

## CHAPTER 2

### LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

#### Literature review and related researches

For the purpose of this study, the review of literature includes (1) human needs; (2) needs of parents of hospitalized children; (3) factors influencing the needs of parents of hospitalized children; (4) responses to the needs of parents of hospitalized children.

#### Human needs

Need has been defined in various ways. According to Montagu (1970), a human need was viewed as an internal tension that resulted from an alteration in some state of the integrated person (Montagu, cited in Yura & Walsh, 1983). Kozier and Erb (1979) defined basic human needs as those necessary things which were required by human beings in order to maintain physiologic and psychological homeostasis. Similarly, Diekelmann and colleagues (1980) defined need as the basic human requirements which could be grouped as physical, emotional and social needs. Yura and Walsh (1983) considered that human needs referred to those that all people

must satisfy to enhance their images of themselves as persons. According to Wolf and colleagues (1983) and Craven and Hirnle (1992), human needs were any physiologic or psychological factors which were necessary, useful or desirable to maintain well-being and life. Narrow and Buschle (1987) defined basic human needs as the factors which must be present for optimal growth and development.

In the nineteenth century, Florence Nightingale attended to patient's needs and considered that much misery was caused not by disease but by failure to meet the patient's needs. She identified basic needs as fresh air, light, warmth, cleanliness of environment, personal cleanliness, elimination, positioning, variety and prevention of hospital diseases (Nightingale, 1859, cited in Narrow & Buschle, 1987).

The human needs may be individual, some relate to a family or a cluster of persons (household unit) and some relate to the community and society-at-large. They can be categorized as (1) biophysical needs of food, health, shelter, and clothing; (2) psychosocial needs encompassing education, employment, communication, mobility, recreation, security, self-realization, growth and development, and participation in social and cultural life (McHale, 1978, cited in Yura & Walsh, 1983).

Maslow's model of human needs provided a hierarchical framework for needs. According to Maslow (1970), human beings were dominated by a number of basic needs that tend to direct behavior until each need was satisfied. These needs were interrelated and tend to be hierarchical. The lower needs must be satisfied before higher level needs could be met and higher level needs did not even emerge until lower level needs had been at least minimally satisfied. The five level hierarchy of needs included: (1) physiological needs; (2) the safety needs; (3) the belongingness and love needs; (4) the esteem needs; and (5) the need for self-actualization.

Kozier and Gas (1967) identified patients' needs which included movement and exercise, hygiene, comfort, nutrition, safety, communication and learning, and spiritual needs. According to Kozier and Erb (1979), basic human needs were common to all people despite each individual had unique characteristics. All people had the same basic needs, but each person's needs were modified by the culture in which the individual lived. People met their own needs relative to their own priorities. Although basic needs generally must be met, some needs could be deferred. Needs were interrelated that some needs could not be met unless related needs were also met. According to Kozier and Erb (1979), the basic human

needs were subdivided into 6 categories: (1) physiologic needs; (2) stimulation needs; (3) protection needs; (4) love and belonging needs; (5) esteem needs; and (6) spiritual needs.

In sum, human needs are all necessary things required to maintain physiological and psychological homeostasis for human healthy or life, which can divided in physical and psychosocial needs. The physical and psychosocial needs are common to all human beings.

#### **Needs of parents of hospitalized children**

Children are very important to their parents (Smith et al., 1982). Hospitalized children have more physical and mental demands on their parents, so parents must arrange time to take care for the ill child in hospital and at the same time looking after other family members (Muller, Harris, & Wattley, 1986). Parents who worry about the health of the child and lack of information about treatment, prognosis and the hospital rules, and always feel frustrated, fear, helpless and anxious (Hymovich, 1984; Smith et al., 1982; Whaley & Wong, 1991). The parental role as the primary caregiver and protector change when the child admitted in hospital, parents feel less control and powerlessness (Muller, Harris, & Wattley, 1986; Thompson, 1995). They desire to do

something that can help their child. At the same time, parents must concern about their own work and financial problem (James & Mott, 1988; Rollins, 1991). Therefore, parents of hospitalized children have many needs to support their child and maintain health of themselves and the whole family.

