



DEVELOPMENT OF PEDIATRIC EPILEPSY CARE PROGRAM



A Thesis Submitted in Partial Fulfillment of the Requirements
for Doctor of Philosophy (SOCIAL AND ADMINISTRATIVE PHARMACY)
Graduate School, Silpakorn University
Academic Year 2020
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By

MISS Raviwan WITTAWASSAMRANKUL



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Epilepsy is a chronic neurological disease associated with physical, psychological, social, and intellectual impacts on children and their families. Inappropriate epilepsy care could affect epileptic children's quality of life. The purposes of this research were to determine gap of epilepsy care from stakeholder perspectives, develop and assess the effect of epilepsy care program (ECP) for pediatric patients. This research was conducted in three phases. In Phase 1, gaps of epilepsy care were identified by interviewing four groups of stakeholders including pediatric patients, caregivers, service providers and finance administrator. The interview questions were developed based on gaps of epilepsy care from literatures. During Phase 2, focus group interview of stakeholders including patients, caregivers, service providers and media experts was conducted to discuss on the development of ECP. In Phase 3, a quasi-experimental study with pre-post design was conducted to assess clinical and humanistic outcomes in pediatric epilepsy patients. Study participants included 16, 11 and 54 individuals for phase 1, 2 and 3, respectively. The participants were constructed via purposive sampling of stakeholders from Queen Sirikit National Institute of Child Health. Content analysis was conducted to make study conclusions for phase 1-2. Descriptive statistics and inferential statistics including Paired t-test and Wilcoxon signed-rank test were used for data analysis in phase 3. Results revealed that a major gap of epilepsy care was lack of knowledge on epilepsy care among pediatric patients and caregivers. Experiences of stress and stigma among caregivers were identified as well. The program consists of three activities: epilepsy care education (ECE), self-help group (SHG) and pharmaceutical care. ECE was provided through several channels e.g., social media, book, telephone. SHG aims for sharing experiences and providing social support among patients, caregivers and multidisciplinary team. Pharmaceutical care was used to identify and manage for medication related problems. For phase 3, the program showed the effects on clinical outcomes including seizure frequency and adherence score. The frequency of seizure ($P < 0.001$) and drug adherence score ($P = 0.001$) among pediatric epileptic patients after participating in the program was significantly different compared to those before participating in the program. In addition, quality of life score among the patients after participating in the program was significantly higher than that before participating in the program ($P < 0.001$). The ECP program can improve the clinical and humanistic outcomes of pediatric epilepsy patients. However, further studies for program implementation and cost-effectiveness evaluation are needed.

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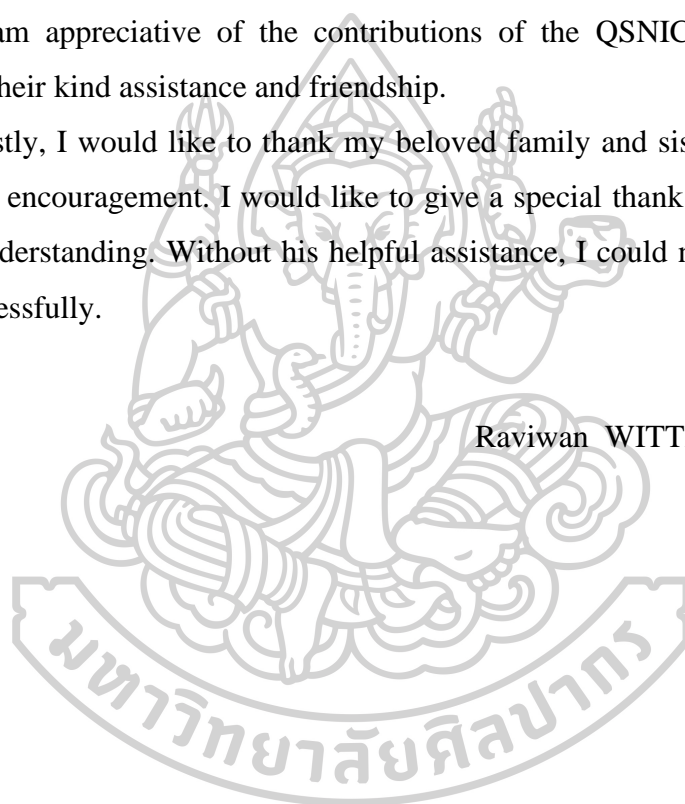
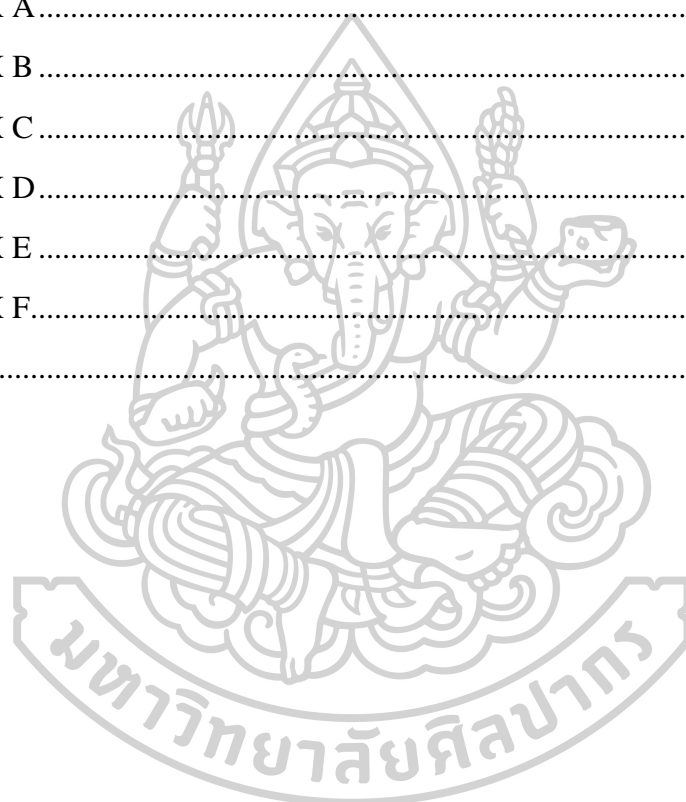


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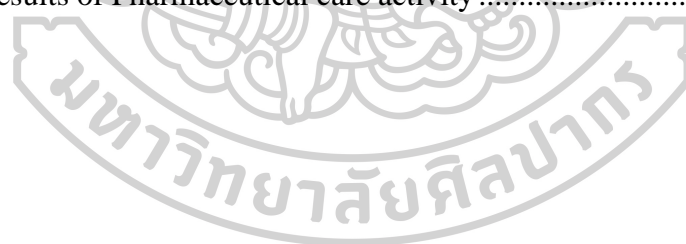
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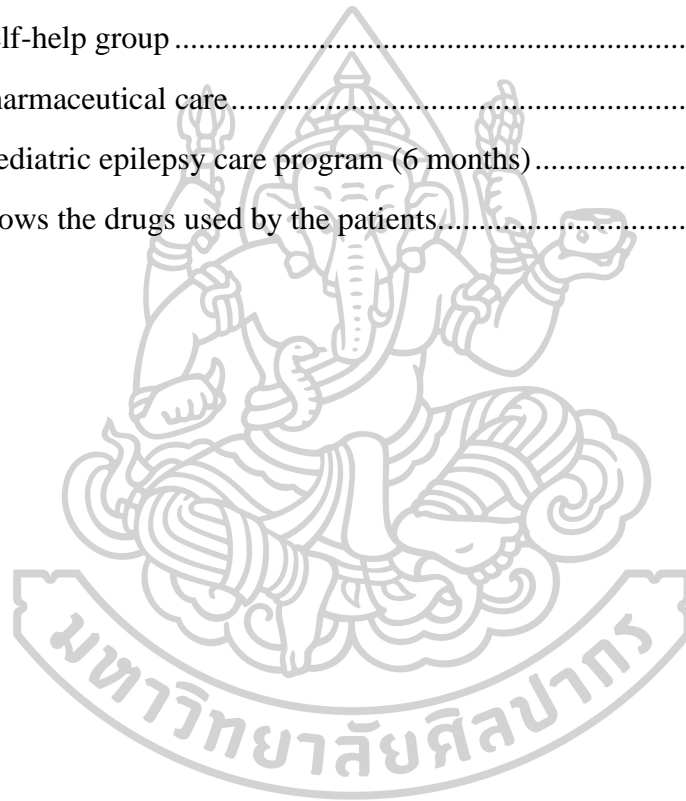
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CHAPTER 1

INTRODUCTION

Epilepsy is a group of symptoms caused by disorders of the nervous system that release abnormal electrical impulses from brain cells, resulting in movement and behavior disorders that occur spontaneously without stimulating factors and are prone to recurrence [1]. Epilepsy is a chronic, non-communicable disease of the nervous system and brain which can be found at all ages of patients. According to the WHO Epilepsy Fact Sheet 2019, it has been reported that nearly 50 million people worldwide suffer from epilepsy, and 80% of them are in developing countries and do not get proper treatment. It estimates the prevalence of active epilepsy is approximately 7-14 per 1000 population [2]. The data also shows that the incidence of epilepsy in developing countries is more often found in children than in the elder due to childbirth, newborn care, and vaccine management in the developing countries is not yet thoroughly comprehensive. While in developed countries, epilepsy is more often found in the elder than in children [2, 3]. A study of pediatric epilepsy cases in the United States in 2016 estimated the number of pediatric epilepsy cases among children aged 0-19 years that the prevalence was 6.8 per 1,000 population and the incidence was 104 per 100,000 population [4]. For Thailand, A study in 2002 found the prevalence of epilepsy was approximately 7.2 per 1,000 population [5]. And according to the data in 2012, Thailand had incidences of epilepsy that caused illness approximately 108 per 100,000 population [6].

Although epilepsy in adults and children does not differ in abnormal distribution of brain waves, there is a difference in pathologies of the disease. Epilepsy in children often does not have an obvious cause and can occur in a newborn [7]. According to the health status survey of Thai people, it was found that more than 50% of pediatric epilepsy cases occur during the first 5 years of age [8]. It can be caused by many reasons, such as brain hypoxia, concussion at birth, head injury, drowning, encephalitis, meningitis, metabolic disorders. Epilepsy is also a cause of death and disability among children aged 0-14 years [7].

Pediatric epilepsy can affect the occurrence of later illnesses that affect the quality of life of epileptic young patients [9]. The effects can be divided into internal and external factors. Internal factors indicated that seizures affect the structure and functions of the body, such as functioning disturbance of eye, ear, nose, throat, cardiovascular and respiratory system, gastrointestinal and digestive system, endocrine system, nervous system, learning, musculoskeletal and motility system. The effects of internal factors can cause risk of injuries, accidents, falls, infections, choking, sudden unexpected death from heart and respiratory failure (SUDEP), cognitive and memory impairment, and mental health impairment. The cognitive and

memory impairment can decrease learning ability, while mental health impairment leads to frequent headaches, insomnia, hyperactivity, risk of depression, and behavioral problems [9, 10]. External factors found in pediatric epilepsy patients are the inability to participate in activities or with others. Neurological problems and learning disabilities can arise limitations of speaking and pronunciation. Abnormal movements can cause a risk of accidents and driving inability. Problems of seizures can cause fear and lack of confidence to go out alone. Problems of interpersonal relationships with others can cause social problems and inability to attend school resulting in low education and limited work opportunity, including a feeling of stigma and lack of self-esteem. All the effects mentioned earlier impact the quality of life of pediatric epilepsy patients, which is consistent with several studies showing the effects of epilepsy on quality of life in children with epilepsy [9, 11-14].

A study of learning and behavioral problems of pediatric epilepsy patients from the Queen Sirikit National Institute of Child Health (QSNICH) found that epilepsy influences the mental health and brain development of school-age children. 25% of epileptic children had attention deficit hyperactivity disorder, and 23% had learning difficulties which increased when study at higher levels, 57% had behavioral issues with a severe degree of 32% [15]. Pediatric epilepsy patients who did not receive appropriate care are unable to control their seizures until adulthood. Some may die from accidents caused by their seizures. Pediatric epilepsy patients with psychological and behavioral problems cannot continue studying at a high-level education, making them be a burden for their parents or relatives to take care of them [16]. It can be seen that Pediatric epilepsy is a significant public health problem.

Some types of epilepsy in children can be a self-healing disease even without medication, such as Benign Rolandic Epilepsy, while most epilepsy types require medication for treatment. Some of them are treated by brain surgery or implant a stimulating device to help control seizures, and some types use dietary therapy to control seizures [7]. The goal of epilepsy treatment in both children and adults is to eliminate or control the seizures, live a normal life, no side effects from antiepileptic drugs, no hospital treatment due to seizures. However, the goal of pediatric epilepsy care will be increased in terms of appropriate emotional maturity, behaviors, learning, and self-development [17, 18].

From international studies, it was found that antiepileptic drug adherence of pediatric epilepsy patients leads to better control of seizures and result in a better quality of life of the patient [19, 20]. Therefore, education and promotion of taking antiepileptic is one of the activities that medical personnel provide for the care of epilepsy patients.

In the past, it was found that epilepsy care for pediatric patients had problems that cause patients to have under-expected outcomes. Problems were studied from the perspective of the person involved in epilepsy care, such as health care providers. Problems encountered from foreign countries included the shortage of personnel, equipment, diagnostic and treatment tools, antiepileptic, and knowledge in diagnosing and treating epilepsy [21]. The result is consistent with studies in Thailand which found that the significant problems were the shortage of medical personnel, lack of diagnostic tools such as Electro Encephalogram, Computerized Tomography (CT) and Magnetic Resonance Imaging (MRI), lack of antiepileptic drugs. It also indicated that 34.5% of community hospitals did not have all classical antiepileptic drugs in the standard list, and modern antiepileptic drugs were limited only in tertiary care hospitals. Therefore, some patients did not have accessibility to the medicines and treatments. For the problem of the referral system, it was found that 87.3% of patients had to waste time and travel expenses, 45.5% of patients in tertiary care hospital received a limited quantity of antiepileptic, 16.4% of patients had to start over diagnosis again [22]. The recommendation for the remedial approach was to establish a clinical practice guideline as a treatment standard, provide training for medical personnel involved in taking care of epilepsy patients, and recommend all hospitals to have all the standard classical antiepileptic drugs [22]. In order to solve the problem of epilepsy care in foreign countries, there was a proposal for the preparation of hospital standards for caring for epilepsy patients, establishing clinical practice guidelines, and resource distribution guidelines [23, 24].

In addition, the perspective of caregivers of children with epilepsy in Thailand found that the problems were anxiety, social burden, stigma feeling, accessibility to antiepileptic drugs, lack of knowledge for patient care, and the relationship with medical personnel [25]. A study abroad found that caregivers of children with epilepsy were concerned and insecure about their ability to care for pediatric epilepsy and need the knowledge to help the caring. From the suggestion of solutions, a study of providing education programs for caregivers of children with epilepsy was conducted to encourage self-management abilities of patients and caregivers with support from medical personnel. Such activities solved the problem of lack of knowledge in caring for pediatric epilepsy patients [26]. In the view of patients, adult epilepsy patients encountered problems that need to be addressed which were feelings of anxiety, depression, social burden, stigma, community beliefs, social acceptance, occupation, accessibility to medicines, lack of treatment equipment, and lack of specialist doctors [13, 14]. While pediatric epilepsy patients encountered problems such as physical limitations for activities, learning both inside and outside school, emotional and behavioral problems, social acceptance, and having friends [27]. It can be seen that child and adult epilepsy patients have different views on the problems of epilepsy care.

However, epilepsy care issues for pediatric patients may be related to the public health service system, payment of services, accessibility to treatment, and economic valuation, which has different contexts in each country [22]. The social perspective is another factor because it affects stigma feeling and socializing with others [28]. It can be seen that there is a gap among the different perspectives of people involved in the care of children with epilepsy. Therefore, it is interesting to adjust all sectors to agree on every aspect to reduce the gap to reach the common targets of the care and treatment that everyone needs. Although clinical epilepsy guidelines have been established for doctors to care for epilepsy patients, standard classical antiepileptic drugs have been distributed to all hospitals comprehensively, and modern antiepileptic drugs have been put in the National List of Essential Medicines for better accessibility to medicines. However, there are still problems in the care of children with epilepsy. Therefore, there should be an effort to develop pediatric epilepsy care programs to help achieve better treatment outcomes.

In foreign countries, there were studies on developed programs and activities in caring for children with epilepsy [29, 30]. The studies started with finding problems or needs of pediatric patients in each group of age first to develop programs with more responsive to their specific needs. Such as the needs of preschool to primary school-age children focusing on physical needs, having age-related activities like friends. In comparison, the late elementary school to adolescence group had more needs on social issues, acceptance, stigma, education, and friends. Adolescent epilepsy patients had diverse needs and perspectives on their illness. These pediatric and adolescent patients could describe their own problems, explain their needs, and tell what affects their quality of life better than their caregivers. Studies in the countries that developed epilepsy care programs for pediatric to adolescent patients focused on the referral system from pediatric epilepsy patients to be adult epilepsy patients so that they could take care of themselves to remain in the treatment system and live normal life [31, 32]. The referral program for epilepsy care among pediatric and adolescent patients is interesting because it must focus on knowledge, attitude, and self-management. Since adolescents have changes in physical and emotional, activities and approaches that interest them are required [31]. There were various outcome measurements for pediatric epilepsy care programs such as knowledge, attitude, perception of self-efficacy, increased self-management of caregivers and patients for better treatment outcomes, better antiepileptic drug adherence, or quality of life improvement of caregivers and patients [33, 34]. Increasing epilepsy care knowledge of caregivers and epilepsy patients resulted in increasing antiepileptic drug adherence and treatment compliance, leading to effective treatment and better control of seizures and disease symptoms. The result was a better quality of life for patients [35, 36]. In Thailand, there were studies of activities that promote behavior change in adult epilepsy patients and their caregivers, such as Self-help groups, Self-management, and Self-efficacy activities. Most of the assessments were on the

knowledge, attitudes, and correct practices of pediatric epilepsy patients and their caregivers [37].

However, in Thailand, adult epilepsy care activities are only drug dispensing and counseling for drug-related problems. There is no model or comprehensive care program for children with epilepsy.

Queen Sirikit National Institute of Child Health (QSNICH) is a tertiary health service facility that provides care and treatment for an average of 1,200 children with epilepsy per month. The institute has provided pediatric epilepsy care, educating about antiepileptic drugs, first aid, and special examination counseling in the epilepsy clinic by pharmacists and nurses. There is not any specific program for this group of patients. All the provided activities may not yet meet the needs of children with epilepsy and their caregivers and not cover all aspects of comprehensive care. Therefore, the development of programs for the care and treatment of children with epilepsy is necessary because pediatric epilepsy is a significant health problem, especially in older children and adolescents aged 11-17. This group of patients is affected by epilepsy in various fields more than younger children. It has goals beyond controlling seizures, including performing activities like ordinary people and having a good quality of life. The evaluation of treatment outcomes in older pediatric patients is broader and responds more to the goals of epilepsy care such as emotional and behavioral development, studying, socializing, stigma, activities, and quality of life of patients. In this group of pediatric patients, a disease-specific quality of life measurement tool can be used. Therefore, this research will develop a pediatric epilepsy care program by studying the situation and problems in caring for this group of patients from various perspectives as input to develop the program to be appropriate and consistent with the national health system. The study results can be used as a guideline for the care of children with epilepsy, leading to better clinical outcomes and improving the quality of life of patients.

Research questions

1. What are the key issues of epilepsy care for pediatric patients today?
2. What should be a good program or model for pediatric epilepsy care?
3. What are the clinical and humanitarian outcomes of patients after receiving an pediatric epilepsy care program?

Objectives of the study

General objective

To develop a pediatric epilepsy care program

Specific objectives

1. To study the condition, problems, and obstacles of epilepsy care for pediatric patients at present
2. To develop epilepsy care programs for pediatric patients
3. To assess the effect of providing an epilepsy care program for pediatric patients. The results were measured in terms of Clinical outcome and Humanistic outcome.

Terms and Definitions

- **Gaps of care** refers to the difference between what is expected and what is actually happening in patient care. In this study, care gaps were examined from the perspective of pediatric patients, caregivers, service providers, and payer which are the problems and obstacles that arise in the care of epilepsy for pediatric patients.
- **Pediatric Epilepsy Patients** refers to children with epilepsy aged 11-17 years.
- **Pediatric Epilepsy Care Program** refers to a model of care for epilepsy patients by focusing on effective care. It covers the aspects of Content, Activity, and Process.
 - *Content* is the body of knowledge used in the care of pediatric epilepsy patients in accordance with the medical practice guidelines. for medical personnel caregivers of pediatric epilepsy patients and the pediatric epilepsy patients.
 - *Activity* is to perform various methods to care for pediatric epilepsy patients such as health education activities. May use several methods such as brochures, individual teaching, or computer-assisted teaching.
 - *Process* is a process that covers the amount of time used, resources used, coordination to achieve Implementation of activities
- **Program result** means the result of the program consisting of Clinical outcome, Humanistic outcome, and Satisfaction of those involved in the pediatric epilepsy care program.
 - *Clinical outcome* includes frequency of seizures per month, number of hospital or emergency room visits due to seizures, and antiepileptic drug adherence.
 - *Humanistic outcome* includes Quality of life of pediatric epilepsy patients and Satisfaction of those involved in the pediatric epilepsy care program.
 - The quality of life is defined as the appropriate level of the patients' living according to fundamental needs which satisfy their physical, mental, emotional, and social needs. It must be sufficient to help create happiness with good physical and mental health. The humanistic outcome consists of 8 domains which consist of

Epilepsy impact, Memory and concentration, Attitude toward epilepsy, Physical functioning, Stigma, Social support, School behavior, and Health perception.

- Satisfaction of the person involved in the pediatric epilepsy care program is considered in terms of the program implementation, problems, and obstacles. The involved person includes pediatric epilepsy patients, caregivers, and medical personnel.

Expected results

This study will create a pediatric epilepsy care program that can assist in the care and management of problems in pediatric epilepsy patients. In addition, the program will be practical and used as a guideline for organizing various activities to achieve clinical and humanistic outcomes, which are the goal of caring for children with epilepsy.

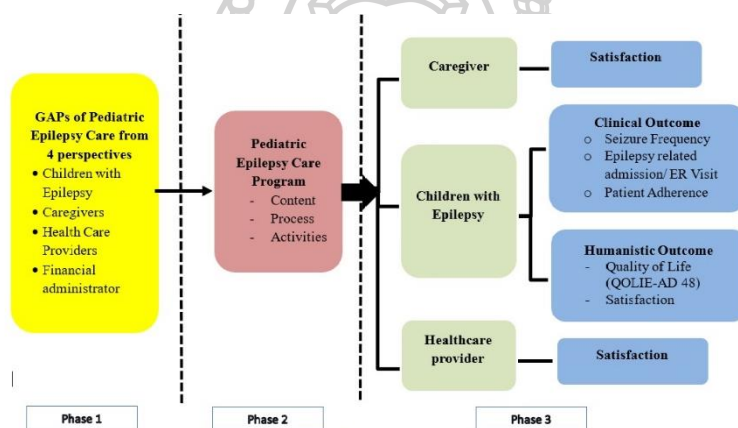


Figure 1 Research conceptual framework

CHAPTER 2

LITERATURE REVIEW

To develop a pediatric epilepsy care program for children with epilepsy, concepts, theories, including conceptual frameworks must be studied to understand various aspects of conditions, problems, and obstacles of epilepsy care for pediatric patients. This literature review examines related factors that lead to the understanding to create a model for the pediatric epilepsy care program that improves pediatric epilepsy care.

