




ORIGINAL ARTICLE

Transition from pediatric to adult care among patients with epilepsy: Cross-sectional surveys of experts and patients in Korea

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Abstract

Objectives: Many pediatric patients with epilepsy require treatment beyond the pediatric age. These patients require transition to an adult epilepsy center. Currently, many centers worldwide run epilepsy transition programs. However, a standardized protocol does not exist in Korea. The basic data required to establish a transition program are also unavailable. We aimed to assess the status and perceptions of patients and epilepsy care providers on transition.

Methods: To assess the status of epilepsy transition, we retrospectively collected data from patients with epilepsy older than 18 years who visited our pediatric epilepsy clinic between March 1990 and July 2019. To assess the perception of transition, we surveyed patients, parents, pediatric neurologists (PN), and adult epileptologists (AE).

Results: In a retrospective chart review, 39 of 267 (14.6%) patients visited the adult epilepsy clinic after consulting a pediatric neurologist, and three patients returned to the pediatric center. The average patient age at transition was 23.29 ± 5.10 years. A total of 94 patients or their guardians and 100 experts participated in the survey. About half of the patients or guardians (44.7%) did not want to transition and emotional dependence was the commonest reason. Most patients (52.1%) thought that the appropriate age of transition was above 20 years. PNs had greater concerns about patients' compliance than AEs. Regarding the age of transition, AEs believed that a younger age (18 years) was more appropriate than PNs (20 years).

Significance: This study describes difficulties in the transition from pediatric to adult epilepsy centers without appropriate support. There were differences in perspectives among patients, parents, and adult and pediatric epilepsy care providers. This study can assist in creating a standardized protocol in Korea.

KEYWORDS

adult health care, epilepsy, pediatric, transition

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1 | INTRODUCTION

Epilepsy is a common neurological disorder with a prevalence of 5 in 1000 children.¹ Nearly 80% of children with epilepsy have at least one disability,² and five-year remission occurs in only 50%–80% of children.^{3,4} In addition, as children with epilepsy become adults, their physical, social, and emotional states change. In order to adapt well to this, environmental changes for epilepsy treatment in the form of transition must appropriately occur. There is a long history of research and design of the transition model, starting in Liverpool, United Kingdom (UK) in 1991. Besides the UK, efforts have been made to enhance the transition system by forming multidisciplinary teams in many other countries, such as Canada and the Netherlands.^{5,6} In this context, a transition task force was recently formed by the International League Against Epilepsy (ILAE) to investigate the opinions of patients and health care workers.

Proper transition is often difficult because various factors interfere with the process. Representatively, we can think of various factors from patients' status to national characteristics, such as comorbid disabilities, reluctance to change to an unfamiliar environment, dependence on the patient's family, medical billing system in each country, and national distribution of experts, etc. In the field of pediatric epilepsy, there is still insufficient research or effort to establish an adoptable system of transition that reflects the reality of each country. The present study aimed to analyze the current state of transition in Korea and to expand differences of opinion by country on the transition process by elucidating the perceptions of patient groups and experts about the transition from pediatric epilepsy care to adult neurologic care in Korea.

2 | METHODS

2.1 | Study design and setting

First, we conducted a retrospective review of the status of transition at a tertiary pediatric epilepsy center. Then, we administered two questionnaires on the perception and knowledge status of transition to doctors and patients (Figure 1).

2.1.1 | Retrospective review of transition at a tertiary center in South Korea

Data were retrospectively collected from patients with childhood-onset epilepsy who visited the pediatric epilepsy clinic of Chungnam National University Hospital between March 1990 and July 2019. Patients with seizure

Key points

- Currently, successful epilepsy transition is not well implemented in Korea, and there is no system for transition.
- The results of the survey revealed that there remains a lack of conceptual awareness of the transition between patients and doctors.
- It is necessary to increase the experience and access of doctors to unfamiliar diagnoses.
- Considering self-management capabilities should not be omitted in constructing the transition process.

remission before the age of 18 years and follow-up duration of less than 2 years were excluded from the data analysis. All patients were informed about the transition from their doctors at the age of 18 years, and the choice of whether to transition was made by the patient or guardian. We analyzed the basic clinical characteristics of patients with epilepsy and the proportion of patients who completed the transition to adult neurologic care. In addition, we identified factors impeding transfer by comparing the clinical characteristics of the transitioned group and the patient group that remained under pediatric care.

2.1.2 | Surveys of perception on transition among patients and experts

Patients' questionnaires were distributed in paper form at the outpatient visit in a tertiary center, and the doctors' questionnaires were distributed via e-mail through the list registered in the Korean Epilepsy Society between December 2019 and November 2020. The questionnaire responses were processed anonymously. At the beginning of the questionnaires, we introduced the concept of transition and the development and implementation status of transition programs in other countries. The questions in our survey were influenced by previous guidelines and surveys conducted in other countries.^{5,7} We have attached the original Korean questionnaires to [Appendix S1 and S2](#). All the questions included selectable examples. If there was no answer to choose from the examples, the respondents had "other" blanks to freely write their opinions.

