# CHAPTER 2

## LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

### Literature review

In this chapter, a review of related literature was divided into four parts:

1. Epilepsy in children,
   - Epilepsy
   - Impact of epilepsy on children
2. School-age children with epilepsy,
3. Self-perception of school-age children,
   - Factors affecting self-perception of children
   - Measurement of self-perception of school-age children
4. Self-perception of school-age children with epilepsy.

### Epilepsy in children

#### Epilepsy

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). Epilepsy is defined as a randomly recurring symptom complex resulting from an episodic disturbance of central nervous system function, associated with an excessive, self-limited, neurona

discharge (Oski, DeAngelis, Feigin, & Warshaw, 1990). Epilepsy is recurrent seizures unrelated to fever or an acute cerebral insult (Nelson, Behrman, Kliegman, & Arvin, 1996). Epilepsy is seizures that occur when there is an imbalance in the electrical activity of the brain (Turner, 1999). The seizures may occur one at a time, or they may occur one after another with little of recovery in between. Any pattern of recurrent seizures can be called epilepsy (Oski, Deangelis, Feigin, & Warshaw, 1990).

In 1981, the international classification of epilepsy classified epilepsy into two types, partial seizures (simple partial, complex partial) and generalized seizures (generalized tonic-clonic, absence, myoclonic and atonic). There are two types of Gastaut's revised classifications of epilepsy, partial and generalized seizures. Partial seizure includes simple partial, complex partial, and secondary generalized seizures. Generalized seizure includes generalized tonic-clonic (grand mal), absence, myoclonic and atonic (Gastaut, 1969 cited in Long & McAuley, 1996).

Generalized tonic-clonic seizures, traditionally known as grand mal, are the most common and dramatic of all seizure manifestations of childhood (Jarvie, 1997). An abrupt arrest of activity and an immediate loss of consciousness clinically characterizes a generalized tonic-clonic seizure. The tonic phase of the grand mal consists of sustained and generalized contractions of flexor or extensor muscles. Usually the tonic phase lasts only a few seconds.

The clonic phase, which is characterized by symmetrical, rhythmic, clonic activity consisting of alternating contraction and relaxation of major appendicular or axial muscle groups (Oski, DeAngelis, Feigin, & Warshaw, 1990).

Children whose seizures begin before the ages of 4 years have more frequent mental retardation, behavioral and learning problems than those whose seizures begin after the age of 4. The younger the age of onset, the greater is the likelihood that the etiology of the disorder will be identified (Holmes, 1987).

The epilepsy foundation of America believes as many as one in 10 children have epilepsy (Snively, Counsell, & McAuley, 1996). Available statistical data indicated that the prevalence rate of epilepsy in children ranged from 1.5-121/1,000 (Eriksson & Koivikko, 1997).

**Management of epilepsy**

Therapeutic management of epilepsy includes anticonvulsant drugs, education of family and child, and attention to associate emotional or learning disabilities (Winkelman, 1999). The goal of drug therapy is to control the seizures with as few drug side effects as possible. The major anticonvulsant drugs used in general tonic-clonic epilepsy are phenobarbital, phenytoin, carbamaxepine and valproic acid (Winkelman, 1999). Drug treatment typically begins with one anticonvulsant agent, with the dosage increased gradually until seizures are controlled. If the first drug proves ineffective, a second drug is added or

another drug will be tried. During this process, it is essential that the children and family should be aware of the need to report changes in sensation and behavior that may signal a toxic reaction, and the importance of close follow up care. Anticonvulsant therapy is actually continued until the children have been seizure free for 2 or 3 years (Homles, 1987).

Long and McAuley (1996) mentioned that for patient education, patients and family members should be instructed to attempt to reduce factors that exacerbate seizure activity such as physical/psychological stress (including constipation, diarrhea), lack of sleep, flashing lights, hypoglycemia, and noncompliance with antiepileptic drug therapy. Education also focuses on informing family members of what to do and how to protect a patient during an epileptic event (lay patient on their side, not place anything in the patient's mouth). Maintaining a seizure calendar is also very important for patients and family members. Parents, teachers and caregivers must pay attention to associate emotional or learning disabilities for monitoring side effects of antiepileptic drugs and the effects of epilepsy (Oski, DeAngelis, Feigin, & Warshaw, 1990).

