

Research Paper

Knowledge, attitudes, and perceptions regarding the transition of epilepsy care among neurologists and pediatric neurologists in Colombia, 2025–2026: A convergent study

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ABSTRACT

Introduction: The transition of epilepsy care from childhood to adulthood is a complex process that directly impacts treatment adherence, quality of life, and clinical outcomes. In Colombia, the implementation of structured transition programs is limited, representing a critical gap in care.

Objective: To assess the knowledge, attitudes, and perceptions regarding the transition in epilepsy care among residents and professionals in neurology and neuropediatrics in Colombia.

Methods: A mixed-methods study with a convergent design was conducted. The quantitative component included 60 participants (29 adult neurologists and 31 neuropediatricians) who completed a structured questionnaire. The qualitative component was conducted through focus groups ($n = 8$) using a phenomenological approach. Bivariate statistical analyses and odds ratio calculations were performed. Qualitative analysis was conducted using thematic coding. Results were integrated through methodological triangulation using joint matrices.

Results: No significant differences were found in most variables related to knowledge and practices. However, pediatric neurologists reported higher levels of training in transition care (52% vs. 21%; $p = 0.013$) and placed greater emphasis on psychosocial aspects and patient autonomy. The availability of formal protocols was low in both groups. Qualitative analysis revealed structural barriers such as system fragmentation, lack of coordination, and the absence of defined processes. Triangulation showed a predominance of convergent findings in emotional dimensions and patient-centered care, and divergences in organizational aspects of the health system.

Conclusions: There is a shared understanding of the transition process, but structural and training gaps persist that limit its implementation. It is necessary to develop structured programs, strengthen professional training, and improve coordination between levels of care. These findings should be interpreted considering the study's limitations, including the small sample size, convenience sampling, and the limited qualitative sample.

1. Introduction

Epilepsy is a chronic neurological disorder characterized by a lasting predisposition to experience epileptic seizures with significant neurobiological, cognitive, and psychosocial consequences. It is recognized as one of the most prevalent diseases of the central nervous system (CNS)

and represents a major global public health problem [1–4], as it is classified as a chronic noncommunicable disease; and according to the World Health Organization (WHO), it poses a significant challenge to health systems, especially in low- and middle-income countries [1,2,5–7].

Managing epilepsy in pediatrics presents distinct challenges,

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particularly during the shift to adult healthcare. This process, known as transition, is defined as a planned individual stage in which adolescents and their families are prepared to ensure adequate care during adulthood [6–9].

It is estimated that 70% of patients diagnosed with epilepsy in childhood survive for 20 years after diagnosis. The transition becomes a critical process aimed at minimizing risks such as morbidity, mortality, and loss of treatment adherence, while preparing patients with chronic conditions and their families to independently and effectively manage care in adulthood [4,7]. This process is particularly complex in epilepsy not only due to the risks inherent to adolescence, but also because of the unpredictable nature of seizures, the frequent presence of neurological and psychiatric comorbidities, and the disease-associated social factors [8–12].

Globally, several transition models have proven effective. However, despite their relevance, there is a gap in the systematic implementation of structured transition programs for epilepsy, particularly in resource-limited settings such as Latin America [10–13]. In Colombia, these difficulties are evident as transition programs are scarce or nonexistent. This constitutes a critical gap: an inadequate transition is associated with higher morbidity, increased risk of mortality, loss to follow-up, and decreased treatment adherence, directly affecting quality of life [7,9,14–16].

Consequently, strengthening transition strategies tailored to the clinical and sociocultural context is a top priority, not only for neuro-pediatricians, but also for adult neurologists. Therefore, the objective of this study is to assess the knowledge, attitudes, and perceptions regarding transition in epilepsy care among residents and professionals in neurology and neuropediatricians. It also aims to understand, from a phenomenological perspective, the lived experiences and meanings attributed to the transition and transfer process for patients with epilepsy. Additionally, the study seeks to integrate these subjective experiences with quantifiable measures of knowledge and attitudes, using a mixed-methods approach to provide a more comprehensive understanding of the phenomenon.

