### **CHAPTER 2**

### LITERATURE REVIEW

The review of the literature in this study includes:

The Critically III Patients

Impacts of Having Relatives in Critical Illness on Their Family Members

Needs of Families who have Members Admitted to Critical Care Units, Dimensions and Measurement of Family Needs:

- 1. Needs of families who have members admitted to critical care units
- 2. Dimensions of family needs
- 3. Measurement of family needs

Nurses' Perceptions of Needs of Families who have Members Admitted to Critical Care Units

The Factors that Influence Families' and Nurses' Perceptions of Needs of Families who have Members Admitted to Critical Care Units:

- The factors that influence families' perceptions of needs of families who have members admitted to critical care units.
- 2. The factors that influence nurses' perceptions of needs of families who have members admitted to critical care units.
- 3. The factors that influence both families' and nurses' perceptions of needs of families who have members admitted to critical care units.

Intensive Care Unit (ICU) and Coronary Care Unit (CCU) in Central Java, Indonesia

### The Critically Ill Patients

Critical illness is defined as the presence of real or potential life-threatening health problems requiring continuous observation and interventions to prevent complications and restore health (Beare & Myers, 1994). In addition, critically ill patients' conditions are totally unstable, nursing dependent, requiring sophisticated technologies and thus requiring many hours of care per patient. The patient also requires constant and intensive multidisciplinary assessment and intervention to restore stability, prevent complications and maintain optimal responses (Kinney et al., 1993). Commonly, the critically ill patients are admitted to the Intensive Care Unit (ICU) or Coronary Care Unit (CCU).

An intensive care unit is a specially staffed, and equipped, separate and self contained section of the hospital for the management of patients with life threatening or potentially life threatening conditions (NSW Department of Health, 1993 cited in Beeby, 2004). ICU patients can be divided into two populations: those who are critically sick and require active therapy, and those who are relatively stable but require specific monitoring not found outside the ICU (Hoyt, Tonnesen, Allen, & Safar, 1991), such as mechanical ventilation and circulatory support. The common diagnoses for patients admitted to intensive critical care units are respiratory failure, acute renal failure, infection, coronary artery disease, acquired immunodefiency syndrome complicated by respiratory failure resulting from pneumocystis carinii

pneumonia, and non-traumatic coma (Hoyt et al., 1991). Also, admission may be a result not only of medical problems but also of motor vehicle accidents, trauma, acute head injury, and major surgery, amongst other conditions (Beeby, 2003, Bucher & Melandar, 1999). Respiratory distress following surgery, trauma or pancreatitis, multiple organ failure, hemodynamic in stability, and post transplantation are considered as requiring admission to critical care units (Department of Surgery, 2004).

### Impacts of having Relatives in Critical Illness on Their Family Members

Hospitalization of a critically ill family member is stressful for the entire family (Leung et al., 2000). The family may view a member's illness as a threat to the family's equilibrium and integrity (Aguilera, 1994). According to Urban (1998) and Cullen, Titler, and Drahozal (2003), the reactions of family members of relatives' critical illness include fear and anxiety, and feeling disorganized. Also, family members experienced helplessness, grief, and change in the family roles and responsibilities (Fleury & Moore, 1999; Hupcey & Penrod, 2000; Johnson et al., 1995). The impacts of critically ill patients on their family members will be categorized as follows:

### 1. Physical impact

When a family member is critically ill, members concentrate all their energy on the patient, at the expense of their own physiologic needs (Dolan, 1991). Family members of intensive care patients may experience stressors that threaten both personal health and family integrity. Horn and Tesh (2000) studied the effect of

critical care hospitalization on family members of 50 patients, and found that family members endure multiple concurrent stressors and exhibit numerous behavioral responses, including changes in eating, sleeping, and activity, which make them more susceptible to physical illness (Halm et al., 1993). Most respondents experienced fewer hours of sleep and poorer sleep quality because of sleeping in ICU. All of the respondents reported changes in eating patterns and types of food eaten because of diminished appetite, and 78 % of the respondents reported changes in many activities and increases in waiting and thinking.

### 2. Psychosocial impact

Psychosocial impact of critically ill patients on their families is fear, anxiety, depression, grief, and shift of responsibility. Fear and anxiety are the common responses of family members to the critical illness (Kinney, Packa, & Dunbar, 1993; Mitchell, Courtney, & Coyer, 2003). Kleiber et al. (1994) found that feelings of fear and loss of control were dominant in the early stages of the critical illness. One study of symptoms of anxiety and depression in family members of intensive care unit patients in 920 family members, Pochard, et al (2001) found that 69.1% of family members of intensive care unit patients had anxiety and 35.4 % had depression. Furthermore, various studies document that family member of critically ill patients experience high levels of anxiety (Kinney, Dunbar, Brooks-Brunn, Molter, & Vitello-Cicciu, 1998, Leung et al., 2000).

Another impact of critically ill patients on the family is grief. Grief is regarded as the total response to the emotional experience of the loss and is manifested in thoughts, feelings and behaviors (Kozier & Erb, 1987 as cited in Beeby, 2003).

