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Improving the transition from pediatric to adult epilepsy care: An expert opinion

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ABSTRACT

The transition from pediatric to adult care is a critical and challenging phase for young people with epilepsy (PwE), often marked by disruptions in care continuity, social stigma, isolation, and difficulties in achieving autonomy. These challenges are further compounded in PwE with neurodevelopmental or psychiatric comorbidities, often resulting in suboptimal medical and psychosocial outcomes and a perceived lack of adequate support. Ensuring a structured, effective *multiprofessional* transition is crucial for preserving quality of life and addressing key issues such as medication adherence, social integration, and life skills, including driving, employment, and relationships.

The TRUST project aims to enhance transitional care by promoting a holistic, integrated approach that considers not only medical but also psychological, familial, and social dimensions. A key initiative within the project is the development of targeted questionnaires designed to systematically assess the medical and psychosocial needs of PwE and their caregivers while evaluating the overall effectiveness of the transition process. These tools were informed by insights gathered during five macro-regional meetings across Italy, which facilitated discussions between pediatric and adult neurologists on best practices and challenges in transition care.

By combining structured data collection with national expert dialogue, the TRUST project seeks to bridge existing gaps in current transitional care practice. The findings will inform future interventions, with the ultimate goal of embedding these questionnaires into routine clinical practice to ensure a more seamless and individualized transition for PwE into adult care settings. Their implementation has the potential to improve communication between healthcare providers, enhance patient engagement, and contribute to better long-term outcomes in adult epilepsy care.

1. Introduction

Each year, approximately 1.1 million children with epilepsy transition into adulthood, shifting care from pediatry to adult neurology [1]. This phase, which coincides with adolescence, is characterized by significant physical and psychological changes and presents distinct challenges for young people with epilepsy (PwE) [2–4]. Risk factors during childhood and adolescence may persist into adulthood, resulting in poorer clinical outcomes [5–8]. While direct evidence linking successful transition to improved quality of life remains limited, holistic transition models can help exploring this potential association [9,10].

One key challenge during transition lies in differing management styles of the professionals involved [7,11]. Pediatric care typically adopts a holistic approach, addressing both the medical and

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psychosocial aspects of a patient's condition, including family dynamics and psychosocial features. In contrast, adult neurology tends to focus more narrowly on neurological symptoms, sometimes lacking appropriate communication with PwE or their caregivers, which can lead to a potential oversight of the broader psychosocial context [7,11,12]. In many cases, PwE first encounter their adult neurologist at the final stage of transition, with no prior contact while still under pediatric care, which may intensify the sense of discontinuity [12,13]. This shift can create uncertainty and a perception of inadequate support among PwE and their caregivers, potentially leading to low compliance, discontinuation of care, worsening of medical and psychosocial outcomes, as well as increased healthcare utilization over time, although specific cost analyses in epilepsy transition populations remain limited [14–17].

Patient empowerment is essential for a successful transition. Access to clear information, active participation in health management, and strong provider-patient relationships help mitigate uncertainty [18,19]. When patients lack trust in their healthcare providers or feel uninformed, their anxiety can intensify, negatively affecting their engagement with care [20,21]. Thus, communication between healthcare providers and patients is not only about information sharing but also about establishing trust, which has a direct impact on patients' satisfaction, anxiety, and overall transition experience.

Lack of appropriate communication can also result in pharmaceutical misuse, where patients commonly do not adhere to their prescribed medications and frequently do not discuss their medication practices with their healthcare providers [22]. Additionally, adult neurologists may sometimes not have access to complete medical histories, making it challenging to set up optimal treatment plans [13]. Moreover, many adult PwE transition into adult care without an updated etiological diagnosis (i.e. genetic), often because their initial evaluation occurred before advances in molecular genetics [23]. This gap may limit the application of more targeted treatments, leading to inadequate therapeutic plans and the continued use of multiple older-generation medications at suboptimal doses [8,14,23].

Beyond medical factors, psychosocial aspects play a crucial role in transition outcomes [9,10]. Lack of family and/or community support can equally affect the quality of transition of young PwE, resulting in enhanced social stigma and isolation which can make it challenging to achieve independence [5,9,24–26]. Family and community resources, including patient associations, can provide essential support to PwE and their caregivers, improving patient's well-being, adaptation, and prognosis [27,28]. Patient associations, in particular, can provide practical advice on aspects of daily life, including driving, sports, contraception, sleep quality, and employment [29,30].