2. Materials and methods

2.1. Study design and setting

A mixed-methods study with a convergent design was conducted, which was approved by the Ethics Committee of the University of Antioquia (Protocol No. 095). All participants signed informed consent forms, and the confidentiality of the information was guaranteed.

The study included a cross-sectional, observational, quantitative, analytical component and a qualitative component using a phenomenological approach based on focus groups. Both components were integrated to provide a holistic understanding of the transition process in epilepsy, in line with the recommendations of the STROBE and the GRAMMS statements.

The phenomenological qualitative component aimed to gain an in-depth understanding of the experiences, perceptions, and meanings that healthcare professionals attribute to the transition process in epilepsy. Through focus group meetings, experiences, barriers, facilitators, and perceived needs were explored. This approach allowed for the capture of the complexity of the phenomenon from the perspective of the involved stakeholders, as well as the complementation of the quantitative findings. The call for participants, aimed at specialists and medical residents nationwide, was disseminated through university hospitals, social media, and the scientific societies: the Colombian Association of Neurology (ACN) and the Colombian Association of Pediatric Neurology (ASCONI). A non-probabilistic convenience sampling method was used.

2.2. Measurements

Following a comprehensive review of the literature and recommendations from experts in epilepsy transition, a structured questionnaire (checklist-style with open-ended questions) was designed to assess knowledge, attitudes, barriers, and needs regarding the transition for adolescents with epilepsy. The draft instrument was reviewed by an expert in epilepsy transition care, who added and revised items to improve clarity and content relevance. No pilot testing was conducted prior to dissemination. The final version was administered digitally via the SurveyMonkey® platform, with an estimated response time of 20–25 min. The final sample consisted of 60 participants (29 adult neurologists and 31 pediatric neurologists). The response rate could not be calculated because the survey was disseminated through open channels (social media and professional associations) rather than direct invitation to a defined sampling frame. Focus group meetings were conducted using semi-structured interviews with open-ended question guides. Eight individuals participated (four adult neurologists and four pediatric neurologists).

2.3. Statistical analysis

Statistical analysis was performed using the R software (R Foundation for Statistical Computing, Vienna, Austria, version 4.5.2). Initially, a data cleaning and variable transformation process was carried out, including recoding categorical variables and grouping infrequent categories. Categorical variables were expressed as absolute and relative frequencies, while continuous variables were summarized using the median and interquartile range (IQR).

A descriptive analysis was performed stratified by medical specialty (adult neurology vs. pediatric neurology). For comparisons between groups, bivariate tests were used according to the nature of the variables: the Mann–Whitney test for nonparametric continuous variables, and Fisher's exact test or the chi-square test for categorical variables. Likert-type scales were treated as ordinal variables.

Variables related to knowledge, clinical practices, barriers, and clinical indicators were interpreted by prioritizing those with the highest frequency. Additionally, odds ratios (OR) with 95% CI were calculated using 2×2 tables to evaluate factors associated with the implementation of the transition process. A p -value < 0.05 was considered significant.

The qualitative analysis was conducted in ATLAS.ti (Scientific Software Development GmbH, 2026) using open coding, category development, and consolidation into central themes, applying thematic coding to identify recurring themes. For the comparative analysis, a code–document matrix was constructed, in which the absolute and relative frequencies of the codes were calculated by focus group. This matrix was used to construct a Sankey diagram.

Methodological triangulation was performed by integrating quantitative and qualitative findings through joint displays in Python software (Python Software Foundation version 3.14.3). The categories emerging from the qualitative analysis, obtained from focus groups using a phenomenological approach, were compared with the variables from the structured questionnaire. To this end, a conceptual correspondence was established between qualitative categories and comparable quantitative variables. The findings were classified as convergent when both sources showed consistent results, divergent when there was a discrepancy between the quantitative data and the reported experience, and complementary when the qualitative categories did not have an equivalent variable in the interview.

The confidentiality of the information and the anonymity of the sources were guaranteed.

3. Results

A mixed-methods analysis was conducted integrating quantitative

and qualitative methods. The results are presented in three sections: first, the quantitative analysis, organized by domain; second, the qualitative analysis, focused on interpreting participants' perceptions and experiences; and finally, a triangulation of the data from the two preceding sections.

