

CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Literature review and related research

For the purpose of this study, literature on dependent-care agent performance of mothers for children with cancer were reviewed. (1) childhood cancer, (2) impact of childhood cancer, (3) Orem's self-care/dependent-care theory, (4) dependent-care demands of children with cancer, (5) dependent-care agent performance of mothers for their children with cancer, and (6) measurement of dependent-care agent performance of mothers for children with cancer.

Childhood cancer

A cancer is a cellular, malignant neoplasm arising from new and abnormal cell growth (Waskerwitz, 1994. In Betz, Hunsberger, & Wringht). Malignant neoplasm is a progressive growth in which there is a loss of differentiation of cells; that is, the cells no longer perform their intended functions. Malignant cells undergo alteration in DNA, leading to transmission of faulty information for cellular development and subsequent uncontrolled growth and loss of normal cellular function (Ashwill & Droske, 1997; Waskerwitz, 1994. In Betz,

Hunsberger, & Wright). Proliferation of these abnormal cells can be viewed as a failure of the surveillance function of the immune system (Ashwill & Droske, 1997).

Cancer is the leading cause of death from disease in children under 15 years of age (Ball & Binder, 1995). The causes of cancer in child are not well defined. The aim of treatment is to cure the child with a minimum of long-term side effects and maintain normal growth and development of the child that can be affected by cancer treatment (Ashwill & Droske, 1997).

The incidence of childhood cancer

Increasing temporal trends in cancer incidence in children were reported recently in many studies. In Gurney and colleagues' study (1996), they observed an average 1% increase in annual incidence rates for all malignant neoplasm combined among children aged less than 14 years in U.S. between 1974-1991 and 2% increase in central nervous system (CNS) tumors. The average annual percentage change (AAPC) was similar for males and females. This result is consistent with that of another study conducted by Bunin and collaborators (1996) in which the cancer incidence rates increased an average of 1% per year between 1970 and 1989 for children under 14 years of age. In Queensland, Australia, a 0.9% per year average increase in cancer

incidence between 1973 and 1988 was observed among 1041 cases (McWhirter & Petroeschovsky, 1991).

Cancer commonly found in childhood includes leukemia, Wilm's tumor, Hodgkin's disease, non-Hodgkin's lymphoma, brain tumors, neuroblastoma, osteosarcoma, rhabdomyosarcoma, and retinoblastoma (Ashwill & Droske, 1997).

Treatment of childhood cancer

The treatment of childhood cancer includes chemotherapy, surgery, radiation therapy, immune therapy, and bone marrow transplantation (Ashwill & Droske, 1997; Ball & Bindler, 1995; Waskerwitz, 1994. In Betz, Hunsberger, & Wringht). The choice of treatment is determined by the type of cancer, its location, and the degree of metastasis (Ball & Bindler, 1995). These treatment modalities are often used in combination. The goal of treatment may be curative, supportive, or palliative (Ball & Bindler, 1995). The details of each kind of treatment are explained as follows.

1. Chemotherapy is the use of drugs (antineoplastic agents) to kill cancer cells or interfere with the proliferation of fast-growing malignant cells (Ashwill & Droske, 1997; Waskerwitz, 1994. Cited in Betz, Hunsberger, & Wringht). Chemotherapy may be given orally, intravenously, intramuscularly, subcutaneously, or intrathecally (Ashwill &

Droske, 1997).

Normal cells, particularly those known to grow rapidly such as bone marrow cells, hair follicle cells, gastrointestinal epithelial cells, and cells of the gonads will be affected by chemotherapeutic agents to various degrees, because of no differentiation between normal and cancer cells. This is why chemotherapy is often accompanied with side effects including nausea and vomiting, anorexia, alopecia, malaise, stomatitis, and bone marrow suppression which manifests a decreased platelet level, WBC level, and RBC level (Ashwill & Droske, 1997). All of the chemotherapeutic agents are immunosuppressive to various degrees. They suppress the function of normal lymphocytes in the immune system. Therefore, the patient is subject to infection (Foley, Fochtman, & Mooney, 1993).

