CHAPTER 1

INTRODUCTION

Background and significance of research problem

Nephrotic syndrome (NS) is the most frequent chronic renal disorder in children (Jacobson, Striker, & Klahr, 1995). It is categorized into three groups: congenital, primary, and secondary (Ball & Bindler, 1995). In the United States, NS in childhood was associated with a high morbidity rate and a mortality rate over 50% during the first half of the twentieth century. With control of edema and subsequent decreased susceptibility to infection through the use of ACTH or cortisone in the early 1950s, the mortality rate decreased by about 20% (Nash, Edelmann, Bernstein, & Barnett, 1992). Either in China or the United States, children with primary NS account for 90 percent of childhood NS cases (Tang, 1990; Nash, Edelmann, Bernstein, & Barnett, 1992).

In China, while the mortality rate of children with NS has decreased due to more advanced treatment, the morbidity rate of childhood NS has increased (Wang, 1983). In a pediatric referral center in Beijing, Childhood NS has

increased from 45.3 cases during 1956 to 1965 to 146 cases annually from 1986 to 1992 and accounted for 28% of 505 renal disorder cases in 1992 (Zhang, Shen, Feld, & Stapleton, 1994). In the First Affiliated Hospital of Beijing Medical University, Chinese children with NS constituted 38% of pediatric patients with kidney disease during 1980s (Tang, 1990).

In Guangzhou, one of the big cities in China, medical records of hospitals indicated that an incidence of NS is high. In the First Affiliated Hospital of Sun Yat-sen University of Medical Sciences (SUMS), during January 1995 to August 1997, there were 258 children with NS admitted in this hospital, of these 86 (33.3%) were school-age children (66 new cases, 20 old cases). There were about 100 children with NS per month visited the Out-patient Department of this hospital which 30 of them were school-age children (The First Affiliated Hospital of SUMS Medical Records, 1995-1997). In the Second Affiliated Hospital of SUMS, during January 1995 to August 1997, there were 102 hospitalized children with NS, with 36 were school-age children (24 new cases, 12 old cases). There were about 50 out-patient children with NS cases per month which 12 of them were school-age children (The Second Affiliated Hospital of SUMS Medical Records, 1995-1997).

To control NS, corticosteroid therapy as prednisone

is adopted. Nevertheless, an alkylating agent as cyclophosphamide is replaced in steroid non-responsive cases. As known, both medical treatments have several side effects. The most common side effects of corticosteroid therapy are adrenal insufficiency, obesity, cushingoid habitus, infection, cataracts, hypertension, osteoporosis, and peptic ulcer disease (Nash, et al., 1992; & Lehne, Moore, Crosby, Hamilton, 1994). It has long been known that growth in stature diminishes markedly and may cease entirely in children with uncontrolled NS (Nash, et al., 1992). The side effects of cyclophosphamide therapy include leukopenia, alopecia, hemorrhagic cystitis, anorexia, abdominal pain, nausea, and vomiting; and the most serious side effect is carcinogenesis (Nash, et al., 1992). In China, medical treatment for NS is a combination between Western and Chinese traditional medicine. Literature related to side effects of Chinese traditional medicine is not available. According to the author's experiences as a pediatric nurse of the First Affiliated Hospital of SUMS, the side effects of corticosteroid and alkylating agent were found among children with NS. However, the side effects of Chinese traditio-nal medicine are not reported.

A nature of the disease and the side effects of medical treatment result in a great threat to children, families, and society. As one type of common chronic illness

in children, NS influences the child's physical, emotional, social, and cognitive development (Foster, Hunsberge, & Aderson, 1989). Disturbances in psychosocial function are common in children with NS. Anxiety and guilt are frequent emotional responses (Nash, et al., 1992). During corticosteroid therapy, some children have marked changes in personality (Korsch & Barnett, 1961, cited in Nash, et al., 1992). Children with NS may suffer from altered self-esteem and self-concept due to changes in body appearance such as obesity, cushing face, and short stature (Foster, et al., 1989). Also, children with NS, like children with other types of chronic illness, may have fear, confusion, and embarrassment. The chronic condition may reduce the potential for healthy socialization of the children (Foster, et al., 1989). Children with NS as other chronically ill children encountered discrimination, and the most common source of discrimination problems originated within schools (Turner, Holaday, Corser, Ogletree, & Swan, 1994). In addition, children with NS has frequent hospitalization which usually makes school-age children with NS worry about changing in physical appearance, losing of friends, delaying of learning, and decreasing in level of academic achievement (Futcher, 1988).

NS in children also affects many spheres of family

life, including finance, emotion, and behavior (Li, Ma, Liu, Sun, Zhou, & Zhang, 1991). Once the children are diagnosed as nephrotic syndrome, they are admitted to the hospital for at least a month to receive full care and treatment (Hu, 1996). It is possible that at least one parent may have to give up working or reduce his or her time in the work force when his or her child is hospitalized, which may result in substantially less family income. The family of NS child will also face with stress related to the child's physical vulnerability, personal grief reactions, and feelings of guilt and blame. The family must continually strive to have a balance between normal functioning and sensitivity toward their child's special needs. The family faces the challenge of adapting behavior patterns and activities to accommodate treatment regimens into their daily lives (Foster, 1989).

