THAI MOTHERS' REPORTS OF SYMPTOMS IN YOUNG CHILDREN RECEIVING CHEMOTHERAPY

By

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ABSTRACT

TITLE: Thai Mothers' Reports of Symptoms in Young Children Receiving Chemotherapy

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Background: In recent years, childhood cancer in Thailand has become a more curable disease with aggressive treatment. Symptoms related to cancer treatment, however, have a significant impact on children's quality of life. The problematic symptoms of young children undergoing chemotherapy for cancer have been little studied due to the children's inability to self-report. There is an urgent need to examine symptoms related to cancer treatment in children aged 1 to 5 years old.

Purposes: This study described mothers' perceptions of symptoms and symptom management in their young children during three days of chemotherapy treatment for cancer. In addition, the relationships among maternal sensitivity, maternal parenting stress, and mothers' perceptions of their children's symptoms were explored.

Methods: This study was a prospective and descriptive study. Fifty Thai mothers and their children were recruited at the Queen Sirikit National Institute of Child Health in Bangkok, Thailand between January and June 2009. The questionnaires for mothers included demographic data, a 3-day symptom dairy, a maternal sensitivity questionnaire, and a parenting stress index. Children wore an actiwatch for 3 days to validate mothers' reports of trouble sleeping.

Results: The modified MSAS assessed the prevalence, frequency, intensity, and distress of 9 symptoms the day before chemotherapy (Time1, T1 (baseline)) and 3 days after receiving chemotherapy treatment. Change of appetite was reported as the most prevalent symptom for the six time points. The results for the repeated measures ANOVA indicated a significant time effect with means increasing from time 1 (baseline) to time 2 (morning day 1), and then decreasing at each subsequent time period. Symptom frequency, intensity, and distress were rated by Thai mothers as less than found in previous studies. Majority of mothers used vigilant caring and distraction to manage several symptoms of their young children. Higher parenting stress index scores were related to higher post-chemotherapy symptom scores. However, children's sleep times from actiwatch were consistent with mothers' report of trouble sleeping.

Discussion: Young children with cancer undergoing chemotherapy did not encounter isolated symptoms but rather multiple symptoms. Young children experienced greater symptoms the first day of chemotherapy and then symptoms decreased progressively at each subsequent time period. Symptoms associated with chemotherapy side effects or post procedure may have received minimal attention by mothers. In contrast, symptoms related to contextual stimuli such as the insertions of needles or lumbar puncture allowed mothers to make reasonable assessments. Thai culture and hospital environment in this study may have influenced mothers' perceptions of symptoms in their young children leading them to report lower prevalence, intensity, and distress than those in the western culture. Thai mothers have great a concern about young children eating. The traditional interpretation of maternal-child interaction might not be appropriate for mothers of children with cancer. Perhaps they observed their children more closely due to the life threatening cancer and effectively reported their children's symptoms. Finally, the findings indicated that mothers are appropriate as reporters of their children's symptoms. Nonetheless, several factors should be considered when considering the accuracy of mothers' reports, such as their knowledge of chemotherapy side effects, stress, parenting styles, culture, and the meaning of diagnosis.

Key words

Young children
Symptoms
Mothers' Reports
Thai Mothers
Cancer
Chemotherapy

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CHAPTER 1

INTRODUCTION

In the United States between 2001 and 2005, cancer was diagnosed in children under the age of 15 years at an annual rate of 150 per million (Ries et al., 2007). Of these children, 46% were younger than 5 years of age with leukemia and brain tumors accounting for approximately 56 % of the malignancies in this age group (Ries et al., 2007). Similarly, in Thailand, the average incidence of childhood cancer between 1995 and 1997 also affected children aged younger than 5 years old at the same rate (46%) with leukemias (38.7%), brain tumors (15.9%), and lymphomas (10%) comprising two-third of all childhood cancer (Wiangnon et al., 2003).

The 5-year survival rate of all childhood cancer in the US is increasing (Ries at al., 2007), carrying with it a great economic and emotional cost. In Thailand, while the survival rate of childhood cancer is not available, it can be expected to be higher because treatment of cancer in Thailand follows Western standards, the Children's Cancer Study Group (CSG), a U.S. and Canadian clinical trial cooperative group (Laosombat, Wongchanchailert, Sattayasevana, Wiriyasateinkul, & Watana-Arepornchai, 2002). Much of the improvement in survival rates can be attributed to improvements in cancer treatment, in particular the intensification of chemotherapy. Cancer treatment usually lasts one to three years.

As survival rates have improved, increased attention has been given to the symptoms that children experience during their cancer treatment. Symptoms may be directly related to the cancer itself, such as pain from the presence of cancer, or may occur as a consequence of the treatment, such as nausea or fatigue. Previous studies found that symptoms related to treatment such as pain are a critical problem (Ljungman, Kreuger, Gordh, & Sorensen, 2006, Van Cleve et al., 2004) affecting the quality of life in the children and their families during cancer treatment (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). In the U.S., much of the research on treatment-related symptoms in adults and children with cancer has focused on single symptoms, yet most patients with cancer experience more than one symptom at a time (Beck, Dudley, & Barsevick, 2005; Docherty, Sandelowski, & Preisser, 2006). Similarly, in Thailand, studies have also explored specific symptoms, such as pain and fatigue (Jongudomkarn, Aungsupakorn, & Camfield, 2006; Koolsu, 2001).

Recent work in the U.S. has examined symptom clusters (Barsevick, Whitmer, Nail, Beck, & Dudley, 2006; Beck et al., 2005; Dodd, Miaskowski, & Paul, 2001; Gedaly-Duff, Lee, Nail, Nicholson, & Johnson, 2006). Children with cancer also experience multiple symptoms, such as pain, fatigue, sleep disturbance, nausea, and vomiting (Collins et al., 2000; Collins et al., 2002; Docherty et al., 2006; Gedaly-Duff et al., 2006; Gibson, Garnett, Richardson, Edwards, & Sepion, 2005; Williams, Schmideskamp, Ridder, & Williams, 2006).

Although children aged 2 to 5 years have the highest incidence of childhood cancer, studies across cultures have focused to date on school-age children and adolescents who can provide self-reports of symptoms, a gold standard for measuring the subjective experience of symptoms (Gedaly-Duff et al., 2006; Hockenberry et al., 2003). Thus, young children with cancer are understudied in the area of their symptom experience during chemotherapy treatment. Measurement of symptoms in young children is a challenging problem because of limited language development (Tarbell, Cohen, & Marsh, 1992). This age group is not able to provide verbal self-reports. Mothers of young children are an appropriate source for a proxy rating of the children's symptoms for several reasons. Mothers are generally the most available informants, are usually the most knowledgeable about the children's behavior across time and situations, are almost always closely involved with the medical treatment, and may manage their child's symptom(s) at the hospital and in the home. Furthermore, all Thai mothers are required to stay with their young children during hospitalization, meaning that they can observe the child almost all of the time.

Young children experience cancer treatment differently than older children and adolescents do, and consequently they demonstrate different patterns of stress (Kazak & Baxt, 2007). Young children express the stressors of cancer diagnosis and treatment through their behaviors due to developing and immature cognitive abilities; thus, noticing changes in daily routines and the presentation of physical pain or other symptoms may be a more useful method of learning more about their symptoms. Cancer treatment is also synthesized through sensory motor experiences and early learning and memory function of these experiences (Kazak et al., 2007). Medical management and emotional or behavioral responses to the cancer treatment potentially disrupt the normative developmental progress of these young children with cancer. For example, Zahr and colleagues (1994) found that young Lebanese children with leukemia were perceived by their mothers as more difficult and more irregular in behavior than children with congenital heart disease or asthma.

In Thailand, young children receive intravenous chemotherapy through peripheral intravenous methods and some of them need to stay in the hospital. In the U.S., where most chemotherapy treatments are in outpatient settings, the standard of practice has become to insert central lines to reduce the repetition of painful peripheral line starts. Conscious sedation for lumbar punctures also impedes pain management. Thus, it can be expected that children in Thailand may experience symptoms related to cancer treatment differently from those in the U.S, including increases in pain and sleep problems. There is a need to learn more about young Thai children's symptom experience during chemotherapy treatment using appropriate methods (Docherty, 2003).

No previous studies have reported agreement of symptom reporting between mothers and young children. Studies in the U.S. and Canada, however, have reported high correlations between parents and health care professionals on ratings of pain and multiple symptoms in young children (Riddell, Stevens, Cohen, Flora, & Greenberg, 2007; Zisk, Grey, Medoff-Cooper, & Kain, 2007). These findings suggest that parents are able to serve as acceptable informants of their children's symptoms and that parent proxy reporting may be useful as a component of symptom assessment as instruments are developed and refined for use in younger children.

When comparing the reporting of symptoms by parents and by school-age children, reports by mothers have underestimated or overestimated symptoms (Chambers, Giesbrecht, Craig, Bennett, & Huntsman, 1999; Collins et al., 2000). Perhaps older children do not tell their parents of all symptoms because of their developing independence. Other influencing factors may be the children's age, gender, and cognitive ability to communicate subjective symptoms as well as the mothers' sensitivity and stress.

However, it is almost always the mothers' view of their children's symptoms and behavior that is critical in determining what is done about any problem, and this is likely to continue into the children's early adolescence. Thus, the variables influencing the mothers' perceptions need to be explored to understand how they respond to and manage their young children's symptoms. According to research on maternal-infant attachment, a key dimension of the mother's influence is maternal sensitivity, defined as a mother's ability to perceive and interpret accurately her infant's signals and communications, and respond appropriately (Ainsworth, Bell, & Stayton, 1974). For example, the sensitive mother assesses her child's pain signals and takes appropriate actions to soothe both the physical and emotional dimensions of the infant's symptoms. In contrast, mothers with less sensitivity usually do not respond to their children's cues, and over time those children learn to avoid or ignore their mothers, having perceived their mothers as rejecting (Ainsworth, 1979; Riddell et al., 2007). No published studies have examined maternal sensitivity and mothers' perceptions of their children's symptoms. Maternal judgment of their children's symptoms, such as pain, may be an expression of maternal sensitivity. For effective symptom management, it is necessary to understand how maternal sensitivity is related to maternal perception of children's symptoms during chemotherapy.

National studies support the fact that across cultures, mothers of a young child with chronic illness such as cancer have high stress (Krulik et al., 1999; Martinson et al., 1999). For example, Chinese mothers of children with cancer have reported significantly higher parental stress scores than mothers of disabled children (Hung, Wu, & Yeh, 2004).

The influence of maternal sensitivity and maternal stress on mothers' report of symptoms has not been investigated. Mothers provide the everyday care of feeding and comforting their children during hospitalization for cancer treatments as well as at home. Little is known about how Thai mothers perceive, interpret, and manage their children's symptoms. Nor is it known if maternal stress while caring for a child with cancer influences sensitivity to their children's cues and demands. In addition, there is a need to know how maternal sensitivity and stress influence mothers' perception of their children's symptoms while receiving chemotherapy treatment. This study assessed not only young children's symptoms as reported by their mothers, but it also assessed Thai mothers' sensitivity to their children's behavior and their stress during their children's hospital stay in relation to their response to and management of their children's symptoms.

Aims of the Study

The primary aims of this study were to:

1. Describe mothers' perceptions of symptoms in their young children at six time points (morning and evening for three days) during chemotherapy treatment for cancer.

2. Describe mothers' management of their young children's symptoms and their perceptions of the symptom management outcomes.
3. Explore the relationships among maternal sensitivity, maternal stress, and mothers' perception of their young children's symptoms.

The secondary aim was to explore the relationship between young children's pain and sleep as reported by their mothers.

Significance to Nursing

This study provides information about symptoms in young children with cancer. In addition, mothers' sensitivity and stress while caring for their young children with cancer is described. Knowledge about how these variables influence mothers' perceptions and management of their children's symptoms may make it possible for nurses to improve their assessment of mothers and facilitate the mothers' care of their children during their hospitalization and home care for chemotherapy. This could lead to important interventions for mothers and their children undergoing childhood cancer treatment that will reduce the children's symptom distress and prevent long-term problems in children as well as improve the mothers' perceptions of parenting their children during illness.

CHAPTER 2

REVIEW OF LITERATURE

This chapter describes the literature related to symptoms in young children during cancer chemotherapy treatment and more specifically in Thailand. First, childhood cancer in the U.S and Thailand is introduced, and cancer treatment, particularly chemotherapy, is described. Then, symptom studies in young children are discussed. Development of symptom expression in young children is explained to better understand how young children experience symptoms. This chapter also reviews methodological issues for measuring symptoms in young children and explains why this study used mothers' reported perceptions. Characteristics of maternal sensitivity and maternal stress are then discussed as to how they may influence a mother's perception of her child's symptoms. Finally, the conceptual framework that guided the study of mothers' reports of symptoms in young children is described.

Childhood Cancer

Incidence of Childhood Cancer

In the United States between 2001 and 2005, approximately 159 out of every 1 million children younger than 15 years of age were diagnosed with cancer each year (Ries et al., 2007). Higher cancer rates occurred in children younger than 5 years of age (46%) and with rates for 5-to 9 years olds (24%) and 10 to 14-year-olds (30%) being fairly similar but lower (Ries et al., 2007). The common malignancies were leukemia and brain tumors, accounting for approximately 56 % of cancer cases in children younger than 5 years and 58% of all age groups.

In Thailand, the incidence of childhood cancer from all hospitals is unavailable. However, between 1995 and 1997, the incidence rate from five cancer registries was estimated at 93 per million per year. Leukemias (38.7%), brain tumors (15.9%), and lymphomas (10%) comprised two-thirds of all childhood cancer, and the age-peak for incidence was under 5 years old (46%), particularly for acute lymphoblastic leukemia (Wiangnon et al., 2003). The overall cancer incidence rates for children under 15 years old are highest in the Bangkok canter registry (56%), compared to other registries, including Chiang Mai (13.5%), Khon Kaen (13.1%), Lamphang (5.7%), and Songkhla (11.8%) (Wiangnon et al., 2003). Wiangnon et al. suggested there might be underreporting from other hospitals and private hospitals. Furthermore, the higher incidence in Bangkok might be partly due to parents from other parts of Thailand moving to Bangkok to receive the best medical treatment for their children.

The Queen Sirikit National Institute of Child Health is the largest public children’s hospital and a part of the Bangkok center registry, which serves as the center for children’s illness in Thailand and for the entire population of children with cancer being treated in the central area of Thailand. Between 2003 and 2007, 411 cases of childhood cancer were recorded. Acute lymphoblastic leukemia (ALL) was the most common (75.4%), and children aged younger than 5 years were most affected by ALL (46.1%) (Hematology Department of the Queen Sirikit National Institute of Child Health, 2008). With improved aggressive treatment, the 5-year survival rate of childhood cancer in the U.S. increased (Ries et al., 2007), carrying with it greater economic and emotional costs. In Thailand, while the survival rate of childhood cancer is not available, it can be expected to be higher as in other developing countries. Treatment of cancer in Thailand follows Western medical guidelines especially those of the Children’s Cancer Study Group (CSG), a U.S. and Canadian clinical trial cooperative group (Laosombat et al., 2002).

Cancer and Cancer Treatment

Cancer in children differs from cancers in adults (Leonard, 2002). One major of difference is origin. Tumors in children often are composed of embryonic cell types (similar to fetal cells) whereas most malignancies in adults are carcinomas, involving epithelial tissues, which occurs very rarely in children. The disparity between tissue types in pediatric versus adult cancers holds true until 15 years of age (Leonard, 2002).

Because childhood cancers often arise from deep-seated tissue, they do not present visual, palpable, or functional abnormalities until they are very large. Thus, nearly 80% of children with cancer have distant metastases or systemic disease at the time of diagnosis. This challenge has led to the use of an aggressive combined multimodal therapy that has been highly successful in the treatment of adult cancer (Leonard, 2002).

Leukemia and brain tumors are the most common cancers of children younger than 5 years; therefore, the critical issues related to these two forms of cancers are presented in the following paragraphs. These issues are, however, relevant to children undergoing treatment for other types of cancer as well.

Most cancers present symptoms before the diagnosis is made. For leukemia, fatigue, fever, and leg pain may occur at the time that parents seek medical attention for the child. In the case of leukemia, blood counts establish the initial diagnosis, followed by bone marrow aspiration and a lumbar puncture. For brain and other solid tumors, the diagnostic procedures may include computed tomography (CT) scans and magnetic resonance imaging (MRI).

After a diagnosis is made, treatment is started as soon as possible with a goal of obtaining a remission or disease-free state (Ettinger, Bond, & Sievers, 2002). For leukemia, the initial phase of treatment is called induction, i.e., inducing a remission. Consolidation and maintenance phases follow, respectively. Consolidation treatment is designed to prevent the occurrence of central nervous system disease and takes 1 to 2 months. Maintenance treatment continues for 2 to 3 years (Westlake & Bertolone, 2002). Generally during this treatment, children are seen monthly for blood counts and chemotherapy. Maintenance chemotherapy is generally tolerated with fewer symptoms.

Solid tumor treatment is different from that for leukemia. First, surgery removes the tumor. Then, chemotherapy and/or radiation therapy may be used in conjunction with surgery to eradicate the remaining cells. The next step is to prevent micrometastases by giving maintenance chemotherapy. Treatment varies from several months to as much as two years (Ryan-Murray & Petriccione, 2002). Importantly for this study, all children go through aggressive treatment for a considerable time.

Chemotherapy. A chemotherapeutic agent destroys malignant cells that are unresponsive and that replicate uncontrollably to a child’s immune system.

Antineoplastic agents kill rapidly dividing cells (Ettinger et al., 2002). Because young children have more body tissues with dividing cell populations because of their physical development, they are susceptible to acute and long-term adverse effects on cerebral and somatic growth and development (Ettinger et al., 2002).

In general, a combination of chemotherapeutic agents is used to cause multiple kinds of damage to cells and to stop reproduction. There are several categories of chemotherapeutic agents available: alkylating agents, antimetabolic, plant alkaloids, antibiotics, nitrosourea compounds, enzymes, steroids, and immunotherapy. All chemotherapeutic agents have both side effects and toxic responses. Chemotherapy agents cause cell death not only of cancer cells but also of other normal, rapidly dividing cells, particularly those in the gastrointestinal system, hair follicles, and blood cells (Docherty et al., 2006). The immediate effects of cell death in the gastrointestinal system are nausea, vomiting, mucositis, diarrhea, and constipation; in the hair follicles, it is alopecia; and in the bone marrow, the effects are anemia, neutropenia, and thrombocytopenia (Docherty et al., 2006).

Chemotherapy treatment in Thailand. As mentioned above, the Queen Sirikit National Institute of Child Health (QSNICH) uses the cancer treatment guidelines from the Children’s Cancer Study Group (CSG) (Hematology Department of the Queen Sirikit National Institute of Child Health, 2008). However, there are some differences in treatment application in Thailand. For example, most children in the U.S. receive intravenous chemotherapy treatment as outpatients while Thai children are inpatients because of the distance from their homes. Most Thai children do not have their own or their parents’ health insurance, but they can still access healthcare services and treatment without cost during hospitalization. In a public hospital, children receive the basic necessary treatments for cancer during hospitalization; they stay in a large room with other children with cancer. Furthermore, they receive intravenous chemotherapy through the peripheral intravenous method whereas children in the US receive it through a port or external catheter. Only female caregivers, specifically mothers, are allowed to stay with their children during the night. Because most mothers provide bedside care for their children almost all of the time in the hospital, they have the opportunity to talk and share their experiences with other mothers and compare their child’s symptoms with those of other children.

During scheduled treatment days, young children typically come to the outpatient clinic for blood tests and/or bone marrow biopsies. If blood counts are too low or toxicities are evident, treatment and hospitalization are delayed another week. Then, intravenous chemotherapy treatments are administered through peripheral vessels. Some drugs, such as methotrexate, take more than eight hours to infuse. For these reasons, most young children are admitted to an inpatient ward.

The majority of symptoms that children experience during treatment are caused by cell death induced by chemotherapy (Docherty et al., 2006). Managing symptoms is especially important because unrelieved symptoms can potentially lead to treatment refusal, treatment interruption, or poor outcomes (Hockenberry & Hooke, 2007) and may disrupt the normative developmental progress of young children with cancer (Kazak et al., 2007).

Young Children with Cancer

The toddler period, usually considered age 1 to 3 years, is a period in which enormous changes take place in the child and, consequently, in the family as well. During the toddler period, the child accomplishes a wide array of developmental tasks. A critical milestone of toddler development is being able to form about 50 words and two-word sentences by 2 years of age. Erikson's (1963) developmental task for the toddler period is to form a sense of autonomy and independence versus shame and doubt. During the toddler period, children develop from the sensory motor to the preoperational stage of cognitive development.

The preschool period is traditionally defined as ages 3, 4, and 5 years. A 3-year-old child has a vocabulary of about 900 words. These words are used to ask questions constantly, mostly "how" and "why" questions; 4- and 5-years-old children continue to ask many questions and are able to describe something from their day in great detail. Erikson's (1963) development task for the preschool period is to gain a sense of initiative and to learn how to do things. Preschoolers have a number of universal fears, such as fear of the dark and of abandonment. This age group is still operating at a cognitive level that prevents them from understanding conversation. They are self-centered, which makes it difficult for them to share and view someone else's perspective.

During these two ages, social-emotional development is central. Bowlby (1969) described four phases of attachment that are thought to be foundational for social-emotional development. In phase I, the pre-attachment phase (0 to 3 months), infants do not discriminate between people when showing attachment behavior or a desire to be in close physical proximity. In phase II, attachment (3 to 6 months), children increasingly orient to familiar persons while also seeking proximity exclusively to familiar caregivers, particular their mothers. In phase III, clear-cut attachment, from 6 months on they use the mother as a secure base from which to explore. In phase IV, a goal-corrected partnership (starting at the age of about 3 years) is developed in which physical proximity is still very important, but the child is now able to insert the caregiver's goals into his or her own plan for proximity. After that, the older preschooler is able to operate internally on goals and plans for self and others and to engage in goal-corrected negotiation with the caregiver regarding a shared plan for proximity (p. 542).

The toddlers and preschoolers with a long-term illness such as cancer can be expected to exhibit normal attachment behaviors. However, if a toddler has physical limitations such as having pain, fatigue, and nausea and vomiting, he or she may not have the physical ability to achieve a sense of independence. Preschoolers with cancer may have difficulty achieving a sense of initiative, because they may be limited in their ability to participate in activities that stimulate initiative.

For the purpose of this study, young children were defined as children aged 1 to 5 years. Whereas there is a significantly broader literature on the impact of cancer on school-age children and adolescents and their families, little study has focused on young children in particular. Young children are assumed to be too young to understand the cancer diagnosis and treatment conceptually. It may be more difficult to understand why they must come to the hospital, have procedures, and take medicines as well as why they cannot participate in family and pre-school activities as usual. Young children experience and understand cancer behaviorally: changes in daily routine, physical pain, or changes in their primary caregiver's affect. Medical treatments and emotional or behavioral responses to the cancer treatment may easily disrupt the normative developmental progress of younger children with cancer, particular their psychological development (Kazak et al, 2007).

Symptom Experience in Young Children with Cancer

Symptoms in children with cancer may be directly related to the cancer itself, such as pain from the presence of cancer, or may occur as a consequence of the treatment, such as nausea or fatigue. However, the majority of symptoms result from the treatment (Docherty et al., 2006; Ljungman, Gordh, Sorensen, & Kreuger, 2000). Symptoms related to cancer in adults, adolescents, and school-age children have been studied, but the findings cannot be generalized to young children because of significant differences in the type of cancers, treatments, and age. Understanding symptom distress in this age group is important because unrelieved symptom distress may contribute to interruption of treatment as well as disruption of normative developmental progress (Docherty, 2003).

Chemotherapy is associated with a wide range of symptoms. The most common symptoms are pain, fatigue, nausea and vomiting, sleep disturbance, lack of appetite, and psychological symptoms. Studies have focused on individual symptoms and global symptoms.

Studies of Individual Symptoms

Four individual symptoms have been studied in children with cancer who were undergoing chemotherapy treatment: pain, fatigue, nausea and vomiting, and sleep disturbance. Only the pain symptom has been examined in young children with cancer.

Pain. Pain is the most common symptom experienced by children with cancer. Two longitudinal studies examined pain in young children with cancer (Van Cleve et al., 2004; Zernikow et al., 2005). Van Cleve and colleagues (2004) interviewed 95 children with ALL aged 4 to 17 years and their parents about children's pain experience during the first year after diagnosis. The intensity of pain rated by 59 young children (4-7 years) was 1.6 to 2 (range scores 0 to 4) and locations of pain rated were legs, abdomen, and head/neck, respectively. This study collected data by using seven treatment phases as points for interviews. Children and their parents were asked questions only one time at each time point. Therefore, this study had missing data when some children reported no pain at the time of interview. Additionally, the researchers did not report validity and reliability of this self-report measure of pain for young children (Van Cleve et al., 2004).

Zernikow and colleagues (2005) studied the pain experience in 409 children aged 2 months to 12 years from 28 of 78 departments of pediatric oncology in Germany. Children were divided into four age groups, including younger than 2.5 years (n = 46), 2.5 to 4.9 years (n = 90), 5- 11.9 years (n = 161), and less than 12 years (n = 112). The researchers interviewed children and parents at four time points, including the day of the first interview, within the last 24 hours of the interview, at one week, and at one month. They found 15%, 28%, 50 %, and 58 % of cases reported pain etiology at each of the four time points respectively. The median pain intensity for the most severe pain episode within the last 4 weeks was 6.7 (0 - 10 of rating) (Zernikow et al., 2005). Unfortunately, symptoms for each age group were not reported, and subjects included both inpatients and outpatients with different treatments (chemotherapy and radiation). Thus, the symptoms of young children undergoing chemotherapy treatment remain underreported and understudied.

Two other studies found that pain related to treatment is a greater problem than pain due to disease itself (Forgeron, Finley, & Arnaout, 2006; Ljungman, Gordh, Sorensen, & Kreuger, 1999). Forgerson and colleagues (2006) examined pain prevalence. They used chart review and interviewed 14 inpatient and 21 outpatient children age 2 to 17 years with various types of cancer and their parents at a hospital in Jordan. Seventeen children had pain at the time of the interview and 20 children had pain during the day of interview. The content analysis identified six themes: 1) pain should have been managed, 2) pain and suffering from cancer and treatment were God’s will, 3) parents’ worst pain was the emotional pain of the child’s diagnosis, 4) parents believed that their presence ameliorated their child’s pain, 5) parents desired shared decision-making, and 6) it was the child’s responsibility to express pain.

Ljungman and colleagues (1999) interviewed 55 children with cancer (age 1 to 19 years) and their parents in Sweden. They evaluated the extent and causes of pain, the use of methods for monitoring pain intensity, principles of pain management, and adverse effects of pain treatment. They divided the subjects into two groups: a younger group (aged < 5 years) and an older group (aged ≥ 5 years). Pain was a common symptom and a major problem during different phases of cancer treatment, and pain evaluation was unsystemic. Pain due to treatment and procedures was a greater problem than pain due to cancer itself. Younger children (from parental report) and children with shorter disease duration were more concerned about procedural pain. Parents claimed to judge their child's pain better than professionals. This study suggested that pain identification and treatment can be substantially improved through increased use of methods for pain evaluation and by teaching families about pain and pain treatment. Although this study used both young children's self-report and parental report for pain, they reported only parental report of pain.

Furthermore, Ljungman and colleagues (2000) used the data from the previous study (1999) to investigate how the experience of pain varied during cancer treatment. Material was divided into three categories: time from diagnosis: 1-3 months, 4-9 months, and more than 10 months. Procedure-and treatment-related pain were the major problems initially. Procedure pain gradually decreased, but treatment-related pain was constant and dominating. Intensive pain during the 3 months before the interview was significantly more often experienced by the group diagnosed 1-3 months; for each time from diagnosis, intensive pain was reported always for 65%, 17%, and14% respectively. Pain intensity measurement was seldom performed, and parents increasingly considered themselves better judges of their children's pain than nurses and physicians. The investigators concluded that parents may adapt to the pain situation with increasing confidence and knowledge. During cancer treatment, the children tended to have increasing depression, anxiety, difficulty going to sleep, tiredness, and reduced appetite. These symptoms might reflect a growing psychological impact of disease and treatment.

In 2006, Ljungman and colleagues compared the viewpoints of children and parents with those of professionals, on different aspects of pain in children with cancer based on the data of their previous study in 1999. The findings suggested that both families and professionals shared the opinion that pain was a common symptom during different phases of cancer treatment. The groups agreed that treatment-related pain was the most critical problem, followed by procedure- and cancer-related pain.

Most studies that have examined pain in children with cancer measured intensity and/or prevalence. Few studies have examined multiple dimensions of pain in children (Jacob, Hesselgrave, Sambuco, & Hockenberry, 2007; Van Cleve et al., 2004). Jacob and colleagues (2007) examined the pain experiences of children age 8 to 17 years with various types of cancer during hospitalization. Location, intensity, and quality of pain, pain medications, amount of pain relief, and perceptions of sleep and activity during hospitalization were described. Data were collected once daily from the day of admission for up to a maximum of 5 consecutive days during hospitalization. The findings showed that more than half of the patients (27 of 49 patients) had pain. The highest pain intensity ratings occurred on day 1, consistent assessment and implementation of pain intervention within 24 hours of admission was recommended, with particular attention to persistent pain during the 24 hours after procedures (such as a lumbar puncture or bone marrow aspiration). The most frequent pain locations were the abdomen (18.4%), chest (14.3%), and lower back (12.2%). In contrast, Van Cleve and colleagues (2004) reported legs

(26.5%), abdomen (16.6%), head and neck (16.6%), and back (14.2%) as the most frequent locations. The most frequently used descriptions of pain reported in these two studies were *annoying, uncomfortable, hurting*, and "*comes and goes*."

Some of these studies were longitudinal studies. Most of them were one-time measurements, used small samples, assessed a wide age range, and included different types of treatment. Therefore, little is known about pain symptoms in younger children with cancer undergoing chemotherapy treatment.

Fatigue. No published studies of fatigue have been explored in young children with cancer although fatigue has been studied extensively in adults. Recently, Hinds, Hockenberry-Eaton, and their research teams examined cancer- and treatment-related fatigue in children 7 to 12 years old and in adolescents 13 to 18 years old (Hinds et al., 2007; Hockenberry et al., 2003). Using a new instrument, children, parents, and staff nurses rated the child's fatigue prevalence and intensity. Adolescents undergoing treatment for cancer rated fatigue as their most prevalent and intense cancer- and treatment-related effect. Parents and staff nurses rated it similarly. The results suggested that fatigue in older children with cancer may be one of the most distressing symptoms experienced by this population.

Gibson and colleagues (2005) reported the results of a questionnaire-based survey completed by 224 parents and 235 healthcare professionals in the United Kingdom (UK). Parents and healthcare providers of children and adolescents with cancer reported fatigue as a moderate to serious symptom. Furthermore, Hinds and colleagues (2007) found that fatigue did not occur alone but was related to other symptoms. They identified the relationship between fatigue and sleep problems in children during hospitalization and found that patients who experienced more awakenings had significantly higher fatigue scores than those with fewer awakenings.

Nausea and vomiting. Clinically, nausea and vomiting are the most commonly reported side effects of cancer treatment. Yet few studies in children have directly explored nausea and vomiting in children with cancer. Lo and Hayman (1999) examined the relationship between parent and child (8-18 years old) reports of nausea and vomiting related to acute and delayed chemotherapy. Twenty parent-child dyads completed the Adapted Rhodes Index of Nausea and Vomiting every 12 hours for 3 days. Although this study examined the multi-dimensions of nausea and vomiting, those particular results have not been published. The authors concluded that parents' observations of their children's experience of nausea and vomiting were accurate (Lo & Hayman, 1999).

Docherty and colleagues (2006) used the Pediatric Nausea, Vomiting and Retching Guide to measure frequency, duration, severity, and distress for all three symptoms in a case study of a teenage girl undergoing treatment for cancer. This study found a consistent pattern of high peaks in morning nausea and vomiting immediately following a cycle of chemotherapy. Periods of respite occurred between cycles of chemotherapy (Docherty et al., 2006).

Sleep. Sleep has a healing function for children associated with increased protein synthesis and growth hormone release that contributes to tissue renewal, and it compensates for energy deficits acquired during daily functions (Hind et al., 2007). Using the actigraphy, epidemiological studies have found total sleep times for U.S. healthy children ages 1, 2, and 3-5 years to be approximately 11.5, 10.5, and 10 hours, respectively (Sadeh, 2004; Ward, Gay, Alkon, Anders, & Lee, 2008). Sleep disturbance is another of the most common symptoms experienced by children with cancer. Yet published studies have not directly examined sleep in young children with cancer.