Patients' questionnaires were administered to patients older than 16 years and their parents attending our pediatric epilepsy clinic. All patients had childhood-onset

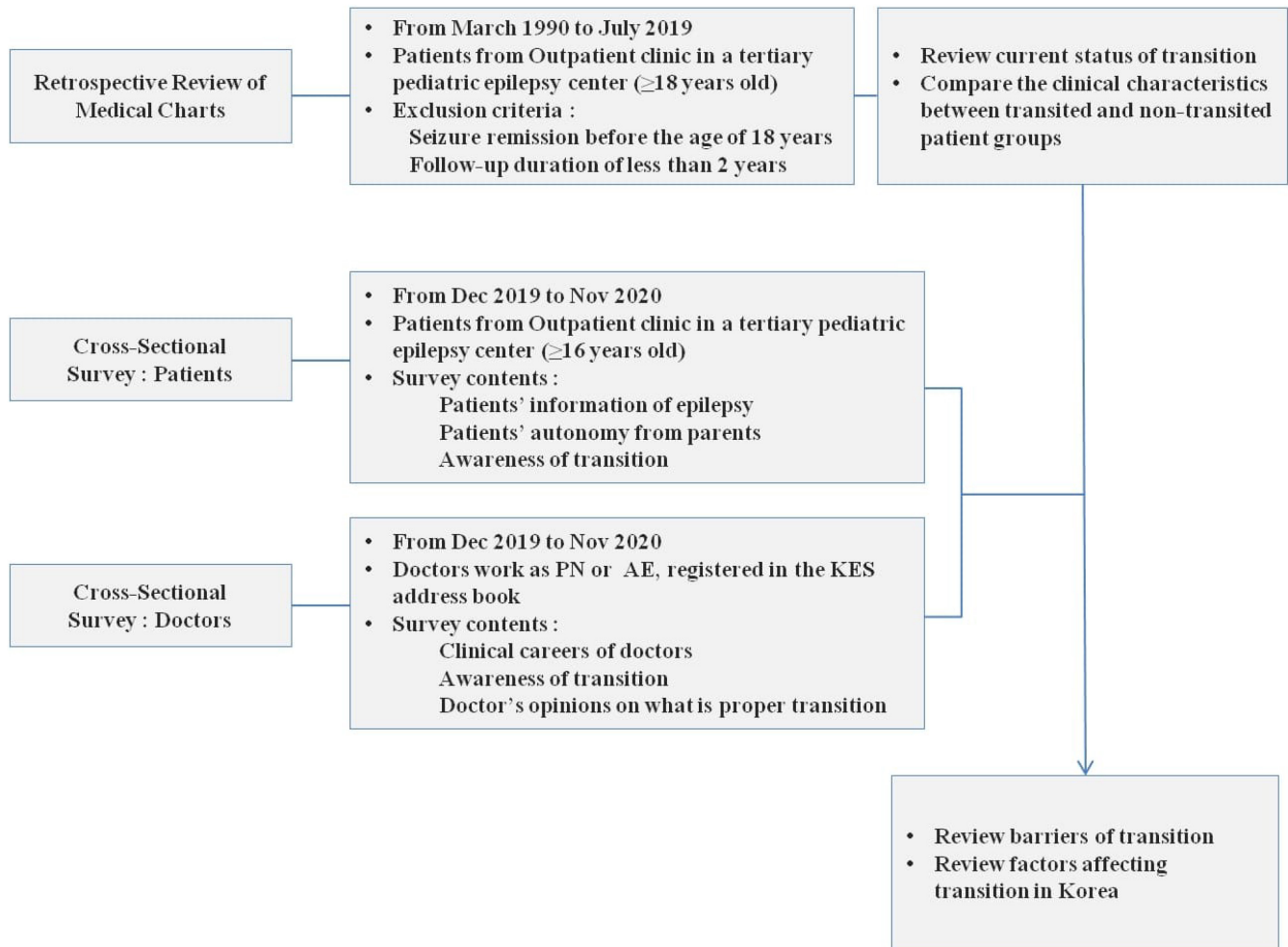


FIGURE 1 Study flow diagram: Retrospective review of the status of transition and a cross-sectional survey among patients and doctors

epilepsy. When it was impossible to receive the questionnaire response directly from the patient, a questionnaire was administered to the accompanying guardian, usually their parent. The questionnaire included a total of 21 questions: Q1–10 about patient information (year of birth, sex, duration of epilepsy, recent seizure frequency, seizure-free period, treatment methods, knowledge about their current state, types of diagnostic tests performed, and concurrent diseases) and Q11–21 about their awareness of transition (age at transition, patient autonomy from parents, and patient counseling required during transition).