**Impact of epilepsy on children**

According to Bakwin and Bakwin (1974), the impact of epilepsy on children is identified in three aspects. Firstly, the impact on intelligence. The view is widely held

that the intellect tends to deteriorate with epilepsy and the majority of epileptics are mentally retarded (Bakwin & Bakwin, 1974; Dulac, Bulteau, Pedersen, & Uldall, 1997; Oski, DeAngelis, Feigin, & Warshaw, 1990). The most frequent mental disturbance associated with epilepsy is intellectual inadequacy (Lennox, 1971, cited in Bakwin & Bakwin, 1974). Deterioration has also been attributed to the repeated anoxia and increased intracranial pressure that accompany recurrent convulsions, cerebral dysrhythmia, the periods of amnesia or the manic episodes of a psychomotor seizure are considered to be factors in 20 percent of defectiveness. Lennox also found that 14% of epileptic children were definitely mentally retarded, and another 22% were slightly subnormal. James (1996) mentioned that epilepsy had a higher prevalence in children with an IQ below 50 and affected approximately 50% of children with disabilities who also had cerebral palsy.

Secondly, epilepsy may have impact on children's emotional development. Many children with chronic conditions have been found to have concomitant emotional problems. Research suggests that the incidence of emotional problems is especially high for children with epilepsy (Austin, Rising, & McNelis, 1991; Bridge, 1972 cited in Bakwin & Bakwin, 1974). Children with epilepsy may suffer alienation, depression, loneliness, and fear (Isaace & McElroy, 1980; Rose, 1987; Turner-henson, 1994). The pronounced influences like emotional disturbances may have on the course of the seizures (Bridge, 1972 cited in Bakwin

& Bakwin, 1974). Emotional difficulties in the epileptic child arise as a result of awareness that he/she is different from his/her peers and of the need to adjust hopes and ambitions to the limitations set by the disease (Bakwin & Bakwin, 1974). Long-term experience of epilepsy may make the child feel shame (Wang, 1996).

Thirdly, almost half of the children with epilepsy have conduct disorders of various degrees (Sullivan & Gahagan, 1971 cited in Bakwin & Bakwin, 1974). A survey found out that 36% of children with epilepsy limited their activity because of epilepsy (Wei-ling & Rajan, 1997). These authors also mentioned that most of the children with epilepsy were hyperkinetic, antisocial, cruel, stubborn and destructive. These disorders took the form of rage, temper tantrums, lying, stealing, nail biting, and speech difficulties. Isolation from normal and stimulating contacts, fear, shame, and discouragement may lead to a stagnation of thought and action that closely resembles deterioration (Bakwin & Bakwin, 1974).

Antiepileptic drugs have been reported to have a variety of adverse effects on behavior, performance and mental function in children (Engel, 1989; Mandelbaum, Burack, & Daswani, 1993). A study showed an increasing of attention-seeking, aggressive and demanding behavior when antiepileptic drug polypharmacy was present (Espie, Gillies & Montgomery, 1990).

In summary, epilepsy is a randomly recurring symptom complex resulting from an episodic disturbance of central

nervous system function, associated with an excessive, self-limited neuronal discharge (Oski, DeAngelis, Feigin, & Warshaw, 1990). It is a common neurological condition most often diagnosed in childhood. The management of epilepsy includes the use of anticonvulsant drugs, education and counseling parents. Studies indicated that epilepsy affected children in a variety of ways including their intelligence aspect, emotional development and conduct or behavior disorder.

**School-age children with epilepsy**

According to Piaget 1961, school-age children between 6 to 12 years old are dominated by concrete operations (Piaget, 1961 cited in Shaffer, 1985). Operation means that the school age children can think logically and systematically, which was impossible in previous developmental stages. Concrete means that the thinking must be based on concrete informational input, they cannot think abstractly like adolescents. Thus, the school age children have competent cognition, but not in full blossom. Children aged 8 and older cannot only make discrete judgments about their competence in different domains, but they have also constructed a view of their general self-worth as a person (Harter, 1985).

School-age children are in a period of industry versus inferiority (Erickson, 1963). To establish their industry, not only do they struggle for independence and productivity, but also accomplish the mission to go to

school, master important social and academic skills, establish relationships with peers, compare self with peers and find social acceptance. School-age children are characterized by the development of new interests and involvement in activities. The children take pride in accomplishments in sports, school, home, and community. If the children cannot accomplish what is expected, the result will be a sense of inferiority (Erikson, 1963).