Pediatric Epilepsy; Impact and Burden of Disease

Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and the neurobiological, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one.

Epilepsy is a chronic disorder of the brain that affects people of all ages. About 50 million people with epilepsy were reported from 108 countries around the world. Nearly 80% of people with epilepsy live in low- and middle-income countries. The risk of premature death in people with epilepsy is up to three times higher than for the general population[3]. In industrialized countries, the incidence of epilepsy was generally between 40-70 per 100,000 people per year, while in developing countries, the number was 100–190 per 100,000 people per year. The worldwide prevalence was between 5-40 per 1,000 persons [38, 39]. In Thailand, there were 1.8 million people who had at least 1 seizure before 5 years old. The estimate of epilepsy patients in Thailand was 700,000 people. The prevalence of Epilepsy patients in Thailand was estimated at 7.2 per 1,000 persons. Incidence of Epilepsy was 98.8 and 108.1 per 100,000 population year [5, 40]. Nevertheless, 3.5 million people worldwide develop epilepsy annually, 40% are younger than 15 years, and more than 80% live in developing countries [41]. From literature reviews, epilepsy caused high healthcare expenditure and affected patients' physical and mental health, which resulted in morbidity and mortality.

Causes of Epilepsy by ages, from neonatal to 3 years: Prenatal injury, Perinatal injury, Metabolic defects, Congenital malformations, CNS infections, and Postnatal trauma. From 3 to 20 years: Genetic predisposition, Infections, Trauma, Congenital malformations, and Metabolic defects. From 20 to 60 years: Brain tumors, Trauma, Vascular Disease, and Infections. In older than 60 years group: Vascular disease, Brain tumors (metastatic), Trauma, Systemic metabolic derangements, and Infections. The incidence of new cases per year is high in childhood, decreases in adulthood, and rises again in older people [42].

The global burden of epilepsy was estimated to 0.5% of the total disease burden or 7 million Disability-Adjusted Life Years of the global burden of disease.[11] The highest contribution to the annual medical cost was hospitalization, followed by antiepileptic drugs [43]. The health care cost of epilepsy was estimated at \$12.5 billion per year [44]. Children with uncontrolled epilepsy significantly used more healthcare resources and had an economic burden twice greater than children with stable epilepsy [45]. For the impact of physical health, children with epilepsy had a higher mortality risk than children without epilepsy. Overall, people with epilepsy have a 1.6 to 11.4 times greater mortality rate than expected. There was a risk of Sudden Unexpected Death from Epilepsy (SUDEP) 8 per 10,000 populations. Accidents, suicide, vascular disease, pneumonia, and factors directly are also related to the underlying causes. In childhood-onset epilepsy, the standardized mortality ratio (SMR) is 5.3–9.0 [46].

Pediatric Epilepsy Comorbidity Internal Factors

The pediatric epilepsy comorbidity internal factors consist of body functions or structures such as 1. constitutional/general health systems 2. eye systems, including seeing function 3. ear, nose, and throat systems 4. cardiovascular system 5. respiratory system 6. gastrointestinal and digestive system 7. genitourinary and reproductive systems 8. musculoskeletal and movement systems 9 dermatologic or skin and related systems 10. nervous and sensory system functions 11. psychiatric system and mental functions 12. endocrine and metabolic systems 13. hematologic and lymphatic systems 14. immunologic and allergies symptoms

As results from the dysfunction of the above systems, impairments, or disabilities that patients encounter can be: accidents from seizures, ENT infections, SUDEP; 2-3 times the standardized mortality ratio, aspiration risk, constipation, polycystic ovarian syndrome, fracture risk, drug rashes, cognitive and memory impairments, migraine, and sleep impairments mental health impairments including depression, ADHD, anxiety and behavior problems

Pediatric Epilepsy Comorbidity External Factors

The external factors [9] consist of activities or participations such as 1. neurologic: learning and applying knowledge, general tasks and demands, communication 2. self: mobility, self-care, and self-efficacy: successful coping 3. lifestyle and relationships: domestic life, interpersonal interactions, and relationships 4. society: major life areas (school, employment), Community, social, and civic life.

Therefore, limitations or restrictions that affect the patients are: 1. cognitive limits, memory limits, speech/language limits 2. accidents; driving fear or uncertainty of having a seizure; repeated loss of control 3. interference with daily life, psychosocial and relationship problems 4. academic limits; employment limits and absence, stigma; misunderstanding.

Epilepsy has impacts on general intellectual function, cognitive impairment. In addition, adverse effects of its medication effects on learning ability and school attendance of children with epilepsy [47, 48]. In the psychosocial aspect, children with epilepsy significantly have mental health comorbidities more than those without the disease, such as depression, anxiety, attention-deficit/hyperactivity disorder (ADHD), conduct problems, and developmental delay. Furthermore, epilepsy patients were mostly unemployed, could not get married, and childless [49].

Behavioral problems in epilepsy children study in Queen Sirikit National Institute of Child Health (QSNICH) found the prevalence of behavioral problems in Epilepsy children were 57%. Complex partial seizures had the most severe behavioral problems, and Generalized tonic-clonic seizures had the least. The prevalence of learning problems was 23%, ADHD 58%, and developed attention problems 25%. There was statistical significance between behavioral problems and friendships, parent relationships, and housework skills [15].

Epilepsy also impacts school attendance. Teachers are perceived to be apprehensive about seizures and suggested staying home even if the patient was feeling well [48]. A study of awareness among schoolteachers in Thailand that did not

understand children with epilepsy may lead to misunderstanding and social stigma. For example, 46.6% of 360 school teachers believed that epilepsy is a chronic, incurable disease, and 15% of them preferred to place all children with epilepsy in a special classroom. [50].

Epilepsy also impacts caregivers. A study found that 80% of caregivers reported a decline in social activities after the onset of epilepsy in their children. 75% affected daily routines, 52% experienced frustration, 76% felt hopeless, 60% encountered financial difficulties. The essential expenditure was the cost of drugs 54% and traveling to hospital 36% [47].

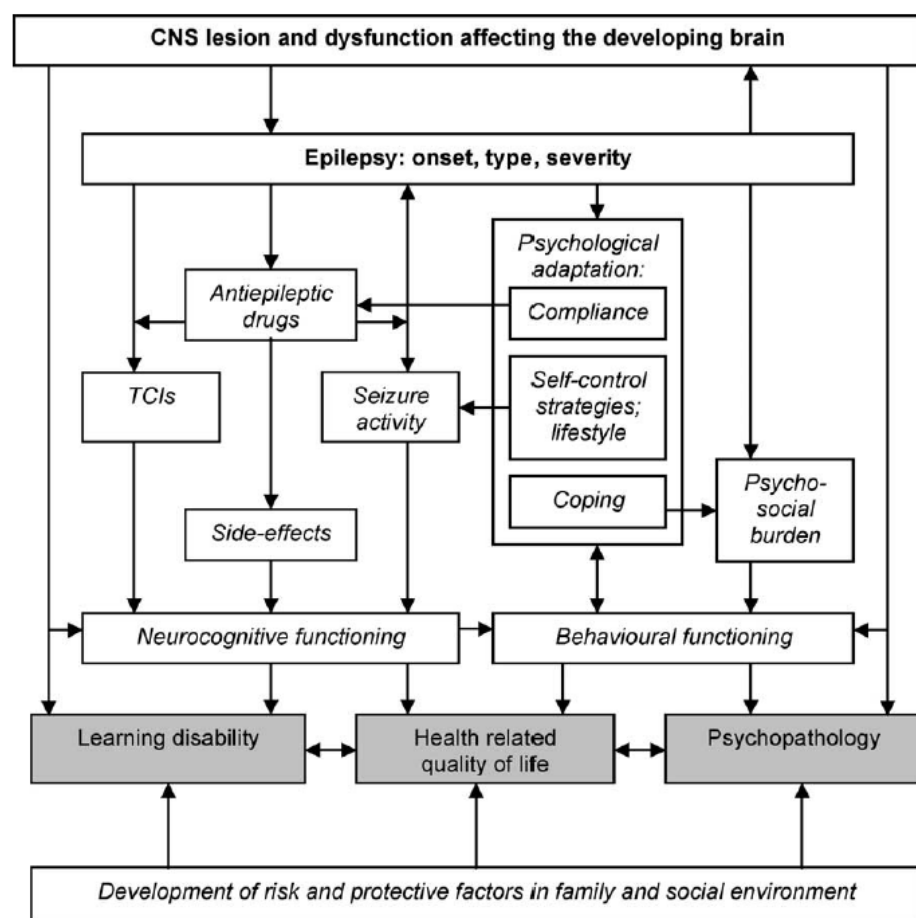


Figure 2 Development of mental health dysfunction in the child with epilepsy

The quality of life of epilepsy patients was lower than people without epilepsy [9]. The caregivers also lost incomes for taking care of their children with epilepsy and sometimes have stress and depression [51].

Causes of epilepsy in children.

Epilepsy is a malfunction of the brain. which may or may not find abnormalities from EEG which can explain the causes that cause epilepsy as follows

1. Anomalies of the process of brain formation since in the womb (congenital anomaly)
2. Genetic disorders that affect brain function or structure (genetic disease)
3. Disorders or complications before, during, or after childbirth, such as infection in the womb, lack of oxygen during childbirth
4. Autoimmune disease
5. Brain tumor or fast-growing cells in the brain in some syndromes
6. Brain infection including complications that follow from infection
7. No exact cause.

Epilepsy Diagnosis

The updated "Classification of the epilepsies" will help improve the diagnosis, focus better on the cause, and provide a helpful guide to management in a wide range of people with epilepsy. The seizure and epilepsy types depicted in the following figure are used in this study.

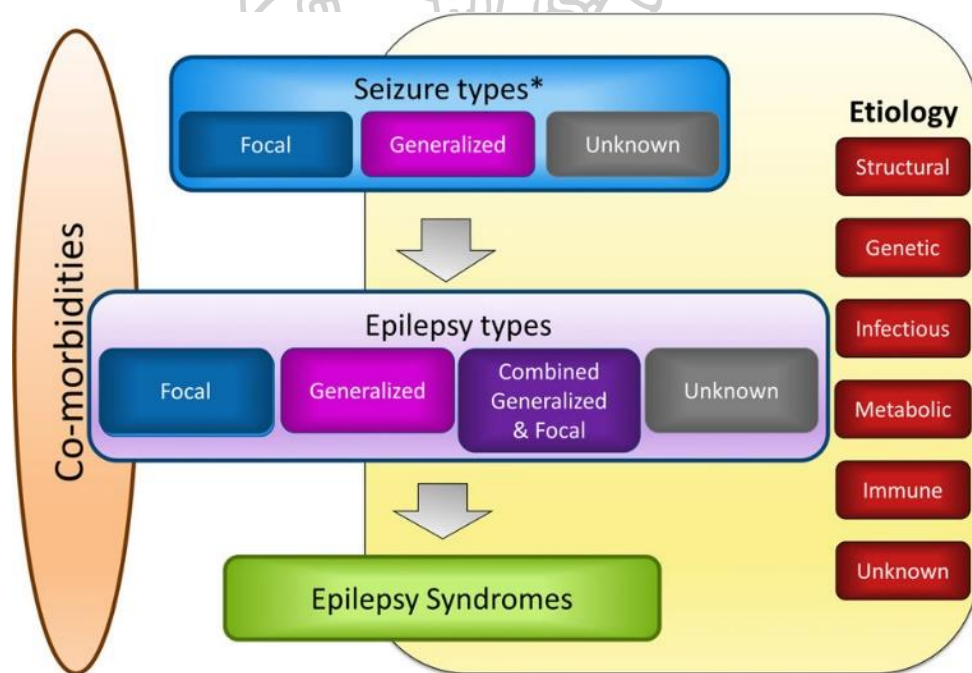


Figure 3 Framework for classification of the epilepsies.
*Denotes onset of seizures.[52]

From the abovementioned, Pediatric Epilepsy is a chronic psycho-neurological disease that causes economic healthcare burden. Pediatric epilepsy impacts physical health, mental health, emotion, behavior, cognition, learning, academic achievement, stigma, and psychosocial. Children with epilepsy also caused the caregivers economic

and emotional problems. Thus, pediatric epilepsy should receive holistic assessment and care in many aspects, such as Epilepsy and comorbidity, psychiatric, social, and economic aspects.

Pediatric Epilepsy Care

The goal of epilepsy treatment is to control or reduce the frequency of seizures, minimize side effects, and ensure compliance, allowing the patient to live as normal a life as possible and have a good quality of life [53].

Epilepsy is considered to be resolved for individuals who have remained seizure-free for the last 10 years or with no seizure medicines for the last 5 years [1].

The aspect of Quality in Pediatric Epilepsy Care [28] is to

1. provide good patient outcomes such as seizure control, proper behavior, academic attendance, and social functioning
2. Early and accurate diagnosis and optimal treatment
3. role and Involvement of parents/caregivers.
4. Integrate school and Community organizations for epilepsy care delivery.

Good clinical outcome of patients with epilepsy was considered by seizure controlled. Antiepileptic drugs may decrease the risk of future occurrence of epileptic seizures. However, monotherapy can control seizures 70%. If there is no seizure in 2-5 years, the doctor may consider tapering off antiepileptic drugs. Almost 70% of patients with epilepsy have seizure-free in 5 years, while 30 % of patients may have to take antiepileptic drugs continuously to control seizures [54, 55].

Quality of life

Definition WHO 1948: A state of complete physical, mental and social well-being and not merely the absence of disease and infirmity.

Health-related quality of life [56] is the level of total well-being and satisfaction associated with an individual's life and how this is affected by disease and treatment. Health-related quality of life is involved in normal human activities such as physical, psychological, economic, cognitive, social, and emotional.

Instruments to measure quality of life or health-related quality of life for adults are SF-36 and WHOQOL, which are not suited for the disease-specific instrument.

There are many epilepsy-specific questionnaires for HRQOL in children and adolescents, such as

1. Impact of Children Neurologic Disability Scale – ICND (Camfield et al., 2003)
2. Quality of Life in Epilepsy for Adolescents questionnaire- QOLIE-AD 48 (Carmer et al.,1999)

3. HRQOL in Pediatric Epilepsy Scale (Arunkumar et al., 2000)
4. Quality of Life in Childhood Epilepsy Questionnaire – QOLCE (Sabez et al., 2000)
5. HRQOL Instrument for Children with Epilepsy – CHEQOL-25 (Ronen et al. 2003)
6. Epilepsy and Learning Disabilities Quality of Life Scale – ELDQOL (Buck et al., 2007)
7. DISABKIDS Chronic Generic Measure, with Epilepsy Specific Module (Simeoni et al., 2007)
8. Glasgow epilepsy outcome scale for young persons – GEOS-YP (Townshend et al., 2008)
9. Epilepsy and children questionnaire – ECQ (Coda et al., 2001)
10. Escala de calidad de vida del niño con epilepsia – CAVE (Herranz & Casas, 1996)
11. HRQOL for Brazilians – QVCE-50 (Maia Filho et al.,)

However, the evidence of patient-reported outcome measures (PROMs) for people with epilepsy and to provide recommendations to the Department of Health of PROMs for epilepsy.

The literature review of the evidence-based and multi-disciplinary panel discussions underpin final recommendations to the Department of Health. Two of the most reported pediatric epilepsy-specific patient-reported outcome measures (PROMs) are:

- a) Health-Related Quality of Life in Children with Epilepsy
- b) Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48)

Both are recognized as epilepsy-specific questionnaires for HRQOL and Quality of life for children and adolescents with epilepsy. However, the patient-reported outcome questionnaire is more realistic reflex the quality of life than their parent-reported. In addition, QOLIE-AD-48 has a cross-cultural translation from English to Thai. This makes it possible to measure Thai children with epilepsy's quality of life according to this study.

The Projects' Objectives To support Departments of Health in identifying needs and promoting education, training, treatment, services, research, and prevention nationally, the following objectives have been set for each demonstration project [3]:

1. To reduce the treatment gap and the physical and social burden of people with epilepsy by intervention at a community level.
2. To train and educate health professionals.

3. To dispel stigma and promote a positive attitude to people with epilepsy in the community.
4. To identify and assess the potential prevention of epilepsy.
5. To develop models for the promotion of epilepsy control worldwide and its integration in participating countries' health systems.

Somsak and group studied the Problems and solutions for epilepsy services in the northeastern of Thailand [22] summarized gaps of epilepsy care that were 1) Lack of medical specialists 2) Lack of diagnostic facilities 3) Antiepileptic drugs system (AEDs) 4) Drug level monitoring 5) Treatment and referral system.

This study also suggested each issue in the suggestion following; 1) arrange workshop or training program for General practitioner in epilepsy diagnosis and treatment, develop Neurology Network Consultant and provide specific CPG/ manual; drug administration, Status epilepticus treatment, etc. 2) Develop a guideline for infrastructures using in epilepsy diagnosis and should adopt this program to clinical practice guideline. 3) standard AEDs (Antiepileptic drugs) should be available in every hospital drug lists and new AEDs must be available in secondary and tertiary care hospitals 4) develop CPG for Drug level monitoring and develop drug level monitoring network for primary care hospitals [22].

Epilepsy care from the perspective of pediatric patients found that related to biomedical factors from epilepsy factor and comorbidity factor and their psychosocial such as physical limitation, emotion, learning, social and self-perception [57].

Epilepsy care from the perspective of caregivers found problems in Knowledge and Coping Skill, Emotional such as anxiety and depression which involved to their children, social support and relationship among physician-patient-caregiver [26].

CHAPTER 3

RESEARCH METHODOLOGY

The objective of this research is to develop a treatment program for pediatric epilepsy patients. The study was proceeded in groups related to the care of pediatric patients with epilepsy, including pediatric patients themselves, caregivers, medical personnel, and personnel in related fields. The research was conducted at the Department of Medicine, Queen Sirikit National Institute of Child Health (QSNICH).

This study was divided into 3 phases as follows:

- **Phase 1** Situation analysis for the assessment of problems, obstacles.
- **Phase 2** Development of epilepsy care program for pediatric patients.
- **Phase 3** Assessment for the developed Pediatric epilepsy patients care program.

This research has been certified from the Human Research Ethical Committee, Queen Sirikit National Institute of Child Health (QSNICH), Thailand.

Project number: REC.097/2018 (Full Board).

Project code: Document No.60-048,

Date of certification:

- Phase 1 and Phase 2 on 20 October 2017
- Phase 3 on August 3, 2018
- Approval for project extension until June 30, 2020 (Appendix 1).

The research has followed the requirement of QSNICH Human Research Ethical Committee. Participants of age between 11-12 years had the consent letter to join the project for those of age between 7-12 years REC-QSNICH.09 and REC-QSNICH.08

Participants of age between 13-17 years and over 18 years will have the consent letter to join the project (REC-QSNICH.07) according to the document of QSNICH Human Research Ethical Committee (Appendix 2)

The research methodologies of each part were described as follows:

Phase 1 Situation analysis for the assessment of problems, obstacles

1.1. Research design

This is a qualitative study.

1.2. Population and samples

Population were those involved in pediatric epilepsy patient care, consisting of pediatric epilepsy patients themselves, caregivers, and the medical personnel providing treatment as well as the financial policy maker of the hospital.

Sample groups included those involved in pediatric epilepsy patients care, consisting of pediatric epilepsy patients themselves, caregivers, and the medical personnel providing treatment as well as the financial policy maker of the hospital who were selected by the criteria as follows:

- 1) Pediatric epilepsy patients of age between 11-17 years who have been diagnosed with epilepsy (ICD-10, codes G40-G41) for at least 3 years, have been received at least one antiepileptic drug, have had at least one seizure in the past 6 months, and enable to communicate effectively.
- 2) Caregivers who are responsible for taking care of the participating pediatric patient.
- 3) Medical personnel providing treatment are service providers who perform medical care for pediatric epilepsy patients with at least 5 years of experience, consisting of pediatric neurologists, pediatricians, pharmacists and nurses.
- 4) The financial policy maker of the hospital is the chief financial officer of the QSNICH.

The researcher selected a sample group of 16 people by method of purposive sampling

- Pediatric Neurologist 1 person

(With 21 years of experience in pediatric epilepsy patient care and working in medical schools and tertiary care hospitals. Currently, holding the position of Pediatric Neurology President, Epilepsy Society of Thailand)

- Pediatric Neurologist 1 person

(With 9 years of experience in pediatric epilepsy patient care, and working in tertiary care hospital)

- Pediatrician	1 person
(With 5 years of experience in pediatric epilepsy patient care, and working in secondary hospitals)	
- Nurse caring for pediatric epilepsy patient	1 person
(With 9 years of experience in pediatric epilepsy patient care, and working in medical schools and tertiary hospitals)	
- Pharmacist caring for pediatric epilepsy patients	1 person
(With 9 years of experience in pediatric epilepsy patient care, and working in a tertiary hospital)	
- Deputy Medical Director of Financial Policy	1 person
(With 6 years of experience in this position working in a tertiary hospital)	
- Pediatric epilepsy patients of age between 11-17 years	5 people
- Caregiver for pediatric epilepsy patients	5 people
Total	16 people

1.3. Research Procedure

- 1) Literature review on gaps in health care from the perspectives of patients, caregivers, service providers, and those who pay for the treatment, in order to know what the issues related to each phase should be.
- 2) Develop the interview form and check its' quality in terms of accuracy and content validity.
- 3) Improve the interview form and use it in collecting actual data.
- 4) Analyze the data and summarize the results of the Phase 1 study.

1.4. Research instruments

The instrument used in this study was the in-dept interview using the semi-structure questionnaire form created for determining the points of interview for the sample group. There are totally 4 interview forms which contain different questions to be used for each sample group as follows (Appendix 3)

- 1) General information includes gender, age, title, duration of decease or duration of being a caregiver or relation to a pediatric epilepsy patient care.

- 2) Experiences related to epilepsy or the care of patients with epilepsy and opinions on such events.
- 3) Problems, obstacles, and gaps in epilepsy treatment for pediatric patients, and proposed solutions.

The sub-issues in each sample group consisted of:

Group 1: Pediatric epilepsy patients' opinions

- 1) Physical limit or living a different life from others due to epilepsy.
- 2) Learning ability and intellectual problems.
- 3) Psychosocial problems such as acceptance by teachers, friends and community.
- 4) Self-perception such as self-acceptance, happiness.

Group 2: Caregivers of pediatric epilepsy patients' opinions

- 1) Knowledge and skills in epilepsy patients care.
- 2) Emotional disorders or the stigma of epilepsy patients.
- 3) Social burdens, cost concerns, social stigma. Concerns about the patient's future.
- 4) Relationships between caregivers, patients, and care providers

Group 3: Opinions of Medical personnel caring for pediatric epilepsy patients

- 1) Shortage of skillful medical personnel
- 2) Shortage of tools and diagnostic equipment
- 3) Shortage of anticonvulsants and therapeutic drug monitoring (TDM)
- 4) Problems in treatment and referrals

Group 4: Opinions of those involved in the financial policy of QSNICH

- 1) Referral problems
- 2) Problems related to medical billing of pediatric epilepsy patients to other government agencies
- 3) Factors affecting Epilepsy Care for Pediatric Patients
- 4) Perspectives on Standards of Epilepsy Care for Pediatric Patients

- 5) Guidelines for the development of programs to address the problems of pediatric epilepsy care in the context of Thailand

1.5. Inspection of research instruments' quality

The quality of the interview forms for content validity was examined by 5 experts (as listed in Appendix 4) and the forms are evaluated by using the Index of Item-Objective Congruence (IOC). All questions achieve IOC score at 0.5 or higher.

