

## CHAPTER 1

### INTRODUCTION

#### Background and significance of research problem

Cancer is not only a life threatening disease, but also the leading cause of disease-related death in children under 15 years of age. In 1988, 1,638 children in USA died of cancer (Ball & Binder, 1995). Among children under 14 years of age, there was a 1% average yearly increase in the incidence rates of all malignant neoplasm combined between 1974 and 1991 and this analysis was based on more than 12,000 childhood cancer cases (Gurney, Davis, Severson, Fang, Ross, & Robinson, 1996). The American Cancer Society (cited in Moore & Mosher, 1997) estimated that appropriately 1,382,400 new cases of cancer were diagnosed in the United States in 1997. Of these cases, an estimated 8,000 were children. Cancer in children includes leukemia, Wilm's tumor, Hodgkin's disease, non-Hodgkin's lymphoma, brain tumors, neuroblastoma, osteosarcoma, rhabdomyosarcoma, and retinoblastoma (Ashwill & Droske, 1997).

In China, the incidence of childhood cancer combined is not yet available. However, information can be implied from the bed use of hospitals and the incidence of childhood leukemia because it is the most common cancer in

childhood. The morbidity of childhood leukemia in China is about 2.64-7.09 per 100,000 (Xu, 1992). In the Second University Hospital of Hua Xi Medical University (HXMU), children with leukemia constitute 40% of pediatric patients with blood diseases and leukemia is the most common cause of hospitalization for childhood chronic illness. There were almost 100 leukemic children admitted to the Second University Hospital in 1997 and 80 in 1995 (The Second University Hospital of HXMU Medical Records, 1995-1997). Other kinds of childhood cancers such as solid cancer including Wilm's tumor, Brain tumors, Neuroblastoma, et al., were admitted to the surgical department of the First University Hospital of HXMU.

In the past, receiving a diagnosis of cancer meant impending death. In recent decades, however, with improved diagnostic techniques and the proper medical treatment the survival duration of some chronic deadly diseases, including cancer, is longer than before. Another study also showed that approximately 71% of children affected with cancer today survived for more than five years (Parker, Tong, Bolden, & Wingo, 1997). Today, about 70% of childhood cancer can be cured (Boman & Bodegard, 1995).

Although cancer is diagnosed in more children each year, the mortality rate among children with cancer decreased from 8.3 per 100,000 in 1950 to 3.5 per 100,000 in

1986 (Whaley & Wong, 1991). This data suggests that there are more cancer survivors. Baird and colleagues (1991) reported a 40% increase in long-term survival from the 1960s. Meadows and her colleagues (1989) estimated that one out of one thousand 20-year olds was a survivor of cancer in 1990.

Cancer is treated with one or more combined therapies: surgery, chemotherapy, radiation, immune therapy, and bone marrow transplantation (Ashwill & Droske, 1997; Ball & Bindler, 1995; Waskerwitz, 1994, In Betz, Hunsberger, & Wright). The choice of treatment is determined by the type of cancer, its location, and the degree of metastasis.

Side effects of treatments are commonly found including anorexia, nausea and vomiting, alopecia, leukopenia, hepatotoxicity, nephrotoxicity, and bone marrow suppression which results in a high risk for infection (Lehne, Moore, Crosby, & Hamilton, 1994). Drug noncompliance due to severe nausea and vomiting is reported as high as 33% in children and 59% in adolescents (Gardner, & Oleness, 1981).

However, the acute and long-term effects of treatments also have been well identified. These effects include physical, psychological, social, and cognitive impacts (Foster, Hunsberge, & Aderson, 1989). Regarding physical effects, pain and distress are common. With respect

to psychological effects, poor self-esteem and body-image (Mullis, 1992), worse adjustment responses and more anxiety (Moore & Mosher, 1997; Overbaugh & Sawin, 1992; Waterworth, 1992) were reported. Also, children with cancer may have fear, confusion, and embarrassment in social environments. As for the social impact, the potential for healthy socialization of children with cancer may be reduced (Foster, Hunsberge, & Aderson, 1989). For children who survive childhood malignancy, difficulties in obtaining employment, insurance, and reintegration into the education system have been reported. Similarly, cognitive functioning deficit such as learning problems and decline in IQ scores among children with cancer receiving CNS prophylaxis, especially at an early age have been found (Cousens, Ungerer, Crawford, & Stevens, 1991).