3.1. Quantitative analysis

A total of 60 participants were included, comprising adult and pediatric neurologists who completed the structured questionnaire. The general characteristics did not differ significantly across most variables. However, a significant difference by gender was observed, with a higher proportion of women in pediatric neurology. Most participants in both groups work in university hospitals. (Table 1).

In the comparative analysis between adult and pediatric neurologists regarding general knowledge of transition (Table 2), no statistically significant differences were found in most variables. Although a higher proportion of pediatric neurologists reported being familiar with the concept of transition (84% vs. 76%; $p = 0.4$) and the difference between transition and transfer (39% vs. 24%; $p = 0.2$), these differences were not significant. Training on clinical transition was more common among pediatric neurologists (52% vs. 21%; $p = 0.013$). Likewise, although it did not reach statistical significance, pediatric neurologists tended to perform more structured transition processes (48% vs. 24%; $p = 0.051$). Finally, the availability of formal transition protocols for epilepsy was low in both groups, with no significant differences ($p = 0.6$).

Increased patient independence was significantly more frequently selected by pediatric neurologists as an indicator for evaluating an effective transition process (84% vs. 59%; $p = 0.030$). (Table 3).

Pediatric neurologists rated multiple key components of attitudes and perceptions regarding the transition more highly than adult neurologists, especially in the importance of disease awareness ($p = 0.019$), lifestyle education ($p = 0.024$), risks in adolescence ($p = 0.032$), psychosocial support ($p = 0.004$), preparation for independent living ($p = 0.001$), and the need for structured programs ($p = 0.016$). Although both groups recognize the importance of these aspects, pediatric neurologists tend to rate them more frequently as "very important." No significant

Table 1
General characteristics of the respondents.

Variable	Adult Neurology N = 29 ¹	Pediatric Neurology N = 31 ¹	p- value ²
Age	37 (29.5–44.5)	42 (38–45.75)	0.16
Did not respond	2	1	
Gender			0.038
Female	10 (34%)	19 (61%)	
Male	19 (66%)	12 (39%)	
Years of clinical experience			0.4
<5 years	10 (34%)	5 (16%)	
>10 years	10 (34%)	12 (39%)	
0 years	2 (6.9%)	2 (6.5%)	
5–10 years	7 (24%)	12 (39%)	
Primary place of work			0.2
Institutional practice	0 (0%)	4 (13%)	
Private practice	3 (10%)	2 (6.5%)	
Non-university hospital	4 (14%)	6 (19%)	
University hospital	22 (76%)	19 (61%)	
Department where clinical practice is carried out			0.3
Antioquia	14 (48%)	12 (39%)	
Cundinamarca	7 (24%)	3 (9.7%)	
Valle del Cauca	2 (6.9%)	4 (13%)	
Atlántico	2 (6.9%)	2 (6.5%)	
Bolívar	0 (0%)	4 (13%)	
Others	4 (14%)	6 (19%)	

¹ Median (RIC); n (%).

² Mann Whitney U; Pearson's Chi-square test; Fisher's exact test.

Table 2
General Knowledge About Transition.

Variable	Adult Neurology N = 29 ¹	Pediatric Neurology N = 31 ¹	p- value ²
Are you familiar with the concept of transition?			0.4
No	7 (24%)	5 (16%)	
Yes	22 (76%)	26 (84%)	
Do you know the difference between transition and transfer?			0.2
No	22 (76%)	19 (61%)	
Yes	7 (24%)	12 (39%)	
Have you received any training on clinical transition?			0.013
No	23 (79%)	15 (48%)	
Yes	6 (21%)	16 (52%)	
Do you carry out transition processes?			0.051
No	22 (76%)	16 (52%)	
Yes	7 (24%)	15 (48%)	
Do you have a formal transition protocol for epilepsy?			0.6
No	26 (90%)	26 (84%)	
Not sure	3 (10%)	3 (9.7%)	
Yes	0 (0%)	2 (6.5%)	

¹ n (%).

² Pearson's Chi-squared test; Fisher's exact test.

Table 3
Clinical indicators for evaluating an effective transition process.