1.6. Data Collection

The researcher uses the in-depth interview method in data collection from caregivers and pediatric epilepsy patients. One interview was conducted face-to-face for a patient and the caregiver(s) altogether and more interviews were conducted separately by phone to verify and get information most consistent with reality. The conversations were recorded with a voice recorder. Each interview took 15-20 minutes. Interviews were conducted in the QSNICH epilepsy clinic area from October 25 to November 18, 2017.

Among the medical personnel who provide treatment are specialists in pediatric neurology, including pediatricians, pharmacists, nurses caring for pediatric - epilepsy patients, and the chief financial officer of QSNICH. We provided the in-depth interview by face-to-face and by phone interviews at QSNICH and Ramathibodi Hospital during 4-19 December 2017. Conversations were recorded with a voice recorder.

1.7. Data Analysis

The researcher transcribed the recorded data, then, making content analysis by dividing into issues, classifying data, assessing duplicates, grouping, and summarizing the opinions towards the childcare program for epilepsy for the issue of content and processes, the results of the conclusions had been verified with the interviewee before being developed into a program for further study in Phase 2.

Phase 2 Develop an epilepsy care program for pediatric patients.

2.1 Research design

This is a qualitative study.

2.2 Population and samples

Population means people in QSNICH who involved in the pediatric epilepsy patient caring development program, consisting of pediatric epilepsy patients themselves, caregivers, personnel in various professions who provide care for pediatric epilepsy patients, and children's media & activities specialists.

Sample of this phase are/were selected by the following criteria

1. Pediatric epilepsy patients aged between 11-17 years who have been diagnosed with epilepsy (ICD-10, codes G40-G41) for at least 3 years, have been received at least one antiepileptic drug, have had at least one seizure in the past 6 months, and enable to communicate effectively.
2. Caregivers who are responsible for taking care of the participating pediatric patient.
3. Medical personnel providing treatment are service providers who perform medical care for pediatric epilepsy patients with at least 5 years of experience, consisting of pediatric neurologists, pediatricians, pharmacists, and nurses.
4. Children's media & activities specialists who have at least 5 years of experience in children's media development and organizing activities for pediatric patient

The researcher selected a sample group of 11 people by method of purposive sampling

- Pediatric neurologist	
- Epilepsy Clinic pharmacist	1 person
- Epilepsy Clinic Nurse	1 person
- Pediatric Psychiatrists	1 person
- Special Education Teacher	1 person
- Social Worker	1 person
- Children's Media and Activities Specialist	1 person
(7 years of experience in media and children's activities, working in the university)	
- Pediatric Epilepsy Patients of age between 11-17 years	2 people
- Caregivers for Pediatric Epilepsy Patients	2 people
Total	11 people

2.3 Research Procedure

- 1) Gather problems, requirement, and suggestions for solutions from those involved in pediatric epilepsy patient care in Phase 1, then, draft a developed care program Included activity content process for pediatric patients with epilepsy.

- 2) Organize a meeting to present the developed program and conduct a hearing to the opinions of the sample group via focus group.
- 3) Analyze the acquired information to improve the program and make a conclusion on the pediatric epilepsy care program That is suitability and possibility for implementation, for further study in Phase 3.

2.4 Research Instruments

The research instrument used in Phase 2 study was the focus-group and semi-structured interview forms for opinion of sample group in the Pediatric Epilepsy Care Program, which Consisted of the following points (Appendix 5):

- 1) General information includes gender, age, titles, duration of disease or being a caregiver of pediatric epilepsy patient or related to the media or developed program.
- 2) Opinions towards the pediatric epilepsy patient care program considering from suitability and possibility of implementation.
 - **Activity:** The activities for pediatric epilepsy patients consisting of epilepsy care education, self-help group, and pharmaceutical care should be done in various methods for example, pamphlet, class learning, private learning, or computer-assisted instruction, which those activities are to be created from the information provided by pediatric epilepsy patients, caregivers, and child activities specialists.
 - **Content:** The contents to be used in various activities related to the major/minor knowledge, topic of interests for pediatric epilepsy patient care which is in accordance with the medical practice for healthcare professionals, caregivers of pediatric epilepsy patients, and pediatric patients. Those contents were generated from the information provided by doctors, pharmacists, nurses, media and child activities specialists.
 - **Process:** The process which covers the time spent, resources used, and coordination to achieve the implementation of activities. Data were collected from doctors, pharmacists, nurses, and caregivers of pediatric epilepsy patient.
- 3) Recommendations for the development of care programs for pediatric epilepsy patients, and the implementation.

2.5 Quality inspection for research instrument

The quality of the interview forms for content validity was examined by 5 experts (as listed in Appendix 3) and the forms are evaluated by using the Index of Item-Objective Congruence (IOC). All questions achieve IOC score at 0.5 or higher.

2.6 Data Collection

The researchers presented a draft of pediatric epilepsy care program to receive opinions and suggestions from the sample group via focus groups, which were held at QSNICH during 1 February - 15 March 2018. There were total 5 groups, as follows:

Details of Focus group discussion

Group 1 (1 February 2018)

- Respondents were pediatric epilepsy patients and their caregivers.

Group 2 (5 February 2018)

- Respondents were pediatric psychiatrists, pharmacists and social workers.

Group 3 (15 February 2018)

- Respondents were pediatric neurologists, nurses, special education teachers, social workers, and media & children's activities specialists

Group 4 (2 March 2018)

- Respondents were pediatric epilepsy patients and their caregivers, for a second time.

Group 5 (15 March 2018)

- Respondents were pediatric neurologists, pediatric psychiatrists, pharmacists, and nurses at the Pediatric Epilepsy Clinic, special education teachers, social workers, and children's events journalists.

2.7 Data Analysis

The researcher transcribed the recorded data, then, making content analysis by dividing into issues, classifying data, grouping, and summarizing the opinions towards the childcare program for epilepsy for the issue of content and processes, the results of the conclusions had been verified with the group discussion participants before being developed into a program for further study in Phase 3.

Phase 3: Assessment for the developed Pediatric epilepsy patients care program

3.1 Research model

It was a one-group pre-post quasi-experimental design.

3.68 Population and sample group

The population are pediatric epilepsy patients, caregivers, and a multidisciplinary team who provide epilepsy care service at the QSNICH.

The sample group were pediatric epilepsy patients, caregivers, and a multidisciplinary team who provide epilepsy care service at the QSNICH.

The criteria for selecting the samples in each group are as follows:

- 1) Pediatric epilepsy patients under treatment program at the Outpatient of the QSNICH who contains the following qualifications.

Inclusion Criteria

- Age between 11-17 years
- Having been diagnosed with epilepsy (ICD-10, codes G40-G41).
- Having received at least one anticonvulsant drug for at least 1 month prior to study participation.
- Having got at least one seizure in the past 6 months
- Enable to speak, read, listen, understand and handle with the survey
- Giving consensus to participate in the study

Exclusion Criteria

- Having a progressive neurological condition such as a brain tumor, neurodegenerative diseases, subacute sclerosing panencephalitis, neuronal ceroid lipofuscinosis, tuberous sclerosis with degeneration, West disease or idiopathic degenerative encephalopathy associated with infantile spasms, Werdnig-Hoffmann disease, and hereditary spastic paraplegia
- Having the condition of mental retardation and have dependency on others for the completion of daily activities, with a primary caretaker.
- Also having other serious diseases that may affect the quality of life, such as having cancer or being terminally ill.

- 2) Caregivers of pediatric epilepsy patients under epilepsy treatment at the outpatient of QSNICH who contains the following qualifications

Inclusion Criteria

- Being responsible for care & medication of pediatric epilepsy patients who participate in the study for at least 4 days a week.

- Enable to provide general information about illness and seizures, health care, and handle with the care for decease
- Giving consensus to participate in the study

Exclusion Criteria

- Stay together with the patient less than 4 days a week.

Calculating the sample size

Sample size was calculated by using data from the previous study of the pediatric epilepsy treatment program, and the frequency of seizures in the experimental group was reduced. The convulsions that required emergency visits has been decreased from 0.90 ± 0.95 to 0.22 ± 0.58 times [32]

Representation of formula used for calculating the sample size are as follows:

Effect size (mean difference) = -0.68, SD of mean difference = 1.55, alpha = 0.05, beta = 0.20, $Z_{\alpha/2}$ = Two-tailed where Type 1 error is equal to 0.05 got 1.96 Z_{β} = Type 2 error at power 80% got 0.84 [58]

$$n = \left[\frac{(Z_{\alpha/2} + Z_{\beta})\sigma}{\Delta} \right]^2$$

$$41 \text{ คน} \quad n = \left[\frac{(1.96+0.84)(1.5548)}{0.68} \right]^2 = \left[\frac{2.8 \times 1.5548}{0.68} \right]^2 = \left[\frac{4.3534}{0.68} \right]^2 = (6.402)^2 =$$

From the above formula, the number of samples was equal to 41 people with 30% allowance to prevent sample loss makes the sample group equal to 54 people.

In conclusion, the total number of 54 pediatric epilepsy patient was matched with 54 caregivers.

- 3) Personnel in the multidisciplinary team providing treatment for pediatric epilepsy patients at the QSNICH during the study period, who organized several activities in the program, totally 19 people consist of
 - Pediatric Neurologist 4 people
 - Epilepsy Clinic Pharmacist 1 person

- Epilepsy Clinic Nurse	4 people
- Brain Clinic staff	5 people
- Special education teacher	1 person
- Counselling nurse	1 person
- Psychologist	1 person
- Social Worker	1 person
- Children's Media and Activities Specialist	1 person

Total

19 people

3.3 Research Methods

- 1) Explained the study overview, consent process, and the details of the upcoming program, activities, procedures, and process to those involved in implementing a pediatric epilepsy care program developed for pediatric epilepsy patients in the outpatient department.
- 2) Recruited sample group and collected baseline data.
- 3) Implemented the pediatric epilepsy treatment program for patients and their caregivers.
- 4) Periodically followed up the post-test outcomes after the 6 months duration.
- 5) Evaluated satisfaction of pediatric epilepsy patients, caregivers, and personnel in multidisciplinary team towards the program.
- 6) Analyzed the data and make conclusions from the study.

3.4 Research Tools

Pediatric Epilepsy Care Program

The pediatric epilepsy care program consisted of 3 activities: epilepsy care education, self-help groups, and pharmaceutical care. Each activity consisted of content, process, and communication channels. The details of the program are prescribed in Phase 2 study.

The research instruments for pediatric epilepsy patients

Consisted of 4 data recording forms as follows:

1) Case record form

This is the record for gender, age, current education level, health insurance, area of living, age at onset of seizures, duration of epilepsy, types of epilepsy, types of seizures, comorbidities, and current antiepileptic drugs used.

This is the record for frequency of seizures, number of hospitalizations related to epilepsy, and medication cooperation score (Appendix 6).

Frequency of seizures will be calculated by taking the mean of monthly seizure frequency from the total number of seizures in the 6-month period, both before and after participating in the program.

The medical adherence score is shown in percentage. It was calculated according to the formula [59], from the number of anticonvulsant pill received and the remaining ones. The higher percentage showed the higher medical adherence.

$$\text{Adherence} = \left[\frac{\text{No. of receiving pills} - \text{No. of remaining pills}}{\text{No. of pills taken daily} \times \text{days}} \right] \times 100$$

2) Quality of life in Epilepsy for Adolescence-48, Thai version (QOLIE-AD-48)

Quality of Life Measurement of Adolescent Epilepsy Patients (QOLIE-AD-48) was developed through a cross-cultural translation methodology conducted by Parinda Pholvisut [60] and was allowed for use in this study (Appendix 7). The instrument was tested for accuracy and confidence with the item-coefficient score during 0.67-1.0, internal consistency and reliability with Cronbach's alpha coefficient = 0.92 for the total score, the test-retest reliability of the interview form = 0.93 [60], consisted of 48 questions, in 8 domains, as follows:

- Epilepsy impact (12 questions)
- Memory /Concentration (10 questions)
- Attitude toward epilepsy (4 questions)
- Physical functioning (5 questions)
- Stigma (6 questions)
- Social support (4 questions)
- School behavior (4 questions)

- Health perception (3 questions)

Rating and Interpretation [60, 61]

Pediatric epilepsy patients had to answer the questions in Likert Scale assessment dividing in 5 levels. The resulting scores were interpreted as a subscale score of 0-100, The subscale scores of each domain were averaged and multiplied by the weighted values of each domain which will establish point-values of each.

- The total score of all domains was the quality-of-life score of pediatric epilepsy patients.
- A higher quality of life score reflects a better quality of life.
- A quality-of-life score below 50 reflects a poor quality of life.
- A quality-of-life score greater than 80 reflects a quality of life similar to that of a normal person.

3) Satisfaction Evaluation of Child Epilepsy Care Program

For pediatric patients or caregivers, the satisfaction questionnaire has 3 parts: general information, satisfaction towards the program, channels for pediatric epilepsy patient care and recommendation (Appendix 8)

- General information includes gender, age, current education level.
- Satisfaction towards the Child Epilepsy Care Program. Questions are provided in multiple choices with 5-level rating Scale for 18 questions.
- Recommendations for the Child Epilepsy Care Program in form of open-end for 1 question.

Rating and Interpretation

Feedback level	Points
Strongly satisfy	5 points
Satisfy	4 points
Neutral	3 points
Dissatisfy	2 points
Totally dissatisfy	1 point

The satisfaction score was interpreted by calculating the average and divided into 5 levels.

Average Feedback Levels	Level of Feedback
4.51 - 5.00	Strongly satisfy
3.51 - 4.50	Satisfy
2.51 - 3.50	Neutral
1.51 - 2.50	Dissatisfy
1.00 - 1.50	Totally dissatisfy

The research instruments for caregivers of pediatric epilepsy

Consisted of 2 data collection forms as follows:

- 1) General data recording form
 - This is the record for gender, age, and relationship with the patient
- 2) Questionnaire on satisfaction with the pediatric epilepsy care program

For pediatric patients or caregivers, there are 3 parts: general information, satisfaction towards the program & channels for pediatric epilepsy patient care, and recommendation (Appendix 8)

- General information includes gender, age, education level.
- Satisfaction towards the pediatric epilepsy care program. Questions are provided in multiple choices with 5-level rating Scale for 18 questions.
- Recommendations for the Child Epilepsy Care Program in form of open-end for 1 question.

The research tools for the multidisciplinary team of providers involved in pediatric epilepsy care programs

Consisted of 1 data collection form as follows:

1) Questionnaire on Satisfaction with the Child Epilepsy Care Program

For multidisciplinary team, there are 3 parts: general information, satisfaction towards the program, and recommendation in writing (Appendix 8)

- General information includes gender, age, type of personnel and type of work
- Satisfaction towards the Child Epilepsy Care Program. Questions are provided in multiple choices with 5-level rating Scale for 10 questions.
- Recommendations for the Child Epilepsy Care Program in form of open-end for 1 question.

3.5 Quality inspection for research instruments

The quality of the interview forms for content validity was examined by 5 experts (as listed in Appendix 3) and the forms are evaluated by using the Index of Item-Objective Congruence (IOC). All questions achieve IOC score at 0.5 or higher.

3.6 Data collection

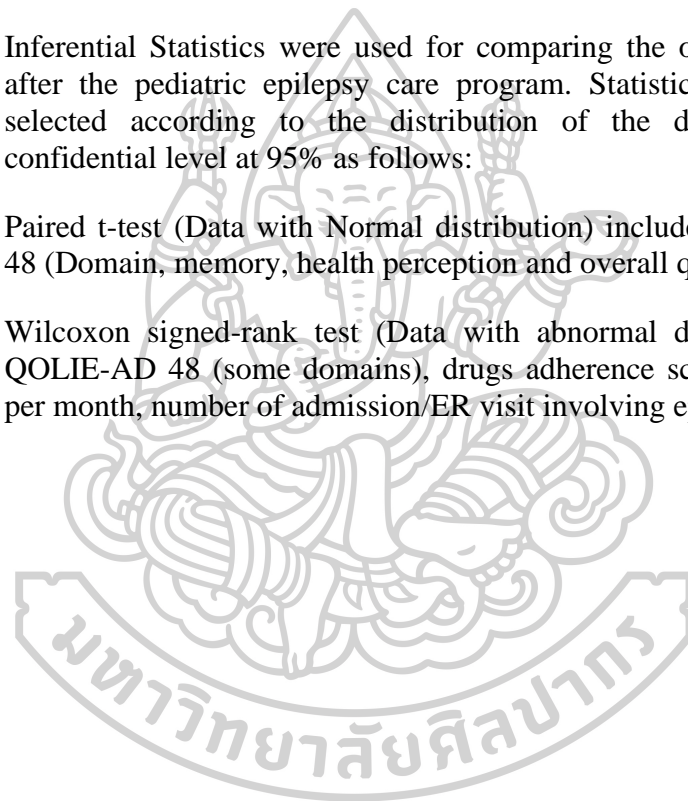
The researcher collected the data from pediatric epilepsy patients, caregivers and personnel in multidisciplinary teams at out-patient department. of The Brain Clinic of the QSNICH on Wednesdays and Thursdays, during 8:00 a.m. - 1:00 p.m. from October 2018 - September 2019. Details of data collection can be classified according to the results of the study as follows:

- 1) General information of pediatric patients and caregivers. The researcher collected data from medical records and interviewed patients and caregivers by using a general data record form. Data was collected before starting the program.
- 2) Clinical outcomes included with the frequency of seizures, hospitalizations and ER visits due to seizures, and medical adherence score. The researcher collected data from medical records and interviewed patients and caregivers by using the clinical outcome record form. Data was collected during the following periods : in the month 0 which is pre-programed period before the start of the program and in the 6th month period when the program was manipulated. Data was recorded at every time they came to see the doctor by appointment.
- 3) Humanistic outcomes included with the patient's quality of life of. Data was collected via QOLIE-AD 48, with pediatric epilepsy patient self-administrated. The data was collected in the month 0 which is pre-programed period before starting the program, and at 6 months after the Program.

- 4) Satisfaction towards the pediatric epilepsy care program was measured by getting data via the satisfaction questionnaire given to patients, caregivers and the multidisciplinary team for self-administered. We collected the data in the 6th month after administering the program.

3.7 Data Analysis

- 1) Descriptive statistics, which were frequency, percentage, mean and
 - Standard deviation was used for describing general characteristics of the sample as well as clinical outcomes, quality of life of pediatric patients, and satisfaction for the pediatric epilepsy care program.
 - Inferential Statistics were used for comparing the outcomes before and after the pediatric epilepsy care program. Statistical test method was selected according to the distribution of the data, and determine confidential level at 95% as follows:
 - Paired t-test (Data with Normal distribution) includes score QOLIE-AD 48 (Domain, memory, health perception and overall quality of life)
 - Wilcoxon signed-rank test (Data with abnormal distribution) includes QOLIE-AD 48 (some domains), drugs adherence score, average seizure per month, number of admission/ER visit involving epilepsy in 6 months.



CHAPTER 4

STUDY RESULT

The purpose of this study was to develop an epilepsy care program for pediatric patients. The study was conducted on people involved in epilepsy care for pediatric patients, including pediatric epilepsy patients, caregivers, healthcare professionals and financial policy administrators. The study was divided into 3 parts as follow.

Part 1 : Results of Phase 1 study - Situation analysis for the assessment of problems, obstacles .

- 1.1 Problems from the perspective of pediatric epilepsy patients
- 1.2 Problems from the perspective of caregivers
- 1.3 Problems from the perspective of medical personnel
- 1.4 Problems from the perspective of the financial policy maker
- 1.5 Conclusion of problems and obstacles of pediatric epilepsy patients caring

Part 2 : Results of Phase 2 study – Development of epilepsy care program for pediatric patients.

- 2.1 Designing intervention for each gap
- 2.2 Recommended activities
- 2.3 Recommended process
- 2.4 Recommended content
- 2.5 Personnel and administration
- 2.6 Sequence of activity
- 2.7 Channel or media for pediatrics

Part 3 : Results of Phase 3 study - Assessment the outcomes of the program developed for pediatric epilepsy patients and their caregivers.

- 3.1 Demographic data of children with epilepsy and caregivers
- 3.2 Assessment of clinical outcomes

3.3 Assessment of humanistic outcome

- Quality of life in children with epilepsy
- Satisfaction of Pediatric Epilepsy Program in pediatric epilepsy patients, caregivers and multi-disciplinary team.

Part 1 : Results of Phase 1 study - Situation analysis for the assessment of problems, obstacles and gaps in caretaking for pediatric epilepsy patients

The data has been collected by interviewing people involved in the care of pediatric epilepsy patients, i.e., pediatric epilepsy patients, caregivers of pediatric epilepsy patients, medical personnel caring for pediatric epilepsy patients, and financial policy maker, total 16 participants. The study result is divided into 5 parts which are

1.1 Problem from the perspective of pediatric epilepsy patients

From the interviews with 5 children with epilepsy, aged between 11-17 years, the following information was obtained:

- Physical limitation or different way of living due to epilepsy

It was found that pediatric epilepsy patients perceived themselves indifferent from others, and they are capable to do everything as normal people, but the caretakers do not allow them to.

<Quotes>

“I can do everything same as my friend such as playing ball with them. I like playing ball, and I’m good at it.” – [Patient 1]

“No problem, I am the same as others. I always feel like this. Maybe it’s because I always have a seizure just in the nighttime, so, I have no concern about it” – [Patient 3]

“No limitation for me, I can do anything, but my mom doesn’t let me do For example, climbing stairs which I have done before, but if mom see me climb it, she will be fussy.” – [Patient 2]

- Learning ability and Intelligence

It was found that pediatric epilepsy patients perceived themselves having no learning problem, there was no difference from others. The patients feel happy with their study and school life.

<Quotes>

“There is no problem with studying. I can do everything as same as my friend, ...I am good at study.” -- [Patient 5]

“I am obedient to my mother and teacher. I like going to school. I study English with my teacher...I love her very much. I talked in English with the teacher, and she admired me of that.” -- [Patient 2]

“Studying is normal, like my friend, but taking medicine sometimes makes me so sleepy. I can't remember what I have read.... Umm, the grade dropped a bit.” -- [Patient 3]

- Psychosocial problems

It was found that pediatric epilepsy patients were accepted by teachers, friends and community. 4 in 5 of them enjoyed school life, having friends and teachers. Some were being bullied and teased by friends, but all of them were protected by the teacher and other good friends. This cause low rate of harassment.

<Quotes>

“I'm fine and happy, I don't feel any difference. There are a lot of people I like. I have joined football group. I like playing football. Sometimes, I was pushed and fell, but I was not angry at all.” -- [Patient 4]

“Everyone at school knows about it. It means nothing to us, we can play together. They also helped taking care of me when going to camp... my mom let me join. I don't have seizures so often.”-- [Patient 1]

“I have been bullied by a male, not by girl... Actually, he teased me a little bit, and I've got angry...he said the devil came. I didn't fight him, he did nothing but teasing me. I told the teacher, and the teacher told him that I was not a devil.... no devil existed. At that time, I didn't tell my mom...and now I feel no anger at all.” [Patient 2]

- Self-perception

It was found that all pediatric epilepsy patients were aware that they had epilepsy. Majority was not worried about the illness as long as they can live their normal lives. Only when having seizures made them feel uncomfortable.

<Quotes>

“Epilepsy is not troublesome to me at all. It is not dangerous. The doctor told me to take the pill every day, then the illness will be controllable.” – [Patient 3]

“Actually, Epilepsy is not that bad. I can live the simple life, just don’t limit own self too much.” – [Patient 4]

“It is suffered when having a seizure. I feel uncomfortable. ... I want to be cured.” – [Patient 2]

Regarding the recommendations and guidelines for solving problems in caring for pediatric epilepsy patients, it was found that pediatric epilepsy patients had a need for knowledge about their illness. By this way, it is suggested to use a variety of formats and communication channels such as infographics, social medias, and sharing groups.