Tearfulness, sadness, and other grief behaviors may be seen as the responses. This is because an admission in the ICU and CCU are often perceived as a sign of a near-death situation (Hudak, 1998).

Having relatives in ICU and CCU will affect family roles and responsibilities (Hupcey & Penrod, 2000; Johnson et al., 1995), such as increased responsibilities and change in routine, and reflect the physical and emotional burdens. In a study to explore the impact of a critical care illness on the family, Titler. Cohen, and Craft (1991) found that disruption of home routines and role conflict were frequently identified by family members as changes resulting from the stressful experience of having a family member in a critical care unit.

Seeing the sick patient in the hospital environment reinforces their worry. Their sense of helplessness in not knowing how to help their sick members adds to their distress (Urban, 1998). Moreover, family members in critical care units may experience stress, disorganization, and helplessness, which may ultimately result in difficulty in mobilizing appropriate coping resources, thus leading to anxiety (Hickey, 1993; Kinney et al., 1998; Leith, 1998; Mendonca & Warren, 1998; Urban, 1998).

### 3. Spiritual impact

Critical illness affects the family members' spirituality. Individuals can have a serious spiritual problem that causes distress, or experience a spiritual euphoria that may create eustress (Taylor, 2003). Spiritual impacts may occur when an individual faces emotional stress, physical illness or death (Narayanasamy, 1999). These effects have been supported by Mitchell, Courtney, and Coyer (2003). Family members are distressed as they cope with the uncertainty of the immediate and long-term outcomes

for their relatives, including possible death or disability. These events challenge the person's usual approaches to finding consolation and meaning, particularly in the face of suffering (Reed, 1991 as cited in Narayanasamy, Clissett, Parumal, Thompson, Annasamy, & Edge, 2004).

In conclusion, most critically ill patients' family members are greatly influenced by fear and anxiety, grief, disorganization, helplessness, and changed family roles and responsibilities. These situations can cause psychosocial, physical, and spiritual impacts on the family, and will lead to difficulty in mobilizing appropriate coping resources of patients' family members during critical illness.

### Needs of Families who have Members Admitted to Critical Care Units, Dimensions, and Measurement of Family Needs

### 1. Needs of families who have members admitted to critical care units

Humans are complex organisms, influenced by and responsive to both internal and external environments. Our behaviors, our feelings about self and others, our values, and priorities we set for ourselves are all the result of physiologic and psychosocial needs (Taylor, Hillis, & Priscilla, 1993). Abraham Maslow (Maslow, 1970 is cited by Potter, & Perry, 2001) ranked human needs on five levels. The five levels in ascending order are physiologic needs, safety and security needs, love and belonging needs, self-esteem needs, and the need for self-actualization (Potter & Perry, 2001). Human needs are ranked on an ascending scale according to how essential the needs are for survival.

Critical illness threatens the family's most basic function, the support of the basic survival needs of family members (Hickey, 1993). According to the U.S. Bureau of Census, family is composed of persons joined together by bonds of marriage, blood, or adoption and residing in the same household (Friedman, 1998). Since the family unit is the sum of its members, when one member becomes critically ill, the whole family is affected. Families react automatically to the critical illness of a family member in a manner that will be least disruptive and upsetting to the family's structure and the sick family member. They employ a variety of coping behaviors to alleviate the crisis of critical illness (Herz, 1980 is cited by Hickey, 1993).

Molter (1979) conducted an exploratory descriptive study identifying needs of families of ICU patients using structured interviews of 40 relatives. She also presented the needs in family members of the critically ill such as spouse, children, siblings, aunts, and parents. The interviews utilized a 45-item questionnaire of needs statements that was constructed from literature reviews and surveys of graduate nursing students. Molter (1979) identified the family's primary needs as hope. Moter (1979) found that chaplains, friends and relatives along with medical and nursing staff met this need. Further significant needs of families of ICU patients identified were the need for honest information and the need to know that the staff cared about the patient.

In Daley's (1984) study, she utilized a modified version of Molter's initial study to identify the needs of the family in the first 72 hours of patient admission to the ICU. Daley's rationale for identifying these needs was that the family was in crisis during the first hours following their relative's admission to the ICU and their

established family roles and functions were disrupted. Interview should not take place earlier than 24 hours because in this period family members would have difficulties in following directions and concentrating on the questions, and the average length of stay in ICU was 72 – 96 hours (Lee & Lau, 2003). Daley (1984) contended if the family needs were identified and met it would be easier for families to regain their emotional stability and cope with the crisis situation. This investigation was conducted using structured interviews to study a sample of 40 relatives. The results of Daley's (1984) investigation were similar to those of Molter (1979). Hope and information were rated as a high priority of the families of ICU patients. Daley (1984) recognized the primary need for the family as the need to know what may be the expected outcome. Results of this study indicated that family members need to have their immediate anxieties relieved by medical and nursing staff.

Then, Leske (1986) adapted Molter's (1979) initial questionnaire, to assess the needs of relatives of ICU patients. The needs statements were rearranged so as to change the order of the list and an additional open-ended question was added to identify needs that had not been recognized by Molter (1979). This instrument was named as Critical Care Family Need Inventory (CCFNI). Leske (1991) examined the internal consistency reliability and construct validity of CCFNI. Family need data were obtained from 677 subjects, collected by 21 nurse investigators in 14 states over a period of 9 years (1980-1988). Five dimensions were identified and they were labeled as needs for support, comfort, information, closeness and reassurance.