Variable	Adult Neurology N = 29 ¹	Pediatric Neurology N = 31 ¹	p- value ²
Continuity of care	25 (86%)	23 (74%)	0.2
Improved quality of life for the patient	21 (72%)	26 (84%)	0.3
Fewer visits to the emergency room and hospitalizations	20 (69%)	24 (77%)	0.5
Increased patient independence	17 (59%)	26 (84%)	0.030
Reduction in seizures	17 (59%)	23 (74%)	0.2

¹ n (%).

² Pearson's Chi-squared test.

differences were found in perceptions of the training received ($p = 0.11$); both groups perceive their training as insufficient (supplementary material, Appendix 4).

After calculating the odds ratios, only clinical experience of more than 10 years was a predictor of transition processes being performed (OR 6.56; 95% CI: 2.04–21.09; $p = 0.002$). Fig. 1.

3.2. Qualitative analysis

The categories related to the transition process in epilepsy were grouped into five clusters: subjective perception, emotions and conflicts, perceived needs, barriers to care, and expectations. In the subjective perception cluster, elements such as meaningful experiences, a sense of family, and adaptation in communication stood out. In the emotions and conflicts category, distress, anxiety, frustration, resistance, and over-protection regarding the transition process predominated, reflecting the difficulty of the disengagement process:

"It's a little hard for me to let them go, but it's also hard for the patients to leave; they worry about what will happen when they switch doctors" (GF1 P 1).

Perceived needs included implementing a structured process, patient education and empowerment, support for follow-up, and strengthening self-care. Barriers, meanwhile, encompassed administrative factors,

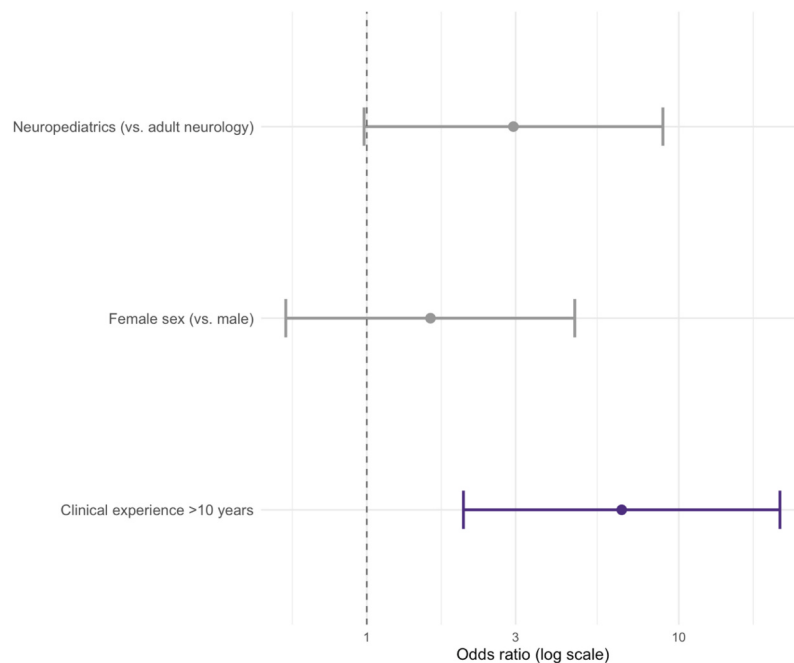


Fig. 1. Factors associated with the transition process. Displays a forest plot of factors independently associated with completing the transition process, presented as odds ratios (OR) on a logarithmic scale. Three variables are shown: Neuropediatric specialty (vs. Adult Neurology) and Female sex (vs. Male sex) (both in gray) have wide confidence intervals that cross or near OR = 1, suggesting uncertain or modest associations. In contrast, Clinical experience > 10 years (highlighted in violet) demonstrates a notably higher OR (approximately 7–8), with its entire confidence interval well above 1. Clinical experience was assessed independently of specialty, as both adult and pediatric neurologists could report more than 10 years of practice.

health system issues, and clinical team challenges, with particular emphasis on service fragmentation, communication difficulties, the absence of protocols, and a lack of coordination between specialties. See Fig. 2.

