CHAPTER 1

INTRODUCTION

Background and Significance of the Research Problem

Epilepsy is a chronic brain disorder characterized by recurrent unprovoked seizures. It is a common neurological disorder in adolescents. The incidence and prevalence in adolescents reported from several countries has shown variation. In the United States, England, and Canada, the incidence in adolescents ranged from 20-48 cases/100,000 adolescents per year (Annegers, Dubinsky, Coan, Newmark, & Roht, 1999; Camfield, Camfield, Gordon, Wirrell, & Dooley, 1996; Kurt, Tookey, & Ross, 1998). The prevalence in adolescents in England, Spain and Lithuania was 4.3-6.3 cases/1,000 adolescents (Endziniene, Pauza, & Miseviciene, 1997; Kurtz et al., 1998; Luengo et al., 2001). In Asia, the prevalence in adolescents in Singapore, India, and Pakistan ranged from 4.9-9.87 cases/1,000 adolescents (Aziz, Güvener, Akhtar, & Hasan, 1997; Kun, Ling, Wah, & Lian, 1999; Radhakrishnan et al., 2000; Sridharan & Murthy, 1999).

In Thailand, a study of incidence and prevalence of epilepsy among adolescents is limited. According to an epidemiology survey of mental disorders in Thailand, the prevalence of epilepsy among Thais 15-60 years old in Bangkok was 13 cases/1,000 persons (Thavichachart et al., 2001), and in the whole country was 7 cases/1,000 persons (Bunditchat, 1999). Similar to the above findings, the prevalence of epilepsy among all ages in small rural area of Nakorn Rachasrima province was 7.2 cases/ 1,000 persons (Asawavichienjinda, Sitthi-Amorn, Tanyanont, 2002).

Epilepsy is a chronic illness that causes enormous problems among adolescents, including disruption of daily activities, behavioral problems, psychosocial problems, decreasing cognitive function, and injuries. Seizures interrupt adolescents' activities such as eating, studying, working, and playing sports. These make the patients unable to perform normal daily activities. Adolescents with epilepsy experience behavioral problems more than those who are healthy or have other chronic illnesses (Austin, Huster, Dunn, & Risinger, 1996; Austin, Smith, Risinger, & McNeis, 1994; Carlton-Ford, Miller, Brown, Nealeigh, & Jennings, 1995; Devinsky et al., 1999; McDermott, Mani, & Krishnaswami, 1995). Psychosocial disturbance commonly occur in adolescents with epilepsy, including depression, anxiety, poor-quality sleep, low self-esteem, and uncertainty about seizures (Carlton-Ford, Miller, Brown, Nealeigh, Jennings, 1995; Dunn, Austin, & Huster, 1991; Ettinger et al., 1998; Hore & Mann, 1994; Long & Moore, 1979; Zeigler, Erba, Holden, & Dennison, 2000). Moreover, psychosis can also be found among these adolescents. A study found that persons with epilepsy have a 10% chance of developing interictal psychoses (schizophrenia-like psychosis) whereas in the general population, the figure is around only 0.8% (Lindsay, Ounstead, Richards, 1979, as cited in Torta & Keller, 1999). In addition, epilepsy has been found to decrease cognitive function (O'Donoghue & Sander, 1997). Mental retardation and cerebral palsy are related to high risk of epilepsy (Mitchell & Neintein, 1996). Adolescents with epilepsy may sustain injuries during seizure attacks. Up to 38% of persons with epilepsy have reported trauma results from seizures such as blunt injury, laceration, fractures, dislocations and burns (Neufeld, Vishne, Chistik, & Korczyn, 1994, as cited in Ficker, 2000). Further more, some adolescents may die from accidents and sudden unexpected death from epilepsy. Several studies found that the mortality rate in persons with epilepsy increases two or three times compared with that in the general population (Bowley & Kerr, 2000; Ficker, 2000, O'Donoghue & Sander, 1997).

Besides having impacts on adolescents, epilepsy causes psychosocial difficulties for all family members. Family members often experience stigmatization, stress, poor self-esteem, depression, anger, guilt, and frustration (Austin, 1988; Ellis, Upton & Thompson, 2000; Thomas & Bindu, 1999; Ziegler et al., 2000).

