CHAPTER 1

INTRODUCTION

Background and significance of research problem

Heart disease in children is divided into two major groups, congenital and acquired heart disease (Whaley & Wong, 1991). Congenital heart disease (CHD) is a defect in the heart or great vessels, or persistence of a fetal structure after birth (Jane, 1995). The incidence of CHD in children is generally reported to be 4 to 10: 1000 live births (Hoffman, 1990 cited in Whaley & Wong, 1991). An estimated 40,000 babies are born with CHD in the United States yearly (Nadas, 1986). In Qatar, the incidence of CHD was 12.23/1000 live births in the period between 1984 to 1994 (Robida, Folger, & Hajar, 1997). Acquired heart disease refers to a disease processes or abnormalities that occur after birth and can be seen in a normal heart or in the presence of congenital heart defects (Whaley & Wong, 1991). It includes rheumatic fever (RF), pericarditis, myocarditis, infective endocarditis, Kawasaki Disease (KD) and cardiomyopathy (Holbrook, 1993). During the 1960s and 1970s, RF almost disappeared. However, in the late 1980s, a recurrence of RF occurred in the United States (Thompson, 1995). It occurs most in children 6-15 years of age, with a peak incidence at 8 years (Adele, 1999). It remains a

devastating problem in developing countries (Veasy, 1994). Pericarditis may be caused by infectious or noninfectious disease. A wide range of symptoms of myocarditis makes determination of the exact incidence difficult. Retrospective studies have found its prevalence of 3.5% to 5%. A closer approximation of the incidence of clinically significant myocarditis may be three to five cases per 100,000 per year (Nichols, Cameron, Greeley, Lappe, Ungerleider, & Wetzel, 1995). Infective endocarditis includes the entities referred to as acute and subacute bacterial endocarditis as well as infections of nonbacterial endocarditis such as those caused by viruses, fungus, and other agents (Behrman, Kliegman, & Arvin, 1996). Kawasaki Disease occurs most frequently in Japan and in children of Japanese heritage regardless of where they live (Rauch, 1987). It has become a leading cause of AHD in children in the United States (Whaley & Wong, 1991). Although the incidence of cardiomyopathy in children is small, it accounts for 4.8% of all cardiac deaths in childhood and one half of the survivors have cardiac disability (Tripp, 1984 cited in Whaley & Wong, 1991).

In China, the incidence of CHD is about 7 to 8: 1000 live births (Song & Gong, 1992). At the same time, the incidence of AHD in children is increasing because of infection, autoimmune responses, environmental factors and familial tendencies (Li, Su, & Chen, 1994). According to statistics of three hospitals in Shenyang during January 1998 to January 1999, medical records of hospitals stated

that the incidence of heart disease in children were as follows: In the First Teaching Hospital of China Medical University, there were 409 children with heart disease admitted to the pediatric ward of this hospital, and 122 (29.8%) were school-age children. In the Second Teaching Hospital of China Medical University, there were 616 children with heart disease admitted to the pediatric ward, and 204 (33.1%) were school-age children. In Shenyang Children Hospital, there were 403 hospitalized children with heart disease, and 108 (26.8%) were school-age children. Therefore, heart disease have become very common among school-age children and represents an important health problem for this population in China (Li, Su, & Chen, 1994).

Some CHD repair themselves, some require medication and medical management, and others need surgical correction. Approximately 80% of infants with CHD can be cured or helped with corrective surgery. The majority of children after surgery will be able to lead normal lives, though one third develop problems later in childhood (Nadas, 1986). Management of AHD include administering medication, monitoring oxygenation and circulatory status, promoting energy conservation, maintaining adequate nutrition, supporting families, and reinforcing teaching (Opperman & Casoandra, 1998). Usually, heart disease in children can be a long-term chronic condition (Jane, 1987).

Both CHD and AHD affect cardiac function. According to the Heart Disease Committee of New York, cardiac function can be classified into four classes. Class I-III: Limitation

of physical activity from no to light to marked respectively. Class IV: Unable to carry on any physical activity without discomfort (Joyce, Black, & Matassarin-Jacobs, 1987). The nature of the disease may result in a great threat to the children and the family. Heart disease influences the children's physical, emotional, social, and cognitive development (Foster, Hunsberger, & Aderson, 1989). Also heart disease affects many spheres of family life, including finance, time, emotion, and behaviors. If these children with heart disease can perform self-care behaviors well, the impact of the illness could be lessened.