A few studies have examined sleep in children with cancer during hospitalization (Hinds et al., 2007; Jacob et al., 2007). Hinds and colleagues (2007) studied nocturnal awakenings and sleep environment interruptions in 25 children (age 7 to 18 years) with cancer who were hospitalized for two to four days to receive chemotherapy. They assessed the relationships among nocturnal awakening, sleep environment interruption, sleep duration, and fatigue. They found that the number of nocturnal awakenings per night as measured by actigraphy ranged from none to 40. Children and adolescents hospitalized for scheduled chemotherapy experienced about eight times the number of nocturnal awakenings as healthy children in their home sleep environments. What is more, the number of room entries by a staff member or parent was 3 to 22 times per night shift. The chemotherapy affects the children’s normal sleep cycles and contributes to more night awakenings, especially with corticosteroids. Hospitalized pediatric patients with cancer experienced more nocturnal awakenings, had more fatigue, and slept longer.

Jacob and colleagues (2007) examined the variation in pain, sleep, and activity during hospitalization for 49 children (ages 8-17 years) with cancer. Data were collected once daily from the day of admission for up to a maximum of 5 consecutive days during hospitalization. A numeric rating scale (NRS) was used to determine the amount of sleep as reported by the patient to the question “How much sleep did you have during the night?” (0 = did not sleep at all to 10 = slept a lot). Twenty-five percent of the patients reported sleep scores ≤ 5 on the NRS. Sleep widely varied whether patients had no pain or had mild, moderate, or severe pain. The mean sleep scores for children who reported severe, moderate, and no/mild pain were 6.5 (± 1.9 SD), 6.3 (± 2.9 SD), 7.0 (± 2.4 SD), respectively.

While it is known that sleep disturbances occur in hospitalized children and adolescents with cancer, the prevalence or the characteristics of sleep disturbances in very young children with cancer receiving chemotherapy in the hospital is not known. Clinical experience suggests that this age group is at risk for sleep disturbances caused by physical, emotional, and environmental factors. Many factors have been identified with poor sleep in hospitalized children: noise, lights, lack of control, and separation from parents, loss of normal routine, anxiety, pain, and unfamiliar environment (Collins et al., 2002; Dogan, Ertekin, & Dogan, 2005; Hinds et al., 2007; Jacob et al., 2007) as well as bad smells, less favorite food intake, and sleep interruptions (Koolsu, 2001).

There is evidence that pain often prolongs sleep onset and interferes with the depth and continuity of sleep states. There are at least four physiological pathways through which these effects may occur: 1) pain sensations directly disrupt sleep states, 2) acute pain in particular may activate threat-related arousal in a manner that is incompatible with sleep, 3) chronic and recurrent pain heighten vigilance to signals of the onset of pain, and 4) pain and pain-related illness disturb cognitive and affective processes that prolong sleep onset and result in disruptions in the quantity and quality of sleep (Lewin & Dahl, 1999). The interaction of pain and sleep problems has yet to be investigated systematically. The most obvious effects involve a vicious cycle of pain sensations disrupting sleep, sleep deprivation resulting in impaired coping that could result in affective disturbance, more attention to pain symptoms, and high-risk behaviors. All of these have the potential to worsen the perception of pain, slow the healing process, and consequently disrupt sleep (Gedaly-Duff & Huff-Slankard, 1998; Lewin et al., 1999).

As noted above, symptom studies of children with cancer have shown that these children experience pain due to the chemotherapy. During hospitalization, children are more likely to have sleep problems not only related to chemotherapy, but also other symptoms and a different sleep environment as well.

Studies of Global Symptoms

Recent studies have examined fatigue, pain, and sleep disturbances in adult, school-age children, and adolescents. For example, Dodd and colleagues (2001) proposed the notion of studying symptom clusters and whether these symptoms are linked. They conducted a secondary analysis of a large dataset to determine the effect of the concurrent, related symptoms of pain, fatigue, and sleep disturbance on functional status during three cycles of chemotherapy in 93 adults. Fatigue and pain were found to affect patients' functional status, and fatigue was the largest contributor to the disruption in function. However, sleep disturbance was not statistically significantly correlated with other symptoms, and no strong inter-correlations among the three symptoms were found to form a cluster. Beck (2005) examined the symptom cluster of pain, sleep disturbance, and fatigue in 84 patients with cancer and with multiple primary diagnoses who were experiencing pain. Mediation analyses found that pain was related significantly to fatigue in individuals experiencing cancer pain. Some of the effect of pain on fatigue was mediated by sleep disturbance, and pain had a direct effect on fatigue, too.

Gedaly-Duff and colleagues (2006) examined this symptom cluster in children with ALL, aged 8 to 18 years old. After receiving outpatient chemotherapy, children with ALL reported pain, sleep disturbance, and fatigue over three days. Furthermore, this study found other symptoms related to chemotherapy treatment, such as nausea and vomiting, lack of appetite, numbness, and itching. However, these three studies of symptom clusters (Beck et al., 2005; Dodd et al., 2001; Gedaly-Duff et al., 2006) did not study other side effects of chemotherapy treatment such as nausea, vomiting, and sadness that may disturb sleep or affect other symptoms.

As mentioned above, Docherty and colleagues (2006) examined the daily symptom experience of a teenage girl undergoing treatment for cancer. Quantitative and qualitative data collection and analysis techniques were used to ascertain the pattern in her daily experiences of pain, nausea, vomiting, retching, stress, sleep alteration, and anxiety. In a key finding, the predictability evidenced in her symptom patterns was in direct contrast to her perception that there was no predictability or pattern to her symptoms. Her experience with her symptoms was strongly related to how the symptoms occurred together rather than as to how they occurred individually. The findings suggest that her symptom distress was multifaceted and dynamic.

Collins and colleagues (2000) developed the Memorial Symptom Assessment Scale (MSAS) to determine symptom prevalence, characteristics, and distress in children with various types of cancer (age 10 to 18 years). The children, who included 45 inpatients and 115 outpatients who had recently received chemotherapy, had significantly more symptoms (11.6 ± 6.0) than patients who had not received chemotherapy for more than 4 months (5.2 ± 5.1). The most prevalent symptoms in these older children were lack of energy, pain, drowsiness, nausea, cough, lack of appetite, and psychological symptoms. The mean number of symptoms per patient in the inpatient group (12.7 ± 4.9) was significantly greater than the outpatient group (6.5 ± 5.7) ($p<0.01$). Later, the authors developed an MSAS for children age 7 to 12 years (Collins et al., 2002), and they surveyed the experience of symptoms in school-aged children with cancer. Children did a self-report of symptoms and parents did a symptom checklist to check validity. The results found that these children experienced multiple symptoms. The prevalent symptoms included lethargy, pain, insomnia, itching, lack of appetite, worry, nausea, and sadness, respectively. Fifteen inpatients experienced significantly more symptoms than 134 outpatients did. More recently, Johnson (2008) explored symptoms related to disease and treatment in 51 outpatient adolescents with cancer age 10 to 19 years. This study found that the most prevalent symptoms were tiredness (67%), nausea (51%), pain (48%), and change in appetite (48%); the most distressing symptoms were worry (83%), pain (70%), and nausea (62%).

A few studies have identified symptom experiences in younger children with cancer; however, the children had limited communication abilities. Thus, their symptoms could not be fully identified or known (Williams, Schmideskamp, Ridder, & Williams, 2006). However,, Williams and colleagues (2006) studied multiple symptoms in 11 children age 2 to 18 years using the Therapy-Related Symptom Checklist (TRSC, child version), which was completed by parents or caregivers. The most frequent symptoms were pain, nausea and vomiting, fatigue, and sleep disturbance. Further, this study found a relationship between parental report of symptoms and clinical rating of child's functional status that showed that parents were able to serve as acceptable informants of their child's symptoms.

In summary, research supports the hypothesis that children with cancer do not experience isolated symptoms but rather clusters of symptoms. Although some studies were longitudinal studies, most studies used a one-time measurement, small samples, a wide age range, and different types of treatment. In contrast, this current study examined global symptoms in young children with cancer (ages 1 to 5 years) during chemotherapy treatment.

Symptoms of Children with Cancer in Thailand

There are unpublished studies that have explored global and specific symptoms in young Thai children. Two studies examined symptom experiences in school-age Thai children with leukemia (Koolso, 2001; Pharnit, 2004). Using the modified Piper Fatigue Scale and the Scale of Contributing and Alleviating Fatigue factors, Koolsu (2001) studied fatigue in children with leukemia, age 7 to 15 years, during chemotherapy treatment in Thailand. She found that the peak rise of fatigue level occurred on the second day of chemotherapy. The contributing factors were noises, bad smells, light, sleep interruptions, sleep pattern changes, inability to perform preferable activities, less food intake, having side effects of chemotherapy, and receiving painful procedures.

Another study explored the lived experience of 13 school-age Thai children (age 9 to 12 years) with leukemia (Pharnit, 2004). Findings from this study revealed that the illness experiences of school-aged patients with leukemia consisted of six themes: 1) it hurt: children experienced pain from both illness symptoms and treatment procedures; 2) there was a perception of never-ending sickness: the feeling of discomfort from symptoms and side effects of treatment that occurred over and over again; 3) the children were bored: some experienced this repeatedly across their illness and treatment; 4) the children encountered fear: hospitalization made children frightened, i.e., needle, ghost, and death; 5) they were ashamed of baldness (hair loss); 6) they were unable to do what they wanted: illness and side effects of treatment made children unable to do what they wanted.

Children in this study described their pain due to cancer treatment, particularly chemotherapy, more than pain due to cancer. Children who received chemotherapy through peripheral intravenous administration or through the lumbar spinal cord reported their pain was from needles and leakage of chemotherapy agents. However, good experiences also emerged: children gained more attention from their families and friends during illness. This study provided information that cancer-related symptoms and treatment influence school-aged patients. These studies supported the idea that Thai children experienced symptoms related to treatment and that hospitalized children experienced more pain.

Development of Symptom Expression

Although research on the development of symptom expression is limited, existing developmental studies have provided data that children express symptoms depending on their age and experience (von Baeyer & Spagrud, 2003). During the toddler and preschool years, symptom distress becomes shaped increasingly by the child's growing understanding of emotions and the ability to anticipate outcomes and feelings. Negayama (1999) examined the development of reactions to pain of inoculation in children and their mothers. About 50% of 3-year-olds cry before an injection, suggesting that because of their previous experience, they anticipate and fear the pain of the imminent injection (Negayama, 1999). By preschool age, children are also developing the ability to feign, exaggerate, or suppress outward signs of pain, if doing so carries some gain for the child (e.g., avoiding an injection or painful therapy, or getting out of bed). The most rapid developmental changes in pain expression probably occur before 3 years of age. At the age of 3 years and beyond, there are continued changes in pain expression (e.g., less crying in older children given the same physical stimulus).

This study also found that children's responses to symptoms were influenced by the responses of their parents and other adults. Japanese mothers responded with less empathy to 6-year-olds showing decreased painful reactions, with an increase in smiles (mainly as a reaction to the children's strong cry). The smiling was taken as a non-empathic response to the older children's pain, which would be consistent with the mothers' making an effort to teach their children to suppress their pain expression.

Children older than 5 years quickly decreased the strong cry after inoculation, which was in sharp contrast to the younger children (Negayama, 1999).

Similarly, Fearson and colleagues (1996) observed preschool-aged children during active play at their daycare centers. The severity of incidents was measured, as well as the intensity and duration of children's responses (e.g., crying) and the nature of the adult response that followed (e.g., ignoring or cuddling the child). Interestingly, the adult response was predicted by the child's expression of distress but not by the incident itself, so that a child who cried about a very minor incident was more likely to receive care than a child who responded stoically to a more severe incident. This finding suggests that individual differences in children's responses to pain may be maintained and magnified by differential adult response.

Social influences on symptom expression also exist in the hospital, in interaction with healthcare providers. For example, in the U.K, nurses in an orthopedic ward were found to actively discourage children from displaying their pain: they frequently "constructed pain as unreal, unwarranted or not deserving help" (Byrne et al., 2001, p 72). Children who did not complain of pain or ask for analgesics were described by nurses as "very good" or "great." Children's response to symptoms can be strongly influenced by the society in which they grow up and the behavior of their parents and other important adults.

Symptom Expressions in Thailand

Buddhism influences the Thai people to avoid confrontation and refrain from expressing emotion. It teaches them to rid themselves of distress by endeavor and calming the mind, and it advises children to accept their condition rather than attempt to change them (Jongudomkarn et al., 2006). These beliefs may influence symptom expression. The expression of sorrow, pain, or anger may displease others, which would not be socially acceptable. Thai people are taught to be considerate and not bother others, especially not to bother more senior or authoritative people like healthcare professionals. Common Thai sayings that exemplify this socialization include “Mai pen rai” (“It doesn’t matter”) and “Kep ngam khwam ru suk wai nai jai” (“Refrain your feeling in your heart,” or, in other words, “Big boys don’t cry”) (Jongudomkarn et al., 2006, p.162). Accordingly, when Thai children have pain, they report this to their mothers rather than healthcare providers. For example, Jongudomkarn et al. (2006) reported the mother of a 9-year-old girl with aplastic anemia as saying, “Every time my child comes to the hospital, she is in pain. When she has pain, I can only tell her to endure it. If it’s too much, then we ask the nurse for some pills” (p. 161). This finding confirms that the culture in which a child is raised affects the experience, expression, and response to symptoms. Pain in school-aged children was expected to be endured. It is not known how mothers teach their young children with life-threatening illnesses, such as cancer, to express or repress their symptoms.

Symptom Management and Outcomes in Young Children with Cancer

A few studies have examined symptom management and outcomes in young children with cancer. For example, Van Cleve and colleagues (2004) studied pain in 95 children with ALL age 4 to 17 years during the first year after diagnosis. Parents completed the management measures and functional status questionnaire. The most frequently used strategy for pain management was stressor modification (e.g., medication, sleep, hot/cold, and massage). Parents of younger children (age 4 to 7 years) reported higher scores of the perception of management effectiveness, and functional status was above the median score.

Another study used Orem's self-care theory to study care strategies used for multiple symptoms by 11 parents of children age 2 to 18 years (Williams et al., 2006). One care strategy was diet/nutrition/ lifestyle change (e.g., more high-fat, high-calorie foods; new foods; any food child likes; and much sleep and rest) as well as mind/body control (e.g., play, video games, television, reading, activity puzzles, breathing exercises, relaxation methods, and player). However, this study was limited by its small sample size and the fact that the researchers did not address the different strategies used for younger children and older children.

Forgerson and colleagues (2006) interviewed 22 parents in Jordan about their attitudes and beliefs regarding the meaning of pain and their child's pain management. Some parents believed that pain could be managed, and some parents believed that pain and suffering from cancer and treatment were part of God's will. These findings support again the idea that culture influences the meaning and management of pain.

Most studies of symptom management and outcomes in children have investigated single symptoms such as pain, and have used wide age ranges and various cancer treatments. Studies are needed to explore symptom perception in different cultures, such as the Thai culture. Investigations of symptom management and outcomes in young children are needed.

Methodology Issues

The efficacy and effectiveness of symptom measurement are essential for determining symptom management in children. Most available measures were developed for pain assessment. However, while multiple pediatric pain measures exist, they are inconsistently used across the type of pain or the developmental age span.

Three approaches to measuring symptoms in children include self-report, observational or behavioral, and physiological. The ideal would be a combination of measures, including self-report and one or more of these other approaches (Chambers, Craig, & Bennett, 2002). However, physiological changes in variables such as respiration rate and heart rate are only loosely correlated with events related to symptoms and many other states, such as exertion or fever (von Baeyer, Piira, Chambers, Trapanotto, & Zeltzer, 2005). Moreover, correlations of physiological items with other observed behaviors and with self-report are, in general, not well established. There is also evidence to suggest that physiological indicators are less sensitive to change in distress following an intervention as compared to subjective and behavioral measure (Walco, Conte, Labay, Engel, & Zeltzer, 2005).

Self-Report

It is considered desirable to obtain and rely most on self-report measures when these are available, since there is broad consensus that pain is primarily understood to be a subjective experience. However, self-report in children is not always practical or feasible. For example, this approach would not be applicable for preverbal children and nonverbal and cognitively impaired children (von Baeyer & Spagrud, 2007). Furthermore, despite the recognition of the multidimensional nature of symptoms, self-report measures can generally be used with children who are old enough to understand and use self-report scales, are not overly distressed, do not have impaired cognitive or communicative abilities, and whose self-report ratings are not considered exaggerated or minimized due to cognitive, emotional, or situational factors (von Baeyer et al., 2007).

Stinson and colleagues (2006) have systematically reviewed the psychometric properties, interpretability, and feasibility of self-report pain intensity measures for children and adolescents for use in clinical trials evaluating pain treatments. They found that no single scale was found to be reliable and valid across age groups or pain types, with the majority of scales lacking reliability and validity in pre-school children. Communication barriers pose challenges to establishing reliability and validity of pain intensity self-report measures in young children. Preschool children may lack the requisite comprehension level to use measures and tend to favor the extreme ends of scales (Chambers et al., 2002).

Several studies have shown that children older than 5 years can use self-report for pain or symptom measurement. In contrast, some studies have found that school-aged children also have difficulty reporting their pain and need their parents’ help (Collins et al., 2002). Stanford and colleagues (2006) examined young children’s ability to use the Face Pain Scale-Revised (FPS-R) for pain responses to vignettes and investigated the role of developmental factors in predicting their ability to use the scale: 112 healthy children age 3 to 6 years were assessed for their ability to accurately use a common faces scale to rate pain in hypothetical vignettes depicting pain scenarios common in childhood. Accuracy was determined by considering whether the children's judgments of pain severity matched the pain severity depicted in the various vignettes. The children were also administered measures of numerical reasoning, language, and overall cognitive development. Results indicated that 5- and 6-year-old children were significantly more accurate in their use of the FPS-R in response to the vignettes than 4-year-old children, who in turn were significantly more accurate than 3-year-old children. However, the authors summarized that many young children, age 3 to 6 years, experienced difficulties using the FPS-R when rating pain in hypothetical vignettes. Therefore, it is not clear if children 5 years and younger can provide self-report and especially when using a multidimensional measurement and experiencing long-term pain.

Varni and colleagues (2007) examined the hypothesis that children as young as 5 years can reliably and validly report their health and quality of life. This study collected child self-report data on 8,591 children age 5 to 16 years. Participants were recruited from general pediatric clinics, subspecialty clinics, and hospitals in which children were being seen for well-child check-ups, mild acute illness, or chronic illness and from a state children's health insurance program in California. The findings indicated that the subgroup of 5 to 7 years of age had the lowest internal consistency coefficient.

Observation

Observational measures of symptoms are needed for use with children who are too young to understand and to use a self-report scale, too distressed to use a self-report scale, and/or impaired in their cognitive or communication abilities (Keller & Keck, 2006; von Baeyer et al., 2007). Over the course of child development, systematic transformations can be observed in the way pain is expressed or communicated (von Baeyer et al., 2005).

Most observational instruments were initially designed to measure pain and to accommodate a particular age range, but many have been applied to a broader age range. Methods for observational measurement of brief acute pain (e.g., procedural pain) are much better established than methods for measuring long-lasting and chronic pain. Little is known about what signs of long-term or chronic pain are visible to an observer. Chronic pain, except during acute exacerbations, is likely to be manifested in complex changes such as increased irritability, low mood, difficulty with sleep, hostility, and change in appetite, all of which require knowledge of the individual’s baseline condition and temperament.

When observing young children, discriminating pain intensity from distress, unpleasantness, and fear should be carefully considered (von Baeyer et al., 2007). Few researchers have presented discriminate validity data showing that their observational scales can differentiate pain intensity from its affective aspect or from other negative emotional states and reactions. Similarly, for self-report, most children under 8 or 9 years of age have difficulty discriminating between the sensory experience of pain and the affective response (i.e., distress or fear) to painful sensations (Goodenough et al., 1999). Furthermore, the relationships of the observer to the child also affect the accuracy of the assessment. An observer who is familiar with the child's normal behaviors may be better able to identify pain-related behaviors than a clinician less familiar with the child. In addition, children are often more expressive in the presence of parents than strangers (Goodenough et al., 1999; von Baeyer et al., 2007). For children with cancer, parents thought that they were better judges of their child's pain than nurses and physicians (Ljungman et al., 2006). Therefore, to observe pain in young children, it is necessary to include the mother or primary caregiver who knows the child's temperament and behavior best.

Mother's Report

The primary caregivers (particularly mothers) of young children are an appropriate source of proxy rating of the children's symptoms for a number of reasons. Mothers are the most universally available informants, are usually the most knowledgeable about their child's behavior across time and situations, are almost always closely involved with the medical treatment, and are better placed than other proxy raters to evaluate relative symptoms (i.e., how the child is compared to pre-treatment status). Although mothers and school-age children and adolescents are known to disagree in some areas when questionnaires are used, some studies also have reported high correlations between parents and children on ratings of pain and fatigue symptoms (Chambers et al., 1998; Hockenberry et al., 2003) and between parents and healthcare professionals or researchers (Riddell, Stevens, Cohen, Flora, & Greenberg, 2007; Williams et al., 2006; Zisk et al., 2007).

Riddell and colleagues (2007) found that a mother's immediate pain judgment (the NRS of a 0-10 scale) during routine immunization was strongly related to the composite measure of infant pain as observed through facial expression, cry, and body expression by research coders. The authors suggested that maternal pain judgments of the non-verbal infants were more heavily determined by a combination of the infant's general display of negative face, body, and cry rather than the infant's specific pain face.

Parents of children with cancer are able to serve as informants of their children's symptoms (Williams et al., 2006). A study by Williams et al. (2006) explored the relationship between parent report of symptoms and clinician rating of child's functional status. However, it is not possible to conclude that parents, particularly mothers, are more accurate than clinicians because determining accuracy in young children's symptom experience is not possible due to the children's inability to report their subjective experience.

In addition, maternal reports are sometimes unreliable (Chambers et al., 2005; Zisk et al., 2007). For example, Zisk and colleagues (2007) explored socio-demographic and personality characteristic predictors of parental pain perceptions in children undergoing surgery. Findings showed that less educated parents and social parents were more likely to avoid giving analgesia. Parents with higher conscientiousness scores were more likely to perceive that analgesia was appropriate to use for child pain. The authors suggested that parent characteristics can be used to identify parents at risk for these misconceptions.

It is almost always the mothers’ view of their children’s symptoms and behavior that determines there is a problem, and this is likely to continue into the child’s early adolescence. Therefore, parents may be in a unique position to advocate for appropriate care for their young children. Maternal report has limitations and may not be reliable at all times. Therefore, a discussion of maternal variables such as maternal sensitivity and maternal distress influencing mothers’ report follows.

Maternal Variables

Maternal Sensitivity

Maternal sensitivity is defined as a mother’s ability to perceive and interpret accurately her infant’s signals and communications, and then respond appropriately (Ainsworth et al., 1974, p. 934). Sensitive mothers do so on the basis of their insightfulness and their capacity to see things from the infant’s point of view. In contrast, insensitive mothers do not base their interventions on the infant’s perspective but rather on other factors, such as their own states and wishes, general ideas about infants’ needs, or other determinants unrelated to the infant’s specific emotional needs (Shin, Young-Joo, & Mi Ja, 2006).

Bowlby (1973) theorized that instinctive behaviors intensify when a child is under stress due to separation from the primary attachment figure, from exposure to an unfamiliar person or situation, or from physical distress such as hunger or pain. The experience of hospitalization involves separation from parents, encounters with strangers, and physical distress (Bowlby, 1973). Riddell and Chambers (2007) suggested that an optimal situation would have sensitive mothers assess their child's pain signals and take appropriate actions to soothe both the physical and emotional dimensions of their infant's symptoms. Over time, infants know they can use their mothers as a secure base, and that their mothers will respond to their symptoms such as pain. In contrast, mothers with inconsistent sensitivity sometimes do and sometimes do no require intense child pain behaviors in order to take action. Mothers with less sensitivity do not respond consistently to their children's cues. Over time their children learn to avoid or ignore their mothers because they perceive their mothers as rejecting. In sum, mothers with less or inconsistent sensitivity may be less effective at reporting and managing the child's symptoms.

Based on observational ratings of children's behavior during separation from parents and encounters with strangers, children can be classified as having secure or insecure attachment (Ainworth, 1979). A securely attached child is thought to have an internal representation or working model in which the caregiver is trusted to be available to provide help whenever needed—in other words, to be a secure base for the child's exploration of the world. The securely attached child expresses distress openly when experiencing a stressor and seeks proximity with the caregiver. As the children grow older, they deal with mild threats independently and confidently.

There are three forms of insecure children: anxious-ambivalent, anxious-avoidant, and disorganized, as the attachment patterns are labeled. Anxious-ambivalent children have internalized a working model of their mothers as inconsistently responsive. They protest everyday situations because they have no confidence in their mother's availability. They are angry because, unsure of what to expect, they fear disappointment. Anxious-avoidant children experience their mothers as rejecting; they defend against a painful rebuff by avoidance. Finally, disorganized-attached children may have experiences of abuse, abandonment, or other causes that make them fear their mothers or caregivers. Such children may exhibit fleeing behaviors with their mothers.

The results of meta-analyses have confirmed that caregivers rated as *sensitive* are significantly more likely to have secure infants than caregivers rated as *less sensitive* (De Wolff et al., 1997). These findings sufficiently support a causal link between maternal sensitivity and infant attachment security to guide the effects of maternal sensitivity intervention on infant attachment.

The contextual demands placed on maternal sensitivity may change over time, and these changes in demands may be associated with normative changes in the children as they acquire new interactive skills for expressing more complex ideas (Thomson, 1999). For example, a recent longitudinal study of 1345 families found that maternal sensitivity with 6-, 15-, 24-, and 36-month-old children increased from 6 to 36 months for children classified as secure or resistant but not for children classified as avoidant or disorganized (Mills-Koonce, Gariepy, Sutton, & Cox, 2008). Higher maternal depressive symptoms were associated with lower levels of sensitivity for all mothers, although this effect was significantly less severe for mothers of securely attached children. Maternal sensitivity can be examined as a function of individual psychosocial influences and as a property of the more complex, ongoing, and interactive relationship between the parent and child.

Several studies found that most mothers across cultures are sensitive to their children (Chaimongkol et al., 2006; Mizuta, Zahn-Waxler, Cole, & Hiruma, 1996; Moran et al., 1992). For example, Moran et al. found that the mean scores of maternal sensitivity in 40 mothers of 12-month-old infants was .73 (SD = .18). Similarly, the mean scores of maternal sensitivity in Thai mothers were comparable at .70 (SD = .09). Most children were classified as having a secure attachment. In other words, most mothers with consistent sensitivity appropriately responded to their child's signal or distress including their children's symptoms and their children perceived their mothers as a secure base.

Given the minimal amount of literature regarding how a child's symptoms are impacted by the dyadic relationship between parent and child, Riddell and Chambers (2007) proposed two possible scenarios that develop over time. First, the children's most intense symptom behaviors are positively reinforced by parental attention and less intense reactions are extinguished because they are not reinforced. Alternatively, less-sensitive/less-consistent mothers may cause their children to display less-vigorous signaling to their caregivers (Sweet, McGrath, & Symons, 1999) because the children have either learned to alter their symptom experience by themselves or learned that their energy is wasted trying to elicit help from their caregiver.

No published studies have examined maternal sensitivity and mothers' perception of their children's symptoms. Perhaps maternal judgment of children's symptoms such as pain is a situation-specific manifestation of maternal sensitivity. For example, a study by

Riddell et al. (2007) found that maternal pain judgments were more heavily determined by a combination of the children's general nonverbal display of negative face, body, and cry rather than the infant's specific pain face.

In a study of pain in Thailand, Jongudomkarn and colleagues (2006) found that when Thai children experienced pain, their parents shared it. For example, a 9-year-old said, "When I am in pain, my Mom is beside me, hugging me and touching me. When I have a pain in my leg or arm, my Mom will massage me." When she cries, her mom said, "Be patient and hug her." When experiencing pain, most children believed their parents and other family members would look after them. They would then try to endure the pain until it became unbearable. When they did express their pain, it would always be to their parents rather than a healthcare worker, who reduced the pain in a timely manner (p. 161). In sum, this study supported that culture influences how Thai people express and manage symptoms. However, this does not mean that this effect decreases mothers' sensitivity as well as their ability to report their children's symptoms.

Maternal Stress

Parents of children with cancer, particularly mothers, have a critical role to play both in providing care and in facilitating the children's acceptance of treatment (Nelson, 2002). Mothers face considerable responsibility for administering home-based treatments and explaining the illness to their children (Svavarsdottir, 2005; Van Dongen-Melman, Van Zuuren, & Verhulst, 1998; Woodgate & Degner, 2004). For example, Woodgate and Degner (2004) interviewed 28 children age 4.5 to 18 years and their parents to explore and describe the symptom course in childhood cancer. Families strove to protect their ill children. In addition, compared with parenting children with chronic illness, Chinese mothers of children with cancer reported significantly higher parental stress scores than mothers of disabled children (Hung, Wu, & Yeh, 2004).

For mothers of young children with cancer, clinical experience suggests that a mother may feel some relief that her child is young and may not be able to remember the treatment. In addition, there is less need to explain cancer and its treatment because her child is too young to understand. A mother, however, is often the primary source of information regarding her child's symptoms and must observe, report, and manage her child's symptoms at the hospital and at home. Therefore, a mother of a young child may worry that her child may not be able to communicate his or her distress (e.g., pain, feeling sick). In addition, she might be challenged, particularly with a toddler, to administer medication and other treatments (Kazak et al., 2007; Roy & Russell, 2000).

These demands potentially contribute to maternal stress. Mothers who take care of their children during hospitalization may experience a more stressful situation than at home. Shields and King (2001), who surveyed mothers of hospitalized children in Australia, Britain, Indonesia, and Thailand, found that mothers in all these countries were primarily concerned with treating the child's illness and in facilitating the child's recovery. Mothers were concerned with their own work (employment), but this was a much larger consideration in Indonesia and Thailand, where no social security systems exist.

Relationships among Maternal Variables and Mothers' Perceptions of Symptoms in Their Children

No study has explored maternal sensitivity in mothers caring for young children with cancer or examined the relationships among maternal sensitivity, maternal stress, and maternal perception of her child's symptoms although Abidin's (1995) model of parental stress provides a perspective for assessing parental functioning. This perspective is congruent with attachment theory, in that parenting stress or the parents' psychological dysfunction is not only affected by the child's and parents' characteristics but also by contextual factors.

Existing studies have supported the idea that maternal stress influences the quality of attachment and maternal sensitivity. For example, Moran et al. (1992) examined the impact of parenting stress on maternal sensitivity in 19 mothers of delayed children who received home visits from infant therapists. Mothers with a higher level of parenting stress in the child domain had less maternal sensitivity. Lower levels of maternal sensitivity were related to their developmentally delayed infants' inabilities to stimulate and to respond in sensitive interactions with their mothers.

Riddell and colleagues (2007) additionally examined the influence of maternal factors on infants with pain and maternal responses to the infant. During telephone interviews, mothers were asked to recall pain levels for the day after the immunization of their children. The authors found that maternal psychopathology was a significant determinant of day 1 maternal pain recall. The authors suggested that perhaps mothers who reported greater psychopathology had higher recall of infant pain due to negative cognitive biases. These findings could support the idea that maternal stress may influence mothers' more negative perceptions of their children's pain.

Summary

It is necessary to know the sensitivity of mothers who care for young children during chemotherapy treatment because these children experience multiple symptoms related to treatment and they cannot communicate their symptoms to others. They need their mothers as primary caregivers to recognize their symptoms and to help them to reduce their symptom distress. When Thai children have pain, they have been found to tell their mothers (Jongudomkarn et al., 2006). Mothers make complex judgments about the meaning of symptoms and the efficacy of treatment for their young children. Thus, it is necessary to learn more about how mothers' stress, while caring for their children with cancer, influences their sensitivity to their children's cues and demands. More understanding of the relationships between maternal sensitivity and stress in Thai mothers may inform healthcare providers as to how to help mothers to more effectively manage their children's symptoms.

Conceptual Framework

The theoretical framework of symptoms underlying this study was derived from the sociocommunication model of infant pain (Craig & Pillai Riddell, 2003) and the middle-range theory of unpleasant symptoms (TOUS) (Lenz, Pugh, Milligan, Gift, & Suppe, 1997).

Overview of The Sociocommunication Model of Infant Pain

Infant pain assessment and management is based on the concept of the dyadic relationship between the infant and caregiver (Craig et al., 2003). Bowlby's attachment theory, concerning an infant's instinct to secure safety from the parent and for a parent's instinct to protect the infant, provides the broader theoretical context and specific mechanisms for understanding how the infant in distress is influenced by the caregiver and vice versa (1969). The infant's experience and expression of pain are subsequently impacted by the caregiver's ability to detect the infant's pain signals and discern an appropriate course of action. The influence of parenting behavior on infant pain expression may become greater as the infant and parent build a relationship over time (Riddell et al., 2007).

According to this model, biological factors (genetics, nutrition, injury, and disease) and socio-environmental factors (family, socio-economic status, community, and culture) must be elucidated for a comprehensive understanding of pain. The sociocommunication model of infant pain purports an understanding of infant pain as a sequence of nonlinear stages within the child, within the caregiver, and between the child and caregiver. This model emphasizes the interdependence of stages by depicting feedback loops (i.e., arrows in both directions) among stages. The model also suggests that larger spheres of influence (e.g., family, community, culture) separately influence the infant and the caregiver.

