CHAPTER 1

INTRODUCTION

Background and significance of the research problem

Epilepsy is a chronic seizure, which is a sudden, involuntary, time-limited alteration in function occurring as the result of an abnormal discharge of neurons in the central nervous system (Holmes, 1987). It is a common neurological condition, which is most often diagnosed in childhood (Holmes, 1987). Worldwide, the incidence of epilepsy is 49 cases per 100,000 populations (May, 1990), and approximately 10 out of 100,000 children are recognized as epileptic (Long & McAuley, 1996). Available statistical data indicates that the prevalence rate of epilepsy in children ranges from 1.5-121/1,000 (Eriksson & Koivikko, 1997). However, the authors of this study do not state the source of data. In the United States there is 1% of the population affected by epilepsy (Long & McAuley, 1996), but the prevalence rate for children was not available in this study. Many surveys conducted in Asia have shown very different numbers on prevalence rates of epilepsy: 9.99/1,000 for Pakistan, 4.4/1,000 for China, and 1.5/1,000 for Japan (Jallon, 1997). Jarvie (1997) stated that in the last ten years, the incidence rate of epilepsy is increasing.

The incidence of epilepsy in the People's Republic of China (PRC) is one of the highest in the world (Cheng et al., 1995). In addition to the prevalence rate of epilepsy indicated by Jarvie (1997), the 1990 PRC National Epilepsy Study reported that the prevalence rate was more than 4-6/1,000 in China (Wang, 1996). However, such a rate included both adults and children. Xi'an City is the biggest central city of northwest China with a resident population of more than 7 million (Census of Resident Population in Xi'an, 1996). In northwest China the prevalence rate of epilepsy is 5-7/1,000. Thus, there is approximately 36,000 people with epilepsy in Xi'an. However, the prevalence rate for children with epilepsy is unavailable (Xi,an Hospital Annual Record, 1997). In addition everyone with epilepsy who lives in the entire northwest of China comes to Xi'an hospitals. Even though the number of children with epileptic in Xi'an City cannot be estimated, the record of the Second Teaching Hospital of Xi'an Medical University showed that there were approximately 3,000 epileptic children admitted to the inpatient unit annually (Xi,an Hospital Annual Record, 1997). In urban areas of Xi'an City are the Second Teaching Hospital of Xi'an Medical University and the Children's Hospital in Xi'an. These two hospitals provide similar health services and most of the people in Xi'an City prefer to go to these hospitals.

Epilepsy is a recurrent illness characterized by at least two seizures, one seizure does not constitute a

diagnosis of epilepsy (Long & MuAuley, 1996). Thus, seizures and epilepsy are interchangeable. According to Gastaut's revised classification of epilepsy, there are two types of seizures, partial and generalized seizures (Gastaut, 1969 cited in Long & McAuley, 1996). Partial seizures include simple partial, complex partial, and secondary generalized seizures. Generalized seizures include generalized tonic-clonic (grand mal), absence, myoclonic and atonic. The generalized tonic-clonic seizures, traditionally known as grand mal, are the most common and most dramatic of all seizure manifestations of childhood (Jarvie, 1997).

The impact of epilepsy on children includes the aspects of intelligence, emotional development, and conduct (Bakwin & Bakwin, 1974). Regarding the impact of epilepsy on intelligence or cognitive development of the child, the most frequent mental disturbance associated with epilepsy was found to be intellectual inadequacy (Dulac, Bulteau, Pedersen, & Uldall, 1997; James, 1996; Lennox, 1971 cited in Bakwin & Bakwin, 1974). Epileptic children did less well academically than normal children (Wei-ling & Rajan, 1997).

With respect to the impact of epilepsy on behavior disorders of the child, almost half of the children with epilepsy had conduct disorders of various degrees (Sullivan & Gahagan, 1971 cited in Bakwin & Bakwin, 1974; Wei-Ling & Rajan, 1997). Bakwin and Bakwin (1974) found that most of the epileptic children were hyperkinetic, antisocial, cruel, stubborn and destructive. Their disorders took the form of

rage, temper tantrums, lying, stealing, nail biting, and speech difficulties (Bakwin, & Bakwin, 1974).

As for the impact of epilepsy on the emotional development of the child, it has long been recognized that children with epilepsy have an increased incidence of emotional problems (Austin, Risinger, & McNelis, 1991; Bakwin & Bakwin, 1974). They may suffer alienation, depression, loneliness, and fear (Isaace & McElroy, 1980; Rose, 1987; Turner-henson, 1994).

In addition to emotional problems, children with epilepsy may have psychosocial problems. Epilepsy has always been considered taboo, causing prejudice and rejection. Sometimes children with epilepsy feel inferior and experience difficulties in their social environment (Somoza, Forlenza, Brusino, & Licciardi, 1993). When seizures are controlled, psychological problems may persist (Kaufman, 1993). The effect on children's health caused by worrying about the problems mentioned above is more serious than the effect caused by seizures of the disease itself (Wang, 1996).

School-age children, who represent a significant proportion of the population, are the primary group to be prepared for the future (Dumas & Pelletier, 1999). School-age children between 8 to 12 years old not only make discrete judgments about their competence in difference domains, but they have also constructed a view of their general self-worth as a person (Harter, 1985).

