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Health Assessment of Chinese Adolescents with Epilepsy in the Preparatory Phase of Transition Process from Pediatric to Adulthood: A Single-Center Study Using the Omaha System

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ABSTRACT

Objective: Epilepsy is one of the most common childhood-onset neurological disorder characterized by both seizures and the related comorbidities. The preparatory phase in transition refers to a dynamic process of identifying and resolving health issues to ensure seamless continuing care from childhood to adulthood. This study identifies the health issues of the preparatory phase in transition from children to adulthood using the Omaha System.
Methods: This prospective, single-center study enrolled 86 adolescents with epilepsy in China. The Problem Classification Scheme and Problem Rating Scale for Outcomes of Omaha System were used to evaluate transition-induced health problems.
Results: These health problems cover all four domains of the problem classification scheme of the Omaha System, and the specific distribution is related to the type of epilepsy. The results of the four-category classification evaluation showed that the most common health problem is health-related behavioral problems (46.1%), followed by psychosocial problems (23.0%), physiological problems (20.6%), and environmental problems (10.3%). The distribution of these health problems in generalized seizures, focal seizures, and generalized-focal seizures are significantly different ($P < 0.01$). The results of the outcome rating scale showed that 83.4% of the children had minimal knowledge, 84.2% had inconsistently appropriate behaviors, and 86.7% had moderate symptoms.
Conclusions: The health problems of patients with epilepsy during the preparatory phase of transition process from pediatric to adulthood should be emphasized. Identification of health problems though the Omaha System can improve management for adolescents with epilepsy, including prevention, nursing care, social support, and therapeutic interventions.

Introduction

Overall, 50% of pediatric epilepsies will develop into adult epilepsies, which may last a patient's entire life (Geerlings et al., 2015). Epilepsy is a neurological disorder characterized by seizures, which is associated with a high prevalence of comorbidities including motor skill impairments, learning disabilities, and mental health issues (Geerlings et al., 2015; Lindsay, Kingsnorth, & Hamdani, 2011). Additionally, poor drug compliance, substance abuse, smoking, alcohol abuse, unplanned pregnancies, and other lifestyle factors are associated with a higher risk of incidence and severity of epileptic disorders in adolescence (Borlot et al., 2014; Borlot & Andrade, 2016; Lewis & Noyes, 2013). Health issues during the transition process from pediatric to adulthood are receiving increasing attention (Lindsay et al., 2011). Pediatric and adolescent health-care providers themselves also experience roadblocks during the transition to adult care, mainly due to a lack of preparation for transitional care (Schultz, 2013). Furthermore, the evaluation of health outcomes during the transition period is still under-studied (Burke et al., 2018; Crowley et al., 2018; Geerlings et al., 2015; Geerlings et al., 2016). Therefore, it is important to assess and evaluate the medical and psychosocial issues during the transition period.

Systematic and sufficient preparation is essential for the prevention and management of health problems in the transition period from pediatric to adulthood. Camfield et al. and Kuchenbuch et al. both recommended that preparation should be initiated at age twelve (Camfield, Camfield, & Pohlmann-Eden, 2012); whereas Camfield et al. even emphasized that preparation should be taken as early as possible for children with severe and chronic epilepsy, e.g., Lennox–Gastaut syndrome (P. R. Camfield, Bahi-Buisson, & Trinka, 2015). Although problems of transition from pediatric to adulthood and the concept of preparation period are widely recognized in chronic diseases, limited evidence is available regarding health problems and required care in adolescents

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with epilepsy (Borlot et al., 2014; Borlot & Andrade, 2016; Iyer & Appleton, 2013).

The Omaha System is a research-based, comprehensive, standardized health-care taxonomy consisting of a classification component (Problem Classification Scheme), a care plan component (Intervention Scheme), and an evaluation component (Problem Rating Scale for Outcomes) (KS, 2009). In this study, we used the Omaha System to assess health issues of Chinese adolescents with epilepsy in the preparation phase of the transition process from pediatric to adulthood.

Materials and methods

Population

Informed consent from guardians of underage teens and teens ages 18 was obtained, and adolescents under 18 years of age provided informed assent at enrollment. The study protocol was approved by the Ethics Committee of Children's Hospital of Chongqing Medical University.