2. Surgery is used to remove or dedulk a solid tumor such as Wilm's tumor and also used to determine the stage and type of cancer (Ball & Bindler, 1995; Waskerwitz, 1994. In Betz, Hunsberger, & Wright). For some tumors, a complete surgical excision is preferable. In most cases, surgery is usually combined with another treatment modality, such as radiotherapy and/or chemotherapy, to manage any sites of metastases and micrometastases (Waskerwitz, 1994. Cited in Betz, Hunsberger, & Wright).

The surgical complications: staging laparotomy and

pelvic surgery are operative procedures used to define disease extent and usually include lymph node sampling with inspection and biopsy of the liver and any other suspicious areas (Marina, 1997). The use of staging laparotomy increases the risk of intestinal obstruction and adhesion (Heyn, 1992; Donaldson & Link, 1987; Hays, 1986; Green, 1983;) which fortunately have a low mortality rate (Hays, 1986; Green, 1983). Pelvic surgery can cause disruption of autonomic pathways and result in retrograde ejaculation, which can impair fertility (Heyn, 1992).

3. Radiation therapy or radiotherapy is individually dosed for the specific disease and to the patient's size and age (Ashwill & Droske, 1997). Radiotherapy is most often employed in combination with surgery or chemotherapy in the treatment of leukemia, lymphomas, and solid tumors. It is also used alone to achieve palliation of symptoms caused by tumor masses (Waskerwitz, 1994. Cited in Betz, Hunsberger, & Wringht). The area to be irradiated includes the tumor site and sometimes other involved areas, such as lymph glands. The total dose of radiation is divided and given over several weeks in general once daily 4 to 5 days per weeks for a period of 2 to 6 weeks (Ball & Bindler, 1995).

The side effects of radiotherapy can occur acutely, during the treatment or shortly after treatment is

completed, or as late effects presenting in future years. These effects include fatigue, nausea, vomiting, anorexia, mucositis, bone marrow suppression, and skin reactions such as erythematous (Ashwill & Droske, 1997).

4. Immune therapy is the use of biologic response modifiers, such as interleukin-2, lymphokine-activated killer cells, or radio-labeled monoclonal antibodies (Ball & Bindler 1995). The action of many of these agents is not completely understood, and some agents have more than one effect. Because knowledge about these biologic response modifiers is limited, the potential side effects are not well identified (Ball & Bindler 1995).

5. Bone marrow transplantation (BMT) has become accepted therapy for the treatment of several hemotologic and oncologic disorders in recent years (Ashwill & Droske, 1997; Waskerwitz, 1994. Cited in Betz, Hunsberger, & Wright). There are three types of BMT which are allogeneic, autologous, and syngeneic. The purpose of a BMT is to provide the child with healthy bone marrow that can produce functional blood cells. A Child can be rescued from a life-threatening bone marrow depression by the transplant of marrow cells. Additionally, immune cells in the transplanted marrow may help to kill remaining leukemic cells in the host (Gale & Champlin, 1986, Cited in Betz, et al., 1994).

The common complications in the days and weeks

after a BMT include graft-versus-host disease, mucositis, diarrhea, fevers, nosebleeds, and interstitial pneumonitis (Ashwill & Droske, 1997).

Impact of childhood cancer

Childhood cancer requires long-term treatment and care. The nature of cancer and the side effects of the treatment may cause great impact on many aspects on not only the children but also the families.

1. Impact of childhood cancer on the child

Children with cancer undergo a great deal of stress due to their disease, its treatment, and its potential latent effects. These children may experience delayed mastery of developmental tasks, intimacy, and independence and may have long-term psychological sequelae (Heiney, 1989). Childhood cancer may influence the child's physical, psychological, and social development as follows (Foster, et al., 1989).

1.1 Physical impact

Pain may be an early or late sign and symptom of cancer. It also can be caused by treatment and diagnostic procedures and also many kinds of side effects and punctures (Ashwill & Droskes, 1997). The cause of pain may also be bone metastases, obstruction of a hollow viscus, nerve involvement, infection, and muscosal ulcerations (Mulne &

Koepke, 1985). Several antineoplastic drugs such as carmustine and dacarbazine can cause local pain during infusion. Vesicant medications can cause pain and tissue necrosis if they extravasate into tissues (Mulne & Koepke, 1985).