Many studies documented needs of parents when their children were hospitalized. These needs can be categorized as follows.

#### 1. Information need

Usually, parents do not know what happen to their child when the child is admitted. They lack information about the illness as well as the unfamiliar hospital environment and that may cause stress to parents (James & Mott, 1988). Getting information can help parents reduce stress and enhance their ability to cope with the child's hospitalization as well as their ability to take care of their child (Hymovich, 1984; Mott, Fazekas, & James, 1985; Snowden & Kane, 1995). Information needs include:

##### 1.1 Information about the child's illness.

Parents need to know the facts of the child's condition, the cause of the disease, the treatment plan as well as the prognosis and how the disease affect the child's development (Fisher, 1994; Kasper & Nyamathi, 1988;

Kristjansdottir, 1991; Moyer, 1989; Meeropol, 1991; Smitherman, 1979; Snowdon & Kane, 1995; Wills, 1983). Furthermore, parents want to have questions answered honestly and having explanations given in terms that are understandable. They need to ask repeated questions; and need to receive written information about the child's health status which can be reviewed later (Harris, 1981; James & Mott, 1988; Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Kristjansdottir, 1991; Muller, Harris, & Wattley, 1986).

Terry (1987) identified the needs of parents of children aged 3 to 10 years who were admitted in a surgical unit of a large children's hospital. The parents identified that the need for information was mostly important to them. They wanted to know what was wrong with the child and what would happen to the child.

Similarly, parents of chronic illness children aged from 15 months to 21 years in Meeropo's (1991) study identified that information about diagnosis, effect of diagnosis on child's development were mostly important to themselves and their children.

## 1.2 Information about child care.

Parents need a defined role to take care of their child in the hospital (Smith et al., 1982). According to Muller, Harris, and Wattley (1986), parents did little help

to their child adaptation if they had no information about what to do and how to do. Parents need advice on how to care for the child in a medically acceptable way (Muller, Harris, & Wattley, 1986); need to know how to explain to the child about illness and hospitalization (Castiglia & Harbin, 1992), need to understand the child's reaction to the hospitalization and know how to support them (Kirschbaum, 1990; Marlow, 1977); and need to know how to take care of the child at home after discharge (Castiglia & Harbin, 1992; Snowdon & Kane, 1995).

1.3 Information about the hospital rules and routines.

Leaving their familiar surrounding to a new environment where nurses and physicians control and determine routines, parents may feel confuse and anxious (Whaley & Wong, 1991). Parents would like to have explanations of what it will be like before entering the wards. Being informed about the visit time and other hospital rules, having introduce about staffs and the environment of the hospital such as place to eat and drink and buy something are also needed (Harris, 1981; James & Mott, 1988; Whaley & Wong, 1991).

2. Need for the best medical care and nursing care for the child.

Parents are the primary caregiver to their child. They provide general health care and protection for their child (Smith et al., 1982). When the child have a health problem and must be admitted to the hospital, parents seek help from professionals to maintain health of the child, but usually they worry that nurses had not enough time to care for the child (James & Mott, 1988). Parents see themselves as ultimately responsible for their child's care but in the hospital they cannot do everything for the child like they usually do at home because the nurses and physicians determine the routines. They need to be able to trust that the health professionals were competent and effectively care for their child (Hayes & Knox, 1984; Vincent, Alexander, Money, & Patterson, 1996).

Smitherman's (1979) observation identified that generally parents needed to see that their hospitalized child was receiving competent physical care. Parents need to be assured that the child get the best medical care and nursing care, also need to be assured that a staff care about their child when they leave the hospital (Jacono et al., 1990; Kasper & Nyamathi, 1988; Kirschbaum, 1990; Kristjansdottir, 1991; Petrillo & Sanger, 1980).