However, the purpose of this model is to explain pain experience in infants and their caregivers. As children with cancer experience multiple symptoms, the present study used the theory of unpleasant symptoms to better understand how multiple symptoms occur and how these symptoms affect each other.

Overview of the Theory of Unpleasant Symptoms (TOUS)

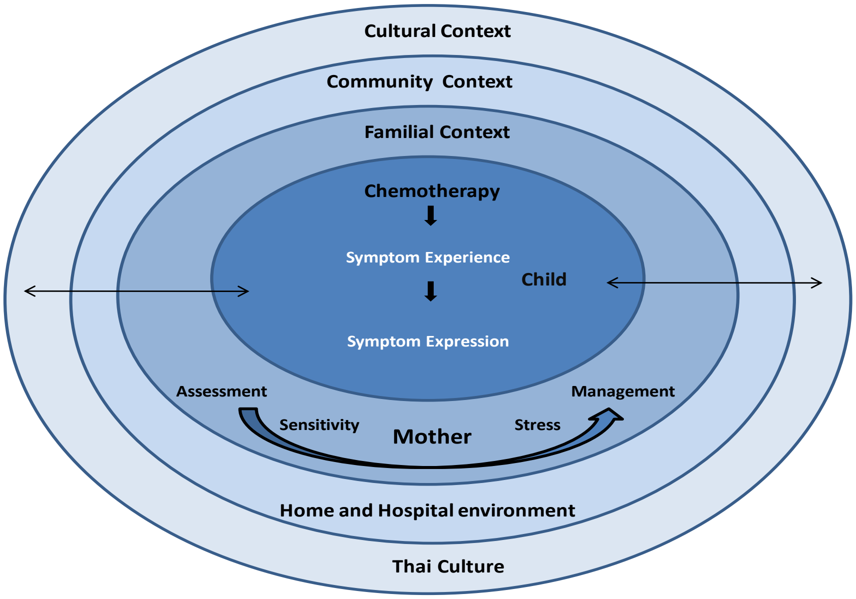
According to Lenz and colleagues (1997), TOUS focuses on the symptom experience, with multiple symptoms occurring together rather than one symptom in isolation (Figure 1). The symptoms are seen as multiplicative rather than additive.

Symptoms can be considered alone or in combination. Symptoms have the dimensions of intensity (severity), timing (frequency, duration, and relationship to events), distress (the person's reaction to the sensation), and quality (descriptors used to characterize the symptom, location of symptom, or response to intervention). The quality dimension may be especially difficult, depending on the culture and language of the patient, and the number of symptoms experienced at the same time. *Symptoms* have antecedent factors such as physiological factors, psychological factors, and environmental factors. These antecedents are interactive and reciprocal.

The conceptual model of mother's perception of symptoms in young children receiving chemotherapy

The modified model of sociocommunication of infant pain was referred to as the model for the study of mothers' perceptions of symptoms in young children receiving chemotherapy (see Figure 1). The outermost oval represents the cultural context, the second oval the community context, the third oval the familial context, and the fourth oval represents the child.

Figure 1. The Conceptual Model of Mother's Perception of Symptoms in Young Children Receiving Chemotherapy.



Symptom Expression is defined as how a child reacts to tissue stress and damage with vigorous vocal and non-vocal activity, thereby providing a means for inferring his or her subjective state. Symptom expression is not only influenced by the internal symptom experience but also by other social factors such as the presence of healthcare providers versus mother, or being in the hospital versus being at home. *Mother* refers to the biological mother who is a primary caretaker of her child. *Maternal sensitivity* refers to the mother's perception of her ability to accurately interpret, and appropriately and promptly respond to, her child's signals and demands. *Maternal stress* refers to the mother's perceptions of her distress, parent-child dysfunctional interaction, and difficult child behavior. *Maternal distress* is defined as the distress a mother is experiencing in her role as a parent as a function of personal factors that are directly related to parenting. The mother-child dysfunctional interaction is defined as the mother's perception that her child does not meet her expectations and that the interactions with her child are not reinforcing to her as a parent. A *difficult child* is defined as the mother's perceptions of some of the basic behavioral characteristics of her child that are either not easy or difficult to manage. *Mother's assessment of symptoms* refers to the mother's interpretation of her child's expression of symptoms. The mother's ability to interpret her child's symptoms may be impacted by factors such as her sensitivity, stress, and belief system, and the context of the surrounding environment. *Mother's management of symptoms* refers to the mother's decision to manage her child's symptoms. Based on her perception of symptoms, a management decision is made to take action or not. *Hospital environment* refers to the hospital environment, hospital nurses, physicians, other children and their parents, and the circumstances of the hospital that may influence children's experience and expression, as well as the mother's perceptions of her child's symptoms. *Home environment* refers to the home environment, the parents, the family members, and the circumstances of the home that may influence the child's experience and expression, as well as the mother's perceptions of her child's symptoms. *Thai culture* refers to belief systems and patterns of learned behaviors in Thai society that may influence the child's experience and expression, and the mother's perceptions of her child's symptoms.

Limited scope of this study

The goal of this study was to explore a mother's perceptions of her young child's symptoms while the child was undergoing chemotherapy treatment. This study was focused on symptom management only and did not include any attempt to test the model in its entirety. The first necessary step in the examination of a mother's assessment of symptoms in young children was to be able to identify a readiness (ability) of the mother to respond to the general demands of her young child. Therefore, this study measured maternal sensitivity and maternal stress before examining the mother's assessment of her child's symptoms. Subsequently, the study examined the relationships among the mother's perceptions of her child's symptoms, maternal sensitivity, and maternal stress.

The research questions

The research questions informing this study were as follows:

1. How do mothers perceive their young children's symptoms during chemotherapy treatments for cancer?
2. How do mothers manage their young children's symptoms and how do they evaluate their management?
3. What are the relationships among maternal sensitivity, maternal stress, and mothers' perception of symptoms in their young children during chemotherapy?
4. What is the relationship between symptoms of sleep and pain in young children as reported by their mothers?

CHAPTER 3

RESEARCH DESIGN AND METHODS

The primary aims of this prospective, descriptive study were to 1) describe mothers’ perceptions of symptoms and symptom management in their young children during three days of chemotherapy treatment for cancer, and 2) explore the relationships among maternal sensitivity, maternal parenting stress, and mothers’ perceptions of their children’s symptoms. The secondary aim was to explore the relationship between young children’s pain and sleep as reported by their mothers. A sample of toddler and preschool children with cancer has been selected because there are gaps in the literature regarding mothers’ perception of symptom management in their young children with cancer (Docherty, 2003). For these aims, fifty Thai mothers were asked to document symptoms of their children receiving chemotherapy, and evaluate their management of symptoms twice a day for three days while in the hospital or at home. The mothers were asked to complete the maternal sensitivity and the maternal stress instruments before their child received chemotherapy.

This study had three phases, including (1) preparation of instruments (translation and back-translation process, and evaluation by the Thai experts); (2) a pilot study with 5 Thai mothers and their children who resembled the study population by doing the full study procedure; and (3) the full study. The details of the three phases are described in the instrument section.

Sample

Fifty Thai mothers and their children diagnosed with cancer and receiving intravenous chemotherapy were invited to participate. Data were collected only from mothers who stayed in the hospital with their children, or were primary caregivers of their children at home.

Inclusion Criteria

The inclusion criteria for mothers' were: (a) a biological mother (over 18 years old), (b) able to read, write, and understand Thai, (c) having a child with cancer receiving intravenous chemotherapy, (d) living with the child receiving chemotherapy in hospital and at home, and (e) mothers and their children were willing to participate for 3 consecutive days and give informed consent.

Mothers were not recruited during diagnosis and first treatment because of the distress caused by the cancer diagnosis. Children were excluded if they had other chronic diseases that require daily medications (e.g. diabetes and renal failure).

No data were available to calculate a power analysis and determine the sample size for the primary aims. The sample of 50 Thai mothers with toddler or preschool children (ages 1 to 5 years) with cancer was considered reasonable for establishing the magnitude of relationships between variables (Miller & Kunce, 1973; Halinski & Feldt, 1970).

Setting

Data were collected at the Queen Sirikit National Institute of Child Health in Bangkok, Thailand. There are four regions of Thailand and each region has a tertiary hospital taking care of children with cancer. The Queen Sirikit National Institute of Child Health serves the children with cancer in the central region of Thailand that includes urban and rural settings (Hematology Department of the Queen Sirikit National Institute of Child Health, 2008).

Protection of Human Subjects

The proposal was approved by the Human Research Committee of OHSU Knight Cancer Institute and the Institutional Review Board of Oregon Health & Science University (IRB) in the US. The Committee on Human Research of the Queen Sirikit National Institute of Child Health and the Department of Medicine Service of Ministry of Public Health approved this study in Thailand.

All eligible participants were approached and invited to participate. The study was explained to the mothers and their children by the researcher. Questions were answered and written consent was obtained from the mothers and verbal assent was obtained from the children. The participants retained of a copy of the consent form. Confidentiality of the data was protected. Identification numbers replaced names on the data collection materials. The researcher has research education in protecting human subject confidential information. The importance of maintaining confidentiality was emphasized. Data instruments were stored in locked file cabinets with access only by the researcher. Data used in professional communications such as conferences and publications had personal identifying information removed.

This study involved minimal risk to the mothers and children who participated. There were few risks for the participants. Mothers could experience emotional distress in answering questions in the diaries and questionnaires. The self-report of maternal sensitivity and maternal stress could result in some anxiety. Since the mothers were asked personal information and their children’s symptom twice a day for three days, there was a potential risk for mothers to experience some distress related to the feelings that some items identified. However, in this current study, mothers and their children did not report emotional distress in participation.

While there were some risks to participation in this study, there were also benefits. Mothers who participated in this study could benefit by becoming more aware of their sensitivity, their stress, their children’s symptoms, and management strategies that were available for them to use. Furthermore, they could obtain skills and important information about measuring their child’s symptoms.

Recruitment process

Two steps were used to contact potential participants. First, the researcher examined hospital records to identify eligible participants with cancer. A tag was attached in front of the children’s medical record in order to identify eligible participants. Second, the eligible mothers were contacted by a hospital staff person about study participation.

If eligible children and their mothers were willing to participate, the researcher explained the purpose of the study, characteristics of the questionnaires, participation procedure, duration, risk and discomforts, benefits, alternatives, confidentiality, financial costs (none), liability, and the mothers' and children's right to participate and withdraw any time without any consequence to the patients' treatments from the hospital. The mothers who were willing to participate in this study signed the consent form (See Appendix A).

Measurement of variables

The following section describes the instruments used to measure the study variables. The study variables and instruments are summarized in Table 1. There were five instruments used in this study that include the demographic questionnaire, maternal sensitivity, maternal stress, a 3-day symptom diary, and a wrist actigraph. Structured interview questions were used by the researcher to elicit information for better understanding the influence of Thai culture.

Table 1

Study Variables and Instruments

Variables	Instruments	Sources
Sample Characteristics	Demographic questionnaire	Mother
Maternal Sensitivity	A Modified Thai Maternal Behavioral Q-Set (MBQS)	Mother
Maternal Stress	The Parenting Stress Index/Short Form (PSI/SF)	Mother
Symptoms	The Memorial Symptom Assessment Scales	Mother
	(MSAS)	Mother
	Maternal judgment of child pain	Mother
	Body Outline	Children
	Child 3-day sleep questions and Actigraphy	
Symptom Management	Open-ended Questions	Mother
Symptom Management Outcome	Perception of Management Effectiveness	Mother

Demographic questionnaire

This questionnaire included questions about the children (e.g., age, gender, school, knowing diagnosis, time since diagnosis, and hospital records for treatment); and their families (e.g., father's and mother's age, education, and income; number of children; marital status; other caregiver in household; living area; and mother's health problems). See Appendix B.

Maternal sensitivity

A Modified Thai Maternal Behavioral Q-Set (MBQS) (Im, Houck, Park, Oh, & Suk, 2008) was used to measure mothers' perception of their sensitivity to their child (See Appendix C). This maternal report instrument was derived from the original that used trained observers of maternal child interaction instrument criteria. There are 16 items. Mothers were asked to rate their children's behaviors on a 9-point Likert scale (from 1= not true to 9 = very true). Higher scores on these scales reflect more sensitive, responsive parenting. This instrument was derived from the MBQS (Chaimongkol et al., 2006; Pederson & Moran, 1995b; Pederson et al., 1990). The MBQS measures the quality of maternal behaviors during mother-infant interaction at home and is appropriate for use with children 6 months to 5 years of age. The MBQS uses a Q-set that consists of 90 items, that were created based on descriptions of maternal behavior predicting qualitative differences in attachment, particularly on the descriptions of sensitivity provided by Ainsworth (1979). The MBQS encompasses descriptions of a mother's ability to recognize her child's cues and signals or situations that might require her response, to respond promptly to these situations, and to respond appropriately.

The MBQS has been translated into Thai by Chaimongkol and Flick (2006) and used with 110 Thai mother-infant dyads, suggesting this instrument worked for a Thai middle-class population. The Thai MBQS was validated by five Thai experts who were familiar with attachment theory and developmental psychology. Convergent validity was tested by calculating the association between the MBQS with the Home Observation for Measurement of the Environment items (HOME) that describes maternal sensitivity, and attachment Q-Set (AQS). The Thai MBQS positively correlated with Home and AQS ($r = .29, p < .01; r = .45, p < .001$, respectively) (Chaimongkol et al., 2006).

The 90-item Thai translated MBQS (Chaimongkol et al., 2006) was not feasible for a study of mother-children dyads attending a clinic or center for cancer treatment due to time constraints and different environment contexts. Therefore, this study used a modified-Thai MBQS (Im et al., 2008) that converted observed items to mothers' reported items. Im and collegues (2008) modified the MBQS using the older Version 2.1(Pederson et al., 1990) to measure mothers' perception of their sensitivity. The measure of maternal perception of sensitivity found 15 items from behaviors identified by Pederson and colleagues (1990) to be most like and most unlike the prototypically sensitive mother, and from characteristics identified by Pederson and colleagues that distinguished mothers of the most secure and the least secure infants (overlapping items were removed). The items selected were reworded to ask mothers directly about their children instead of the original wording that was designed for outside observers of the maternal child interaction.

This study collected data while mothers were caring for their toddler and preschool child at hospital or at home. Thus, the Modified Thai Maternal Behavioral Q-Set (MBQS) (Im et al., 2008), a 9-point Likert scale, was used instead of Q-Sort by observer (Pederson et al., 1995b). The 9-point Likert scale of Thai MBQS was developed from MBQS version 3.1 (Chaimongkol et al., 2006), whereas the 9-point Likert scale for maternal sensitivity, 15 items, was developed from MBQS version 2.1 (Im et al., 2008) . There are 12 items that are similar in the two versions. This study added 4 items to help identify “the most sensitive mothers” from Thai MBQS version 3.1; these are items 13 to 16. Therefore, there are 16 items in the Thai maternal sensitivity scale. The Thai MBQS (Chaimongkol et al., 2006) added the word *mothers* for each item to rate mother behavior. For example, the item in the English MBQS is “Notices when B is distressed”. This item in the Thai MBQS reads “Mother notices when baby is distressed”. Thus, the statements of each item had mothers rate their behavior with their children. Evidence supported that maternal self-report reflected observed behaviors related to mothers’ sensitivity to their children’s behaviors and was used in the study. This scale was used for a study with 233 Korean mothers of children with atopic skin disease. The alpha coefficient for the total scale was 0.92 (Im et al., 2008). In the current study, the internal consistency for the Maternal Sensitivity Questionnaire was adequate, with a Cronbach alpha of .85 (See Table 2).

Maternal stress

The Parenting Stress Index/Short Form (PSI/SF) (Abidin, 1995) was used to measure maternal stress (See Appendix D). The PSI/SF, 36 items, is a direct derivative of the Parenting Stress Index full-length test (Abidin, 1995). All items on the short form are contained on the long form with identical wording. The PSI/SF was developed at the request of clinicians and researchers who regularly use the full-length PSI and indicated the need for a valid measure administered in less than 10 minutes.

The PSI/SF consists of three subscales: Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC) (See Appendix D). The PD subscale measures distress directly related to parenting a sick child (i.e., impaired sense of parenting competence, restrictions on other life roles, parental conflict, lack of social support, depression). The PCDI subscale measures the mother's perception that her child does not meet her expectations, and that the interactions with her child are not reinforcing at home or her as a parent. The DC subscale measures behavioral characteristics of children that make them either easy or difficult to manage. These characteristics are assumed to be the child's temperament, but also include patterns of defiant, non-complaint, and demanding behavior. Each subscale consists of 12 items that are scored on a 5-point Likert scale (from 1 = strong agree to 5 = strong disagree). The total stress score summarizes the three subscale scores, and provides an overall indication of a mother's parenting stress (from 36 to 180). A parenting stress total raw score at or above the 90th percentile indicates significant stress in the mother-child dyad, and that mother and her child should seek professional counseling (Abidin, 1995).

The PSI/SF was translated and used across cultures in Asia, such as China, Malaysia, Korea, Japan, Cambodia and Thailand. The PSI is available by Psychological Assessment Resources who is responsible for all translated languages. The test- retest and internal consistency reliability in parents of healthy children were .84 and .91, respectively (Abidin, 1995). Evidence of validity was established with a correlation of .94 between the PSI/SF and the original PSI (Abidin, 1995). The internal consistency with Cronbach alphas of this current study were .86 for the total Parenting Stress Index, .81 for the Parental Distress Subscale, .77 for the Parent-Child Dysfunctional Interaction Subscale, and .83 for the Difficult Child Subscale.

Symptoms

All measures of symptoms were used together in a 3-day symptom diary that included a measure of MSAS, body outline, maternal judgment of child pain, and sleep questions. Actigraphy was used to measure sleep and naps over the 3 days. The 3-day symptom diary was used by mothers to document their children daily symptoms and sleep information in the morning and at bedtime. The use of a 3-day symptom diary with children, adolescent, and their parents has been found to be a particularly useful method of collecting data on symptoms associated with cancer (Docherty et al., 2006; Gedaly-Duff et al., 2006).

The Memorial Symptom Assessment Scale (MSAS, 7-12) (Collins et al., 2002) was used to measure nine symptoms of young children with cancer (i.e. feeling tired, sadness, itchiness, pain, worry, trouble eating, nausea, sleep problem, numbness or tingling) (See Appendix E). The frequency, intensity, and distress were assessed for each symptom. Frequency was measured on a 4-point Likert scale (0 = none to 4 = all the time, intensity on a 3-point Likert scale (1 = a little to 3 = a lot), and distress on 3-point Likert scale (1 = not at all to 3 = very much). In addition, an open-ended item was added at the end so that mothers could add a symptom that was not included in MSAS (7-12). The MSAS (7-12) was developed for assessment of symptoms in young children 7 to 12 years of age with cancer. Creation of MSAS (7-12) was based on symptom prevalence, severity, and distress collected as part of the validation study of MSAS (10-18) in children with cancer 10 to 18 years. The 8 items selected are highly prevalent symptoms that together reflect both physical and psychological distress, including, tried, sad, itchy, pain, worried, trouble of eating, vomiting, and sleep problem. Johnson (2008) added symptoms of numbness or tingling in MSAS for her study that investigated symptoms and quality of life with adolescent undergoing cancer treatment. This study found that numbness and tingling was a prevalent symptom that has been associated with a commonly used cancer drug called vincristine (Ettinger et al., 2002); therefore, the symptom of numbness or tingling was added in MSAS (7-12) used by the Thai mothers in this study.

Initial psychometric testing of the MSAS (7-12) was conducted with 149 inpatient and outpatient children who were undergoing treatment at either British or Australian medical centers (Collins et al., 2002). There was no significant difference between the British and Australian children in the degree of difficulty experienced in completing MSAS (7-12). Validity was evaluated by comparing the medical record, parental report, and concurrent assessment on visual analogue scales for selected symptoms. Parents also used the child MSAS (7-12) to report their children's symptoms. The overall alpha coefficients were similar for MSAS (7-12) test and retest samples with a combined value of .67. There was moderate agreement between parent and child for symptoms of nausea ($k = 0.46$), pain ($k = .46$), and lethargy ($k = .42$). There was fair agreement for anorexia ($k = .20$), sadness ($k = .33$), and insomnia ($k = .20$). Itch ($k = .11$) and worry ($k = .16$) had poor agreement. Children tended to report itch and insomnia more often than the parent ($p < .001$), and the parents reported sadness more often than the children ($p = .02$). These results showed that mothers and their children may have agreement for more frequent and bothersome symptoms that are easily observed. These results also raise the question about why the symptoms are perceived differently. Perhaps other factors may influence their perceptions, such as children's age and gender, and cognitive ability to communicate subjective symptoms, and for mothers' variables such as sensitivity and stress. Cronbach alphas were not reported for MSAS in this current study because symptoms were not expected to be internally consistent over the three days. Thus, the alpha coefficient is not substantively meaningful.

Maternal judgment of child pain is a 10 point numeric rating scale (Jensen, Karoly, O'Riordan, Bland, & Burns, 1989). The mothers used this scale to report their child's pain intensity (0 = "no pain at all" and 10 = "A lot of pain"). The NRS has been shown to be a valid and reliable measure of pain intensity with strong levels of clinical feasibility and utility (Breivik et al., 2008). For three days of pain rating, once in the evening and once in the morning, mother was asked to rate pain intensity, using a four-point verbal categorical rating scale at the end of the MSAS. This question contributed construct validity of the pain question of MSAS. A significant correlation was found between the corresponding pain MSAS symptom and maternal judgment of child pain ($r = .43$, $p < .05$).

Body Outline for Symptom Location was used to determine the locations of pain, itching, and numbness or tingling (See Appendix E) because the MSAS (7-10) does not assess the locations of symptoms. This instrument has been widely used by clinicians, parents, and children for pain assessment (Van Cleve et al., 2004; Van Cleve & Saveda, 1993).

Actigraphy was used to validate mothers' reports of trouble sleeping on the MSAS. Actigraphy provided continuous body movement data using a wristwatch-sized microprocessor that senses motion with a piezoelectric beam accelerometer (See Appendix F). In this study, actigraphy was programmed to produce an average activity count for each 30 seconds of recording. Actigraphy has been widely used in infants and young children (Acebo et al., 2005; Ancoli-Israel et al., 2003; Ward et al., 2008). Furthermore, Sadeh's (2004) and Ward's studies (2008) support that actigraphy is an accurate and noninvasive method for monitoring nocturnal awakenings and sleep duration in young children. They suggest that the two methods (i.e., actigraphy and sleep diary) should be used together to assess sleep in children.

The following variables were used to describe nighttime sleep and daytime naps: (a) sleep start time, defined as the time of the start of the first 3 or more consecutive minutes of sleep; (b) sleep end time, defined as the end time of the last 5 or more consecutive minutes of sleep; (c) sleep minutes, defined as minutes during the sleep period scored as sleep; (d) percentage wake after sleep onset, defined the percentage of time spent awake after sleep onset occurred, and (e) an awakening episode defined as awake lasting continuously for at least 5 minutes.

After the data were collected, the Actigraphy watch was placed on a reader connected to the computer and the data were downloaded into the Actiware program (Respironics Mini Mitter, 2006). The investigator set the rest interval (i.e., time in bed) for each night before the software could score sleep-wake activity and compute selected statistics. Setting the rest interval required a reasonable correspondence between event markers on the actigraphy record and/or diaries to limit overestimation of sleep related to quiet activity, watch removal, or failure. In this study, event markers and/or diaries were used to set the rest intervals. If the event markers and/or diaries were missing or incongruent with the actigraphy record, but a clear sleep period was visible, the rest interval was set according to actigraphy. Individual mean scores for total sleep time (TST), wake after sleep onset (WASO), and sleep efficiency were calculated only for participants who had at least 2 nights of scored actigraphy during data collection. Time variables were reported according to 24-hour clock, a time keeping convention in which the day runs from midnight to midnight, and was divided into 24 hours, numbered from 0 to 23. Sleep variables were reported in minutes. As a reference, the ideal sleep durations for children aged 1 to 3 years are 12 to 14 hours and 11 to 12 hours for children aged 3 to 5 years (Mindell & Owen, 2003).

The Child 3-day sleep questions were used to validate mothers' report of sleep problem on the MSAS and the sleep-wake activity recorded by actigraphy. Sleep questions included: (a) bed time (i.e, time the child was put down to bed for sleep at night; (b) rise time (i.e., time the child woke up in the morning); and (c) nap time (i.e., time the child was put down to sleep during the day. The sleep diary also included evening activities, medications, and any unusual events that occurred during the day or night that might affect the child's sleep.

Symptom Management

Mothers were asked about the most difficult symptoms their children experienced and the strategies they used to manage them. Symptom management strategies used by clinical staff were recorded from the child's medical record (See Appendix G).

Perception of Symptom Management Effectiveness

Perceptions of symptom management effectiveness was measured using an investigator developed numeric rating scale (i.e. 0 = “not effective”, 10 = “very effective”) (See Appendix G). Higher scores indicated greater effectiveness. The Perception of Management Effectiveness (a 100-mm word graphic rating scale, measured from the left, with the higher scores indicating greater effectiveness) has been used by parents’ reporting pain during cancer treatment in children as young as age 4 years (Van Cleve et al., 2004).

Semi-structured interview

The instruments used in this study were developed primarily in Western cultures with Western perspectives. Because cultural factors may influence Thai mothers’ perceptions, a semi-structured interview was developed by the investigator to gain a better understanding of these variables in Thai culture (See Appendix H). The interview questions were developed from a literature review of qualitative studies on parents caring for a child with chronic condition or cancer. The main questions were: What is the meaning of cancer? chemotherapy treatment and symptom related to chemotherapy treatment? What caused your child symptoms? What role did you play in symptom management? How did you learn to recognize symptoms and act on what you see? What strategies worked best to relieve your child’s symptom? What can doctors or nurses do to better relieve your child’s symptom? What advice would you give to a parent whose child has been recently diagnosed with cancer and has symptoms? How are your child’s symptoms related to each other? and, Do you think management of your child's symptom such as pain may have an effect on his/her other symptoms?

Chart Review

Children's medical records were reviewed to confirm the treatment plan, symptom assessments, medications, laboratory results, and other health problems. The data from the child's medical record were used to compare and explain the mothers' reports in the 3-day symptom diary (See Appendix I).

Study Phases

This study had 3 phases, including (1) preparation of instruments; (2) a pilot study with 5 Thai mothers and their children who resembled the study population by doing the full study procedure; and (3) the full study (See figure 2).

Phase 1: Preparation of the Instruments

Four instruments needed either content validity testing and/or translation before they could be used in Thailand. The instruments were maternal sensitivity, maternal stress, a 3-day symptom diary, and a wrist actigraph. The maternal sensitivity and maternal stress instruments were available in Thai but the 3-day symptom diary was not. The 3-day symptom diary consisted of the MSAS, body outline, maternal judgment of child pain, symptoms management, perception of relief of symptoms, and sleep questions. All needed translation. Because the MSAS is a standardized questionnaire that has never been translated into Thai or used in Thai culture, translation and a content validity process of the Thai translation was conducted.

Figure 2. Study Phases.

Phase 1: Translation of a 3-day symptom diary by 3 English-Thailand Bilingual Readers and Speakers
2 Ph.D students in Nursing and 1 Physician

↓

Content validation for Thai version of a 3-day symptom diary by 5 Experts
2 Pediatric Oncologists, 1 Oncology Nurse
1 Nursing Instructor, 1 PH.D pediatric nurse

↓

Content Validity Index (CVI) was equal or greater than .80

↓

Back Translation of 3-day symptom diary by a bilingual expert

↓

Phase 2: A Pilot Study to Test Content Clarity and Utility of 3-day symptom diary, Maternal sensitivity, and Parenting Stress Index with 5 mothers
And Test Utility of Actigraphy with 5 children with cancer

↓

Phase 3: Conduct full study using final version of instruments with 50 Thai mothers and their children with cancer

Translation process of the 3-day symptom diary. The translation process followed Brislin's (1970) guidelines for back-translation for cross-cultural research. Brislin suggested that translation be performed by at least two independent translators and undertaken by teams (Brislin, 1970). The translation team for this study included two PhD students in nursing and one physician who were bilingual in English and Thai. The Thai version of the 3-day symptom diary was evaluated by the researcher and concerns about the translation were discussed with the translators. The Thai version of the MSAS

(7-12) was finalized by the researcher based on discussions with the three translators, and was ready to be tested for content validity.

Content Validity by Experts. Experts in research and clinical practice in Thailand were required to validate the appropriateness of the MSAS instrument in Thai culture (DeVellis, 2003). DeVellis (2003) suggested five to ten experts, who meet the criteria of expertise, evaluate the content validity of the instruments. The content validity of the MSAS (7-12) was assessed by five Thai experts: two pediatric oncologists, one doctorally-prepared pediatric nurse, and two experienced pediatric hematology-oncology nurses. All the experts are familiar with child development, and caring of children with cancer and their families. Their names and qualifications are presented in Appendix J.

The five experts reviewed the items using the guidelines suggested by Imle and Atwood (1988). The conceptual definitions and operational definitions related to the questionnaires were provided to the experts. The experts rated each item in terms of its congruence to the definitions, uniqueness, and clarity and understandability in Thai culture. Experts responded to three questions for each item. The first two questions relate to the item's congruence to the definition and its uniqueness, assessing content validity. The last question evaluates the clarity of the item. The experts responded "Yes" or "No" to each of the three questions.

According to Lynn (1986), the judgment-quantification stage of content validity requires four out of the five experts endorse an item to establish content validity beyond the .05 level of significance. Therefore, the content validity indexes (CVI), as the proportion of items rated as "Yes" by the content validators, were calculated. The value of equal to or greater than .80 was acceptable (Lynn, 1986). Clarity of each item was confirmed also by agreement between four out of five experts. The wordings of the questions of the adapted instruments were revised based on the results of the agreement criteria and suggestions from the experts.

Back Translation of 3-day symptom dairy. The final version of the 3-day symptom dairy, including the MSAS (7-12), maternal judgment of child pain, body outline, and child sleep questions, was translated back into English. A translator without a priori knowledge of the original English version of the instruments is recommended to reduce bias (Brislin, 1970). Therefore, unexpected meanings or interpretations may be revealed in the back-translated version. A bilingual person with a degree in linguistics was used to conduct the back-translation. The English version and the back-translated version were compared by the Thai researcher and her mentor. The comparison considered semantic, idiomatic, experiential, and conceptual equivalence of each item (Brislin, 1970). Discrepancies between the English and back-translated versions were discussed by the researcher and her mentor to develop the final Thai version.

Phase 2: A Pilot Study to Test Content Clarity and Utility from Thai mothers and Children

Phase 2 was designed to evaluate the item clarity, cultural appropriateness, and utility of a 3-day symptom dairy, maternal sensitivity questionnaire, and parenting stress index (PSI/SF) for Thai mothers caring for young children with cancer. This phase was also designed to evaluate the utility of actigraphy in children ages 1 to 5 years.

The questionnaires were used with five Thai mother respondents who resembled the study population to assess the clarity and utility of items on the 3-day symptom diary, the maternal sensitivity, and parenting stress index (PSI/SF) in the context of Thai culture.

A Pilot Study Procedure. The research nurse taught the mothers how to record data in their 3-day symptom dairy. The mothers used the 3-day symptom diary to evaluate the utility of the instruments at the midmorning and before bedtime over the 3-day period.

The five children with cancer were asked to wear the actigraph continuously for at least 48 hours. Their mothers were instructed to push the event marker on their child's actigraph at bedtime, wake time, and nap time.

Children wore the actigraph continuously at least 48 hours. Mothers were instructed to keep the actigraph on continuously and record those removal times in the diary. They also were instructed to push the event marker of their child's actigraph at bedtime and wake time. At the end of the third day, data from each actigraph was downloaded and checked against the mother's 3-day symptom diary. Children under 3 years old were asked to wear the actigraph on their leg and those 3 years and older were asked to wear the actigraph on their arm.

The event marker from the actigraphy was used to determine bedtime and wake time. Data from actigraphy was use to validate bedtime and wake time from the 3-day question diaries reported by mothers. Activity counts were analyzed using the autoscoring program for sleep-wake activity available in Actiware 5 software

(Respironics-Minimitter, Inc. 2006). The research nurse called the mother once a day to answer the questions about the diary and the actigraph, remind them to complete the diaries, and make sure the watch was functioning.

After the 3 days, the research nurse met again with mothers and children, and retrieved the watches, questionnaires of maternal sensitivity, parenting stress index, and the 3-day symptom diary. The mothers were asked the following question about the 3-day symptom diary.

1. Were the instructions clear?
2. Did you have any trouble following the order of questions or the skip patterns?
3. Did you have any problems understanding what kinds of answers were expected?
4. Were there any questions that irritated you or made you feel uncomfortable?
5. How long did it take you to fill out the questionnaires and diary for each time and each day?
6. Did you get tired because of the time it took to fill out the diary?
7. Did wearing the actigraph bother your child?

The children were also asked if they had any trouble wearing the actigraph. All hard copies of questionnaires were reviewed and considered in the revision of final questions to improve clarity, utility and cultural appropriateness.

