CHAPTER 1

Introduction

This chapter presents the background and significance of the research problem, objectives, research questions, and definition of terms of the study.

Background and Significance of the Research Problem

The preterm birth has a very large number as shown in the statistics of the World Health Organization (WHO) that around 15 million babies are born premature every year (WHO, 2015). The preterm birth rate is as low as 5% in many northern European countries and as high as 18% in some African countries with more than 60% of preterm babies being born in sub-Saharan Africa and South Asia. The high preterm birth rate is related to a high number of births in these two continents (Blencowe et al., 2012). In Thailand, Supapannachart (2013) indicated that there are about 80,000 babies who are born preterm every year, accounting for around 8-10 % of all live births. From 2012 to 2014, the proportion of low birth weight infants (LBW-weight less than 2,500 grams, mostly preterm) born at a regional hospital, East of Thailand, was 14.1%, 15.3% and 14.3% of all live births respectively (A regional hospital, labor room record, 2014).

The preterm or premature infant is defined as an infant born before 37 completed weeks of gestation (American College of Obstetricians and Gynecologists [ACOG], 2016; WHO, 2015). As they are born too early, almost all of their major body systems are not yet fully formed and the degree of immaturity is a function of the duration of gestation. Low gestational age results in a physiological immaturity, which causes health problems in several systems such as respiratory, cardiovascular, gastrointestinal, and immune systems (Davidson, London, & Ladewig, 2012; Kenner & Ellerbee, 2012). Particularly, respiratory distress syndrome (RDS) which mostly found in preterm infants and rarely found in term infants (Davidson et al., 2012). Preterm infants are therefore

considered a high risk group and required hospital stay of more than 48 hours after birth for their survival (Kenner & Ellerbee, 2012).

Hospitalization of preterm infants affects both the babies and their parents. Being exposed to a variety of stimuli in a hospital such as a loud environment and invasive medical procedures causes preterm infants physiologic stress and being influenced by a greater number of stressors is associated with decreased preterm infant's brain size in the frontal and parietal regions (Smith et al., 2011). A inappropriate developmental environment where there is a high level of noises from various machine alarms and lighting from neonatal care unit creates negative physiologic responses (Brown, 2009; Wachman & Lahav, 2011), disrupt sleep and wake states, and psychological stress (Fraser, 2013). In addition physical separation of parents and their newborns after birth is another adverse factor stemming from the hospitalization even though physical contact is essential for the creation of early attachment (Kenner & Ellerbee, 2012) as a parent and infant bonding begins during pregnancy and continues after birth (Klaus, Kennell, & Fanaroff, 2013). According to Kennell and Klaus, the first few hours after birth are important to develop healthy parent-infant bonding; if parent-infant pairs are separated or do not establish bonding during the first few hours, any bond formed later may not be strong (Mooney, 2010). These findings prompted several hospitals to enhance a mother-infant bonding by promoting early physical contact and supporting family involvement (Klaus & Kennell, 1982). Encouraging early mother-infant contact after birth and rooming-in could increase the length and success of breastfeeding and these could decrease failure to thrive, abuse, neglect, and abandonment of infants (Kennell & Klaus, 1998).

Parents are affected by the hospitalization of their preterm babies as they are the primary providers of care and love to their infants. All parents expect that their babies will be born at term and healthy; however, such unexpected situations as premature labor can occur, causing them stress because of emotional unpreparedness. These parents encounter multiple crises and overwhelming feelings of responsibility, helplessness, and frustration (Fraser, 2013). Seeing their preterm infants in the neonatal care unit, parents experience psychological distress, anxiety and depression (Klaus, Kennell, & Edwards, 2011; Gambina et al., 2011). Furthermore, hospitalization of

preterm infants may strain spousal relationship due to parents' emotional distress and lack of fathers' involvement in caring for their infants (Manning, 2012). Families must deal with financial problems because parents must incur nonmedical out-of-pocket expenses as a result of parents' having to travel and buy food outside the home (DiFazio & Vessey, 2011; Hodek, Schulenburg, & Mittendorf, 2011). Emotional unpreparedness of parents from preterm birth can impact the parent's ability to recognize baby's signals and can affect their ability to interact with their baby (Lindberg & Ohrling, 2008). Moreover, negative emotions of parents and experiences associated with prematurity or infant illness have led them to have less contact their infants or leave the units (Arockiasamy, Holsti, & Albersheim, 2008; Malakouti, Jabraeeli, Valizadeh, & Babapour, 2013). Therefore, they pass the infant care to the staff and have less involvement in their infant care.