### 3. Need for parental role.

Parents are legally responsible for the health and well-being of their children (Smith et al., 1982). But in the hospital, medical and nursing personnel assume control of the child's care, therefore, the parents' role have been interrupted (Kasper & Nyamathi, 1988). Since parents give up the role of parents of a well child and take on the unfamiliar role of parents of a sick child, they worry about their ability to parent their child and may feel helpless, dependent, less control, and powerless (Smith et al., 1982). Normally, parents need to feel useful and important to their child as parents (Kirschbaum, 1990; Kristjansdottir, 1991; Smitherman, 1979; Terry, 1987). They need to be with the child, participate in child's care and have input in decision making about the child's care (Algren, 1985; Magakat, 1992; Kasper & Nyamathi, 1988; Terry, 1987). Thus nurses should realize the important role of parents to promote children's physical and emotional well-being and support parental role and closed parent-child relationship through the hospitalization.

A qualitative, exploratory field study was conducted by Kasper and Nyamathi (1988). The researchers interviewed 15 parents whose children were between 6 months and 12 years of age admitted to the hospital to determine parental role

needs. The finding showed that parents needed to stay with the child and to participate in their child's care in anyway possible.

Algren (1985) surveyed role perception of 20 mothers of hospitalized children. The result showed that the majority of mothers preferred to perform many child-care activities for their hospitalized children. All mothers wanted to feed their child and most of them wanted comforting their child and stay with their child during procedures.

#### 4. Need for emotional support

Hospitalization of the child is a stressful experience to their parents. Parents feel anxious, fearful, powerless, and guilty (Smith et al., 1982). They need mental rest and relief (Hinds et al., 1996). Furthermore, parents' stress and anxiety could communicate to the child easily (Muller, Harris, & Wattley, 1986). Receiving emotional support can reduce psychological stress, help parents adapt and cope successfully (James & Mott, 1988; Whaley & Wong, 1991). Parents need someone near to support, need opportunity to express feelings and discuss with others, such as nurses, family members, friends or other sympathetic parents (Kasper & Nyamathi, 1988; Kirschbaum, 1990; Meeropol, 1991; Mott, Fazes & James, 1985; Moyer, 1989; Smitherman, 1979; Snowdon & Kane, 1995; Wills, 1983). At the same time, parents need to

keep a close relationship with other family members (Kirschbaum, 1990; Terry, 1987). They need other family members to be able to visit the child at the same time to maintain a sense of family togetherness and need a telephone nearby so they can use to contact their family (Kirschbaum, 1990; Petrillo & Sanger, 1980). Many parents report that it is very helpful to have someone with whom they can talk to, and because this person may not necessarily be a family member, support groups may be very helpful in meeting this needs (Jackson & Vessey, 1992).

Crout (1979) and Farrell and Frost (1992) reported that parents of hospitalized children had a strong need to relieve anxiety that they might have about their child's condition.

Result of Winkel's (1988) study indicated that 37% of the parents desired to join a support group to discuss emotions of their children who suffered from juvenile rheumatoid arthritis.

Similarly, Kristjansdottir(1991) used a qualitative approach to explore and identify areas of needs among parents of 2- to 6- year-old children who were hospitalized. The result indicated that parents needed to have a planned meeting with other parents to share and discuss their experience.

##### 5. Physical need.

Parents are individuals who have their own basic needs to maintain health. However, parents spend a great deal of time and energy to take care of the hospitalized children and may have no time to fulfill their own needs (Smith et al., 1982). While parents take care for their children in the hospital, they need time and a place to rest or sleep, they need food and drink, and need a bathroom near the ward. Also, they need someone concern about their own health (Jacono et al., 1990; Kristjansdottir, 1991; Terry, 1987; Wills, 1983).