Nausea and vomiting are frequent side effects of many antineoplastics. Moreover, anticipatory nausea and vomiting, due to psychological factors, may occur even before the patient receives his or her dose of chemotherapy (Mulne & Koepke, 1985).

Poor linear growth and short adult stature are common complications following successful treatment of childhood cancer. The younger the child and the female sex seem to be significant and independent risk factors for short adult height (Sklar, 1997). Neoplastic disease is commonly associated with three basic systemic effects: Anorexia, a hypermetabolic state, and a negative nitrogen balance, which are often accompanied by increasing weight loss. These effects may vary widely with individual patients according to the type and stage of the disease from mild to the extreme forms of debilitating cachexia seen in advanced disease (Williams, 1993). The stomatitis, nausea, diarrhea, and malabsorption due to cancer and its treatment contribute to much food intolerance. Radiation to the head and neck often produces increasing anorexia and nausea and a loss of

appetite. Therefore, the imbalance of decreased intake and increased demand creates a negative nitrogen balance and indicates the wasting of body tissue. When radiotherapy impairs bone growth, it can cause leg-length discrepancy, scoliosis, and short stature (Marina, 1997). The patients most affected are those treated before puberty with high-dose, large-volume radiotherapy. Radiation can also produce deficiency of growth hormones or other hypothalamic or pituitary hormones or both. A recent study (Roman, 1995) reported impaired growth hormone response in 11 of 25 children treated with surgery and chemotherapy for osteosarcoma. However, early diagnosis and timely therapy of the endocrine sequelae of cancer treatment ensure that these individuals will reach their optimal growth potential (Sklar, 1997).

1.2 Psychological impact

As prescribed earlier, the psychological impact includes poor self-esteem and body image, anxiety and guilt, bad adjustment responses and coping, fear, confusion and embarrassment.

Mullis (1992) investigated the self-esteem of school-age children with leukemia and compared it to that of healthy children. 13 school-age children who had leukemia and were undergoing chemotherapy treatment at a hospital clinic, and 50 school-age children without chronic illness

were included in the study. The result indicated that children with leukemia suffered from altered self-esteem on one subscale of Self-esteem Inventory (school academics) and had a less adaptive emotional state than healthy children.

Greenberg, Kazak, and Meadows (1989) presented data on psychological adjustment for a sample of 8- to 16-year-old long-term cancer survivors and a matched group of healthy children. The results indicated that the children with severe medical latent effects have a poorer total self-concept and more depressive symptoms than those with no or mild to moderate latent effects.

Frequent hospitalization and medical treatment make the child worry about losing friends. Absence from school can delay learning and damage high levels of academic achievement (Futcher, 1988).

The outcome of the patient's coping with the illness and treatment was assessed in 30 young adult childhood cancer survivors. Using statistical cluster analysis, three clusters were produced that were interpreted as good, intermediate, and poor coping containing 40%, 33%, and 27% of the total group, respectively. The overall cluster differences were statistically significant (Boman & Bodegard, 1995).

Chang and colleagues (1987) found that one third of 42 survivors of childhood cancer experienced moderate to

severe emotional maladjustment such as passivity, social withdrawal, agitation, and anxiety.

1.3 Social impact

Children who survive childhood malignancies, have difficulty in reintegration into the education system and obtaining employment, and insurance in their later life (Heath, 1996). Frequent hospitalization and treatment may reduce the potential for healthy socialization of children with cancer (Foster, et al., 1989).

Children who received CNS prophylaxis, especially at an early age, are at high risk for cognitive difficulties, which may place the children at high risk for late social problems (Hymovich & Roehnert, 1989).

2. Impact of childhood cancer on their families

The family is the social environment for children. The diagnosis of childhood cancer is a devastating event to all family members (Cornman, 1993).