A total of 84 Chinese families, who visited the epilepsy service clinic of Children's Hospital affiliated to Chongqing Medical University in China between January 2017 and December 2017, were enrolled. Children with a physician-confirmed diagnosis or highly probable diagnosis of (childhood-onset) epilepsy were included in the study. The inclusion criteria included: 1) a confirmed diagnosis of epilepsy according to the International League against Epilepsy (ILAE) classifications; 2) age 10–18 years; 3) the course of epilepsy is no less than half a year; and 4) compliance of the children and their guardians to the interview. The exclusion criteria included: 1) history of brain surgery; 2) usage of central nervous system medications and other neurological or psychiatric disorders; 3) patients diagnosed with non-epileptic seizures only; or 4) mental retardation (IQ < 70).

Data collection

The data in this cross-sectional study were collected via medical records, clinic or community visits, and telephone interviews by well-trained and experienced health workers who were familiar with the Omaha System. Regular meetings were organized to discuss potential health problems and Knowledge-Behavior-Status (KBS) scoring. The data included three sections: 1) demographic and medical history such as gender, age, comorbidities, duration of epilepsy preceding the evaluation, types of epilepsy, electroencephalogram (EEG), and control of epilepsy; 2) Health problems; 3) KBS scoring of health problems.

Participants' health problems and KBS scoring were assessed and evaluated using the Omaha System. The Chinese version of the Omaha System was translated from the original, back-translated and adjusted for cultural adaptation, the content validity was 0.85, and Cronbach's alpha which was used to measure the reliability was 0.729 (Tan, Liu, Wen, et al., 2011). The study team has investigated the feasibility of Omaha System in the nursing of children with epilepsy in China (Cui, Xianlan, & Shuangzi, 2016), and constructed the nursing record sheet of Epilepsy Children's Transitional Nursing based on the Omaha System. The sheet, combined with a retrospective analysis of 110 medical records and literature review, was constructed after three-round of group discussion, and the experts' authority score of two-round by Delphi method were 0.784 and 0.803. The coefficient of authority (Cr) of sheet was 0.889, and the Kendall coefficient was between 0.450 and 0.861 (Cui, Zheng, Shuang-Zi, Cheng, & Wang, 2017).

The sheet of Problem Classification Scheme consisted of 12 health-related problems (58 signs and symptoms) of Omaha problem classification system covering physiological, environmental, psychosocial, and health-related behavioral domains (for each individual, the specific problems were subclassified and described as symptoms and/or signs when the health problem domain(s) was identified). Problems Rating Scale for Outcomes using a 5-point Likert scale was adopted to evaluate the KBS (KS, 2009). This scale includes three aspects: 1) Knowledge (ability of the client to remember and interpret information): 1 = no knowledge, 2 = minimal knowledge, 3 = basic knowledge, 4 = adequate knowledge, 5 = superior knowledge; 2) Behavior (observable responses, actions, or activities of the client fitting the occasion): 1 = not appropriate behavior, 2 = rarely appropriate behavior, 3 = inconsistently appropriate behavior, 4 = usually appropriate behavior, 5 = consistently appropriate behavior; and 3) Status (condition of the client in relation to objective and subjective defining characteristics): 1 = extreme signs/symptoms, 2 = severe signs/symptoms, 3 = moderate signs/symptoms, 4 = minimal signs/symptoms, 5 = no signs/symptoms. A higher score represents a better health condition.

The sheet was filled in with blue pen. If there were new or revised nursing problems during collection, the information was added or corrected with red pen. Each sheet was suitable for one patient with epilepsy and family.

Statistical analysis

Continuous variables were expressed as the mean ± standard deviation (SD), and categorical values were shown in the form of frequencies (percentage, %). The differences in health problems were examined using the chi-squared test for categorical variables. All analyses were conducted using SPSS 20.0 software (IBM Corp., Armonk, NY, USA). An alpha of $p < 0.05$ was considered statistically significant.

