidisciplinary care, including the involvement of a transition coordinator, as well as patients' associations and specialists such as psychiatrists, psychologists, rehabilitators, social workers, geneticists, and neurosurgeons, as required. The continuity of care should follow a timely planned pathway, coping with the special needs of patients. Additionally, the establishment of dedicated transition spaces and the allocation of financial resources by healthcare institutions and policymakers will enable the consistent delivery of high-quality transition services.

As opposed to previous studies[4,5,26–28] noting limited experience in caring for patients with rare and complex epilepsies, present results from EpiCARE centers revealed the necessity of prioritizing the pathway for specific epilepsy syndromes.[22,29] Continuity of care in such cases has special health implications that need to be carefully respected.[5] Respondents recognized the need for tailored transition protocols, emphasizing specialized training for staff in this delicate process. These observations align with a caregiver-based survey[30] where many adult patients with Dravet syndrome were still followed by pediatric neurologists. The recent paper by Nabbout et al.[4] presents a model with dedicated time and space with a day hospital where different specialists are available on a personalized programmed day hospital planning to finalize the transition process and transfer the patients in optimal conditions.

Coping with comorbidities emerged as a clear unmet need, reflecting lower confidence of adult neurologists in treating severe forms of childhood-onset epilepsies and transitioning young adults with multiple disabilities[27,28,31] that transition programs should tackle with a high priority.

Based on these observations, we recommend that centers seeking to improve their transition pathways consider implementing multidisciplinary transition teams, formalizing transition protocols with personalized planning, ensuring dedicated time and resources for transition activities, and fostering strong collaboration with patient advocacy groups. Such measures may help overcome common barriers and promote seamless, patient-centered transitions from pediatric to adult epilepsy care.

A limitation of this survey is the incomplete participation of all EpiCARE centers, with a risk of selection bias in the group of responders, potentially leading to an overrepresentation of sensitization to the topic. Moreover, the overrepresentation of certain countries may reflect varying levels of national engagement with the topic, but also introduces a potential bias in the interpretation of the overall findings. However, among the responding centers, the majority reported the absence of a formal transition protocol. We believe this further underlines the relevance of the issue and suggests that even among engaged centers, the transition process remains a significant unmet need. The participation of a consistent number and a very detailed status of participating HCPs encompassing opinions of pediatric and adult neurologists allowed for the initiation of a solid foundation to begin a process of harmonizing the transition practices among these highly specialized centers.

Since the survey was addressing mainly rare and complex epilepsies being addressed to ERN EpiCARE centers, some caution should be taken to generalize our results to the transition of other types, less complex, of epilepsies. However, many centers have dual expertise in their national setting and take charge of common epilepsies. Moreover, tailoring these programs to patients' specific needs in such programs can benefit all patients with epilepsies, regardless of their epilepsy type or severity.

5 | CONCLUSION

This survey underscores the critical need for creating transition programsspecialized for rare and complex epilepsies. Addressing barriers with tailored protocols, adequate infrastructures and resources, multidisciplinary involvement, and a timely, planned transfer can significantly enhance the whole transition process (Figure 2).

By incorporating patient and caregiver perspectives, we could improve continuity of care to support young adults with epilepsy in achieving greater autonomy.

AUTHOR CONTRIBUTIONS

Conceptualization: V.D.G., M.M., R.N.; Survey design and development: V.D.G., M.M., R.N., L.P., B.T.H., I.B., V.B., F.B., F.D., T.G., F.R., G.R., I.B.; Data analysis and interpretation: V.D.G., M.M., R.N.; B.T.H.; Drafting of the manuscript: V.D.G., M.M., R.N., L.P.; Critical revision of the manuscript: V.D.G., M.M., R.N., F.B., G.R.; Supervision: R.N.

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CONFLICT OF INTEREST STATEMENT

VDG has served on scientific advisory boards for Longboard Pharmaceuticals and Dr. Schar Kanso, has received grants from Jazz Pharmaceuticals, and has received speaker and consultancy fees from Jazz Pharmaceuticals, Orion, Novartis, Nutricia, Vitaflo, and Dr. Schar Kanso. FB has served on scientific advisory boards for Eisai, Takeda Pharmaceuticals, UCB, Angelini, Jazz Pharmaceuticals, and Ethypharm; has received speaker honoraria from UCB, Eisai, Angelini, and Ethypharm. F.R. has served on the scientific advisory board for Biocodex, GW-Jazz, and Zoogenix; speaker honoraria from UCB and GW-Jazz. The remaining authors have no conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. All authors have read and approved the final version of the manuscript.

ETHICS STATEMENT

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.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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