In each of these studies, (Daley, 1984; Leske, 1986; Leung et al., 2000; Lee & Lau, 2003; Molter, 1979) the family members of patients admitted to the ICU were

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faced with a highly stressful situation. They had significant needs that needed to be addressed in order to assist them cope with the crisis effectively. It is often nursing staff that can assist family by identifying and meeting their needs of hope, honest information and caring about the patient.

### 2. Dimensions of family needs

The literature has identified several family needs, such as the needs for safety, the need for love, the need for acceptance, the need for confidence, the need for good relationship, the need to ventilate emotions, the need for involvement in care, and the need to make sense of the experience (Bond, Draeger, Mandleco, & Donnelly, 2003; Hampe, 1975; Hickey, 1993; Maslow, 1970 as cited in Potter, & Perry, 2001; Scheep, 1991; Terry, 1992 as cited in Thaipak, 2001). However, this study will focus on 5 family needs which have already covered needs for acceptance, and love, as stated below:

### 2.1 Needs for support

Support is the active help and assistance that are given to family members to enable them to cope with the crisis situation (Andrew, 1998 as cited in Beeby, 2004). Support or lack thereof, will either assist the family to cope with their grief or be overwhelmed by the crisis situation. Family members need support to express feelings and emotions, handle financial and family problems, obtain spiritual consultation, and feel concern for themselves (Leske, 1991).

By supporting the family, critical care nurses have the ability to assist the family in crisis. Critical care nurses can assume the responsibility for assessing the adequacy of the family's ability to function during the crisis and for providing or

coordinating the necessary services to help families restore their equilibrium (Hickey, 1993). As a result, a patient's family members can give support to his or her relative. From the literature, family support has been found to play a significant part in promoting the patient's recovery and progress (Giuliano, Giuliano A., Bloniasz, Quirk, & Wood, 2000; Kosco & Warren, 2000).

Even though family members did not rank support needs as high on the CCFNI as they did on proximity, assurance, and information needs (Boonbarwornrattanakul, 1998; Redley, Beanland, & Botti, 2003), emotional support has been emphasized by the family members in numerous studies (Lee & Lau, 2003; Mendonca & Warren, 1998; Mi-Kuen et al., 2000). The majority reported that support did not come from healthcare professionals, but rather from relatives and close friends. On the contrary, Lee, Chien, and Mackenzie (2000) found that doctors and nurses were identified as the most appropriate person to meet their needs.

### 2.2 Needs for comfort

Comfort needs include convenient bathroom, comfortable furniture, nearby telephone, good food, and an attitude of acceptance from hospital staff allowing family members to remain near the ill member for longer and a more tolerable period of time (Kleinpell & Powers, 1992; Horn & Tesh, 2000). Even physical rest, peacefulness, safety, and a respite from the hospital environment reflected comfort need (Kolcaba, 1994; Leske, 1991).

On the other hand, patients' family members rated that their personal needs were less important (Al-Hasan & Hweidi, 2004; Horn & Tesh, 2000; Lee et al., 2000). Evidently, most family members did not have much concern about their personal and

physical needs. Physical comfort needs included disruptions in physiologic mechanisms that need correcting and maintaining of homeostasis (Kolcaba, 1994). The families' immediate needs appeared to be focused on the care of the critically ill patient and on being with the patient, rather than on their own feelings and comfort (Jamerson et al., 1996; Lee et al., 2000; Leung et al., 2000). According to Leske (1991), older family members and family members with previous experience of critical illness are more likely to rate comfort as important.

In addition, Lee and Lau (2003) pointed out that most of the unmet needs identified in their study were related to hospital facilities (e.g. furniture, waiting room, telephone, and toilet) and unit policy (e.g. visiting hours). Similarly, the literature has suggested that a waiting area with comfortable furniture should be provided near the patient because a supportive environment is important for the well-being of family members (Brickhill, 1995; Halm et al., 1993).

### 2.3 Needs for information

Information needs mean the needs of family members related to the information, explanation, prescription, and advice from health care providers given in terms that are understandable, clear, accurate, and exact (Leske 1991). This finding was consistent with Moser, Dracup, & Marsden, (1993), who indicated that strategies to assist families were the easily understandable language terms directly related to their needs. Also, families want to receive effective and intelligible information devoid of inconsistencies (Azoulay et al., 2001).

Furthermore, realistic information about treatment of the ill member helped families know what to expect and what to do next (Leske, 1991). The information

might be obtained from healthcare providers or by being with or seeing the patients. Information about the relative and tracking his/her progress are needed to alleviate family members' stress and uncertainty. The patient's family members wanted to know the facts concerning the patient's condition, the diagnosis, treatment plan, the unit which gave care after ICU, and the costs of services (Al-Hasan & Hweidi, 2004; Molter, 1979). However, the type of information that families want from nurses is related to the patient's general well being (Henneman & Cardin, 2002), such as vital signs (stable vs. unstable), comfort level and sleeping patterns, and patients' family members do not expect the nurses to give information about prognosis, diagnosis, or treatment plan.