Doctors' questionnaires were e-mailed to pediatric neurologists and adult epileptologists nationwide through the Korean Epilepsy Society. Upon clicking on a hyperlink in the e-mail, one was automatically led to the questionnaire in a Google form. The questionnaire for doctors included a total of 15 questions: Q1–3 and Q6 about doctors' information (type of affiliated hospital, duration of epilepsy treatment experience, proportion of patients with epilepsy, and type of specialty), Q4–5 about prior knowledge of the transition system, Q6–15 about

opinion on transition (appropriate age for transition, barriers in the transition process, familiarity with patient diagnosis, opinions on selection of target transition groups, and program composition). One or multiple answers were selected from multiple-choice items according to the content of the question, and a Likert scale of 1–5 was used for Q11–12.

2.2 | Statistical analysis

Categorical variables are presented as percentages (%) and frequencies (n). Differences between groups were analyzed as nominal variables using the chi-squared test or Fisher's exact test, as appropriate. Data assessed using Likert scales were analyzed on an equal continuous scale using independent samples *t*-tests to compare differences between groups. The statistical analyses were performed using SPSS Statistics for Windows version 21.0 (IBM Corporation, Armonk, NY, USA). Analysis items with *P*-values <.05 were considered statistically significant.

2.3 | Ethical considerations

The study protocol was approved by the Institutional Review Board of Chungnam National University Hospital (CNUHIRB 2019-12-057). The retrospective chart review of the current transition status was exempted from the need to obtain informed consent from participants. Written informed consent was obtained from both patients and doctors before the survey began.

3 | RESULTS

3.1 | Retrospective chart review about the status of transition

A total of 267 patients were identified who were diagnosed with childhood-onset epilepsy and continued treatment for at least 2 years at a single tertiary center between March 1990 and July 2019. (Table 1) Their mean age at the time of retrospective chart review was 24.34 ± 4.93 years old. Although all patients were recommended to transit to the adult clinic at the age of 18~20 years, only 39 patients (14.6%) had transitioned. The mean age of the 39 patients who visited adult epilepsy centers was 23.12 ± 4.06 years. Among them, 3 patients returned to the pediatric epilepsy center due to underlying problems such as congenital heart disease management at the pediatric cardiac center. After transitioning to the adult neurology department, 74% of patients underwent diagnostic tests, such as electroencephalogram (EEG) and magnetic resonance imaging (MRI), and 44% of patients underwent changes in antiepileptic drugs.

When we compare the clinical characteristics between transited and non-transited patients, the proportion of male patients was higher in the transited group than in the non-transited group (2.54:1 vs 1.01:1, $P = .013$). And the total follow-up duration was longer in the transited group than in the non-transited group (18.17 ± 7.34 vs 15.51 ± 7.36 years, $P = .038$). However, there was no significant difference in the mean age at the diagnosis of epilepsy (8.34 ± 4.79 vs 8.45 ± 5.32 years, $P = .930$), and the trend in the number of AEDs at the last follow-up visit showed no differences between the two groups ($P = 1.000$). Eight patients who required other treatments for refractory seizures, such as VNS and epilepsy surgery, wanted to remain at the pediatric epilepsy center. The nontransited patient group had a higher proportion of patients with intellectual disability (28.2% vs. 56.82%, $P = .002$). Both groups had similar proportions of children with psychiatric problems, such as depression, anxiety, attention deficit hyperactivity disorder, and schizophrenia (23.07% vs. 28.5%, $P = .564$). Two patients had died suddenly at the ages of

26 and 28 years and had refused transition until their last follow-up (Table 1).

3.2 | Results of patients' survey

A total of 94 participants completed the questionnaire: 66 (70.2%) parents and 28 (29.8%) patients. The male-to-female ratio was 1.08:1, and 41.5% of patients aged 16 to 18 years and 58.5% of those older than 18 years responded to the questionnaire. (Appendix S3) Most patients chose the proper age for the transition as beyond the age of 20 (52.1%). (Table 2) For this question, 22 of 23 patients, who selected "others," wrote down as "do not need transition." Seventeen of the 22 respondents were older than 18 years. Except for 3 out of 17, all patients had complicated epilepsy. The proportion of patients who could not visit the hospital alone was 58.5%, with the commonest reason being "unable to handle the process alone" (74.5%). In response to the question about the desired method of transition: "refusal to undergo transition" was selected by 44.7%, "simple consultation form" was selected by 22.3%, "multidisciplinary approach from 2-3 years before transition" was selected by 19.2%, and "simple consultation form with explanatory materials" was selected by 13.8%. The reason for reluctance was "emotional dependence on pediatric neurologists" among 53.1%, "unfamiliarity with the new environment" among 26.5%, "concerns about a unified system for multidisciplinary team approach" among 14.3%, and "concerns about the experience of adult neurologists in pediatric epilepsy" among 14.3%. It should be noted that no respondent selected the items "lack of guidelines and knowledge about transition" and "lack of a nationally unified system for multidisciplinary team approach" in the questionnaires.