Results of Pilot study

Results of the questionnaire. The five mothers in the hospital were able to answer all of the items on each questionnaire. They needed 8 to 15 minutes to complete the modified Thai Maternal Behavioral Q-Set (MBQS) and Parenting Stress Index / Short Form. They spent 8 to 10 minutes reporting symptoms of their child the first time. Then, for other times of the mothers' report, they took less time, about 5 to 8 minutes, because of familiarity with the diary. Four of their children were discharged on the evening of third day. Therefore, after their children received chemotherapy, the mothers could report symptoms of their children twice a day for 5 time points due to being discharged.

Results of review questionnaires. All mothers reported that almost all questions were clear, except the symptoms of numbness; four mothers did not know the children could have this symptom. One child had vomiting but his mother reported only nausea. None of the mothers said that any item irritated, made them uncomfortable, or tired because of the time it took to fill out the diary. They reported being familiar with the diary because of the same questions each time. However, three mothers were confused about the time period being reported for their child's symptoms. When asked about their child's symptoms the day before receiving chemotherapy, they reported their child's symptoms the day of receiving chemotherapy rather than the child's symptoms prior to chemotherapy. The researcher decided to use all items without modification but separated the questions of symptoms the day before receiving chemotherapy from the 3-day symptom diary. For use of the MSAS for the full study, the researcher needed to clarify the symptoms of numbness or tingling and nausea and vomiting for mothers. For the symptom of numbness or tingling, the researcher taught mothers how to observe this symptom, such as the child did not want to walk, touch, or use their hands or feet. For symptoms of nausea and vomiting, the researcher had to clearly explain that if their child had vomiting the mother had to report this symptom in the question of other symptoms. For the actigraphy, the five children did not complain of any trouble of wearing actigraphy. The mothers did not report difficulties keeping the actigraphy on and removed it only when it could get wet. The times the watch was removed were recorded in the diary.

Phase 3: A Full Study

Phase 3 was a full study. In this phase, all final versions of questionnaires were used with 50 Thai mothers and their children.

Full Study Procedure

Young children with cancer and their mothers were informed about the study by the researcher when the child was in the outpatient clinic for cancer treatment. After determining eligibility, the researcher explained the study to both the child and mother. After obtaining informed consent, the biological mother was asked to complete demographic data, maternal sensitivity and maternal stress questionnaires, and the baseline report of symptom using the MSAS before the child received chemotherapy. For children treated as inpatients, the researcher taught the mother how to record data in their 3-day symptom diary after the child was admitted to the ward and before the child received the chemotherapy. For children treated as outpatients, the researcher taught the mother how to record data in their 3-day symptom diary after their child met the doctor and before the child was discharged from the outpatient clinic after receiving the chemotherapy.

After the child received chemotherapy, the mothers completed the symptom diary. The mothers used the symptom dairy to document their child's symptoms in the morning and before bedtime over the 3-day period. Each child was asked to wear a wrist actigraph continuously for the 3-day period. On the second day, the researcher met the mothers or called them to remind them to fill out the symptom diary and to keep the actigraph on their children. After data collection, the mothers returned the diaries and the wrist actigraph to the researcher. At that time they were interviewed by the researcher about their child's symptom experience, strategies they used to manage their child's symptoms, and outcomes. In addition, the mothers were interviewed for their understanding of their child's cancer and symptom experience from their cultural perspective. Finally, mothers and their children received 300 Baht (10 dollars) for participating in the study to help with transportation costs and as a token of appreciation for their time.

Data management

Data verification

Prior to analysis the data were cleaned to ensure accurate and valid analyses. Data were entered using a double-entry process into separate Excel spreadsheets. To verify the data, the excel spreadsheets were compared and all discrepancies were resolved by rechecking the hardcopy of the data and changing the erroneous entries. This process was followed until the two spreadsheets had no discrepancies. The verified data were then imported into SPSS 17.0.

Checking accuracy

Descriptive statistics, including histograms or scatter plots for each variable, item, and scale were used to clean the data prior to analyses. Frequency charts were analyzed to ensure that all data values fell into the range of possible values for each variable and to identify outliers. Frequency charts were also used to ensure that individual coding for missing values matched the number of total missing values. The descriptive values were examined to ensure that range of values fell within the expected range, that means and standard deviations were such that the standard deviation did not exceed the mean. The histograms were used for continuous variables to visualize the distribution and identify potential outliers.

Missing data

Missing data were infrequent with rates of 6 % for the MSAS. Data for 50 participants were analyzed because there were missing data for less than 20 percent of all items (complete data for more than 80 percent). For the PSI, scores were calculated if at least 11 of 12 items of each subscale were complete. The missing data convention was to compute the average score for the completed items within that subscale and round the average to the nearest whole number and then to assign the rounded scored to the missing items and sum the subscale score. For example, if a respondent's item scores for the parental stress (PD) subscales are 1, 3, 3, 4, 2, 1, 1, 2, 4, 5, 2, and one item score is missing, the averaged score for the remaining items is (1 + 3 + 3 + 4 + 2 + 1 + 1 + 2 + 4 +

5 + 2) / 11 = 2.5. After rounding 2.5 to the nearest whole number, the missing item was assigned a 3, and the PD subscale score is 31. The PSI/SF includes the items of defensive responding. There was one mother who had defensive responding scores of 7. The PSI scores of this mother were not analyzed because the defensive score was less than 10, meaning an incredible (unbelievable) value.

Data analysis of specific aims

PRIMARY AIM 1*:* Describe mothers' perception of symptoms in their children at six time points (morning and evening for three days) during chemotherapy treatment for cancer.

Analysis: Multiple sources of data were used to provide a full description of symptoms in young children with cancer reported by their mothers including mother's report of symptoms, actigraphy with diaries, and qualitative interviews. Frequency distributions were constructed for each symptom. Means and standard deviations were computed for frequency, intensity, and distress of symptoms. Actigraphy readings provided objective descriptions of sleep-wake activity in terms of total sleep time and night awakenings. The interview data helped elucidate mother's perceptions of their child's symptoms. A repeated measure ANOVA was used to compare symptoms across six time points for three days. A nonsignificant interaction would imply that the symptom patterns across time were the same. A significant main effect due to time would signify that there were differences in the dependent variables at the different measurement time points. Polynomial contrasts were used to determine where these differences occurred.

PRIMARY AIM 2: Describe mothers’ management of their children’s symptoms, and the symptom management outcomes.

Analysis: Multiple sources of data also were used to provide a full description of symptom management and symptom management outcome reported by mothers including mother’s report of symptom management and outcome, qualitative interview, and chart review. Frequency distributions were constructed for symptom management methods used by mothers. Means and standard deviations were computed for mothers’ perception of symptom management outcomes. Interview data and patient data (from chart review) helped clarify mother’s perception of their management for their child’s symptoms.

PRIMARY AIM 3: Explore the relationships among maternal sensitivity, maternal stress, and mothers’ perception of their children’s symptoms.

Analysis: Means and standard deviations were computed for maternal sensitivity and maternal stress. Pearson correlation was used to test correlations among maternal sensitivity, maternal stress, and children’s symptoms reported by their mothers. Multiple regressions were used to predict mothers’ report of their children’s symptoms. Specifically, maternal sensitivity and maternal stress as two independent variables were used to predict child’s symptoms as a dependent variable with demographic variables – child’s age and gender, and maternal education-entered as covariates.

SECONDARY AIM: Explore the relationship between young children’s pain and sleep as reported by their mothers.

Analysis: Pearson correlations were used to test the correlation among young children's pain and sleep as reported by their mothers. The interview data and patient data (from chart review) helped clarify the relationship between young children's pain and sleep during receiving chemotherapy treatment.

CHAPTER 4

RESULTS

The primary aims of this study were to describe mothers' perception of symptoms and symptom management in their young children during three days of chemotherapy treatment for cancer and to explore the relationships among maternal sensitivity, maternal parenting stress, and mothers' perception of their children's symptoms. The secondary aim was to explore the relationship between young children's pain and sleep as reported by their mothers. The characteristics of the mothers and their children that constituted this sample will be reported first, followed by the results reported according to the specific aims.

Sample

Child Characteristics

The sample consisted of fifty young children with cancer. As shown in Table 2, nearly two thirds were male (*n* = 32, 64%). Most of the children were preschool aged (3 to 4 years old) and were, on average, three and a half years old (*M* = 3.44, *SD* = 1.47). The most common cancer diagnoses in these children were leukemia, neuroblastic tumor (neuroblastoma), renal tumor (Wilm's Tumor) and other diagnoses, such as brain tumor (medulloblastoma), lymphoma (Non-Hodgkin lymphoma), retinoblastoma, rhabdomyosarcoma, and ovarian cancer (see Table 2). The time since diagnosis ranged from 1 to 28 months, with one third diagnosed three months or less and one third having been diagnosed for more than one year (see Table 2). Over half of children did not know their cancer diagnosis (*n* = 31, 62 %).

Slightly over half of children (*n* = 26, 52%) were treated with chemotherapy as outpatients and the other half (*n* = 24, 48%) were treated as inpatients in the hospital. Children received one or more (range 1 to 5) of following intravenous or intrathecal chemotherapeutic agents on the first day of data collection: vincristine, methotrexate, mercaptopurine, etoposide, cyclophosphamide, carboplatin, mesna, cytarabine, ifosfomide, cisplatin, endoxan, cytoxan, dexamethasone. The mean numbers of agents administered at the first day, second day, and third day of data collection were 1.78 (*SD* = 1.12), 0.98 (*SD* = 1.07), 0.69 (*SD* = 0.94), respectively. Over one third (*n* = 19, 38%) had a lumbar puncture or intrathecal agent during the first day of data collection.

The majority of the children were in the maintenance (*n* = 14, 28%) and consolidation (*n* = 12, 24%) phases of chemotherapy for leukemia. Data were collected in the home setting for outpatients and in the hospital for inpatients.

Table 2

Children's Demographic and Clinical Characteristics as a number and a percentage of the sample (N = 50)

Variables	*N*	%
Gender		
Female	18	36
Male	32	64
Age (years)		
Mean = 3.44 years, *SD* = 1.47		
1	8	16
2	6	12
3	9	18
4	10	20
5	17	34
Diagnosis		
Leukemia		
Acute Lymphocytic	26	52
Acute Myelogenous	2	4
Neuroblastic Tumor (Neuroblastoma)	6	12
Renal Tumor (Wilm's Tumor)	6	12
Other tumors	10	20
Time since diagnosis (months)		
Mean = 9.32, *SD* = 7.64		
1 – 3	16	32
4 – 6	11	22
7 – 12	7	14
> 12	16	32
Treatment setting		
Inpatient	24	48
Outpatient	26	52

Maternal Characteristics

Fifty mothers participated in the study. As shown in Table 3, ranging in age from 20 to 44 years old, the majority of women were in their twenties and thirties (*M* = 31.5 years, *SD* = 6.83). Half of the mothers had not completed high school. Over half of mothers were employed and reported household income of less than 15,000 Baht ($ 454). Those reporting income between 15,000 and 100,000 Baht ($ 454 to 3,030) comprised approximately two-fifths of the sample (42%). Most of mothers were married (74%) and had other family caregivers (74%) for their sick child, including husbands, grandmothers, and aunts. Nearly half the mothers had only one child (*n* = 23, 46%), with the rest ranging in number of children from 1 to 3 (*M* = 1.60, *SD* = .64). For mothers who had more than one child, the majority of these mothers had the one older than the sick child (*n* =19, 38%). Over half of mothers and their families lived outside Bangkok.

Table 3

Maternal Demographic Characteristics as a number and a percentage of the sample (N = 50)

Variables	*N*	%
Age (years)		
Mean = 31.5, *SD* = 6.83		
20 - 29	25	50
30 - 39	16	32
> 40	9	18
Education (years)		
< Primary school	1	2
Primary school	11	22
Middle school	13	26
High school	13	26
Some college	6	12
College graduate	6	12
Employment Status		
Unemployed	20	40
Employed	29	48
Unknown	1	2
Monthly Household Income (Thai Baht)		
< 5,000	6	12
5,001-10,000	13	26
10,001-15,000	7	14
15,001-20,000	6	12
> 20,000	15	30
Unknown	4	8
Marital Status		
Married	37	74
Divorced or Separated	4	8
New Married	3	6
Unknown	6	12

Findings

This study was designed to describe mothers' perception of symptoms and symptom management in their young children during three days of chemotherapy treatment for cancer. In addition, this study explored the relationships among maternal sensitivity, maternal stress, and mothers' perception of their children's symptoms. The maternal sensitivity questionnaire, the parenting stress index, and the MSAS index to assess symptoms were administered to mothers on the first day of data collection before the children received chemotherapy treatment. Subsequently, mothers completed symptom diaries twice a day for three days. Descriptive statistics are reported for all measures.

Aim 1

Describe mothers' perception of symptoms in their young children during three days of chemotherapy treatment for cancer.

The modified MSAS assessed the prevalence, frequency, intensity, and distress of 9 symptoms the day before chemotherapy (Time1, T1 (baseline)) and the first day (Time 2, T2), the first night (Time 3, T3), the second day (Time 4, T4), the second night (Time 5, T5), and the third day (Time 6, T6) of chemotherapy (see Table 4). The nine symptoms included tiredness, sadness, itching, pain, worry, appetite, nausea, trouble sleeping, and numbness and tingling. Cronbach alphas were not reported for MSAS because symptoms are not expected to be internally consistent but to vary over time. Thus, the alpha coefficient is not substantively meaningful. The numeric rating scale of pain contributed construct validity of the pain question of MSAS. There was a high significant positive correlation between the corresponding pain of MSAS symptom and maternal judgment of child pain (*r* = .43, *p* < .05).

Change of appetite was reported as the most prevalent symptom for the six time points, with the means ranging between .48 and .64 (*SD* = .48 - .50). The mean total numbers of symptoms at each assessment were: T1, 2.24 (*SD* = 2.26); T2, 3.96 (*SD* = 2.80); T3, 3.54 (*SD* = 2.89); T4, 3.42 (*SD* = 2.45); T5, 2.76 (*SD* = 2.43); and T6, 2.24 (*SD* = 2.24).

Table 4

Mean and Standard Deviations of Prevalence for Individual and Total Symptoms.

Variables	T1 *M (SD)*	T2 *M (SD)*	T3 *M (SD)*	T4 *M (SD)*	T5 *M (SD)*	T6 *M (SD)*	T2-T6 *M (SD)*
Tiredness	.20 (.40)	.48 (.50)	.38 (.49)	.38 (.49)	.38 (.49)	.22 (.41)	.38 (.37)
Sadness	.18 (.48)	.30 (.46)	.28 (.45)	.30 (.46)	.22 (.41)	.20 (.40)	.26 (.36)
Itching	.32 (.47)	.48 (.50)	.38 (.49)	.30 (.46)	.24 (.43)	.28 (.45)	.32 (.32)
Pain	.22 (.41)	.50 (.50)	.34 (.47)	.28 (.45)	.16 (.37)	.12 (.32)	.28 (.30)
Worry	.44 (.50)	.48 (.50)	.42 (.49)	.40 (.49)	.46 (.50)	.30 (.46)	.41 (.40)
Appetite	.48 (.50)	.58 (.49)	.54 (.50)	.64 (.48)	.60 (.49)	.50 (.50)	.57 (.38)
Nausea	.14 (.35)	.42 (.49)	.46 (.50)	.42 (.48)	.28 (.45)	.20 (.40)	.36 (.34)
Trouble sleeping	.20 (.40)	.38 (.49)	.40 (.49)	.32 (.47)	.26 (.44)	.20 (.40)	.31 (.34)
Numbness & Tingling	.02 (.14)	.10 (.30)	.06 (.23)	.04 (.19)	.04 (.19)	.04 (.19)	.06 (.18)
Total Number of Symptoms	2.24 (2.26)	3.96 (2.8)	3.54 (2.89)	3.42 (2.45)	2.76 (2.43)	2.24 (2.24)	3.16 (2.18)
Others (fever, nightmare, headache, faint)	.08 (.27)	.24 (.43)	.28 (.45)	.26 (.44)	.12 (.32)	.26 (.59)	.23 (.45)

Before chemotherapy, the most prevalent symptoms were change in appetite (*n* = 24, 48%), worry (*n* = 22, 44%), and itching (*n* = 15, 30%) (see Table 5). In terms of frequency, these three symptoms were rated most often as “a short time” to “a medium amount” of time, with the means ranging between 1.06 to 1.58 (*SD* = .25 - .57). In terms of distress, these symptoms were rated as “not at all” distressing to “medium” distress by participants who reported them, with the means ranging between 1.25 to 1.32 (*SD* = .45 - .57). The symptoms rated as “most intense symptoms” were worry and itching, with intensities rated as “little” to “medium” by the highest percentage of participants who reported them, with the means ranging between .56 to .91 (*SD* = .63 - .87). The first day after chemotherapy, the most prevalent symptoms were changes in appetite (*n* = 29, 58%), pain (*n* = 25, 50%), tiredness (*n* = 24, 48%), and worry (*n* = 24, 48%) (see Table 6). For night 1, the most prevalent symptom remained changes in appetite (*n* = 27, 54%), and included nausea (*n* = 23, 46%) and worry (*n* = 21, 42%) (see Table 7). As shown in Table 8, the most frequent symptoms for day 2 were changes in appetite (*n* = 32, 64%), tiredness (*n* = 23, 46%), nausea (*n* = 21, 42%), and worry (*n* =20, 40%) and, as shown in Table 9, the most frequent symptoms night 2 were changes in appetite (*n* = 30, 60%), worry (*n* = 23, 46%), and tiredness (*n* =19, 38%). Changes in appetite (*n* = 25, 50%), pain (*n* = 25, 50%), and worry (*n* = 15, 30%) were the most frequent symptoms for day 3 (see Table 10). During the three days with five time points, the majority of mothers rated each symptom frequency as “a short time” to “a medium amount” of time, symptom intensity as “little” to “medium,” and symptom distress as “not at all distressing” to “medium” distress.

Table 5

Prevalence and Characteristics of Symptoms on the Memorial Symptom Assessment Scale before Chemotherapy (N = 50) (T 1)

Degree When Symptom Was Present														
Symptom	Prevalence *n* (%)	Frequency				Intensity				Distress				
		Short *n* (%)	Med *n* (%)	Almost All *n* (%)	*M* *(SD)*	Little *n* (%)	Med *n* (%)	A lot *n* (%)	*M* *(SD)*	Not at all *n* (%)	Little *n* (%)	Med *n* (%)	Very much *n* (%)	*M* *(SD)*
Tiredness	10 (20)	4 (8)	6 (12)	0	1.60 (.51)	4 (8)	6 (12)	0	1.60 (.51)	0	1 (2)	6 (12)	0	1.30 (.82)
Sadness	7 (14)	5 (10)	2 (4)	0	1.29 (.49)	5 (10)	2 (4)	0	1.29 (.49)	0	3 (6)	1 (2)	1 (2)	1.14 (1.07)
Itching	15 (30)	15 (30)	1 (2)	0	1.06 (.25)	12 (24)	4 (8)	0	1.25 (.45)	8 (16)	7 (14)	1 (2)	0	.56 (.63)
Pain	11 (22)	6 (12)	5 (10)	0	1.45 (.52)	6(12)	5 (10)	0	1.45 (.52)	4 (8)	3 (6)	3 (6)	1 (2)	1.08 (1.24)
Worry	22 (44)	16 (32)	5 (10)	1 (2)	1.32 (.57)	12 (32)	5 (10)	1 (2)	1.32 (.57)	7 (14)	12 (24)	1 (2)	2 (4)	0.91 (.87)
Appetite	24 (48)	10 (20)	14 (28)	0	1.58 (.50)	n/a	n/a	n/a	n/a	5 (10)	15 (30)	2 (4)	2 (4)	1.04 (.81)
Nausea	7 (14)	4 (8)	3 (6)	0	1.43 (.54)	n/a	n/a	n/a	n/a	2 (4)	5 (10)	0	0	.71 (.49)
Trouble sleeping	10 (20)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	7 (14)	2 (4)	1 (2)	1.40 (01)
Numbness & Tingling	1 (2)	1(2)	0	0	1 (.00)	1 (2)	0	0	1 (.00)	1 (2)	0	0	0	1 (.00)
Other	4 (8)	1(2)	2 (4)	1 (2)	2.00 (.82)	2 (4)	1 (2)	1 (2)	1.75 (.96)	1 (2)	1 (2)	1 (2)	1 (2)	1.67 (1.53)

Table 6

Prevalence and Characteristics of Symptoms on the Memorial Symptom Assessment Scale during Chemotherapy Day1 (N = 50) (T 2)

Degree When Symptom Was Present														
Symptom	Prevalence *n* (%)	Frequency				Intensity				Distress				
		Short *n* (%)	Med *n* (%)	Almost All *n* (%)	*M (SD)*	Little *n* (%)	Med *n* (%)	A lot *n* (%)	*M (SD)*	Not at all *n* (%)	Little *n* (%)	Med *n* (%)	Very much *n* (%)	*M (SD)*
Tiredness	24 (48)	12 (24)	10 (20)	2 (4)	1.58 (.65)	12 (24)	10 (20)	2 (4)	1.58 (.65)	5 (10)	9 (18)	9 (18)	1 (2)	1.25 (.85)
Sadness	15 (30)	9 (18)	5 (10)	1 (20)	1.47 (.64)	8 (16)	7 (14)	0	1.47 (.52)	3 (6)	6 (12)	5 (10)	1 (2)	1.27 (.88)
Itching	24 (48)	19 (38)	5 (10)	0	1.21 (.42)	18 (36)	6 (12)	0	1.25 (.44)	9 (18)	10 (20)	4 (8)	1 (2)	.88 (.85)
Pain	25 (50)	22 (44)	3 (6)	0	1.12 (.33)	18 (36)	6 (12)	1 (2)	1.32 (.56)	6 (12)	13 (26)	5 (10)	1 (2)	1.04 (.79)
Worry	24 (48)	14 (28)	9 (18)	1 (2)	1.46 (.59)	11 (22)	12 (24)	1 (2)	1.58 (.58)	3 (6)	12 (24)	6 (12)	3 (6)	1.38 (0.88)
Appetite	29 (58)	8 (16)	17 (34)	4 (8)	1.86 (.64)	n/a	n/a	n/a	n/a	6 (12)	12 (24)	7 (14)	4 (8)	1.31 (.97)
Nausea	21 (42)	15 (30)	5 (10)	1 (2)	1.33 (.58)	n/a	n/a	n/a	n/a	7 (14)	8 (16)	5 (10)	1 (2)	1.00 (.89)
Trouble sleeping	5 (10)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	1 (2)	7 (14)	10 (20)	1 (2)	1.58 (.69)
Numbness & Tingling	5 (10)	5 (10)	0	0	1.00 (.00)	5 (10)	0	0	1.00 (.00)	2 (4)	1 (2)	2 (4)	0	1.00 (1.00)
Other	12 (24)	3 (6)	7 (14)	2 (4)	1.92 (.67)	5 (10)	7 (14)	0	1.58 (.52)	5 (10)	2 (4)	4 (8)	1 (2)	1.78 (.97)

Table 7

Prevalence and Characteristics of Symptoms on the Memorial Symptom Assessment Scale during Chemotherapy Night1 (N = 50) (T 3)

Degree When Symptom Was Present														
Symptom	Prevalence *n* (%)	Frequency				Intensity				Distress				
		Short *n* (%)	Med *n* (%)	Almost All *n* (%)	*M (SD)*	Little *n* (%)	Med *n* (%)	A lot *n* (%)	*M (SD)*	Not at all *n* (%)	Little *n* (%)	Med *n* (%)	Very much *n* (%)	*M (SD)*
Tiredness	19(38)	7(14)	10(20)	2(4)	1.74 (.65)	7(14)	9(18)	3(6)	1.79 (.71)	4(8)	9(18)	3(6)	3(6)	1.21 (1.03)
Sadness	14(28)	7(14)	6(12)	1(2)	1.57 (.65)	7(14)	6(12)	1(2)	1.57 (.65)	4(8)	5(10)	4(8)	1(2)	1.14 (.95)
Itching	19(38)	18(36)	1(2)	0	1.11 (.46)	17(34)	2(4)	0	1.11 (.32)	8(16)	9(18)	2(4)	0	.68 (.67)
Pain	17(34)	14(28)	3(6)	0	1.18 (.39)	11(22)	5(10)	1(2)	1.41 (.62)	10(20)	6(12)	1(2)	0	1.00 (.94)
Worry	21(42)	14(28)	6(12)	1(2)	1.38 (.59)	13(26)	6(12)	2(4)	1.48 (.68)	4(8)	12(24)	2(4)	3(6)	1.20 (.95)
Appetite	27(54)	13(26)	9(18)	5(10)	1.70 (.78)	n/a	n/a	n/a	n/a	8(16)	11(22)	6(14)	4(8)	1.07 (.92)
Nausea	23(46)	16(32)	6(12)	1(2)	1.35 (.57)	n/a	n/a	n/a	n/a	5(10)	13(26)	4(8)	1(2)	1.04 (.77)
Trouble sleeping	20(40)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	12(24)	4(8)	4(8)	1.60 (.82)
Numbness & Tingling	3(6)	3(6)	0	0	1.00 (.00)	2(4)	1(2)	0	1.33 (.58)	1(2)	1(2)	1(2)	0	1.00 (1.00)
Other	14(28)	4(8)	8(16)	2(4)	1.86 (.66)	6(12)	6(12)	2(4)	1.50 (.76)	7(14)	2(4)	5(10)	0	1.43 (.79)

Table 8

Prevalence and Characteristics of Symptoms on the Memorial Symptom Assessment Scale during Chemotherapy Day2 (N = 50) (T 4)

Degree When Symptom Was Present														
Symptom	Prevalence *n* (%)	Frequency				Intensity				Distress				
		Short *n* (%)	Med *n* (%)	Almost All *n* (%)	*M* *(SD)*	Little *n* (%)	Med *n* (%)	A lot *n* (%)	*M* *(SD)*	Not at all *n* (%)	Little *n* (%)	Med *n* (%)	Very much *n* (%)	*M* *(SD)*
Tiredness	23(46)	13(26)	7(14)	3(6)	1.48 (.67)	15(30)	4(8)	4(8)	1.43 (.73)	9 (18)	9 (18)	2 (4)	3 (6)	.91 (.99)
Sadness	15(30)	9(18)	6(12)	0	1.40 (.51)	9(18)	6(12)	0	1.40 (.51)	8 (16)	5 (10)	1 (2)	1 (2)	.67 (.90)
Itching	15(30)	10(20)	5(10)	0	1.33 (.49)	10(20)	5(10)	0	1.33 (.49)	4 (8)	8 (16)	3 (6)	0	.93 (.70)
Pain	14(28)	9(18)	5(10)	0	1.36 (.50)	6(12)	6(12)	2(4)	1.71 (.73)	4 (8)	7 (14)	2 (4)	1 (2)	1.00 (.88)
Worry	20(40)	16(32)	4(8)	0	1.21 (.42)	15(30)	5(10)	0	1.26 (.45)	4 (8)	13 (26)	3 (6)	0	1.00 (.58)
Appetite	32(64)	13(26)	15(30)	4(8)	1.68 (.65)	n/a	n/a	n/a	n/a	12 (24)	10 (20)	10 (20)	2(4)	.94 (.89)
Nausea	21(42)	13(26)	5(10)	1(2)	1.39 (.61)	n/a	n/a	n/a	n/a	4(8)	12 (24)	3 (6)	0	1.00 (.59)
Trouble sleeping	16(32)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	2(4)	10 (20)	4 (8)	0	1.13 (.62)
Numbness & Tingling	2(4)	2(4)	0	0	1.00 (.00)	2(4)	0	0	1.00 (.00)	1(2)	1 (2)	0	0	.50 (.71)
Other	13(26)	7(14)	498)	2(4)	1.62 (.77)	9(18)	4(8)	0	1.15 (.56)	3(6)	8 (16)	2 (4)	0	1.00 (.00)

Table 9

Prevalence and Characteristics of Symptoms on the Memorial Symptom Assessment Scale during Chemotherapy Night2 (N = 50)(T 5)

Degree When Symptom Was Present														
Symptom	Prevalence *n* (%)	Frequency				Intensity				Distress				
		Short *n* (%)	Med *n* (%)	Almost All *n* (%)	*M* *(SD)*	Little *n* (%)	Med *n* (%)	A lot *n* (%)	*M* *(SD)*	Not at all *n* (%)	Little *n* (%)	Med *n* (%)	Very much *n* (%)	*M* *(SD)*
Tiredness	19(38)	11(22)	8(16)	0	1.44 (.51)	10(20)	9(18)	0	1.50 (.51)	10(20)	4(8)	5(10)	0	.72 (.89)
Sadness	11(22)	7(14)	4(8)	0	1.40 (.52)	9(18)	2(4)	0	1.20 (.42)	8(16)	2(4)	1(2)	0	.40 (.70)
Itching	12(24)	8(16)	4(8)	0	1.33 (.49)	7(14)	5(10)	0	1.42 (.52)	3(6)	7(14)	2(4)	0	.92 (.67)
Pain	8(16)	7(14)	1(2)	0	1.13 (.35)	6(12)	2(4)	0	1.25 (.46)	3(6)	5(10)	0	0	.63 (.52)
Worry	23(46)	18(36)	5(10)	0	1.23 (.43)	18(36)	4(8)	1(2)	1.27 (.55)	7(14)	12(24)	3(6)	1(2)	.91 (.81)
Appetite	30(60)	12(24)	17(34)	1(2)	1.64 (.56)	n/a	n/a	n/a	n/a	9(18)	13(26)	7(14)	1(2)	1.00 (.86)
Nausea	14(28)	12(24)	2(4)	0	1.14 (.36)	n/a	n/a	n/a	n/a	8(16)	6(12)	0	0	.77 (.73)
Trouble sleeping	13(26)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	2(4)	7(14)	4(8)	0	1.15 (.69)
Numbness & Tingling	2(4)	2(4)	0	0	1.00 (.00)	2(4)	0	0	1.00 (.00)	1(2)	1(2)	0	0	.50 (.71)
Other	6(12)	3(6)	2(4)	1(2)	1.67 (.82)	3(6)	3(6)	0	1.17 (.75)	5(10)	0	1(2)	0	.67 (1.16)

Table 10

Prevalence and Characteristics of Symptoms on the Memorial Symptom Assessment Scale during Chemotherapy Day3 (N = 50) (T 6)

		Degree When Symptom Was Present												
Symptom	Prevalence *n* (%)	Frequency				Intensity				Distress				
		Short *n* (%)	Med *n* (%)	Almost All *n* (%)	*M* *(SD)*	Little *n* (%)	Med *n* (%)	A lot *n* (%)	*M* *(SD)*	Not at all *n* (%)	Little *n* (%)	Med *n* (%)	Very much *n* (%)	*M* *(SD)*
Tiredness	11(22)	7(14)	4(8)	0	1.40 (.52)	8(16)	3(6)	0	1.30 (.48)	3(6)	4(8)	4(8)	0	1.10 (.88)
Sadness	10(20)	7(14)	3(6)	0	1.33 (.50)	6(12)	4(8)	0	1.44 (.53)	4(8)	3(6)	3(6)	0	1.00 (.86)
Itching	14(28)	9(18)	5(10)	0	1.36 (.50)	9(18)	5(10)	0	1.36 (.50)	4(8)	9(18)	2(4)	0	.81 (.66)
Pain	6(12)	3(6)	3(6)	0	1.50 (.55)	4(8)	2(4)	0	1.33 (.52)	0	4(8)	2(4)	0	1.33 (.52)
Worry	15(30)	11(22)	5(10)	0	1.33 (.49)	10(20)	6(12)	0	1.40 (.51)	2(4)	9(18)	4(8)	1(2)	1.27 (.80)
Appetite	25(50)	10(20)	13(26)	2(4)	1.74 (.62)	n/a	n/a	n/a	n/a	6(12)	10(20)	9(18)	0	1.04 (.77)
Nausea	10(20)	6(12)	4(8)	0	1.40 (.52)	n/a	n/a	n/a	n/a	2(4)	5(10)	2(4)	0	1.00 (.68)
Trouble sleeping	10(20)	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	0	6(12)	3(6)	1(2)	1.50 (.71)
Numbness & Tingling	2(4)	1(2)	1(2)	0	1.50 (.71)	1(2)	1(2)	0	1.50 (.71)	1(2)	1(2)	0	0	.50 (.71)
Other	9(18)	5(10)	4(8)	0	1.44 (.53)	5(10)	4(8)	0	1.44 (.53)	2(4)	3(6)	4(8)	0	1.22 (.90)

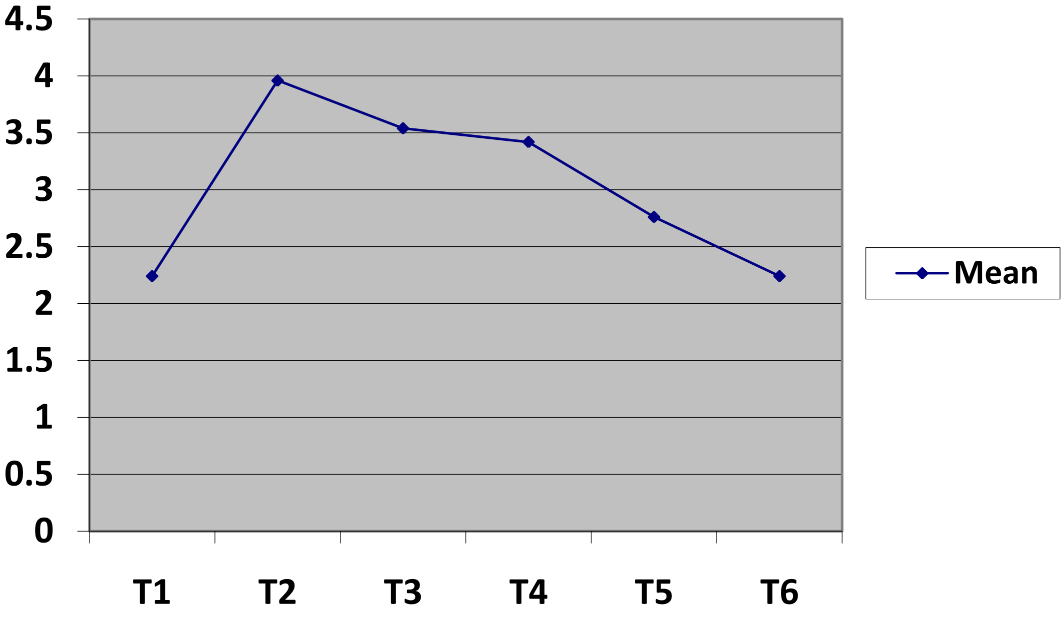
The means and standard deviations for number of symptom scores at each time period are presented in Table 11. As shown in the table, the mean number of symptoms increased from the day before chemotherapy (T1) to the morning of the first day (T2), and decreased thereafter. To assess whether the number of symptoms perceived by mothers across the six time periods were significantly different, a one-way within-subjects repeated measures ANOVA was conducted. The standard univariate repeated measures ANOVA revealed a significant time effect, F (5, 26) = 9.12, $p < .001$. The sphericity assumption (the homogeneity of variance of differences assumption) was violated; therefore, the alternative test, Greenhouse-Geisser, was used to evaluate multivariate significance (Green & Salkind, 2007). The results for the repeated measures ANOVA also indicated a significant time effect, Wilks's $\Lambda = .54$, F (5, 45) = 7.66, $p < .01$, multivariate $\eta^2 = .46$.