Information need was rated as very important in many studies of family needs in different critical care settings (Daley, 1984; Kleinpell & Powers, 1992; Leske, 1986; Lee, 1998; Leung et al., 2000; Molter, 1979; Norris & Grove, 1986; Warren, 1993), and in culturally diverse groups (Al-Hasan & Hweidi, 2004; Walters, 1995; Waters, 1999).

### 2.4 Needs for proximity

Proximity is the need to be near the critically ill member (Molter, 1979; Leske, 1991). This includes visiting frequently, receiving daily information, being called at home about condition changes and transfer plans, and talking to the nurse (Bijttebier, Delva, Vanoost, Bobbaers, Lauwers, & Vertommen, 2000; Leske, 1991). The ability to visit frequently and have fewer limits on visiting times is seen as a way to promote closeness and emotional support (Leske, 1991), it will also bring about a reduction of

the patient's feeling of isolation and improve family satisfaction with the critical care experience (Cullen et al., 2003).

Family members want to be near their loved ones who are sick, physically and emotionally (Lesske, 1986; Mendonca & Warren, 1998; Molter, 1979). Not only do they want to provide support by being there but also their physical presence allows them to witness how their family members were being cared for (Henneman & Cardin, 2002). One study of anxiety during critical illness of a family member found that some families wanted to be involved with the physical care of the patient, for example feeding and hygiene, care of tubes, turning, and positioning (Reider, 1994). In addition, family members needed to be with their relatives to maintain the natural bond among them (Al-Hasan & Hweidi, 2004).

Kleiber et al. (1994) further reported that the need to be with or near the patient was most intense during the initial stages of the critical illness and lasted until the patient had shown signs of stabilization, improvement or recovery. Nurses can be proactive in the situational crisis by promoting the family situation and their involvement in the patient's care together with the provision of relevant information about their condition and treatment (Wooley, 1990).

### 2.5 Needs for assurance

Feelings of fear and loss of control were dominant in the early stages of the critical illness (Kleiber et al., 1994). According to Twibell (1998) assurance is directly linked in meaning to the needs such as family perceptions of the chance of recovery, level of family stress, and the effectiveness of frequently used coping styles.

All families need assurance for a realistic appraisal of the situation. Assurance is one strategy to alleviate stress, avert a potential crisis, and reduce uncertainty (Leske, 1991). Within the family needs literature, hope has consistently been identified as a priority need (Ploufield, 1999; Vaicheeta, Kongsuktrakul, & Vrolan, 1999). The importance of the need for hope has been consistently emphasized by families during the critical illness of a family member (Hampe, 1986; Molter, 1979). Oddy, Humphrey, and Utley (1978 as cited in Ploufield, 1999) defined hope as the person's belief that a positive outcome will result. Family members expressed with certainty that the patient would recover.

Hope reflects a more spiritual notion that fate is not predetermined and that the patient's emotional and physiologic responses to critical illness are influenced by the care that is provided, thus the word hope may refer to the family's hope that the patient is comfortable during the illness (Henneman & Cardin, 2002), that he/she is receiving the best possible care, and that either a comfortable recovery or death will follow (Hickey, 1993), will not suffer and will die peacefully (Dolan, 1991). Family members have also expressed the need to protect and maintain the dignity of the critically ill patient (Burr, 1998). Addressing the family's need for hope of recovery will empower the family to cope with the crisis (Beeby, 2003).

Some studies found that information and assurance needs figured highly in the critical care setting (Lee et al., 2000; Leung et al., 2000; Norris & Groves, 1986; Quin et al., 1996; Wong, 1995), whereas needs related to comfort and support were perceived to be less important (Al-Hasan & Hweidi, 2004; Kleinpell & Powers, 1992;

Mendonca & Warren, 1998). Families were eager to identify the patient's progress, and lack of current information about the patient served to heighten their anxiety.

Based on a review of relevant literature, the needs of family members of critically ill patient are the response of the family in crisis. Hospitalization in ICU and CCU are stressful event for the patient and the family. This event will lead to turn into a crisis. Moreover, patients' families are in a state of disequilibrium; they are more susceptible, more open to intervention during this state. The families will seek help from others. Identifying the needs of family members of critically ill patients will facilitate nurses in helping family members to improve their abilities to resolve the crisis and return to equilibrium. By providing the family with information, support, coping strategies, or referrals to support agencies, the critical care nurse can foster family acceptance of the critical care hospitalization of their family member.

### 3. Measurement of family needs

It is essential to assess the family unit, what the critical illness means to the family members, how the family members have been affected by the illness, and the support that is required by family members. The instrument used most commonly to measure family needs among family members of critically ill patients is Critical Care Family Needs Inventory (CCFNI). The purpose of CCFNI is to assess the degree of importance on a wide variety of needs with family members of critically ill adult patients (Leske, 1991).