In Q16-18, patients were asked to select an appropriate age for special counseling; 66% of respondents in "marriage and pregnancy," 45.8% of "alcohol drinking and driving," and 37% of "employment and career" wanted to be educated at the age of 20 or older. Unlike the other two items, where the number of patients who selected before the age of 18 was few, 23.4% of the patients selected that they should receive education on related topics early before the age of 18 with regard to "employment and career." The number of patients who responded "yes" to the items requiring additional components during transition was as follows: 57 patients (60.6%) selected "diagnostic evaluation such as EEG," 50 patients (53.2%) selected "financial supports or assistants," and 70 patients (74.5%) selected "mental health or intellectual function tests."

In the "unable to undergo the process alone" group, most patients (90.2%) wanted to delay transition or did

TABLE 1 Comparison of clinical characteristics between transited and nontransited patients in the retrospective chart review between March 1990 and July 2019 (n = 267)

| Variables | Transited patients (n = 39) | Non-transited patients (n = 228) | P value |
|---|-----------------------------|----------------------------------|---------|
| Male: female | 2.54: 1 | 1.01: 1 | .013* |
| Age at diagnosis of epilepsy, years (mean ± SD) | 8.34 ± 4.79 | 8.45 ± 5.32 | .930 |
| Follow-up duration, years (mean ± SD) | 18.17 ± 7.34 | 15.51 ± 7.36 | .038* |
| Age at the time of retrospective chart review, years (mean ± SD) | 26.52 ± 5.44 | 23.96 ± 4.76 | .003* |
| Age at which patients visited adult epilepsy centers, years (mean ± SD) | 23.12 ± 4.06 | – | |
| Number of AEDs at last follow-up visit (mean ± SD) | 2.26 ± 1.63 | 2.33 ± 1.57 | .792 |
| Number of AEDs at last follow-up visit (n) | | | |
| No current AED treatment | 2 (5.13%) | 12 (5.26%) | 1 |
| Monotherapy | 13 (33.33%) | 75 (32.89%) | |
| Polytherapy | 24 (61.54%) | 141 (61.84%) | |
| Seizure frequency (n) | | | |
| Daily | 2 (5.12%) | 15 (6.57%) | .888 |
| Weekly to monthly | 2 (5.12%) | 21 (9.21%) | |
| Yearly | 9 (23.07%) | 56 (24.56%) | |
| Less than once per year | 26 (66.6%) | 136 (59.65%) | |
| Other epilepsy treatments | 0 | VNS, 5; epilepsy surgery, 3 | |
| Numbers of sudden deaths | 0 | 2 | |
| Brain MRI lesions | 14/33 (42.42%) | 76/149 (51%) | .033* |
| Intellectual disability | 11/39 (28.2%) | 129/228 (56.82%) | .002* |
| Psychological problems (depression, anxiety, ADHD, schizophrenia) | 9/39 (23.07%) | 65/228 (28.5%) | .564 |

Abbreviations: SD, standard deviation; AED, antiepileptic drug; MRI, magnetic resonance imaging; ADHD, attention-deficit hyperactivity disorder.

*P-value <.05.

not want to transit. Twenty-one of 41 patients (51.2%) selected “over 20 years of age,” and 16 of 41 (39.0%) selected “others” with “does not require transition” as a descriptor. Among patients who wanted to transit, those who were unable to process medical visits alone wanted to transit at an older age ($P = .017$). During transition, they were likelier to need financial support or assistance ($P = .019$). (Appendix S4) These results are consistent with the tendency of patients with intellectual disabilities to remain in pediatric epilepsy clinics in our retrospective chart review.

3.3 | Results of doctors' survey

A total of 100 doctors responded: 52 were epilepsy specialists and adult neurologists (AEs), and 48 were pediatric neurologists (PNs). Similar proportions of doctors in both groups worked at tertiary hospitals: 67.3% and 64.6% of AEs and PNs, respectively. However, there were no primary care providers among PNs. Clinical treatment experience, the proportion of epileptic outpatients,

and the percent of prior knowledge of transition program were evenly distributed in both groups. In response to the multiple-response questions on prior knowledge on routes for transition, 24 (61.5%) of the 39 respondents indicated that they learned about them through papers, 16 (41.0%) through lectures, and 21 (53.8%) through symposiums or conferences. (Appendix S5).

