ORIGINAL RESEARCH

Behavioral Dilemmas and Support Requirements of Self-Management for Chinese Adolescents with Epilepsy During Transition Readiness: A Mixed-Methods Study

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Objective: The study aimed to describe and explore the behavioral dilemmas and support-requirement characteristics of self-management for epileptic adolescents during transition readiness.

Methods: A convergent mixed-methods study was conducted. Patients (N=654) in eight hospitals in China completed a demographic and disease characteristics questionnaire and measures of epilepsy transition readiness, self-management of epilepsy, and perceived social support, and 17 patients and family care-givers were interviewed simultaneously.

Results: Adolescents with epilepsy (AWEs) had low levels of self-management and transition readiness, and moderate levels of social support. Multivariate linear regression showed that age, antiepileptic drug type, comorbidities, family structure, transition readiness, and social support were statistically significant in the regression model (p<0.05). Seven themes emerged in the qualitative analysis related to self-management behavioral dilemmas, and 11 themes emerged for support requirements. The findings from the qualitative and quantitative analyses were combined to create a conceptual model based on the SMART framework and the social cognitive theory.

Conclusion: The findings indicate that the state of self-management behaviors of Chinese AWEs is not promising. The influential factors and characteristics are complex and systematic.

Practice Implications: This study provides insights into the self-management practices of AWEs in China and expands previous self-management and transitional readiness strategies and models.

Keywords: convergent mixed-methods, adolescence, self-management of chronic diseases, epilepsy

Introduction

Epilepsy is the most prevalent chronic condition that affects the brain. It has been diagnosed in more than 50 million individuals globally, and close to 80% of the affected individuals are from low-and middle-income nations.[1] Although epilepsy affects people of all age groups, its occurrence is consistently higher in children than in other age groups: it affects 3.2 to 5.5 out of every 1000 individuals in developed nations, and 3.6 to 44 out of every 1000 individuals in underdeveloped nations.[2] There are over nine million patients with epilepsy in China, among whom two-thirds are adolescents under 18 years old.[3] In 50% of the cases of childhood-onset epilepsy, the disease continues into adulthood and subsequently needs to be managed by adult healthcare providers.[3–7] Adolescents with epilepsy (AWEs) who need to transition to adult healthcare services not only face many challenges related to their disorder, such as acute seizures, but also biological, comorbid behavioral, emotional, cognitive, physical, and cognitive impairments, as well as social developmental challenges, as they transition into adults.[5,6,8,9] Insufficient or poor treatment transition readiness from childhood to adulthood can lead to poorly

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controlled seizures, which influence self-identity, autonomy, treatment adherence, and complex conditions.[5,8–11] Patient self-management behaviors are important in controlling epilepsy because reduced adherence to treatment protocols is one of the main reasons for recurring seizures and comorbidities. Another challenge is that there is little consensus among researchers about the definition of self-management.[12] Based on the general literature on self-management and, more specifically, on epilepsy, self-management has been defined as the ability of children and young people and their families to manage daily life with epilepsy by using the core self-management skills, namely, problem solving; decision making; resource utilization; formation of a healthy patient/healthcare practitioner (HCP) relationship; and actively trying to create an effective, dynamic, and continuous self-regulation practice.[13] The objective behind the development of such skills is to ensure better seizure control, well-being, and quality of life. AWEs and their families require professional help in order to inculcate the discussed self-management skills and, thereby, to meet the challenges of the disease.

HCPs need to offer self-management training for patients with epilepsy, as this is an essential competency.[14] The key in home and community-based treatment (HCT) for adolescents with chronic diseases is their overall self-management, which not only strengthens the depth, diversity, and scope of HCT, but also contributes to the early development of self-management ability in the transition readiness of adolescents with chronic diseases.[15,16] Moreover, as transition service platforms in China are not yet developed, there is little systematic support for studying transition services across the HCT spectrum. A self-management intervention involves a microscopic interaction between AWEs and their families that can meet the transitional needs of adolescents and families with chronic diseases under conditions of limited medical resources, and it can potentially reduce service costs. Therefore, building the self-management capacity of AWEs during transition in China is a key issue.

It is a formidable task for adolescents with neurological diseases to participate in a self-management project during the process of transition readiness.[17] First, self-management practices that align with adolescents' cognitive, physical, and mental requirements are important components of delivering patient-centered care.[18] Second, the level of health care, medical resources, and transition service status of a location also needs to be considered. Third, unanticipated episodes of illness may cause regression in self-management skills, which requires repeated instruction.[19] Moreover, the impact of epilepsy's characteristics, including the unpredictability of seizures, is associated with various psychosocial comorbidities (eg, anxiety, depression, social isolation, and cognitive challenges), affects biological development, and creates stigma issues, which are more pronounced during adolescence.[20] However, existing research ignores self-management concepts, behavioral characteristics, and stakeholder needs for the transition readiness of AWEs, and it fails to provide strong evidence about self-management barriers and support strategies.[10,21,22] These previous findings highlight the need to prioritize (a) the integration of data about the barriers faced by AWEs and the factors that promote self-management behaviors, and (b) the summarization of the influencing factors determined through quantitative and qualitative methods that focus on various stakeholders.

The exploration of the relationship between transition readiness and self-management of adolescents with chronic diseases is a broadly and thoroughly discussed topic.[23] Self-care ability is often used as a predictor of transition readiness.[24] It is suggested that for adolescents to transition to adult healthcare services, they need to be prepared by pediatric healthcare providers, who need to explain to them the increased responsibilities that accompany self-management.[16] In addition, studies have found that adolescents may not be confident about their self-management and decision-making skills and may, therefore, need support and time to develop these skills during the transition readiness phase.[25] Therefore, the exploration of transition readiness and self-management for AWEs based on the authority of a theory can contribute to insights in the field.