The comparative analysis between the focus groups revealed differences in the distribution of codes. Neuropediatricians reported a higher proportion of codes related to structural barriers, particularly the lack of defined processes (73.9%), the absence of teamwork (73.7%), and administrative barriers (65.4%). This group also emphasized educational elements such as patient education (90%), empowerment (81.8%), and self-care (100%) (see table in [supplementary material](#), Appendix 5).

For their part, adult neurology professionals most frequently highlighted aspects related to discontinuity of care, including abrupt change (100%), lack of continuity (100%), and the absence of clear information (100%). Both groups agreed on the presence of a significant emotional burden, particularly in terms of distress, concern about change, and uncertainty (Appendix 5). The codes where the different specialties agreed refer to the barriers that make the transition process difficult. (Fig. 3).

3.3. Data triangulation

Methodological triangulation performed using joint displays in Python allowed for the integration of quantitative and qualitative findings, revealing a predominance of convergent and complementary results.

Among the convergent findings, emotional dimensions such as distress, anxiety, and uncertainty experienced by professionals during the transition and transfer process were observed. The complementary findings identified in the emerging categories of the semi-structured interview were: meaningful experience, sense of family, and need for support. In that interview, participants highlighted the importance of the family during childhood in both groups:

“Family involvement is very important, and it is different from that of adults” (GFAP2).

The need for support in adulthood was also commented:

“I think children have better-established pathways than adults... which ensures support.” (GFAP2).

Other factors like comorbidities, such as cognitive impairment, were also identified as barriers to performing the transition; one participant added: *“But when children have disabilities, that transition is very difficult; parents resist it. I’ve had patients who petition to be allowed one last consultation... because it’s the last one. The last time is very important to people”* (GFNIP1).

Likewise, in the “significant experience” category, participants noted how the bonds formed during pediatric care create resistance to transfer: *“First, letting them go is difficult. It’s a bit hard for me to let them go. But also, it’s hard for the patients to leave”* (GFNIP1). These categories have no direct equivalents in the structured questionnaire.

The divergent findings focused on the structural and organizational components of the healthcare system, including administrative barriers, difficulties in coordinating appointments, communication problems, team fragmentation, and the absence of formal transition processes. ([Supplementary material](#), Appendix 6).

4. Discussion

This study assessed the knowledge, attitudes, and perceptions regarding the transition in epilepsy among a convenience sample of Colombian neurologists (residents, pediatric and adult neurologists) using a mixed-methods design with convergent integration. We found that the transition process is not systematically implemented but depends largely on individual factors such as clinical experience, prior training, and the institutional context. The International League Against Epilepsy (ILAE) states that just 9% of professionals have structured transition programs, highlighting a worldwide care gap, not just a local one. This is also consistent with the findings of McManus MA et al. [17], who noted that transition in chronic diseases remains a complex process, especially in middle-income systems with limited resources such as Colombia [18–20]. It is important to note that although some