As a result of our survey, the differences in thinking between AEs and PNs were very clear, probably due to differences in their experiences. (Table 3) For patients with normal development, 44.2% of AEs recommended transition at 18 years, while 47.9% of PNs recommended transition after 20 years. For patients with an intellectual disability or comorbid diseases, the recommended age distribution for transition appeared to be delayed in both groups. Most AEs (36.5%) recommended transition at 18 years; 5.8% and 19.2% recommended transition at 19 and 20 years, respectively. In contrast, 35.4% of PNs recommended transition after 20 years, and 39.6% of PNs did not recommend transition. For the question about the preparatory age for transition, AEs mostly selected

TABLE 2 Patients' thoughts about transition in the survey from December 2019 to November 2020 (n = 94)

| Variables | n | % |
|--|----|------|
| Proper age for transition | | |
| Under 18 years | 3 | 3.2 |
| At 18 years | 9 | 9.6 |
| At 19 years | 10 | 10.6 |
| Over 20 years | 49 | 52.1 |
| Others | 23 | 24.5 |
| Ability to visit medical facility alone | | |
| Yes | 39 | 41.5 |
| No | 55 | 58.5 |
| Reasons why patients need help with medical visits | | |
| Can handle it alone, but needs emotional support of parents | 8 | 14.6 |
| Unable to handle the process alone | 41 | 74.5 |
| Failure to administer regular medications | 4 | 7.3 |
| Others | 2 | 3.6 |
| Desired procedure for transition | | |
| Multidisciplinary approach from 2–3 years before transition | 18 | 19.2 |
| Simple consultation form | 21 | 22.3 |
| Simple consultation form with explanatory materials | 13 | 13.8 |
| Refusal to undergo transition | 42 | 44.7 |
| Reasons for reluctance to transition | | |
| Emotional dependence on pediatric neurologists | 26 | 53.1 |
| Unfamiliarity with the new environment | 13 | 26.5 |
| Lack of guidelines and knowledge about transition | 0 | 0 |
| Lack of a nationally unified system for multidisciplinary team approach | 0 | 0 |
| Concerns about the experience of adult neurologists with pediatric epilepsy | 7 | 14.3 |
| Concerns about the care of comorbid diseases diagnosed in childhood (e.g., congenital heart disease) | 2 | 4.1 |
| Others | 1 | 2 |
| Proper age for counseling on marriage and pregnancy | | |
| Under 18 years | 5 | 5.3 |
| At 18 years | 5 | 5.3 |
| At 19 years | 5 | 5.3 |
| Over 20 years | 62 | 66 |
| Others | 17 | 18.1 |
| Proper age for counseling on alcohol drinking and driving | | |
| Under 18 years | 7 | 7.4 |
| At 18 years | 10 | 10.6 |
| At 19 years | 16 | 17 |

TABLE 2 (Continued)

| Variables | n | % |
|--|----|------|
| Proper age for transition | | |
| Over 20 years | 43 | 45.8 |
| Others | 18 | 19.2 |
| Proper age for counseling on employment and career | | |
| Under 18 years | 22 | 23.4 |
| At 18 years | 13 | 13.8 |
| At 19 years | 13 | 13.8 |
| Over 20 years | 35 | 37.3 |
| Others | 11 | 11.7 |
| Need to recheck diagnostic evaluation of epilepsy (EEG, etc.) | | |
| Yes | 57 | 60.6 |
| No | 37 | 39.4 |
| Need for counseling about financial support or assistance | | |
| Yes | 50 | 53.2 |
| No | 44 | 46.8 |
| Need to re-evaluate mental health or intellectual function | | |
| Yes | 70 | 74.5 |
| No | 24 | 25.5 |

Abbreviation: EEG, electroencephalography.

“13–16 years” (42.3%), and PNs mostly selected “after 18 years” (56.3%). From these results, AEs selected more items indicating appropriate transition at an early age than PNs. As a result of multiple responses to the factors that might affect transition, both groups showed high response rates for “refusal from patients and their parents due to emotional support problems” and differences in the clinical environment. In contrast to the results of the patients' survey, the lack of guidelines and knowledge about transition and the lack of a nationally unified system for a multidisciplinary team approach were selected by AEs and PNs.

Upon asking doctors about familiarity with diseases and comorbidities, AEs and PNs showed statistically different scale distributions, except in the categories of juvenile myoclonic epilepsy and focal cortical dysplasia (Figure 2). AEs showed high rates of 1 point (strongly unfamiliar) for Dravet syndrome, epilepsy due to genetic syndromes, epilepsy due to cutaneous diseases, and epilepsy due to metabolic disorders, compared to PNs. The results showed that differences in the incidence of epilepsy according to age groups could affect doctors' clinical experience and familiarity.