Table 11
Ranges, Means, and Standard Deviations for Total number of Symptom Scores at each Time Period (N = 50)

Time	Range		*M*	*SD*
	Potential	Actual		
T1	0-9	0 - 8	2.24	2.26
T2	0-9	0 - 9	3.96	2.80
T3	0-9	0 - 9	3.54	2.89
T4	0-9	0 - 9	3.42	2.45
T5	0-9	0 - 9	2.76	2.43
T6	0-9	0 - 8	2.24	2.24

As levels of the within-subjects symptoms factor represent quantitative scores that are equally spaced, it is more appropriate to conduct polynomial contrasts than paired-samples t-tests between time periods (Green & Salkind, 2008). Follow-up polynomial contrast indicated a significant quadratic effect with means increasing from time 1 (baseline) to time 2 (morning day 1), and then decreasing at each subsequent time period, F (1, 88) = 24.35, p <. 01, partial η^2=.33. Mean symptoms increased the first day of chemotherapy treatment and decreased progressively after that (See figure 3).

Figure 3. Mean for Total number of Symptom Scores at each Time Period (N = 50)



An independent sample t-test was conducted to evaluate the mean number of symptom scores between inpatients and outpatients. Before chemotherapy, the mean numbers of symptom scores between inpatients (M = 2.88, SD = 2.40) and outpatients (M = 1.65, SD = 2.00) were not significantly different, t (48) = 1.96, p = .056. After chemotherapy, the two groups of patients significantly differed in the mean symptom scores, *t* (48) = 2.59, *p* < .01. The mean number of symptoms in the inpatient group (*M* = 3.99, *SD* = 1.91) was significantly greater than that of the outpatient group (*M* = 2.44, *SD* = 2.14).

The body outline was used by mothers to locate symptoms of pain, itchiness, and numbness and tingling in their children. Before chemotherapy, the pain was reported most frequently in the arm (*n* = 2/8) and the abdomen (*n* = 2/8). Other reported pain locations were head, mouth, and leg. The most frequently reported locations of itchiness were the back (*n* = 11/11), arm (*n* = 6/11), leg (*n* = 4/11), chest (*n* = 3/11), and pelvic area (*n* = 1/11). One mother reported her child had numbness in the legs.

On the first day after chemotherapy, mothers reported their children had pain at the head, mouth, arm, hand, abdomen, back, and leg. The most frequent locations for pain early in the day were the hand with the intravenous insertion site (*n* = 6/11), lower back (*n* = 5/21), leg (*n* = 5/21), and abdomen (*n* = 4/21); for the first night, the locations included the leg (*n* = 4/16), arm (*n* = 3/16), low back(*n* = 3/16), and hand (*n* = 3/16). Locations were reduced the second day to the leg (*n* = 6/18), head (*n* = 5/18), and hand (*n* = 4/18), and the second night to the abdomen (*n* = 2/7) and arm (*n* = 2/11). On the third day after chemotherapy, mothers reported pain in locations of the head (*n* = 2/7) and abdomen (*n* = 2/7).

Itchiness was reported in the locations of the head, chest, back, arm, pelvic area, hand, leg, and abdomen. The most frequent locations of itchiness the first day were the arm (*n* = 6/11), pelvic area (*n* = 4/11), and leg (*n* = 4/11) and locations the first night included the leg (*n* = 7/13) and arm (*n* = 5/13).The second day, itchiness was restricted to the leg (*n* = 9/15) and arm (*n* = 4/15); results were similar for the second night (leg, *n* = 5/13; arm, *n* = 4)and the third day (arm, *n* = 5/8; leg, *n* = 4/8). A few mothers reported numbness for each day with the locations reported as the hand, leg, and foot.

Aim 2

Describe mothers' management of their young children's symptoms and the symptom management outcomes

Mothers identified the most important of their child's symptoms and reported the symptom management strategies they used for each symptom. Before chemotherapy, the majority of mothers reported the most important symptoms were loss of appetite (*n* = 5/27, 19%), pain (*n* = 5/27, 19%), and worry (irritated and annoyed) (*n* = 4/27, 15%). The first day after chemotherapy, mothers reported the most important symptoms were pain (*n* = 4/21, 8%), nausea and vomiting (*n* = 4/21, 19%), and loss of appetite (not eating) (*n* = 4/21, 19%) with pain (*n* = 7/21, 33%) and worry (*n* = 4/21, 24%) the most important the first night. The second day, mothers reported pain (*n* = 4/17, 19) and itchiness (*n* = 3/17, 18%) as the most important symptoms; findings were similar for the second night (itchiness, *n* = 3/10 (30%); pain, *n* = 3/10 (30%). The third day after chemotherapy, mothers reported the most important symptoms as pain (*n* = 4/14, 29%), itchiness (*n* = 4/14, 29%), and fever (*n* = 3/14, 21%). Pain was the most important symptom reported during three days. The majority of the pain symptoms were caused by having intravenous therapy and lumbar punctures.

Symptom management strategies used by mothers to alleviate their children’s symptoms were vigilant care, distraction (e.g., play, read and television), massage, mouth rinse, diet/nutrition, and life style change (e.g., new food, any food the child liked, supplemental vitamins, much sleep and rest, avoiding crowded area). Some mothers reported that their children received medication for pain, nausea, vomiting, and fever (see Table 12).

Symptom management from chart review

Eleven children received antiemetic (Onsia or Plasil) before they received chemotherapy, especially metrotrexate. Five children received an antiemetic again after they received chemotherapy in the hospital for day 1, and two children for day 2. Three children who had pain from intrathecal chemotherapy or lumbar puncture received pain relief medication (paracetamol) for day 1. Two children had headaches and received pain relief medication for 3 days.

Table 12

Symptoms Reported by Mothers and Their Management

Symptoms	Symptom Management
Pain	- Limit movement - Lie down and rest - Massage and sleep - Warm and cold compression - Vigilant care - Take paracetamol (Tylenol Plain external) medication for pain relief - Watching television or reading
Loss of Appetite	- Encourage all kinds of foods - Try new foods - Drink juice fruit - Give the child foods that he/she really likes - Describe the benefits of foods - Lets her eat when and whatever want to eat - Try supplement vitamins
Worry	- Distraction with television and play , divert attention - Do not know how to deal - Do not pay attention - Moms buy toys and play with the child - Hold, sooth and closely care - Moms lets she/he do what she/he want because she/he has to take medications - Do not blame the child

Table 12 (Cont)

Symptoms Reported by Mothers and Their Management

Symptoms	Symptom Management
Fever and low immunity	- Damp towels - Take antibiotics and paracetamol (Tylenol) - Daily Vitamins - Vigilant care - Antibiotic / Meet the doctor
Nausea and vomiting	- Distraction with television and play , divert attention - Vigilant care - Massage her back - Prescribed medication mentioned
Itchy	- Keep skin clean and moisturized - Staying in warm water - Watch for any bruising
Numbness	- Exercise his legs - Massage
Sore mouth	- Mouth rinse with Normal Saline - Take more water - Mouth sore medicine gel

Symptom Management Outcome

The 10-point numeric rating scale of management effectiveness assessed mothers' perception of their management of their children's symptoms. Before chemotherapy, the scores for symptom management outcome ranged between 1 and 10, and averaged 6.76 (*SD* = 2.61). Across the three days after chemotherapy, the symptom management outcome scores ranged between 1 and 10, and averaged between 6.68 and 7.35; see Table 13.

Table 13

Ranges, Means, and Standard Deviations for Symptom Management Outcome Scores at each Time Period

Time	*n*	Range		*M*	*SD*
		Potential	Actual		
T1	26	1 - 10	1 – 10	6.76	2.61
T2	27	1 - 10	1 – 10	7.22	2.56
T3	23	1 - 10	2 – 10	7.56	2.48
T4	19	1 - 10	2 – 10	6.68	3.14
T5	12	1 - 10	2 – 10	7.25	3.13
T6	14	1 - 10	2 – 10	7.35	2.76

Aim 3

Explore the relationships among maternal sensitivity, maternal stress, and mothers' perception of their children's symptoms

The 16-item scale of Thai Maternal Sensitivity questionnaire assessed maternal sensitivity and the 36-item scale of Parenting Stress Index/Short Form assessed maternal stress. In the current study, internal consistency for the Maternal Sensitivity questionnaire was adequate, with a Cronbach alpha of .85. For the Parenting Stress Index, the internal consistency estimates for the current study were comparable to those in previous research, with Cronbach alphas of .86 for the total Parenting Stress Index, .81 for the Parental Distress Subscale, .77 for the Parent-Child Dysfunctional Interaction Subscale, and .83 for the Difficult Child Subscale. There was a not significant correlation between parental stress index scores and illness duration. However, there was a significant difference on of parenting stress index scores between mothers of young children diagnosed with cancer less than 3 months and those of children with longer diagnosis. Mothers of children with cancer longer than 3 months had higher parenting stress scores than those of children with cancer of less duration.

Correlation coefficients were computed among maternal sensitivity scores, parenting stress index scores (total and subscales), and total prevalent scores for mothers' perception of their children's symptoms. The results of the correlation analysis presented in Table 14 show that three of the six correlations were statistically significant and greater than or equal to $r = -.33$. There was a statistically significant negative correlation between maternal sensitivity scores and parenting stress index scores ($r = -.36$, $p < .05$) with lower maternal sensitivity scores related to higher parenting stress scores. In contrast, there was a statistically significant positive correlation between parenting stress index scores and the number of post-chemotherapy child symptoms perceived by mothers ($r = .33$, $p < .05$). Essentially, higher parenting stress index scores were related to higher post-chemotherapy symptom scores. The numbers of symptoms perceived by mothers at baseline and post-chemotherapy were strongly correlated ($r = .47$, $p = .01$), so that the higher the number of symptoms at baseline, the higher the number of symptoms post-chemotherapy. The correlations between maternal sensitivity scores and the number of symptoms perceived by mothers at baseline and post-chemotherapy were not significant.

Table 14

Correlations among Scores on Maternal Sensitivity (MS), Parental Stress Index (PSI), and Child's Baseline Symptoms and Post-chemotherapy Symptoms

Variables	*1*	*2*	*3*	*4*	*M*	*SD*
1. MS total	--	-.36*	.02	-.06	120.86	12.57
2. PSI total	--	--	.09	.33*	92.25	17.71
3. Baseline Symptoms (T1)	--	--	--	.47**	2.24	2.26
4. Post-chemotherapy Symptoms (T2 – T6)	--	--	--	--	3.18	2.16

**p < .01. *p < .05.

A hierarchical multiple regression (*n* = 49) was conducted to determine whether mothers' parenting stress significantly predicted the perception of their children's post-chemotherapy symptoms after controlling for the children's age (1 – 2 year = 0, 3-5 years = 1), gender (boy = 0, girl = 1) and maternal education (≥ high school graduation = 0, < high school graduate = 1). The scatter plot for the two variables, parenting stress index and the post-chemotherapy symptom scores, indicates that the two variables are linearly related such that as parenting stress index scores increased, the post-chemotherapy symptom scores increased. Table 15 displays the correlations between these variables. In step 1, the results of the hierarchical multiple regression analysis indicated that child's age and gender, and maternal education did not explain a significant proportion of children's post-chemotherapy symptoms.

Table 15

Correlations among Scores on PSI, Child's Post-chemotherapy Symptoms, Child's Age and Gender, and Maternal Education (n =49)

Variables	*1*	*2*	*3*	*4*	*5*	*M*	*SD*
1. Post –chemotherapy Symptoms	--	.27*	-.24*	.24*	-.02	3.16	2.18
2. PSI	--	--	-.11	.13	-.25*	92.25	17.71
3. Age	--	--	--	-.20^t	-.26*	.71	.46
4. Gender	--	--	--	--	-.02	.35	.48
5. Maternal Education	--	--	--	--	--	.76	.43

**$p < .01$. *$p < .05$. t < .10.

In step 2, the parenting stress index variable was entered after controlling for the demographic variables. The result of this analysis indicated parenting stress index scores accounted for a significant proportion (21%) of post-chemotherapy symptom variance after controlling for the children's age and gender, and maternal education, $\Delta R^2 = .10$, $\Delta F(1, 44) = 5.67$, $p < .05$ (see Table 16). There was a moderate and significant positive association between higher parenting stress index scores and a greater number of post-chemotherapy symptoms ($b^* = .33$, $p < .05$). These results suggest that mothers who reported higher parenting stress index scores tended to report a greater number of post-chemotherapy symptoms although they have different education levels, and children with different age and gender.

Table 16

Hierarchical Multiple Regression Modeling for Variables Predicting Post-chemotherapy Symptoms

Variable	*R*	R^2	ΔR^2	ΔF	*b*	*SE b*	*b**
Step 1	.32	.10	.10	1.76			
Child's Age					-1.07	.711	-.22
Child's Gender					.90	.65	.20
Maternal Education					-.41	.73	-.08
Step 2	.45	.21	.10	5.67*			
Child's Age					-1.05	.68	-.22
Child's Gender					.73	.63	.16
Maternal Education					-.76	.71	-.15
PSI					.05	.02	.33*

$^*P < .05$.

The Parental Stress Index consists of three subscales that are Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (CD). The results of the correlation analysis presented in Table 17 show that only the PCDI subscale moderately and significantly related to post-chemotherapy symptoms ($r = .33$, $p < .05$).

Table 17

Correlations among Scores on Maternal Sensitivity (MS), Parental Stress Index Subscales (PSI), and Child's Baseline Symptoms and Post-chemotherapy Symptoms

Variables	*1*	*2*	*3*	*4*	*5*	*M*	*SD*
1. MS total	--	-.30*	-.42**	-.20	-.07	120.86	12.57
2. Parental distress	--	--	.54**	.37**	.08	28.90	7.90
3. Parent-Child Dysfunctional Interaction	--	--	--	.41**	.33*	28.96	6.60
4. Difficult Child	--	--	--	--	.24 ^{t}	34.39	7.91
5.Post-chemotherapy Symptoms (T2 – T6)	--	--	--		--	3.18	2.16

** p <.01. * p < .05. t < .10.

A hierarchical multiple regression (n = 49) was conducted to determine whether mothers' Parent-Child Dysfunctional Interaction significantly predicted the perception of their children's post-chemotherapy symptoms after controlling for the children's age and gender, and maternal education. In step 1, the results of the hierarchical multiple regression analysis indicated that child's age and gender, and maternal education did not explain a significant proportion of children's post-chemotherapy symptom.

In step 2, the Parent-Child Dysfunctional Interaction variable was entered after controlling for the demographic variables. The result of this analysis indicated the Parent-Child dysfunctional interaction subscale score accounted for a significant proportion (20%) of post-chemotherapy symptom variance after controlling for the children's age and gender, and maternal education, R^2 *change* = .09, *F change* (1, 44) = 5.18, $p < .05$ (see Table 18). There was a moderate significant positive association between higher Parent-Child Dysfunctional Interaction and a greater number of post-chemotherapy symptoms ($b^* = .34$, $p < .05$). These results suggest that mothers who reported higher Parent-Child Dysfunctional Interaction scores tended to report a greater number of post-chemotherapy symptoms although they have different education levels, and children with different age and gender.

Table 18

Hierarchical Multiple Regression Modeling for Variables Predicting Post-chemotherapy Symptoms

Variable	*R*	R^2	ΔR^2	ΔF	*b*	*SE b*	*b**
Step 1	.32	.10	.10	1.75			
Child's Age					-1.07	.71	-.22
Child's Gender					.90	.65	.20
Maternal Education					-.41	.73	-.08
Step 2	.45	.20	.09	5.18*			
Child's Age					-.98	.68	-.21
Child's Gender					.60	.64	.13
Maternal Education					-1.02	.75	-.20
PCDI					.11	.05	.34*

*$P < .05$.

The mean of total Parenting Stress Index scores between inpatients (*M* = 96.22, *SD* = 16.14) and outpatients (*M* = 88.73, *SD* = 18.59) were not significantly different, *t* (47) = 1.50, *p* = .14. For maternal sensitivity scores, the homogeneity of variance assumption was violated; therefore, a Mann-Whitney *U* test was conducted to evaluate the difference of mean maternal sensitivity scores between inpatients (*M* = 117.00, *SD* = 14.32) and outpatients (*M* = 124.42, *SD* = 9.67). The results of the test were not significant with the average rank for inpatients of 21.75 and for outpatients of 28.96.

The Secondary Aim

Explore the relationship between young children's pain and sleep as reported by their mothers

Actigraphy was used to validate mothers' report for sleep problem of MSAS. Mothers were instructed to keep the actigraphy on continuously and record those removal times in the diary. They also were instructed to push the event marker of their child's actigraphy at bedtime, naptime and wake time. Forty-six mothers had kept the actigraphy on continuously and recorded those removal times in the diary. Forty-four mothers pushed the marker of their child's actigraphy at bedtime, naptime, and wake time. The times that they pushed event markers of their child's actigraphy also were consistent with the bedtime, naptime, and wake time of sleep questions of the 3-day sleep diary.

Mothers of inpatient children aged 1 to 2 years reported that their children had higher sleep problems than others in each time point and highest sleep problems at day 1 after receiving chemotherapy, with the means between .33 and .78 (*SD* = 44 - 53) (see Table 19).

Table 19

Mean and Standard Deviations of Trouble Sleeping of MSAS Reported by Mothers

Sleep	Inpatients		Outpatients	
	1-2 years (*n* = 9) *M (SD)*	3-5 years (*n* =15) *M (SD)*	1-2 years (*n* = 5) *M (SD)*	3-5 years (*n* = 21) *M (SD)*
T1	.56 (.53)	.13 (.35)	.40 (.54)	.05 (.23)
T2	.78 (.44)	.40 (.50)	.40 (.55)	.19 (.40)
T3	.67 (.50)	.53 (.52)	.40 (.55)	.19 (.40)
T4	.56 (.53)	.33 (.49)	.40 (.55)	.19 (.40)
T5	.44 (.53)	.27 (.46)	.40 (.55)	.14 (.35)
T6	.33 (.50)	.33 (.49)	.20 (.44)	.08 (.22)

Similarly for actigraph data, inpatient children aged 1 to 2 years had the shortest naptime (*M* = 66.56, *SD* = 55.98 - 63.44) and total sleep time (*M* = 628.89, *SD* = 140.42) for day 1 after chemotherapy and had longer sleep in day 2 (*M* =694.28, *SD* =71.36) (see Table 20). In contrast, outpatient children aged 1 to 2 years had the longest total sleep time for both days (*M* =735.30 - 751.50, *SD* = 62.08 – 74.80).

Table 20

Mean and Standard Deviations of Nap time, Wake-Time, and Total Sleep Time in minutes

Day	Variables	Inpatient		Outpatient	
		1-2 years (*n* = 9) *M (SD)*	3-5 Years (*n* = 15) *M (SD)*	1-2 years (*n* = 5) *M (SD)*	3-5 Years (*n* = 21) *M (SD)*
1	Nap Time	66.56 (55.98)	82.96 (40.23)	63.20 (24.81)	74.88 (45.16)
	Wake Time	97.00 (40.92)	77.33 (25.16)	69.20 (59.54)	102.85 (61.79)
	Total Sleep Time	628.89 (140.42)	683.43 (94.46)	735.80 (74.08)	629.63 (83.86)
2	Nap Time	65.20 (28.35)	85.20 (36.74)	63.30 (45.94)	117.30 (63.44)
	Wake Time	137.44 (69.71)	70 (38.61)	81.60 (54.06)	104.26 (54.43)
	Total Sleep Time	694.28 (71.36)	643.69 (122.14)	751.70 (62.02)	636.61 (84.99)

The Pearson correlation test was conducted to evaluate the correlation between symptoms of pain and trouble sleeping after chemotherapy in young children as reported by their mothers. There was a significant positive correlation between symptoms of pain and trouble sleep (r = .27, *p* = .05) (see Table 21).

Table 21

Correlation between Symptoms of Pain and Trouble Sleeping of Young Children as reported by Their Mothers by MSAS

Variables	Pain	Trouble Sleep	*P* Value
Pain	--	.27	.05*
Trouble Sleep	--	--	--

The Pearson correlation test was used to evaluate the correlations among symptoms (Table 22). Pain was related to tiredness, sadness, itchiness, worry, nausea, and numbness with correlations ranging between .31 and .49. The symptom of trouble sleep was related to sadness, worry, and appetite problem with the correlations ranging between .31 and .57. Sadness was only one symptom that was related to all symptoms, with correlations ranging between .36 and .56, $p < .001$. Tiredness was strongly related to sadness ($r = .74$, $p < .001$). This symptom was also correlated to other symptoms, including itchiness, pain, changes of appetite, and nausea, with correlations ranging between .35 and .62.

Table 22

Summary of Correlations, Means, and Standard Deviations for Scores on Post-Chemotherapy Symptoms

Variables	1	2	3	4	5	6	7	8	9	*M*	*SD*
1. Tiredness	--	.74**	.46**	.35*	.57**	.44**	.62**	.34	.30	.38	.37
2. Sadness		--	.52**	.49**	.56**	.47**	.49**	.36**	.39**	.26	.36
3. Itchiness			--	.31*	.44*	.57**	.35*	.24	.31*	.32	.32
4. Pain				--	.35*	.25	.38**	.27	.45**	.28	.30
5. Worry					--	.39**	.37**	.57**	.24	.41	.40
6.Appitite						--	.52**	.31*	.27	.57	.38
7.Nuasea							--	.25	.31*	.36	.34
8.Trouble sleeping								--	.18	.31	.34
9.Numbness									--	.06	.18

** $p < .01$. * $p < .05$.

Based on the previous study, a hierarchical multiple regression ($n = 50$) was conducted to determine whether the symptom of worry significantly predicted the symptom of tiredness after controlling for symptoms of trouble sleeping, pain, and nausea. In step 1, the results of the hierarchical multiple regression analysis indicated that symptoms of sleep, pain, and nausea accounted for a significant amount of the variation in the symptom of tiredness, $R^2 = .43$, F (3, 46) = 11.32, p < .001.

In step 2, the symptom of worry was entered after controlling for sleep, pain, and nausea symptoms. The result of this analysis indicated worry accounted for a significant proportion (51%) of symptom of tiredness variance after controlling for other symptoms, R^2 change = .47, F (1, 45) = 8.18, $p < .05$ (see Table 23). There was a significant positive association of a moderate magnitude between more worry interaction and more tiredness during post-chemotherapy ($b^* = .38$, $p < .01$). These results suggest that mothers who reported that their children had more worry tended to report more tiredness during post-chemotherapy symptoms, especially when their child had greater nausea.

Table 23

Hierarchical Multiple Regression Modeling for Variables Predicting Tiredness after Chemotherapy Symptoms

Variable	R	R^2	ΔR^2	ΔF	b	$SE\ b$	b^*
Step 1	.65	.43	.38	11.32			
Trouble Sleep					.20	.13	.18
Pain					.12	.15	.10
Nausea					.58	13	.53***
Step 2	.72	.51	.47	8.18			
Trouble Sleep					-.01	.14	-.01
Pain					.06	.14	.05
Nausea					.50	.13	.46***
Worry					.35	.12	.38**

**$p < .01$. ***$p < .001$.

CHAPTER 5

DISCUSSION

This chapter discusses seven critical findings that add to the literature about symptoms in young children with cancer (ages 1 to 5 years) during chemotherapy treatment. For the first study aim, these include the following findings: 1) young children experience multiple symptoms; 2) symptoms change over three days of chemotherapy treatment, increasing the first day of chemotherapy treatment and decreasing progressively after that; 3) Thai mothers rated symptom frequency, symptom intensity, and symptom distress as less than has been found in previous studies; 4) change of appetite was reported as the most prevalent symptom for the six time points. According to the second aim, 5) the symptom management strategies used by mothers were found to be distraction and vigilant care. Furthermore, 6) analysis of the third aim revealed that higher parenting stress index scores were related to higher post-chemotherapy symptom scores. Finally, from a methodological perspective, 7) the mothers' reports were valid.

While the symptoms of school-aged children and adolescents have been demonstrated in previous research studies at different time points of treatment, this study examined the symptoms of young children over three days of chemotherapy treatment. This study not only demonstrated that young children with cancer experienced multiple symptoms during those three days of chemotherapy, but it also investigated maternal factors associated with mothers' perception of symptoms in their young children receiving chemotherapy. This study demonstrated that mothers' perception could be used for assessing symptoms in young children, although culture influences young children's expression of symptoms and their mother’s perceptions. These findings should be useful to healthcare providers in understanding symptoms in young children with cancer and their mothers’ perceptions in the development of interventions of symptom management. Hopefully, these results will inform future studies for symptom management in young children to reduce the burden of their symptoms.

These varying issues are now discussed in more detail. The findings are also discussed as they relate to the conceptual model in Figure 1. The model illustrates the broad approach taken in this study with respect to the symptom experience of young children receiving chemotherapy, and the focus on the environment that influences the symptom expression of these young children and the perceptions of the mothers who reported the symptoms of their young children.

Experience of Multiple Symptoms

The young children in this study, age 1 to 5 years, experienced multiple symptoms during chemotherapy. The most prevalent symptoms over three days of chemotherapy were change in appetite (lack of appetite), worry, tiredness, nausea and vomiting, itchiness, trouble sleeping, pain, and sadness. This finding is consistent with the finding of Williams and colleagues (2006), who studied multiple symptoms in children age 2 to 18 years. Those authors found that the frequent symptoms reported by parents were nausea, fatigue, pain, hair loss, sore mouth, vomiting, loss of appetite, weight loss, fever, and constipation. As in the current study, mothers reported that their children with cancer experienced multiple symptoms during and after chemotherapy treatment, although different measures were used.

Children in the study by Collins and colleagues (2002) also experienced multiple symptoms. The prevalence of symptoms included lethargy, pain, insomnia, itchiness, lack of appetite, worry, nausea, and sadness, respectively. However, these school-aged children with cancer experienced fewer symptoms than the toddler and preschool children in the current study the day before chemotherapy and nearly half as many symptoms the 3 days after chemotherapy. This difference was likely because all of the young children in this current study were receiving chemotherapy whereas the Collins and colleagues' study had a mix of different cancer treatments, such as chemotherapy and radiation. Although both studies used the MSAS, the current study used it only with younger children.

Further, the children in this study did not experience isolated symptoms, but rather symptoms were associated with each other. For example, sadness was related to all other symptoms. Pain was moderately or strongly related to tiredness, sadness, itchiness, worry, nausea, and numbness. Trouble sleeping was moderately or strongly correlated to sadness, worry, and appetite problems. Tiredness was moderately or strongly related to sadness, itchiness, pain, changes in appetite, and nausea. Furthermore, mothers who reported their children as having more worry and nausea tended to also report that their child had more fatigue. These findings suggest that there is an interplay between psychological and physical symptoms. Perhaps pain is not clearly expressed by young children and the expressions are interpreted by their mothers as psychosocial symptoms, such as worry or sadness.

There was significant association between pain and trouble sleeping in this current study. This finding is consistent with previous findings in the literature, which found a symptom cluster of pain, sleep disturbance, and fatigue. For example, Beck et al. (2005) examined the symptom cluster of pain, sleep disturbance, and fatigue in adult patients with cancer and with multiple primary diagnoses. They found that pain was related significantly to fatigue in individuals experiencing cancer pain. Some of the effect of pain on fatigue was mediated by sleep disturbance, but pain had a direct effect on fatigue as well. In this current study, troubled sleep could be a mediator of the relationship between pain and fatigue due to mothers' use of sleep as a management strategy when their children had symptoms such as pain and fatigue. Unfortunately, the number of children in this study who, according to maternal report, experienced the symptom cluster of pain, sleep disturbance, and fatigue, was too small to analyze.

In contrast, Jacob and colleagues (2007) examined the variation in pain, sleep, and activity during hospitalization for children (age 8 to 17 years) with cancer. The mean sleep scores for children who reported severe, moderate, and no or mild pain did not significantly differ. It may be that pain did not significantly relate to trouble sleeping due to the small sample size of children who reported both pain and trouble sleeping.

In summary, young children with cancer undergoing chemotherapy did not encounter isolated symptoms but rather multiple symptoms. These physical and psychological symptoms may have a reciprocal relationship.

Symptoms Changed over Time

The young children in this study experienced greater symptoms the first day of chemotherapy and then symptoms decreased progressively at each subsequent time period. Pain was rated greater the first day and then decreased over the subsequent three days. These findings are similar to those of Jacob and colleagues (2007), who reported that school-aged children and adolescents with cancer experienced greater pain and sleep problems on day 1 of five consecutive days of hospitalization. These results support the idea that symptoms of children with cancer should be consistently assessed and managed especially within the first 24 hours of receiving chemotherapy or diagnostic procedures (such as lumbar puncture and bone marrow aspiration).

All young children in this current study received chemotherapy through peripheral intravenous or lumbar spinal injections. Needle injections and leakages of chemotherapy agents caused pain. Most mothers reported pain as an important symptom. In addition, they associated the pain with a procedure rather than as a side effect of chemotherapy drugs. Furthermore, the majority of the children were in the maintenance phase of treatment for leukemia, receiving intravenous chemotherapy only the first day of each treatment. Therefore, symptoms such as pain were rated highest for the first day and decreased after that.

It is possible that the mothers had not been informed by the healthcare providers about chemotherapy symptoms because most of the nurses who were taking care of children with cancer were general pediatric nurses. There were only two pediatric oncology specialty nurses in this hospital and they worked in the outpatient clinic.

Therefore, the mothers might have not been educated about symptoms associated with chemotherapy side effects, so post-procedure effects might have received minimal attention from the mothers. In contrast, symptoms related to visible stimuli such as the insertions of needles or lumbar puncture allowed the mothers to make reasonable assessments. The finding related to the mothers' expectations is discussed in more depth below.

Symptom Characteristics and Distress

Consistent with other studies, the prevalence of each symptom in this study was not related to its frequency, intensity, and distress (Collin et al., 2002; Johnson, 2008). For example, mothers reported a high prevalence of change in appetite but it was not highly distressing for most of the children. These results confirm the findings from previous studies that the prevalence of a symptom was not necessarily related to its dimension. Most mothers rated the characteristics of the symptom her child had as follows: frequency as “a short time” to “a medium amount” of time, intensities as “little” to “medium,” and distress as “not at all” distressing to “medium” distress. In contrast, school-aged children with cancer in the U.S. (Johnson, 2008), and in Australia and England (Collins et al., 2002) rated each symptom as stronger, with frequency reported as “medium amount” to “almost all the time,” intensity as “medium amount” to “a lot,” and distress as “medium amount” to “very much.”