Cancer in children also affects many aspects of family life, including emotion, behavior, and finance (Cornman, 1993; Martinsonn, Su, & Liang, 1993; Birenbaum, 1991). Low self-esteem, depression, life stress, and low marital relationship satisfaction were reported by family members of children with cancer (Cornman, 1993; Magni, Messina, DE Lee, Moscono, & Carli, 1983; Lascari & Stehbens, 1973; Kalnins, Churchill, & Terry, 1980). Moreover, the family faces the challenges of adapting behavior patterns and activities such as withdrawal of family members from

each other and society and postponement of vacations. The family also faces a financial strain or burden (Lansky, Black, & Cairns, 1983).

Each family in China can have only one child because of the national birth control policy. Therefore, children are really important to their parents. Having been diagnosed with cancer that is incurable, the children need both long term treatment and care, which will affect family members in various ways as mentioned previously.

In the hospitals, the Chinese children with cancer and their parents receive information from doctors and nurses regarding diagnosis, treatment, the complications of cancer, and the side effects of the treatment. They also receive advice regarding nutrition, infection prevention such as avoiding contact with infected playmates, administering medication at home, and methods to handle pain and vomiting. This information and advice is given in the form of pamphlets, booklets and other health educational materials. If the child and his family can follow the advice of doctors and nurses, it was believed that they should not have frequent complications. In order to motivate the children to comply with the advice of health professionals, they should understand the direct benefit of taking good care of themselves. Even though some children can perform self-care activities to some extent, they need assistance or

help from their mothers or caregivers.

Self-care practices are the activities that individuals initiate and perform on their own behalf in maintaining life, health, and wellbeing (Orem, 1985). Orem's Self-care Theory (1991) operates on the assumption that each human has a need to care for himself or herself. In the case of a young child, he needs help from his mother who acts as caregiver for her child. Orem (1995) also introduced the concept of dependent-care that is defined as "the continuing health-related personal regulatory and developmental care provided by responsible adults for infants and children or persons with disabling conditions." (p .9). Orem (1995) further explained that children require complete care or assistance with the self-care activities. Such activities include providing for the nutritional, safety, hygiene, and developmental needs of children. These needs are classified as universal, developmental, and health deviation self-care requisites (Orem, 1995). Because of the developmental condition, illness, and the side effects of treatment, the child with cancer needs dependent-care from his/her mother or caregivers. In particular, the mother is the person within the family who performs most of the health-related activities to maintain the child's health (Spector, 1985). If mothers performed dependent-care inappropriately or inadequately, nursing intervention should

be established to meet the dependent-care requisits.

In the hospitals in China, except for regular treatment for cancer, the most frequent causes of hospitalization of the child with frequent cancer are relapse and complications such as fever, infection, and bleeding. The major causes of death are life-threatening infections and bleeding. To some degree, one contributing factor might be related to inappropriate self-care activities of children and/or dependent-care activities of their mothers. In the ward, the parents sometimes allowed the child with cancer to eat food that was spicy, cold, raw, and unclean if the child asked for it. Then diarrhea or severe GI infection often occurred. Sometimes this is due to caregiver's having no knowledge about this. Some parents said that the child was very miserable when diagnosed as having cancer. So they agreed with whatever the child wanted no matter if it was reasonable or not. Stopping administering medication and regularly follow up personally occurred in some cases. To optimize the mother's ability to provide adequate and appropriate care for her child with cancer, nurses need to have baseline information regarding maternal performance of dependent-care activities. However, research in the area of mothers' care associated with children's health is limited (Moore & Gaffney, 1989). According to the reviews of the literature, research

describing the dependent-care agent performance of Chinese mothers whose children were diagnosed with cancer is unavailable. In order to facilitate dependent-care agent performance of Chinese mothers, it is necessary to determine how well the Chinese mothers perform dependent-care activities for their children with cancer. Thus, the result of this study will give nurses a better understanding of the mothers' performance in order to help mothers to be better able to care for their children. This understanding can contribute to the body of nursing knowledge in this area and guide nursing practices for promoting dependent-care practices of mothers for children with cancer.

#### **Objectives of the study**

The objective of this study was to identify the level of dependent-care agent performance of mothers for children with cancer.

#### **Research questions**

The research question of this study was : What is the level of dependent-care agent performance of mothers for children with cancer?



### Scope of the study

The study was conducted on Chinese mothers of children with any type of cancer in two hospitals in Chengdu, China, from November 1998 to January 1999.

### Definition of terms

**Dependent-care Agent** Refers to Chinese mother of the child with any type of cancer.

**Dependent-care agent performance** Refers to the activities that the responsible Chinese mother performed to meet her child's care needs which consist of three dimensions including universal, developmental and health deviation. In this study, it referred to a mother's activities in caring for her child with cancer. It was measured using the Dependent-care Agent Performance Questionnaire modified from Moore and Mosher's (1997).

**Children with cancer** Refers to boys and girls aged 1 to 15 years old who are diagnosed as having cancer.