SMART is a socio-ecological framework for transition readiness that emphasizes several factors, including objective factors, potentially modifiable factors, stakeholders, and systems that influence readiness, as well as their reciprocal relationships. According to the SMART framework, the emphasis is on the child, who is considered to be at the center of broader systems, and this focus is intended to better operationalize influencing factors to improve transition readiness.[26] The SMART framework was chosen in this study because it provides a clear socio-ecological perspective that explains the interrelationships between potential influencing factors for the self-management behaviors of AWEs. Social cognitive theory has an important place in this study because it is a theory of social learning processes which stresses the formative pathway of behavior.[27] Because of the characteristics of middle-level theories, it can be combined with SMART to clarify the framework of self-management behavior promotion and development to create an empirical model for self-management interventions to promote safety during transitional readiness.

Thus, this study aimed to collect qualitative data on stakeholder's experiences and perspectives that are combined with quantitative data to define determinants of self-management behavior and support requirements for AWEs during transition. A convergent mixed-methods approach was used to identify the factors. To this end, a conceptual model was constructed according to the SMART framework and the social cognitive theory, in order to classify and visualize the relevant factors.

Materials and Methods
Study Design
A convergent mixed-methods study was conducted that compared and integrated quantitative and qualitative results in order to comprehensively answer the research questions.[28] The qualitative data were collected simultaneously in order to inform the quantitative data. From March-July 2022, a total of 654 AWEs in eight specialized children and general hospitals in China answered questions about their demographics and disease characteristics and completed the three scales described below. A small qualitative sample was used because it can provide more in-depth understanding of the investigated phenomenon.[28,29] Semi-structured interviews and a mixture of inductive and deductive approaches were applied as qualitative methods and were used to gain a contextualized understanding of behavioral dilemmas and support needs related to self-management among 17 participants (AWEs and their family caregivers). The flow diagram of the study is shown in Figure 1.
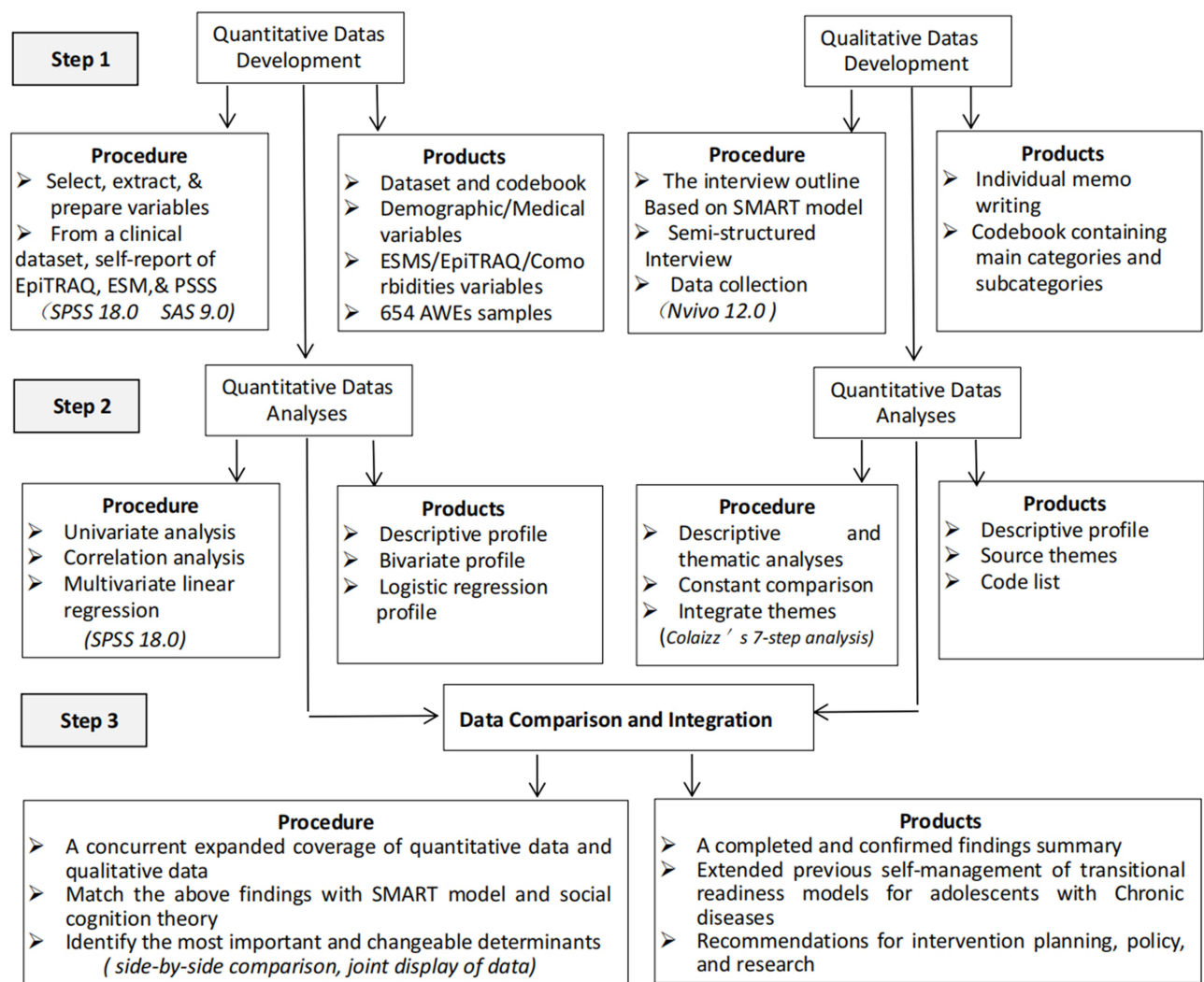

Figure 1 Algorithm used in the mixed-methods analyses of this study.