For school-age children, a sense of accomplishment involves the ability to cooperate and to compete with others and to cope more effectively with people (Whaley & Wong, 1995). Peer relationships serve many socializing functions and greatly influence the development of self-concept (Matthiesen, 1994). The psychosocial development of school-age children involves two factors, development of a sense of industry and advancement of self-concept through successful achievements (Erikson, 1963). Positive self-concept develops when children are curious about the environment, display appropriate levels of anxiety according to the task, and experience independent behaviors (Matthiesen, 1994).

The impact of seizures can be devastating on the development of school-age children (Henley, 1997). School-age children with epilepsy frequently do poorly academically and socially (Bourgeois, 1998; Mitchell, Scherer, & Baker, 1993). A study showed that school-age children with epilepsy were at risk of developing behavior problems, like significant poorer adaptive behaviors and behavior disturbances (Jones & Christine, 1993). Another study showed

that 60.9% of school-age children with epilepsy were psychologically maladjusted, reflecting a less favorable social environment at school (Danesi, 1993). A survey found that 28% of school-age children were ashamed of their epilepsy, and 54% of school-age children worried that seizures may occur at any time (Wei-ling & Rajan 1997).

When seizures are controlled, psychological problems may persist, and the pressure from psychosocial problems can result in recurrent seizures as well as seriously influencing the school-age children's life in a very negative manner (Kaufman, 1993). The intrinsic variables play a more significant role in predisposing school-age children to cognitive and learning problems than do antiepileptic medication (Mandelbaum, Burack, & Daswani, 1993).

In summary, school-age children who represent a significant proportion of the population are a primary group to be prepared for the future. Many studies indicated that epilepsy affects the children's life in a variety of way.

**Self-perception of school-age children**

Harter (1985) stated that self-perception is the way one feels about and describes oneself. According to Willoughby, King and Polatajko, self-concept is how an individual describes himself or herself (Willoughby, King, & Polatajko, 1996 cited in Whaley & Wong, 1998). Therefore the terms self-perception and self-concept may be used interchangeably. Self-esteem and self-image apply some of

the elements presented by Harter (1985) in her concept of self-perception (Dumas & Pelletier, 1999). Stuart and Sundeen (1987) defined self-perception as a person's view of him/her self is not exclusively a collection of the views, expectations, and desires of others. Self-perception is the nuclear of a child's learning experiences, work, socialization, and way of expressing love (Phillips & Bernstein, 1989).

According to Harter (1985), self-perception involves six components: scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth.

Scholastic competence is evaluated based on how children perceive their performance at school. Social acceptance refers to children's perception of their popularity and how well they are accepted by their peers. Athletic competence is their perception of their ability in sports and games. Physical appearance refers to children's view of their weight, height, and other features. Concerning behavioral conduct, children are asked how happy they are with their behavior and whether or not they think they behave appropriately. Finally, global self-worth describes children's levels of satisfaction with how they live their lives and with themselves as individuals (Harter, 1985). These six components are important elements of a child's mental health, which protect the child from psychopathology (Grizenko & Fisher, 1992).

Harter (1985) further states that a person is not born with self-perception. Rather, it is a social creation that develops as a result of interactions with others. Firstly, infants learn that physically they are different from the environment. If basic needs are met and affection is experienced, the child begins life with positive feelings about self and internalizes other people's attitudes toward self. Self-perception is also a result of children's self-appreciation based on their values, beliefs, and ideals (Taylor, Lillis, & Lemone, 1993).

L'Ecuyer (1990) has found that children between 6 and 11 years of age are in the "expansion of self" stage. Children of this age have a variety of experiences in school, and they develop relationships with peers and with teachers. They also become exposed to social events such as games and sports. By the age of 10, children are preparing for the reorganization of self, in which they become a teen-ager, searching for their own identity. Among school-age children all aspects of self-perception are important, because self is expanding rapidly at that age (Harter, 1985; L'Ecuyer, 1990) and mental health promotion and the prevention of mental illness involve efforts to help develop healthy self-perception among children (Gast, 1992).