Given the complexities of transition, structured approaches are needed to ensure continuity of care. In Italy, Diagnostic-Therapeutic Care Pathways (PDTA) have been developed at the regional level to ensure standardized, multidisciplinary management of PwE [31,32]. Among these, the PDTAs from Emilia-Romagna, Lombardy, Tuscany, and Veneto include dedicated sections on the transition from pediatric to adult care, providing specific recommendations to support continuity [31]. More recently, a fifth PDTA was approved in Sardinia (March 2024), further contributing to this national framework [32]. Despite these initiatives, significant gaps remain in clinician training and awareness of best practices for transition [14,23,33–35].

The TRUST project was developed to address these challenges by promoting a multidisciplinary, patient-centered transition model. At its core is the development of targeted questionnaires designed to systematically assess both medical and psychosocial needs during the transition process. Although not yet adopted and validated in routine clinical practice, these tools aim primarily to improve communication between pediatric and adult care teams, fostering a more coordinated and comprehensive transition. A secondary objective is to gather real-world experiences that can help identify common barriers and ultimately inform future policy decisions and healthcare strategies.

2. Questionnaires

A central component of the TRUST project is the development of structured questionnaires designed to address critical gaps in the transition from pediatric to adult epilepsy care. These tools will serve a dual purpose: systematically collecting data on patient and caregiver experiences while simultaneously informing future interventions to enhance the transition process.

The questionnaires were designed to provide a standardized framework for evaluating the medical, psychological, and social challenges faced by PwE and their caregivers. By capturing these dimensions, they offer healthcare providers a structured approach to developing patient-centered strategies aimed at improving long-term outcomes.

Although no formal Delphi process was adopted, the questionnaire design was guided by structured discussions in five macro-regional meetings involving experienced pediatric and adult neurologists. Moreover, a sociologist with expertise in epilepsy-related communication contributed to the design phase, ensuring that the content was culturally sensitive and aligned with the lived experience of PwE and their caregivers. The meetings, held in Bologna, Milan, Naples, Rome, and Verona, facilitated dialogue among healthcare professionals, enabling the exchange of perspectives on best practices and challenges in transition care. Insights during these sessions informed the structure and content of the questionnaires, ensuring their relevance to real-world clinical practice. Although patients were not formally involved in the macro-regional meetings, the content of the questionnaires was strongly informed by clinical experience and direct, long-term interactions with PwE and caregivers, ensuring their perspectives were substantially reflected in the final design.

Ultimately, a total of four distinct questionnaires were developed, each addressing different aspects of the transition process. Importantly, only one questionnaire should be administered per respondent at each time point, depending on the timing of the transition (before or after) and on whether the patient is self-sufficient or has severe epilepsy, in which case the caregiver is expected to complete it. Available in both paper and digital formats via QR code, these tools go beyond traditional clinical evaluations by incorporating quality of life assessments, psychosocial factors, and overall transition effectiveness. Each questionnaire takes approximately 10–15 min to complete, and no patient or caregiver is expected to complete more than one questionnaire. While not formally validated, they were designed for clinical usability. Unlike standardized quality of life assesments, these tools focus on transition-specific aspects including communication, perceived support, and system gaps [36]. Their implementation in clinical practice would allow for a more comprehensive understanding of patient and caregiver needs, ultimately shaping more effective transition models.

The first questionnaire was designed to target PwE transitioning from pediatric to adult care. Its primary function is to guide the initial conversations between the PwE and their new adult neurologist, and can be administered either by the child neurologist during the final pediatric visits or by the adult neurologist at the first adult care appointment. The document should also be included in the documentation transferred to the adult care provider (Fig. 1). A corresponding questionnaire was created for caregivers of PwE with severe forms of epilepsy who are not self-sufficient (Fig. 2).

The third questionnaire was developed to assess the effectiveness of the transition process from the perspective of PwE who have been under adult care for at least one year. This tool measures the perceived efficiency of the transition, identifies ongoing issues that may need attention, and evaluates the long-term success of transition initiatives (Fig. 3). An equivalent questionnaire was developed for caregivers of PwE with severe epilepsy who are not self-sufficient (Fig. 4).