<Quotes>

“I want to know more about my illness. We should know in order to treat it in the right way. But how to know and by which channel, it need to be considered. -- [Patient 3]

“I want to join the group of epilepsy people to share the moments and experience. It can be in form of a Line group.” -- [Patient 3]

“I want to read online. Open a chat group and share to all. I think it’s useful. Hard copy is not attractive to read. But if it is in the form of document link online or infographics, it is more interesting.” -- [Patient 4]

1.2 Problem from the perspective of caregivers

The result from interviewing 5 caregivers of pediatric epilepsy patients can be summarized as below

- Knowledge and skill for caretaking of epilepsy patients

It was found that caregivers had a need to gain knowledge in different aspects of caring for pediatric epilepsy patient. Some caregivers misunderstood about the

right way of caring such as limitations for the patients to do the activities, and they were so concerned about the epilepsy and the future of their patients.

<Quotes>

“Normally, what I did was just observing my child. I did not search for more knowledge. Only know how to do first aid. I want a doctor to teach me more methods of caring, so that I can take better care of my child.” -- [Caregiver 1]

“I would like to know what can be the triggers for the convulsion. Hot & cold temperature, stress, or being among crowded are related to the symptom or not. My child had got convulsion when going out. I want to do the preventive care.”-- [Caregiver 3]

“I want my child to take a little medicine. Taking medicine for a long time is not good. I don't know if the retard was caused by drugs or not. I've read about side effects, and got worried.”-- [Caregiver 5]

“I want to know everything, it will be helpful for my child. Actually, I already have some knowledge, but I still want to know more.”-- [Caregiver 2]

“If not necessary, I don't want him to go anywhere. I always be worried that the convulsion might cause injury, and the teacher would be unable to cope with the situation.”-- [Caregiver 5]

- Emotional problem and inferiority complex caused by epilepsy

Most of the caregivers considered that the patients has no complex about both the epilepsy and their own future. However, they aware that the epilepsy patients has severe emotional problem which need to be managed.

<Quotes>

“The child does not worried because he is unconcerned. But I worry for him. He was a good kid and obedient. Lately, he becomes a little bit stubborn as normal teenagers.” -- [Caregiver 4]

“I want him to stand on his own, and be able to control his emotion. It will be better if he doesn't have to lean on us for all the time. I want him to improve social skill. Sometimes, he doesn't want to play with his friend, instead, he want to associate with the teacher. He prefers being with adult than with ones of the same age. This is not good, people need friends anyhow.”-- [Caregiver 2]

- Social burden

Most of the caregivers has no concerns about the cost of caring since they have the rights of government supported medical treatment such as medical treatment program for handicap and universal health insurance. Instead, the caregivers feel stigmatized and concerned about the patient's future, such as education and occupation.

<Quotes>

“I am not much worried because I use a handicap card. It fully covers the cost of medicine.” --[Caregiver 5]

“I use the Universal health insurance (Gold card) and have no problem. Just follow up and check for the timing of coverage, otherwise I have to pay first.” -- [Caregiver 1]

“I’m worried about his schooling, and about his earning for living. I want him to study in higher level to have good career in the future.” -- [Caregiver 1]

“He stopped his studying while he was in the second grade caused by the limitation of health. Until now he has dropped the study for 2 years. Due to the epilepsy, he got a severe convulsion that he had to get into the hospital. The situation is not better, and finally the family decided to let him stay home until now. He is so lonely and want to go back to his friend...I feel so sorry for him.” -- [Caregiver 4]

“My concern is about his learning ability. Now he can just read and write. I am not so worried about his future because everything has been well prepared for him. Just a little afraid of being fooled by others.”

- Relationship among caregivers, patients and care providers.

From a caregiver's point of view, the relationship among pediatric epilepsy patients, their caregivers and treatment providers is good, and it leads to the cooperation from patients for medication and self-caring.

<Quotes>

“He likes the doctor and follow the doctor’s instruction. He is glad when the doctor encourage him.” [Caregiver 2]

“I always ask for information from doctor who takes good care of us. There is no convulsion since the medication program start. [Caregiver 3]

It was found that caregivers were interested how the pediatric patients from other families are taken care. They also need several channels to educate. Moreover, faster & easier communication channel such as social media, text files are needed.

<Quotes>

“Mom wants to know about other people. How do they take care of their epilepsy child? There might be some good practice for us to follow.” -- [Caregiver 1]

“I want to use technology. Either electronic files, Line, or Facebook, It will be easier to read.” -[Caregiver 2]

“Video clips, LINE Group, Facebook group, either closed group or open chat. Anything online is just O.K. Hard copies like books or pamphlets are always be disregarded.” -- [Caregiver 3]

“Need some special hotline in order to get the necessary information at any time. Sometimes, local hospital cannot give good information.” -- [Caregiver 4]

1.3 Problem from the perspective of medical personnel

From interviews with 5 people of medical personnel which are doctors, nurses and pharmacists, the following information was obtained:

- Shortage of skillful medical personnel

The problem is not the shortage of specialist for epilepsy, but it is the distribution of specialist. It is suggested to create the medical personnel network and remote mentoring system. Multi-disciplinary team such as nurses together with pharmacist should be formed up.

<Quotes>

“I think there is no shortage of skillful personnel. The knowledge can be gained from networks, but the important problem of providing care is about how the knowledge will be applied to suit each patient.” [Provider 5]

“The distribution the doctors specialized in epilepsy is low. According to the above quote, the knowledge is not the matter, the problem is distribution of personnel. The “Node” platform sounds good but it must be supported by the proper service plan.” -- [Provider 1]

“Almost 100 pediatricians in the country are good at neurology and skillful enough to be mentor. But the problem is the distribution of personnel. Remote provinces still lack of mentors. The solution is to create a long-distanced consulting

system or create a team consisting of nurses, pharmacists, and other assistants so that the doctor can be supported by the team. ” [Provider 2]

- Shortage of tools and diagnostic equipment

From the perspective of medical personnel, it is found that there is no shortage of tools and diagnostic equipment because there is a network including of both large and small hospitals enabling sharing of resources as a pool.

<Quotes>

“We have a network system for supporting of medical knowledge, tools and diagnostic equipment, so, it’s O.K. No problem.” – [Provider 2]

“Every big hospital has a CT Scanning machine, MRI machine is available at the provincial hospital. By this way, it is enable to manage a pool to share. What we need for local hospital is EEG because it's not so expensive. However, the problem may be about the reading of result, but if the forwarding system is set up, it would help solving the problem.” – [Provider 1]

- Shortage of anticonvulsants and therapeutic drug monitoring (TDM)

In view of medical personnel, there is no shortage of antiepileptic drugs. Currently, there is sufficient number of standard treatment options available.

<Quotes>

“There is no need for all new drugs. Just have a standard drug for treatment. I don't mind generic drugs. But I want them being distributed in “Batch” to every district. The distribution should be done by the government. Distributing and switching process should be managed, so it would be a very good model.” [Provider 1]

“Local medicine is at the same quality as foreign medicine. Doctors have more choice for selection.. And many hospitals already have all four standard antiepileptic drugs.” -- [Provider 2]

“Now patients can access to a lot of drugs. Many antiepileptic drugs are already on the main drug list. The referral system is also very helpful. I think there is no shortage of antiepileptic drugs, but the problem is to take it evenly.” -- [Provider 4]

- Treatment and referral problems

Medical personnel suggested that there is no problem in treatment or caring for pediatric epilepsy patients, and so as the network hospital referral system. There are only some suggestions for proper preparation for pediatric epilepsy patients and their caregivers before the referral.

<Quotes>

“At the community hospital, only pediatrician is on duty. there is no neurologist for both children or adults, if EEG is required, the patients will be referred to the provincial hospital. Anyway, they can start the medication and follow up (F/U) at their own affiliated hospital. In case if epilepticus status occurs, an expert opinion can be provided, and referral is accepted

“Regarding the referral, it needs to educate both the patients and the caregivers how to take good care of themselves. At the big hospital, doctors, nurses, pharmacists may not closely communicate with them. Patients need to be well prepared.”- [Provider 5]

The medical personnel have suggested the idea to solve the problem of pediatric epilepsy patient that the knowledge should be provided to the patients and their caregivers for proper practice. Moreover, the self-help group will create the interdependency among the patients and caregivers in group for basic care. It is also suggested to integrate the caring of the pediatric epilepsy patient to cover in multi-aspects such as social, learning and mentality. Multi-disciplinary team will collaborate with neurologist to harmonize the treatment cycle.

<Quotes>

“I'm worried about people's knowledge. What does it mean? Actually, even though the standard of Thai people is improved, but misunderstandings still exist and cause improper practice in caring. This is the real problem. – [Provider 1]

“The focus should be on how to make the patients and the caregivers aware of the problem. They should know what kind of symptom is considered abnormal and need to see the doctor. Caregivers should know the proper practice and social attitudes towards epilepsy patients” -- [Provider 1]

“At hospital, there will be physical & mental development assessment for pediatric epilepsy patients. The nurse at the clinic will help observe to take care of their learning. In girl patients who have reached reproductive age, contraception will be given. The obstetrician, epilepsy specialists, nurses, and parents will to help take care and evaluate whether the surrounding is considered a risk or not. And if parents

are really worried, maybe there will be a home visit team to closely support and provide help to them” --- [Provider 5]

“The caring should cover in all aspects, either social, academic, and psychiatric problems” - [Provider 2]

“I used to form up a peer support group to let them help each another for basic case. Actually, some patients create a Line group and then invite the nurse to join the Line group.” [Provider 5]

1.4 Problems from the perspective of the financial policy maker

- Referral problems

Queen Sirikit National Institute of Child Health's financial policy maker commented that the referral problem involves the reimbursement of money from payers (such as NHSO) to hospitals that take care of referral patients. It's a policy issue. It is suggested to distribute the budget for support, prevention and rehabilitation to reduce the number of patients entering the treatment process.

<Quotes>

“In my opinion, these problems cannot be solved because it is matter of policy. The proposal is to ask the government to increasing distribution of the budget for support, prevention, and rehabilitation to decrease the number of patients entering the treatment system.”

- The problem of medical cost reimbursement

Queen Sirikit National Institute of Child Health's financial policy maker commented that currently, the per capita treatment budget in patients with epilepsy is underestimated since the medicine for treatment is at high cost, and the reimbursed amount for medical expenses might be lesser than the actual one. It is suggested to review the treatment limit per capita to meet the actual cost. In case if the new antiepileptic drugs of high price is needed, there should be co-payment from the affiliated hospital. The patients themselves should also be involved in the payment. Also, the production capacity for local drugs should be increased.

<Quotes>

“The reimbursement of medical care cost for pediatric epilepsy patients is very problematic because epilepsy decease always needs higher quality drugs for effective

treatment. Of course, the higher quality, the higher price. so, the actual cost is higher than the reimbursable amount. To solve such problem, the recommendation is as follow

1. *Increase the per capita treatment budget by referring to the actual cost.*
2. *The payer should continuously support for the medication cost. Even though the patient get better, the long-termed medical treatment is still needed. In case if the price of medicine is high and the affiliated hospital is unable to pay, the patients and their caregivers will have to bear such the high cost and it may lead to inconstant medical treatment.*
3. *Patient co-payment program should be considered.*
4. *Strengthen the potential of local drug manufacturer in order to provide high quality product at low price, at the same time, building trust in local drugs among doctors who treat patients is necessary as well."*

For the suggestions of problem, the financial policy maker of the Queen Sirikit National Institute for Child Health recommends developing the plan for pediatric epilepsy patient caring program, then, submit proposal to the organization who bear the cost such as NHSO and ask for the financial support. In this case, the supporting data about impact and cost-effectiveness of the activities must be prepared.

<Quotes>

"If we need NHSO to support the activities we proceed, we have to show them the impact and work out for cost effective issue. Also we have to make NHSO realize that the problem about the children is a big issue which is worth investing. But this is quite difficult since Thailand is on the way to aging society and people always focus on that rather than focusing on child problem."

1.5 Conclusion of problems and obstacles of pediatric epilepsy patients caring

From the interview results, problems, obstacles and recommendations for caring for pediatric epilepsy patients can be concluded as follows:

1. Lack of knowledge and skills in epilepsy care of pediatric epilepsy patients and their caregivers

This is the universal problem for either pediatric epilepsy patients, their caregivers, or medical personnel. The knowledge covering epilepsy, treatment, drug use, and proper practice are needed. Specific care, such as caring for adolescents, support for their learning, monitoring for safe activities is necessary for pediatric patients and their

caregivers. The recommendation is to provide multi-channels of information support especially via online.

2. Learning problems, life in school & society and emotional problems of pediatric epilepsy patients

From the caregivers' point of view, it was found that some pediatric epilepsy patients face the problems of studying in normal education system. Several of them have to drop their study, possibly due to the epilepsy, which affects intelligence and learning ability. Emotional problems in pediatric epilepsy patients may also be found. The samples are children of school age who must attend school. They are in school society and having interaction with teachers and friends. School life is like social life for young patients.

3. Concerns, stigma of caregivers and social burden

The caregivers of pediatric epilepsy patients always have anxiety for disease status, how to manage problems, and their lack of caring skills. They are also concerning about the patient's future, such as education, occupation, and complex for disease which cause them some discriminated feelings.

However, gaps of pediatric epilepsy care related to the health service system, such as shortage of skillful medical personnel, shortage of tools and diagnostic equipment, referral problems including the problem of medical cost reimbursement. It is not taken into the program development as it is a systemic gap that requires further management at the policy level. From the interviews with the sample groups, there are recommendations for caring for pediatric epilepsy patients as follows:

1. Set up self-help group to share experiences among pediatric epilepsy patients and their caregivers.

From the perspective of pediatric epilepsy patients and their caregivers, they want a group of patients and caregivers from other families to meet and share knowledge & caring experience for epilepsy patients. The medical personnel also give support opinion for such idea because it will allow patients and caregivers to help each another. This is a good solution for primary care problem.

2. Multi-disciplinary team should be set up

The medical personnel propose the integrated caring program to pediatric epilepsy patients. Coverage in all aspects both socially, academically, and mentally

monitoring by a multidisciplinary team consisting of medical personnel who provide the treatment and other professional personnel involved in social and childcare, psychological and educational, such as social workers, special education teachers, and psychologists, by working together with caregivers and participation in caring for pediatric epilepsy patients

3. Various communication channels and formats are required

Epilepsy pediatric patients and caregivers suggested to provide various forms of communication channels which is considered simple, fast and easy to access by using technology such as creating infographics, video clip, and using social media such as LINE application, Facebook.

Part 2 Results of the Phase 2 study to develop an epilepsy care program for pediatric patients.

In order to develop pediatric epilepsy patient care program, the researchers analyzed the results of the Phase 1 study, which consisted of problems, obstacles and gaps in caring for pediatric epilepsy patients.

In Phase 1 study, the researcher found some gap which can be used for the care program development as follows.

2.1 Lack of knowledge and skills in epilepsy care of pediatric epilepsy patients and their caregivers

In order to close this gap, we should organize educational activities which cover the knowledge of disease, treatment, medication, proper practice, specific cares such as adolescence care, learning care, monitoring for safe activities. Various kinds of media should be used for easy access, especially via online.

2.2 Learning problems, school life and society, emotional problems of pediatric epilepsy patients

Epilepsy always makes the patients have difficulty in continuing their education in normal system, and it will affect their future learning, occupation and living of pediatric patients with epilepsy. However, this problem can be addressed by letting the special education teacher evaluate the patient's learning ability and giving proper advice to those who have limitation to be able to return to school or non-school education. Also, the professional social worker can provide some help to support the

future careers of pediatric patients and the psychologist can take care for emotional problem

2.3 The problems of anxiety and stigma of caregivers and the patients as a social burden

The anxiety of caregivers was caused by several concerns which were the patient's epilepsy disease status concern, the problem management concern, lack of care skills concerns, and patient's future concern such as education, occupation, acceptance of the condition of the disease. These concerns lead to stigma in feeling of caregivers. The problem might be relieved by sharing with other caregivers to create empathy among each another and lead to better understanding of the problem, acceptance and adaptation to cope with the problem.

Therefore, in the development program, there should be learning exchange activities among the caregivers and also the patients. There should also be a multidisciplinary team participating in the activity in order to find, evaluate and suggest the correct approach according to academic principles which patients and caregivers can apply to manage their problems appropriately.

From the interviews with the sample group, there are recommendations for caring for pediatric epilepsy patients as follows:

1. Self-help group to share experiences of pediatric epilepsy patients and the caregivers.
2. Joint treatment team
3. Various communication channels and platform

The goal for developing the pediatric epilepsy patient care is to create a better quality of life for the child with epilepsy. The researcher reviewed the literature and found that the concept of self-efficacy, self-management can be the guideline for patients and caregivers to learn and adapt to promote seizure control and enhance their well-being.

From 5 times of doing focus group, the issues related to develop the pediatric epilepsy care program, it was found that the opinions of communication channels by caregivers and pediatric patients were differ from that of medical personnel. Because medical personnel stated that social media via LINE and Facebook pose a risk to patients' rights. Finding a solution for building security, such as using LINE Official, is therefore an option. And there will be a review of people who can join by system admin.

Currently, the practice for caring of pediatric epilepsy patients are:

- 1) Diagnosis, treatment, medication, and follow-up treatment by a pediatric neurology specialist.
- 2) Pharmaceutical care, searching for drug problems, consulting, and solving drug problems by a pharmacist of the brain clinic (In the case of a doctor consulting or having problems with medicines).
- 3) Providing appointment information, patient follow-up and educate the correcting caring practice by a nurse at the Brain Clinic.
- 4) Prescription and providing information on medicines by the pharmacist on duty at the dispensing room.

However current practice for caring of pediatric epilepsy patients also has care gaps. Finding these problems such as emotional problems, school attendance, working, relationships, mental health and psychosocial which may not be taken care of. Closing the gap is therefore something that should be important as well.

The researcher, therefore, developed a pediatric epilepsy patient care program with additional activities from the existing ones as mentioned above. The new developed program consists of various activities, each of which has content, process and communication channels as follows:

Activity 1 Epilepsy care education

It is an activity that aims to provide knowledge on how to properly care for children with epilepsy according to academic principles. The information in the specified scope of contents will be presented at least twice a day via various channels where they can exchange their ideas such as

- (1) Epilepsy Kids Club Line Official or a private group on Facebook. Two-way communication between the members in group (patients and caregivers) and the administrators of platform. For Line Official, the administrators can send information to all members at the same time, and member can send their question to the administration in private. But in Facebook, sending message in comment is not private.
- (2) Moreover, the education will be in form of pamphlets or books as well.
- (3) The telephone hotline was arranged in case if questions arise.

To enhance participation of patient and caregiver, question answering to get reward will be held at every 2-3 months, and special prize for the most active member of the group activities is available.

Content

Contents for this activity is divided into 3 levels according to the importance and necessity of information that pediatric epilepsy patients and their caregivers should know.

- **Major epilepsy care knowledge** is the basic knowledge about epilepsy and necessary treatment such as seizures, what is epilepsy, causes of epilepsy, symptoms, type of epilepsy, first aid, guidelines for people with seizures, epilepsy triggers, treatment procedures, epilepsy and treatment, medication for epilepsy and anticonvulsant information.

- **Minor epilepsy care knowledge** is the knowledge of lesser priority. These are frequently asked questions such as childhood epilepsy, school-age epilepsy, epilepsy in adolescence, women with epilepsy, diet with epilepsy, ketogenic diet & epilepsy, injurious food for epilepsy, epilepsy with alternative medicine, epilepsy & orthodontics, or a broader context that is not specific only to epilepsy, such as caring for children and adolescents. Problems of comorbid conditions found in epilepsy patients, dealing with bullying in schools, special education, case studies from the childcare team with epilepsy, etc.

- **Interesting epilepsy care knowledge** is the content that patients are interested about do and don't activities, for example, water splashing in Songkran, hiking, going to the beach, driving, hobbies, occupation, playing sports, etc.

Process

1. Develop media for knowledge sharing. The researcher used data from the book "Epilepsy, the more you know...the more you love (ลมชัก ยิ่งรู้จัก...ยิ่งรักเธอ)" of the Integrated Epilepsy Research Group, Khon Kaen University as references to use as media together with some part of researcher's own developed media. Moreover, pamphlet is also used as a media for patients and caregivers.

2. Create communication channels to provide information such as LINE Official Application – “Epilepsy kids club “ and Facebook Private Group - “Epilepsy kids club“.

3. Invite patients and caregivers to join the communication channels which can be traced back. The registration for entering group should be taken into account for the rights of patients.

4. Content will be posted on Line and Facebook 2-3 times a day, covering all 3 levels of content, and repost the contents in cycles as follows:

- Major Epilepsy Care Knowledge to be reposted in 4-6 weeks.

- Minor Epilepsy Care Knowledge to be reposted in 2-3 months.
 - Interesting Epilepsy Care Knowledge to be repost in 3 months or more.
5. Follow up member's attendance and response to questions, such as additional inquiry or discuss about the posted contents.

Communication channel

1. Online: LINE Official Application – “Epilepsy kids club “and Facebook Private Group - “Epilepsy kids club “

- LINE Official Application – “Epilepsy kids club “Group administrator can provide Epilepsy care information to all members in group and each member can contact or ask questions privately to group administrator.

- Facebook Private Group - “Epilepsy kids club “Group administrator can provide Epilepsy care information to all members, members can response via the comment in post. The comments are publicly seen by members. But they can not provide the post themselves.

2. Offline: Book and brochure about Epilepsy care information. Telephone.

Responsible person: Clinical pharmacist 1 person (study researcher)



Figure 4 Communication channel

Activity 2 Self-help group

Self-help Group is an activity that aims to exchange learning experiences in pediatric epilepsy patient care among caregivers and the patient themselves, and to create empathy, to understanding oneself, to understand others in order to change perceptions, thoughts, attitudes until leading to adaptation and development of one's own skills. There will be multidisciplinary team participated the exchange in group in

order to evaluate, search, and suggest the correct approach according to academic principles that patients and caregivers can use to manage problems appropriately. The activity is also a way to create good relationship between patients, caregivers and health team in the style of two-way communication.

The multidisciplinary team participating in the self-help group includes:

- Clinical pharmacist experienced in pharmaceutical care or pharmaceutical care in pediatric epilepsy who can provide the pharmaceutical care to pediatric epilepsy patients and can act as a case manager to summarize the history of illness, treatment & goals, and can screen problems in pediatric epilepsy patient care or other problems for the multidisciplinary team.
- Special education teacher experienced in working with children and youths who have a variety of disabilities. The Special education teacher will be the consultant for epilepsy child education and coordinate & refer the patient to the education system either public or private school as appropriate. Also, they will help the patients to achieve their highest potential and strive to progress beyond their limitations.
- Counseling nurses being trained as counselling nurse, who has experience in counseling with pediatric patients and their families regarding the care and management of health problems in chronic disease patients, and who can find out health care problems of pediatric epilepsy patients.
- Pediatric psychologist experienced in evaluating problems who provide clinical psychology diagnosis such as IQ test, brain pathology, and organic test in case if referred by a neurologist. The Clinical Psychologist will provide counseling and psychological therapy for both children and families. In the case of thinking, emotional or behavioral complex has been found.
- Social workers trained for social work program who is able to give career counseling, and help the families navigate the foster care system and to assess programs and services that improve their lives.