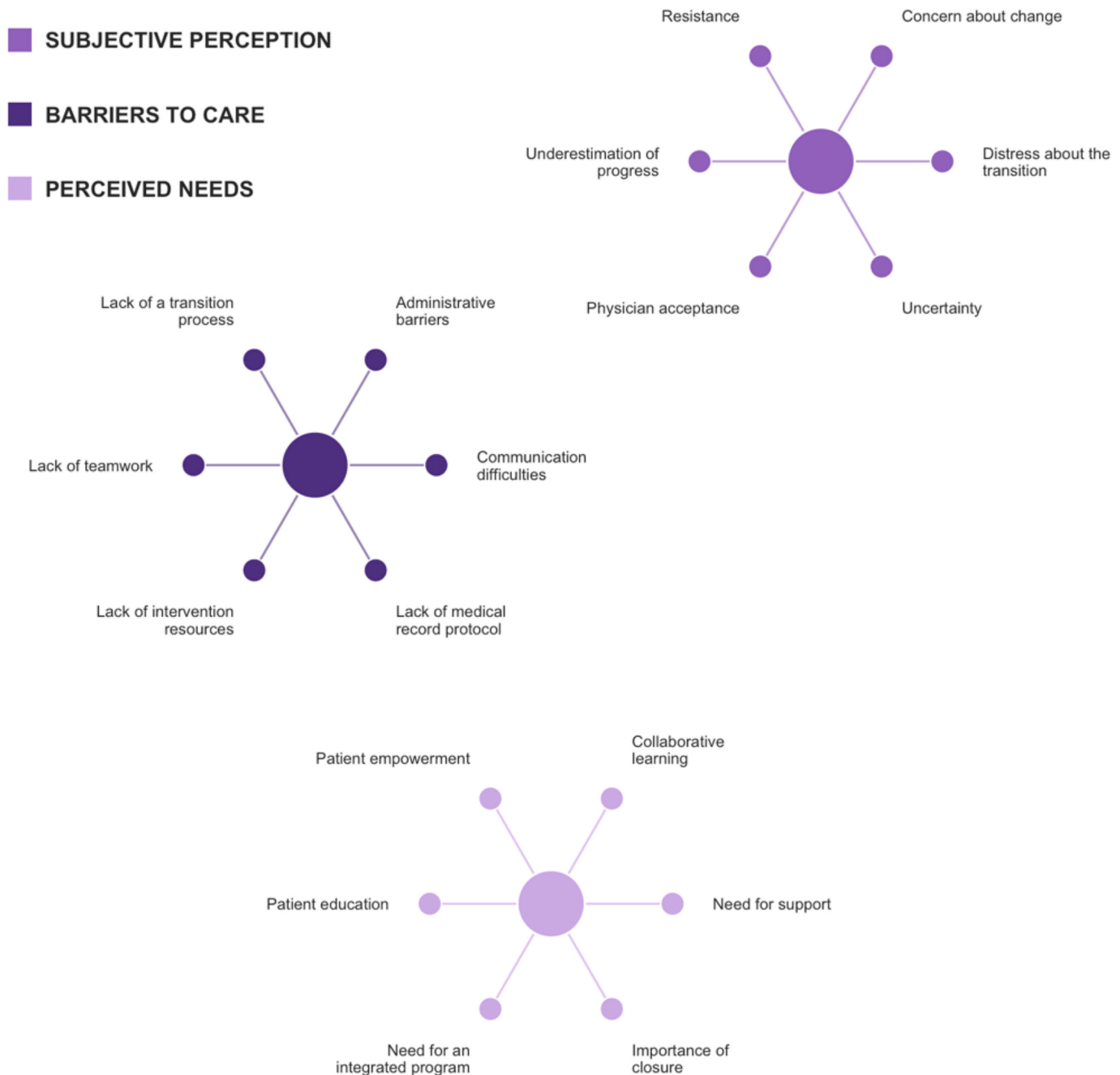


Fig. 2. Relational model of categories in the transition process for patients with epilepsy. Relational concept map illustrating the qualitative thematic framework derived from the transition process for patients with epilepsy. Three central domains anchor the model: Subjective Perception, Perceived Needs, and Barriers to Care, each color-coded and interconnected through multiple subcategories.

professionals selected the option of implementing transition protocols, upon further inquiry into what these entailed, only one neuropsychiatric specialist reported having a formal protocol. The others referred solely to a telephone conversation with the treating colleague, without using a standardized protocol.

From the quantitative analysis, no significant differences were found in most knowledge and practice variables between adult and pediatric neurologists, suggesting a shared conceptual foundation for the transition process. Professionals recognize the importance of the transition but do not necessarily have the tools to implement it [17,22].