The multiple response questions to doctors in Table 4 included members required for a multidisciplinary transition team and additional education processes required

TABLE 3 Doctors' thoughts about transition in the survey from December 2019 to November 2020 (n = 100)

| | AE (n = 52) | PN (n = 48) | P-value |
|---|----------------|----------------|---------|
| Age for transition in normal developmental patients | | | |
| Under 18 years | 17 (32.7%) | 0 | 0.000* |
| At 18 years | 23 (44.2%) | 11 (22.9%) | |
| At 19 years | 9 (17.3%) | 9 (18.8%) | |
| Over 20 years | 3 (5.8%) | 23 (47.9%) | |
| No transition | 0 | 1 (2.1%) | |
| Others | 0 | 4 (8.3%) | |
| Age for transition in patients with intellectual disability or comorbid diseases | | | |
| Under 18 years | 8 (15.4%) | 0 | 0.000* |
| At 18 years | 19 (36.5%) | 5 (10.4%) | |
| At 19 years | 3 (5.8%) | 3 (6.3%) | |
| Over 20 years | 10 (19.2%) | 17 (35.4%) | |
| No transition | 9 (17.3%) | 19 (39.6%) | |
| Others | 3 (5.8%) | 4 (8.3%) | |
| Age to begin preparation for transition | | | |
| 10–13 years | 1 (1.9%) | 0 | 0.000* |
| 13–16 years | 22 (42.3%) | 5 (10.4%) | |
| Over 17 years | 15 (28.9%) | 13 (27.1%) | |
| Over 18 years | 14 (26.9%) | 27 (56.3%) | |
| Others | 0 | 3 (6.2%) | |
| Factors that affect transition^a | | | |
| Refusal to undergo transition due to emotional support problems or unfamiliarity | 28 (53.9%) | 32 (66.7%) | |
| Differences in clinic environment | 30 (57.8%) | 41 (85.4%) | |
| Lack of guidelines and knowledge about transition | 26 (50%) | 17 (35.4%) | |
| Lack of a nationally unified system for multidisciplinary team approach | 24 (46.2%) | 19 (39.6%) | |
| Others | 3 (5.8%) | 0 | |

Abbreviations: AE, adult epileptologist; PN, pediatric neurologist.

^aMultiple response question.

*P-value < .05.

during transition. “Patients and caregivers,” “pediatric neurologists,” and “adult neurologists” ranked the highest as basic members. Compared to AEs, PNs more frequently responded to the combination of “rehabilitation doctors,” “psychiatrists,” “doctors for underlying or comorbid

disease,” and “social work teams.” Similar proportions of respondents selected “coordinators” in both groups. In response to questions among doctors for additional counseling and education during transition programs, “transition readiness checklists for patients and caregivers,” “driving,” “pregnancy planning,” “mental health screening,” “self-care assessment,” and “financial consultation” obtained high percentages (over 70%) in both groups. “Sexuality and contraception,” “alcohol,” and “notice of possibilities of sudden unexpected death in epilepsy” showed higher response rates among PNs than AEs.

4 | DISCUSSION

Epilepsy is a lifelong disease, and 30–40% of patients diagnosed with epilepsy in childhood and adolescence require continuous treatment into adulthood.⁸ The transition of a child with epilepsy to the adult clinic is a time to leave a child-friendly space and requires a mature ability to deal with the communication process of medical visits as an adult, as well as to confirm self-care abilities.¹⁰ Various academic societies and institutions have suggested guidelines for the proper timing of transition and the formation of a program structure that helps the transition to be successful. The American Academy of Pediatrics suggested that 14–15 years is an appropriate age to begin discussing transition with pediatric patients.¹¹ As another example, in the transition program administered by the Ministry of Health and Long-term Care in Ontario, Canada, the follow-up treatment plan for epilepsy regarding prognostication and remission of epilepsy is implemented for patients aged 10 to 15 years. Between the ages of 16 and 17 years, a detailed transition plan is explained at the pediatric neurology department, and medical progress is summarized for referral to an adult neurologist. Finally, the patient is transferred to an adult neurologist at 18 years of age or older with additional tests and counseling.¹² A common suggestion for transition in previous studies is not to simply change the treatment location and attending physician simultaneously but to provide patients with information about the change in advance and include a step-by-step preparation process through collaboration with related departments.

Currently, there is no system for the transition of pediatric patients with epilepsy in Korea. First, we assessed the status at an actual pediatric epilepsy clinic, as indicated in the first aspect of the study flow chart. All patients were verbally encouraged to transition when they reached the age of 18 years; however, the actual implementation rate at our institution was only 14.6% between March 1990 and July 2019. Furthermore, patients who underwent transition first visited the adult outpatient clinic at an average age of 23.12 ± 4.06 years, which was later than recommended.