3. Discussion

The transition from pediatric, family-centered care to adult

General Data

- Gender: Male, Female, Other
- Age: 16-17 years, 18-22 years, 22-25 years, over 25 years
- Education Level: Below high school, High school diploma, University attendance, Other (please specify)
- Current Occupation: Studying, Working, Other (please specify)
- Do you have siblings? (Yes/No)
- Who do you live with? (please specify)
- Are there any family members with disabilities? (Yes/No)
- Do your parents live together? (Yes/No)
- Education level of Parent 1: Below high school, High school diploma, College degree, Other (please specify)
- Education level of Parent 2: Below high school, High school diploma, College degree, Other (please specify)
- Occupation of Parent 1: (please specify)
- Occupation of Parent 2: (please specify)

Emotional and Cognitive Well-being

Family Context:

- Is epilepsy perceived negatively within your family? (Never, Sometimes, Often, Always)
- Are you autonomous in daily activities? (Never, Sometimes, Often, Always)

Living with Epilepsy:

- Does epilepsy make you lose confidence in the future? (Never, Sometimes, Often, Always)
- How satisfied are you with your health status? (Rating 1 to 4; 1=Poor, 2=Fair, 3=Good, 4=Excellent)
- How much does epilepsy impact your daily life? (Rating 1 to 4; 1=Very little/Not at all, 2=A little, 3=Moderately, 4=A lot)
- What aspects of your daily life does epilepsy impact? (Multiple choice possible)
    - None
    - Fatigue
    - Negative thoughts
    - Concentration difficulties
    - Instability
    - Eating habits
    - Physical activity
    - Sexuality/libido
    - Other (please specify)
- Are you afraid of having a new seizure? (Never, Sometimes, Often, Always)

Pharmacological Therapy and Quality of Life:

- Do you think your therapy negatively affects your quality of life? (Yes/No)
- Are you afraid to change your current therapy? (Yes/No)
- Are you autonomous in taking your medication? (Yes/No)
- Do you have other physical or psychological problems? (Yes/No)
- Are you taking medication for other illnesses? (Yes/No)
- Are you concerned about transitioning to adult clinic care? (Yes/No)

Physical Well-being:

Quality of Sleep:

- How many hours do you sleep? (please specify)
- Do you wake up feeling rested? (Never, Sometimes, Often, Always)
- Do you experience daytime sleepiness? (Never, Sometimes, Often, Always)

Interpersonal Relationships:

- Do you have people you can rely on in times of need? (Yes/No)
- Do you have friends? (Yes/No)
- If yes, are your friends aware that you suffer from epilepsy? (Yes/No)

Fig. 1. Questionnaire for persons with epilepsy (PwE) transitioning from pediatric to adult care, designed to guide initial consultations and deepen understanding of PwE experiences. Administered by pediatric neurologists at final visits or by adult neurologists at the first visit.

Social Inclusion:

- Education: Has epilepsy influenced or affected your academic performance at school/university? (Never, Sometimes, Often, Always)
- Have you had difficulties managing epilepsy at school/university? (Never, Sometimes, Often, Always)
- Have you had a support teacher or an individualized educational plan? (Yes/No)

Employment:

- Have you had difficulties finding/managing a job due to epilepsy? (Never, Sometimes, Often, Always)
- Do you think you will have difficulties finding/managing a job in the future due to epilepsy? (Yes/No)

Society:

- Do you believe there is correct information/knowledge about epilepsy? (Never, Sometimes, Often, Always)
- Do you think it is useful to have relationships with a patient association? (Yes/No)
- Are you part of an epilepsy community? (Yes/No)

Certifications:

- If you practice sports, have you had difficulty obtaining a competitive sports fitness certification from a sports medicine specialist? (Yes/No)
- Are you informed about how you can obtain a driving license?