Moreover, in China, the illness increases health care cost of the society because as it has to provide most of the cost for sick children whose parents work in government departments. According to available medical records of hospitals in China, many school-age children with NS were hospitalized frequently with relapse of disease and infection. Fan (1994) reported 7 relapse cases among 20 hospitalized children with NS aged three to thirteen years during 1990 to 1993 in Houma City, Shanxi Province. The factors related to these relapses were respiratory infection,

skin infection, taking steroid irregularly, and high-salt diet. In Guangzhou City, during January 1995 to August 1997, there were 20 cases of school-age children with NS relapse in the First Affiliated Hospital of SUMS (The First Affiliated Hospital of SUMS Medical Records, 1995-1997). And there were 12 cases in the Second Affiliated Hospital of SUMS. The factors related to these relapses were being unaware of infectious prevention, reducing doses of prednisone by their parents, and not going to see the physician as schedules (The Second Affiliated Hospital of SUMS Medical Records, 1995-1997).

Usually in these hospitals, children with NS and their parents receive information about preventing relapse and infection during hospitalization. Nurses provide the children and parents information about administrating medication and observing the common side effects of steroid therapy. Also, nurses provide them information about observing signs of relapse such as edema, and testing urine for protein. In addition, nurses provide them information about following a salt-restricted diet as long as the child is on corticosteroid therapy or shows signs of NS, going to see physician as schedules, and preventing infection such as avoiding contact with infected playmates.

Therefore, relapse and infection among these Chinese

school-age children with NS might reflect either improper self-care practices of the child or inappropriate children care management of the families. Besides the part of child care management of the family; promoting of self-care practices of these children with NS may be the best way to lessen numbers of infection, relapse, and hospitalization. If these children with NS can perform self-care well as what nurses advised, they would have no or lesser relapse and infection, impaired skin integrity, fluid volume excess, altered nutrition less than body requirements (Ball & Bindler, 1995). Consequently, unnecessarily prolonged course of therapy or doses corticosteroid will be avoided, and its side effects as well as psychological stresses will be lessen. Moreover, good self-care practices of children with NS can reduce the physical, emotional, and economic burdens of their families. The question is how well Chinese school-age children with NS perform self-care practices. However, no research report related to self-care practices of NS children is available. Therefore, self-care practices of Chinese school-age children with NS is highly needed to study. The study would provide baseline information for further studies on promoting self-care practices of these children.

Orem's self-care theory discusses the concept of self-care (Orem, 1995). According to Orem (1995), self-care practices are the activities that individuals perform on

their own behalf in maintaining life, health, and well being. When an individual engages in self-care practices, it is necessary to meet three types of self-care requisites: universal, developmental, and health-deviation. In Orem's publications, it was noted that children require less assistance with care as they become older and learn how to perform and take responsibility for self-care (Orem, 1985, 1991, 1995). School-age children refer to boys and girls age between 6 and 12 years, whose developmental stage is between those of early childhood and adolescence. With growth of muscle and maturation of neural system, school-age children are able to perform physical activities such as eating, taking a bath, and brushing teeth (Havighurst, 1972). Related literature indicated that school-age children are able to actively participate in self-care practices in the areas of hygiene, food, and activity and rest (Facteau, 1980; Graham & Uphold, 1992; Whaley & Wong, 1994; Jiang, 1997). Therefore, school-age children with NS would be able to perform self-care practices in their daily lives.

Although self-care practices are important for school-age children with NS as previously described, no literature on self-care practices of school-age children with NS is available neither in China nor other countries. Therefore, a study of self-care practices of Chinese school-age children with NS is needed as it will contribute

to the body of nursing knowledge in this area and guide nursing practice for promoting self-care practices of Chinese school-age children with NS.

Objective of the study

The objective of this study was to identify the level of self-care practices of Chinese school-age children with nephrotic syndrome.

Research question

What is the level of self-care practices of Chinese school-age children with nephrotic syndrome?

Scope of the study

The research was conducted on selected school-age children with primary NS whose age between 6 to 12 years and attending Out-patient Department of three hospitals in Guangzhou City, China, during December 1997 and February 1998.

Definition of terms

Self-care practices: referred to activities that individuals perform on their own behalf in maintaining life, health, and well-being. These actions were directed toward meeting three different types of self-care requisites: universal, developmental, and health-deviation. Operationally, they were measured by School-age Children with Nephrotic Syndrome Self-care Practices Interview Guide developed by the investigator.

Chinese school-age children referred to Chinese boys and girls between the age of 6 to 12 years who admitted at least one time in one of three hospitals and attending Out-patient Department of these hospitals in Guangzhou, China. They were divided into three sub-age groups: 6 to 8 years were early school-age children, 8 to 10 years were middle school-age group, and 10 to 12 years were late school-age children.

Nephrotic syndrome	referred to primary nephrotic syndrome manifesting proteinuria, hypoalbuminemia, edema, and hyperlipidemia; and is unassociated with systematic diseases.