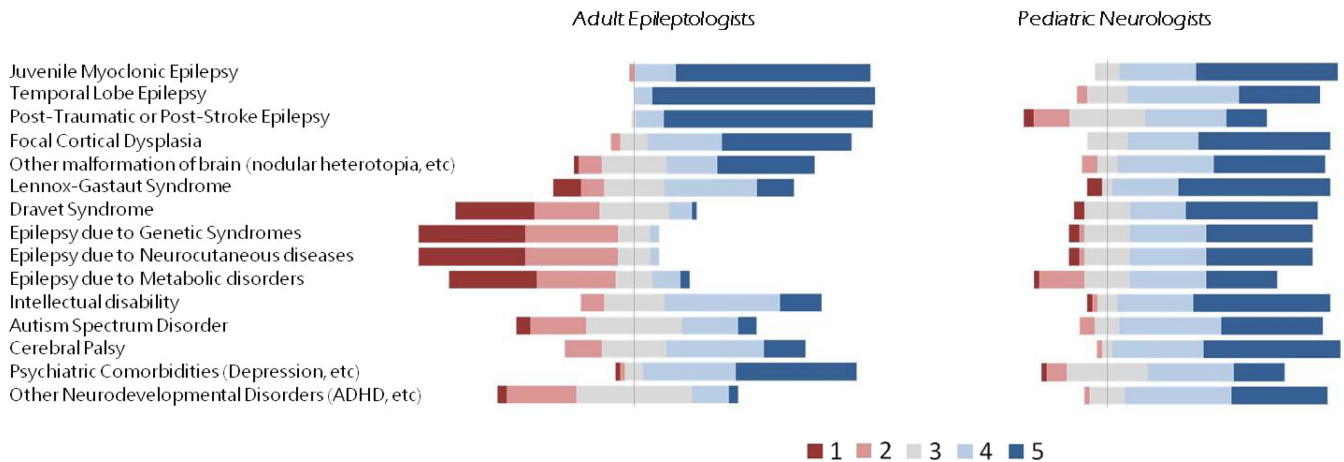


FIGURE 2 Comparison of familiarity with diseases between adult epileptologists ($n = 52$) and pediatric neurologists ($n = 48$) determined via a survey among doctors. The values are presented as percentages for each group (Likert scale: 1 = strongly unfamiliar, 5 = strongly familiar)

In Korea, there are no age restrictions regarding the use of medical insurance for patients with chronic illnesses that started during childhood; thus, many patients remain in pediatric care, even as adults. In a previous single center study in Korea, patients above 18 years of age, who visited pediatric emergency department due to neurologic symptoms, had been gradually increased from 2013 to 2017.⁹ In addition, patients with intellectual disabilities tended to remain at the pediatric clinic ($P = .002$). These patients may have more barriers to a successful transition, such as difficulty in finding suitable providers and transition programs focused on patients with self-advocacy and require more preparatory time.¹³ However, the exact cause analysis of why the patients refused transition was limited in this retrospective chart review, so we prepared a survey.

The results of the survey among patients and doctors identified several important barriers to transition. First, there remains a lack of conceptual awareness of the transition between patients and doctors. In the question regarding the proper transition period, 52.1% of patients selected the age of 20 years or older. In addition, 22.3% of patients desired transition by way of a simple consultation form. These results show that patients lack an accurate understanding of the transition process. Among doctors, only 32.7% of the respondents had prior knowledge about existing research or programs on transition among epilepsy patients, indicating the need for active introduction and education on pre-existing successful implementation programs. In addition, AEs generally selected preparation for transition at the age of 13–16 years and transition at 19–20 years, whereas PNs selected preparation at age 18 and transition after the age of 20 years. Therefore, it is necessary to induce a balanced perspective on the transition and prepare a suitable treatment environment. Second, it is necessary to increase the experience and access of doctors to unfamiliar diagnoses. Borlot et al. reported a difference

in confident diagnosis and treatment of epilepsy between adult neurologists and PNs.⁷ Our survey results were similar to those of that study. Also, among patients surveyed in our study, 14.3% had concerns about the clinical experience of AEs, while 4.1% had concerns about the care of comorbid diseases diagnosed during childhood. Having visited the hospital for a long time, patients tend to know more about their conditions and generally make decisions in a direction they believe to be safe for them. Therefore, this could be a factor impeding the transition process. Third, preconceived notions about the outcomes of transition are barriers that need to be addressed. The emotional dependence of patients on PNs was high (53.1%). They believed that noncompliance with the transition was not due to lack of knowledge or guidelines for implementation, or lack of a unified system, despite having a somewhat distorted view of the transition process and insufficient knowledge. Education and systems for transition that reduce these patients' preconceived notions should also be established. Fourth, self-management capabilities related to intelligence, psychological state, and environmental and economic factors should not be omitted in constructing the transition process.¹⁴ In our study, there were different responses to the transition time according to intelligence or underlying disease. Providing information about lifestyle changes as adults, such as driving, employment, pregnancy, and drinking alcohol, is also a goal of transition programs.⁶ However, our study had limitations to be considered in interpreting the results, as the patients and their guardians were surveyed at a single tertiary hospital. In addition, 71.3% of a total of 94 patients had had no seizures in the preceding year or had well-controlled seizures for 1 to 5 years; thus, a selection bias of the sample group may have occurred. In addition, a small number of patients with underlying diseases were included, implying a possible bias in the general patient opinion.