The CCFNI has been used extensively in some research (Curry, 1995; Lee & Lau, 2003; Leung et al., 2000; O'Maley et al., 1991; Patitas, 1999). The CCFNI is one of the family needs instrument, which was used extensively to measure family needs

in adult critically ill patients. The scale is widely used and has been found to have high internal consistency. The reliability of the total scale according to Cronbach's alpha was ranged from internal consistencies of 0.88 to 0.92 (Leske, 1991). Leung et al. (2000) studied the validation of the CCFNI in a China population and found that the correlation coefficient for test-retest reliability was .90. The Cronbach's alpha coefficient was .84 and for the five domains ranged from .65 to .82. The CCFNI can be used to describe family needs in various populations, and explore correlates or determinants of specific needs and their importance (Leske, 1991). Based on these conditions, this measurement will be used in this study to measure the family needs of critically ill patients.

### Nurses' Perceptions of Needs of Families who have Members Admitted to Critical Care Units

Perception is the way a person views her/himself, the environment, and her/his relationship with others in the environment. Another definition of perception is derived from the senses of vision, hearing, touch, and smell (Barry, 1996). In addition, Bodie and Chitty (1993 as cited in Mi-Kuen, et al., 1999) defined perception as the selection, organization, and interpretation of incoming stimuli into meaningful messages, and different people coming from different backgrounds perceive information differently because of personal experience, previous knowledge, alertness, perception, and social cultural background.

Studies have shown that caring for the families of patients who are critically ill is believed to be an essential component of the nurse's role and responsibility for

meeting the needs of family (Gelling, 1999; Hardicre, 2003). However, there is a lack of understanding of the relationship between family needs and patient outcomes, and nurses do not perceive meeting family needs as their responsibility influence nurses' perception of family needs (Mi-kue et al., 1999; Titler et al., 1991). On the other hand, Cullen et al. (2003), in their study about family and pet visitation in the critical care unit, reported that one third of critical care nurses said that they did not have the skills needed to meet the psychosocial and emotional needs of families.

Holistic nursing care in the ICU and CCU includes assessment and identification of family needs when relatives have a life-threatening illness (Beeby, 2003). As professional holistic care providers, nurses respond to the needs of the patient's physiological illness and they also contribute to the patient's and family's psychological and spiritual being and the coping strategies required for critical situation (Hudak, Gallo, & Morton, 1998).

Not many studies have examined the difference of family members' and nurses' perceptions of family needs in critical units. Norris and Grove (1986) conducted a study using descriptive survey, which identified the psychological needs of families of the ICU patient. Relatives and nursing staff were surveyed in order to compare the perceptions of the psychosocial needs of the families of ICU patients. The perceived needs of families indicated a high priority for hope. Again the recurrence of the need to receive honest information about the patient's condition and feel that the staff cared about the patient was evident. The staff, however, did not recognize the family's need for information and need to feel that staff cared about the patient. Yet they did not list hope as such a high priority. Norris and Grove (1986)

suggest the reason that hope was ranked as a lower priority was that the nurse is an objective individual, who was not a member of the patient's family, thus they might be unwilling to give hope to the family if they perceived it as being false hope. This finding was the same as that of a study conducted by O'Malley et al. (1991), which compared families' and critical care nurses' perceptions of the needs of families of critically ill patients in intensive care units, in the United States.

Kleinpell and Powers (1992) identified important needs of families of critically ill patients, and the degree to which these needs were being met. Sixty four family members and 55 nurses who had at least 6 months experiences in critical care were asked to complete a modified version of CCFNI (Molter & Leske, 1983). They reported that several needs of family members were both more important and less satisfactorily met than nurses perceived. These needs included the knowledge given about which staff members could give what type of information, the directions as to what to do at the bedside and to have friends nearby for support. Nurses may have undervalued the need for family members to have specific information about staff member roles, as well as what to do at the patient's bedside and having friends nearby for support.

In Hong Kong, Mi-kuen, French, and Kai-kwong (1999) examined differences in family and nurses perceptions of the importance of 45 needs in critically ill neurosurgical patients. A total of 52 family members and 36 nurses in three neurosurgical special care units in Hong Kong were asked to complete the Chinese version of the CCFNI. The rank order of most important needs reported by family members indicated that the majority of needs were related to assurance, whereas

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needs for support and comfort were much less important. When rating needs, nurses underrated most of the needs considered important by family members. Need for proximity was also underrated in importance by nurses when compared to family ratings, and needs for support were heavily overrated by nurses.

In China, Leung et al. (2000) used the Chinese version of CCFNI to identify family members' perceptions of their immediate needs within 48 to 96 hours following admission of a relative to a critical care unit and to compared their perceptions with critical care nurses' perceptions of the family needs. Leung et al. (2000) surveyed a convenience sample of 37 Chinese family members and 45 registered nurses in a 10-bed ICU and 2-bed CCU in Hong Kong. Leung et al. (2000) categorized their result into four main areas of needs. These were the needs for assurance, information, support, and proximity. They detected a few significant differences between the family members' and critical care nurses' rankings of the needs statements. Some of the differences in need importance between family members and nurses could have been related to family members' perceptions as to who might be the most suitable professional to meet specific needs.