Notable differences were identified: a higher proportion of the transition process was observed in pediatric neurology compared to adult neurology (48.4% vs. 24.1%). The transition process is

accompanied by a greater emphasis on dimensions such as autonomy, psychosocial support, and preparation for independent living. Usually, pediatric care emphasizes a patient-centered approach focused on development; by nature, the pediatric neurologist establishes a longitudinal relationship with the patient and their families, fostering a more comprehensive view of the process [4,21]. Many factors can be discussed regarding the facility in which neuropsychiatricians interact with patients and families; this may be because their training as pediatricians centers on a more holistic view of patients and on accompanying them through the developmental phases of an individual. In contrast, adult neurologists have less formal training and tend to prioritize traditional clinical outcomes such as continuity of care and reduced hospitalizations. This pattern has been described in studies such as those by While

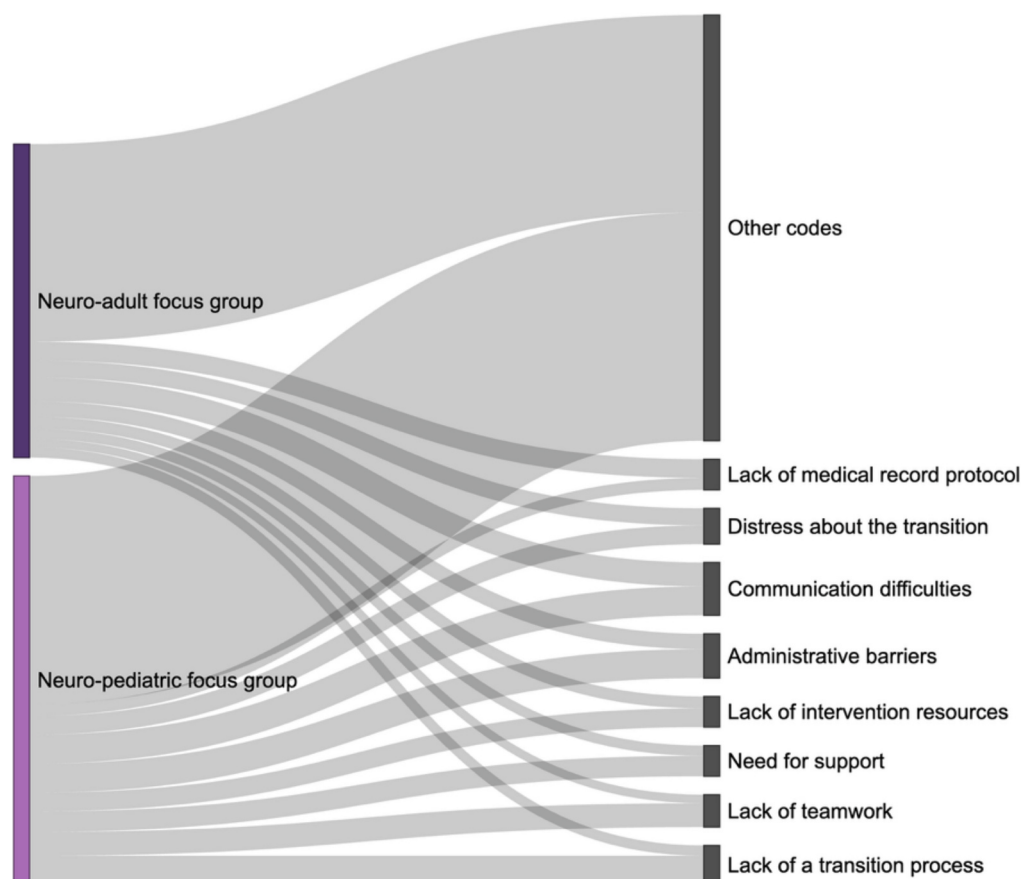


Fig. 3. Distribution of codes by focus group using a Sankey diagram. Sankey diagram illustrating the distribution and relative weight of qualitative codes identified across two focus groups: the Neuro-adult focus group (upper segment) and the Neuro-pediatric focus group (lower segment). The width of each flow reflects the frequency or prominence of each code within each group.

A. et al.; adult services may focus on biomedical aspects and the resolution of acute problems [21], whereas the pediatric model is family-centered [14,23,24].

In this sense, the difference in care models implies not only a shift in who is the focus of care but also in clinical priorities and in how the transition is interpreted. The pediatric approach tends to anticipate and support the transition process in a structured manner, whereas the adult approach often addresses its consequences when the process has not been adequately planned.