Parent involvement in care is exemplified by parents being involved in caring for their child by staying near their child and actively participating in decision-making processes related to their child's care (Coyne, 1996), as well as through other physical, psychological and social activities performed by parents to improve the health and/or psychological well-being of the child (Power & Franck, 2008). According to Stull and Deatrick (1986), direct involvement activities meant routine physical care and comforting while indirect involvement activities included discussion with health care professionals. Schepp (1995) used the term of parent participation instead of parent involvement and identified the four components of parent participation, consisting of (1) participation in routine care (e.g., feeding, bathing, changing the child's dress and staying with their hospitalized child), (2) participation in technical care (e.g., checking vital signs; taking temperature, going with the child for special tests such as x-ray, and staying with the child during technical procedures), (3) participation in sharing information about their child's condition or treatment, and (4) participation in decision-making about their child's care.

In Western literature, most studies examined the experience of parents having a preterm infant (Hollywood & Hollywood, 2011; Lee, Long, & Boore, 2009; Malakouti et al., 2013) or the experience of parents providing care for their hospitalized preterm infants (Bjork, Thelin, Peterson, & Hammarlund, 2012; Blomqvist & Nyqvist, 2011;

Russell et al., 2014). In Thailand, Thongkhong-uam (2009) explored the experiences of parents with premature infants; other published studies related to parent involvement in caring for hospitalized newborn infants. Several quantitative studies employed four components of Schepp (1995) to examine the levels of parent participation and related factors (Pholanun, Kantawang, & Klunklin, 2013; Supaporn, Klunklin, & Urharmnuay, 2013; Tepmalapunsiri, Chaimongkol, & Pongjaturawit, 2011). In addition, two qualitative studies were conducted. Pathom-aree (2008) conducted a study on maternal participation in caring for newborn babies in NICU. The findings revealed that maternal participation was a continuous process composed of two phases: the initiation of participation and getting the best on going actions for the sake of the baby. In the first phase, mothers described coming into an unfamiliar world, coping with difficulties and confusing feeling, and their desire to act for their babies. In the second phase, mothers were facing reality, feeling happy at being a mother, developing willpower, providing mutual support to the babies, and demonstrating dedication toward their babies. In another qualitative study, Rungamornrat, Karnjanawanich, and Muangyoo (2012) explored maternal participation in caring for a premature infant on a respirator. The findings indicated that mothers were uncertainty of the baby's life with special care needs and they attempted to find causes of having preterm baby. While maternal participation was limited due to their baby's conditions, they cared for their babied by following nursing guidelines such as storing their breast milk and touching their baby during their visit. They sought information about their baby and prayed to the holy idols for their baby's recovery. However, these studies did not explore how the socio-cultural factors influencing parent involvement in caring for their preterm infants.

Parental involvement in preterm care has both positive and negative consequences. The positive consequences include attachment between parents and preterm infants (Fernandes & Silva, 2015; Lee et al., 2009), promoting preterm infant development in such aspects as sense of trust, cognitive development, and social development (Kenner & Ellerbee, 2012), and promoted preterm infant outcomes such as reduced length of hospital stay (Gregson & Blacker, 2011), infection rate, and rate of re-admission (Somlaw, 2011). Because of their involvement, parents gained more confidence in caring for their preterm infants and maintaining parental roles (Lee et al., 2009; Malakouti et al., 2013), and increased maternal breastfeeding rates (Gregson & Blacker,

2011). However, not all parents feel comfortable with assuming the responsibility for their infants' care as some parents may be pressured and under such great psychological stress. When taking part in caring for their hospitalized preterm infants, especially in the initial phase, parents have reported negative feelings such as guilt, helplessness, fear, anxiety, and stress (Bjork et al., 2012; Hollywood & Hollywood, 2011; Malakouti et al., 2013). Overall, the current research suggests that parent involvement brings more positive consequences than negative ones.