Setting

The present study was headed by the Children's Hospital of Chongqing Medical University, which is among the top three pediatric hospitals in China. In 2021, 3,668,200 outpatient and 102,200 inpatient visits were recorded, and out-of-town patients comprised nearly 40% of the visits. In addition, this study included eight other hospitals in China that are classified as guiding hospitals by the China Association Against Epilepsy. Among them, there were 2 general hospitals and 6 children's hospitals; 3 hospitals were located in the western region, 2 in the central region, and one each in the north, south, and east of China.

Participants

A convenience sample of AWEs visiting eight children's hospitals and general hospitals across the country was recruited for the study. The inclusion criteria were: (1) those set forth in the 2018 International League Against Epilepsy guidelines for epilepsy seizure and classification; (2) age 12–18 years; and (3) provision of informed consent by the guardians/caregivers of the patients. The exclusion criteria were: (1) refusal to participate by patients and their guardians/caregivers; and (2) critical disease stage or (3) the presence of intellectual development disorder, a Wechsler Intelligence Quotient [IQ] score < 70 points, or detection of severely impaired brain function. The patient's information that was included and excluded was examined through inquiries to participants and having the clinical nursing staff check electronic medical records. Masks bearing the faces of cartoon characters were presented as gifts to the questionnaire respondents. Generally, the sample size for multivariate analysis should be 10 to 20 times the number of variables.[30] As our analysis included four demographic variables, three clinical variables, and three independent variable scales (13 dimensions), the minimum required size was 200 AWEs. A total of 734 questionnaires were sent out, of which 654 were sent back; this amounted to a valid response rate of 89.10% (Supplementary Figure 1).

The participants in the qualitative phase of the study were a sample of patients who participated in the questionnaire survey, using a purposive sampling method to maximize variation in participants' educational level, age, gender, course of disease, family structure, and other factors. In total, 17 participants (n = 10 AWEs; n = 7 main family caregivers, FCs) were recruited for the qualitative phase.

Tools

Quantitative Research

Data on the demographic and disease characteristics of the AWEs were obtained with the help of a questionnaire (see Table 1).

Table 1 Self-Management Scores of AWEs with Different Characteristics

Variable	Items	Phase 1				Phase 2
		N=654, %	Self-Management score ± s	F	P	N=17, %
Demographic variables						
Age(years)	12–14	358, 54.74%	57.25±8.80	53.481	<0.001	6, 35.29%
	15–18	296, 45.26%	62.44±7.42			11, 64.71%
Gender	Female	292, 44.65%	61.77±8.30	3.921	0.048	7, 41.18%
	Male	362, 55.35%	60.52±7.77			10, 58.82%
Patient Insurance	Public Insurance	94, 14.37%	61.40±9.24	3.038	0.052	4, 23.53%
	Private Insurance	167, 25.54%	62.32±7.08			5, 29.41%
	No Insurance	393, 60.09%	61.65±7.95			8, 47.06%
Family structure	Nuclear family	315, 48.17%	62.50±2.65	9.623	<0.001	7, 41.18%
	Stem family	251, 38.28%	60.37±7.35			6, 35.29%
	Floating family	88, 13.45%	57.73±6.26			4, 23.53%

(Continued)

Table 1 (Continued).

Variable	Items	Phase 1				Phase 2
		N=654, %	**Self-Management score ± s**	***F***	**P**	**N=17, %**
Medical variables						
Epilepsy Type	Focal	322, 49.24%	60.42±7.19	3.769	0.002	6, 35.29%
	Generalized	203, 31.04%	57.76±8.09			4, 23.53%
	Mixed	71, 10.86%	56.25±7.74			3, 17.65%
	Unknown	58, 8.86%	62.80±8.54			4, 23.53%
Epilepsy medication type (Primary medication if on poly-therapy)	Carbamazepine (CBZ)	39, 6.00%	60.54±9.59	7.256	<0.001	2, 11.76%
	Oxcarbazepine (OXC)	88, 13.46%	59.35±8.65			3, 17.65%
	Levetiracetam (LEV)	146, 22.32%	63.06±7.71			1, 5.88%
	Valproate (VPA)	141, 21.56%	61.06±7.66			4, 23.53%
	Lamotrigine (LTG)	137, 20.95%	72.46±6.87			3, 17.65%
	Topiramate (TPM)	65, 9.94%	71.54±7.06			1, 5.88%
	Other (LCM, CZP, ESM, ZNS)	38, 5.81%	64.63±9.77			3, 17.65%
Comorbidities	Neurodevelopmental spectrum disorders	57, 8.72%	69.76±7.12	24.315	<0.001	2, 11.76%
	Psychiatric disorder	46, 7.03%	68.42±9.58			3, 17.65%
	Above all	52, 7.95%	71.21±11.76			1, 5.88%
	None	389, 59.48%	73.38±6.69			6, 35.29%
	Other comorbidities	110, 16.82%	66.30±7.43			5, 29.41%

Transition readiness was measured with the Chinese version of the Epilepsy Transition Readiness Assessment Questionnaire (EpiTRAQ), developed by Clark et al,[31] which our research team was authorized to use. The Chinese EpiTRAQ contains 35 items measuring six dimensions: managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities. Each item was scored on a scale of 1 to 5, with 1 representing the lowest level of readiness and 5 representing the highest level of readiness. The Cronbach's alpha values of the dimensions of EpiTRAQ ranged from 0.724 to 0.984. Its split-half reliability was 0.642–0.871, and its test-retest reliability was 0.923.