Results

Clinical characteristics

There were 51 males and 33 females, with the mean ± SD age of 14.4 ± 3.2 years. The mean ± SD duration of epilepsy was 10.2 ± 4.6 years. Twenty-six children were diagnosed with generalized seizures (31.0%, including absence, myoclonic, atonic, tonic, and tonic–clonic seizures), 25 children were diagnosed with focal seizures (29.8%, including focal aware seizures, focal impaired awareness seizures, focal motor seizures, focal non-motor seizures), and 33 children were diagnosed with generalized-focal seizures (39.3%, referring to both generalized and focal seizures). EEG was normal in 9 patients (10.7%), and paroxysmal discharges in 75 patients (89.3%), respectively. Seizure frequency control (Seizure Control = SC vs. non-SC) was defined as the proportion of patients who showed a ≥ 50% reduction in seizure frequency between the initial and final visits (Moura et al., 2015). We observed 55 children (65.5%) with SC and 29 children (34.5%) with non-SC, respectively. The clinical characteristics of the adolescents with epilepsy are summarized in Table 1.

Table 1
Clinical characteristics of adolescents with epilepsy (n = 84).

Items	Cases	Proportions
History (Years)		
<5	23	27.4%
5–10	42	50.0%
>10	19	22.6%
Seizure type		
Generalized	26	31.0%
Focal	25	29.8%
Generalized-focal	33	39.3%
EEG		
Normal	9	10.7%
Abnormal	75	89.3%
Epilepsy control		
Seizure control	55	65.5%
Non-seizure control	29	34.5%

Epilepsy-related comorbidities were either psychological or physical dysfunctions including the neuro-musculoskeletal system, urinary system, skin, and digestive system. Sleep disorders, emotional disorders, and migraines were the most common comorbidities in Fig. 1.

Health problems

A total of 582 health problems were identified, as shown in Table 2. According to the four-category classification, health-related behavioral problems were the most common (46.1%), followed by psychosocial problems (23.0%), physiological problems (20.6%), and environmental problems (10.3%). Among the children with generalized seizures, health-related behavioral problems were the most common (16.8%), followed by physiological problems (7.6%), psychosocial problems (5.7%), and environmental problems (2.6%). Among the children with focal seizures, health-related behavioral problems were the most common as well (6.2%), followed by psychosocial problems (4.0%), environmental problems (2.4%), and physiological problems (1.4%). Among the children with generalized-focal seizures, health-related behavioral problems were the most common (23.0%), followed by psychosocial problems (13.4%), physiological problems (11.7%), and environmental problems (5.3%). The distributions of these problems according to the different types of seizures were significantly different ($P < 0.01$). The proportions of the top ten health problems in these three groups are shown in Fig. 2.

KBS scoring of health problems

According to the 5-point Likert scale, 83.4% of the children scored as having minimal knowledge in the *Knowledge* aspect, 84.2% scored inconsistently appropriate behavior in the *Behavior* aspect and 86.7% scored moderate signs/symptoms in the *Status* aspect in Table 3.

Table 2
The proportions of the health problems in four domains (n = 582) (n, %).

Seizures	Health-related behaviors	Psychosocial	Physiological	Environmental
Total	268 (46.1%)	134 (23.0%)	120 (20.6%)	60 (10.3%)
Generalized	98 (16.8%)	33 (5.7%)	44 (7.6%)	15 (2.6%)
Focal	36 (6.2%)	23 (4.0%)	8 (1.4%)	14 (2.4%)
Generalized-focal	134 (23.0%)	78 (13.4%)	68 (11.7%)	31 (5.3%)
P value	<0.001	<0.001	<0.001	0.009

Discussion

To the best of our knowledge, the application of the Omaha System for improving the health care of epileptic adolescents has not been reported. This is the first study to focus the health problems using the Omaha System during the preparatory phase in transition process from children to adulthood. Our findings showed that the Omaha System was an applicable tool to assess health problems comprehensively. The findings of this study could cover the shortage of initiated transitional care in hospital, community or home to some extent and provide support for the establishment of epilepsy children-to-adulthood transitional care programs in China.