In summary, not many studies have been conducted on the differences between patients' family members and nurses' perceptions of family needs in critically ill patients. More information is needed about intensive care nurses' perceptions of family needs and the concordance between family and nurse perceptions of the importance of those needs. From the literature, all the studies mention the 5 dimensions including support, comfort, information, proximity, and assurance; however, they are ranked differently in different studies. Culture has also

been found to influence the expression of family needs in critical illness (Rukholm et al., 1991). Moreover, the perceptions of family members and nurses were also found to be different.

# The Factors that Influence Families' and Nurses' Perceptions of Needs of Families who have Members Admitted to Critical Care Units.

This section reviews the literature related to several factors that influence the families' and nurses' perception of family needs of critically ill patients as follows:

# 1. The factors that influence families' perceptions of needs of families who have members admitted to critical care units

1.1. Gender, age, and the relationship of the relative to the ill person

Findings related to gender, age, and the relationship of the relative to the ill person as factors influencing family members' perceptions of family needs of critically ill patients are reviewed in this section. A study conducted by Lee and Lau (2003) reported that female subjects (N = 13) rated the needs to see the patient frequently and to visit any time as more important than did male subjects (N = 15). Bijttebier et al. (2000) revealed a significant association of age with the need for comfort (r = 16, p = .03), suggesting that the relatives' need for comfort increases with age. No significant difference in need was identified between children, spouse, grandson/daughter and siblings in immediate needs of adult family members, indicating similar perceptions when a loved one was hospitalized in ICU (Boonbarwornrattanakul, 1998). This finding was consistent with that of Price et al.

(1991), which revealed that parents, spouses, siblings, adult children and significant others generally ranked needs in a very similar way.

### 1.2 Culture and religion

Some studies found that the family needs of critically ill patient are different across cultures (Kai-Kwong 1999; Kleinpell et al.1992; Leung et al., 2000; Mikuen, French, & Watters, 1999; O'Malley et al., 1991,), and also religion influences the perceptions of family in critical care (Kai-Kwong et al., 2000; Mikuen et al., 1999; Waters, 1999). In Hong Kong and China, where there is a strong belief in external forces such as luck, fate and chance, strong values in the Confucianist, Buddhist, and Taoist traditions, maintaining hope as an important need may be explained in part by family members (Kai-Kwong et al., 2000). On the other hand, African American family members who were Protestant rating "telling me about chaplain services" much higher than White family members who were Protestant and Catholic (Watters et al., 1999).

In Indonesia, the individual Javanese serves as a harmonious part of the family or group. The nuclear family is the most important group. Attention and care, sharing of burdens, as well as mandatory obligations, are expected among family members (Koentjaraningrat, 1985). In addition, mutual assistance and sharing of burdens, within both the family and the community, should reflect the concept of "rukun" (Murder, 1978 as cited in Koentjaraningrat, 1985). The definition of rukun is soothing over of differences, cooperation, mutual acceptance, quietness of heart, and harmonious existence. Therefore, it is customary for the family members as well as the close relatives and friends to pray and eat together as a group. The Javanese

undertake hardship and suffering deliberately for religious reasons in any critical situation, or when experiencing a crisis in family life (Koentjaraningrat, 1985). Also, Javanese people believe in "nrimo" (acceptance). Nrimo is defined as acceptance of destiny that is to think in the positive way to promote keeping a peaceful mind (Ferguson, 2002).

The majority of the Javanese people are Muslims and the rest are Christians, Buddhists, and Hindus (Riyadi, 1994 as cited in Suza, 2003). Islam is influential in shaping the interpersonal relationships of the Moslems. It is expressed in most daily activities of the people. In an Islamic community, the family system is very strong, they are close and have strong relationship (Huda, 2004). The worldview of Islam towards health and illness incorporates the notion of receiving illness, fear, suffering, and death with patience, meditation and prayers (Mills, 1996; Hussein, 2000). In times of distress and illness, the Muslim finds the greatest solace and comfort in the remembrance of God (Huda, 2004). Despair, hopelessness, and frustration are sin in Islamic belief because everything that happens on the earth is with God's supervision. Hope and optimism for the best life in the future is embedded in Islamic philosophy (Mills, 1996).

The severely ill person, who might be distracted by his pain, greatly appreciates a companion who can read the Qur'an to him/her and remind him/her of God. For Muslim people, praying and reading the Qur'an are very important. This is a direct link between the worshipper and Allah. Prayer provides support and hope, and involves finding a meaning, purpose and direction in life (Carson, Soekan, & Grimm,

1988 as cited in Wilson & Miles, 2001). They usually perform prayers fives times a day at designated times. Prayers for forgiveness for any past sins will also be said.

Visiting the sick is a sacred duty according to Islam, and so the patient might receive many visitors, who will pray with and for the patient (Huda, 2004; Husein, 2000). For the Muslim, visiting a sick brother or sister in faith is a basic form of worship to bring one closer to God (Huda, 2004). A common saying of the Propehet Mohammed is that a Moslem to another Moslem is like one body; if an organ complains, the other organs respond with insomnia and fever (Al-Hasan & Hweidi, 2004). In other words, provision of support and maintenance bonds among people are highly encouraged in the Javanese culture.