Self-management ability was measured with the Epilepsy Self-management Scale (ESMS) developed by DiIorio et al.[32] The Chinese ESMS, introduced by Wang,[33] consists of 20 items measuring five dimensions: medication management, information management, safety management, seizure management, and lifestyle management. Each item is rated on a 5-point scale from "Never" to "Often" (some items were reverse-scored) for a total score of 20–100. Higher scores were indicative of better-self-management. The Cronbach's alpha value for ESMS was 0.829, and its test-retest reliability was 0.743.

Social support was evaluated using the Social Support Rating Scale (SSRS) designed by Shuiyuan,[34] which contains ten items that measure three dimensions: subjective support, objective support, and support utilization. The total score ranges from 12 to 66, with scores ≤22 indicating a low level of support, scores of 23–44 indicating a moderate level of support, and scores of 45–66 indicating a high level of support. The Cronbach's alpha value was 0.890–0.940, and the test-retest reliability was 0.920.

Qualitative Research

Face-to-face, semi-structured interviews were used to explore factors that affect self-management behaviors during transition readiness of AWEs. The interview guidelines were based on the SMART. The interview guidelines elucidated the pre-existing and modifiable factors that affect transition readiness from individual, family, community, and healthcare perspective. The interview questions covered the exploration of cognitive, affective, and social processes that contribute to self-management behaviors. The interviews with children with epilepsy (CWEs) and caregivers also reflect the requirement of the SMART model for multi-stakeholder linkages. The interview outline was developed from interviews with experts who provide treatment and care for patients with chronic pediatric diseases (Supplementary Table 1).

Data Collection

Quantitative Research

The questionnaires were distributed at pediatric epilepsy specialist clinics and specialty wards by clinical nursing staff. The surveyors, who received unified training, explained to potential participants the objectives, significance, methods, safety, and ethical compliance with regard to ensuring the anonymity of the participants. The surveyors also assisted with the completion of the questionnaires according to the answers provided by the respondents, and checked the data on the disease characteristics and clinical history.

Qualitative Research

The interviewer stayed with the target participants while they completed the questionnaire and answered their queries. After the participants completed the questionnaire, they were asked if they would participate in a 20-30 min semi-structured interview. The reasons for conducting the interviews were explained to the willing AWEs or families, and then they agreed on a time and place. As a result of the semi-structured format, the respondents were able to discuss each question freely and provide a response based on their experiences. The interviews were conducted by a trained qualitative researcher, who was a specialist nurse with good communication and working skills. They clarified the aims, methods, and content of the interview to the interviewees, and promised to observe the principles of confidentiality and anonymity.

Data Analysis

Quantitative Research

The data obtained from the quantitative analyses were checked and verified by two authors in Phase 1, following which the statistical analyses were conducted. The SPSS 18.0 software was used for all the statistical analyses. Measurement data were expressed as mean ± standard deviation, and count data were expressed as the number of cases and proportions (the chi-square [χ^2] test was used for inter-group comparisons). Univariate analyses were conducted using t-tests and analysis of variance (ANOVA), and multivariate analyses were conducted using logistic regression. $P < 0.05$ was considered to indicate statistical significance.

Qualitative Research

Transcripts from the interviews were entered into, stored in, and managed by the same software program, namely, NVivo 12.0, to ensure the integrity of the data analysis. The data were analyzed using the Colaizzi seven-step method for phenomenological research.[35] These are the seven steps: (1) Reading the data gathered from the interview several times to gain a preliminary understanding of the data; (2) Highlighting meaningful statements that are in line with the research questions; (3) Summarizing and refining the meaningful statements and coding them; (4) Summarizing the coded data to identify common concepts and create themes, subject groups, and categories; (5) Linking the subject to the research object to obtain a detailed understanding of the subject; (6) Describing the essential structure of the phenomenon under study; and (7) Sending the final results of the analysis to the participants for verification. Saturation was verified by recruiting two new participants whose results showed that their interviews contained all the important codes and topics.[36] Hence, we decided that the sample of 17 interviews was suitable at this stage:[37] the total interview length of 510.5 minutes and comprised a total of 94,164 characters.

Comparison and Integration of Qualitative and Quantitative Data

In convergent studies, data analysis comprises three phases.[28] First, we analyzed the qualitative data with the seven-step method, as described earlier, and then we statistically analyzed the quantitative data. Next, we conducted the mixed-methods analyses. The themes emerging from the qualitative findings were compared side-by-side and integrated with the quantitative results in terms of AWEs' demographic characteristics, medical characteristics, status, and factors influencing self-management, transition readiness, and social support, and comparing views about behavioral dilemmas and support requirements. The comparison and integration of the data resulted in confirmed and expanded findings, forming a joint display of the data.

Results

Demographic and Medical Results

A total of 654 participants were included in the quantitative analysis. Of these, 362 (55.35%) were male and 292 (44.65%) female; 358 (54.74%) were above 12–14 years of age and 296 (45.26%) were between the ages of 15–18. For the qualitative phase, 17 participants, including ten AWEs, three mothers, one father, and three grandparents, were invited for the interview. The demographic and clinical data of all the participants are provided in Table 1.

Quantitative results

Univariate analysis of self-management. Comparative results showed that individual factors (ie, age, gender, and family structure) and medical factors (ie, epilepsy type, epilepsy medication, and comorbidity) were associated with self-management scores of AWEs that were statistically significant (P<0.05, Table 1).

Self-management level, transition readiness, and social support. The results showed that the average total ESME score was 66.78±4.08 (possible total score = 20–100), the average EpiTRAQ score was 2.52±0.42 (a score gradient of 1–5), and the average total SSRS score was 3.21±1.45 (Table 2).