Fig. 1. (*continued*).

neurology represents a significant and often challenging phase for PwE and their caregivers. This period is frequently characterized by a lack of multidisciplinary collaboration and coordination between pediatric and adult neurology teams, as well as by a lack of effective communication between adult neurologists and PwE or their caregivers [12]. Insights from macroregional meetings highlighted significant regional disparities in implementing multidisciplinary practices in Italy. Notwithstanding existing PDTAs, healthcare institutions often lack the operational frameworks to support best practices in transition, exacerbated by logistical constraints and a cultural gap between pediatric and adult care. Such inconsistency leads to varied experiences for PwE; some benefit from well-coordinated transitions, while others face fragmented care and a feeling of abandonment. Addressing these issues requires structured interventions to ensure continuity of care and optimize long-term patient outcomes [37]. While existing tools like the Australian Transition Questionnaire, GOT Transition, and Ready-Steady-Go offer general guidance, they are either not epilepsy-specific, require adaptation, or are too detailed for routine use [38–40]. In contrast, the TRUST questionnaires were specifically developed with a focus on epilepsy and aim to address both medical and psychosocial needs of PwE and their caregivers. They are intentionally brief, practical, and adaptable to different patient profiles and key stages of the transition process. While they do not serve as formal health passports, these tools represent a preliminary yet meaningful step toward enhancing communication between care teams and supporting continuity of care during this critical phase. These tools aim at providing a structured and standardized means of capturing the lived experiences of young adults, identifying specific barriers to effective transition, and highlighting critical gaps that could compromise both medical care and psychosocial well-being. By integrating patient-reported insights, the questionnaires reinforce a holistic approach, recognizing that medical stability alone is insufficient for a successful transition. Emotional adjustment, social inclusion, and family support are integral factors that influence adherence, independence, and long-term patient outcomes. Despite their potential value, these questionnaires are not yet embedded in routine clinical practice. However, they represent an essential step toward a more structured and patient-centered transition model and should be systematically integrated into standard care to ensure that both medical and psychosocial dimensions are adequately addressed.

In addition to assessing patient experiences, the questionnaires have the potential to enhance collaboration between pediatric and adult neurology teams. Effective co-management between these specialists is essential for a smooth transition, particularly in the optimization of pharmacotherapy [8,23]. Regular joint reviews and therapeutic adjustments (therapeutic cleanup) should be conducted to ensure a comprehensive evaluation of the patient's medication history, to reduce the risk of side effects and account for pharmacoresistance phenomena [14]. Ideally, an officially recognized period of co-management between pediatric and adult neurologists should be established, reinforcing the importance of multidisciplinary collaboration in transition care. While the questionnaires are intended to be administered by either pediatric or adult neurologists, their structured format can support communication if systematically shared across teams, serving as a transition summary and continuity tool.

Beyond their immediate role in patient care, the data collected from these questionnaires can provide meaningful insights into the current state of transition practices. By identifying gaps and challenges, they offer an evidence-based foundation for improving transition strategies and informing future policy changes. In parallel, a structured, ongoing information campaign targeted at adult neurologists in epilepsy centers will be essential in raising awareness of best practices, ensuring that transition care evolves based on real-world patient and caregiver experiences. Institutional support will be key in facilitating the widespread adoption of these strategies.

Effective communication between healthcare providers and PwE is essential to fostering trust, which in turn influences healthcare engagement and adherence [41]. Trust is built not only through clinical expertise but also through clear, transparent communication that reassures patients during this vulnerable period. The structured use of patient-reported outcomes, such as those gathered through the TRUST questionnaires, can enhance this communication by ensuring that patient concerns and expectations are actively acknowledged and addressed.

Family and community efforts, such as patient associations, also play a crucial role in supporting PwE during the transition. For instance, the community can provide a crucial platform for patients and caregivers to share experiences with others facing similar challenges, fostering a sense of solidarity and mutual understanding. Additionally, associations can assist patients in accessing social services, particularly in cases involving disabilities, further enhancing their quality of life and integration into society. Transitioning during adolescence can also be the ideal time to effectively communicate practical aspects related to sexuality, employment, contraception, and driving. It is important to note that the questionnaires were not designed as educational tools *per se*. However, the insights gathered from them can further identify areas where additional education or intervention may be needed. Providing easily accessible, structured educational materials tailored to young PwE could be particularly beneficial in addressing transition challenges.