Content

The content for the Self-help group relates to the care of pediatric & adolescent epilepsy patients, problems with comorbid conditions that may occur in epilepsy patients such as ADHD, mental & emotional states, educational information for special children's groups, other learning, and preparing & providing careers for special children.

Process

1. Preparation stage

1.1 Clinical pharmacists make appointments for pediatric epilepsy patients and their caregivers to join the self-help group on a voluntary basis, then they clarified the purpose guidelines of joining the program.

1.2 Clinical pharmacists prepare patient information illness history, treatment, treatment goals and the results of screening problems in caring for pediatric epilepsy patients or other issues to the multidisciplinary team 1 day in advance of joining the self-help Group.

2. Organize self-help group activity in the room provided. The medical personnel team who are clinical pharmacists, special education teachers, counseling clinic nurses, pediatric psychologists, social workers, caregivers and pediatric epilepsy patients. Each activity will take 40-60 minutes with participants from 1-4 families. Caregivers and pediatric epilepsy patients must join the self-help group at least once.

3. Group operation begins with building relationships, introducing themselves, and explaining the purpose of joining the group, then giving opportunities for pediatric epilepsy patients and their caregivers to exchange information about problems and experience in managing past problems at the following issues

- 1) Epilepsy knowledge
- 2) Attitude
- 3) Behavior
- 4) Effects of epilepsy.

During the exchange of knowledge, there will be a team of medical personnel to help guide and answer the questions, The group operation will be ended with summarizing the things they learned together.

4. After the self-help group, the medical personnel team will discuss to make a conclusion for the follow up issues. The pharmacist will pass on the information, problem issues and preliminary corrections in the patient medical records. In case if the problem need to be referred, It will be referred to the attending physician. The personnel team can make an appointment to forward the case.

5. If pediatric epilepsy patients and their caregivers still having problems requiring follow-up, clinical pharmacists will advise them to rejoin the group. However, if pediatric patients with epilepsy and their caregivers have no problem to follow up, they can join the self-help group on voluntary basis.

Communication channel

- Face-to-face communication

Responsible person: The multidisciplinary team 5 persons (abovementioned)

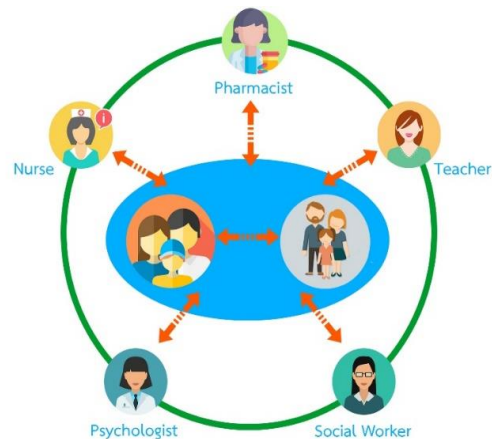


Figure 5 Self-help group

Activity 3 Pharmaceutical care

The objective of this activity is to find out about drug & treatment problems in pediatric epilepsy patients to lead to the management of problems related to drug therapy. It will help the patients to have good treatment results. The clinical pharmacist is the main operator together with the attending physician, patients themselves and their caregivers. It is a 2-way communication with 3 patterns which are face-to-face consultation, telephone consultation and LINE Official Application to follow up on drug problems and solve them.

Content

The contents consist of knowledge about epilepsy and medical treatment specific to the patients' epilepsy, the drug they take, effect of drug use, and precautions. The content is specific to each patient and caregiver and consistent to each patient's disease. In case if other problem is found, such as caring for children & adolescents, or co-morbid conditions, the clinical pharmacist of pharmaceutical care work will record it as a common problem and to coordinate and forward to the group.

Process

1. Pharmacists perform pharmaceutical care as follows:

1.1 Collecting and organizing patient specific information such as treatment history, treatment goal, drugs received, clinical symptoms and current clinical outcomes.

1.2 Determining the presence of medication-therapy problems, e.g. in the case of a new epilepsy patient, starting a new anticonvulsant, modifications in the drug or drug treatment or in cases of drug problems such as drug allergy, drug toxicity, adverse drug reaction, drug interaction and drug adherence evaluation are found, or in case the patients need additional information about drugs. The patients of the aforementioned cases will be referred to the brain clinic.

1.3 Summarizing patients' health care needs and specifying pharmacotherapeutic goals. creating an individualized care plan that collaboration with the patient and other health professionals.

1.4 Implementing the care plan, redesigning the pharmacotherapeutic regimen and monitoring plan. Record the pharmaceutical care issue such as drug related problems, and give advice for medication.

1.5 Monitoring the patient over time during follow-up encounters to evaluate the effectiveness of the plan and modify it as needed. Clinical pharmacist makes an appointment with the patients and their caregivers to follow up about the pharmaceutical care after meeting the doctor to adjust the process appropriately.

2. Pharmaceutical care takes about 20-30 minutes. Clinical pharmacists can find out the problems with patients since the first visit. The counting of pharmaceutical care will be towards continuous follow-up. Caregivers and pediatric epilepsy patients must attend at least 2 visits to pharmaceutical care follow up.

3. Clinical pharmacists recommend that pediatric epilepsy patients and their caregivers who still have problems require further follow-up visit for pharmaceutical care. However, if the patients and their caregivers have no problem to follow up, they can receive pharmaceutical care voluntarily.

Communication channel

1. The face-to-face communication with the clinical pharmacist at Counselling room in Epilepsy Clinic is a search for drug problems, intervention, medication advice and follow up on problem solving. (This study uses 1 clinical pharmacist)

2. Telephone Contact with a clinical pharmacist In the case of requirement to ask questions about medicines or report the results of solving drug problems

3. LINE Official Application channel "Epilepsy Kids Group" which has a clinical pharmacist as administrator if the patients need to ask questions about medicines or report the results of solving drug problems

Responsible person: Clinical pharmacist 1 person (study researcher)



Figure 6 Pharmaceutical care

Pediatric epilepsy care program

The developed pediatric epilepsy care program consists of three main activities:

- 1. Epilepsy care education** which aims to educate a correct understanding for pediatric epilepsy patient care through various communication channels. Online media administrator posts at least 2 contents per day on each platform; Facebook and LINE Official and also be in charge for telephone call.
- 2. Self-help group** which aims to be a channel to exchange experiences of care and management of problems related to the care of pediatric epilepsy patients. The Pediatric epilepsy patients and their caregivers must participate the Self-help group at least one time.
- 3. Pharmaceutical care** which aims to manage drug and treatment problems by clinical pharmacists. Pediatric epilepsy patients and their caregivers will receive Pharmaceutical Care with at least two follow-up visits.

The pediatric epilepsy care program is a 6-month program for pediatric epilepsy patients and their caregivers. Epilepsy care education activities are continued from the start of the program until its end. Self-help group and pharmaceutical care activity were given when the patients and their caregivers come to see the doctor at appointment for treatment. The pediatric epilepsy care program has the characteristics as shown in the Figure belows:

Pediatric Epilepsy Care Program (6 months)

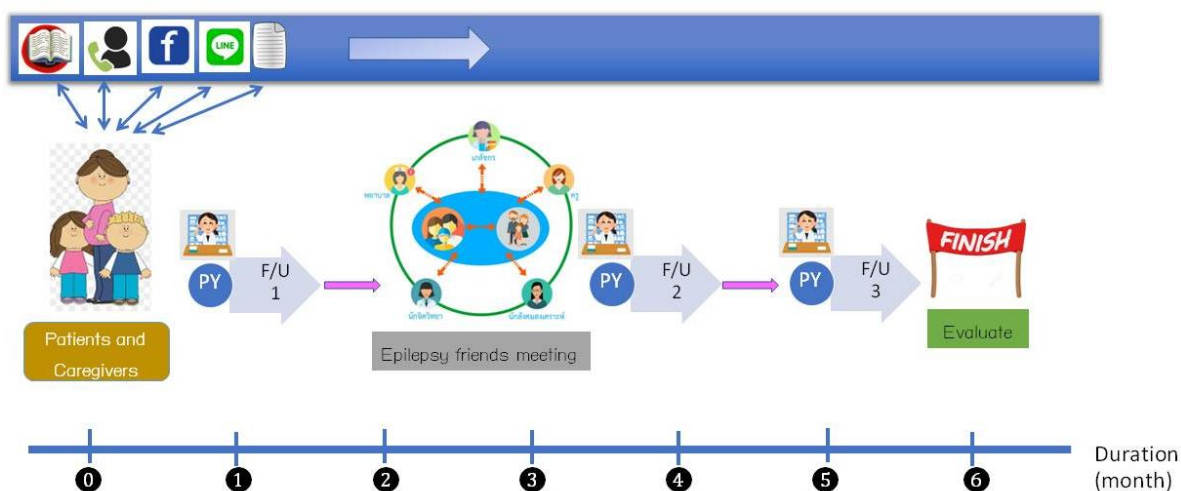


Figure 7 Pediatric epilepsy care program (6 months)
In figure PY refers to clinical pharmacist

The pediatric epilepsy care program will be used along the original services at epilepsy clinics with more activities. From the original services which is pediatric epilepsy patients visit a pediatric neurologist for treatment and prescription then they meet a clinical pharmacist to get pharmaceutical care and meet nurses to get advice on epilepsy care and to verify order before leaving the clinic.

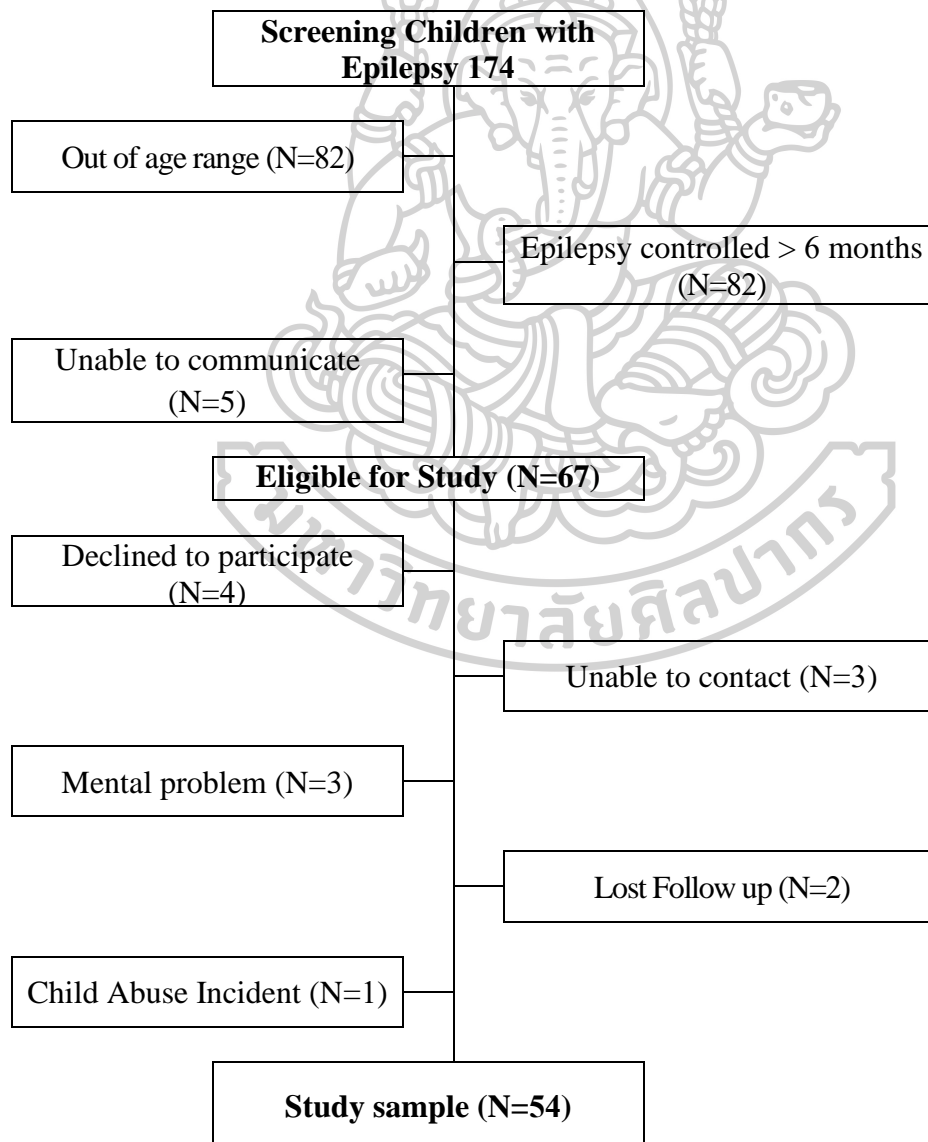
The activities in the pediatric epilepsy care program was the self-help group which they have to join before seeing their doctor on the date of treatment. The appointment will be done in advance to let the entire multidisciplinary team can prepare patient information, and the medical personnel in the clinic know the results of the activity. The other activity is Epilepsy Care Education which the patients and their caregivers will get the information via several communication channels throughout the duration of the program. Other treatment services at other epilepsy clinics remain unchanged.

Part 3 Results of the Phase 3 study: Assessment the outcomes of the program developed for pediatric epilepsy patients and their caregivers.

From the pediatric epilepsy care program developed in the Phase 2 study, the researcher conducted a 6-month trial in pediatric epilepsy patients aged 11-17 years and their caregivers. The results before and after entering the program were compared in terms of clinical outcomes, quality of life score, and satisfaction with the program.

3.1 Demographic data of children with epilepsy and caregivers

The steps to recruit patients according to eligibility criteria for participation in the study are depicted in the following figure. The screening had been commenced in August 2018 and completed in July 2019.



From the general characteristics of pediatric patients enrolled in Table 1, 26 males (48.15%) and 28 (51.85%) females of age between 10 years 4 months and 17 years 6 months, 30 of them (55.56%) were diagnosed with Focal Epilepsy, and 39 (72.22%) had Focal Seizure. The average age at onset of seizures was 7.93 ± 4.76 years (from the range of 1 month - 15 years 10 months). The average duration of the disease was 5.13 ± 4.82 years (from the range of 1 month - 14 years 7 months). 25 patients (46.30%) had other comorbidities such as ADHD, mild mental retardation, slightly lower intelligence level, depression, visual impairment, abnormal movement, and muscle problems. Most of the patients remained in the education system. It was found that 8 patients (14.81%) did not continue their studies. They had to stay at home and work from home instead. 35 participants' domiciles (64.81%) were in Bangkok and the vicinity. Details are shown in the below table.

Table 1 General characteristics of pediatric epileptic patient.

Demographic data	Number (Percentage)
Gender	
- male	26 (48.15)
- female	28 (51.85)
Total	54 (100.00)
Age (year)	
- 10 - 11 year	11 (20.37)
- 12 – 13 year	17 (31.48)
- 14 – 15 year	21 (38.89)
- 16 – 17 year	5 (9.26)
Total	54 (100.00)
Type of Epilepsy	
- Focal Epilepsy	30 (55.56)
- Generalize Epilepsy	10 (18.52)
- Combined Epilepsy	8 (14.81)
- Unknown	6 (11.11)
Total	54 (100.00)
Type of Seizure	
- Focal Seizure	39 (72.22)
- Generalize Seizure	12 (22.22)
- Unknown	3 (5.56)
Total	54 (100.00)
Age of onset	7.93 ± 4.76 (range 1 month – 15 year 10 month)
Duration of illness	5.13 ± 4.82 (range 1 month – 14 year 7 month)
Co-morbidity	
- yes	25 (46.30)
- no	29 (53.70)
Total	54 (100.00)
Domicile	
- Bangkok	23 (42.59)

Demographic data	Number (Percentage)
- Vicinities of Bangkok	12 (22.22)
- Upcountry	19 (35.19)
Total	54 (100.00)
Current education level	
- Primary school	33 (61.11)
- Secondary school	17 (31.48)
- High school	3 (5.55)
- University	1 (1.85)
Total	54 (100.00)

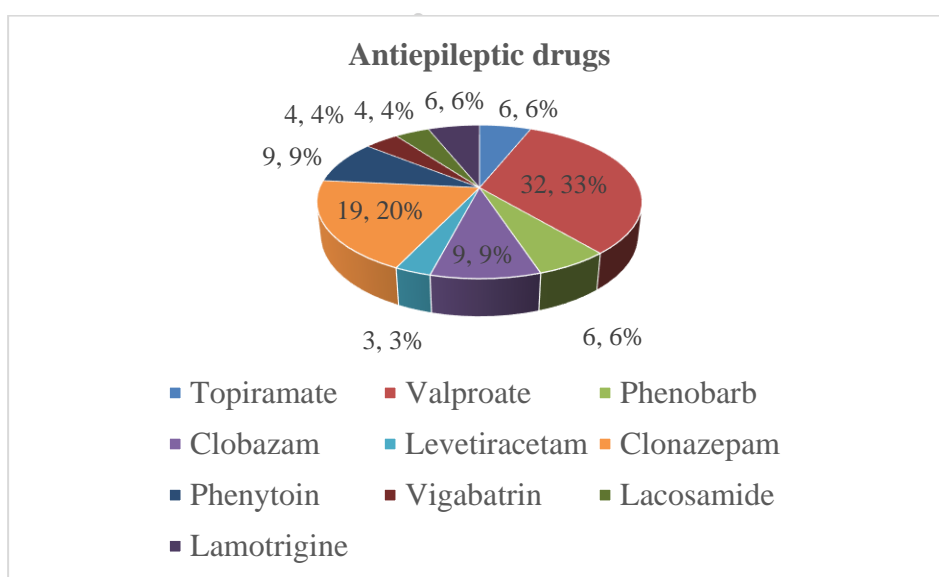


Figure 8 shows the drugs used by the patients.

Arrangement in descending order: Valproate (32.65%), Clonazepam (19.39%); Clobazam, Phenytoin (9.18%); Topiramate, Phenobarbital, Lamotrigine (6.12%); Vigabatrin, Lacosamide (7.08%), and Levetiracetam (3.06%).

Seventy-one Caregivers of children with epilepsy participated in the study, of which each pediatric patient may have more than one caregiver participating in the program. At least one caregiver participated in all activities in accordance with the program requirements. Most of the caregivers who participated were 44 mothers (61.97%) and 18 fathers (25.35%). 47 of the caregivers (66.20%) had education in between junior high school to diploma level. Details are shown in the below table.

Table 2 General characteristics of caregivers *

Demographic data	Number (Percentage)
Caregivers	
- Mother	44 (61.97)
- Father	18 (25.35)
- Sibling	3 (4.23)
- Uncle/ Aunt	3 (4.23)
- Grandparents	3 (4.23)
sum	71 (100.00)
Current education level	
- Primary school	10 (14.08)
- Junior high school	20 (28.16)
- High school	16 (22.53)
- Diploma	11 (15.49)
- University	7 (9.86)
- Postgraduate	2 (2.81)
- Not specified	5 (7.04)
sum	71 (100.00)

* one patient participated in the program with one caregiver or more.

The activities provided in the program included epilepsy care education, self-help group, and pharmaceutical care. It was found that pediatric patients and their caregivers had participated in complete program activities. Epilepsy care education activity among the patients was primarily performed through LINE, followed by books, Facebook, and phone. While the caregivers were through books, LINE, phone, and Facebook, respectively. Details are shown in Table 3.

Table 3 Number and percentage of participation in epilepsy care education activity*

Activity	Chanel	Children with epilepsy (N= 54) Number (percentage)	Caregivers (N= 71) Number (percentage)
Epilepsy care education	LINE Official	32 (62.75)	51 (71.81)
	Facebook	26 (50.98)	29 (40.85)
	Telephone	22 (43.14)	42 (59.15)
	Book	30 (58.82)	52 (73.24)

* one patient participated in the program with one caregiver or more.

For self-help group participation, it is found that pediatric epilepsy patients had come to join the group 1 time (44.44%), 2 times (50%), and 3 times (5.56%). While the Pharmaceutical care activity had been joined 3 times (46.30%) and 2 times (35.19%). Details are in the table.

Table 4 Number and percentage of participation in self-help group and pharmaceutical care activities

Activity	Number of participations	Children with epilepsy and caregivers
Self-help Group	1	24 (44.44)
	2	27 (50.00)
	3	3 (5.56)
	Sum	54 (100.00)
Pharmaceutical care	2	19 (35.19)
	3	25 (46.30)
	4	7 (12.96)
	6	3 (5.56)
	Sum	54 (100.00)

3.2 Assessment of clinical outcomes

Clinical outcomes measurement consisted of mean seizure frequency per month, drug adherence score, and the number of hospital or emergency department visits during 6 months.

Table 5 shows the clinical outcome results measuring that number of seizures before and after participating in the program had a statistically significant difference. The mean pre-programmed seizure frequency is 15.97 ± 33.02 times per month. Mean of post-programmed seizure frequency is 9.80 ± 24.58 at P-Value < 0.001 . Pre-programmed drug adherence score is 93.06 ± 11.63 %, and the post-programmed score is 95.46 ± 9.12 % at P-value 0.001.

There was no difference between before and after participating in the program for the number of hospital or emergency department visits. The mean of the pre-programmed visit is 1.19 ± 0.43 times, and the mean of the post-programmed visit is 1.09 ± 0.35 times with a P-value 0.132.

Table 5 Effects of Pediatric Epilepsy Care Program on Clinical Outcomes

Results	Pre-programmed	Post-programmed	P-value
Average of seizure frequency per month ^a	15.97 ± 33.02	9.80 ± 24.58 ¹	< 0.001 *
Drug Adherence Score ^a	93.06 ± 11.63	95.46 ± 9.12	0.001*
Number of hospital or emergency department visit ^a	1.19 ± 0.43	1.09 ± 0.35	0.132

* Statistically significant at the level of $\alpha = 0.05$

^a Non normal distribution, Wilcoxon sign rank test

¹ Calculated from the number of seizures in 6 months after start joining the program and divided by the number of months to be average per month.

There were changes in antiepileptic medication of 5 patients. 3 patients had drug replacement because their seizure could not be controlled to the required level with the used drugs. After replacing the drug, all of them had better control of seizures. 1 patient was given additional doses because it was found that seizures occurred more often near menstruation. Therefore, the drug was prescribed to take during the period to reduce seizures. 1 patient received medication reduction due to achieving the satisfied control level of seizures. One drug was discontinued, but the other antiepileptic drugs were still carried on. In conclusion, 4 patients had been changed and increased their antiepileptic drugs (7.4%). Of the 54 pediatric patients, 14 (25.92%) were diagnosed with epilepsy 2 months before joining the program. As being new epilepsy patients, adjusting antiepileptic drugs and various knowledge about epilepsy care are involved.

From Table 6, 90.74% of the patients continue to use the same drugs as they have been using. 3 (5.55%) have drug replacement, 1 (1.85%) get additional doses. 1 (1.85%) get drug reduction.

Table 6 Medication change during pediatric epilepsy care program

Medication	Number (Percentage)
Fixed drugs (as used before)	49 (90.74%)
Change of drugs	
- Replacement	3 (5.55%)
- Increase	1 (1.85%)
- Decrease	1 (1.85%)

3.3 Assessment of humanistic outcome

Quality of life in children with epilepsy

When looking at the quality-of-life scores of pediatric epilepsy patients, there was a statistically significant difference between pre-programming and post-programming, as shown in Table 6.

Overall, the Quality-of-life score before and after participating in the program were 60.65 ± 13.20 and 65.89 ± 12.48 , respectively, with a statistically significant difference at P-Value 0.001.

When divided into different domains, it was found that there was a statistically significant difference in terms of epilepsy impact, physical function, social support, and health perceptions. Whereas in the domains of memory and concentration, stigma, school behavior, and attitude toward epilepsy, there was no statistically significant difference.