Guidance value of the Omaha Problem Classification Scheme for the preparatory phase of the children-to-adulthood transitional care

During the transition period, chronic diseases may result in an imbalance between physical and psychological development, conflict between independence and dependence, and dilemmas between self-recognition and social interaction. All of these factors can cause or exacerbate related health problems. Among all the comorbidities, sleep disorders were found in 58.3% of all adolescents to be the most common health issue. Somnolence, insomnia, and shifted sleep patterns were among the most commonly observed TEAEs (treatment emergent adverse events) associated with almost all AEDs (Moavero, Pisani, Pisani, & Curatolo, 2018). Emotional disorders were observed in 36.9% of the children, mainly manifesting as irritation, depression, social withdrawal, and aggression. Migraine was observed in 27.4% of patients, which is also common in these families and encompasses migraine with and without aura. Being overweight or obese was found in 19 children (22.6%). Obesity is a considerable side effect of antiepileptic medications. EEG showed abnormalities in 89.3% of the children, and only 10.7% of the children were seizure-free, and non-SC was observed in 29 children (34.5%). At a certain point, children with comorbidities and ongoing seizures have to meet the challenges of transitioning from a family-centered pediatric care to the individual-centered adult care (Corrigan, Broome, & Dorris, 2016).

Evaluation of health problems qualitatively and quantitatively can provide robust evidence for care plans. In the current study, we found health problems induced by generalized, focal, and generalized-focal seizures covered all four domains in the Omaha System. Health-

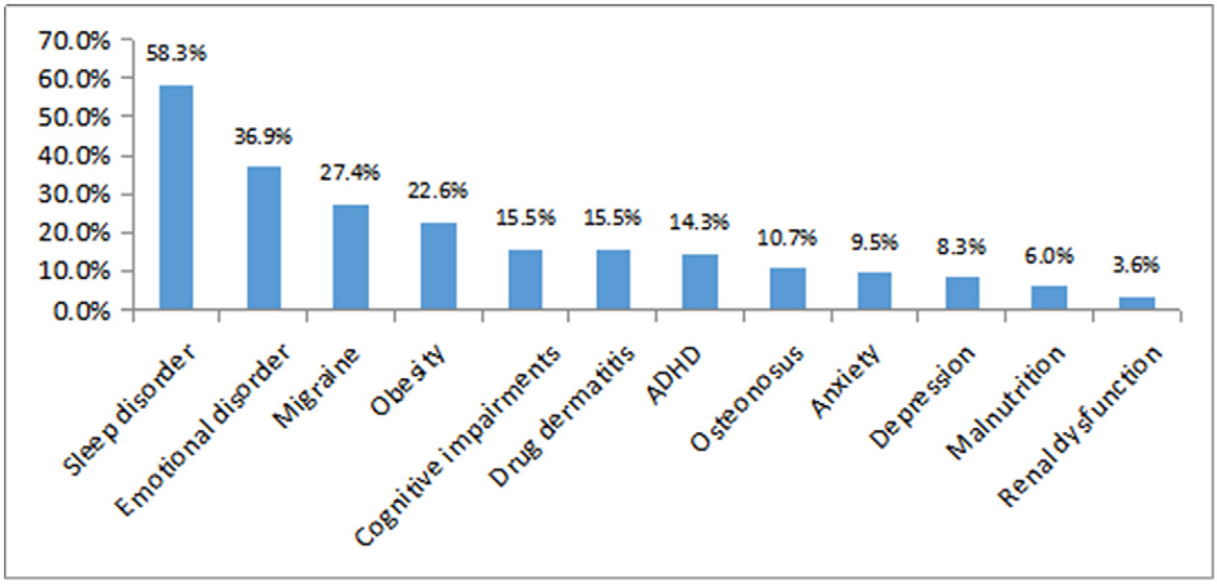

Fig. 1. Comorbidities of the patients.