General Data of the Person with Epilepsy

- Gender: Male, Female, Other
- Age: 16-17 years, 18-22 years, 22-25 years, over 25 years
- Educational Level: Below high school, High school diploma, Other (please specify)
- Current Occupation: Studying, Working, Other (please specify)
- Does the person have siblings? (Yes/No)
- With whom does the person live? (please specify)
- Are the parents cohabiting? (Yes/No)
- Are there other family members with disabilities? (Yes/No)
- Who is the caregiver? (please specify)
- Educational Level of Parent 1: Below high school, High school diploma, College degree, Other (please specify)
- Educational Level of Parent 2: Below high school, High school diploma, College degree, Other (please specify)
- Occupation of Parent 1: (please specify)
- Occupation of Parent 2: (please specify)

Emotional and Cognitive Well-being Family Context:

- Is the epilepsy experienced negatively within your family? (Never, Sometimes, Often, Always)
- Does the person with epilepsy require continuous assistance in daily activities? (Yes/No)
- Does the person with epilepsy have reduced autonomy due to:
    - Motor disability? (Yes/No)
    - Cognitive disability? (Yes/No)
    - Behavioral disability? (Yes/No)
- Are there moments of difficulty between you and the person you care for? (Never, Sometimes, Often, Always)

Pharmacological Therapy and Physical Well-being

Pharmacological Therapy:

- Do you think the therapy has negative effects on the quality of life of the person you care for? (Never, Sometimes, Often, Always)
- Are you afraid to change the current therapy of the person you care for? (Never, Sometimes, Often, Always)
- Does the person you care for suffer from other physical and/or psychiatric diseases? (Yes/No)
- If yes, does the person take other medications besides those for epilepsy? (Yes/No)
- Does the person require rehabilitation? (Yes/No)
- Is the person autonomous in taking their therapy? (Yes/No)
- Are you concerned about the transition of the person to adult clinic care? (Never, Sometimes, Often, Always)
- Are you concerned about managing the future of the person when they will be alone? (Never, Sometimes, Often, Always)

Dietary Habits and Sleep Quality:

- Does the person follow a special diet? (Never, Sometimes, Often, Always)
- Does the person sleep well? (Never, Sometimes, Often, Always)
- Does the person suffer from daytime sleepiness? (Never, Sometimes, Often, Always)

Social Inclusion:

- Have there been difficulties in managing the person in their educational journey? (Never, Sometimes, Often, Always)
- Does the person have a disability certification? (Yes/No)
- Does the person receive a disability allowance? (Yes/No)
- Does the person have a legal guardian? (Yes/No)
- Does the person rely on support centers in their free time? (Yes/No)
- Do you think it is useful to have relationships with a Patient Association? (Yes/No)
- As a caregiver, are you part of an epilepsy community? (Yes/No)

Fig. 2. Questionnaire for caregivers of persons with epilepsy with severe epilepsy, designed to establish dialogue with adult neurologists. Administered by pediatric neurologists at final visits or by adult neurologists at the first visit.

Ultimately, a successful transition ensuring continuity of care for PwE requires a significant cultural and organizational shift within the adult healthcare system. Raising awareness among adult neurologists about best practices, implementing targeted training and dedicated initiatives, and promoting the use of standardized patient-reported outcomes such as questionnaires are essential steps in improving transition care. Although the current post-transition questionnaires primarily assess the perceived quality of the transition process, future iterations could benefit from integrating specific quality of life measures to better capture changes in psychosocial well-being. By combining institutional support, multidisciplinary collaboration, and patient-centered approaches, these efforts can help ensure that PwE experience a more seamless and supportive transition into adult neurology care.

General Information

- Gender: Male, Female, Other
- Age: 16-17 years, 18-22 years, 22-25 years, over 25 years
- Educational Level: Below high school, High school diploma, Other (please specify)
- Current Occupation: Studying, Working, Other (please specify)
- Do you have siblings? (Yes/No)
- Who do you live with? (please specify)
- Are your parents cohabiting? (Yes/No)
- Are there any other family members with disabilities? (Yes/No)
- Education Level of Parent 1: Below high school, High school diploma, College degree, Other (please specify)
- Education Level of Parent 2: Below high school, High school diploma, College degree, Other (please specify)
- Occupation of Parent 1: (please specify)
- Occupation of Parent 2: (please specify)