2.1 Impact on parents

The parents of children with cancer will face stress related to the child's physical vulnerability, personal grief reactions, and feelings of guilt and blame. They must continually strive to strike a balance between normal functioning and sensitivity towards their child's special needs. These parents also face the challenges of

adapting behavior patterns and take activities to accommodate treatment regimens into their daily life (Foster et al., 1989).

Cornman (1993) reported lower self-esteem of mothers of children with cancer than that of fathers. Both parents reported more life stress in this study. Parents of children with cancer may encounter much stress stresses related to coping with the child's illness. Magni and colleagues (1983) reported an increased incidence of parental anxiety, and depression.

Parents of children with cancer also complain of a variety of somatic problems including fatigue, insomnia, and lack of appetite (Lascari & Stehbens, 1973). Sleeping disturbance was also found (Magni, et al., 1983).

Kaplan, Grobstein, and Smith (1976. Cited in Kalnins, Churchill, & Terry, 1980) found that 80% of the families were perceived to have problems after the diagnosis of leukemia of a child. Serious marital problems were reported by 70% of the families, of which 5% resulted in divorce and 18% ended in separation. Low marital-relationship satisfaction, withdrawal of family members from each other and society, and breakdown of the family structure have also been reported (Kalnins, Churchill, & Terry, 1980; Lansky, Carirns, Hassanem, Juehr, & Lowmas, 1978).

The majority of research regarding the financial burden of childhood cancer are related to costs during the child's treatment. Many families continue to have long-term outstanding medical debts and financial strain (cornman, 1993; Lansky, Black, & Cairns, 1983).

In China, because of the reform of the medical treatment fee, almost all of the child's medical costs should be paid by his/her family. When the child suffers from cancer, the family will probably face more financial problems in China than in other countries.

In addition, once the child was diagnosed as having cancer, the parents were willing and encouraged to stay with the child. It is possible that at least one of the parents may have to stop working temporarily, or reduce his or her time in the work force in order to take care of their child when the child was hospitalized, which may result in substantially less family income. Added to the treatment cost, the family will face with a financial burden.

2.2 Impact on siblings

As the result of parents being overtaxed and distracted by the ill child, the healthy siblings suffer a loss of attention. Anger, jealousy, and resentment are common among healthy siblings (Futcher, 1988). Limited social contact of the family can result in a sibling's feeling of isolation, feeling left out, and inferior (Whaley

& Wong, 1991). Taylor (1980) also stated that two thirds of healthy siblings expressed feelings of isolation, egocentricity, deprivation, and inferiority. Siblings of the sick children have higher incidence of school problems, mental disturbances, and behavioral problems (Cunningham, 1982, cited in Cornman, 1993; McKeever, 1983, cited in Fitcher, 1988). However, in China, most families have only one child. Therefore kind of impact may not be obvious as in other countries.

In summary, when a child was diagnosed of having cancer, the child and his or her family will be affected not only physically, but also psychologically and socially. Thus, more attention should be paid to the latent effects of the cancer and its treatment on the child as well as on the family.

The suffering children should learn to care for themselves. However, due to developmental conditions, illness, and the side effects of treatment, the child with cancer needs help or assistance from caregivers to care for himself or herself.

Orem's self-care/dependent-care deficit theory

Orem's self-care/dependent-care deficit theory of nursing is composed of three constituent theories: the theory of self-care/dependent-care, the theory of self-

care/dependent-care deficit, and the theory of the nursing system. The central idea of the theory is self-care that is defined as learned behaviors that purposely regulate human structural integrity, functioning, development and personal health and well-being.

According to Orem (1991), Self-care is deliberate action. Self-care is a response to self-care requisites or demands that an individual experiences. The concept of dependent-care 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." (Orem, 1995, p.9). Children require complete care or assistance with self-care activities. Such activities include providing for the nutritional, safety, hygiene, and developmental needs of children. When an individual engages in self-care/dependent-care practices, it is necessary to meet three types of self-care/dependent-care requisites: universal, developmental, and health deviation.