Epilepsy also affects Thai national economics directly and indirectly. Costs of epilepsy, which include direct costs and indirect costs, are high. Direct costs are the cost of diagnostic procedures, medications, hospitalization, monitoring blood level of antiepileptic drugs, and surgery. Indirect costs are the results of disabilities, such as loss of employment, loss in household activities, transportation cost, and cost of the family caregiver's time devoted to the care of the persons with epilepsy. In the United States, the total annual costs were 12.5 billion dollars with the indirect cost accounting for 86% of the total (Begley et al., 2000). Although the cost of epilepsy in Thailand has not been reported, the economic burden of epilepsy in Thailand may resemble those in the United States in terms of high indirect costs. In addition, with the advance of new antiepileptic drugs, surgery techniques and investigative procedures, the direct cost of epilepsy has also increased. The increasing direct cost and the high indirect cost of epilepsy are economic burdens which add additional strain to the economic problems of Thailand.

The impacts of epilepsy can be reduced if seizures are controlled. Successful seizure control needs not only good medical regimens and effective antiepileptic drugs, but also individual self-care behaviors, such as regular taking of antiepileptic drugs in adequate doses over prolonged period of time, observing side effects of antiepileptic drugs, avoiding factors triggering seizures, preventing injury during epilepsy attacks, and managing their own life style.

Lack of self-care behavior for epilepsy control can lead to treatment failure. Research has shown that missing or altering anti-epileptic drug dosages can cause adverse drug reactions and increase the risk of seizure recurrence (Buck, Jacoby, Baker, & Chadwick, 1997). One study found that adolescents who did not comply with epilepsy regimen had more seizures than those who complied (Neufeld, Sadeh, & Cohn, 1994).

Therefore, the adolescents with epilepsy should perform self-care behavior to control the inevitable attacks of epilepsy. However, neglect of self-care behaviors were commonly found among adolescents with epilepsy. Failure to comply with anti-epileptic drug therapy is common among young people (McMenamin & O’Connor Bird, 1993). One study found that adolescents were significantly more likely to be non-compliant with their drug regimen than other age groups, and one of the most powerful predictors of missing antiepileptic drugs was being a teenager (Buck et al., 1997). Moreover, only 20 % of the adolescents complied fully with their epilepsy regimens, 18 % tried to follow the instructions concerning a regular life style (e.g., regular bed times, regular schedule for medication intake, etc.), and 32% of them had home-monitoring, such as keeping a diary of seizures (Kyngäs, 2000).

Nurses in the health care team can play an important role in facilitating or promoting adolescents' self-care behavior. Before intervention in any form can be provided, factors affecting the self-care behavior of adolescents with epilepsy should be thoroughly explored.

According to Orem's self-care deficit nursing theory, self-care behavior is affected by self-care agency and basic conditioning factors (Orem, 2001). Self-care agency is human capabilities to engage in self-care behavior. Knowledge is a part of self-care agency which is essential for self-care behavior. Knowledge will encourage individuals to understand and learn about the diseases and treatment, and to be able to choose the self-care behavior. Several studies in patients with chronic diseases found that knowledge related to self-care behavior (Chantapet, 1993; Duang-pang, 1988; Watanasin, 1991). Basic conditioning factors are the internal and external factors of individuals that affect self-care behavior (Orem, 2001). Age, income, family support and peer support are the basic conditioning factors which were found to have relationship with self-care behavior among persons with epilepsy (Dilorio, Faherty, & Manteuffel, 1992; Dilorio, Faherty, & Manteuffel, 1994; Kyngäs, 2000; Maskasame, 1985).

In addition, Bandura's self-efficacy theory proposes that self-efficacy is the belief in one's ability to perform actions, and persons will do the action if they perceive self-efficacy (Bendura, 1997). Therefore, self-efficacy is one of variables that affect self-care behavior. The studies in adults with epilepsy showed that self-efficacy influences self-care behavior (Dilorio et al., 1992; Dilorio et al., 1994).

Although many studies supported the relationship between age, family income, family support, peer support, epilepsy self-efficacy, knowledge, and self-care behavior (Chantapet, 1993; Dilorio et al., 1992; Dilorio et al., 1994; Duang-pang, 1998; Kyngäs, 2000; Watanasin, 1991; Maskasame, 1985) these studies have limited generalization to Thai adolescents with epilepsy because several studies were conducted in adults. The adults' decision making to engage in self-care behavior might differ from that of adolescents because the developmental state, knowledge, and life experience are different. In addition, some studies were conducted in adolescents in Western country, which are different in culture, context and family system from Thai society. No evidence supports whether factors affecting self-care behavior among the Western adolescents with epilepsy are generalized to Thai adolescents with epilepsy.

Furthermore, all of the previous studies did not intend to examine direct effects and indirect effects of predictors on self-care behavior. Little is known about the magnitude of effects and the how the factors work to affect self-care behavior. As a result, appropriate intervention promoting self-care behavior cannot be designed to maintain its effects on outcome.