Table 7 QOLIE-AD 48 score Pre and Post pediatric epilepsy care program

Items	Pre-program (Mean±SD)	Post-program (Mean±SD)	P-value
Epilepsy Impact ^a	21.47±5.51	23.52±4.70	0.013*
Memory/ Concentration ^b	10.14±3.56	10.90±3.27	0.08
Physical Functioning ^a	4.38±2.02	5.37±2.26	0.002*
Stigma ^a	7.90±3.45	8.09±2.96	0.712
Social Support ^a	1.19±0.51	1.34±0.43	0.041*
School Behavior ^a	5.06±1.01	5.15±0.99	0.507
Attitude Toward Epilepsy ^a	3.76±1.66	4.01±1.93	0.232
Health Perceptions ^b	6.72±1.96	7.50±1.81	0.006*
Total score ^b	60.65±13.20	65.89±12.48	< 0.001*

* Statistically significant at the level of $\alpha = 0.05$

^a abnormal distribution, wilcoxon sign rank test

^b normal distribution, paired t-test.

Satisfaction of the patients, caregivers, and multidisciplinary team to the Pediatric Epilepsy Care Program

The following table shows the satisfaction with the pediatric epilepsy care program. The overall satisfaction is 4.46±0.74, meaning satisfied. The patients, caregivers, and multidisciplinary team were satisfied in every aspect. The most satisfied is implementation, followed by benefit, content, process, and activity, respectively.

Table 8 Satisfaction on pediatric epilepsy care programs

Satisfaction	Score	Satisfaction level
Overall satisfaction with the program	4.46±0.74	Satisfied
Satisfaction to a specific aspect of the program		
- Application	4.46±0.74	Satisfied
- Benefit	4.40±0.79	Satisfied
- Content	4.37±0.75	Satisfied
- Process	4.25±0.80	Satisfied
- Activity	4.18±0.73	Satisfied
Satisfaction to activity: epilepsy care education, children with epilepsy (N=54)		
- Line	4.07±1.08	Satisfied
- Telephone	3.83±1.39	Satisfied
- Facebook	3.81±1.19	Satisfied
- Book	3.60±1.13	Satisfied
Satisfaction of activity: epilepsy care education caregivers (N=71)		
- Line	4.35±0.95	Satisfied
- Telephone	4.17±1.11	Satisfied
- Book	3.98±1.17	Satisfied

- Facebook	3.93±1.30	Satisfied
Satisfaction of Activity: Self-help group		
Children with Epilepsy and Caregivers	4.24±1.05	Satisfied
Satisfaction of Activity: Pharmaceutical care		
Children with Epilepsy and Caregivers	4.48±0.87	Satisfied

Most of the questions of pediatric epilepsy care were antiepileptic drug-related, such as adverse reactions, drug interactions, drug information, drug and vaccinations, mail delivery of medicines, taking medicine when sick or have a fever, taking pills between meals too close, forget to take pills.

There were also epilepsy-related questions, such as how to know it is a seizure or not a seizure, factors stimulating seizures, how to recover from the disease, moody easily caused by the disease or drugs taken, able to participate in school activities or not, consultation on school life of children with epilepsy.

Other than questions related to epilepsy, there were comments from the pediatric patients (15 comments). Most of the comments were compliments and admiration for joining the group, receiving knowledge and information by easy-to-read infographic image. There was no suggestion from the patients. The comments of the caregivers (25 comments) mostly complemented the activities in the program and thus gained more knowledge. Suggestions from the caregivers such as they found that the content was repeated when they joined the group activity for the second time but knowing new participants was great, preferred to use Line or phone call for counseling because specific information for their cases can be provided, would like to know how to encourage young patients, would like the pharmacist to ask the children whether they understand their disease, preferred more direct conversation because sometimes communication by text messages was hard to understand, would like to see pharmacists more, and would like to join the group activity less frequent.

The following table shows general information of the medical personnel involved in using the pediatric epilepsy care program (N=19)

Table 9 General information of the medical personnel

General information	Number (percentage)
Gender	
- Male	3 (15.79)
- Female	16 (84.21)
Sum	19 (100.00)

Position	
- Pediatric neurologist	4 (21.05)
- Epilepsy clinic nurse	5 (26.32)
- Epilepsy clinic technician	5 (26.32)
- Social worker	2 (10.53)
- Psychologist	1 (5.26)
- Clinical pharmacist	1 (5.26)
- Special education teacher	1 (5.26)
Sum	19 (100.00)

The following table shows the opinions of medical personnel on the pediatric epilepsy care program. The overall score on the program is 4.53 ± 0.51 , meaning very satisfied.

Satisfaction levels ranked in descending order were the benefit to the patients, making patients know their medication, reducing adverse drug reaction, making patients know their disease, and making patients take medication well.

Table 10 Opinions of medical personnel on pediatric epilepsy care program

General aspects	Score	Agreement
Opinions to the program:		
- No additional working time	3.32 ± 0.89	Neutral
- No additional process	3.42 ± 0.96	Neutral
- Patient to know the disease	4.53 ± 0.51	Strongly agree
- Patient to know the drugs	4.58 ± 0.51	Strongly agree
- Patient's drug adherence	4.53 ± 0.61	Strongly agree
- Reduce patient's adverse reaction	4.58 ± 0.61	Strongly agree
- Benefit to medical personnel	4.47 ± 0.61	Agree
- Benefit to patient	4.63 ± 0.50	Strongly agree
- Satisfy the implementation	4.47 ± 0.61	Agree
- Overall satisfaction	4.53 ± 0.51	Strongly agree

The opinions of medical personnel on the pediatric epilepsy care program (5 comments) were mostly complementation. They would like the program to continue activation. However, there were suggestions such as the program should have drug knowledge for nurses of Neurology department in terms of mechanism and adverse reactions of each antiepileptic drug to make them able to give the knowledge to patients more accurately and efficiently.

Results of the activities performed by medical personnel for patients and caregivers in the pediatric epilepsy care program

Results of Epilepsy care education activity

It was found that medical personnel who was the administrator sent information about the care for children with epilepsy through various channels throughout the pediatric epilepsy care program, consisting of Line 675 times, Facebook 303 times, 40 books distributed, and 69 phone calls answering.

334 communications were found via Line, Facebook, and telephone, respectively. The contacts were made by pediatric patients 133 times (39.82%) and caregivers 201 times (60.18%). It was found that the questions were related to pediatric epilepsy care 115 times (34.43%), other health problems 24 times (7.19%). Contacts other than those mentioned above (58.39%) were unrelated to health issues, such as greetings, thanks for providing information, and chatting.

The most common question from the incoming epilepsy-related questions was antiepileptic-related such as adverse reactions, drug interaction, medicine or vaccine that can take while taking antiepileptic drugs, taking drugs for 2 meals too close, and forget to take the drugs. Questions other than the antiepileptic-related were seizures identifying, abnormal emotion, participation in school activities, Tele-pharmacy by mailing delivery, and school life consultation.

Results of Self-help group activity

It was found that there were information and coordination between departments for patient referral while attending the self-help group activity of the pediatric epilepsy care program. The most referral was made to special education teachers, social workers, psychiatrists, nurses, and physicians, descendingly. Details are in Table 10.

Table 11 Case's referral and coordination between departments

Refer case to	Number (Percentage)	Detail
Special education teacher	6 (37.50)	- Continuing study (3) - Educational guidance (1) - Bullying in school (1) - Coordinating with schoolteachers about falls accident (1)
Social worker	5 (31.25)	- Occupation of Patient (2) - Occupation of Patient's parent (1) - Financial assist (1) - Criminal risk (1)
Psychologist	3 (18.75)	- Psychiatrist consultation (1) - Psychiatry for Parent (1) - IQ evaluation (1)
Nurse	1 (6.25)	- Parent consultation (1)
Physician	1 (6.25)	- Medical certificate on motility

Results of Pharmaceutical care activity

The clinical pharmacist gave pharmaceutical care to 39 pediatric epilepsy patients 125 times. Counseling on drug information service was the highest on the list 62 times (49.60%), followed by counseling on pediatric epilepsy care 20 times (16.00%). Most of solving medication problems were the drug adherence problem of not taking medication on time, 20 times (16:00%). Details are in the table.

Table 12 Results of Pharmaceutical care activity

Activity	Detail	Number
Solving medication problem	Unnecessary drug therapy	1
	Dosage too high	3
	Drug allergy	1
	Adverse drug reaction	10
	Drug interaction	8
	Drug adherence	20
Counseling	Drug Information service	62
	Pediatric epilepsy care	20
Sum		125

CHAPTER 5

CONCLUSION AND DISCUSSION

The research on “Development of Pediatric Epilepsy Care Program” was divided into 3 phases with the objectives as follows: Phase 1 To study the existing problems and obstacles of epilepsy care for pediatric patients; Phase 2 To develop a pediatric epilepsy care program, and Phase 3 To assess the effect of using the developed pediatric epilepsy care program.

The study was conducted from August 2018 to July 2019. In Phase 1, qualitative research was used by conducting in-depth interviews with patient care stakeholders, including pediatric patients, caregivers, treatment providers, and finance administrators. It was found that the main problem in patients and caregivers was a lack of knowledge and skills in caring for pediatric epilepsy patients. Other problems encountered included problems of learning, living in school and the society, anxiety, feeling stigmatized, psychosocial aspect, relationship between caregivers, patients, medical personnel, reimbursement of medical expenses, and referral. There were suggestions that the care of pediatric epilepsy patients be performed by a multidisciplinary team to jointly care for the pediatric patients and building networks to share resources.

Phase 2 was qualitative research. The researcher used the results of the Phase 1 study to develop a pediatric epilepsy care program using group discussions and present them to the stakeholders, including pediatric patients, caregivers, care providers, and specialists in media and child development. The developed program consisted of 3 types of activities 1) Epilepsy Care Education, 2) Self-help Group, 3) Pharmaceutical Care, in which each activity had different contents, processes, and channels.

The program was evaluated by practical implementation in Phase 3. Quasi-experimental study with one-group pre-post design was used in this phase. Interventions, which were the program activities developed from Phase 2, were given to 54 pediatric epilepsy patients aged 11-17 years and 71 caregivers. All study participants received all three interventions and were measured for the outcomes six months after the program.

From the clinical outcome measurement, the seizure frequency of pediatric patients after the program was significantly reduced (from 15.97 ± 33.02 to 9.80 ± 24.58 ; $P < 0.001$), and the drug adherence after the program had a statistically significant increase in scores (from 93.06 ± 11.63 to 95.46 ± 9.12 ; $P = 0.001$). The humanistic outcome in terms of quality of life showed that pediatric epilepsy patients had a statistically significant increase in quality-of-life scores compared to the pre-programmed scores. ($P < 0.001$). The quality-of-life scores in epilepsy impact, physical function, social and health perception were statistically significantly higher than before receiving the program. In terms of satisfaction with the program, the

pediatric patients and their caregivers satisfied with the overall of the program (score 4.46 out of 5). Their satisfaction in each aspect of the program, including contents, activities, processes, benefits received, and implementation was at a high level as well. For the satisfaction of the multidisciplinary team who provided care in the program, the overall satisfaction was at the highest level (score 4.53 out of 5).

Discussions

This research is the first development of a pediatric epilepsy care program in Thailand. It is a comprehensive program from the perspective of stakeholders in epilepsy care. It has various activities that respond to the problems and needs of those involved, targeting both pediatric patients and caregivers. In the past, there were programs developed for caregivers only, by using VCD and handbooks as the media to educate caregivers on proper behavior in caring for school-aged children with epilepsy [62], and by using Computer Assisted Instruction (CAI) as a medium to improve self-efficacy and expectations for epilepsy care outcomes [63].

From the gap in the care of pediatric epilepsy patients from the caregiver's perspective, it was found that there are concerns about the stigma associated with epilepsy, including the education and future of pediatric patients [26, 64]. It is consistent with studies abroad that have found that caregivers are stressed and worried about the illness that will affect the education and future of young patients. They are also unconfident of their abilities to care for pediatric epilepsy patients and need the knowledge to assist them in caring for pediatric epilepsy patients [26, 64]. The findings are in line with the results of a study in Thailand that found caregivers of children with epilepsy had a high level of need for patient care information, such as how to care for patients with seizures, prognosis, methods and procedures of the doctor's treatment. In addition, they also needed mental supports to strengthen their resilience, such as recognizing that caregivers love and care for patients, receiving hope and encouragement from the healthcare team and family members, and listening to problems of patient care by physicians [25].

From the perspective of healthcare providers and financial administrators found that, at present, there are more specialized doctors providing care for epilepsy patients than in the past but centralized in large hospitals and lack of distribution in the outer region. According to the study of Somsak Tiamkao et al., the availability of care services for epilepsy patients was limited in specialized medical personnel. It may be because the survey took place in 2007, and the study's problem was found in small health care facilities in the outer region, such as community hospitals. At present, there are more specialized physicians. However, the problem may be resolved through the networking of health facilities in combination with communication technologies to assist in treatment, such as telemedicine, innovation in health care that is being adopted today. In some countries, guidelines for treating pediatric epilepsy patients with telemedicine have been established during the pandemic of the coronavirus disease 2019 (COVID-19) [65].

The development of a pediatric epilepsy care program with various activities can help manage problems found in pediatric patients and their caregivers. The goal is

to provide pediatric patients and caregivers with self-management skills, take care of the illness, and manage problems caused by the illness properly. Start with educating about epilepsy and its caring, which is necessary to enable patients and caregivers to understand the underlying disease condition and deal with problems appropriately. Most of the programs from studies in pediatric patients and caregivers focused on educating through various methods, for example, the FLIP&FLAP program and other media, including handbooks, comic books, short films, and games. The outcomes, including knowledge scores, pediatric self-management skills, and patients' quality of life, were improved [66]. Knowledge enhancement in caregivers and patients can increase drug adherence and treatment compliance, leading to effective treatment, better control of disease symptoms, good seizure control, resulting in a better quality of life of patients [35]. In addition, a study found that drug education, drug information, drug problem discovery, and drug problem management can increase drug adherence, leading to better treatment outcomes and a better quality of life for patients. Therefore, pharmaceutical care is another activity that enables patients to manage problems from using antiepileptic drugs and encourage drug adherence.

Joining a self-help group is a form of activity with the concept of giving and taking help system based on mutual respect, sharing responsibility, and agreeing on what is beneficial. The activity was applied to improve self-efficacy for developing skills in self-management of patients with various diseases and caregivers such as psychiatric disorders and chronic non-communicable diseases [67]. In the past, there was ACINDES program developed as a group activity of pediatric epilepsy patients, parents, and medical personnel. It provided knowledge and had activities to train pediatric patients to take the role of leadership in managing their own health with support from parents and consultation from medical personnel. As a result, it was found that the frequency of seizures among patients was reduced, and parents improved their knowledge, attitudes, and behaviors for epilepsy care which was explained by social support factors that affected the patient and caregiver's ability to care for the disease [68].

The results of implementing the developed pediatric epilepsy care program from this study were consistent with the hypothesis. In other words, this program can improve the clinical and humanistic outcomes of pediatric epilepsy patients.

The study's results showed that after the pediatric patients and caregivers received the program, the frequency of seizures was reduced, and the drug adherence was increased, and both are significant. However, the number of hospitalization and emergency department visits remained unchanged. The results found are consistent with the results of the study [68] that showed decreasing in seizure frequency among the participants of the ACINDES program after 12 months. However, unlike the result from the study [69], it found no difference in the frequency of seizures in the studied group before and 3 months after the FAMOSE program. The result of unchanged seizure frequency may be related to the time of measuring after the program. In this study, the researcher used a 6-month time after participation in the program for the outcome measurement because the difference in seizure frequency from pharmacotherapy generally becomes apparent after 3 months, so it may be reasonable that the measuring should be taken more extended period.

The quality of life for the pediatric patients in this study was measured by QOLIE-AD 48 before and 6 months after receiving the pediatric epilepsy care program. There was a significant increase in quality-of-life scores overall, and individual aspect of the quality-of-life score, consisting of epilepsy impact, physical function, social and health perceptions. Compared with the study [70] using the Harter self-competency instrument, that found a pre-posterior difference in social competency, social skill, and participation in normal activity. However, no difference was found in scholastic competency, athletic competency, appearance competency, behavior competency, self-esteem competency, self-care skill, parent behavior, disclosure of epileptic status.

The quality-of-life outcomes of the other studies were measured by information from parents. They found that parental anxiety was decreased [71]. In addition, there was the improvement in parent adaptation about epilepsy, anxiety about epilepsy, rules and limitation [69], and allowing a child to sleep at friends' home more often [68], which reflected the quality of life as a normal child or adolescent.

For the satisfaction with the program, it was found in this study that both pediatric patients and their caregivers were satisfied with the pediatric epilepsy care program.

The strength of the pediatric epilepsy care program in this study is that the program has been made from considering the stakeholders' needs compared to their problems to identify the gaps of pediatric epilepsy care. It was then developed into a program that aims to reduce or eliminate those gaps. The program was measured in both clinical and humanistic outcomes, including the patient's quality of life. All of these were done to make the program comprehensive and responsive to the goal of pediatric epilepsy care, which are minimization of seizures, ability to do activities like ordinary people, and improved quality of life. Despite the mentioned strength, there are implementation's restrictions of the program's activities as follows:

1. Since the "Epilepsy care education" activity uses communications through various social media channels, the patients' rights and security of their personal data must be considered. In addition, if the program is widely used with many participants, there must be a system administrator to help control the security of information, monitor the posting of messages, and keep everything in the appropriate way.
2. For the "Self-help group" activities, the diversity of specialized medical personnel and other specialists participating in the program will make the activity more effective. However, this brings a limitation that the activity is convenient to be set up only in large hospitals in the level of tertiary care or super-specialist hospitals. Therefore, the application of telemedicine or professional network or teleconference systems is necessary to help organize the activity in areas far away from specialized personnel.

3. The "Pharmaceutical care" activity requires a pharmacist who is qualified as a case manager. Knowledge, experiences, and skill in the areas beyond drug-related are necessary, including patient's environmental data analyzing, coordination with multidisciplinary personnel, interpersonal skills with patients and caregivers to help the program goes in the right direction.
4. The pediatric patients participating in the study were 11-17 years old, aged from children to adolescents. These pediatric patients have been treated in QSNICH since childhood. They already trust the personnel of the hospital. As a result, it has gained cooperation and a good relationship with the hospital's multidisciplinary team.
5. The method of this study does not have a control group, so the confidence in the results comparing from the studied group only may not be equal to those with a control group.

Recommendations for implementing the pediatric epilepsy care program

1. In practice, the results of this study showed that the program benefits patients and caregivers. Nevertheless, the program may need to be considered in terms of implementation and personnel qualifications. Moreover, if it can be developed as a continuous-used program, there will be an improvement and becoming more effective.
2. In terms of management and policy, the program should be studied further in cost-effectiveness due to more personnel involved in providing pediatric epilepsy care. More personnel mean more cost and may affect the profit or service charge. Regardless of margin, the program is suitable for a patient-oriented or non-profit organization. It is also worth considering that the program can be used in conjunction with the regular pediatric epilepsy care service to enhance the treatment level.





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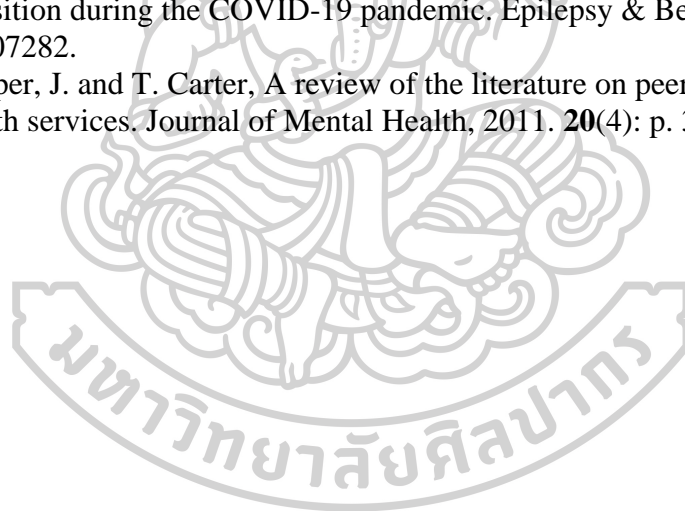
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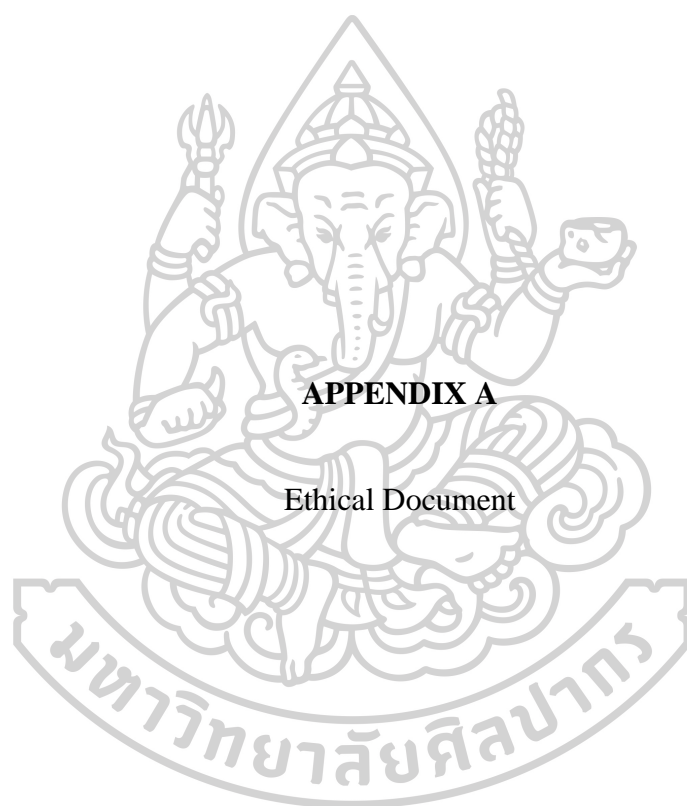
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APPENDIX A

Ethical Document



คณะกรรมการจริยธรรมการวิจัยในมนุษย์
สถาบันสุขภาพเด็กแห่งชาติมหาราชินี

8 สิงหาคม 2561

โครงการวิจัยเรื่อง : การพัฒนาโปรแกรมการดูแลโรคลมชักสำหรับผู้ป่วยเด็ก (Development of Pediatric Epilepsy Care Program)
ผู้ดำเนินการวิจัย : เกศขจรหญิงวิวรรณ วิทวัสสำราญกุล
สถานที่ดำเนินการวิจัย : สถาบันสุขภาพเด็กแห่งชาติมหาราชินี
ระยะเวลาดำเนินการ : 1 กรกฎาคม 2561 – 30 มิถุนายน 2562
เอกสารที่พิจารณา :