**Factors affecting self-perception of children**

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). According to Harter's concept, positive self-perception derives from

strong relationships, feeling recognition from others, succeeding in academic events, participating in games and sports and having a good sense of self-control (Harter, 1985).

From a developmental viewpoint, self-perception is a concept that changes in every stage of life. It is expected that self-perception may change with age (L'Ecuyer, 1990 cited in Dumas & Pelletier, 1999). The most systematic effects identified on school-age children's self-perception are sex and education levels (Harter, 1985). With the grade level increase, the scholastic and global self-worth decreases (Harter, 1985). A study indicated that sex was independently associated with children's self-competence (Holden, et al, 1997). Some studies conducted among children with chronic illness show that boys see themselves as more athletically competent than do girls. In contrast, girls see themselves as better behaved than do boys (Harter, 1985; Roff, et al, 1993). Another study reported that boys had more positive self-perceptions on most nonacademic self-scales, but both the older boys and older girls reported less favorable self-esteem than their younger peers on the scales for reading and school in general (Watkins, Dong, & Xia, 1997). However, a study indicated that girls had more behavioral problems than boys (Austin, Risinger, & McNelis, 1991).

Self-perception of school-age children can also be influenced by illness, by the duration of the illness and the disease severity (Hu, 1996). Usually, children with chronic

diseases have a long duration of illness. Because school age is an important period of self-perception development, if the onset of illness is around this period of time, the changed physical appearance or impaired physical abilities, along with the effects of treatment procedure are all threats to their development. A study showed that children with epilepsy were consistently more behaviourally disturbed and had lower self-esteem than children with diabetes (Hoare & Mann, 1994). This study also mentioned that the long duration of illness was the most consistent illness variable associated with poor behavioral adjustment in the two groups (Hoare & Mann, 1994). Children whose first diagnosis is during their preschool and school age, the longer the duration of illness, the lower self-concept they have (Turner-Henson, 1994). Turner-Henson (1994) also suggested that for children with chronic illness more discrimination was reported in children with activity-limiting problems and with visible handicaps. Children with epilepsy may experience discrimination because of the physical appearance change or physical disabilities (Turner-Henson, 1994). Therefore, duration of illness and severity of the disease are possible factors related to chronically ill children's self-perception.

Social factors may influence self-perception of school-age children, mostly the component of self-worth. Peers and parents support are the biggest contributors to children's self-worth followed by teachers and close friends support (Harter, 1985). According to Harter (1989), a child who is doing well in domains deemed important will suffer

some loss of self-worth if socio-emotional support is not forthcoming. Findings of a study also highlight the role parents and teachers may play by promoting self-esteem at home and school (Young, Werch, & Bakema, 1989).

**Measurement of self-perception of school-age children**

Two scales were commonly used for the measurement of self-perception. Firstly, the Pyrt-Mendaglio self-perception scale (Pyrt-Mendaglio, 1992 cited in King, 1997) which includes four subscales: academic, athletic, social, and evaluation. The four subscales include 24 items. Secondly, Harter's (1985) Self-perception Profile for Children, which consists of 6 components and 36 items. The six components include scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth. Scholastic competence is evaluated based on how children perceive their performance at school. Social acceptance refers to children's perception of their popularity and how well they are accepted by their peers. Athletic competence is their perception of their ability in sports and games. Physical appearance refers to children's view of their weight, height, and other features. Concerning behavioral conduct, children are asked how happy they are with their behavior and whether or not they think they behave appropriately. Finally, global self-worth describes children's level of satisfaction with how they live their lives and with themselves as individuals (Harter, 1985).

In summary, self-perception is the way one feels about and describes oneself. This is very important for school-age children. The factors affecting self-perception include age, gender, education level, duration of illness, severity of the disease, and parents' and peers' support. Self-perception can be measured using the instruments developed by Pyrt--Mendaglio (1992) and Harter (1985). In this study, Harter's Self-perception Profile for Children was used.