TABLE 4 Comparison of thoughts of AE and PN on transition program composition (n = 100)

| Variables | AE (n = 52) | PN (n = 48) |
|--|-------------|-------------|
| Members required for a multidisciplinary transition team ^a | | |
| Patients and caregivers | 45 (86.5%) | 41 (85.4%) |
| Pediatric neurologists | 52 (100%) | 47 (97.9%) |
| Adult neurologists | 52 (100%) | 46 (95.8%) |
| Rehabilitation doctors | 19 (36.5%) | 29 (60.4%) |
| Psychiatrists | 27 (51.9%) | 38 (79.2%) |
| Doctors for underlying or comorbid disease | 25 (48.1%) | 26 (54.2%) |
| Social work team | 18 (34.6%) | 25 (52.1%) |
| Coordinators | 26 (50%) | 27 (56.3%) |
| Others | 2 (3.8%) | 0 (0.0%) |
| Assessment and counseling process required for transition program ^a | | |
| Transition readiness checklists for patients and caregivers | 47 (90.4%) | 44 (91.7%) |
| Driving | 41 (78.9%) | 43 (89.6%) |
| Pregnancy planning | 41 (78.9%) | 43 (89.6%) |
| Sexuality and contraception | 30 (57.7%) | 36 (75.0%) |
| Self-care assessment | 39 (75.0%) | 37 (77.1%) |
| Family dynamics | 34 (65.4%) | 32 (66.7%) |
| Financial consultation | 37 (71.2%) | 36 (75.0%) |
| Mental health screening | 43 (82.7%) | 43 (89.7%) |
| Alcohol | 29 (55.8%) | 40 (83.3%) |
| Hobbies and social activities | 18 (34.6%) | 18 (37.5%) |
| Notice of possibilities of SUDEP | 23 (44.2%) | 34 (70.8%) |

Abbreviations: AE, adult epileptologist; PN, pediatric neurologist; SUDEP, sudden unexpected death in epilepsy.

^aMultiple response questions.

Previous studies have shown the positive influence of using transition centers for adolescents by facilitating engagement with adult clinics.^{15,16} A paper published in Liverpool, UK, which has been creating and operating transitional programs since 1991, showed that most transition epilepsy clinic centers usually included both AEs and PNs. Ten of the 15 clinics supported nurse specialists in addition to doctors.¹⁷ Rarely, as at the Pitié-Salpêtrière Hospital in Paris, France, do some hospitals directly provide one-day multidisciplinary treatment, and in Germany, the Bethel Foundation Hospital conducts workshops by way of lectures for non-medical staff.⁶ Considering the budget and time limits of the participating manpower, the ideal method is to gather at one place and proceed with the implementation of multidisciplinary treatment. However, to create an efficient and workable system, a step-by-step guidebook and images distributed at a certain age using mobile devices might be considered.¹²

Although domestic study results on transition for other chronic diseases of childhood and adolescence have been published recently,¹⁸⁻²⁰ there have been scarce of research results in the field of pediatric epilepsy. This study is significant as it is the first study conducted in Korea on the

transition of care for epilepsy. Depending on the country's medical environment, cultural awareness, and living environment, the demands and perceptions of the details of the specific process of implementation would inevitably differ. This study provides basic data that can be reflected upon when planning an organizational or systematic process for future implementation by surveying patients and doctors on the level of awareness of transition in Korea and each demand for detailed items. The results of the doctors' survey are particularly representative as the questionnaire targeted epilepsy specialists working at various hospitals in Korea. Thus, these results can be reflected in the setting of the transition program. On the other hand, if this local point of view is applied to the transition program, it will be necessary to consider whether it can be developed in line with the international level. And there is still much work to prepare for the structural stability of the transition process.

In conclusion, patients' and experts' awareness about transition was negative in this study, and they wanted to prepare for it at a later age compared to the results of studies conducted overseas. In addition, we suggest that the transitional program should be constructed to reflect

these points as the perspectives on the components and importance required in the preparatory transition process may differ between AEs and PNs. Examining the status of our perceptions of implementation is the first step toward realizing a program for implementation. After planning for program implementation, the responses of patients and experts should be studied at several hospitals composed of various patient groups according to the plan, and a comparative study on the change in implementation status should be conducted as the final goal of the program. Further studies are needed to establish a transition program and its implementation results.

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CONFLICT OF INTEREST

None of the authors has any conflict of interest to disclose. 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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