Universal self-care requisites are common to all human beings during all stages of the life cycle, adjusted to age, developmental state, and environmental and other factors. They are associated with the life process, with the maintenance of the integrity of human structure and functioning, and with general well-being (Orem, 1991). When it is effectively provided, self-care or dependent-care

organized around universal self-care requisites fosters positive health and well-being (Orem, 1995). The following eight self-care requisites are common to all human beings:

1. The maintenance of a sufficient intake of air.
2. The maintenance of a sufficient intake of water.
3. The maintenance of a sufficient intake of food.
4. The provision of care associated with elimination processes and excrements.
5. The maintenance of a balance between activity and rest.
6. The maintenance of a balance between solitude and social interaction.
7. The prevention of hazards to human life, human functioning, and human well-being.
8. The promotion of human functioning and development within social groups in according with human potential, human limitations and the human desire to be normal (Orem, 1995. p.191).

Developmental self-care requisites are associated with human developmental processes and with conditions and events occurring during various stages of the life cycle and events that can adversely affect development. Initially these requisites were subsumed under the universal self-care requisites (Orem, 1995). Developmental self-care requisites are relevant to the initial formation of human structural,

functional, and behavioral features of individuals and their dynamic movement toward increasingly higher and more complex and intricate levels of organization and functioning.

Health-deviation self-care requisites are associated with genetic and constitutional defects, human structural and functional deviations, with their effects, and with medical diagnostic and treatment measures (Orem, 1991). There are six categories of requisites:

1. Seeking and securing appropriate medical assistance in the event of exposure to specific physical or biologic agents or environmental conditions associated with human pathologic events and states, or when there is evidence of genetic, physiologic, or psychological conditions known to produce or be associated with human pathology.

2. Being aware of and attending to the effects and results of pathologic conditions and states, including effects on development.

3. Effectively carrying out medically prescribed diagnostic, therapeutic, and rehabilitative measures directed to preventing specific types of pathology, to the pathology itself, to the regulation of human integrated functioning, to the correction of deformities or abnormalities, or to compensation for disabilities.

4. Being aware of and attending to or regulating

the discomfoting or deleterious effects of medical care measures performed or prescribed by the physician, including effects on development.

5. Modifying the self-concept in accepting oneself as being in a particular state of health and in need of specific forms of health care.

6. Learning to live with the effects of pathologic conditions and states and the effects of medical diagnostic and treatment measures in a life-style that promotes continued personal development (Orem, 1995, pp.201-202).

Many basic conditioning factors (Orem, 1995), can affect the abilities to engage in self-care or affect the kind and amount of self-care required. There are ten factors or types of factors which are age, gender, developmental state, health state, sociocultural orientation, health care system factors, family system factors, pattern of living including activities regularly engaged in, environmental factors, and resource availability and adequacy.

In summary, Orem's self-care/dependent-care deficit theory provides holistic perspectives for assessing self-care/dependent-care performance of individuals. It can be used as the conceptual framework for this study.

Dependent-care demands of children with cancer

Self/dependent-care requisites arise not only from

disease, injury, disfigurement, and disability but also from medical care measures prescribed or performed by physicians (Orem, 1995). In this study, the following literature will be reviewed to describe possible dependent-care demands of children with cancer according to Orem's self-care theory.

1. Universal dependent-care demands of children with cancer

As stated earlier, universal dependent-care requisites include the followings:

1.1 Air, water, and food

The maintenance of sufficient intakes of air, water, and food provide individuals with the materials required for metabolism and energy production (Orem, 1995). Like a healthy child, a regular diet is suitable for the child with cancer during remission. The child should take all kinds of food, such as rice or noodles, vegetables and fruit, meat (pork, chicken, and fish et al.), eggs, and milk. Water and food must be clean. However, if the child's nutritional status is altered due to the disease and side effects of the treatment, it needs to be corrected. This will be explained under health deviation.

1.2 Eliminative process and excrements

Effective care associated with elimination processes and excrements should ensure effective control over the materials eliminated (Orem, 1995). Elimination of

excrements should be one time a day both in a healthy child and a child with cancer and good hygiene habits such as washing hands before eating and brushing teeth should be fostered.