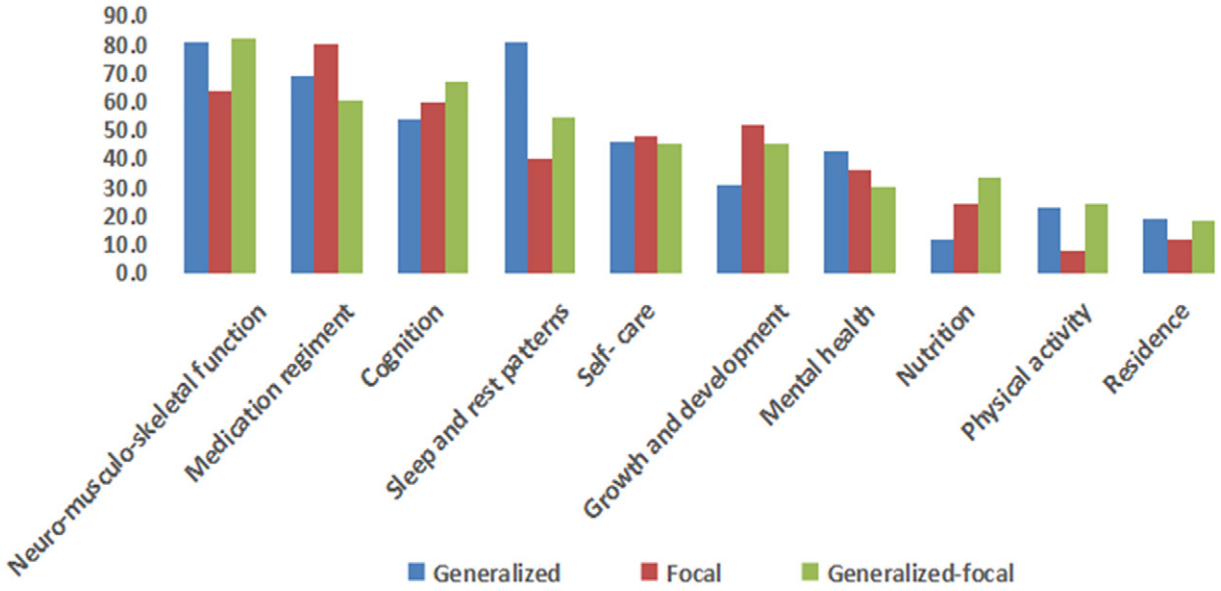

Fig. 2. The first ten health problems in the three groups.

related behavioral problems were the most common (46.1%), including pharmacotherapy, poor nutrition status, sleep disturbances, self-care disability, impaired physical activity, and insufficient health care supervision. Psychosocial problems occupied 23.0% of all health problems, including growth and developmental abnormalities, mental disturbances, and interpersonal relationship disorders. Physiological problems (20.6%) and environmental problems (10.3%) relatively few, represented by nervous-muscular-skeletal and cognitive dysfunctions and neighborhood insecurity. In addition, the problems in these various domains may interact with each other, generate cumulative adverse effects, and even result in a vicious cycle. Health problems in the psychosocial, physiological, environmental and health-related behavioral domains have overlapping and synergistic effects (Topaz, Golfenshtein, & Bowles, 2014). For example, the disease condition and environmental forces of adolescents affect their psychological and behavioral performance, and conversely, their cognitive and behavioral patterns affect disease recovery. The cumulative effects of health problems can persist into the adult stage for adolescents with epilepsy (Cui et al., 2017). On the contrary, positive coping strategies contribute to a constructive life trajectory if the disease-related crisis is positively utilized. It is worth mentioning that the health problems in our study covered all the domains in the Omaha Problem Classification Scheme, suggesting that a multi-disciplinary, multi-team, and multi-stage collaborative work is required for the transitional care for pediatric with epilepsy.

The distributions of health problems in diverse types of epilepsy are considerably different. One potential explanation is that epilepsy seizures have a heterogeneous pathogenesis and manifest in various clinical forms (Blair, Germain, Bernard, & Maria, 2017). Additionally, antiepileptic drug (AED) administration and comorbidities may have side effects on the pathophysiology of epilepsy (Keezer, Sisodiya, & Sander, 2016). Therefore, pediatric epilepsies exhibit a broad spectrum of health problems. Children with generalized seizures, tonic and clonic seizures usually cause behavioral and physiological problems. Whereas focal seizures associated with partial sensorimotor seizures and psychomotor seizures can cause psychosocial problems and cognitive impairments which are more severe.

It is usually challenging for nurses to recognize health problems accurately, whereas the Omaha Problem Classification Scheme can directly identify the problems according to the patient's symptoms and signs. In the present study, the neuro-musculoskeletal dysfunction was the most common problem in adolescents with epilepsy (75.5%), especially in children with generalized and generalized-focal seizures as neurological and motor systems were more vulnerable (Caraballo, Silva, Beltran, Calvo, & Caballero, 2019).

Problems caused by a medication regimen were the second most common, affecting approximately 70.0% of all the children. The health problems included AEDs-induced adverse effects, compliance to recommended dosage, effective drug storage, safeguards for drug supply and convenience of medicine taking. It is possible that these problems may be related to the administration of narrow-spectrum AEDs.