Multivariate linear regression of self-management. The multivariate linear regression model was developed by the conditional fitted ratio using the forward stepwise method, with self-management scores as the dependent variable and statistically significant variables in univariate analyses as independent variables ($\alpha_{in} = \alpha_{out}$). The results showed that age, epilepsy type, AED (antiepileptic drug) type, comorbidities, family structure, transition readiness, and social support were statistically significant in the model (P < 0.05, Table 3).

Qualitative Results

Behavioral dilemmas. Seven initial themes emerged from the interviews: Sickness stigma, Conflicts between comorbidities and role expectations, Limited personal growth, Difficulty with medication management, Difficulty with symptom management, Difficulty with daily life, and Difficulty with social adaptation (Supplementary Table 2-1).

Support requirements. Support requirements for self-management during transition readiness were initially classified into 11 themes, including: Social care, Family support, Effective patient-physician communication, Effective seizure management, Assessment and feedback of transition readiness, Psychosocial concerns, Medication skill management,

Table 2 ESMS, EpiTRAQ, and SSRS Scores of AWEs (Score ±s)

Subscale	Score Mean ± SD	Average Score of the Items Mean ± SD	Sort
ESMS	66.78±4.08	3.30±0.62	
Information Management	18.76±2.52	3.66±0.53	1
Safety Management	10.78±1.62	3.60±0.54	2
Lifestyle Management	14.11±2.01	3.41±0.50	3
Drug Management	13.10±1.50	3.25±0.50	4
Seizure Management	11.96±2.11	2.98±0.37	5
EpiTRAQ	84.05±6.17	2.52±0.42	
Appointment Keeping	20.88±3.45	3.07±0.58	1
Talking With Providers	5.01±1.15	2.90±0.48	2
Managing Daily Activities	25.28±4.03	2.83±0.45	3
Tracking Health Issues	19.15±4.35	2.09±0.38	4
Managing Medications	12.62±3.48	2.11±0.49	5
SSRS	33.12±4.35	3.21±1.45	
Subjective Support	17.94±2.55	4.47±0.60	1
Objective Support	7.53±1.80	2.51±0.64	2
Support Utilization	7.13±1.61	2.34±0.54	3

Table 3 Multiple Linear Stepwise Regression of the Self-Management Scores of AWEs (N=654)

Item	Partial Regression Coefficient	Standard Error	Standardized Regression Coefficient	t value	P value
ESMS-Information Management					
Constant term	3.845	0.966	-	3.979	<0.001
EpiTRAQ-Talking With Providers	1.041	0.072	0.476	14.503	<0.001
SSRS-Subjective Support	0.098	0.035	0.099	2.803	0.005
SSRS-Support Utilization	0.176	0.056	0.113	3.142	0.002
Age	0.215	0.049	0.145	4.341	<0.001
Family Structure	0.079	0.115	0.082	2.682	0.032
ESMS-Drug Management					
Constant term	9.367	0.644	-	14.536	<0.001
EpiTRAQ-Managing Medications	0.185	0.016	0.436	11.769	<0.001
SSRS-Objective Support	0.027	0.069	0.032	2.909	0.041
Epilepsy medication type	−0.041	0.072	−0.023	−0.561	0.575
Comorbidities	−0.179	0.053	−0.127	−3.380	0.001
Age	0.034	0.033	0.038	1.035	0.304
ESMS-Seizure Management					
Constant term	3.175	0.522	-	6.123	<0.001
EpiTRAQ-Talking With Providers	0.071	0.037	0.115	2.359	0.019
EpiTRAQ-Tracking Health Issues	0.315	0.024	0.651	13.165	<0.001
SSRS-Objective Support	−0.018	0.032	−0.016	−0.582	0.023
SSRS-Support Utilization	0.032	0.036	0.025	0.899	0.004
Epilepsy medication type	−0.124	0.035	−0.092	−3.556	<0.001
Comorbidities	−0.036	0.054	−0.017	−2.668	0.002
ESMS-Lifestyle management					
Constant term	5.961	0.679	-	8.786	<0.001
EpiTRAQ-Talking With Providers	0.879	0.058	0.504	15.072	<0.001
SSRS-Subjective support	0.108	0.026	0.138	4.142	<0.001
Gender	−0.192	0.135	−0.047	−1.405	0.16
Family structure	0.156	0.095	0.055	3.632	0.003
ESMS-Safety management					
Constant term	0.531	0.433	–	1.227	0.227
EpiTRAQ-Managing Daily Activities	0.323	0.011	0.745	28.259	<0.001
SSRS-Objective Support	0.048	0.024	0.053	2.019	0.044
Comorbidities	0.051	0.043	0.031	3.182	0.018

Knowledge of the disease, Information management, Positive psychological feelings, Motivation for health management (Supplementary Table 2–2).

Mixed-Methods Findings

The comparison and merging of the data resulted in confirmed and expanded findings, forming a joint display of the data (Supplementary Tables 3–1 and 3–2).