Parent involvement in caring for hospitalized preterm infants is related to many factors, including infant factors, parental factors, healthcare professional factors, environmental conditions, and hospital policies. The appearance of the preterm infant is different from that of a full-term or healthy infant. Most parents are unprepared for premature birth and their infant's size, appearance, and condition, making them hesitant to touch their preterm infants (Fraser, 2013; Lee et al., 2009). As preemies have a unique appearance and need specialty care, parents who had lack of knowledge and skills would find it difficult to be actively involved in caring for their premature infants (Baker & McGrath, 2009; Lee et al., 2009). Moreover, inadequacy of support from nursing staff, lack of communication and limitation of visiting hours may be obstacles to effective parenting (Lee et al., 2009). The physical environment may also affect parents of hospitalized preterm infants as they may feel helpless when seeing their preemies being treated with invasive medical equipment. Parents said that they were afraid of the medical equipment and it took quite a long time for them to overcome those fears and be able to take part in their infants' care (Hollywood & Hollywood, 2011). Therefore, parent involvement is dependent on many factors.

Several intervention studies involved parents of preterm infants with the four major foci including: 1) enhancing parents' abilities regarding preterm infant care by promoting their self-efficacy and equipping them with parental knowledge and skills, 2) lessening parental psychological problems, 3) supporting attachment and bonding, and 4) promoting preterm infant outcomes. In Western and other literature, most intervention studies were conducted to learn about parental involvement in hospitalized preterm infants, and examine the effectiveness of educational programs (Bracht, O'Leary, Lee, & O'Brien, 2013; Shieh et al., 2010) on parents' abilities to provide care

for their preemies such as feeding, bathing, clothing, and cleaning. Some studies were done to examine the effectiveness of peer group support (Preyde & Ardal, 2003) and the Creating Opportunities for Parent Empowerment (COPE) program (Melnyk, et al., 2006) on maternal stress and parents' mental health outcomes. With regard to the effectiveness of kangaroo care on maternal attachment (Ahn, Lee, & Shin, 2010; Cho et al., 2016), preterm infant outcomes and breastfeeding rate of mothers (Gathwala, Singh, & Singh, 2010; Gregson & Blacker, 2011; Moniem & Morsy, 2011) were also major research foci.

One important focus of Western intervention studies was on developmentally supportive care such as the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and its goal was to reduce the complications of prematurity (McAnulty et al., 2009; Peters et al., 2009), enhance the infant's neuro behavioral competence or improve preterm infant outcomes (Als et al., 2012) as well as promote the relationship between parents and infants and healthcare professionals (Kleberg, Hellström-Westas, & Widström, 2007). NIDCAP was designed to provide education and specific training in developmental observation and assessment for health care professionals who give care for high-risk newborn infants and their families (Als & NIDCAP Federation International, 2013). This program aims to maximize parent participation in the care of their high-risk newborns.

In Thai literature, several intervention studies examined the effectiveness of perceived self-efficacy programs (Bunmachu & Theunnadee, 2015; Srilamai & Teerarungsikul, 2015), empowerment programs (Chaingam, Parktoop, & Chaimongkol, 2011), and educational programs (Suknithi, Thampanichawat, Wichiencharoen, & Lerthamatewe, 2012) on parental knowledge and abilities in care, and preterm infants' outcomes. The effectiveness of perceived self-efficacy programs (Sawattrakool, 2011), empowerment programs (Bualuang, 2009) and educational programs (Lektae, 2008) on parental psychological problems was also studied while there were some studies on the effectiveness of kangaroo care (Sangsawang, Punthmatharith, & Prateepchaikul, 2010) and the massage program (Chomklien & Jerapaet, 2008) on maternal attachment and bonding. Most intervention programs demonstrated the effectiveness of enhancing parental ability in care, decreasing parental psychological problems, promoting

attachment and bonding, and improving preterm infant outcomes. However, most interventions were constructed from the researcher's perspectives and based on western concepts.