Findings of Wills's (1983) descriptive exploratory study showed that all mothers taking care of their infants with tracheostomy reported their sleeping pattern changed and needed to rest. According to Smith and colleagues (1982), parents who needed sleep became irritable and unable to concentrate. Inadequate sleep might reduce their ability to make rational decisions, cope with the stresses of the illness, and maintain a functioning routine at home.

##### 6. Need for financial support.

Hospital fee, no time to work or long distance travel to the hospital may cause financial burden to parents of hospitalized children (Thompson, 1995). Frequently parents concern about the financial problem and need support, especially if the child need a long-term hospitalization

(James & Mott, 1988; Rollins, 1991; Wills, 1983).

In sum, although some studies focused on a specific condition that the child suffered a critical illness or a chronic illness, the parents' needs have more or less the same contents. Parents need honest and clearly information about the child's illness, need to know how to take care of their child, both physically and emotionally, as well as the information about hospital rules and routines. They need their child receive the best care in the hospital. Also they need to feel useful and important to the child's health and participate in child's care to enhance their parental role. They need emotional support from professionals, family members and others. At the same time, they have their own basic needs and need for financial support. All these needs are important to maintain the physical and psychosocial well-being of both the child and the parents.

#### **Factors influencing the needs of parents of hospitalized children**

Some studies considered the factors associated with needs of parents of hospitalized children including age of the child, types of illness, duration of the illness, number of children's prior admissions, family income and educational level of the parents (Fisher, 1994; Hymovich, 1976, cited in

Wills, 1983; Moyer, 1989; Phongkampan, 1994). The results of these studies showed no significant difference in the needs of parents and these factors. However, whether or not age and type of illness of the child will influence parental needs is worthwhile to be explored furthermore. As a pediatric nurse, the researcher is interesting in these two factors.

#### Age of children

According to Whaley and Wong(1991), children can be grouped into different age groups by common characteristics: infant(less than 1 year), toddler(1-3 years), preschooler (3-6 years), school-age children (6-12 years) and adolescent (12-18 years). Children in different age groups have different cognitive development levels, and their perceptions and reactions to the illness and hospitalization will be affected by their cognitive development level (Castiglia & Harbin, 1992; Foster, Hunsberger, & Anderson, 1989; Neff & Spray, 1996). According to Neff and Spray (1996), infants had more fear to separate from parents and to pain. Similarly, toddlers fear of separation from parents, loss of control and pain. However, hospitalization is less threatening to preschoolers than toddlers because of increasing outside contact. Preschoolers are self-centered and magical-thinking, they perceive illness as punishment for misbehavior. School age- children must deal with absence from school and peers,

but they can easily adapt to being separated from parents and can accept hospitalization more readily than preschoolers. Adolescents concern more about loss of control, enforced dependency on others and body image (Foster, Hunsberger, & Anderson, 1989; Neff & Spray, 1996).

Since parents must take care for their ill child physically and support them emotionally, their concerns may be different according to their child's age. Parents of younger children may have more concerns about feeding, rearing of the children, and more fear about whether the disease will threaten the children's life or not (Neff & Spray, 1996). Since younger the children are, more dependent they are on their parents. Parents of the younger children, therefore, must spend more time in hospital, thus, they have less time to concern about other family members and themselves (Pillitteri, 1981). For the older children, parents may have less anxiety because of the children's less upset and more cooperation with hospitalization (Wolfer & Visintainer, 1976), but they need to think more about children's socialization and provision for schooling (Pillitteri, 1981; Neff & Spray, 1996). Therefore, parents' needs may be influenced by children's age.

There are few researches studied the influence of the age of children on parents' needs. Hymovich (1976, cited in

Wills, 1983) also asserted that parents' needs were common to all parents regardless of the child's age. Moyer(1989) reported that regardless of the age of the child, their parents expressed a need for advice and support with child care. Similarly, in Phongkampan's (1994) unpublished master's thesis, she studied needs and received responses of 256 mothers of hospitalized children aged less than 14 years. The finding indicated that most needs of parents among children with different age groups were the same. However, at present, as one family one child policy has been implemented in China, once the child get sick, the parents worry and want the child recover as soon as possible. Furthermore, parents may be more overprotect to the young child, so the younger the child, parents may be more worry and have more needs. Therefore, in China it is interesting to explore whether the age of hospitalized children affect the parents' needs.