There were two domains of self-management behavioral dilemmas for AWEs during transition readiness, including objective factors and potentially modifiable factors according to the SMART model, seven subthemes of which are pertinent. These were: (1) Four sub-themes that confirmed the quantitative findings, including conflicts between comorbidities and role expectations, difficulty with symptom management, difficulty with daily life management, and difficulty with social adaption, and (2) Three subthemes that expanded the quantitative findings, including conflicts between pressure from public opinion and social needs, conflicts between family structure and personal growth, and difficulty with AED management.
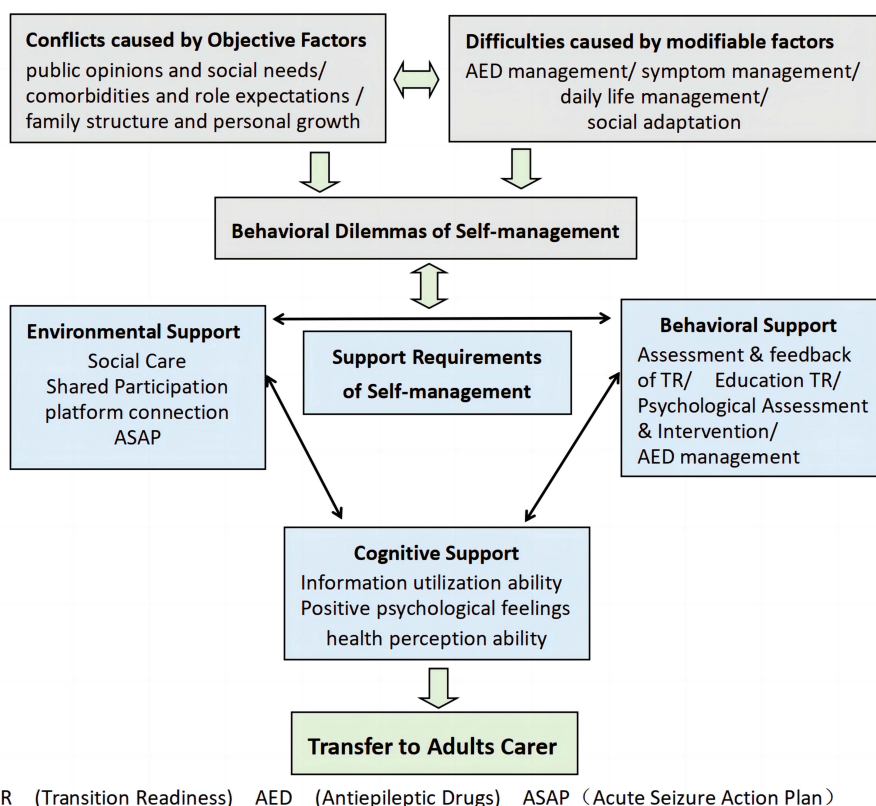
Note:TR (Transition Readiness) AED (Antiepileptic Drugs) ASAP（Acute Seizure Action Plan）

Figure 2 Conceptual model of influencing factors and support requirements.

There were three domains that affected health behaviors in Social Cognitive Theory.[38] Based on Social Cognitive Theory, three domains were formed, including environmental support, cognitive support, and behavioral support related to support requirements for self-management during transition readiness, which involved 11 sub-themes. (1) Six of these themes (social care, assessment feedback for transition readiness, psychological assessment interventions, AED management, education about transition readiness, and positive psychology) confirmed the quantitative findings. (2) Five themes (patient and family engagement, child-adult medical communication platform linkage, application of localized Acute Seizure Action Plan, information utilization, and motivation of health perception) expanded on the quantitative findings. Therefore, we created a rough conceptual model according to the SMART framework and the social cognitive theory, in order to classify and visualize the identified factors (Figure 2).

Discussion

This mixed-methods study allowed us to attain a comprehensive understanding of negative and advantageous factors of self-management for AWEs during transitional readiness. A joint display of data in Supplementary Tables 3-1 and 3-2 show the results of comparing and merging the quantitative and qualitative findings, and the influence of the domains and subthemes of behavioral dilemmas and support requirements on the variables in the self-management model.

Status of Self-Management, Transition Readiness, and Social Support for AWEs

The AWEs' scores for ESMS, EpiTRAQ, and SSRS included the total score and the average score of each subscale and each dimension, The dimensions of each subscale were ranked according to their mean score (Table 2). The average total score for transition readiness in this study was 2.52±0.42, which was lower than that found by Clark (3.85–0.94),[31] and the overall level of self-management was lower (66.78±4.08) than reported by Wang (71.23±5.22). Age is an important variable for adolescents with chronic disease during transition readiness.[16] This may be because this study's sample was ≤18 years old, and were therefore younger than the previous study's sample.

The scores for the items in ESMS, EpiTRAQ, and SSRS are shown in the joint display of data in the supplementary section (Supplementary Tables 3–1 and 3–2). Seizure-management had the lowest average dimension score of the ESMS (2.98±0.37). This indicates that AWEs have an increasing requirement for quality of out-of-hospital activities, which may be related to a lack of applicable educational tools for out-of-hospital acute seizures among AWEs and their families in China.[22] The appointment-keeping dimension had the highest average score (3.07±0.58) on the EpiTRAQ. This is because hospitals use information technology (apps) for appointments and adolescents with chronic illness are able to use the apps. Medication management had the lowest EpiTRAQ average score (2.11±0.49), which was consistent with the findings of Yang.[39] Side-effects may contribute to ongoing issues about adherence to medications that affect one's education and personal life (eg, socializing with friends).[21] The total average score for social support on the SSRS was 33.12±4.35, a moderate level. This is consistent with the findings of the Liu et al study of parents of children with epilepsy.[40] The subjective support dimension of the SSRS had the highest average score, indicating AWEs received more emotional support from their families or friends; support utilization had the lowest score, which may be related to the unusual behavior of seizures. Support utilization, as the key to effectiveness of social support, is directly related to the effectiveness of social support.[41] This suggests that healthcare workers should accord importance to the development of social resources and management skills in the personal growth of AWEs.

In addition, we found that participants had a high willingness to engage in the questionnaire. The valid return rate of 89.10% may be due to the fact that some patients' suggestions about the type of gifts they would like to receive were solicited before the research, and the small gifts may have increased participants' interest in responding. Then, the investigators were asked to introduce the research topic so that the respondents felt relevant to the health management of themselves. Finally, the selection of times to administer the questionnaire may have also contributed to the high completion rate. The ward patients completed the questionnaire in the afternoon because their treatment was relatively less time-consuming; the outpatient clinic patients were more inclined to wait for treatment and examination.