School-age children have a variety of experiences in school. They develop relationships with peers and with teachers and they also become exposed to social events such as games and sports (Dumas & Pelletier, 1999). School-age children are more aware of differences in perspectives among people, social norms and moral imperatives (Whaley & Wong, 1995). They are sensitive to social pressures and become preoccupied with issues of self-criticism and self-evaluation. Because school-age children depend on adults for material and emotional resources, their self-concept is likely to be most vulnerable during this time (Whaley & Wong, 1997). Self-concept is how an individual describes himself or herself (Willoughby, King, & Polatajko, 1996 cited in Whaley & Wong, 1998), in which Harter (1985) called self-perception.

Harter (1985) noted that self-perception involves six components: scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth. Positive self-perception derives from strong relationships, feeling of recognition from others, succeeding in academic events, participating in games and sports, and having a good sense of self-control.

Among school-age children all aspects of self-perception are important (Harter, 1985; L'Ecuyer, 1990). Mental health promotion and the prevention of mental illness involves efforts to help develop healthy self-perception

among school-age children (Gast, 1992; Grizenko & Fisher, 1992).

School-age children with epilepsy frequently have behavior disturbances, do poorly academically and socially (Austin, Huster, Dunn, & Huberty, 1997; Baker, 1993; Bourgeios, 1998; Jones & Christine, 1993; Mitchell, Scherer, & Baker, 1993). A study showed that school-age children with epilepsy were psychologically maladjusted, reflecting a less than favorable social environment at school (Danesi, 1993). The pressure from psychosocial problems can result in recurrent seizures as well as seriously influence the school-age children's life in a very negative manner (Kaufman, 1993).

Self-perception is a concept that changes in every stage of life and is influenced by every aspect of our lives (L'Ecuyer, 1990 cited in Dumas & Pelletier, 1999). Studies on self-perception of chronically ill children show that there are some factors related to self-perception and its components of school-age children (Harter, 1985; Holden, et al, 1997). Self-perception may change with age (L'Ecuyer, 1990 cited in Dumas & Pelletier, 1999). Sex and school grade can also influence the self-perception of school-age children. With the grade level increase, the scholastic and global self-worth decreases (Harter, 1985). A study indicated that girls had more behavioral problems than boys (Austin, Risinger, & McNelis, 1991). Important others are contributors to children's self-worth (Harter, 1985). For

those children whose first diagnosis is around their preschool and school age, the longer the duration of illness the lower self-concept they have (Turner-Henson, 1994). Discrimination of children with chronic illness was reported of children with activity-limiting problems (Turner-Henson, 1994).

Epilepsy affects self-perception of school-age children in a variety of ways. School-age children with epilepsy may be at risk by absenteeism (Zhang, 1997). They cannot catch up with their studies, so they may view themselves as not being good at schoolwork. These children frequently do poorly socially (Mitchell, Scherer, & Baker, 1993), do not have good friends and are not liked (Hickey, 1992). School-age children with epilepsy who are afraid of the onset of seizures may not go outside to play with other children, and do not feel good playing sports (Cramer, 1993; Wang, 1996). School-age children affected by epilepsy are not happy with the way they look and they may face significant feelings of physical negativity about themselves (Markwick & Sage, 1997) and may have behavior achievement deficits (Turk, 1993). Long-term experience of epilepsy may make school-age children feel shame, and unhappy with themselves (Wang, 1996).

The threat posed by epilepsy on school-age children, raises questions about the self-perception of these children on what and how they feel and describe themselves, what personal factors influence their self-perception, and its

components. Only one study was found related to the present study. Henley, (1997) found that the diagnosis of epilepsy, the presence of seizures, and seizure related effects profoundly influenced how children saw themselves. The author further stated that ideas of incompetence and disability then undermined school performance and socialization of these children. No studies regarding self-perception of school-age children with epilepsy have been found in China. Therefore, it is important to conduct a study regarding self-perception of epileptic children in this country. Better understanding of self-perception among school-age children aged 8-12 years with epilepsy and personal factors influencing self-perception of these children would facilitate nurses to plan for appropriate care and support for the children and their families.

Objectives of the study

1. To describe the self-perception of school-age children with epilepsy.

2. To describe the relationship between self-perception of school-age children with epilepsy and personal factors including age, gender, education level, frequency of seizures and duration of illness.

Research questions

1. What is the level of self-perception of school-age children with epilepsy?

2. Is there a relationship between self-perception of school-age children with epilepsy and personal factors including age, gender, education level, frequency of seizures, and duration of illness?

Hypothesis

There is a relationship between the self-perception of school-age children with epilepsy and personal factors including age, sex, education level, frequency of seizures, and duration of illness.

Scope of the study

The research was conducted on school-age children with epilepsy in the Second Teaching Hospital of Xi'an Medical University and the Children's Hospital in Xi'an, from November 1999 to January 2000.

Definition of terms

Self-perception refers to the way one feels about and describes oneself. It can be measured by Harter's Self-perception Profile for Children, which involves six components (1) scholastic competence, (2) social acceptance, (3) athletic competence, (4) physical appearance, (5) behavioral conduct, and (6) global self-worth (Harter, 1985).

School-age Children refers to boys and girls aged between 8 to 12 years.

Epilepsy generalized tonic-clonic seizure (grand mal).