Cognitive impairment was the third health problem (60.2%), mainly manifesting as repetitive languages or behaviors, disorientations, memory disabilities, concentration disabilities, calculation disabilities, visual or perceptual disturbances, and linguistic disorders.

The fourth problem was sleep disturbance (58.4%), which was predominantly identified in patients with generalized seizures. Professional sleep advice and intervention is required for improving the sleep quality of these adolescents with epilepsy.

The fifth problem was self-care disability (46.5%), characterized by an unwilling/unable/amnestic ability to care for themselves, including self-health maintenance, self-monitoring, and self-care ability, which makes it difficult for the children to face and overcome during the transition process. A combination of improving self-care ability and family support should be highlighted (Betz et al., 2016).

The sixth problem was growth and developmental imbalance (42.7%), which may be related to the fluctuation of psychological and endocrine factors during adolescence as well as the disease itself (P. Camfield et al., 2017).

Table 3
KBS scoring of the first ten health problems.

Problems	KBS scores (mean ± SD)		
	Knowledge	Behavior	Status
Neuro-musculoskeletal function	2.1 ± 0.2	3.1 ± 0.5	3.2 ± 0.2
Medication regimen	2.2 ± 0.1	2.5 ± 0.5	2.9 ± 0.5
Cognition	2.0 ± 0.8	3.0 ± 0.6	3.3 ± 0.5
Sleep and rest patterns	2.3 ± 0.5	2.9 ± 0.5	3.1 ± 0.6
Self-care	2.1 ± 0.3	2.6 ± 0.4	3.0 ± 0.2
Growth and development	2.3 ± 0.4	2.9 ± 0.7	3.0 ± 0.4
Mental health	2.3 ± 0.5	3.3 ± 0.0	3.5 ± 0.2
Nutrition	2.9 ± 0.6	3.4 ± 0.3	3.2 ± 0.6
Physical activity	3.7 ± 0.3	2.8 ± 0.2	3.1 ± 0.4
Residence	2.1 ± 0.7	2.8 ± 0.6	3.2 ± 0.9

The seventh problem was psychological disorder (38.2%), which includes emotional instability, distress, inferiority, and loss of interest. These problems affect patients' life quality and could cause a deleterious long-term prognosis (P Camfield et al., 2017; Devinsky, 2014). Therefore, early diagnosis and appropriate treatment of health problems should be emphasized for alleviating adverse psychological effects.

The eighth problem was poor nutritional status (23.0%), which may be attributable to the administration of AEDs. Some AEDs (such as sodium valproate, carbamazepine, and gabapentin) can even cause multi-organ injuries, and hence, regular physical and laboratory examinations are necessary.

The ninth problem was abnormal physical activity (18.4%), especially in children with generalized and generalized-focal seizures. This may be due to the limitation of activity and excessive safeguards from the family.

Residence-related problems were present in 16.5% of individuals, mainly caused by a shortage of safety equipment, a lack of safe place for sports, and other limited resources (e.g. economic or community services), which may refer to the regional management and medical insurance coverage and policies.

The health problems as well as the epilepsy-related comorbidities bring challenges to transitional care, such as psychological stress, behavioral adverse events of AEDs contributing to noncompliance, and substance abuse, which are associated with an increased risk of epileptic seizures (Chiron & An, 2014; Geerlings et al., 2015; Geerlings et al., 2016). Drug discontinuance (temporary or permanent) caused by excessive worry about adverse effects, information-acquiring disability due to the epilepsy-induced intellectual deficiency, inferiority complex, and even a suicidal tendency of these patients and poor compliance to regular anti-epileptic treatments are other substantial challenges for health workers.

Thus, the practitioners should be aware of the existing and potential health problems during the preparatory phase of transitional care. Family-supporting, independent health behaviors, education, psychological support, and promotion of a healthy life style are critical arenas for intervention (Betz et al., 2016). We recommend health care strategies for the preparatory phase provide support for children with epilepsy and their families from multiple perspectives, such as relevant diseases knowledge, multidisciplinary plans of transition care, and transitional services by a combination of pediatric and adult medical teams. Therefore, the children's self-management skills and psychological endurance as well as their family support system can be improved. Furthermore, health workers should pay more attention to the growth and developmental quality of adolescents with epilepsy including screening, intervention, and tracking of the comorbidities, and establish positive clinician-patient interactions, which facilitates the psychological stability of the children.