As patients approaches death, they will expect to have their family gathered around them for a final farewell. When death approaches, the close family and friends try to support and comfort the dying person through supplication as well as remembrance of Allah and His will. Passages from the Qur'an will be read to them and the "shahadah" recited. For the Muslim, it is important that no direct contact occurs between a non-Muslim and a Muslim patient, especially if the staff member is of the opposite gender. It is important to wear gloves at all times when touching patients (Huda, 2004).

In conclusion, if one family member encounters a stressful life event, then the whole family shares the burden, prays together, and shows collective obligation toward coping with the crisis. There is a strong sense of commitment in most Javanese and Muslim people to maintain their roles and relationship in critical situations, thereby enabling the family system to remain in a state of equilibrium.

### 1.3 Previous hospital experience

How the family who has members admitted to critical care units responds to this situational crisis depends on the ability of those involved to draw on coping skill learned from life experiences. When people are confronted with a problem that cannot be resolved in the usual way, subjective feelings such as anxiety, fear, and helplessness are experienced (Kinney et al., 1993).

Previous hospital experience influenced the perceptions of family. Jamerson et al., (1996) suggested that an assessment of previous experience of visiting ICU should be made because such experience might affect the ability to cope with the present situation. The family members who have had previous hospital experiences may know the expectations of the institution and be more knowledgeable of medical practice (Kosco & Warren, 1999; Mendonca & Warren, 1998). In addition, subjects with experience of visiting ICU perceived talking about feelings and knowing the expected outcome as more important than did those without experience (p = 0.001) (Lee & Lau, 2003). Another study done by Redley et al. (2003) reported that family members with previous experience of critical illness rated comfort as more important than did those who had not had experience of critically ill relatives.

### 1.4 Financial resources

Families are quickly struck by the strain the hospitalization places on their finances. Money must be available to cover the patient's charges; family members' meals, lodging, and transportation; and other daily living expenses such a rent, house and car payments, and utility bills. Families may have health insurance coverage

provided by their employers, others may be eligible for medical or other state-funded programs (Desai, Jodie, & Bryant, 2002).

In Indonesia, most government employees receive private health insurance as part of their remuneration, as do many who work for private companies and businesses. For the lower society, which is a large proportion of the population, health insurance is unavailable. For very poor people the government provides free health care. However, patients' family members may still buy a certain amount of drugs, intravenous fluid, tubing, and other treatments that are not included in the health assurance or free health care (Shield & Hartati, 2003). So, the care of critically ill patients is expensive.

### 1.5 Subjective experience

Family's perception of critical illness is influenced by subjective experience based on coping strategies, past experiences with illness, family traditions, and the patient's role in the family (Kerr & Bowen, 1988 cited in Mi-Kuen et al., 1999). Also, the perception depends on the individual or personal beliefs that he or she brings to a crisis situation (Gelling, 1999). These beliefs will be based on many factors, including education, upbringing, past experiences and social-economic background, and will influence how a person interprets and reacts to the crisis situation.

## 2. The factors that influence nurses' perceptions of needs of families who have members admitted to critical care units

### 2.1 Subjective feelings and personality factors

The nurse's subjective feelings (likes and dislikes) toward the family can also influence the nurses' perception of family needs (Hickey & Lewandowski, 1988).

Because, patients in the advanced care unit have a longer length of stay, they have multi-system failure, and require much more physical care, they contribute to the burden of nurses (Titler et al., 1991). In addition, the nurse's perceived stress, knowledge of psychological aspects in dealing with families in crisis, and the security role of the nurse are significant factors influencing the nurse's attitudes (O'Malley et al., 1991). As a result, the nurses' responses are neglected and focus remains on the patients' needs only (Titler et al., 1991).

In addition, personality factors of critical care nurses have characterized them as task oriented and having an external locus of control. Answering questions, describing progress, and providing explanations of events and therapies are task-oriented behaviors and provide for a less stressful avenue of interaction with families. As a result, discussion of subjective aspects such as grief, loss, and anxiety are more difficult (O'Maley et al., 1991).

#### 2.2 Environment

Environment affects nurses' attitudes towards family needs. The amount of time to complete tasks, the nurse's perceived stress, knowledge of psychologic aspects in dealing with families in crisis, and security role of the nurse were significant factors influencing the nurses' attitudes (O'Malley et al., 1991). Nurses focus on preservation of life. As a result, family needs may be ranked lower by the critical care nurses related to the priorities of intense physical care and longer-term family relationship. Minimizing family needs or reducing interaction with the family allows the nurse to treat the patient as a clinical problem. Although this adaptive

strategy allows the nurse to work in a stressful environment, the strategy is stress-producing for families and patients.

### 2.3 Responsibility

Another factor influencing nursing perception is that nurses may not perceive family needs as a nursing responsibility. Nurses responded that meeting family needs was not solely a nursing responsibility. Family needs were perceived as less important compared to the factors of time and patient care responsibilities. O'Maley et al., (1991), found that nurses perceived the interaction with families as threatening. The nurses' perceptions of the person best able to meet family needs are as follows. (1) social services should handle family financial needs and problems, (2) the physician should talk to the family daily and have knowledge of the patient's prognosis, (3) administration should provide comfortable furniture and good food, and (4) the chaplain should discuss visiting arrangements with the family.