1. แบบเสนอโครงการวิจัยเพื่อขอรับการพิจารณาจากคณะกรรมการจริยธรรมการวิจัยในมนุษย์สถาบันสุขภาพเด็กแห่งชาติมหาราชินี (REC-QSNICH.03) (REC 03 version 4.0 date 1 Aug 2018 : ฉบับภาษาไทย)
2. คำอธิบายสำหรับผู้เข้าร่วมในโครงการวิจัย (Information Sheet for Research Participant) (REC-QSNICH.05) Phase 3 Adolescent 13-17 (version 4.0 date 1 Aug 18) (version 4.0 date 1 Aug 2018)
3. คำอธิบายสำหรับผู้เข้าร่วมในโครงการวิจัย (Information Sheet for Research Participant) (REC-QSNICH.05) Phase 3 Caregiver Provider (version 4.0 date 1 Aug 18)
4. คำอธิบายสำหรับผู้เข้าร่วมในโครงการวิจัยสำหรับอาสาสมัครเด็ก อายุ 7-12 ปี (Information Sheet for Research Participant) (REC-QSNICH.06) (version 4.0 date 1 Aug 18)
5. หนังสือแสดงความยินยอมเข้าร่วมโครงการวิจัย (Informed Consent Form) (REC-QSNICH.07) Phase 3 Adolescent 13-17 (version 4.0 date 1 Aug 18)
6. หนังสือแสดงความยินยอมเข้าร่วมโครงการวิจัย (Informed Consent Form) (REC-QSNICH.07) Phase 3 Caregiver Provider (version 4.0 date 1 Aug 18)
7. หนังสือแสดงความยินยอมเข้าร่วมโครงการวิจัยสำหรับผู้แทนโดยชอบธรรม/ผู้ปกครอง (Informed Consent Form) (REC-QSNICH.08) (version 4.0 date 1 Aug 18)
8. หนังสือแสดงความยินยอมเข้าร่วมโครงการวิจัยสำหรับอาสาสมัครเด็กอายุ 7-12 ปี (Informed Assent Form) (REC-QSNICH.09) (version 4.0 date 1 Aug 18)
9. แบบบันทึกข้อมูลผู้เข้าร่วมวิจัยการประเมินผลโปรแกรมการดูแลโรคลมชักสำหรับผู้ป่วยเด็ก
10. แบบสอบถามความคิดเห็นโปรแกรมการดูแลโรคลมชักสำหรับผู้ป่วยเด็ก
11. แบบฟอร์มคำแนะนำสำหรับผู้ป่วยโรคลมชักที่ได้รับยาตัวใหม่
12. แบบสอบถามคุณภาพชีวิตของผู้ป่วยโรคลมชักกลุ่มวัยรุ่น (QOLIE-AD-48) ฉบับภาษาไทย

คณะกรรมการจริยธรรมการวิจัยในมนุษย์ สถาบันสุขภาพเด็กแห่งชาติมหาราชินี ได้พิจารณารับรองโครงการวิจัยโดยยึดหลักเกณฑ์ตามคำประกาศเฮลซิงกิ (Declaration of Helsinki) และแนวทางการปฏิบัติการวิจัยทางคลินิกที่ดี (ICH GCP) ทั้งนี้ให้ดำเนินการวิจัยตามเอกสารฉบับภาษาไทยเท่านั้น โดยขอให้รายงานความก้าวหน้าทุก 12 เดือน

(แพทย์หญิงรัตโนทัย พลับรุ่งการ)

ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์
สถาบันสุขภาพเด็กแห่งชาติมหาราชินี

เลขที่ : REC.097/2561 (Full Board)

รหัสโครงการ : Document No.60-048

รับรองตั้งแต่วันที่ 3 สิงหาคม 2561

ถึงวันที่ 2 สิงหาคม 2562

เลขที่เอกสารรับรอง : REC.097/2561

ประชุมครั้งที่ 8/2561

วันที่ 9 กรกฎาคม 2561

สำนักงานจริยธรรมการวิจัย สถาบันสุขภาพเด็กแห่งชาติมหาราชินี
อาคารสถาบันสุขภาพเด็กแห่งชาติมหาราชินี ชั้น 12
420/8 ถนนราชวิถี แขวงทุ่งพญาไท เขตราชเทวี กรุงเทพฯ 10400
โทร. 1415 ต่อ 5210, 5211

Institutional Review Board Number; IRB00007346

Federal Wide Assurance; FWA00002250

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EC-QSNICH

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REC-QSNICH.36T



คณะกรรมการจริยธรรมการวิจัยในมนุษย์
สถาบันสุขภาพเด็กแห่งชาติมหาราชินี

9 กรกฎาคม 2562

- โครงการวิจัยเรื่อง : การพัฒนาโปรแกรมการดูแลโรคลมชักสำหรับผู้ป่วยเด็ก
(Development of Pediatric Epilepsy Care Program)
- ผู้ดำเนินการวิจัย : เกศษกรหญิงรวิวรรณ วิทวัสสำราญกุล
- สถานที่ดำเนินการวิจัย : สถาบันสุขภาพเด็กแห่งชาติมหาราชินี
- ระยะเวลาดำเนินการ : 1 กรกฎาคม 2561 - 30 มิถุนายน 2563
- เอกสารที่พิจารณา :
1. แบบรายงานความก้าวหน้า (Progress report) และขอต่ออายุหนังสือรับรองโครงการวิจัย (REC-QSNICH.21) (Document No.60-048) ลงวันที่ 27 พฤษภาคม 2562

คณะกรรมการจริยธรรมการวิจัยในมนุษย์ สถาบันสุขภาพเด็กแห่งชาติมหาราชินี ได้พิจารณารับทราบการรายงานความก้าวหน้า และรับรองการขอต่ออายุหนังสือรับรองโครงการวิจัยโดยยึดหลักเกณฑ์ตามคำประกาศเฮลซิงกิ (Declaration of Helsinki) และแนวทางการปฏิบัติการวิจัยทางคลินิกที่ดี (ICH GCP) ทั้งนี้ให้ดำเนินการวิจัยตามเอกสารฉบับภาษาไทยเท่านั้น โดยขอให้รายงานความก้าวหน้าทุก 12 เดือน

(แพทย์หญิงรัตโนทัย พลับรู้งการ)

ประธานคณะกรรมการจริยธรรมการวิจัยในมนุษย์
สถาบันสุขภาพเด็กแห่งชาติมหาราชินี

- เลขที่ : REC.119/2562 (Full Board)
- รหัสโครงการ : Document No.60-048 รับรองตั้งแต่วันที่ 3 สิงหาคม 2562 ถึงวันที่ 2 สิงหาคม 2563
- เลขที่เอกสารรับรอง : REC.097/2561 (Re.-1) แจ้งที่ประชุมครั้งที่ 8/2562 วันที่ 8 กรกฎาคม 2562

สำนักงานจริยธรรมการวิจัย สถาบันสุขภาพเด็กแห่งชาติมหาราชินี Institutional Review Board Number; IRB00007346
อาคารสถาบันสุขภาพเด็กแห่งชาติมหาราชินี ชั้น 12 Federal Wide Assurance; FWA00002250
420/8 ถนนราชวิถี แขวงทุ่งพญาไท เขตราชเทวี กรุงเทพฯ 10400

โทร.1415 ต่อ 5213, 5214

EC-QSNICH

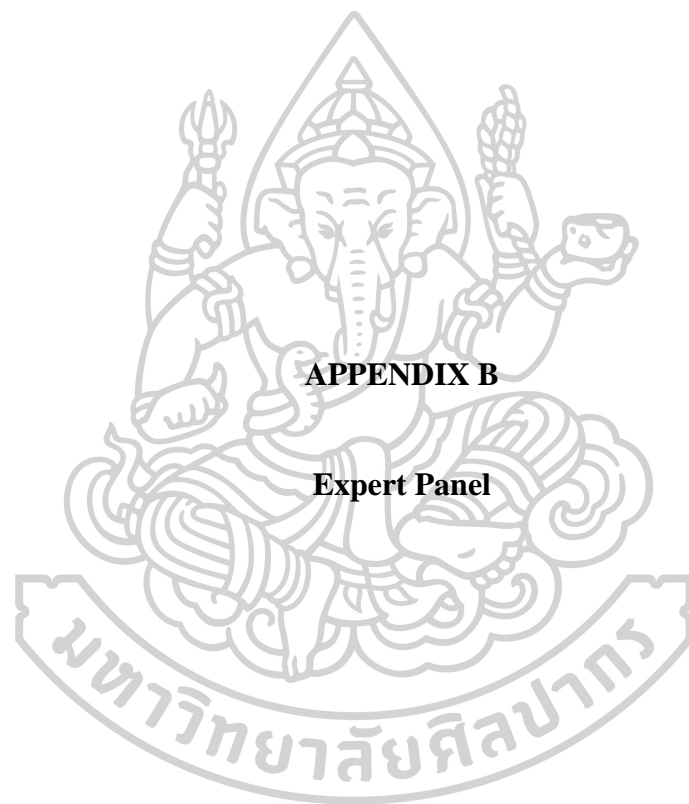
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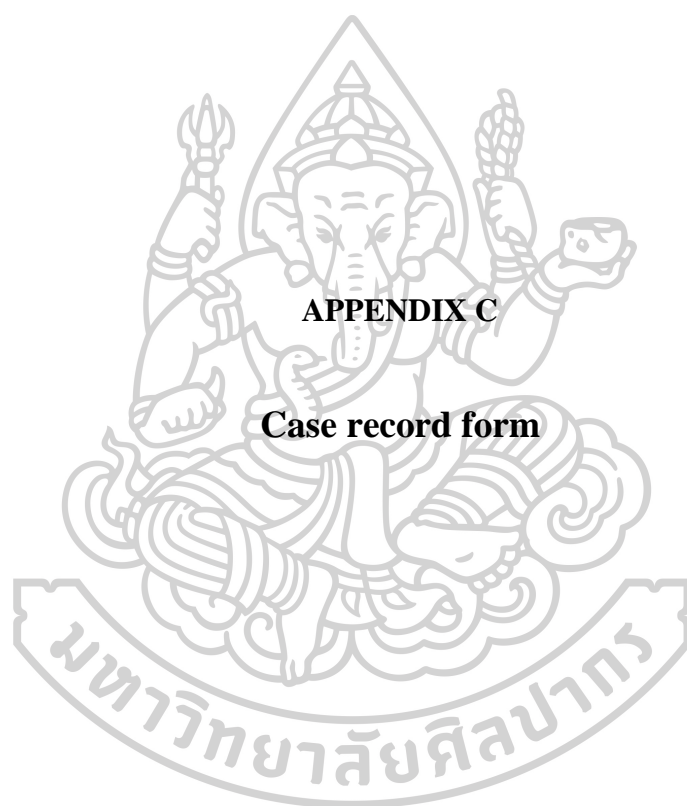
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Expert panel

1. Anannit Visudtibhan, MD Professor of Pediatric and Pediatric Neurology Ramathibodi Hospital, Faculty of Medicine, Mahidol University
Pediatric Neurology President, Epilepsy Society of Thailand
2. Somsak Tiamkao, MD Professor of Internal Medicine and Neurology Division of Neurology, Department of Medicine, Faculty of Medicine, Khon Kaen University
Head of Integrated Epilepsy Research Group, Srinagarind Hospital, Faculty of Medicine, Khon Kaen University
3. Pranee Mueangnoi, MD Assistant Professor Child and adolescent psychiatry Department Queen Sirikit National Institute of Child Health
4. Sineenard Mungmanitmongkol Nurse : Division of Neurology Department of Medicine, Faculty of Medicine, Khon Kaen University
Secretary of Integrated Epilepsy Research Group, Srinagarind Hospital, Faculty of Medicine, Khon Kaen University
5. Major Phattira Chaisuwan Nurse : Division of Neurology, Department of Medicine, Phramongkutklo Hospital



APPENDIX C

Case record form

Record form for study “Development of Pediatric Epilepsy Care Program”

Date.....

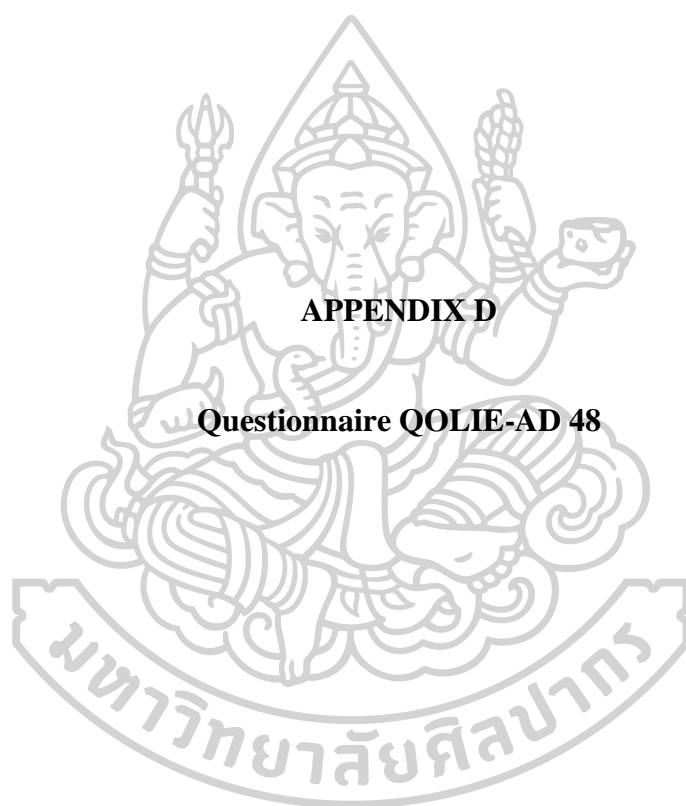
Part 1 Demographic Data

Patient Code..... Sex..... Age..... Current Education.....
 Health Scheme..... Accommodation.....
 Age of Onset..... Seizure duration..... Epilepsy Type.....
 Seizure Type..... Co-morbidity.....

Caregivers of Patient code..... Sex..... Age.....
 Accommodation..... Relationship..... Time of Care.....

Part 2 Clinical Data

Topic	Date.....	Date.....	Date.....
Antiepileptic drugs/amount			
Remaining AEDs/amount			
Adherence score			
Seizure frequency			
No. of ER Visit			
No. of Admit			
DRP/ Counseling			
Remark/ next F/U			



APPENDIX D

Questionnaire QOLIE-AD 48

**แบบสอบถามคุณภาพชีวิตของผู้ป่วยโรคลมชักกลุ่มวัยรุ่น
(QOLIE-AD-48) ฉบับภาษาไทย**

วัตถุประสงค์

: การศึกษานี้ต้องการตรวจสอบความเที่ยงตรงและความแม่นยำของแบบสอบถามคุณภาพชีวิตผู้ป่วยโรคลมชัก

(QOLIE-AD-48) ฉบับภาษาไทย

คำแนะนำของการตอบแบบสอบถาม

1. แบบสอบถามแบ่งเป็น 2 ส่วน
 - ส่วนที่ 1 คำถามเกี่ยวกับสุขภาพทั่วไป
 - ส่วนที่ 2 คำถามเกี่ยวกับผลกระทบของโรคลมชักและยากันชัก
2. ให้ตอบโดยวงกลมเลือกข้อที่ตรงกับความรู้สึกของคุณมากที่สุด
3. มีบางข้อคำถามที่คล้ายกันให้ตอบด้วย
4. ถ้าสงสัยเกี่ยวกับคำถาม ไม่เข้าใจ ให้ถามหรือทำเครื่องหมายไว้ในแบบสอบถาม
5. จะไม่ตอบข้อใดก็ได้ หรือจะยุติการตอบเมื่อใดก็ได้ทุกเวลาโดยไม่มีผลกระทบใด ๆ ต่อตัวผู้เข้าร่วมวิจัย

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(Cramer et al., Epilepsia,1999; 40: 1114-1121).

โรคลมชักมีผลต่อชีวิตท่านอย่างไร ?

คำถามเหล่านี้จะถามเกี่ยวกับสุขภาพของท่าน

ว่าท่านรู้สึกอย่างไรและสามารถทำกิจกรรมต่างๆตามปกติได้อย่างไร ถ้าท่านไม่มั่นใจการตอบคำถาม

โปรดให้คำตอบที่ดีที่สุดเท่าที่ท่านเข้าใจ

ส่วนที่ 1 สุขภาพโดยทั่วไป

1. โดยทั่วไป สุขภาพของท่านเป็นอย่างไร.....

(5) ดีเยี่ยม (4) ดีมาก (3) ดี (2) พอใช้ (1) ไม่ดีเลย

2. เปรียบเทียบกับเมื่อ 1 ปีที่ผ่านมา ปัจจุบันสุขภาพของท่านเป็นอย่างไร.....

(5) ดีขึ้นมาก (4) ดีขึ้นบ้าง (3) เหมือนเดิม (2) เลวลงบ้าง (1) เลวลงมาก

ภาวะสุขภาพของท่านในปัจจุบัน มีผลกระทบหรือเป็นข้อจำกัดในการทำกิจกรรมต่างๆ เหล่านี้หรือไม่ ในช่วง 1 เดือนที่ผ่านมา	บ่อยมาก (1)	บ่อย (2)	บางครั้ง (3)	ไม่บ่อย (4)	ไม่มีเลย (5)
3.กิจกรรมที่ต้องออกแรงมาก เช่น วิ่ง ยกของหนักๆ เล่นกีฬาที่ใช้แรงมาก เช่น เล่นยิมนาสติก, เล่นสเก็ต					
4.กิจกรรมที่ออกแรงปานกลาง เช่น ปั่นจักรยาน เดินไปโรงเรียน					
5.กิจกรรมที่ออกแรงเล็กน้อย เช่น หิ้วของหนัก, ถือกกระเป๋าบรรจุหนังสือเต็มกระเป๋า					
6.กิจวัตรประจำวันส่วนตัว เช่น อาบน้ำ แต่งตัว					

ในช่วง 1 เดือนที่ผ่านมา สุขภาพร่างกายของท่าน หรือปัญหาทางอารมณ์ (เช่น ซึมเศร้า หรือวิตกกังวล) มีผลต่อการทำงานหรือกิจวัตรประจำวัน (เช่น งานบ้าน ทำการบ้าน ดูแลเด็ก เรียนพิเศษ) บ้างหรือไม่ ถ้ามีบ่อยครั้งเพียงใด

	บ่อยมาก (1)	บ่อย (2)	บางครั้ง (3)	ไม่บ่อย (4)	ไม่มีเลย (5)
7. ทำงานหรือกิจกรรมได้น้อยกว่าที่ตั้งใจไว้					
8. ทำกิจกรรมการเรียน, งานบ้าน, กีฬา หรือกิจกรรมอื่นไม่ได้อย่างที่เคย					
9. มีความยากลำบากในการทำกิจกรรมการเรียน, งานบ้าน, กีฬา หรือกิจกรรมอื่น เช่น ต้องใช้ความพยายามเพิ่มมากขึ้น					

ในช่วง 1 เดือนที่ผ่านมา บ่อยแค่ไหนที่ท่าน.....	บ่อยมาก (1)	บ่อย (2)	บางครั้ง (3)	ไม่บ่อย (4)	ไม่มีเลย (5)
10. ขาดเรียนโดยไม่มีสาเหตุ					
11. มีปัญหาเกี่ยวกับครูหรือคนอื่นในโรงเรียน					
12. มีปัญหาเกี่ยวกับคนอื่นภายนอกโรงเรียน เช่น พนักงานขับรถเมล์, รปภ. หรือ ตำรวจ เป็นต้น					

ในช่วง 1 เดือนที่ผ่านมาบ่อยแค่ไหนที่ท่าน.....	ตลอดเวลา (1)	เกือบ ตลอดเวลา (2)	บางเวลา (3)	นานๆครั้ง (4)	ไม่มีเลย (5)
13. ขาดสมาธิในการทำงานหรือกิจกรรมอย่างใด อย่างหนึ่ง					
14. ขาดสมาธิในการอ่านหนังสือ					
15. คิดไม่ออก หรือคิดช้า					
16. มีความลำบากในการคิด ตัดสินใจแก้ปัญหา หรือ เรียนรู้สิ่งใหม่ๆ					
17. มีปัญหาในการทำงานที่ยาก และ ซ้ำซ้อน เช่น ทำการบ้านที่ยาก, เล่นเกมส์คอมพิวเตอร์					
18. มีปัญหาในการจำสิ่งที่เพิ่งอ่านไปเมื่อชั่วโมงที่แล้ว หรือเมื่อ 1-2 วันก่อนไม่ได้					
19. มีปัญหาในการนึกคำที่เหมาะสมที่จะใช้ไม่ออก					
20. ไม่เข้าใจสิ่งที่ครูสอน หรือฟังครูพูดไม่เข้าใจ					
21. ไม่เข้าใจในสิ่งที่อ่าน					

คำถามต่อไปนี้จะเกี่ยวกับความช่วยเหลือที่คุณได้รับจากบุคคลอื่น (รวมทั้งจากครอบครัวและเพื่อนๆ)

ในช่วง 1 เดือนที่ผ่านมา บ่อยแค่ไหนที่ท่าน.....	บ่อยมาก (5)	บ่อย (4)	บางครั้ง (3)	ไม่บ่อย (2)	ไม่มีเลย (1)
22. มีคนพร้อมที่จะให้ความช่วยเหลือท่าน เมื่อท่านต้องการความช่วยเหลือ					
23. มีคนที่ท่านให้ความไว้วางใจสามารถพูดคุยปัญหาต่าง ๆ ของท่านได้					
24. มีคนที่ท่านสามารถพูดคุยเมื่อรู้สึกสับสน หรือ เมื่อต้องการหาทางแก้ไขปัญหา					
25. มีคนที่ยอมรับท่านอย่างที่เป็น ทั้งในด้านดีและด้านไม่ดี					

ส่วนที่ 2 ผลของโรคลมชักและยากันชัก

ในช่วง 1 เดือนที่ผ่านมา ท่านรู้สึกว่าโรคลมชักและยากันชักมีผลกระทบต่อชีวิตของท่านในด้านต่อไปนี้หรือไม่ ถ้ามีบ่อยเพียงใดที่ท่านรู้สึกเช่นนั้น โปรดเลือกข้อที่ใกล้เคียงกับความรู้สึกของท่านมากที่สุด ในแต่ละข้อ...

(เลือกเพียงหนึ่งช่องในแต่ละข้อ)

	บ่อยมาก (1)	บ่อย (2)	บางครั้ง (3)	ไม่บ่อย (4)	ไม่มีเลย (5)
26. ทำกิจกรรมบางอย่างร่วมกับเพื่อนไม่ได้ เช่น ไปเที่ยว, ทำกิจกรรมนอกหลักสูตร, เล่นกีฬา					
27. รู้สึกตัวเองต้องอยู่อย่างโดดเดี่ยว และแยกตัวเพราะโรคลมชัก					
28. ขาดเรียนเพราะชัก หรือผลของยากันชัก					
29. ท่านใช้โรคลมชักหรือผลข้างเคียงจากยากันชักเป็นข้ออ้าง เพื่อหลีกเลี่ยงในสิ่งที่ไม่อยากทำ					

ในช่วง 1 เดือนที่ผ่านมา ท่านรู้สึกว่โรคลมชักและยากันชักมีผลกระทบต่อชีวิตของท่านในด้านต่อไปนี้หรือไม่ ถ้ามีบ่อยเพียงใดที่ท่านรู้สึกเช่นนั้น โปรดเลือกข้อที่ใกล้เคียงกับความรู้สึกของท่านมากที่สุด ในแต่ละข้อ...(เลือกเพียงหนึ่งข้อในแต่ละข้อ)

	บ่อยมาก (1)	บ่อย (2)	บางครั้ง (3)	ไม่บ่อย (4)	ไม่มีเลย (5)
30. รู้สึกว่าน่าอาย หรือ แตกต่างจากเพื่อนที่ต้องกินยากันชัก					
31. รู้สึกว่าโรคลมชักหรือผลจากยากันชักทำให้เรียนได้ไม่ดี					
32. รู้สึกว่าอาการชักทำให้มีข้อจำกัดเวลาจะทำงานหรือทำกิจกรรม					
33. รู้สึกว่าโรคลมชักหรือยากันชักทำให้ท่านต้องพึ่งพาคนอื่น					
34. รู้สึกว่าโรคลมชักหรือผลจากยากันชักเป็นข้อจำกัดในการเข้าสังคมกับเพื่อน หรือ การคบเพื่อนต่างเพศ					
35. รู้สึกว่าโรคลมชักหรือผลจากยากันชักเป็นข้อจำกัดในการเล่นกีฬา หรือ ทำกิจกรรมที่ต้องใช้แรง					

36. ในช่วง 1 เดือน ที่ผ่านมา ท่านรู้สึกอย่างไรกับผลข้างเคียงของยากันชักที่ท่านกินอยู่ เช่น น้ำหนักขึ้น, เป็นสิว, ผมร่วง เป็นต้น

ที่ท่านกินอยู่หรือไม่ รู้สึกอย่างไร.....