Qualitative analysis revealed that the transition is perceived as a complex process (not only clinical but also emotional) characterized by distress, uncertainty, and resistance. Parents are accustomed to the same healthcare provider during a long period of time; the sudden change can result in the “fear of transition”, a significant barrier for patients and professionals [6,12,25]. One possible explanation is that transition involves not only a change in care but also a reconfiguration of the therapeutic relationship, especially in chronic conditions with a high psychosocial burden such as epilepsy.

In addition, there were differences in how each specialty perceives the barriers in the process. Pediatric neurologists more frequently emphasized structural limitations, such as a lack of defined processes, teamwork, and administrative barriers. Adult neurologists highlighted problems related to discontinuity of care, which they linked to barriers in social support for adult patients. [11,26,27]. A possible explanation for this finding is that pediatric neurologists are involved in the initial phase of the process, so they identify the system’s limitations more clearly, while adult neurologists face the consequences of these failures, such as loss of follow-up and lack of clinical information. This also complements the results with the odds ratios. The pediatric neurologist

group had more professionals with over 10 years of experience (Table 1), which was associated with a higher probability of implementing a transition protocol (Fig. 1). Pediatricians are constantly aware that their time with patients is limited; once patients reach adulthood, they will be referred to another specialist. Combined with the ability to identify healthcare limitations, preparation for the moment of change is especially important. Additionally, in Colombia, some programs offer a pediatric neurology fellowship available to both pediatricians and adult neurologists, so to become a neuropsychiatrist, the physician must complete additional years of training, increasing the overall years of experience.

Methodological triangulation enabled us to integrate the structured interview and survey findings, showing that although there is agreement regarding the understanding of the process and its clinical importance, differences persist in its implementation, particularly in the organizational components. This has already been described in models of chronic disease care, where the main barrier is not knowledge, but rather the lack of systems to facilitate its application [12,13,20,26–29]. In the present study, this gap is evident when comparing the high value placed on the process with the limited availability of formal protocols.

The results should be interpreted with the study’s limitations in mind. The sample size and non-probability sampling limit the generalizability of the results. Furthermore, the study included only medical professionals, and most of the participants were affiliated with a university hospital; because they were constantly surrounded by residents and fellowship students, our participants may have been more aware of the importance of the transition process. Additionally, we did not incorporate other key stakeholders such as nurses, psychologists, or social workers, nor the perspectives of patients and caregivers. The

literature has shown that transition is a multidimensional process that requires the participation of these stakeholders to be effective [9,30]. Furthermore, the available evidence comes primarily from high-income countries, which limits its direct applicability to contexts such as Colombia, where structural barriers are greater [13,20,31].

5. Conclusions

Overall, the transition in epilepsy presents a paradox: there is adequate understanding of its importance, yet implementation remains limited and depends on individual factors.

The differences identified between pediatric neurology and adult neurology reflect not only variations in training but also in how each specialty experiences the transition process, is educated, and prefers to monitor. All of which influence its implementation.

The integration of mixed methods revealed that while the quantitative component identifies gaps in training and practice, the qualitative component highlights the emotional and systemic complexity of the process, providing a more comprehensive understanding of the physician's perspective. These results suggest that the development of transition programs for epilepsy must go beyond knowledge generation, focusing instead on creating organizational structures, specialized training, and integrating multidisciplinary teams.

In this regard, transition in epilepsy should not be understood solely as a clinical process but as a comprehensive one that requires coordination among stakeholders, levels of care, and sociocultural contexts to achieve a meaningful impact on health outcomes.

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Ethical Statement:

We confirm that we have read the journal's position on issues related to ethical publication and affirm that this report is consistent with those guidelines.

Data Availability Statement

The data supporting the findings of this study are available from the corresponding author upon reasonable request.

CRedit authorship contribution statement

Jesly Hael Doria Atencia: . **Angie Lizeth Galíndez González:** Writing – review & editing, Writing – original draft, Investigation. **Joel Doria Atencia:** Writing – review & editing, Validation, Software, Methodology, Investigation, Formal analysis, Data curation. **Dagoberto Cabrera Hemer:** . **Gustavo Ariza Marriaga:** Visualization, Validation, Supervision, Conceptualization. **Jaime Carrizosa Moog:** Writing – review & editing, Visualization, Validation, Project administration, Investigation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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