1.3 Activity and rest

The maintenance of balance between activity and rest controls voluntary energy expenditure and regulates environmental stimuli (Orem, 1995). Exercise is essential for developmental progress in a number of areas, including muscle development and stimulating body functions and metabolic processes. Selecting activities, such as group activities, play with peers, et al., that stimulate, engage, and provide physical movement, effective responses, intellectual effort, and social interaction are needed.

Children with cancer are allowed to resume their usual activities with no severe complications during remission (Ball & Bindler, 1995). Adequate sleeping is also required.

1.4 Solitude and social interaction

Social interaction is essential to obtain the material resources essential to life, growth, and development (Orem, 1995). Maintaining that quality and balance is necessary for the development of personal autonomy and enduring social relations that foster effective functioning of individuals. Through play with others,

children are able to become involved with one or several peer groups in which they can gain status as respected members.

However, children with cancer may experience separation from friends, some family members, and significant others due to their disease and frequent hospitalization (Waskerwitz, 1994. In Betz, Hunsberger, & Wringht).

Rigid social restriction must be tempered with the child's need for resuming normal activity. Ordinarily the child can return to school when the absolute neutrophil count is above 500/mm³ (Whaley & Wong, 1991). If the level falls below this value, cautious isolation from crowded areas is advisable to prevent infection.

1.5 Prevention of hazards and promotion of normalcy

Prevention of hazards contributes to the maintenance of human integrity and to the effective promotion of human functioning and development (Orem, 1995). The promotion of normalcy prevents the development of conditions that constitute internal hazards to human life and the human functioning and development (Orem, 1995). The child needs to know hazards and safety. Safe environments are also needed. All measures should be instituted to control transfer of infection during hospitalization, such as the use of a private room, restriction of all visitors,

strict hand-washing techniques, and wearing masks when going to public places (Whaley & Wong, 1991). Children who have a low platelet count (below 100,000/mm³) are advised to avoid those activities that might cause injury or bleeding, such as riding bicycles and contact sports (football and basketball). Meticulous mouth care and rectal area hygiene are essential (Whaley & Wong, 1991).

2. Developmental dependent-care demands of children with cancer

Developmental dependent-care requisites are associated with human developmental processes and events occurring during various stages of the life cycle and events that can adversely affect development (Orem, 1995).

Long-term illness may delay a child's development. Therefore, children with cancer are at risk of delayed development because of frequent complications and remission of the illness as stated in the impact of childhood cancer. The promotion of development is needed. These self-care requisites are subsumed under the universal self-care requisites mentioned above. In addition, the child with cancer should be watched or observed regarding growth and development.

3. Health deviation dependent-care demands of children with cancer

Health deviation dependent-care requisites for

children with cancer include the following six categories:

3.1 Seeking and securing appropriate medical assistance.

The treatment of pediatric cancer include both acute episodes of illness and relatively uncomplicated periods of maintenance therapy. For the duration of therapy, the child with cancer is seldom free from the demands of at least outpatient medical care. When required, appropriate medical assistance should be available. Regular clinic visits and complete blood counts (CBC) are needed. The mother and the child should be reminded to call for medical assistance if any specific questions or concern arise.

3.2 Being aware of and attending to the effects and results of pathologic conditions and states, including effects on development.

Specific types of cancer show wide variations in prognosis, length of treatment, intensity of treatment, and residual patterns of permanent impairment. In order to participate in self-care or dependent-care actively, the child and his/her family need to know basic information about childhood cancer such as diagnosis, manifestations, prognosis, and its effects on body functioning and on the family.

For children with cancer, the malignant cells compete with normal cells for nutrients, which increase the

metabolic needs of the clients. Clients with cancer typically complain of anorexia and taste distortions (Robuck, 1995, In Potter & Perry). During this period of time, optimal nutritional support and the correction of nutritional deficits are needed.

Children with cancer always have anemia and decreased RBC levels because of cancer and the side effects of its treatment (Whaley & Wong, 1991) which decrease the oxygen-carrying capability of blood. A continuous state of severe anxiety also increases the metabolic rate and the oxygen demands. They need adequate provision of qualified air.