Factors Influencing Self-Management During Transition Readiness

The variables with statistically significant differences in the univariate analysis and the significant social support and transition readiness variables were used as independent variables, and the total score of the 5 dimensions of self-management was used as the dependent variable in the multivariate linear stepwise regression (Table 3).

Demographic and Medical Factors

Age influences the self-management behavior of children and young adults because they go through many changes according to life stage in terms of education, social relationships, and brain and biological development.[21] The study showed that age was a factor affecting information management in epilepsy self-management ($P<0.01$). This may be related to the improvement in information integration and processing ability with the increase in age, and the gradual opportunity to use information software to manage information. Hence, age should be considered in the content and the approach to information recognition and acceptance during transition readiness. Our findings showed that comorbidities were significantly associated with drug management, seizure management, and safety management ($P<0.01$). This suggests that the evaluation of, and interventions for comorbidities of AWEs need to take into account the above factors. The study also demonstrated the importance of family structure for information management ($P<0.05$) and lifestyle management ($P<0.05$) of ESMS. This is a reminder that family members may serve as models for the information management of adolescents with chronic illness. Meanwhile, as the family is the foundation of adolescent socialization, changes in family structure may positively or negatively affect an adolescent's lifestyle.[9] This suggests that taking advantage of different family resources and stimulating the positive effects of family functioning on self-management during transition could be an area of research inquiry.

Social Support and Transition Readiness Factors

Social support has an important positive influence on the self-management of adolescents with chronic illness.[15] Our results showed that objective support had an effect on AWEs' self-management of medication, seizures, and safety ($P<0.05$), and that subjective support had an effect on self-management of information and lifestyle ($P<0.01$). Moreover, support utilization was related to self-management of information and seizures ($P<0.01$). This suggests that we should

expand the various aspects of social support to develop content related to the self-management of AWEs. For example, engaging in active social and psychological support interventions and activities, maintaining the evaluation of psychosocial status during the process of transition readiness through family follow-up, and establishing volunteer service clubs to increase positive feelings can enhance confidence in self-management.

Model of Self-Management During Transition Readiness

The SMART model presents a systems approach that extends beyond patient knowledge and skills related to their disease and focuses on both the limiting and facilitating factors, as well as the role of several stakeholders, that is, patients, parents, and care providers. The study examined behavioral dilemmas caused by objective factors and modifiable factors, based the guidance of the SMART model, and focused on the contributions of AWEs and family caregivers to better understand and predict the variables that are amenable to intervention. Social cognitive theory is composed of four parts: triadic interaction determinism, observational learning, self-management, and self-efficacy, stressing cognition as the determinant of behavior. The dynamic presentation of support requirements for self-management in this study is based on the triadic determinism of environment, cognition, and behavior in social cognitive theory. As support requirements are the main focus of this research, it was selected as the central action that links the results related to dilemmas with the results for requirements. Cognitive support as a determinant is a key condition connecting the supply requirements to transfer outcomes, as shown in Figure 2. The combination of the two theories can help one to look critically at the conversion between dilemmas and the supportive relationship between the individual and the environment.

Dilemmas Caused by Objective Factors Reflected in Three Conflict Themes

Pressure from Public Opinions and Social Needs

External factors, such as cultural differences, have an effect on stigmatizing, but the intensity of "stigma" is also related to internal factors (eg, sense of inferiority).[42] Functional magnetic resonance imaging has shown that AWEs' emotional recognition patterns have a major effect on social interaction during the transition age.[5] This suggests that AWEs and family members should be given scientific information that takes cultural and individual differences into account; however, changes in the public's perception of epilepsy are also critical.

Conflicts Between Comorbidities and Role Expectations

The burden of comorbidities in epilepsy often exceeds that attributable to epileptic seizures. For example, neuropsychiatric comorbidities are common among 43% of AWEs.[43] Therefore, we should improve the screening and treatment of comorbidities of epilepsy, and refine self-management interventions, taking the characteristics of different comorbidities into account.

Conflicts Between Family Structure and Personal Growth

Our study found that grandparents raising AWEs was common due to their traditional cultural background. Unfortunately, the overprotectiveness of grandparents could limit the development of a child's ability to self-manage, whereas, mobile families lack the time to guide the self-management of AWEs, which broadens the challenges of family structure on personal growth in the transition phase of AWEs.

Four Behavioral Dilemma Themes Related to Potentially Modifiable Factors

Difficulty with Managing Medications

Medication was mostly considered to be important for the management of seizures.[21] Some forms of epilepsy and many anticonvulsants are associated with cognitive impairment, behavioral issues, and side effects, which may affect patients' adherence to the medication regimen. With regard to AWEs, this points to the need for higher levels of medication self-management skills and tools, which extend to drug taking, adverse reactions, purchasing, etc. Personalized AED management is highly expected. In addition to the material items in the assessment scales, the difficulties also included medication storage, administration, supervision, and stigma in the interviews, which extended the scope of medication self-management.

Difficulty with Symptom Management

The low scores for seizure management in the ESMS were expanded upon in the interviews due to the lack of effective health ASAP tools and emergency medications for pre-hospital AS. In China, the current likelihood of using out-of-hospital emergency drugs for children with epilepsy is not optimistic,[44] which has a direct impact on the effectiveness of symptom management.

Difficulty with Daily Life Management

Our conclusion is consistent with the findings of Betz et al[15,16] The authors found that many adolescents and young adults who have conditions with neuro-cognitive limitations face similar challenges in managing daily life activities and disease management.