Several factors could explain why mothers rated their toddler and preschool children's symptoms with fewer symptom characteristics than school-aged children who self-reported on the MSAS. First, the MSAS was originally designed for adult populations and adapted for 7- to 12-year-olds. Perhaps symptom characteristics such as distress are difficult for mothers to report. It may be that the symptoms of school-aged children manifest differently from this young age group. Alternatively, this instrument may not be appropriate for mothers reporting the symptoms of their toddler and preschool-aged children. There is a need to develop an instrument to measure the dimensions of symptoms specific to the report by mothers or caregivers of younger children.

SecondAnother possible reason for maternal report of fewer symptom characteristics is the cultural influence. Most of the children were preschool-aged (3 to 4 years old) and were, on average, 3.5 years old. Children in this age group in Asian cultures are developing the ability to suppress outward signs of symptoms such as pain. For example, Negayama (1999) found that at the age of 3 years and beyond in Japanese children, there are continued changes in pain expression (e.g., less crying in older children given the same physical stimulus) and parents make an effort to teach their children to suppress pain expression. Similarly, in the Thai culture, the expression of sorrow, pain, or anger may displease others and thus would not be socially acceptable. Thai people are taught to be considerate and to not bother others, especially more senior people like healthcare professionals (Jongudomkarn et al., 2006).

Finally, social influences for symptom expression exist in the hospital, in interaction with healthcare providers. Observation data suggested that a child who did not complain of symptoms such as pain would be described by nurses as a very good child compared with others. These results are congruent with the cross-cultural pain literature.

Wang and colleagues (2003) found that most pediatricians in China did not perceive that young children with cancer experienced pain and that they lacked the necessary knowledge of pain.

Similarly, in the U.K, nurses in an orthopedic ward were found to actively discourage children from displaying their pain: they frequently “constructed pain as unreal, unwarranted or not deserving help” (Byrne et al., 2001, p 72). Children who did not complain of pain or ask for analgesics were described by nurses as “very good” or “great.” These findings also suggest that children’s response to symptoms can be strongly influenced by the society in which they live as well as by the behavior of their parents.. The Thai culture and the hospital environment in this current study may have influenced mothers’ perceptions of symptoms in their young children leading them to report lower prevalence, intensity, and distress than those in a Western culture (Collin et al., 2002; Johnson, 2008). Healthcare providers’ attitudes and knowledge need to be explored to learn how they influence clinical practice in management of pain and other symptom.

The Most Prevalent Symptoms

On the first day of receiving chemotherapy, the children had the most prevalent symptoms. These were change in appetite (lack of appetite), pain, tiredness, itching, worry, and nausea.

Change in appetite. Change in appetite was the most prevalent symptom for all six time points in the toddler and preschool children. In contrast, pain and fatigue were reported most by school-aged and adolescent children (Collins et al., 2002; Johnson, 2008). In another study, fatigue and nausea were the most prevalent for children aged 2 to 18 years reported by parents (William et al., 2006).

There are several possible explanations for the different findings. First, this study used mothers' reports whereas the previous studies used the self-reports of the children (Collins et al., 2002; Johnson, 2008). Mothers of toddler and preschool children reported the symptom of change in appetite more often than pain and fatigue. Interview questions found that the symptoms of pain and vomiting were expected as a result of chemotherapy. Loss of appetite was also taught as a side effect of chemotherapy. Mothers have parenting experience with varying appetite change as a sign of change in development, and not eating as a sign of illness. A good appetite usually means being healthy. One-third of children in this study had been diagnosed with solid tumors such as neuroblastomas, Wilm's tumors, and brain tumors, and from the interview data, the mothers of these children thought cancer meant death. Thus, they may have focused on symptoms related to surviving such as appetite and weight loss. Mothers also expressed concern that loss of appetite would cause anemia and they feared that compromised immunity would affect or disrupt the effectiveness of the cancer treatment. Therefore, a change in appetite was an important symptom for mothers to monitor.

Second, the children who received chemotherapy in the clinical and hospital settings experienced stressful procedures, as well as the strange environment of the healthcare setting. For toddlers and preschool children, familiarity and the social context in which foods are presented are the most important factors influencing food preferences (Skolin et al., 2001). Problematic eating behaviors (e.g., picky eaters) are more common in younger children and are possibly exacerbated by chronic illness more often during early development (Powers et al., 2002). Refusal of food by children with cancer was distressing to mothers. The children's food and eating patterns were perceived as vitally important to the children's ability to fight cancer.

Third, all of the young children in this study received intravenous chemotherapy the first day, with half of the children as inpatients and half as outpatients, whereas most of the children in the study by Collins and colleagues (2002) were outpatients, had different treatments (chemotherapy or radiation), and had different times/days of treatment. Half of the children in this present study received chemotherapy agents, such as methrotexate or mercaptopurine, that have associated side effects of anorexia, nausea, and vomiting. In addition, other chemotherapy agents can affect caloric intake due to nausea, vomiting, and mucositis, diarrhea, altered tasted sensations, and anticipatory vomiting (Skolin et al., 2001). As a result, mothers may be more concerned about adequate nutrition for healing and recovery and minimizing the development of negative eating behaviors during treatment. When a child's eating pattern and appetite begin to change during treatment, parents may become overly focused on the feeding process and use strategies aimed at coercing their child to eat. Consequently, this can increase toddler-preschool children's resistance to eating and further suppress nutritional intake.

Finally, eating is a central focus in this age group. Asian mothers were more protective of their young children than Western mothers (Martinson et al., 1999). Thai mothers are so concerned about young children eating that they continue to feed their toddlers and preschoolers, with self-feeding beginning at about 2 years of age. When their children are sick, Thai mothers typically are even more involved with feeding their children than usual. Interview data suggested that most of mothers believed their children needed enough food to assist them with recovery from illness. Similarly, a study by Martinson and colleagues (1999) found that Chinese families of children with cancer focused on proper diet in contrast to Caucasians who largely ignored nutrition but focused on emotional care. To strengthen the child, most of the mothers in this current study supplemented care with cooking special foods such as high-protein foods or fruit juice. Few mothers used traditional medicines such as Thai herbs. Perhaps, Thai mothers in this current study were sufficiently acculturated to Western culture to trust Western rather than Eastern medicine for this serious illness.

Pain. Pain was rated greater the first day and then decreased progressively. Most locations of pain reported by the mothers were observed sites that related to the insertions of intravenous chemotherapy (such as wrist, hand, and arm) and procedure treatments but not the nonvisible side effect of chemotherapy itself such as aching. These findings are consistent with a Thai study (Pharnit, 2004) that found that school-aged Thai children with leukemia experienced pain due to treatment procedures, particularly due to peripheral intravenous chemotherapy with the insertions of needles and the leakage of chemotherapy agents. As noted earlier, in contrast, Jacob and colleagues (2007) found that the most frequent locations of pain in school-aged children and adolescents were the abdomen, chest, and lower back whereas in the study of Van Cleve and colleagues (2004), children with ALL reported that the most frequent pain locations were legs, abdomen, head and neck, and back.

Literature suggests that symptoms such as leg and abdominal pain and headache have been associated with chemotherapy medications such as vincristine (neuritic pain), methotrexate, dexamethasone, and cytarabine. Interview data found that most of the mothers had been taught more about symptoms that related to chemotherapy side effects such as nausea and vomiting than about pain. Perhaps pain and other symptoms such as fatigue related to chemotherapy side effects may be underestimated because the mothers were not taught to watch for them.

Fatigue. Fatigue had a similar finding to that for pain. Gibson and colleagues (2005) surveyed parents' perceptions of cancer-related fatigue in children (2 to 18 years old) with various types of cancer and different treatments. Parents reported the prevalence of other symptoms (e.g., pain, hair loss, and anxiety) more frequently than that of fatigue. The researchers speculated that children and their parents may not have been informed to expect fatigue as a symptom because the notion that children experience fatigue as a symptom may be quite a new concern for healthcare providers in the U.K.

Mothers of young children with cancer perceived multiple symptoms that occur together. Their expectation of symptoms in their children may influence their perceptions. Thus, healthcare providers need to inform the mothers about anticipated symptoms related to the side effects of chemotherapy, especially pain and fatigue.

Symptom Management Strategies Used by Mothers

Thai mothers were asked to rate the most important symptom of their children. Pain was the most important symptom reported during the three days. The majority of pain symptoms were caused by having intravenous therapy and lumbar punctures. The identification of many strategies used to take care of children's pain in this study was parallel to the management strategies in children with cancer found by Van Cleve and colleagues (2004). For example, sleep and rest prevented aggravating the source of pain, possibly preventing increased pain. Thermal modalities such as heat and cold were used, as well as massaging of the painful area.

Most of the Thai mothers reported effective symptom management. This is in contrast to the parents of Latino children with leukemia, in which parents reported a perception of less effective pain management (Van Cleve et al., 2004). It is difficult to know if symptom management strategies for the Thai children were adequate. Mothers may not have reported symptoms spontaneously or may have minimized the symptoms, especially if they considered symptoms related to side effects of chemotherapy light enough to be endurable.

Most of the children who were reported by their mothers as having significant pain did not receive medication to relieve that pain. This result is consistent with a previous study (Lolekha et al., 2004) that found that most HIV-infected Thai children who reported pain did not receive medication, while 10% of the children who received painkillers obtained over-the-counter medication without medical advice.

To relieve the children's symptoms, mothers used a variety of strategies. Distractions such as watching television and play, and vigilant care were commonly used for several symptoms. Diet changes (new foods and any food the child liked) were used to help the child who had a lack of appetite. Alternatively, some parents became less restrictive and allowed poor food choices in an attempt to improve their child's eating. Massage was used for pain by mothers, reflecting a traditional practice in Thailand. This finding is consistent with previous findings (Jongudomkarn et al., 2006) that the expression of pain in Thai families is characterized by ignoring and enduring. In the Thai culture, preschool children are encouraged by parents and family to forget and to think about something else when they have a physical injury.

Again, this result is consistent with the findings that Chinese pediatricians perceived that young children did not experience pain and were less sensitive to pain (Wang et al., 2002). The top barriers to optimal pediatric pain management were identified as fear of opioid addiction and inadequate knowledge of pain management. The healthcare providers' knowledge of symptom management in Thailand in turn may influence mothers' symptom management strategies for their young children with cancer. This needs to be researched further.

Relationships among Symptoms and Maternal Variables

The mean scores of the Parent-Child Dysfunctional Interaction (P-CDI) and Difficult Child (DC) subscales and the parenting stress total scale approached or were above the 90th percentile of Abidin's normative sample. Compared with the normative scores of Western countries, most of the mothers in this study would be referred for professional counseling in stress management. The higher total scores for Thai mothers may result from cultural differences between Thais and Americans, and the differences between the urban and rural Thai regions from which the mothers came. Although Abidin's Parenting Stress Index/Short Form (PSI/SF) is applicable to mothers of healthy

Western children, the clinical threshold established may not be valid for Thai mothers of children with cancer. Thus, there is a need to establish the normative score of the PSI/SF in Thai mothers with healthy children to identify whether differences exist between mothers of healthy children and those of children with cancer.

The findings of this study were similar to Chinese mothers of children with cancer. Yeh and colleagues (2001), who examined the psychometric properties of the Chinese version of the PSI/SF found the PSI/SF applicable to Taiwanese parents. The mean scores of each subscale of the PSI/SF were also above the clinical threshold of stress of the normative sample. A follow-up study compared the parenting stress level of Chinese parents of children with cancer with those of children with physical disabilities (Hung et al., 2004). The parents of children with cancer experienced significantly higher levels of stress compared with the parents of children with physical disabilities on the PCDI and DC subscales of the PSI than on the PD subscale. These findings suggest that parents in the cancer group perceived more stress from parent-child interactions and the child’s characteristics.

There are several possible explanations why mothers of children with cancer tended to reported higher PSI scores than others. The conceptual definition of the difficult child by Abidin (1995) may be problematic when applying the PSI to the population of mothers of children with cancer. Abidin (1995) defined the difficult child as rooted in the temperament of the child, but he also included learned patterns of defiant, noncompliant, and demanding behavior. For example, one item, “my child makes more demands on me than most children,” may not be appropriate for children with cancer. Mothers of children who have cancer may indicate the highest score on this item and consequently inflate the DC score.

Traditionally, women in Thai society are the primary caregivers in families and are expected to be more responsive to nurturing others and caring for sick children. They are often the primary source of information regarding their children's symptoms, and they must observe, report, and manage their children's symptoms at the hospital and at home. Mothers have to watch their sick children suffer through invasive treatments and side effects, and they are not able to protect their children from pain and fear of strangers. Furthermore, mothers of young children may worry that their children may not be able to communicate their symptom distress (e.g., pain, feeling sick). In addition, they might be challenged, particularly with a toddler, to administer medication and other treatments (Kazak et al., 2007; Roy et al., 2000).

Mothers learn that cancer is a severe and even deadly disease that involves an unpredictable course of an initial period of illness followed by remission and the possibility of recurrence in the future. Because toddlers and preschool children are considered too young to understand, mothers are reluctant to discuss the illness with them. Withholding the bad news from children was the most common strategy used by parents in the communication of illness information between parents and children with cancer (Yeh et al., 2001), especially for young children (Clarke et al., 2005). Children who are sensitive to their family's emotional behaviors knew there was something wrong with them even though they did not discuss their illness with others. Consequently, the children created their own perceptions and ideas about their illness, their symptom experience, and their mothers' responses to them (whether or not they could use their mothers as a secure base) by using their imaginations.

Emotional responses of toddlers and preschool children to cancer treatment and their mothers' behaviors may influence their psychosocial development. These responses may influence mothers' perceptions that their sick children are difficult to manage. Similarly, Zahr and El-Haddad's (1998) study found that children with leukemia were perceived by their mothers as more difficult and more irregular than children with congenital heart disease or asthma. These perceptions could lead to increased stress for mothers of young children with cancer, especially stress in the parent-child interaction and in response to the children's characteristics.

Interestingly, this current study found that the mothers whose children with cancer had been diagnosed more than 3 months earlier had higher parental stress index scores than those with children more recently diagnosed. It is possible that mothers of newly diagnosed children may excuse or forgive their children because of newly experiencing this stressful situation, or the life-threatening situation had not yet influenced the child's emotional responses. In contrast, mothers of children with a diagnosis older than 3 months may experience difficulties raising that child who may have emotional responses such as being easily irritated or uncooperative with medication or treatment. Interview data supported the idea that mothers described their preschool children as being resistant about coming to the hospital and accepting treatment because of their fear of painful procedures and chemotherapy treatment.

Several maternal and child characteristics may influence parenting stress index scores. Over half of the mothers were employed, had more than one child, reported a household income of less than 15,000 Baht, and lived outside Bangkok. They may have experienced stress not only related to the treatment of their children's illness, but also because of the disruption to their employment given that there are no social security systems in Thailand. Mothers are faced with many challenges, especially during the first six months of their child being diagnosed; these challenges include maintaining as normal a family life as possible for themselves, their sick child, and any healthy siblings (Woodgate et al., 2004). Mothers have a critical role to play both in the medical care and in facilitating the child's acceptance of treatment (Nelson, 2002). These demands potentially contribute to higher parenting stress scores.

In this study, there was a significant negative correlation between the parenting stress index and maternal sensitivity. This is consistent with other findings that suggest that higher maternal stress contributes to decreased maternal sensitivity. For example, Moran et al. (1992) examined the impact of parenting stress on maternal sensitivity in mothers of developmentally delayed children in a home visiting program. They, too, found that mothers with higher parenting stress index scores in the child domain had decreased maternal sensitivity. It may be that mothers with higher stress are not able to respond sensitively to their child's demands. In other words, higher stress may decrease their sensitivity to their child.

This may explain this study's findings. Mothers with higher stress index scores may not have been able to respond to their child's signals and demands, while their child, who was experiencing several stressful situations of chemotherapy treatment, was not able to react in a way that reinforced the mother's caretaking. This may have led to decreased or inconsistent maternal sensitivity and, then, increased maternal stress as well. In other words, mothers with less sensitivity to their young child may be easily irritated with the sick child who makes more demands during cancer and chemotherapy treatment. Therefore, they reported higher parenting stress index scores. Over time, the young children with cancer may have perceived that they could not use their mothers as a secure base or they may have found that their mothers were not available when they needed help from them. This response may have influenced their emotional development and well-being. Thus, the children would be perceived by their mothers as more difficult to manage. However, this study did not examine children's attachment pattern. This needs to be examined in future studies.

Although this study found a negative relationship between parenting stress index scores and maternal sensitivity scores and a positive relationship between parent stress index scores and mothers' perception of symptoms, there was not a significant correlation between maternal sensitivity and mothers' perception of symptoms. Given the minimal amount of literature regarding how the child's symptoms are impacted by the dyadic relationship between parent and child, Riddell and Chambers (2007) suggested that an optimal situation would have a sensitive mother assess the child's pain signals and take appropriate actions to soothe both the physical and emotional dimensions of the infant's symptoms. Over time, the infant knows that he or she can use his or her mother as a secure base in the way that the mother will respond to his or her symptoms such as pain.

In contrast, mothers with higher stress and inconsistent sensitivity require intense child pain behaviors on some occasions to take actions and do not require intense child pain behaviors at other times to get her to take action. Mothers with less sensitivity usually do not respond to their children's cues. Over time their children learn to avoid or ignore their mothers because they perceive their mothers as not responsive or rejecting. In sum, mothers with less or inconsistent sensitivity may be less effective at reporting and managing the child's symptoms.

In other words, based on the previous study (Moran et al., 1992) of maternal and child interaction in healthy children, it could be hypothesized that mothers with higher stress tend to have less sensitivity and are therefore less observant of their young child's symptoms. Their children may express more visible symptom behaviors for seeking attention from their mothers. Therefore, mothers who reported higher parenting stress may be less sensitive to their children and may tend to report more symptoms in their children. This hypothesis needs to be applied to mothers of young children with cancer. Some items on the parental stress index may not be appropriate for children with cancer, for example, "my child doesn't seem to smile as much as I expect" and "my child makes more demands on me than most children." Mothers of children who have cancer may indicate a higher stress score.

It is not clear if mothers of young children with cancer who reported higher parenting stress index scores and who had either adequate or inadequate sensitivity had sought information about chemotherapy treatment. Perhaps they observed their children more closely due to the life-threatening illness and effectively reported their children's symptoms. The longer mothers took care of their young children with cancer, the better they could report their children’s symptoms. The traditional interpretation of maternal-child interaction might not be appropriate for mothers of children with cancer.

Several limitations should be noted. Maternal sensitivity is not a one-way process but rather a dynamic interaction reciprocal with the child’s response. Children’s characteristics such as temperament or attachment pattern also influence mothers’ and children’s responses. Thus, a self-report measure of maternal sensitivity alone may not be adequate to conclude that mothers with less sensitivity report their children’s symptoms less effectively than those with higher sensitivity. Measures of children’s characteristics such as temperament and attachment pattern would add information about how these variables influence the expression of young children’s symptoms.

Koonce and colleagues (2008) found that maternal sensitivity increased longitudinally from 6 to 36 months for mothers of healthy children classified as secure or resistant. The majority of children in this current study had been diagnosed with cancer less than six months before. The life-threatening situation may have influenced or interrupted maternal sensitivity or the ability of mothers to respond to their child’s demands. Perhaps maternal sensitivity also increases over time in mothers of children with cancer not only as they learn to cope with the life-threatening situation better but also as a part of normative development. Therefore, a cross-sectional study with different ages and different durations of diagnosis might not provide enough information to draw conclusions about the maternal sensitivity of Thai mothers of young children with cancer. A longitudinal study with a larger sample size at each age is needed.

The self-report measure of maternal sensitivity was first used in the Thai culture. There is a need to test the validity of this instrument with the observational version. It is not clear whether mothers with higher stress expected that they should be more sensitive than usual when their children were diagnosed with cancer, and thereby rated their sensitivity lower than those with lower stress. There is a need to replicate this study with an in-depth interview of mothers with higher and lower stress levels.

Validity of Mothers' Reports

Findings in this study point to the validity of maternal reporting. Maternal judgment of the child's pain using the numeric rating scale of pain was used to contribute construct validity to the pain question on the MSAS. There was highly positive significant correlation between the corresponding pain of the MSAS symptom and maternal judgment of child pain. Furthermore, actigraphy was used to validate mothers' reports of trouble sleeping on the MSAS. Mothers were instructed to keep the actigraphy on continuously and record those removal times in the diary. They also were instructed to push the event marker of their child's actigraphy at bedtime, naptime, and wake time. Ninety-two percent of the mothers kept the actigraphy on continuously and recorded those removal times in the diary. Eighty-eight percent of the mothers pushed the marker of their child's actigraphy at bedtime, naptime, and wake time. The times that they pushed event markers of their child's actigraphy also were consistent with the bedtime, naptime, and wake time of sleep questions. Mothers of inpatient children age 1 to 2 years reported that their children had more trouble sleeping than all other study children at each time point and the most trouble sleeping on day 1 after receiving chemotherapy. Similarly for actigraph data, inpatient children age 1 to 2 years had the shortest naptime and total sleep time for day 1 after chemotherapy and had longer sleep in day 2. In contrast, outpatient children aged 1 to 2 years had the longest total sleep time for both days.

These findings suggest that mothers' reports provided reasonable estimates of their children's pain and sleep symptoms. However, it is not possible to conclude that their reporting is as precise or accurate as self-reporting because there are several factors that may influence their perception. Especially for longer-lasting symptoms, mothers must rely on behavioral indicators of these symptoms that they may not anticipate or that may not be as obvious as acute symptoms in response to procedures or treatments. Mothers may overestimate when they have higher stress or underestimate if they are not informed about symptoms of chemotherapy side effects. This current study demonstrated that mothers are close to their children most of the time during hospitalization and at home. Parents recognize changes in their children's condition and discrepancies from their normal behavior. Mothers are, however, dependent on professionals for information, communication, and knowledge concerning their children's disease, symptoms, and treatment.

The findings indicated that mothers are appropriate reporters of their children's symptoms. Nonetheless, several factors should be considered, such as their knowledge of chemotherapy side effects, stress, parenting styles, culture, and the meaning of diagnosis, when considering the accuracy of mothers' reports. If cancer means a threat of death, mothers tend to focus on symptoms related to surviving such as fever, appetite, low immunity, and weight loss more than other symptoms. There is a need to explore other variables influencing mothers' perceptions in order to refine mothers' reports of children's symptoms and to reduce symptom burden in young children with cancer.

Relation of Findings to Conceptual Framework

Young children with cancer experience multiple symptoms due to the cancer itself, chemotherapy side effects, and procedures for treatment. Thai mothers are usually the primary caregiver for their young children with cancer. Maternal variables such as maternal sensitivity and maternal stress influence mothers' perceptions of their child's symptoms. Mothers with less sensitivity are more likely to have higher stress and mothers with higher stress are more likely to report greater symptoms in their young child. The children's variables such as age, gender, and temperament also influence mothers' perceptions as well. For example, as children mature, they learn how to express their symptoms. The Thai culture and environment, especially the hospital environment, influence children's expression of symptoms and their mothers' perceptions. In the Thai culture, the expression of symptoms is not socially acceptable; thus, children and their mothers may not report symptoms spontaneously, minimizing the symptoms when they consider that the symptom should be endured.

Study Limitations

The limitations of this study include the small sample size and selecting participants from only one cancer center. Although maternal variables of stress and sensitivity were explored in this study, the use of self-report limited the information for understanding mothers' perceptions of their child's symptoms. Children's attachment patterns may be associated with mothers' perceptions of their children's symptoms. Furthermore, mothers were asked to answer the stress and sensitivity questionnaires on the day they came to the hospital. They may already have felt higher stress and have lower sensitivity than usual because it was difficult for them to manage their children to come and stay in the hospital. In addition, mothers' knowledge of chemotherapy side effects was not explored, and that might influence their perceptions of their child's symptoms.

The MSAS, originally designed for an adult population and adapted for 7- to 12-year-olds, was studied for the first time in toddlers and preschool children in this study. Some symptoms and their characteristics may be difficult for mothers to assess such as worry, nausea, and numbness, as well as the distress level of each symptom. Adding observational and interview methods to the mothers' reports would provide more contextual and behavioral information for developing an instrument that would refine the maternal or caregiver assessment of young children's symptoms.

Strengths of Design

An important strength of this study was being able to follow participants over three days of chemotherapy, with little missing data. This study explored the multiple symptoms and their characteristics at six time points over three days of chemotherapy treatment. The researcher had perspective data that showed variations in the symptoms in the morning and evening as well as over 3 days of chemotherapy to understand how Thai mothers perceived symptoms in their young children. This study is one of the first to examine symptoms in toddlers and preschool children with cancer. These findings provide valuable information for future prospective and intervention studies for young children with cancer.

While this study used mothers' reports, other variables (mothers' variables such as stress and sensitivity, and the Thai culture) were included to explore how these variables influence mothers' perceptions. Finally, this study also demonstrated that mothers' reporting was reliable by using other measures such as a numeric rating scale of pain, sleep questions, and actigraphy.

Future Directions

As discussed previously, several factors may influence a mother's perception and the child's expression of symptoms, such as the perceptions and beliefs of healthcare professionals about symptoms in young children, the mother's knowledge of symptom management, the child's temperament, and the attachment patterns of young children. Investigating these factors prospectively is essential to learning more about these mothers' perceptions and young children's expression of symptoms.

The PSI/SF and MBQS were used for the first time in Thai mothers of young children with cancer. Normative scores of these instruments have not been previously established in the Thai culture. Investigating the normative scores of these instruments in Thai mothers with healthy children is needed to identify whether differences exist between mothers of healthy children and those of children with cancer. This would benefit healthcare providers who are assessing whether mothers of young children with cancer are ready to care for their young children, if they need help, or if referral to psychosocial counseling in stress management and/or parenting of young children with cancer is necessary.

While this current study suggests that there is a relationship between psychosocial and physical symptoms, future studies could build on this by developing the instrument to measure symptoms in young children, particularly longer-lasting symptoms associated with chemotherapy medication.

The limitations of this study include the small sample size and selecting participants from only one cancer center. Replicating this study with a larger sample size recruited from different centers would increase generalizability. Because the symptoms of young children are thought to have different patterns in different cancers, a longitudinal study investigating symptoms and other factors that affect young children's expression of symptoms would contribute to an understanding of symptoms of young children with cancer, thereby contributing to the quality of their care.

This study demonstrated that mothers perceived that their children experienced multiple symptoms, especially on the first day. The symptom management strategies used most by mothers were distraction and vigilant care, not medication. Interventions are needed to educate not only mothers of young children but also healthcare providers about symptoms in young children. Perhaps investigating how mothers with adequate sensitivity and less stress interact and manage the demands of their sick children would be beneficial for developing strategies for other mothers to care for their children with cancer.

Clinical Implications

The findings of this study may contribute to improving nurses’ understanding of mothers’ perceptions of symptoms in their young children with cancer from a particular cultural group and, equally important, how these perceptions may differ from a Western group. It is important for nurses working with young children with cancer and their mothers to understand how young children experience symptoms during chemotherapy treatment. Indeed, knowing children’s symptom experience and their mothers’ perceptions is essential for nurses involved in caring for the young child and his or her family. This study draws attention to parental stress and maternal roles around young children as they experience symptoms. The findings also reflect the significance of providing information and support for mothers and their young children. Assessment and management of symptoms in young children receiving chemotherapy are very important not only for the children but also their mothers. Healthcare professionals need to be sensitive to the symptoms of young children even though the mothers may report few or no symptoms in their young children.

This study also demonstrated that the need to use the perspective of developmental science across cultures in a symptom experience study. This may allow nurses to access children in different and more culturally specific ways.

Summary

The present study assessed symptoms in toddler/preschool children with cancer. Symptom variation associated with day of chemotherapy (day 1, day 2, and day 3), and mother-child relationship were considered. In addition, the study explored strategies used to manage symptoms, and examined the outcomes of management. This study advances the understanding of mothers' perceptions of symptoms in their young children. In this study, young children with cancer experienced multiple symptoms, these symptoms were related to each other, and most children did not receive medication to relieve their symptoms. Most of the mothers of young children used distraction as a symptom management strategy. Mothers with higher stress tended to report more symptoms in their young children. Finally, mothers were reliable reporters of children's symptoms. These findings should inform future studies aimed at developing interventions for mothers and their young children with cancer.

References

Abidin, R. R. (1995). *Parenting Stress Index*. Lutz, FL: Psychological Assessment Resources.

Acebo, C., Sadeh, A., Seifer, R., Tzischinsky, O., Hafer, A., & Carskadon, M. A. (2005). Sleep/Wake patterns derived from activity monitoring and maternal report for healthy 1-to 5-year-old children. *Sleep*, *28*(12), 1568-1577.

Ainsworth, M. S. (1979). Infant-mother attachment. *American Psychologist*, *34*(10), 932-937.

Ainsworth, M. S., Bell, S. M., & Stayton, D. J. (1971). Individual differences in Strange Situation Behavior of one year olds In H. R. Schaffer (Ed.), *The Origins of Human Social Relations*. New York: Academic Press.

Ainsworth, M. S., Bell, S. M., & Stayton, D. J. (1974). Infant-mother attachment and social development: Socialisation as a product of reciprocal responsiveness to signals. In M. P. M. Richards (Ed.), *The introduction of the child into social world*. London: Cambridge University Press.

Ancoli-Israel, S., Cole, R., Alessi, C., Chambers, M., Moorcroft, W., & Pollak, C. P. (2003). The role of actigraphy in the study of sleep and circadian rhythms. *Sleep, 26*(3), 342-392.

Beck, S. L., Dudley, W. N., & Barsevick, A. (2005). Pain, sleep disturbance, and fatigue in patients with cancer: using a mediation model to test a symptom cluster. *Oncology Nursing Forum, Online. 32*(3), 542.

Breivik, H., Borchgrevink, P. C., Allen, S. M., Rosseland, L. A., Romundatad, L., Breivik Hals, E. K., et al. (2008). Assessment of pain. *British Journal of Anaesthesia*, *101*(1), 17-24.

Brislin, R. W. (1970). Back-Translation for cross-cultural research. *Journal of Cross-cultural Psychology, 1*(3), 185-216.

Byrne, A., Morton, J., & Salmon, P. (2001). Defending against patients' pain: A qualitative analysis of nurses' responses to children's postoperative pain. *Journal of Psychosomatic Research, 50*(2), 69-76.

Bowlby, J. (1969). *Attachment and loss Vol.1: Attachment*. New York: Basic Books.

Bowlby, J. (1973). *Attachment and Loss Vol 2: Separation*. New York: Basic Books.

Bowlby, J. (1980). *Attachment and Loss Vol 3: Loss*. New York: Basic Books.

Bowlby, J. (1982). Attachment and loss: Retrospect and prospect. *The American Journal of Orthopsychiatry, 52*(4), 664-678.

Bowlby, J. (1988). *A secure base: parent-child attachment and healthy human development* Newyork: Basic Book.

Chaimongkol, N. N., & Flick, L. H. (2006). Maternal sensitivity and attachment security in Thailand: cross-cultural validation of western measure. *Journal of Nursing Measurement, 14*(1), 5-17.

Chambers, C. T., Craig, K. D., & Bennett, S. M. (2002). The impact of maternal behavior on children's pain experiences: an experimental analysis. *Journal of Pediatric Psychology*, *27*(3), 293-301. doi: 10.1093/jpepsy/27.3.293

Chambers, C. T., Giesbrecht, K., Craig, K. D., Bennett, S. M., & Huntsman, E. (1999). A comparison of faces scales for the measurement of pediatric pain: children's and parents' ratings.[see comment]. *Pain, 83*(1), 25-35.

Chambers, C. T., Hardial, J., Craig, K. D., Court, C., & Montgomery, C. (2005). Faces scales for the measurement of postoperative pain intensity in children following minor surgery. *Clinical Journal of Pain, 21*(3), 277-285.

Chambers, C. T., Reid, G. J., Craig, K. D., McGrath, P. J., & Finley, G. A. (1998). Agreement between child and parent reports of pain. *Clinical Journal of Pain, 14*(4), 336-342.

Clarke, S.-A., Sheppard, L., & Eiser, C. (2008). Mothers' explanations of communicating past health and future risks to survivors of childhood cancer. *Clinical Child Psychology and Psychiatry, 13*(1), 157-170. doi: 10.1177/1359104507080997

Collins, J. J., Byrnes, M. E., Dunkel, I. J., Lapin, J., Nadel, T., Thaler, H. T., et al. (2000). The measurement of symptoms in children with cancer. *Journal of Pain and Symptom Management, 19*(5), 363-377.

Collins, J. J., Devine, T. D., Dick, G. S., Johnson, E. A., Kilham, H. A., Pinkerton, C. R., et al. (2002). The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12. *Journal of Pain and Symptom Management, 23*(1), 10-16.

Craig, K. D., & Pillai Riddell, R. (2003). Social influences, culture and ethnicity. In P. J. McGrath & G. A. Finley (Eds.), *Pediatric pain: biological and socila context* (pp. 159-182). Seattle: IASP.

De Wolff, M. S., & van Ijzendoorn, M. H. (1997). Sensitivity and attachment: A meta-analysis on parental antecedents of infant attachment. *Child Development, 68*(4), 571.