**Self-perception of school-age children with epilepsy**

Epilepsy is considered as one type of chronic illness. Children perceive their chronic illness as having a negative self-concept on themselves (Zeltzer, Kellerman, Ellerberg, & Rigler, 1980). Usually, these chronically ill children suffer from alienation, depression, loneliness, and fear, which they can handle by the mechanisms of denial, aggression, irritation, isolation, paranoia and regression. All these mechanisms impede the process of treatment and restoration (Isaace & McElroy, 1980; Rose, 1987; Turner-henson, 1994). School-age children with epilepsy have significantly lower self-concept scores compared with groups of children with diabetes or healthy children (Matthews, Barabas, & Ferrari, 1986). Seizures, long-term medicine treatment, peer-group problems, social problems, and psychological problem caused by seizures and long-term therapy can influence the child profoundly in many aspects (Besag & Fowler, 1993; Wang, 1996).

Based on Harter's (1985) concept of self-perception, epilepsy influences each component of self-perception of school-age children as follows.

1. Scholastic competence

School-age children with epilepsy frequently do poorly academically (Austin, Huster, Dunn, & Huberty, 1997; Bourgeois, 1998; Mitchell, Scherer, & Baker, 1993; Papavasiliou, Papadimitriou, Manta, & Nilolaou, 1997; Szanto & Humphries, 1997; Turk, 1993). Ideas of incompetence and disability then undermine school performance and socialization (Henley, 1997). They may think that they are not good at school, not smart, and cannot remember things easily (Wang, 1996).

2. Social acceptance

School-age children with epilepsy frequently do poorly socially (Mitchell, Scherer, & Baker, 1993). Sometimes, school-age children with epilepsy feel inferior and experience difficulties in their social environment (Somoza, Forlenza, Brusino, & Licciardi, 1993). They experience social difficulties that form the basis for rejection by peers (La Greca, 1990). A study showed that 60.9% of school-age children with epilepsy were psychologically maladjusted, reflecting a less favorable social environment at school (Danesi, 1993). It is now believed that society influences place extrinsic values on children with chronic illness and how he/she feels about him/herself (Burn, 1982). They do not have good friends, and are not liked (Hickey, 1992).

3. Athletic competence

Athletic competence of school-age children with epilepsy might be modified. They are afraid of the onset of seizure and may not go outside to play with other children. This may lead them to believe that they are not good at sports or other activities, and they would rather watch than play (Cramer, 1993; Wang, 1996).

4. Physical appearance

School-age children with epilepsy can lead to self-damage even can cause accidence (Wang, 1996). So, physical appearance might be a problem. La Greca (1990) noted that children affected by visible physical conditions often felt that they were not satisfied with their appearance. This is based on disability-related appearance factors (Harper, Wacker, & Seaborg-cobb, 1986; Hartup, 1983). The child may face significant negative physical feelings of about him/herself, despite being given the necessary assistance and support (Markwick & Sage, 1997).

5. Behavioral conduct

A study indicated behavior achievement deficits in school-age children with epilepsy (Bougeois, 1998; Dodd & Redmond, 1997; Turk, 1993). Another study showed that school-age children with epilepsy were at risk of developing behavior problems, such as significant poorer adaptive behaviors and behavior disturbances (Jones, & Christine, 1993). They worry about breaking out, it may limit children's daily activity (Wang, 1996). A study indicated

that girls had more behavioral problems than boys (Austin, Risinger, & McNelis, 1991).

6. General self-worth

Previous studies indicated that the stress of the illness on children led to lower self-esteem and less self-confidence, as result of both physical changes and the socioemotional responses of family members and others (Burns, 1982; Laybourn & Hill, 1991; Long & McAuley, 1996; Schofield-King & Newton, 1997; Schuler, Donati, Vella, ramelli, & Vassella, 1997). Epilepsy has always been considered taboo, with prejudice and rejection (Somoza, Forlenza, Brusino, & Licciardi, 1993). Long term experience of epilepsy may make school-age children feel shame (Wang, 1996). School-age children with epilepsy may think that they are different from others. They often feel sad, worry about their situation, and have low self-confidence (Zhang, 1997).

**Conceptual framework**

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) and impact on school-age children's intelligence, emotional and behavioral or conduct disorders. These impact may affect the self-perception of the children defined by Harter (1985) as how one sees and describes oneself. In this study, self-perception of school-age children with epilepsy is based on Harter's (1985) self-perception concept. It is comprised of

six components: scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct, and global self-worth. Based on the reviewed literature, it can be proposed that age, sex, education level, frequency of seizures, and duration of illness may influence the self-perception, and its components, of epileptic children.