(1) แย่มากๆ (2) แย่ (3) เฉยๆ (4) ดี (5) ดีมาก

37. ในช่วง 1 เดือน ที่ผ่านมา พ่อแม่ หรือคนอื่นในครอบครัวใช้การที่ท่านเป็นโรคลมชักหรือกินยากันชักเป็นข้อห้ามหรือจำกัดในการทำกิจกรรมบางอย่างของท่าน มากน้อยเพียงใด.....

(1) มาก (2) ค่อนข้างมาก (3) ปานกลาง (4) เพียงเล็กน้อย (5) ไม่เลย

ใน 1 เดือนที่ผ่านมา ในสถานการณ์ต่อไปนี้ท่านรู้สึกเช่นไร โปรดเลือกข้อที่ใกล้เคียงกับความรู้สึกของท่านมากที่สุด ในแต่ละข้อ.....(เลือกเพียงหนึ่งข้อในแต่ละข้อ)

	เห็นด้วย อย่างยิ่ง (1)	เห็นด้วย (2)	ไม่เห็นด้วย (3)	ไม่เห็นด้วย อย่างยิ่ง (4)
38.ฉันคิดว่าฉันไม่สมบูรณ์แบบเพราะฉันเป็นโรคลมชัก				
39.ถ้าฉันสมัครงานพร้อมกับคนอื่นที่ไม่ได้เป็นโรคลมชัก นายจ้างต้องเลือกคนอื่นมากกว่าที่จะเลือกฉัน				
40.ฉันเข้าใจว่าที่เพื่อนต่างเพศไม่ต้องการมีคบฉันเพราะว่าฉันเป็นโรคลมชัก				
41.ฉันไม่โทษคนอื่นที่รู้สึกกลัวฉันเพราะว่าฉันเป็นโรคลมชัก				
42.ฉันไม่โทษคนอื่นที่เขาให้ความสำคัญในความคิดเห็นของฉันน้อยกว่าคนอื่นที่ไม่ได้เป็นโรคลมชัก				
43.ฉันรู้สึกว่าโรคลมชักทำให้ฉันอารมณ์ไม่มั่นคง				

คำถามต่อไปนี้เกี่ยวกับทัศนคติของท่านต่อโรคลมชัก ในช่วง 1 เดือนที่ผ่านมาท่านมีความรู้สึกดังต่อไปนี้บ่อยเพียงใดโปรดเลือกข้อที่ใกล้เคียงกับความรู้สึกของท่านมากที่สุด ในแต่ละข้อ.....(เลือกเพียงหนึ่งข้อในแต่ละข้อ)

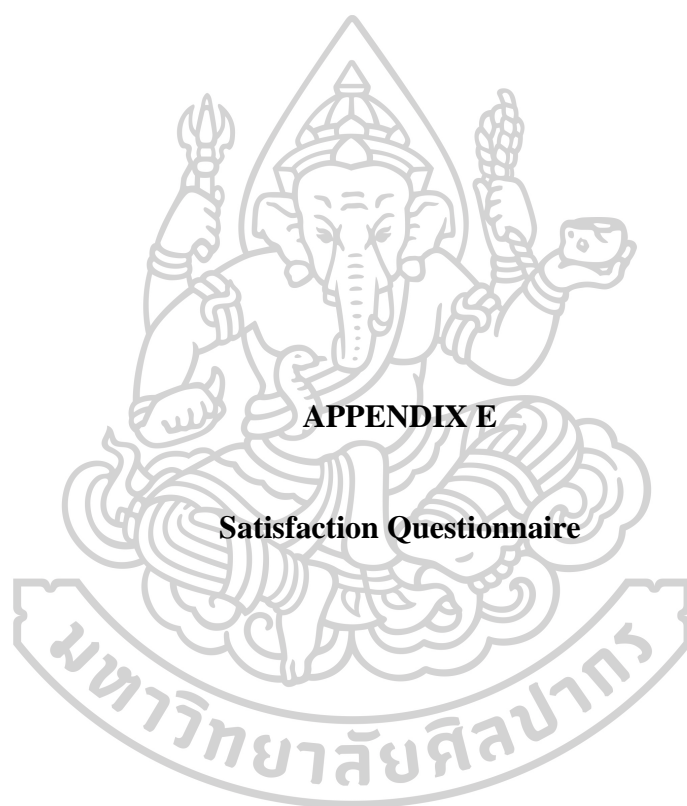
44. การที่ท่านเป็นโรคลมชัก ท่านรู้สึกดี หรือ แย่อย่างไร
 (1) รู้สึกแย่มาก (2) รู้สึกแย่ (3) ไม่แน่ใจ (4) ดีเล็กน้อย (5) ดีมาก
45. ท่านรู้สึกว่ายุติธรรมหรือไม่ที่ท่านเป็นโรคลมชัก
 (1) ไม่ยุติธรรมมาก (2) ไม่ยุติธรรม
 (3) ไม่แน่ใจ (4) ยุติธรรมเล็กน้อย
 (5) ยุติธรรมมาก

46. ท่านมีความสุข หรือ เศร้าอย่างไร ในการที่เป็นโรคลมชัก
 (1) เศร้ามาก (2) เศร้าเล็กน้อย (3) ไม่แน่ใจ (4) มีความสุขเล็กน้อย (5) มีความสุขมาก
47. ท่านจะรู้สึกดี หรือ แย่แค่ไหน ที่ป่วยเป็นโรคลมชัก
 (1) แย่มาก (2) แย่เล็กน้อย (3) ไม่แน่ใจ (4) เล็กน้อยดี (5) ดีมาก
48. ท่านรู้สึก ว่า โรคลมชักเป็นอุปสรรคที่ทำให้ท่านไม่กล้าที่จะเริ่มทำในสิ่งใหม่ ๆ บ่อยแค่ไหน
 (1) บ่อยมาก (2) บ่อย (3) บางครั้ง (4) ไม่บ่อย (5) ไม่มีเลย

ในช่วง 1 เดือนที่ผ่านมา บ่อยแค่ไหนที่ท่าน.....	บ่อยมาก (1)	บ่อย (2)	บางครั้ง (3)	ไม่บ่อย (4)	ไม่มีเลย (5)
ท่านกังวลว่าจะมีอาการชักอีกครั้งหนึ่ง					
ท่านกลัวว่าจะตายจากการชัก					
ท่านกังวลว่าจะได้รับบาดเจ็บระหว่างการชัก					

ขอบคุณที่ตอบแบบสอบถาม

ถ้าท่านมีปัญหาข้อใจ หรือรู้สึกกังวลใจกับการเข้าร่วมโครงการวิจัยนี้ ท่านสามารถติดต่อที่
 ภญ.รวิวรรณ วิทวัสสำราญกุล งานบริการเภสัชกรรมคลินิก สถาบันสุขภาพเด็กแห่งชาติมหาราชินี โทร 086-3601036 ตลอดเวลา



The satisfaction questionnaire for the epilepsy care program for pediatric patients

For medical personnel

“Pediatric Epilepsy Patients Care Program” is an activity consisting of discovery and consultation for drug by a brain clinic pharmacist through various channels such as face-to-face, telephone, providing information via LINE, Facebook, and group visits to find out problems and share experiences between patients, caregivers and medical personnel. The activity “Self-help Epilepsy Kids” which is the group meeting among patients themselves and caregivers for 1-2 times prior to seeing a doctor along the 6-month period of the program as shown in the “New” activity picture diagram.



Explanation : Please tick in the box that best matches to you feeling or opinion related to the participation in the pediatric epilepsy patient care program

General information

1. Gender Female Male
2. Age years
3. You are
 - Doctor Nurse Officer/Assistant to the patient
 - Others, please specify
4. Your task related to “Brain clinic” (Multiple answers)
 - Take a fever, measure weight, measure height
 - Handle with patient’s record before sending to screening nurse
 - Screen and evaluate the patients before sending to doctor
 - Arrange queue and call the patient to the doctor
 - Doctor who give treatment and prescription
 - Make appointment cards and recommend for special medical procedures
 - Counseling before discharging from clinic
 - Record the medical procedure and input patient’s profile to HIS system
 - Member of “Self-help group for Epilepsy Kids”
 - Others, please specify.....

Evaluation for satisfaction on the developed pediatric epilepsy patient care program

What is your opinion towards the “Pediatric Epilepsy Patient Care Program” which has been being operated from 1st August 2018-30th June 2019.

ข้อความ Your opinion towards the pediatric epilepsy care program....	Level of Agreement				
	Most agree	Agree	Fair	Disagree	Most disagree
5. It consume more working time					
6. It increase your work process					
7. It makes the patients and their caregiver have more knowledge about epilepsy					
8. It makes the patients and their caregiver have more knowledge about drug treatment					
9. It help the patients take medicine more regularly					
10. Making the patients know and can handle more for side effect of drugs					
11. Being advantage to you					
12. Being advantage to the patients					
13. I am satisfied with the pediatric epilepsy patient care program					
14. The program should be continued					

15. Suggestion

.....

.....

.....

.....

Thank you for all your comments. The data will be used for developing a better epilepsy care program for pediatric patients.

Satisfaction survey on the developed pediatric epilepsy patient care program

Explanation : Please tick in the box that best matches to you felling or opinion after you have been treated or involve in the pediatric epilepsy patient care program.

General information

1. Gender

- Female Male

2. Age

- More than 10 years - 20 years More than 20 years - 30 years
 More than 30 years - 40 years More than 40 years - 50 years
 More than 50 years - 60 years More than 60 years

3. You are

- Patient
 Caregiver, relationship with the patient:

4. Education

- Elementary school Junior high school High school
 Diploma level Bachelor degree Post-graduated

Evaluation for satisfaction on the developed pediatric epilepsy patient care program

Your opinion towards the pediatric epilepsy care program	Level of agreement				
	Most agree	Agree	Fair	Disagree	Most disagree
5. Contents are appropriate to the epilepsy child care.					
6. The activities in the program is appropriate.					
7. The process is appropriate					
8. Have benefit for taking care of epilepsy child					
9. Can be implemented for epilepsy child care					
10. You are satisfied with the pediatric epilepsy care program					



Channels for getting information or inquiry of pediatric epilepsy child

Explanation : Please tick in the box that best matches to you felling or opinion

11. Have you ever get the information or making inquiry for epilepsy child care via **“Line”**?



- Yes No

12. If **“Yes”** How is your satisfaction on getting information/inquiry via **“Line”**
(1=Least and 5= Most)

			•		
1	2	3	4	5	



13. Have you ever get the information or making inquiry for epilepsy child care via **“Facebook”**?
 Yes No

14. If **“Yes”** How is your satisfaction on getting information/inquiry via **“Facebook”**
(1=Least and 5= Most)

			•		
1	2	3	4	5	



15. Have you ever get the information or making inquiry for epilepsy child care via **“Telephone”**?
 Yes No

16. If **“Yes”** How is your satisfaction on getting information/inquiry via **“Telephone”**
(1=Least and 5= Most)

			•		
1	2	3	4	5	



17. Have you ever get information for epilepsy care from **“Book or other hard copied document”**?
 Yes No

18. If **“Yes”** How is your satisfaction on getting information from **“Book or other hard copied document”**?
(1=Least and 5= Most)

			•		
1	2	3	4	5	



19. Have you ever get the information from inquiry to **“Pharmacist”**?
 Yes No

20. If **“Yes”** How is your satisfaction on making inquiry to **“Pharmacist”**
(1=Least and 5= Most)

			•		
1	2	3	4	5	

21. Have you ever get the information for epilepsy child care from **“Self-help group for Epilepsy Kids”**?
 Yes No

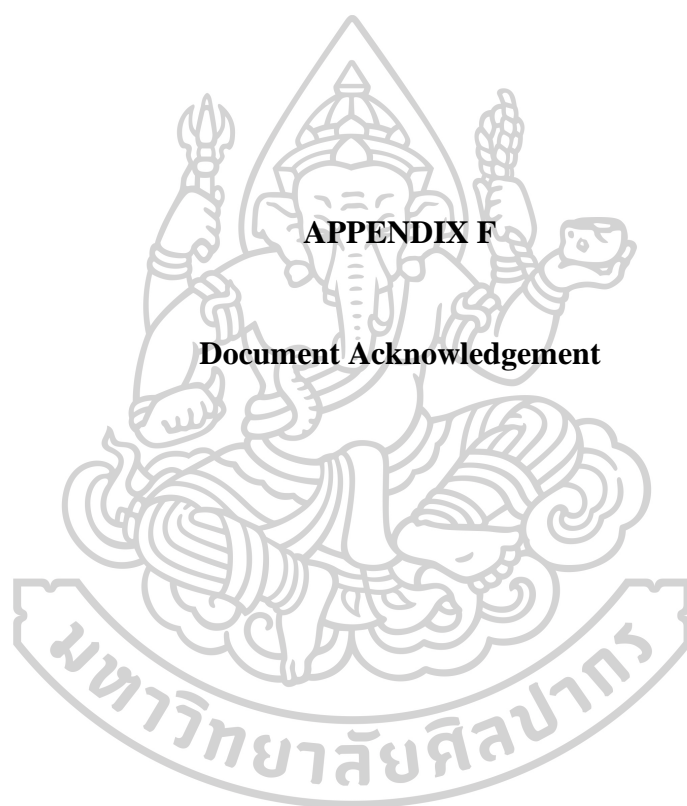
22. If **“Yes”** How is your satisfaction on getting information from **“Self-help group for Epilepsy Kids”**
(1=Least and 5= Most)

			•		
1	2	3	4	5	

23. Suggestion

.....
.....
.....
.....
.....

Thank you for all your comments. The data will be used for developing a better epilepsy care program for pediatric patients.





ภาควิชากุมารเวชศาสตร์
คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี
มหาวิทยาลัยมหิดล

๒๗๐ ถนนพระราม ๖ เขตราชเทวี กรุงเทพฯ ๑๐๕๐๐
โทรศัพท์ ๐ ๒๒๐๑ ๑๔๘๘ โทรสาร ๐ ๒๒๐๑ ๑๘๕๐

ที่ ศธ ๐๕๑๗.๐๖๓/ ๕๔๖๒
วันที่ ๖ ธันวาคม ๒๕๖๑
เรื่อง อนุญาตให้ใช้แบบสอบถาม

เรียน คณะบดี คณะเภสัชศาสตร์

อ้างถึง หนังสือคณะเภสัชศาสตร์ มหาวิทยาลัยศิลปากร ที่ ศธ ๖๘๑๔/๓๑๑๐

ตามหนังสือที่อ้างถึง คณะเภสัชศาสตร์ มหาวิทยาลัยศิลปากร ด้วย นางสาววิวรรณ วิทวัสสำราญกุล นักศึกษาหลักสูตรเภสัชศาสตรดุษฎีบัณฑิต สาขาวิชาเภสัชศาสตร์สังคมและการบริหาร คณะเภสัชศาสตร์ มหาวิทยาลัยศิลปากร ได้รับอนุมัติให้ทำวิทยานิพนธ์ เรื่อง การพัฒนาโปรแกรมการดูแลโรคลมชักสำหรับผู้ป่วยเด็ก โดยมี ภญ.อ.ดร.วารณี บุญช่วยเหลือ เป็นอาจารย์ที่ปรึกษาวิทยานิพนธ์

ในการนี้ คณะวิชา ได้ขอความอนุเคราะห์ให้ นางสาววิวรรณ วิทวัสสำราญกุล ใช้แบบสอบถามชีวิตของผู้ป่วยโรคลมชักกลุ่มวัยรุ่น (QOLIE-AD-๔๘) ฉบับภาษาไทย ตั้งแต่เดือนกรกฎาคม ๒๕๖๑ เป็นต้นไป ตามความละเอียดแจ้งแล้วนั้น

กระผม ศาสตราจารย์ นายแพทย์อนันต์นิตย์ วิสุทธิพันธ์ พิจารณาแล้วไม่ขัดข้อง ยินดีอนุญาตให้ นางสาววิวรรณ วิทวัสสำราญกุล ใช้แบบสอบถามฯ ดังกล่าว

จึงเรียนมาเพื่อทราบ

ขอแสดงความนับถือ

(ศาสตราจารย์ นายแพทย์อนันต์นิตย์ วิสุทธิพันธ์)
หัวหน้าภาควิชากุมารเวชศาสตร์

ที่ ศธ 0514.7.2.19/๐๗๕๖



กลุ่มวิจัยโรคลมชักแบบบูรณาการ
มหาวิทยาลัยขอนแก่น
อ.เมือง จ.ขอนแก่น 40002

๒๒ กุมภาพันธ์ 2561

เรื่อง การตอบรับการขออนุญาตใช้สื่อโรคลมชัก

เรียน คณะบดีคณะเภสัชศาสตร์ มหาวิทยาลัยศิลปากร

ตามที่ นางสาววิวรรณ วิทวัสสำราญกุล นักศึกษาหลักสูตรเภสัชศาสตรดุษฎีบัณฑิต สาขาวิชา
เภสัชศาสตร์ มหาวิทยาลัยศิลปากร ซึ่งทำวิทยานิพนธ์เรื่อง “การพัฒนาโปรแกรมการดูแลโรคลมชักสำหรับผู้ป่วย
เด็ก” ได้ขอความอนุเคราะห์ใช้สื่อการสอนสำหรับผู้ป่วยโรคลมชัก อ้างถึงหนังสือเลขที่ ศธ.๖๕๑๔/๐๐58 นั้น

กลุ่มวิจัยโรคลมชักแบบบูรณาการ มหาวิทยาลัยขอนแก่น มีความยินดีเป็นอย่างยิ่งและอนุญาตให้
นางสาววิวรรณ วิทวัสสำราญกุล นำสื่อการสอนสำหรับผู้ป่วยโรคลมชักของกลุ่มวิจัยโรคลมชักแบบบูรณาการ
มหาวิทยาลัยขอนแก่น ไปใช้เพื่อการพัฒนาโปรแกรมการดูแลโรคลมชักและเพื่อให้เกิดประโยชน์สูงสุดต่อผู้ป่วยเด็ก
โรคลมชักต่อไป

จึงเรียนมาเพื่อทราบ และขอบคุณในการให้ความสนใจในผลงานที่มีประโยชน์

ขอแสดงความนับถือ

รองศาสตราจารย์นายแพทย์ สมศักดิ์ เทียมเก่า

(หัวหน้ากลุ่มวิจัยโรคลมชักแบบบูรณาการ มหาวิทยาลัยขอนแก่น)



คำถามทางบ้าน... Q.1



คำถาม. อายกรู้อะไรเกี่ยวกับโรงเรียนที่ได้เล่นเจ้า/สมาชิกในห้องได้เขียนได้อ่านค่ะ ?

ตอบ : เด็กสามารถเขียนในชั้นเรียนปกติไม่โรงเรียนทั่วไป ที่ภาคธุรกิจและเอกชนได้เยอะ หากดูแลเด็กไหว ไม่มีปัญหาค่าจ้างเรื่องเรียน หรือจะไปเรียนสายอาชีพก็ได้ แต่ถ้าหากเด็กมีปัญหาการเรียน ต้องการโรงเรียนที่มีการจัดการศึกษาแบบเรียนร่วม ให้ได้เล่นกับครูคุณครูการศึกษาพิเศษประจำห้องได้เลย หากไม่มีเรื่องเด็กมีปัญหาการเรียนหรือไม่ จะมาพบคุณหมอเพื่อประเมินก่อนก็ได้ค่ะ



ก้าวที่ยิ่งใหญ่.....สู่เป้าหมาย

การรักสุขภาพของคุณ

- ควบคุมหรือลดความเสี่ยงของการชัก
- ลดอาการข้างเคียงจากโรคซึมเศร้า
- สามารถปฏิบัติตามแผนการรักษาเป็นอย่างดี
- ทำกิจวัตรประจำวันได้ใกล้เคียงคนปกติ มีคุณภาพชีวิตที่ดี

คุณภาพชีวิตสร้างได้ อยู่อย่างเข้าใจและเป็นสุข

- รับประทานยาสม่ำเสมอตามแพทย์สั่ง
- ดูแลสุขภาพร่างกายของตนเองให้ดี โดยเฉพาะเมื่อมีการเริ่มยาใหม่หรือปรับขนาดยา ดังนี้
 - ♦ ความถี่-ความรุนแรงของการชัก
 - ♦ อาการข้างเคียง/การแพ้ยา
- มาพบแพทย์ตามนัด แจ้งความผิดปกติที่พบในช่วงที่ผ่านมาให้แพทย์ทราบ เพื่อปรับการรักษาให้เหมาะสม

โรคซึมเศร้าเป็นโรคที่พบบ่อยในการรักษาเด็ก หากเพียงแต่ทำการยากันชักอย่างเดียว ไม่ปรับเปลี่ยนพฤติกรรมที่เหมาะสม และปฏิบัติตามคำแนะนำของแพทย์

เด็กและวัยรุ่น กลุ่มเป้าหมายเด็กสมาธิสั้น

5 เรื่องต้องรู้

เมื่อทานยากันชัก

- 1 รู้จักชื่อยาที่กิน** ควรบอกชื่อยาที่กินกับแพทย์หรือเภสัชกร ทุกที่เวลาที่เราไปตรวจรักษาหรือรับยา เพราะจะช่วยเพิ่มความปลอดภัยและประสิทธิภาพ
- 2 รู้จักวิธีกินยา** และกินยาถูกต้องตามแพทย์สั่ง หากมีบ้านยาหรือยาเขียนหลังจากกินไปนานกว่า 15 นาที ไม่ต้องทานยาซ้ำ ถ้ามีคบางบดห้ามบดเคี้ยวเพราะทำให้ยาเสียสภาพ
- 3 รู้เวลากินยา** ยาที่กินควรทานตามเวลาที่กำหนด รับประทานวันละ 2 ครั้ง ควรห่างกัน 12 ชั่วโมง หรือรับประทานวันละ 3 ครั้ง ควรทานเช้า ป้าย ก่อนนอน เวลาเดิมๆ และไม่ควรกินยาใกล้นม ยาลดกรด หรือน้ำอัดลม
- 4 รู้จักสังเกตอาการผิดปกติที่เกิดขึ้นกับตัวเอง** ในช่วงเริ่มยาที่กินควรสังเกตอาการหน้า ได้แก่ ผื่น ไข้ คอแดง เน่าจะร่วงนาน 1-3 สัปดาห์หลังเริ่มยา อาการง่วงซึมเป็นอาการข้างเคียงปกติของยากันชัก
- 5 รู้วิธีดูแลสุขภาพ** ผู้ป่วยควรตรวจหาค่าตับไตที่ห้องหมอ ไม่ควรดื่มเครื่องดื่มแอลกอฮอล์หรือใช้ยาอื่นหากมีอาการแพ้ยาหรือแพ้ยาอื่น การรับประทานยา การทำงานใกล้เครื่องจักรใหญ่ ว่ายน้ำ หรือปั่นกีฬา หากยังรักษาไม่อยู่

กลุ่มเพื่อนเด็กลมชัก (Epilepsy Kids Club)

LINE@ Facebook

VITA

NAME Raviwan Wittawassamrankul

DATE OF BIRTH 24 August 2975

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