In Thailand, the high risk newborn infants such as preterm infants and low-birth-weight infants need to be admitted to neonatal intensive care unit (NICU) or sick newborn unit (SNB) (Ministry of Public Health, 2013). Newborns who were critically ill were admitted to the NICU and newborn with general sickness and very sick newborns with uncomplicated conditions were admitted to the SNB (Srisuparb, 2008). The caring of ill newborn infants is performed based on the principles of newborn care following the Safe Motherhood Hospital (SMH) and Hospital Bonds of Family Love (*or Sai-Yai-Ruk*). These principles of newborn care consisted of seven items: 1) temperature control, 2) airways management, 3) infection control, 4) nutrition, 5) specific treatment, 6) parent-infant attachment, and 7) developmental and environmental promotion (Jirapaet & Jirapaet, 2007; Somlaw, 2011). To promote parent-newborn attachment and maternal breastfeeding, well newborns and newborns with minor illnesses (e.g., neonatal jaundice, hypothermia, and preterm infant with stable condition) would stay with mothers at postnatal ward (Jirapaet & Jirapaet, 2007; Somlaw, 2011). For hospitalized newborns with discharged mothers, the newborn unit provided accommodation for discharged mothers, so they can bring their breast milk to their hospitalized newborns and take care of their babies during hospitalization (Somlaw, 2011).

In Thai nursing literature, little is known about how Thai socio-cultural factors influence parent involvement in caring for hospitalized preterm infants, which needs to be explored as parent involvement is likely to be shaped by beliefs and values of Thai parents. To better understand Thai parent involvement in caring for their hospitalized preterm infants, the perceptions of parents, their caregiving practices and the socio-cultural factors that influence their involvement need to be explored. A focused ethnographic study was conducted to explore the current situation in the sick newborn units and to discover the actions that people actually perform and the reasons they give for doing so. This approach enabled the investigation of a specific issue, in a specific setting, among a specific group of people, rather than throughout the entire cultural

system (Cruz & Higginbottom, 2013). Focused ethnography is pragmatic and allows the researchers to capture data on specific beliefs and practices of particular illnesses or particular healthcare processes, as held by patients and practitioners (Higginbottom, Pillay, & Boadu, 2013). The information gained from this study will allow healthcare professionals, nursing educators, and nursing students to attain a better understanding about parent involvement in caring for hospitalized preterm infants. This knowledge can contribute to the development of intervention programs to enhance parent involvement in caring for hospitalized preterm infants in concordance with the needs of Thai parents. This knowledge is also critical for optimally implementing interventions developed in a Western context.

Objective of the Study

The aim of this study is to gain a better understanding of parent involvement in caring for hospitalized preterm infants.

The specific aims of the study are as follows:

1. To explore perceptions of parents regarding parent involvement in caring for their hospitalized preterm infants.

2. To explore caregiving practices related to caring for their hospitalized preterm infants.

3. To explore the socio-cultural factors influence on parent involvement in caring for their hospitalized preterm infants.

Research Questions

1. What are the perceptions of parents regarding parent involvement in caring for their hospitalized preterm infants?

2. What are the caregiving practices related to caring for their hospitalized preterm infants?

3. What are the socio-cultural factors influences on parent involvement in caring for their hospitalized preterm infants?

Definition of Terms

Parent involvement refers to direct and indirect caregiving activities of mothers and/or fathers who provide care for their preterm infants during the period of hospitalization.

Hospitalized preterm infants refer to infants born before 37 completed weeks of gestation who were admitted to the sick newborn unit.