3.3 Effectively carrying out medically prescribed diagnostic, therapeutic, and rehabilitative measures.

Recent data among children with acute leukemia showed that they do not adhere to prescribed treatment regimens like other pediatric patients with chronic illnesses who fail to take prescribed medications (Klopovich & Trueworthy, 1985). Noncompliance with oral chemotherapy has also been demonstrated among children with cancer. Relapse still remains a problem among children with leukemia. Although little is known about why therapy fails, one of the two potential explanations is that the child does not take medication (Swenson & Stewart, 1987). Education, frequent contracting and behavior modification are the most

successful methods of assuring adherence (Swenson & Stewart, 1987). The mother should make sure her child takes the medicine as prescribed.

To monitor the progress of the illness and the effects of the treatments, scheduled clinic visits and diagnostic procedures are required. The child needs to be reminded of this treatment.

3.4 Being aware of and attending to or regulating the discomforting or deleterious effects of medical care measures performed or prescribed by the physician, including effects on development.

Although the treatment destroys the rapidly dividing neoplastic cells, it also destroys normal cells, and usually causes anorexia, nausea, and vomiting, and stomatitis (Ashwill & Droske, 1997). Therefore, cold food is often preferred. An adequate protein-calorie intake is essential to children with cancer as well as adequate fluid intake (Robuck, 1995, In Potter & Perry). Accurate records and keeping a balance of intake and output are essential during treatment. Small and frequent meals will keep the child from losing weight and sometimes hospitalization for nutritional purposes is necessary. Enteral feeding or total parental nutrition should be provided when necessary (Potter & Perry 1995).

Because of bone marrow suppression and immuno-

suppression due to treatment, preventing infection is critical for children with cancer. The use of a private room and the restriction of visitors should be adopted. If the WBC count is below 500/mm³, cautious isolation, such as avoiding being in crowded environment, contacting infected playmates, is advisable (Whaley & Wong, 1991). Oral and skin care are needed. The patient must be cautioned to avoid exposure to common contagious viral diseases.

Hemorrhage is a leading cause of death in children with some kinds of cancer. When the platelet count is below 20,000/mm³, severe spontaneous internal hemorrhage often occur (Whaley & Wong, 1991). Children should avoid those activities that might cause injury or bleeding such as riding bicycles, roller-skating, contact sports. Eating soft food to avoid GI bleeding is also essential. A soft toothbrush is more suitable for children and avoiding crush teeth. When complications occur, appropriate care should be provided and the child taken to hospital as soon as possible.

Pain, discomfort and stress resulting from various treatment modalities and diagnostic procedures also create requisites for dependent-care to be relieved. Therapeutic play, the use of relaxation techniques, hypnosis, and guided imagery are effective measures to help children endure painful procedures. These activities also help them master

skills for dealing with the adverse procedures that have become their new reality.

3.5 Modifying self-concept

One of the most important aspects of childhood cancer is the social isolation that often results from prolonged treatment regimens. Children experience long absences from school while receiving inpatient or outpatient treatment, so that even when they are well they are distant from their original age and peer groups. The immunosuppression and susceptibility to infection that result from chemotherapy further isolate the child and restrict activities that encourage contact with others. Children often develop a new peer group of other ill children and adult care providers, which is limited in its ability to provide normal growth experiences.

Often children must confront not only public response to their illness but also their own feelings about profound body image changes. Some children fight the sick role as part of their denial process for coping with their illness. Others willingly assume the sick role and use it to protect themselves from the conflicts inherent in interacting with well world. The child with cancer needs to foster a good self-concept and the family members especially the mother plays a very important role in influencing how children will perceive themselves during the periods of

treatment. Essential preparation and/or emotional support are needed both during therapy and after (Whaley & Wong, 1991).

3.6 Learning to live with the effects of pathological conditions and states and the effects of medical diagnostic and treatment measures in a lifestyle that promotes continued personal development.