DeVellis, R. F. (2003). *Scale Development* (2 ed.). Thousand Oaks, CA: Sage.

Docherty, S. L. (2003). Symptom experiences of children and adolescents with cancer *Annual Review of Nursing Research, 21*, 123-149.

Docherty, S. L., Sandelowski, M., & Preisser, J. S. (2006). Three months in the symptom life of a teenage girl undergoing treatment for cancer. *Research in Nursing & Health*, *29*(4), 294-310.

Dodd, M. J., Miaskowski, C., & Paul, S. M. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum, 28*(3), 465-470.

Dogan, O., Ertekin, S., & Dogan, S. (2005). Sleep quality in hospitalized patients. *Journal of Clinical Nursing, 14*(1), 107-113.

Ettinger, A. G., Bond, D. M., & Sievers, T. D. (2002). Chemotherapy. In C. R. Baggott, K. P. Kelly, D. Fochtman & G. V. Foley (Eds.), *Nursing Care of Children and Adolescents with Cancer 3rd* (pp. 133-176). Phiadelphia, PA: Saunders.

Erikson, E. (1963). *Childhood and Society*. New York: Norton.

Fearon, I., McGrath, P. J., & Achat, H. (1996). 'Booboos': the study of everyday pain among young children. *Pain, 68*(1), 55-62.

Forgeron, P. A., Finley, G. A., & Arnaout, M. (2006). Pediatric pain prevalence and parents' attitudes at a cancer hospital in Jordan. *Journal of Pain and Symptom Management, 31*(5), 440-448.

Gedaly-Duff, V., & Huff-Slankard, J. (1998). Sleep as an Indicator for Pain Relief in an Infant: A Case Study. *Journal of Pediatric Nursing, 13*(1), 32-40.

Gedaly-Duff, V., Lee, K. A., Nail, L. M., Nicholson, H. S., & Johnson, K. P. (2006). Pain, sleep disturbance, and fatigue in children with leukemia and their parents: a pilot study. *Oncology Nursing Forum, 33*(3), 641-646.

Gibson, F., Garnett, M., Richardson, A., Edwards, J., & Sepion, B. (2005). Heavy to carry: A survey of parents' and healthcare professionals' perceptions of cancer-related fatigue in childrenand young people. *Cancer Nursing, 28*(1), 27-35.

Goodenough, B., Thomas, W., Champion, G. D., Perrott, D., Taplin, J. E., von Baeyer, C. L., et al. (1999). Unravelling age effects and sex differences in needle pain: ratings of sensory intensity and unpleasantness of venipuncture pain by children and their parents. *Pain, 80*(1-2), 179-190.

Green, S. B., & Salkind, N. J. (2007). *Using SPSS for Windows and Macintosh: Analyzing and Understanding Data* (5 ed.). Upper Saddle River: Prentice Hall.

Halinski, R. S., & Feldt, L. S. (1970). The selection of variables in multiple regression analyses. *Journal of Educational Measurement, 7*(3), 151-158.

Hematology Department of the Queen Sirikit National Institute of Child Health. (2008). *The incidence rates of childhood cancer, Unpublished data*. The Queen Sirikit National Institute of Child Health. Bangkok.

Hinds, P. S., Hockenberry, M., Rai, S. N., Lijun, Z., Razzouk, B. I., McCarthy, K., et al. (2007). Nocturnal awakenings, sleep environment interruptions, and fatigue in hospitalized children with cancer. *Oncology Nursing Forum, 34*(2), 393-402.

Hinds, P. S., Hockenberry, M., Tong, X., Rai, S. N., Gattuso, J. S., McCarthy, K., et al. (2007). Validity and reliability of a new instrument to measure cancer-related fatigue in adolescents. *Journal of Pain and Symptom Management, 34*(6), 607-618.

Hockenberry, M., Hinds, P. S., Barrera, P., Bryant, R., Adams-McNeill, J., Hooke, C., et al. (2003). Three instruments to assess fatigue in children with cancer: the child, parent and staff perspective. *Journal of Pain and Symptom Management, 25*(4), 319-328.

Hockenberry, M., Hooke, M., Blinn, J., Birk, A., Plourd, D., & Lavery, A. (2006). You tell us. What are the different symptom patterns that you see in patients? *Oncology Nursing Society News, 19*(12), 6.

Hockenberry, M., & Hooke, M. C. (2007). Symptom clusters in children with cancer. *Seminars in Oncology Nursing, 23*(2), 152-157.

Hung, J.-W., Wu, Y.-H., & Yeh, C.-H. (2004). Comparing stress levels of parents of children with cancer and parents of children with physical disabilities. *Psycho-Oncology, 13*(12), 898-903.

Im, Y., Houck, G., Park, E., Oh, W., & Suk, M. (2008). *The Developmental Characteristics of Children with Atopic Diease and Their Mother-Child Relationship Pattern.* Unpublished manuscript. Oregon Health&Science University.

Imle, M. A., & Atwood, J. R. (1988). Retaining quality validity while gaining quantitative reliability and validity: Development of the Transition to Parenthood Concerns Scale. *Advances in Nursing Science, 11*(1), 61-75.

Jacob, E., Hesselgrave, J., Sambuco, G., & Hockenberry, M. (2007). Variations in pain, sleep, and activity during hospitalization in children with cancer. *Journal of Pediatric Oncology Nursing, 24*(4), 208-219. doi: 10.1177/1043454207299875

Jensen, M. P., Karoly, P., O'Riordan, E. F., Bland, J. F., & Burns, R. S. (1989). The subjective experience of pain. *Clinical Journal of Pain, 5,* 153-159.

Johnson, A. (2008). *Adolecents Recieving Chemotherapy: Sleep, Symptoms, and Quality of Life.* Docteral Doctoral Dissertation, Oregon Health & Science University, Portland, Oregon.

Jongudomkarn, D., Aungsupakorn, N., & Camfield, L. (2006). The meanings of pain: a qualitative study of the perspectives of children living with pain in north-eastern Thailand. *Nursing & Health Sciences, 8*(3), 156-163.

Kazak, A. E., & Baxt, C. (2007). Families of infants and young children with cancer: A post-traumatic stress framework. *Pediatric Blood & Cancer, 49*(S7), 1109-1113.

Keller, V. E. C., & Keck, J. F. (2006). An instrument for observational assessment of nausea in young children. *Pediatric Nursing 32*(5), 420-426.

Koolsu, P. (2001). *Fatigue in Luekemia Children Receiving Chemotherapy*. Master of Nursing Science, Chiang Mai University, Chiang Mai.

Krulik, T., Turner-Henson, A., Kanematsu, Y., Al-Ma'aitah, R., Swan, J., & Holaday, B. (1999). Parenting stress and mothers of young children with chronic illness: A cross-cultural study. *Journal of Pediatric Nursing, 14*(2), 130-140.

Laosombat, V., Wongchanchailert, M., Sattayasevana, B., Wiriyasateinkul, A., & Watana-Arepornchai, W. (2002). The treatment of children with Acute Lymphoblastic Leukemia in Thailand. *Medical Pediatric Oncology, 38,* 266-268.

Leonard, M. (2002). Biologic basis of cancer in children and adolescents. In C. R. Baggott, K. P. Kelly, D. Fochtman & G. V. Foley (Eds.), *Nursing Care of Children and Adolescents with Cancer*. Philadelphia: Saunders.

Lewin, D. S., & Dahl, R. E. (1999). Importance of sleep in the management of pediatric pain. *Journal of Developmental & Behavioral Pediatrics, 20*(4), 244-252.

Lenz, E. R., Pugh, L. C., Milligan, R. A., Gift, A. G., & Suppe, F. (1997). The Middle-Range Theory of Unpleasant Symptoms: An Update. *Advances in Nursing Science, 19*(3), 14-27.

Lenz, E., Suppe, F., Gift, A. G., Pugh, L. C., & Miligan, R. A. (1995). Collaborative development of middle-range nursing theories: Toward a theory of unpleasant symptoms. *Advances in Nursing Science Theory and Knowledge Development, 17*(3), 1-13.

Ljungman, G., Gordh, T., Sorensen, S., & Kreuger, A. (2000). Pain variations during cancer treatment in children: a descriptive survey. *Pediatric Hematology & Oncology, 17*(3), 211-221.

Ljungman, G., Kreuger, A., Gordh, T., & Sorensen, S. (2006). Pain in pediatric oncology: do the experiences of children and parents differ from those of nurses and physicians? *Upsala Journal of Medical Science, 111*(1), 87-96.

Lo, L., & Hayman, L. (1999). Parents associated with children in measuring acute delayed nuasea and vomiting *Nursing & Health Sciences, 1*(3), 155-161.

Lolekha, R., Chanthavanich, P., Limkittikul, K., Luangxay, K., Chotpitayasunodh, T., & Newman, C. J. (2004). Pain: a common symptom in human immunodeficiency virus-infected Thai children. *Acta Paediatrica, 93*(7), 891-898.

Lynn, M. R. (1986). Determination and quantification of content validity. *Nursing Research, 1*(2), 130-149.

Martinson, I. M., Leavitt, M., Liu, C.-Y., Armstrong, V., Hornberger, L., Zhang, J.-q., et al. (1999). Comparison of Chinese and Caucasian families caregiving to children with cancer at home: Part I. *Journal of Pediatric Nursing, 14*(2), 99-109.

Miller, D. E., & Kunce, J. T. (1973). Prediction and statistical overkill revisited. *Measurement and Evaluation in Guidance, 6*(3), 157-163.

Mills-Koonce, W. R., Gariepy, J. L., Sutton, K., & Cox, M. J. (2008). Changes in maternal sensitivity across the first three years: Are mothers from different attachment dyads differentially influenced by depressive symptomatology?

Attachment & Human Development, 10(3), 299-317. doi:10.1080/14616730802113612

Mindell, J. A., & Owens, J. A. (2003). *A clinical guide to pediatric sleep*. Philadelphia: Lippincott, Williams, and Wilkins.

Mizuta, I., Zahn-Waxler, C., Cole, P. M., & Hiruma, N. (1996). Cross-cultural study of preschoolers' attachment: security and sensitivity in Japanese and US dyads. *International Journal of Behavioral Development, 19*(1), 141-160.

Moran, G., Pederson, D. R., Pettit, P., & Krupka, A. (1992). Maternal sensitivity and infant-mother attachment in a developmentally delayed sample. *Infant Behavior and Development*, *15*(4), 427-442.

Negayama, K. (1999). Development of reactions to pain of inoculation in children and their mothers. *International Journal of Behavioral Development, 23*(3), 731-746.

Nelson, A. M. (2002). A Metasynthesis: Mothering other-than-normal children. *Qual Health Res, 12*(4), 515-530. doi: 10.1177/104973202129120043

Pharnit, J. (2004). *Illness experience of school age patients with leukemia.* Master of Nursing Science, Chulalongkorn University, Bangkok.

Pederson, D. R., & Moran, G. (1995b). Appendix B: Maternal Behavior Q-Set. In E. Waters, B. E. Vaughn, G. Posada & Kondo-Ikemura (Eds.), *Caregiving, cultural, and cognitive perspective on secure-base behavior and working models: New growing points of attachment theory and research* (Vol. 60, pp. 247-254): Monograph of the Society for Research in Child Development.

Pederson, D. R., Moran, G., Sitko, C., Campbell, K., Ghesquire, K., & Acton, H. (1990). Maternal sensitivity and the security of infant-mother attachment: A Q-sort study. *Child Development, 61*(6), 1974.

Piaget, J. (1955). The growth of logical thinking from childhood to adolescence. In H. E. Gruber & J. J. Voneche (Eds.), The Essential Piaget (pp. 405-444). New York: Basic Books.

Powers, S. W., Patton, S. R., Byars, K. C., Mitchell, M. J., Jelalian, E., Mulvihill, M. M., et al. (2002). Caloric intake and eating behavior in infants and toddlers with cystic fibrosis. *Pediatrics, 109*(5), e75-. doi: 10.1542/peds.109.5.e75

Respironics Mini Mitter. (2006). *Instruction manual actiwatch communication and sleep analysis software version 5.0*. Bend, OR.

Riddell, R., & Chambers, C. T. (2007). Parenting and pain during infancy. In K. J. S. Anand & B. J. Stevens (Eds.), *Pain Research and Clinical Management: Pain in Neonates and Infants* (3 ed., pp. 289-298). Edinburgh: ELSEVIER.

Riddell, R. R., Stevens, B. J., Cohen, L. L., Flora, D. B., & Greenberg, S. (2007). Predicting maternal and behavioral measures of infant pain: The relative contribution of maternal factors. *Pain*, *133*(1-3), 138-149.

Ries, L. A. G., Melbert, D., Krapcho, M., Stinchcomb, D. G., Howlader, N., Horner, M. J., et al. (2007). SEER Cancer Statistics Review 1975-2005

National Cancer Institute. Retrieved from

doi:http://seer.cancer.gov/csr/1975_2005/results_merged/sect_28_childhood_cancer.pdf

Roy, C. A., & Russell, R. C. (2000). Case study: possible traumatic stress disorder in an infant with cancer. *Journal of the American Academy of Child & Adolescent Psychiatry, 39*(2), 257-260.

Ryan-Murray, J., & Petriccione, M. M. (2002). Central nervous system tumors. In C. R. Baggott, K. P. Kelly, D. Fochtman & G. V. Foley (Eds.), *Nursing care of children and adolescents with cancer 3rd* (pp. 503-523). Philadelphia, PA: Saunders.

Sadeh, A. (2004). A brief screening questionnaire for infant sleep problems: validation and findings for an internet sample. *Pediatrics, 113*(6), e570-577. doi: 10.1542/peds.113.6.e570

Shields, L., & King, S. (2001). Qualitative analysis of the care of children in hospital in four countries[mdash]Part 2. *Journal of Pediatric Nursing, 16*(3), 206-213.

Shin, H., Young-Joo, P., & Mi Ja, K. (2006). Predictors of maternal sensitivity during the early postpartum period. *Journal of Advanced Nursing, 55*(4), 425-434.

Skolin, I., Koivisto Hursti, U.-K., & Wahlin, Y. B. (2001). Parents' perception of their child's food intake after the start of chemotherapy. *Journal of Pediatric Oncology Nursing, 18*(3), 124-136. doi: 10.1177/104345420101800305

Stanford, E. A., Chambers, C. T., & Craig, K. D. (2006). The role of developmental factors in predicting young children's use of a self-report scale for pain. *Pain, 120*, 16-23.

Svavarsdottir, E. K. (2005). Caring for a child with cancer: a longitudinal perspective. *Journal of Advanced Nursing, 50*(2), 153-161. doi: doi:10.1111/j.1365-2648.2005.03374.x

Sweet, S. D., McGrath, P. J., & Symons, D. (1999). The roles of child reactivity and parenting context in infant pain response. *Pain, 80*(3), 655-661.

Tarbell, S. E., Thomas Cohen, I., & Marsh, J. L. (1992). The Toddler-Preschooler postoperative pain scale: an observational scale measuring postoperative pain in children aged 1-5. Preliminary report. *Pain, 50*(3), 273-280.

Thompson, R. A. (1999). Early attachment and later development. In J. Cassidy & P. R. Shaver (Eds.), *Hand book of Attachment: Theory, Research, and Clinical Applications* (pp. 265-286). New York: The Guilford Press.

Van Cleve, L., Bossert, E., Beecroft, P., Adlard, K., Alvarez, O., & Savedra, M. (2004). The pain experience of children with leukemia during the first year after diagnosis. *Nursing Research, 53*(1-10).

Van Cleve, L., & Savedra, M. (1993). Pain location, validity, and reliability of body outline marking by hospitalized 4-7 year-old children. *Pediatric Nursing, 19*(3), 217-220.

Van Dongen-Melman, J. E. W. M., Van Zuuren, F. J., & Verhulst, F. C. (1998). Experiences of parents of childhood cancer survivors: a qualitative analysis. *Patient Education and Counseling, 34*, 185-200.

Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL in pediatric cancer. *Cancer, 94*(7), 2090-2106.

Varni, J. W., Limbers, C. A., & Burwinkle, T. M. (2007). How young can children reliably and validly self-report their health-related quality of life?: An analysis of

8,591 children across age subgroups with the PedsQL 4.0 generic core scales. *Health and Quality of Life Outcomes, 5*, 1. doi:10.1186/1477-7525-5-1

von Baeyer, C. L., Piira, T., Chambers, C. T., Trapanotto, M., & Zeltzer, L. K. (2005). Guidelines for the cold pressor task as an experimental pain stimulus for use with children. *Journal of Pain, 6*(4), 218-227.

von Baeyer, C. L., & Spagrud, L. J. (2007). Systematic review of observational (behavioral) measures of pain for children and adolescents aged 3 to 18 years. *Pain, 127*(1-2), 140-150.

Walco, G. A., Conte, P. M., Labay, L. E., Engel, R., & Zeltzer, L. K. (2005). Procedural distress in children with cancer: self-report, behavioral observations, and physiological parameters. *Clinical Journal of Pain, 21*(6), 484-490.

Wang, X. S., Tang, J. Y., Zhao, M., Guo, H., Mendoza, T., & Cleeland, C. S. (2003). Pediatric cancer pain management practices and attitudes in China. *Journal of Pain and Symptom Management, 26*(2), 748-759. doi: 10.1016/S0885-3924(03)00242-2

Ward, T. M., Gay, C., Alkon, A., Anders, T. F., & Lee, K. A. (2008). Nocturnal sleep and daytime nap behaviors in relation to salivary cortisol levels and temperament in preschool-age children attending child care. *Biological Research for Nursing, 9*(3), 244-253. doi: 10.1177/1099800407310158

Westlake, S. K., & Bertolone, K. L. (2002). Leukemia. In C. R. Baggott, K. P. Kelly, D. Pochtman & G. V. Foley (Eds.), *Nursing Care of Children and Adolescents with Cancer 3rd* (pp. 466-490). Philadelphia, PA: Saunders.

Wiangnon, S., Kamsa-Ard, S., Jetsrisuparb, A., Sriplung, H., Sontipong, S., Sumitsawan, Y., et al. (2003). Childhood cancer in Thailand. *Asian Pacific Journal of Cancer Prevention, 4*, 337-343.

Williams, P. D., Schmideskamp, J., Ridder, E. L., & Williams, A. R. (2006). Symptom monitoring and dependent care during cancer treatment in children: pilot study. *Cancer Nursing, 29*(3), 189-197.

Woodgate, R. L., & Degner, L. F. (2004). Cancer symptom transition periods of children and families. *Journal of Advanced Nursing, 46*(4), 358-368. doi: doi:10.1111/j.1365-2648.2004.03002.x

Yeh, C. H., Chen, M. L., Li, W., & Chuang, H. L. (2001). The Chinese version of the Parenting Stress Index: a psychometric study. *Acta Paediatrica, 90*(12), 1470-1477. doi:10.1111/j.1651-2227.2001.tb01615.x

Zahr, L. K., & El-Haddad, A. (1998). Temperament and chronic illness in Egyptian children. *International Journal of Intercultural Relations, 22*(4), 354-465.

Zahr, L. K., Khoury, M., & Saoud, N. B. (1994). Chronic illness in Lebanese preschoolers: Impact of illness and child temperament on the family. *The American Journal of Orthopsychiatry, 64*(3), 396-403.

Zernikow, B., Meyerhoff, U., Michel, E., Wiesel, T., Hasan, C., Janssen, G., et al. (2005). Pain in pediatric oncology - children's and parents' perspectives. *European Journal of Pain, 9*(4), 395-406.

Zisk, R. Y., Grey, M., MacLaren, J. E., & Kain, Z. N. (2007). Exploring sociodemographic and personality characteristic predictors of parental pain perceptions. *Anesthesia & Analgesia*, *104*(4), 790-798. doi: 10.1213/01.ane.0000257927.35206.c1

Zisk, R. Y., Grey, M., Medoff-Cooper, B., & Kain, Z. N. (2007). Accuracy of parental-global-impression of children's acute pain. *Pain Management Nursing*, *8*(2), 72-76.

List of Appendices

Appendix A: Informed Consent

IRB #4675

OREGON HEALTH & SCIENCE UNIVERSITY

Consent and Authorization Form

TITLE: Thai Mothers' Report of Symptoms in their Young Children Receiving Chemotherapy

PRINCIPAL INVESTIGATOR:	Vivian Gedaly-Duff, DNSc, RN +1-503-494-3866
CO-INVESTIGATORS:	Yupaporn Pongsing, MNS, RN 083-758-1581 Somjai Kanjanapongkul, MD 02-3548433 Ruksamon Srangnok, MNS, RN 081-711-9984

INTRODUCTION

You and your child are being invited to participate in this research study because you are a mother with young child ages 1 to 5 years diagnosed with cancer.

WHY IS THE STUDY BEING DONE?

Researchers at Queen Sirikit National Institute of Child Health and at Oregon Health &Science University in the United States are conducting this research study. The purpose of this study is to learn mothers' report of symptoms such as pain, fatigue and nausea and vomiting, in their young children with cancer during chemotherapy. We want to also learn how mothers manage their young children's symptoms and their perceptions of the effectiveness of symptom management. In addition, we want to know how mothers' characteristics and well being such as maternal sensitivity and maternal stress influence mothers' abilities to report their young children's symptoms. We hope with this information we can find ways to improve management of symptom in young children during chemotherapy treatments.

HOW MANY PEOPLE WILL BE IN THE STUDY?

We plan to have 50 mothers and 50 children in this study. Mothers and their young children with cancer ages 1 to 5 years receiving chemotherapy at the Queen Sirikit National Institute of Child Health will be invited to be in this study.

WHAT WILL I NEED TO DO IF I AM IN THE STUDY?

Your participation will include:

a) Your agreement to take part in the study;
b) Permission to review your child's medical record for information about type of cancer, medical plan of care, laboratories and the type of chemotherapy protocol.
c) Answering paper questionnaires about your child sleep, symptoms (e.g.pain, fatigue, vomiting), maternal sensitivity, and maternal stress. This will take about 20 to 45 minutes.
d) While in hospital or at home, we would like your child to wear a sleep watch and you will answer questions in a diary about your child's sleep and symptoms for 3 days. The sleep watch will record your child's sleep activity continuously for 3 days. It can be worn during showers and washing up. The diaries will ask questions about your child's symptoms, and methods used to relieve symptoms. The diaries will take about

8-15 minutes to fill out in the morning and evening. The research nurse will call you to answer any questions you have, remind you to fill out your diaries, and make sure the watch is working.

e) Return the sleep watch and the diary. The research nurse will meet with you again for 30 minutes at this time to ask some more questions about your child's symptoms.

If you have any questions regarding this study now or in the future, please contact Yupaporn Pongsing at 083-758-1581

HOW LONG WILL I BE IN THE STUDY?

You and your child will be in this study for 4 days. You will be asked to meet the research nurse two times, once before and once after the 3 days of reporting and wearing the watch. The two visits will take place while you are at inpatient ward or the outpatient clinic.

HOW WILL MY PRIVACY BE PROTECTED?

We will protect your privacy in following ways:

1. Your name and your child's name will not be used. Instead, we will identify you by coding your name with a number.
2. Only Yupaporn Pongsing, Vivian Geadaly-Duff (investigators from OHSU, U.S.A), Dr. Somjai Kanjanapongkul and Ruksamon Srangnok (investigator from the Queen Sirikit National Institute of Child Health) will be able to access your research information.

The specific health information we will collect from you will be limited to your child's diagnosis, medical treatment plan, laboratories, and your responses to the questions in the questionnaires and interviews with investigator. The purposes of our use and disclosure of this health are described in the purpose section of this Consent & Authorization Form.

The persons who are authorized to use and/or disclose your health information are all of the investigators who are listed on page one of this Research Consent Form and the OHSU Institute Review Board.

We cannot guarantee absolute confidentiality. You and your child's personal information may be disclosed if required by law. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the Ethical Review Committee for Research in Human Subject of the Queen Sirikit National Institute of Child Health and Department of Medical Service, Ministry of Public Health, Thailand; the OHSU Knight Cancer Institute, the National Cancer Institute, the OHSU Institutional Review Broad and the Office of Human Research Protections, U.S.A.

This authorization will expire and we will no longer keep protected health information that we collect from you in this study when the study is completed.

WHAT ARE THE RISKS OF THE STUDY?

There are no anticipated physical risks involved with this study. The child may feel some bother from the sleep watch but this usually goes away quickly. If it is uncomfortable you may remove the watch.

Some of the questions may seem personal or embarrassing. You may refuse to answer any of questions you do not wish to answer. Counseling is available if you experience distress. If you need to talk to someone about the difficulty you are having, you can call a researcher nurse, who can refer you to resources for families.

In the unlikely event that information is discovered regarding abuse or neglect of a child, the research nurse is legally required to report that information to the Ministry of Social Development and Human Security. If that situation should arise we will inform you before the report is made. A research nurse will be available to provide you with support and referrals if requested.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

You may or may not personally benefit from being in this study. You will see your child's sleep pattern during 3 days. However, this pattern is not used for diagnosis of a sleep problem but it will give you the idea about his/her sleep pattern. Furthermore, by serving as a participant, you may help us learn how to improve care for young children with cancer and their mothers in the future.

WHAT OTHER OPTIONS ARE THERE?

You may choose not to be in the study and this will not affect the care you receive at the Queen Sirikit National Institute of Child Health.

WHAT ARE THE COSTS?

There is no cost to you for participation in this study. Your child will receive a toy. You will receive 300 baht ($10) to compensate of your time for answering questionnaires and being interviewed by researcher.

LIABILITY

It is not the policy of the Queen Sirikit National Institute of Child Health and The U.S. Department of Health and Human service, or any agency funding the research project in which you are participating, to compensate or provide medical treatment for human subject in the events the research results in physical injury.

If you suffer any injury and damage from this research project, you have the right to bring legal action. You have not waived you legal right by signing this form. For clarification on this subject, or if you have further questions, please call the Ethical Review Committee for Research in Human Subject of the Queen Sirikit National Institute of Child Health at 02-354-8333 Ext. 5211 to 5212 or the OHSU Research Integrity Office at+1-503-494-7887.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

You do not have to join this or any research study. If you do join, and later change your mind, you may stop at any time. If you decide not to participate or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

You can stop participating in the study at any time. However, if you decide to stop participating in the study, the sleep watch must be returned. The research nurse will come to the inpatient ward or outpatient clinic to pick up it.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

You may contact Yupaporn Pongsing at 083-758-1581 any time you have questions about the study.

You will be informed of any new findings developed during the course of this study that may change your feelings about being in the study.

If you have any questions regarding you rights as a research subject, you may contact the Ethical Review Committee for Research in Human Subject of the Queen Sirikit National Institute of Child Health at 02-354-8333 Ext 5211 to 5212 or the OHSU Research Integrity Office at 1-503-494-7887.

SIGNATURES

We will give you a copy of this consent form. Your signatures below indicate that you have read entire from and agree to be in this study.

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
PHONE NUMBER (503) 494-7887
CONSENT/AUTHORIZATION FORM
APPROVAL DATE

Mar. 8, 2009

Do not sign this form after the
Expiration date of: 12/09/2009

Mother Signature Date

Witness Signature Date

Witness Signature Date

Investigator’s Signature Date

มหาวิทยาลัยสุขภาพและวิทยาศาสตร์โอเรกอน
แบบคำชี้แจงอาสาสมัครและแบบยินยอมด้วยความสมัครใจของอาสาสมัคร

ชื่อโครงการวิจัย: อาการของเด็กเล็กระหว่างได้รับยาเคมีบำบัดจากการรายงานของมารดาไทย

ผู้ควบคุมวิทยานพนธ์: ดร. วิเวียน กอดาลี-ดัฟฟ์, รองศาสตรจารย์ โทร. (001) 503-494-3866

ผู้ดำเนินการวิจัย: นางสาวยุพาภรณ์ พงษ์สิงห์, พยาบาลวิชาชีพ โทร. 083-7581-581
แพทย์หญิงสมใจ กาญจนาพงศ์กุล, กุมารแพทย์ โทร. 02-354-8333 ต่อ 2217
นางสาวรักษมน สร้างนอก, พยาบาลวิชาชีพ โทร 081-711-9984

บทนำ: ท่านและลูกของท่านได้รับการเชิญเข้าร่วมโครงการวิจัยครั้งนี้ เนื่องจากท่านเป็นมารดาของผู้ป่วย เด็กเล็กโรคมะเร็งอายุ 1 ถึง 5 ปี

วัตถุประสงค์:

โครงการวิจัยนี้เป็นโครงการวิจัยร่วมระหว่างผู้วิจัยของสถาบันสุขภาพเด็กแห่งชาติมหาราชินีและนักศึกษาของมหาวิทยาลัยสุขภาพและวิทยาศาสตร์โอเรกอน ประเทศสหรัฐอเมริกา วัตถุประสงค์ของการศึกษาครั้งนี้ เพื่อศึกษาอาการของผู้ป่วยเด็กเล็ก(เช่น อาการปวด อ่อนแรง และคลื่นไส้ อาเจียน) ระหว่างได้รับยาเคมีบำบัด โดยการรายงานของมารดา และความคิดเห็นของมารดา ในเรื่องการดูแลอาการผู้ป่วยเด็กเพื่อบรรเทาอาการ ไม่สุขสบายต่างๆ นอกจากนี้ผู้วิจัยยังต้องการศึกษา คุณลักษณะของ มารดา เช่น ความเครียด การตอบสนองของมารดาต่อบุตรว่ามีผลต่อ ความสามารถของมารดาในการรายงาน อาการของบุตรหรือไม่ ผู้วิจัยคาดหวังว่าข้อมูลที่ได้รับจากท่านจะนำใช้เป็นแนวทาง ในการให้การช่วยเหลือและ ดูแลผู้ป่วยเด็กเล็ก โรคมะเร็งขณะได้รับยาเคมีบำบัด

จำนวนผู้จะเข้าร่วมวิจัย

ผู้วิจัยวางแผนจะเก็บข้อมูลกับมารดาจำนวน 55 คนและผู้ป่วยเด็กเล็ก อายุ 1 ถึง 5 ปี จำนวน 55 คน มารดาและผู้ป่วยเด็กเล็กทุกคน ที่มาได้รับรักษาด้วยยาเคมีบำบัดที่สถาบันสุขภาพเด็กแห่งชาติมหาราชินี จะได้รับการเชิญชวนให้เข้าร่วมการวิจัยนี้

ขั้นตอนการเข้าร่วมวิจัย: การเข้าร่วมวิจัยของคุณประกอบด้วย

1) ท่านยินดีเข้าร่วมการวิจัย

2) อนุญาตให้ผู้วิจัยเก็บข้อมูลการบันทึกเกี่ยวกับการรักษาของลูกท่าน เกี่ยวกับชนิดของโรคมะเร็ง การวางแผนการรักษา ชนิดของ การรักษาด้วยยาเคมีบำบัด และผลการตรวจทางห้องปฏิบัติการ

3) การตอบแบบสอบถามเกี่ยวกับการนอนหลับ อาการต่างๆ (เช่น ปวด อ่อนแรง อาเจียน) การตอบสนองของแม่ และความเครียดของแม่ จะใช้เวลาประมาณ 20 ถึง 45 นาที

4) ขณะที่อยู่ในหอผู้ป่วยใน หรือ คลินิกโรคเลือด ลูกของท่านจะได้รับการสอบถามให้ยินยอมด้วยความสมัครใจ เพื่อสวมนาฬิกาวัดการนอนหลับ และท่านจะได้รับการสอบถามให้ตอบคำถาม ในสมุดบันทึกอาการ ประจำวันเกี่ยวกับ การนอนหลับและอาการต่างๆของลูก เป็นเวลา 3 วัน นาฬิกาวัดการนอนหลับ จะบันทึกการนอนหลับของลูกท่าน อย่างต่อเนื่อง 3 วัน ลูกของท่านสามารถใส่ ขณะอาบน้ำและ เช็ดตัวได้ สมุดบันทึกอาการประจำวันจะถามคำถาม เกี่ยวกับอาการของลูกท่าน และวิธีในการช่วยบรรเทาอาการนั้นๆ ท่านจะได้รับการร้องขอ ให้บันทึกอาการของลูกท่าน ในเวลาตอนเช้าและตอนหัวค่ำ ซึ่งจะใช้เวลาในแต่ละครั้งประมาณ 8-15 นาที ผู้วิจัยจะโทรศัพท์ สอบถามการตอบแบบสอบถามของท่านในการใช้สมุดบันทึกอาการประจำวัน และสอบถามการใช้นาฬิกาวัดการนอนหลับ

5) หลังจากบันทึกอาการของลูกท่านครบ 3 วัน ท่านจะได้รับการร้องขอให้ส่งนาฬิกาวัดการนอนหลับ และสมุดบันทึก อาการประจำวันคืนแก่ผู้วิจัย และผู้วิจัยจะขอพบท่านอีกครั้งประมาณ 30 นาที เพื่อสอบถาม คำถามต่างๆ เพิ่มเติมที่เกี่ยวกับ อาการและการดูแลลูกของท่าน

หากท่านมีคำถามเกี่ยวกับการวิจัยเรื่องนี้ กรุณาติดต่อ ยุพาภรณ์ พงษ์สิงห์ โทรศัพท์ 083-7581-581