This study, therefore, developed a causal model of self-care behavior for adolescents with epilepsy based on the self-care deficit nursing theory, the self-efficacy theory, and previous studies. In the proposed model, age, family income, family support, peer support, epilepsy knowledge, and epilepsy self-efficacy were predictor variables while self-care behavior was an outcome variable. The causal relationship between variables in the model were investigated.

It can be anticipated that this model would enhance the understanding of factors affecting self-care behavior of adolescents with epilepsy and illuminate how these factors influence self-care behavior. The findings would serve as an important knowledge for research development and guiding interventions to promote self-care behavior among Thai adolescents with epilepsy.

Objectives of the Study

The purpose of this study was to determine the causal relationship among age, family income, family support, peer support, epilepsy knowledge, epilepsy self-efficacy, and self-care behavior in adolescent with epilepsy.

Research Questions

1. How much of the variability in self-care behavior can be explained by age, family income, family support, peer support, epilepsy knowledge, epilepsy self-efficacy and self-care behavior?

2. How do age, family income, family support, peer support, knowledge and self-efficacy affect self-care behavior in adolescent with epilepsy?

3. For possible causal relationships between dependent variables and independent variables in the proposed model of self-care behavior for adolescents with epilepsy, what are the magnitudes of the effects?

Hypotheses

Hypothesis 1: Age has a positive direct effect on epilepsy knowledge.

Hypothesis 2: Age has a positive direct effect on epilepsy self-efficacy.

Hypothesis 3: Age has a positive direct effect on self-care behavior of adolescents with epilepsy.

Hypothesis 4: Family income has a positive direct effect on epilepsy knowledge.

Hypothesis 5: Family income has a positive direct effect on self-care behavior of adolescents with epilepsy.

Hypothesis 6: Family support has a positive direct effect on epilepsy knowledge.

Hypothesis 7: Family support has a positive direct effect on epilepsy self-efficacy.

Hypothesis 8: Peer support has a positive direct effect on epilepsy self-efficacy.

Hypothesis 9: Family support has a positive direct effect on self-care behavior of adolescents with epilepsy.

Hypothesis 10: Peer support has a positive direct effect on self-care behavior of adolescents with epilepsy.

Hypothesis 11: Epilepsy knowledge has a positive direct effect on epilepsy self-efficacy.

Hypothesis 12: Epilepsy knowledge has a positive direct effect on self-care behavior of adolescents with epilepsy.

Hypothesis 13: Epilepsy self-efficacy has a positive direct effect on self-care behavior of adolescent with epilepsy.

Scope of the Study

This study employed a cross-sectional, correlational research design to develop and test the causal model of self-care behavior among adolescents with epilepsy, aged 14-21 years, who attended the outpatient departments of Ramathibodi Hospital, Prasat Neurological Institute, Phramongkutklao Hospital, and King Chulalongkorn Memorial Hospital for at least one year.

Definition of Terms

Adolescents with epilepsy are adolescents aged 14-21 years who has been diagnosed with epilepsy and received antiepileptic drugs for at least one year.

Self-care behavior is deliberate activities that adolescents with epilepsy perform by themselves including complying with medical regimens and attending side-effects of antiepileptic drugs, seeking information and medical assistance, preventing injury due to seizures, avoiding precipitating factors, and promoting normal life. Self-care behavior was measured by the Epilepsy Self-Care Scale which was developed by the researcher based on the self-care deficit nursing theory.

Epilepsy knowledge is epileptic adolescents' perception of information about general knowledge of epilepsy, antiepileptic drugs and side effects, precipitating factors, and safety. It was measured by the Epilepsy Knowledge Scale which was developed by the researcher.

Epilepsy self-efficacy is the belief of adolescents with epilepsy in their ability to perform the tasks and behaviors associated with the daily management of epilepsy. Epilepsy self-efficacy was measured by the Epilepsy Self-Efficacy Scale which was developed by Caplin, Austin, and Dunn (2002).

Family support is epileptic adolescents' perception of the provision of assistance given by family members in various categories, including five aspects of adaptation, partnership, growth, affection, and resolve/commitment (Smilkstein, 1987). Family support was measured using the Family APGAR Questionnaire developed by Smilkstein, Ashworth, and Motano (1982).

Peer support is epileptic adolescents' perception of the provision of assistance given by friends in various categories, including five aspects of adaptation, partnership, growth, affection, and resolve/commitment (Smilkstein, 1978). Peer supported was measured using the Friend APGAR Questionnaire developed by Smilkstein, Ashworth, and Motano (1982).

Assumptions

1. Adolescents with epilepsy are active and capable of performing self-care behavior.

2. Adolescents with epilepsy act deliberately in performing self-care behavior.