Difficulty with Social Adaptation

The roles of social and psychological adaptation in improving health-related quality of life and co-morbidities have received widespread attention.[42] Healthcare providers are encouraged to emphasize social adaptation as an integral part of transition readiness, and to have an understanding of resources from the micro level to the macro level to facilitate this.

The Support Requirements of Self-Management for AWEs During Transition Readiness Include Environmental, Cognitive, and Behavioral Components

Environmental support includes four components: social care, shared participation, platform connection, and ASAP implementation in this study. The findings emphasize the need for effective linkages between hospitals, communities, schools, and families, as well as effective linkages between children and adult healthcare facilities and the need for medical staff to recognize the important role of family members during the process of transition readiness. Attention should also be given to the urgent need for localized ASAP implementation studies.

Cognitive support includes three themes: information utilization training, motivating positive psychological feelings, and health perception. There is moderate- to high-quality evidence to support the clinical effectiveness of mindfulness-based programs on neurocognitive disorders in patients with epilepsy.[42] Mindfulness-based interventions aim to cultivate positive psychological feelings and focused attention in patients and should be incorporated into self-management behavioral training to help AWEs overcome cognitive dysfunction and stimulate positive feelings. Furthermore, the ESEM score for safety management was moderate. The interviews revealed that the ability of AWEs and their families to stimulate health-risk perception had an important influence on safety behaviors. AWEs will be more motivated to perform healthy behaviors if they are aware of the hazards of poor self-management behaviors. Specifically, the perception of behavioral benefits is a significant factor in self-management behavior.

Behavioral support includes continuous assessment and feedback on transition readiness, phased education on transition readiness, regular psychological assessments and interventions, and AED management. Our findings suggest that localized, specific, and validated assessment tools of transition readiness need to be developed; meanwhile, transition readiness assessments, feedback, and behavioral guidance needs to be addressed in self-management intervention programs. Moreover, transition readiness education needs to be conducted in the context of AWEs' self-management requirements and health problems at different stages. As psychosocial assessment is important for the self-management of children with epilepsy,[13] regular psychosocial screening should not be overlooked because of the cognitive limitations of AWEs or their caregivers, or the complexity and insidiousness of neurological symptoms.

Guided by the SMART, this study suggests that objective factors and potential modifiable factors of behavioral dilemmas can be transformed and influenced by each other. For example, the alleviation of social-adaptation problems, which are modifiable factors, may reduce the impact of objective factors on the growth of AWEs due to social opinion, whereas the alleviation of objective comorbidities and role expectation conflicts may reduce barriers to the social adaptation of AWEs. Social Cognitive Theory suggests that behaviors are determined by the external environment and internal cognition, with cognition playing a dominant role. In this study, cognitive support was considered to have a dominant role in the behavioral support of requirements self-management for AWEs during the process of transition readiness.

Limitations

The present study has four main limitations, which may provide ideas for further research. First, the relationship between dilemmas and support requirements as revealed from our conceptual model should be statistically confirmed. Second, because of the disease-specific nature of epilepsy, this research selected the Chinese versions of the EpiTRAQ and ESMS. EpiTRAQ was adapted from the well-validated TRAQ; it was modified to include items related to key concepts in epilepsy quality measures. Based on the retest reliability of EpiTRAQ, it was unclear whether the questionnaire reflects the true level of patients' knowledge or self-management skills.[31] Meanwhile, the ESMS does not focus on the age period of patients with epilepsy. Therefore, we may consider developing a self-management assessment tool of transition readiness for AWEs or chronic neurological disorders to explore the specific status and requirements. Third, the cross-sectional nature of the present study posed a challenge to explaining changes in self-management behavior during transitional readiness over time. Finally, based on the close interaction among stakeholders, the perspectives of healthcare providers toward self-management behavior during transitional readiness are worth exploring.

Practice Implications

With the convergent mixed-methods analyses, the findings could be contextualized based on the perspectives of the interview participants. It provided critical detailed information on the core components of the behavioral dilemmas and support requirements for self-management by AWEs. Significant differences exist among countries and health organizations with regard to clinical context, medical systems, cultural context, conception of family, and attitudes toward transition care. Especially in the case of limited medical resources, research focusing on the dilemmas and strategies of self-management is of practical significance to meet the urgent needs of transition readiness services AWEs and their families. So, a model based on local context is expected to contribute to the existing knowledge database and health behavior models for Chinese adolescents with chronic illness and to expand the previous self-management of transitional readiness models and theories. We feel optimistic that this model could serve as a framework that other investigators and clinicians can use to design, improve, optimize, and promote self-management interventions, assessment tools, and service strategies during the transition of adolescents with chronic diseases.

Conclusion

This study provides insights into the behavioral dilemmas and support requirements of AWEs in China and expands on previous self-management and transitional readiness strategies and models. The findings imply that prioritizing "the voice of the patient" and "the positive role of the family in their health care" in self-management strategies for AWEs under medical care may lead to better response by healthcare services and better care outcomes.

Abbreviations

AWEs, Adolescents with epilepsy; Ass, Acute seizures; HCT, Home and community-based treatment; FCs, Family caregivers; ASAP, Acute Seizure Action Plan; AED, Antiepileptic drug; TR, Transition readiness.

Data Sharing Statement

Data are available from the corresponding author upon a reasonable request.

Ethics Approval and Informed Consent

The study was conducted in accordance with the Declaration of Helsinki. This study was approved by the ethics committee of Children's Hospital of Chongqing Medical University institution (reference number 202233), as well as the management of each participating hospital. Transcripts and records of the analyses were stored on a secure cloud-based server. All the participants provided written informed consent and expressed willingness to complete the investigation. Participants' consent included the publication of anonymized responses. The anonymity of the respondents was protected using digital codes.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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