Childhood cancer has been viewed as a chronic condition, the initial experience of diagnosis and initiation of treatment can be placed within the broader scope of how cancer and its treatment will affect the child and the family throughout the life span (Swenson & Stewart, 1987). The child needs to learn to cope with or manage the pathological conditions of cancer and also the effects of various treatments and accommodate them in his/her daily life.

Dependent-care agent performance of mothers for their children with cancer

Although Orem's self-care theory has been widely used in nursing practice and nursing research, most studies were related to adult illness. The use of the concept of dependent-care was limited.

Moore and Gaffney (1989) developed an instrument to measure mothers' performance of self-care activities for

their children. In 1996, these two authors conducted another study to test Orem's theory of self-care deficit. In this study, the relationship between dependent-care agent performance and basic conditioning factors was examined. Findings based on a sample of 380 mothers of healthy children from age 1 to 16 years revealed that the child's age and ethnic group were significant predictors of a mothers' performance of dependent-care activities for children.

Moore and Mosher (1997) used dependent-care agent performance as one of the variables to measure adjustment response of mothers and their children, aged of 9-18 years, to childhood cancer. In this study, adjustment responses for mothers were defined as dependent-care practices and anxiety. No significant difference emerged between the dependent-care practices of the on-therapy and off-therapy groups of mothers.

In summary, the mother is the major caretaker of the children, when the child is ill or not. However, few studies describing the dependent-care performance of mothers for children have been found. In China, research related to the dependent-care performance of mother for children has not yet been found.

Measurement of dependent-care agent performance of mothers for their children with cancer

In 1989, Moore and Gaffney developed the first instrument measuring activities of mothers performed for meeting the needs of their healthy child. The findings based on a sample of 476 women indicated that the dependent-care agent (DCA) questionnaire had a coefficient alpha of 0.91 with item-total correlation ranging from 0.27 to 0.63. DCA is a 5-choice, 39-item Likert scale. Domains from which items were derived included universal, developmental, and health needs as described in Orem's theory of self-care deficit (Gaffney & Moore 1996). Davies (1993) used this instrument to compare dependent-care activities for well siblings of a child with cystic fibrosis and those of a family without a child with chronic illness. No significance was found.

Moore and Mosher (1997) used Dependent-Care Agent Performance Questionnaire (DCAPQ) to measure the activities that mothers performed to meet their children's (9-18 years old) care needs or enhance their health status. DCAPQ was based on a previously established 39-item instrument (Moore & Gaffney, 1989) to which 16 items were added to make it more applicable to mothers of children with cancer. Scores on the scale ranged from 55 to 275 (higher scores indicate higher level of dependent-care agent performance or

practice). The coefficient alpha is 0.93 for this instrument. The content validity was established by basing items on information from healthy children and children with cancer about their health promotion, organizing the items to represent Orem's (1995) theory, and asking pediatric nurses to evaluate the questionnaire. Construct validity was investigated using factor analysis (Moore & Gaffney, 1989).

In this study, the DCAPO was modified to be suitable for measuring dependent-care performance of Chinese mothers whose children are diagnosed as having cancer according to Orem's theory.

Conceptual framework

Cancer is the leading cause of death from disease in children under 15 years of age (Ball & Binder, 1995). However, with the improved diagnostic technique and the proper medical treatment mortalities, about 70% of childhood cancer can be cured (Boman & Bodegard, 1995), which means made the acute and long-term effects of cancer and its treatments have been well identified. Due to the developmental state, disease, and the side effects of treatment, children with cancer need assistance or help from their mothers or caregivers to care for them.

Orem's self-care/dependent-care deficit theory is used as the framework of this study. According to Orem

(1995), dependent-care agent is someone who provides self-care activities for another whether a child or dependent adult. Dependent-care is "the continuing health-related personal regulatory and developmental care provided by responsible adults for infants and children or persons with disabling conditions." (Orem, 1995. p.9). In this study, dependent-care agent performance of Chinese mothers of children with cancer are activities that the mothers performed on their children's behalf in maintaining life, health, and well-being to meet three self-care requisites including universal, developmental, and health deviation.