# 3. The factors that influence both families' and nurses' perceptions of needs of families who have members admitted to critical care units

### 3.1 Level of education and working experience

Level of education influences both family members' and nurses' perceptions of family needs. Bijttebier et al. (2000), studied 200 adult family members in ICU, and found that the more highly educated the family members were the fewer needs they expressed. In addition, Lee and Lau (2003) found that the better educated the subjects were the more they wanted to know about what was happening to their relatives.

For the critical care nurse, education, a lack of knowledge, and experience were factors influencing critical care nurse's involvement with family, reported by O'Malley et al. (1991). They found that the less experienced nurses may not be as prepared to deal with the needs of family members as the more experienced nurses (Kosco & Warren, 2000; O'Malley et al., 1991). For example, lack of knowledge of social support affected the nurses' attitudes towards giving support for family members (Hildingh, Fridlund, & Segesten, 1994). Leung et al. (2000) also found that there was significant positive correlation between the nurses' postregristration experience and their perception of family need importance. Kosco and Warrens (2000) further reported that there was a significant difference on needs' statements based on years of experiences in critical care nursing, because nurses with more education may have more experience with communication skills and may find it easier to keep the family members informed of the condition of their loved one.

### 3.2 The nature of the patient's illness

The nature of the patient's illness influences family needs. There was a significant difference in needs of family members depending on the characteristics of the patient (Lee & Lau, 2003). Horn and Tesh (2000) reported that family members who anticipated a planned surgery for the patient had a lower stress response score (SD = 10.8) compared with family members of patients who were admitted for an unplanned events and emergencies had a slightly higher stress response score (SD = 7.2). In addition, according to Hickey and Lewandowski (1988), factors that influenced the critical care nurse's involvement most with families are situations related to the patient's actual or impending death.

In summary, there are only a few studies that examine influencing factors related to family members' and nurses perceptions of family needs with critically ill patients. Patients' family members and nurses' perceptions of family needs are influenced by a family's understanding of the situation, subjective experience, gender and the relationship of the relative to the ill person, culture and religion, previous hospital experience, education, subjective feeling, environment, and the nature of the patient's illness.

## Intensive Care Unit (ICU) and Coronary Care Unit (CCU) in Central Java, Indonesia

There are two modes of health care in Indonesia, public and private. There are over 1000 hospitals in Indonesia, and about 34% are private. Public hospitals are administered by the Ministry of Health or, in some cases, by local authorities at city or provincial level. Hospitals are classified according to number of beds and the specialist services available. Class A and B are major referral and teaching hospitals, and district hospitals are either class C (100-400) or D (25-100 beds). Class C hospitals offer some specialist services and are teaching hospitals, while doctors in class D hospitals are general practitioners (Shields, 1999 as cited in Shield & Hartati, 2003).

In addition, Indonesia has an extensive primary health care system. Each subdistrict has at least one community health centre or Pusat Kesehatan Masyarakat (PUSKESMAS), as primary health care, and each district at least has one hospital type B or C. If there are cases that cannot be served at the district hospitals, the cases will be sent to referral hospitals, which have sophisticated equipment, and more specialized physicians and nurses.

Hospitals have different classes of wards, and admission charges vary. Daily rates, for the lowest class of ICU or CCU, range from about 100,000 to 150,000 Rupiahs (equivalent to US \$ 10 and US \$ 15, respectively), while the highest class ICU or CCU costs up to 500,000 Rupiah (or equal to US \$ 50). These ICU or CCU costs are considered expensive for low and middle classes people, who earn around 500,000-1,000,000 Rupiah per-month (or equal to US \$ 56-111). By paying a low class, a poor family will be able to access a bed. However, all equipment, drugs, dressings, intravenous fluid, tubing, blood, and other necessities have to be bought at either the hospital pharmacy or from chemist shops (Shield & Hartati, 2003).

Standards of nursing care in Indonesia vary greatly from place to place, and are dependent on the type of the type of hospital, nurses' educational levels, and the general philosophy of the institution (Shields & Hartati, 2003). In Central Java, the ratio of ICU or CCU nurses to patients either at the A, B, or C classes is one—to-two or three nurse-to-patient. Actually, ICU or CCU need two-to-one nurse-to-patient ratios to provide better care than general wards (Bucher & Melandar, 1999). According to Annual Report from RSUP. Dr. Kariadi (2003), nurses staffs are educated to diploma level at academies. The hospitals' slogan in Indonesia is "Your smile is my cure", and nurses aim to alleviate suffering and support patients and families. The orientation environment has not yet been performed in the some public hospitals. In conclusion, Indonesian health professionals provide high-quality of care, within the constraints of the health system (Shield & Hartati, 2003).

### Summary

The needs of families who have members admitted to critical care units are the responses of the family in crisis. In a crisis situation, family members are in a state of disequilibrium and this will have on physical, psychosocial, and spiritual impacts. Family members need support, comfort, information, proximity, and assurance to resolve the crisis and return to equilibrium. There are many factors that influence the perceptions of family needs, such as gender, age, culture and religion, previous hospital experience, education level, subjective feeling, environment, and the nature of the patient's illness.