Accurate identification of these problems is helpful for targeted prevention and interventions. The Omaha System can be used as a systematic evaluation tool in the transitional care for epilepsy, and it can help to build an individual database for collecting and sharing of information from children to adulthood.

Guidance value of the Omaha Problem Rating Scale for Outcomes for the preparatory phase of the children-to-adulthood transitional care

According to the 5-point Likert scale of KBS scoring, 83.4% of the children had minimal knowledge with regards to disease, nutrition, and neuropsychological disorders. Nurses can provide health education through multiple approaches, such as telephone interviews, hospital online systems, home visits, lectures, and meetings. For those children who scored <3 points, repeated and intensive education is substantially important. Approximately 84.2% of the children displayed inappropriate behaviors. The occurrence of inappropriate behavior may be related to drug inefficacy, side effects, comorbidities, cognitive impairments, painful family relationships, or scarce social support. The "Information-Motivation-Behavior" intervention model could be applied to improve the health behaviors, and the participants should include patients, families, schools, and other relevant social elements. About 86.7% of the children were moderate signs/symptoms in the *Status* aspect. This result may be due to the stable stage of epilepsy or the short-time observation, and thus the evaluation should be sustained over a long-term period rather than a single snapshot. Cooperation among multiple disciplines for KBS assessments and subsequent interventions could be helpful for improving the outcomes. Continuous attention to the KBS score of health problems plays a positive role in monitoring transitional care outcomes. The quantitative evaluation of outcome is conducive to control the intervention effect of the care team and to optimize the care plan.

Suggestions for modification of the Omaha System

The Omaha System is a problem-based terminology recommended by the American Nursing Association, which is widely replicable due to its simple procedures that could be mastered quickly by nurses. When it was used for a specific disease, the Omaha System should be modified to maintain its efficiency (KS, 2009). In the evaluation of adolescents with epilepsy during the transition to adulthood in China, we suggest the following items be added into the Omaha System: 1) the physiological domains: stereotyped behavior, stereotyped speech, misleading aspiration, and apnea; 2) the health-related behavioral domain: tongue biting, difficulty studying, and irregular life style; and 3) the psychosocial domain: sense of shame, etc. The modification allows us to develop a dynamic care strategy for the long-term management of adolescents with epilepsy.

Limitations

There were some limitations need to be acknowledged. First, the single-center data may lead to selection bias. It is possible that patients and families who agreed to participate in the study might care more about their health and may achieve biased results. Further multicenter studies are warranted to validate our findings. Second, to achieve more generalizable conclusions, the duration of the follow-up observation should be prolonged when calculating the KBS scores according to the Omaha Problem Rating Scale for Outcomes. Finally, it is very difficult to ascertain temporal causality due to the cross-sectional study design. Reverse causality is a considerable concern.

Conclusions

This study presents the outcome of using the Omaha System to collect and describe the health problems during the preparatory phase from children to adulthood in China, and details the scope of practice for multidisciplinary teams carrying out transitional care, thus translating knowledge into practice. Identification of these health problems can facilitate the prevention, nursing care, social support, and therapeutic intervention for epileptic adolescents. Furthermore, using the Omaha system to guide the transition to adulthood has the potential capacity to enhance team communication and improve data quality. Use of the system may also enhance the problem-evaluating ability of transitional caregivers and expand the perspectives of nurses.

The Omaha Problem Rating Scale presents visual outcomes of health problems for optimizing the plan of transition, though challenges still exist. To use the Omaha system in medical institutions, families, or communities with various types of epileptic patients in different ages, an information-sharing platform should be constructed to collect and exchange medical information. Further research is needed to evaluate the implementation of this clinical decision, as a digitized electronic health record based on the Omaha system is essential for interoperability and enables utilization of clinical data for epilepsies.

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CRediT authorship contribution statement

Cui Cui: Project administration, Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Shuang-zi Li:** Investigation. **Xian-lan Zheng:** Methodology, Conceptualization. **Wen-jin Cheng:** Investigation, Visualization. **Qing Xia:** Software.

Declaration of Competing Interest

The authors have no conflicts of interest to disclose.

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None.

Data vailability

Datasets generated and analyzed during the present study are available from the corresponding author on reasonable request.

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