From a nurse perspective, self-care behaviors are compliance or adherence behaviors that are synonymous with good or adequate self-care (Prasarnpran, 1992). According to Orem (1995), self-care behaviors are the practices of activities that individuals initiate and act on their own behalf in maintaining life, health, and well-being. Self-care is undertaken by individuals to meet three types of self-care requisites: universal, developmental, and health-deviation. When self-care is effectively performed, human structural integrity, functioning, well-being, and development are maintained and promoted. In addition, Orem (1985) noted that children require increasingly less assistance with care as they become older and learn how to perform and take responsibility for self-care.

School-age children refers to boys and girls between the ages of 6 and 12 years (Adele, 1999). A school-age child is beginning to assume increasing responsibility for health

maintenance and care, and as maturity increases is less dependent upon the adult family members to recognize signs of altered health states or to communicate health care needs. School-age children gain ability to spare on their own behalf and begin to provide subjective information regarding their physical and emotional health that may be unique to the individual and different from perceptions of adult family members (Peggy, 1974). As chronically ill children mature and are capable of providing for their own needs, they become developmentally able to assume certain self-care responsibilities (Deatrick, et al., 1994 cited in Broome, Knafl, Pridham, & Feetham, 1998).

Heart failure is the most common complication among children with heart disease. According to available medical records of hospitals in China, many school-age children with heart disease were hospitalized frequently with heart failure. In Shenyang City, during the past two years, there were 12 cases of school-age children with heart failure in the First Teaching Hospital of China Medical University, 23 cases in the Second Teaching Hospital of China Medical University, and 9 cases in Shenyang General Military Hospital. There were many factors related to the school-age childen with heart disease with heart failure: (1) These children didn't know how to prevent infection. (2) These children were unaware of irregular action and rest. (3) These children did not follow nurses' advise and forgot to take medication as prescribed. (4) These children didn't know to remind their parents to take them to attend doctors

as scheduled. (5) Family care was deficient (Li, Su, & Chen, 1994).

Therefore, heart failure among these school-age children with heart disease might reflect either improper self-care behaviors of the child or inappropriate child care of the families. Besides the part of child care of the family, promoting of self-care behaviors of these children with heart disease may be the best way to lessen numbers of complications and hospitalizations.

As previously described, school-age children with heart disease can perform self-care behaviors, and good self-care behaviors of these children may decrease heart failure and number of hospitalizations, and reduce the impact of illness on their physical, emotional, cognitive, and social development. Moreover adequate self-care behaviors can promote these children to achieve developmental tasks, and also reduce the physical, emotional, financial, and stressful burdens of their families. It is obvious that self-care behaviors are very important for school-age children with heart disease. However, no research reports related to self-care behaviors of school-age children with heart disease. Therefore, a study of self-care behaviors among school-age children with heart disease is necessary. The result of this study will provide information to help nurses understand about self-care behaviors of school-age children with heart disease. Moreover, increased knowledge will assist nurses to promote self-care behaviors of school-age children.

Objective of the study

To identify the level of self-care behaviors of school-age children with heart disease whose cardiac function are in class I-III.

Research question

What is the level of self-care behaviors of school-age children with heart disease whose cardiac function is in class I-III?

Scope of the study

This study was conducted among Chinese school-age children with heart disease whose cardiac function was in class I-III who were between 6 and 12 years old, having at least one hospitalization and attending the Out-patient Department of three hospitals in Shenyang City, during November 1999 to January 2000.

Definition of terms

Self-care Behaviors: refer to practice of activities that individuals perform on their own behalf in maintaining life, health, and well-being. These actions are directed toward meeting three dimensions of self-care requisites: universal, developmental, and health-deviation. Operationally, they are measured by Self-care Behaviors of School-age

Children with Heart Disease Questionnaire (SBSCHDQ) developed by the investigator.

School-age Children with Heart Disease: refer to boys and girls age between 6 and 12 years with congenital or acquired heart disease, whose cardiac function are in level I-III, and who are attending the Out-patient Departments of three hospitals in Shenyang, China.