Questions

- Have you had joint consultations with both the adult and pediatric neurologists during your transition to adult care? (Yes/No)
- If yes, how satisfied were you with these consultations? (Rate 1 to 4; 1=Very dissatisfied, 2=Somewhat dissatisfied, 3=Somewhat satisfied, 4=Very satisfied)
- During your transition to adult care, did you feel supported and welcomed by the neurologist and the adult care team? (Yes/No)
- During your transition to adult care, did you perceive that there was an effective exchange of information between the adult and pediatric neurologists? (Yes/No)
- Have you ever considered discontinuing the transition and not following through with the care at the adult epilepsy center? (Never, Sometimes, Often, Always)
- Did you autonomously choose the adult care center? (Yes/No)
- If chosen autonomously, how did you make the selection? (please specify)

Fig. 3. Evaluation questionnaire for persons with epilepsy, assessing transition process effectiveness after one year in adult care. Measures transition smoothness and ongoing issues, administered by adult neurologists.

General Information of the Person with Epilepsy

- Gender: Male, Female, Other
- Age: 16-17 years, 18-22 years, 22-25 years, over 25 years
- Educational Level: Below high school, High school diploma, Other (please specify)
- Current Occupation: Studying, Working, Other (please specify)
- Does the person have siblings? (Yes/No)
- Who does the person live with? (please specify)
- Are the parents cohabiting? (Yes/No)
- Are there other family members with disabilities? (Yes/No)
- Education Level of Parent 1: Below high school, High school diploma, College degree, Other (please specify)
- Education Level of Parent 2: Below high school, High school diploma, College degree, Other (please specify)
- Occupation of Parent 1: (please specify)
- Occupation of Parent 2: (please specify)

Questions

- Has the person with epilepsy undergone joint consultations between the adult neurologist and the pediatric neurologist during the transition to adult care? (Yes/No)
- If yes, were you satisfied with these consultations? (Yes/No)
- During the transition to adult care, did you feel supported and welcomed by the neurologist and the team at the adult care center? (Never, Sometimes, Often, Always)
- During the transition to adult care, did you perceive that there was an effective transfer of information between the adult and pediatric neurologists? (Yes/No)
- Have you ever considered, as a caregiver, discontinuing the transition and not following through with the care at the adult epilepsy center? (Never, Sometimes, Often, Always)
- Did you autonomously choose the adult care center? (Yes/No)
- If the choice was made autonomously, how did you make the selection? (please specify)

Fig. 4. Evaluation questionnaire for caregivers of persons with epilepsy with severe epilepsy, capturing feedback on the transition process after one year, administered by adult neurologists.

4. Conclusion

The transition from pediatric to adult care for individuals with epilepsy requires structured strategies that go beyond medical continuity, incorporating psychosocial support and patient-centered interventions. The TRUST project's targeted questionnaires represent a crucial step toward achieving this goal by providing a standardized approach to evaluating patient experiences, identifying transition barriers, and informing future improvements. These tools offer practical advantages, including brevity, accessibility, and adaptability to different clinical settings. However, limitations include lack of formal validation, one-time administration, and absence of a scoring system. These aspects may be addressed in future refinements. As of today, their integration into clinical practice could enhance communication between healthcare teams, ensure that both medical and psychosocial needs are addressed, and promote a more individualized transition process. Future efforts should focus on embedding these tools into routine care, using their insights to refine transition protocols, guide professional training, and shape policies that support PwE beyond adolescence. Institutional commitment to these advancements will be essential in transforming transition care into a more structured, data-driven, and patient-focused process. Ultimately, our proposal underscores the need to employ multidimensional tools in routine care, as a foundation to support better long-term outcomes for transitioning PwE.

CRediT authorship contribution statement

Flavio Villani: Writing – review & editing, Validation, Supervision, Conceptualization. **Francesca Bisulli:** Writing – review & editing, Validation, Supervision, Conceptualization. **Francesca Darra:** Writing – review & editing, Validation, Supervision. **Michaela Liuccio:** Writing – review & editing, Validation, Supervision. **Nicola Specchio:** Writing – review & editing, Validation, Supervision, Conceptualization.

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Declaration of competing interest

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