#### Types of illness

Acute illness and chronic illness are two opposite kinds of disease and have a different nature. Acute illness has rapid onset, last short time and usually has severe symptoms (Neff & Spray, 1996). Some acute illnesses may threaten survival (Ellis & Nowlis, 1994). Having an acute illness is an abrupt unscheduled and frightening experience to the child and the parents. Parents have minimal time to



learn about the acute illness. They feel uncertainty about how long the illness will last and whether it will threaten survival, or how quickly recovery may take place. Also they have less time to prepare and adapt to hospitalization. They have more fear of unknown and lack of information (Foster, Hunsberger, & Anderson, 1989; Neff & Spray, 1996). Therefore, the feeling of fear and anxiety caused by the sudden threaten and hospitalization of parents whose child have an acute illness is not generally felt by parents of a chronically ill child (Marlow, 1977).

Chronic illness is the calamity which lasts 3 months or more of the year or requiring at least 1 month of hospitalization of the year (Neff & Spray, 1996). Children with chronic illness need long-term and repetitive hospitalizations. Normally, they have to undergo some invasive and painful procedures. Therefore, parents need to help these children to cope with these situations and protect them from negative experiences of hospitalization (Robinson, 1987). Because parents spend more time to take care of the ill child in the hospital, they may be overwork to care for other family members, and must try to minimize family disruption (Jackson & Vessey, 1992; Robinson, 1987). Also, children with chronic illness may experience developmental lags in acquiring cognitive, communicative, motoric,

adaptive, and social skills compared with other unaffected children. In addition, chronic illness influence child's development more than acute illness because of side effects of drugs, pain, isolation from peers and family. So that parents must concern more about child's development issues (Jackson & Vessey, 1992; Meeropol, 1991; Muller, Harris, & Wattley, 1986). Furthermore, the problem of caring for a chronically ill child is more complex than caring for an acutely ill child and parents need more knowledge and financial support (Jackson & Vessey, 1992; Marlow, 1977). Therefore, parents' needs may be different between parents of acutely and chronically ill children.

Few studies explored whether the needs of parents of acutely and chronically ill children were different. After the extensive literature review, Kristjansdottir (1991) reported that parents' needs had more or less the same content whether their child was hospitalized for elective surgery, chronic illness, terminal illness, or emergency admission. According to Hymovich (1976, cited in Wills, 1983), needs of parents of hospitalized children were common to all parents regardless of the child's type of illness. Therefore, further researches should be done to explore the difference of parents' needs between parents of acutely and chronically ill hospitalized children.

### Responses to the needs of parents of hospitalized children

Responses to parents' needs are very important. Meeting the needs of parents can promote their own health as well as the children's health. If the information needs of parents have not been met, parents' understanding of the child's situation will decrease. They may feel confused and anxious and their ability to take care of the child will be decreased (Whaley & Wong, 1991). According to Kasper & Nyamathi(1988), their ability to cope with the child's hospitalization was influenced. In addition, because how the child understand and adapt to the illness and hospitalization mainly depend on their parents, whether the parents cope effectively can influence the child's understanding and adaptation to hospitalization as well as the treatment outcome (Hind et al., 1996; Gibson, 1988; Schmeltz & White, 1982). According to Kasper and Nyamathi (1988), the unmet parental role needs were likely to create stress to parents. The stress or anxiety can transfer easily to their child with a potentially negative impacts on the child's adjustment and recovery(Schepp, 1991; Muller, Harris, & Wattley, 1986). Petrillo and Sanger (1980) also considered that uninformed or emotionally upset parents were often unable to help their children. Also if the physical needs of parents have not been met, it may cause physical exhaustion which may reduce