ระยะเวลาเข้าร่วมการวิจัย

ท่านจะเข้าร่วมการวิจัย 4 วัน ท่านจะพบผู้วิจัยประมาณ 2 ครั้ง คือ ก่อนและหลังการบันทึกอาการของลูก ในสมุดบันทึกอาการประจำวัน

ความลับของข้อมูล

ผู้วิจัยจะเก็บความลับของท่านโดยชื่อของท่านและชื่อของลูกท่านจะไม่ถูกนำมาใช้ ผู้วิจัยจะใช้หมายเลข แทนที่ชื่อของท่านและลูก มีเพียงทีมผู้วิจัย คือยุพาภรณ์ พงษ์สิงห์ ดร. วิเวียน กอดาลี-ดัฟฟ์ แพทย์หญิงสมใจ กาญจนาพงศ์กุล และ คุณรักษมน สร้างนอก จะสามารถนำข้อมูลของท่านมาใช้ได้ผู้วิจัยจะเก็บรวบรวมเฉพาะข้อมูลเกี่ยวกับด้านสุขภาพของลูกท่าน การวินิจฉัยโรค แผนการรักษา และผลการตรวจทางห้องปฏิบัติการ และ การตอบแบบสอบถามและการสัมภาษณ์ของท่าน วัตถุประสงค์ของการใช้ ข้อมูลสุขภาพนี้ ถูกอธิบายไว้ในส่วนวัตถุประสงค์แล้ว ผู้วิจัยไม่สามารถรับประกันการเก็บความลับได้อย่างสมบูรณ์ ข้อมูลของท่านและลูกของท่านอาจได้รับการเปิดเผยตามข้อบังคับของกฎหมายหน่วยงานที่เกี่ยวข้องอาจตรวจสอบหรือมีสำเนาข้อมูลการบันทึกการวิจัยที่เกี่ยวกับท่านเพื่อการรับรองคุณภาพ เช่น คณะกรรมการการพิจารณาวิจัยในมนุษย์ของสถาบันสุขภาพเด็กแห่งชาติมหาราชินี กรมการแพทย์และคณะกรรมการการพิจารณาวิจัยในมนุษย์ของ มหาวิทยาลัยสุขภาพ และวิทยาศาสตร์โอเรกอน

ความเสี่ยงและความไม่สะดวกอย่างอื่น

การเข้าร่วมวิจัยครั้งนี้ไม่คาดว่าจะเกิดความเสี่ยงใดแก่ท่าน แต่ท่านอาจใช้เวลาในการตอบแบบสอบถามและ ลูกของท่านอาจรู้สึกไม่สุขสบาย จากการใส่นาฬิกาวัดการนอนหลับ ซึ่งในขณะที่ลูกของท่านตื่นและ ลูกรู้สึกรำคาญ หรือมีอาการคัน ท่านสามารถให้ลูกของท่านถอดนาฬิกาและใส่นาฬิกาเฉพาะเวลาที่ ลูกนอนหลับได้ ในกรณีที่ท่านหรือลูกไม่ต้องการเข้าร่วมการวิจัย ท่านสามารถถอดนาฬิกาได้ตลอดเวลาในบางคำถามอาจเป็นคำถามที่เป็นส่วนบุคคล ท่านอาจไม่ตอบคำถามที่ไม่ต้องการตอบ ผู้วิจัยจะประสานกับผู้ให้คำปรึกษาเพื่อให้การช่วยเหลือท่านในกรณีที่ท่านรู้สึกเครียดจากการตอบแบบสอบถามในงานวิจัยนี้ ในกรณีที่ผู้วิจัยพบข้อมูลการทำร้ายเด็ก ผู้วิจัยจำเป็นต้องรายงานหน่วยงานที่เกี่ยวข้องตามกฎหมาย ถ้าเกิดกรณีดังกล่าว ผู้วิจัยจะแจ้งใหท่านทราบก่อน

ประโยชน์

ท่านอาจจะไม่ได้รับประโยชน์โดยตรงจากการเข้าร่วมการวิจัยครั้งนี้แต่ท่านจะได้เห็นรูปแบบการนอนหลับของลูกท่าน อย่างไรก็ตามรูปแแบบการนอนหลับนี้ไม่สามารถใช้ในการวินิจฉัยปัญหาการนอนหลับ ข้อมูลของท่านจะเป็นประโยนช์ในการปรับปรุงการให้การดูแลมารดาและผู้ป่วยเด็กเล็กโรคมะเร็งที่ได้รับ ยาเคมีบำบัดในอนาคต

ทางเลือกอื่น

ท่านอาจตัดสินใจไม่เข้าร่วมการวิจัยครั้งนี้ และการตัดสินใจของท่านจะไม่มีผลต่อการรักษาพยาบาลที่ลูกของท่านจะได้รับต่อไป

ค่าใช้จ่าย

ท่านไม่ต้องเสียค่าใช้จ่ายใดๆทั้งสิ้น ลูกท่านจะได้รับของเล่นจำนวน 1 ชิ้นและท่านจะได้รับเงินจำนวน 300 บาท เพื่อชดเชยการเสียเวลาของท่านในการตอบแบบสอบถามและแบบสัมภาษณ์ในการเข้าร่วมโครงการวิจัยนี้

ผู้รับผิดชอบ

คณะกรรมการการพิจารณาวิจัยในมนุษย์ของ สถาบันสุขภาพเด็กแห่งชาติมหาราชินี และคณะกรรมการ การพิจารณาวิจัย ในมนุษย์ของมหาวิทยาลัยสุขภาพและวิทยาศาสตร์โอเรกอน ไม่มีนโยบายที่จะมอบ ค่าตอบแทนหรือให้การรักษา ในกรณีที่ท่านได้รับอันตรายจากการเข้าร่วมวิจัย ถ้าท่านได้รับอันตรายจากการเข้าร่วมวิจัย ท่านสามารถฟ้องร้องได้ตามกฏหมาย ซึ่งการลงลายมือชื่อของท่าน ในยินยอมเข้าร่วมการวิจัยนี้ ไม่มีผลลิดรอนสิทธิของท่านตามกฏหมายแต่อย่างใด ท่านสามารถติดต่อ สอบถามข้อมูลเพิ่มเติมได้ที่ สำนักงาน คณะกรรมการการพิจารณาวิจัยในมนุษย์ของสถาบันสุขภาพเด็ก แห่งชาติมหาราชินี ที่หมายเลขโทรศัพท์ 02-354-8333 ต่อ 5210 ถึง 5211 หรือ คณะกรรมการสนับสนุน การวิจัยแห่งมหาวิทยาลัยสุขภาพและ วิทยาศาสตร์โอเรกอน ที่หมายเลขโทรศัพท์ 001-503-494-7887

สิทธิของท่าน

ท่านไม่จำเป็นต้องเข้าร่วมการวิจัยนี้ และหากท่านตัดสินใจเข้าร่วมวิจัยแล้วหลังจากนั้น ท่านเปลี่ยนใจภายหลัง ท่านสามารถหยุดการเข้าร่วมวิจัย ได้ตลอดเวลา การไม่เข้าร่วมการวิจัยครั้งนี้ไม่มีผลต่อการรับบริการการรักษา ที่ลูกของท่านจะได้รับต่อไป ท่านสามารถหยุดการเข้าร่วมวิจัยได้ตลอดเวลา อย่างไรก็ตาม ถ้าท่านตัดสินใจที่จะไม่เข้าร่วมการวิจัย ท่านต้องส่งมอบนาฬิกาวัดการนอนหลับคืนให้กับผู้วิจัย

<u>สอบถามเพิ่มเติม</u>

ท่านสามารถติดต่อสอบถามข้อมูลต่างๆเกี่ยวกับการวิจัยนี้ที่ผู้วิจัย นางสาวยุพาภรณ์ พงษ์สิงห์ หมายเลขโทรศัพท์ 081-7581-581 ได้ตลอดเวลา ท่านจะได้รับการแจ้งหากมีการเปลี่ยนแปลงขั้นตอนการดำเนินการวิจัย หากท่านมีข้อสงสัยเพิ่มเติมเกี่ยวกับ สิทธิของท่านสามารถติดต่อสำนักงาน คณะกรรมการการพิจารณาวิจัยในมนุษย์ของ สถาบันสุขภาพเด็กแห่งชาติมหาราชินี ที่หมายเลขโทรศัพท์ 02-354-8333 ต่อ 5210 ถึง 5211 หรือ สนับสนุนการวิจัย แห่งมหาวิทยาลัยสุขภาพและ วิทยาศาสตร์โอเรกอน ที่ หมายเลขโทรศัพท์ 001-503-494-7887

<u>ลายมือชื่อ</u>

ผู้วิจัยจะมอบสำเนาแบบยินยอมความสมัครใจของอาสาสมัคร ลายมือชื่อของท่านที่ได้ลงนามด้านล่างแสดงถึงว่าท่านได้อ่านเอกสารนี้ทั้งหมดและยินยอมเป็นอาสาสมัครของโครงการวิจัยนี้ด้วยความสมัครใจ

____

ลายมือชื่อมารดา วันที่

____

ลายมือชื่อพยาน วันที่

____

ลายมือชื่อพยาน วันที่

____

ลายมือชื่อผู้วิจัย วันที่

สำเนา สำหรับ___อาสาสมัคร
___ผู้วิจัย

Appendix B: Demographic Questionnaire

Family and Child Demographics

We appreciate you telling us about your child and family. In order to be able to describe the children and families who take part in this study, we are asking the following questions.

Part I: Data of the child

1. Child's age _________Years ____________Months
2. Child's Gender ☐ Boy ☐ Girl
3. Does your child know he/she has cancer? ☐ No ☐ Yes

   3.1 What does your child call his/her disease? Please specify_________________
5. How long was your child diagnosed with cancer?

   _________Years________Months
6. What hospital does your child with cancer usually receive treatment?
   - ☐ The Queen Sirikit National Institute of Child Health
   - ☐ Other hospitals, please specify____________________________

Part II: Data of Mother and Family Members

1. Mother's age______________________
2. Mother's education Level
   - ☐ No school
   - ☐ Primary school
   - ☐ Secondary school
   - ☐ High school
   - ☐ Partial College
   - ☐ College/graduated, Please specify______________________________
3. Mother's occupation__________________
4. Father's age_________________________

5. Father’s education Level
   - ☐ No school
   - ☐ Primary school
   - ☐ Secondary school
   - ☐ High school
   - ☐ Partial College
   - ☐ College/graduated, Please specify ________________________________
6. Father’s occupation_____________________
7. Number of children _____________________

   Please specify gender and age ____

____

8. Mother’s marital status
   - ☐ Single
   - ☐ Married
   - ☐ Divorced
   - ☐ Separation
   - ☐ Remarried
   - ☐ Other: Please Specify___________________________
9. Structure of your family
   - ☐ Nuclear family
   - ☐ Extended family
10. Total income of the family_______________________________
11. Living area of the family
    - ☐ Bangkok
    - ☐ Other city, please specify__________________________

12. Do other family members participate in the caregiving tasks of your child with cancer?

☐ No ☐ Yes, please specify______________________________

13. Does mother have any health problem?

☐ No ☐ Yes, please specify___________________________

ข้อมูลส่วนบุคคล

ผู้วิจัยขอขอบคุณท่านในการให้ข้อมูลเกี่ยวลูกของท่านและครอบครัวของท่าน ข้อคำถามต่อไปนี้จะใช้เพื่ออธิบายลักษณะของเด็กและครอบครัวที่เข้าร่วมในการวิจัย

ส่วนที่ 1 ข้อมูลของผู้ป่วยเด็ก

1. อายุของเด็ก_______ปี ________เดือน
2. เพศ ☐ ชาย ☐ หญิง
3. เด็กทราบวินิจฉัยโรคหรือไม่ ☐ไม่ทราบ ☐ทราบ

3.1 เด็กเรียกโรคว่าอย่างไร โปรดระบุ____________________

4. เด็กได้รับการวินิจฉัยโรคตั้งแต่เมื่อไหร่ _______ปี_______เดือน

5. ปกติเด็กเข้ารับการรักษาโรคมะเร็งที่ไหน

☐ สถาบันสุขภาพเด็กแห่งชาติมหาราชินี
☐ โรงพยาบาลอื่น โปรดระบุ________________________

ส่วนที่ 2 ข้อมูลของมารดาและสมาชิกในครอบครัว

1. อายุของมารดา_________ปี_________เดือน
2. ระดับการศึกษาของมารดา

☐ ไม่ได้เข้าเรียนหนังสือ
☐ ประถมศึกษา
☐ มัธยมศึกษาตอนต้น
☐ มัธยมศึกษาตอนปลาย
☐ ระดับประกาศนียบัตร โปรดระบุสาขา_________________
☐ ปริญญาตรี โปรดระบุสาขา_______________
☐ สูงกว่าปริญญาตรี

โปรดระบุระดับการศึกษาและสาขา_____________________

3. อาชีพของมารดา______________________

4. อายุของบิดา___________________

5. ระดับการศึกษาของบิดา

☐ ไม่ได้เข้าเรียนหนังสือ

☐ ประถมศึกษา

☐ มัธยมศึกษาตอนต้น

☐ มัธยมศึกษาตอนปลาย

☐ ระดับประกาศนียบัตร โปรดระบุสาขา_________________

☐ ปริญญาตรี โปรดระบุสาขา_______________

☐ สูงกว่าปริญญาตรี

โปรดระบุระดับการศึกษาและสาขา_____________________

6. อาชีพบิดา________________________

7. จำนวนของบุตร_______________

โปรดระบุอายุและภาวะสุขภาพ____

8. สถานภาพสมรสของมารดา

☐ คู่___________ปี

☐ หย่า_________ปี

☐ แยก_________ปี

☐ แต่งงานใหม่_______ปี

9. โครงสร้างครอบครัว

☐ ครอบครัวเดี่ยว

☐ ครอบครัวขยาย

10. รายได้ทั้งหมดของครอบครัวต่อเดือน______________________

11. ที่ตั้งของที่อยู่อาศัย

☐ กรุงเทพมหานคร

☐ ต่างจังหวัด โปรดระบุ_________________________

12. ท่านมีบุคคลในครอบครัวช่วยในการดูแลลูกที่ป่วยเป็นมะเร็งหรือไม่

☐ ไม่มี ☐ มี โปรดระบุ______________________________

13. ท่านมีปัญหาสุขภาพหรือไม่

☐ ไม่มี ☐ มี โปรดระบุ______________________________

Appendix C: Maternal Sensitivity Questionnaire

Maternal Sensitivity

Instruction: Please read each statement and decide how true the statement is of your behaviors with your child. Put X in the box that best describes how true the statement is of you.

	Items	How much is it true for me								
		Not true				Equally true/ untrue	Very True			
		1	2	3	4	5	6	7	8	9
1	Mother arranges her location so she can perceive baby's signals									
2	Mothers responds to baby's distress and non-distress signals even when engaged in some other activity such as a conversation with visitor									
3	Mother interprets cues correctly as evidenced by baby's response									
4	When baby is distressed, mother is able to identify the source									
5	Mother notices when baby is distressed (e.g., cries, fusses or whimpers)									
6	Mother notices when baby smiles and vocalizes									
7	Mother well resolved interaction with baby—interaction ends when baby is satisfied—also considers the termination of ongoing interactions that baby is enjoying									
8	Mother uses close bodily contact to soothe baby.									
9	Mother's Interactions revolve around baby's tempo and current state									
10	Mother well resolved interaction with baby—interaction ends when baby is satisfied—also considers the termination of ongoing interactions that baby is enjoying									
11	Mother gives a baby opportunity to explore when introducing a new activity.									
12	Mother attends to what the baby is interested in, rather than introducing a new activity.									
13	Mother accepts baby's desire to explore environment without restrictions even when these experiences may be contrary to mother's expectations.									

	Items	How much is it true for me								
		Not true				Equally true/ untrue	Very True			
		1	2	3	4	5	6	7	8	9
14	Mother's interactions appropriately vigorous and exciting as judged from baby's responses									
15	Mother's interventions are effective as evidenced by baby being settled or content.									
16	Mother has delight in interaction with baby.									

การตอบสนองของมารดาต่อบุตร

คำแนะนำ: กรุณาอ่านข้อความ และเลือกตอบในช่องหมายเลขของระดับของพฤติกรรมที่ตรงกับพฤติกรรมของท่านในการดูแลลูกมากที่สุด โดยขีดเครื่องหมายกากบาท **(X)** ในช่องนั้นๆ

	พฤติกรรมของแม่	**ระดับความจริง**								
		จริงมาก				**จริงพอกับไม่จริง**	**ไม่จริง**			
		9	8	7	6	5	4	3	2	1
1	ท่านมักอยู่ในตำแหน่งที่สามารถมองเห็นและได้ยินเสียงลูก									
2	ไม่ว่าท่านกำลังทำอะไรอยู่ก็ตาม ท่านสามารถตอบสนองต่อสัญญาณต่างๆ ของลูกได้ เช่น ยิ้ม หัวเราะ ยื่นมือให้ งอแงหรือร้องไห้ เป็นต้น									
3	ท่านสังเกตรู้ว่าลูกต้องการอะไร และตอบสนองต่อพฤติกรรมของลูกให้ลูกพอใจและมีความสุข (เช่น ลูกงอแง ท่านปลอบโยน สักพักลูกสงบและยิ้มได้)									
4	เวลาลูกร้องไห้งอแง ท่านรู้ว่าอะไรเป็นสาเหตุ									
5	ท่านตอบสนองทันทีต่อการร้องไห้ของลูก (ไม่ว่าร้องไห้แบบใดก็ตาม)									
6	ท่านสังเกตรู้เวลาที่ลูกไม่สบาย หงุดหงิด หรือหวาดกลัว									
7	ท่านสังเกตรู้ว่าลูกหงุดหงิดหรืออารมณ์ไม่ดี และให้การช่วยเหลือได้อย่างเหมาะสม เช่น ลูกโมโห หงุดหงิดเพราะทำบางอย่าง ไม่ได้ ท่านสังเกตรู้และช่วยให้ลูกทำต่อไปได้หรือจัดหากิจกรรมอื่นทดแทน									

	พฤติกรรมของแม่	ระดับความจริง								
		จริงมาก				จริงพอกับไม่จริง	ไม่จริง			
		9	8	7	6	5	4	3	2	1
8	ท่านอุ้มและกอดลูกเพื่อปลอบโยนลูกให้สงบลงจากอาการหงุดหงิดงอแงหรือร้องไห้									
9	ท่านปรับเปลี่ยนกิจกรรมต่างๆได้อย่างเหมาะสมตามความต้องการและสภาวะของลูกในขณะนั้น									
10	ท่านเข้าใจลูกดีว่าเมื่อใดอยากเล่นเมื่อใดอยากหยุด									
11	ท่านเปิดโอกาสให้ลูกสำรวจของเล่นใหม่ๆด้วยตัวเอง ก่อนที่ท่านจะสอนหรือบอกวิธีการเล่น									
12	ท่านให้ลูกเล่นหรือทำกิจกรรมต่างๆตามความสนใจ และความต้องการของลูก									
13	ท่านยอมรับพฤติกรรมของลูก (ที่ไม่เป็นอันตราย) ถึงแม้ตรงข้ามกับที่ท่านอยากให้ลูกทำ เช่น ลูกถนัดซ้ายแต่แม่ก็ยอมรับได้ถึงแม้อยากให้ลูกถนัดขวามากกว่า									
14	ท่านเล่นหรือทำกิจกรรมร่วมกับลูกได้อย่างดีโดยมองเห็นได้ว่าลูกพึงพอใจสนุกสนานและมีความสุข									
15	กิจกรรมต่างๆที่มีท่านเข้ามาเกี่ยวข้องลูกมีความสุขและพึงพอใจ									
16	ท่านยิ้มและหัวเราะอย่างมีความสุขเวลาเล่นกับลูก									

Appendix D: Parenting Stress Index

Parenting Stress Index Short Form

Instructions: For each statement, please focus on the child you are most concerned about, and put X on the response that best represents your opinion.

SA = Strongly Agree, A = Agree, NS = Not Sure, D = Disagree, SD= Strongly Disagree

1	I often have the feeling that I cannot handle things very well	SA	A	NS	D	SD
2	I find myself giving up more of my life to meet my children's need than I ever expected.	SA	A	NS	D	SD
3	I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4	Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5	Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6	I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7	There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8	Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).	SA	A	NS	D	SD
9	I feel alone and without friends.	SA	A	NS	D	SD
10	When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11	I am not as interested in people as I used to be.	SA	A	NS	D	SD
12	I don't enjoy things as I used to.	SA	A	NS	D	SD
13	My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14	Sometime I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
15	My child smiles at me much less than I expected.	SA	A	NS	D	SD
16	When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
17	When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
18	My child doesn't seem to smile as much as I expected.	SA	A	NS	D	SD
19	My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20	My child is not able to do as much as I expected.	SA	A	NS	D	SD
21	It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD

SA = Strongly Agree, A = Agree, NS = Not Sure, D = Disagree, SD= Strongly Disagree						
For the next statement, chose your response from the choices "1" to "5" below.						
22	I feel that I am: 1. Not very good at being a parent 2. a person who has some trouble being a parent 3. an average parent 4. a better than average parent 5. a very good parent	1	2	3	4	5
23	I expected to have closer and warmer feeling for my child than I do and this bothers me.	SA	A	NS	D	SD
24	Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
25	My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26	My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27	I feel that my child is very moody.	SA	A	NS	D	SD
28	My child does a few things which bother me a great deal.	SA	A	NS	D	SD
29	My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30	My child gets upset easily over the smallest things.	SA	A	NS	D	SD
31	My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD
For the next statement, chose your response from the choices "1" to "5" below.						
32	I have found that getting my child to do something or stop doing something is: 1. much harder than I expected. 2. somewhat harder than I expected 3. about as hard as I expected 4. somewhat easier than I expected 5. much easier than I expected	1	2	3	4	5
For the next statement, chose your response from the choices "10+" to "1-3".						
33	Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, ets.	10 +	8-9	6-7	4-5	1-3
34	There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35	My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36	My child makes more demands on me than most child.	SA	A	NS	D	SD

แบบสำรวจความรู้สึกของแม่

คำชี้แจง: กรุณาอ่านข้อความ และเลือกตอบโดยขีดเครื่องหมายกากบาท X ในช่องที่ท่านมีความคิดเห็นว่าตรงกับคุณลักษณะท่านและลูกของท่านมากที่สุด

หย = เห็นด้วยมากที่สุด; หด = เห็นด้วย; มจ = ไม่แน่ใจ; มด = ไม่เห็นด้วย; มย = ไม่เห็นด้วยอย่างยิ่ง						
1	ฉันมักจะคิดว่าฉันไม่สามารถจัดการสิ่งต่างๆได้ดี	หย	หด	มจ	มด	มย
2	ฉันพบตัวเองว่าได้ละทิ้งหลายอย่างในชีวิตเพื่อทำในสิ่งที่ลูกต้องการมากกว่าที่ฉันคาดคิด	หย	หด	มจ	มด	มย
3	ฉันรู้สึกว่าฉันโดนกักกันโดยภาระของการเป็นพ่อแม่	หย	หด	มจ	มด	มย
4	ตั้งแต่มีลูกคนนี้ ฉันมีความรู้สึกว่าไม่สามารถทำในสิ่งที่แปลกใหม่	หย	หด	มจ	มด	มย
5	ตั้งแต่มีลูกคนนี้ ฉันมีความรู้สึกว่าเกือบจะไม่ได้ทำในสิ่งที่ฉันชอบทำ	หย	หด	มจ	มด	มย
6	ฉันไม่ถูกใจกับการซื้อเสื้อผ้าครั้งสุดท้ายของฉัน	หย	หด	มจ	มด	มย
7	มีบางสิ่งบางอย่างที่รบกวนชีวิตของฉัน	หย	หด	มจ	มด	มย
8	การมีลูกทำให้เกิดปัญหาด้านความสัมพันธ์กับสามี หรือคู่สมรสมากกว่าที่ฉันคิด	หย	หด	มจ	มด	มย
9	ฉันรู้สึกว่าอยู่คนเดียวและไม่มีเพื่อน	หย	หด	มจ	มด	มย
10	เมื่อฉันไปงานรื่นเริง ฉันมักไม่สนุกเท่าที่ควร	หย	หด	มจ	มด	มย
11	ฉันไม่ค่อยสนใจผู้คนเหมือนที่ฉันเคยเป็น	หย	หด	มจ	มด	มย
12	ฉันไม่ค่อยสนุกสนานกับสิ่งต่างๆเหมือนที่เคยเป็น	หย	หด	มจ	มด	มย
13	ลูกไม่ใคร่ทำอะไรที่ทำให้ฉันเกิดความรู้สึกที่ดี	หย	หด	มจ	มด	มย
14	บางครั้งฉันรู้สึกว่า ลูกชอบฉันและต้องการอยู่ใกล้ฉัน	หย	หด	มจ	มด	มย
15	ลูกของฉันยิ้มให้ฉันน้อยกว่าที่ฉันคาดคิดไว้	หย	หด	มจ	มด	มย
16	เวลาที่ฉันทำอะไรให้ลูก ฉันรู้สึกว่าลูกไม่ใคร่จะชื่นชมมากนัก	หย	หด	มจ	มด	มย
17	ขณะกำลังเล่น ลูกมักไม่ค่อยรื่นเริงหรือหัวเราะ	หย	หด	มจ	มด	มย
18	ดูเหมือนว่าลูกจะเรียนรู้ไม่ได้เร็วเหมือนเด็กส่วนใหญ่	หย	หด	มจ	มด	มย
19	ดูเหมือนว่าลูกจะไม่ค่อยยิ้มบ่อยเท่าเด็กส่วนมาก	หย	หด	มจ	มด	มย
20	ลูกทำอะไรได้ไม่มากเท่ากับที่ฉันคิด	หย	หด	มจ	มด	มย
21	ลูกของฉันมักใช้เวลานานและยาก ในการสร้างความคุ้นเคยกับสิ่งใหม่	หย	หด	มจ	มด	มย

หย = เห็นด้วยมากที่สุด; หด = เห็นด้วย; มจ = ไม่แน่ใจ; มด = ไม่เห็นด้วย; มย = ไม่เห็นด้วยอย่างยิ่ง						
สำหรับข้อ22 เลือกจากตัวเลือก ข้อที่ 1-5 ข้างล่าง						
22	ฉันรู้สึกว่าฉัน 1. เป็นพ่อแม่ที่ดีมาก 2. เป็นพ่อแม่ที่ดีกว่าพ่อแม่ทั่วไป 3. พอพอกับพ่อแม่ทั่วไป 4. เป็นผู้มีปัญหาในการเป็นพ่อแม่ 5. ไม่ได้เป็นพ่อแม่ที่ดีเลย	1	2	3	4	5
23	ฉันหวังที่จะมีความใกล้ชิดกว่าและอบอุ่นกว่าต่อลูกของฉันมากกว่าที่ฉันเป็นอยู่และสิ่งนี้สร้างความหนักใจให้ฉัน	หย	หด	มจ	มด	มย
24	บางครั้งลูกของฉันทำสิ่งต่างๆ ให้ฉันรำคาญใจ เพียงเพื่อแสดงอำนาจ	หย	หด	มจ	มด	มย
25	ลูกของฉันจะร้องโยเยมากกว่าเด็กส่วนใหญ่	หย	หด	มจ	มด	มย
26	ลูกมักจะตื่นขึ้นด้วยอารมณ์ไม่ค่อยดี	หย	หด	มจ	มด	มย
27	ฉันรู้สึกว่าลูกเจ้าอารมณ์และหงุดหงิดง่าย	หย	หด	มจ	มด	มย
28	ลูกทำบางเรื่อง ซึ่งทำให้ฉันรำคาญใจมาก	หย	หด	มจ	มด	มย
29	ลูกจะตอบโต้อย่างรุนแรง เมื่อมีสิ่งที่ลูกไม่ชอบเกิดขึ้น	หย	หด	มจ	มด	มย
30	ลูกของฉันอารมณ์เสียได้ง่ายกับเรื่องเล็กๆน้อยๆ	หย	หด	มจ	มด	มย
31	การจัดตารางการรับประทานอาหารและการนอนของลูกยากกว่าที่ฉันคิด	หย	หด	มจ	มด	มย
สำหรับข้อ32 เลือกจากตัวเลือก ข้อที่ 1-5 ข้างล่าง						
32	ฉันพบว่าการที่จะให้ลูกทำหรือหยุดทำสิ่งใดสิ่งหนึ่งนั้น 1. ยากกว่าที่ฉันคิด 2. ค่อนข้างยากกว่าที่ฉันคิด 3.ยากเท่ากับที่ฉันคิด 4. ค่อนข้างง่ายกว่าที่ฉันคิด 5. ง่ายมากกว่าที่ฉันคิดไว้	1	2	3	4	5

หย = เห็นด้วยมากที่สุด; หด = เห็นด้วย; มจ = ไม่แน่ใจ; มด = ไม่เห็นด้วย; มย = ไม่เห็นด้วยอย่างยิ่ง						
สำหรับข้อ33 เลือกจากตัวเลือก “10+” ถึง “1-3”						
33	เมื่อพิจารณาอย่างรอบคอบและนับสิ่งที่ลูกทำให้คุณรำคาญ เช่น เกียจคร้าน ไม่สนใจ วุ่นวาย โยเย ขัดจังหวะ ต่อต้าน กรีดร้อง ฯลฯ โปรดนับจำนวนและวงรอบจำนวนชนิดที่คุณนับได้ 1. 1-3 ชนิด 2. 4-5 ชนิด 3. 6-7 ชนิด 4. 8-9 ชนิด 5. มากกว่า 10 ชนิด	10+	8-9	6-7	4-5	1-3
34	มีบางสิ่งที่ลูกทำซึ่งเป็นเรื่องน่ารำคาญต่อฉันมากจริงๆ	หย	หด	มจ	มด	มย
35	ลูกมีปัญหาสุขภาพกว่าที่ฉันคิดมาก	หย	หด	มจ	มด	มย
36	ลูกจะเรียกร้องจากฉันมากกว่าเด็กส่วนใหญ่	หย	หด	มจ	มด	มย

Appendix E: The Memorial Symptom Assessment Scale

Evening 1

Memorial Symptom Assessment Scale
Instructions: We want to find out how your child has been feeling in this evening.

1. Tired

1.1 Did your child feel more tired than he/she usually do?
☐ Yes ☐ No
If yes
1.2 How long did it last?
☐ A very short time ☐ A medium amount ☐ Almost all the time
1.3 How tired did your child feel?
☐ A little ☐ A medium amount ☐ Very tired
1.4 How much did being tired bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

2. Sad

2.1 Did your child feel sad?
☐ Yes ☐ No
If yes
2.2 How long did your child feel sad?
☐ A very short time ☐ A medium amount ☐ Almost all the time
2.3 How sad did your child feel?
☐ A little ☐ A medium amount ☐ Very sad
2.4 How much did feeling sad bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

3. Itchy

3.1 Was your child itchy? ☐ Yes ☐ No
If yes
3.2 How much of the time were your child itchy?
☐ A very short time ☐ A medium amount ☐ Almost all the time
3.3 How itchy did your child feel?
☐ A little ☐ A medium amount ☐ Very itchy
3.4 How much did itching bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

4. Pain

4.1 Did you child have any pain?

☐ Yes ☐ No

If yes

4.2 How much of the time did your child have pain?

☐ A very short time ☐ A medium amount ☐ Almost all the time

4.3 How much pain did your child feel?

☐ A little ☐ A medium amount ☐ A lot

4.4 How much did pain bother or trouble your child?

☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

5. Worried

5.1 Did your child feel worried?

☐ Yes ☐ No

If yes

5.2 How much of the time did your child feel worried?

☐ A very short time ☐ A medium amount ☐ Almost all the time

5.3 How much worry did your child feel?

☐ A little ☐ A medium amount ☐ Very worried

5.4 How much did feeling worried bother or trouble your child?

☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

6. Eating

6.1 Did your child feeling like eating as he or she normally do?

☐ Yes ☐ No

If yes

6.2 How long did this last?

☐ A very short time ☐ A medium amount ☐ Almost all the time

6.3 How much did this bother or trouble your child?

☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

7. Nausea

7.1 Did your child feel like he/she was going to vomit (or going to throw up)?
☐ Yes ☐ No

If yes

7.2 How much of the time did your child feel like you could vomit?
☐ A very short time ☐ A medium amount ☐ Almost all the time

7.3 How much did this feeling bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

8. Sleep

8.1 Did your child have trouble going to sleep?
☐ Yes ☐ No

If yes

8.2 How much did not being able to go to sleep bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

9. Numbness or Tingling

9.1 Did your child have numbness or tingling in his/her hands or feet during today?
☐ Yes ☐ No

If yes

9.2 How much of the time did you feel numbness and tingling?
☐ A very short time ☐ A medium amount ☐ Almost all the time

9.3 How much numbness and tingling did you feel?
☐ A little ☐ A medium amount ☐ A lot

9.4 How much did the numbness and tingling bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

10. Other Symptoms

10.1 Was there anything else that made your child feel bad or sick during today?
If so, please write it here: ____

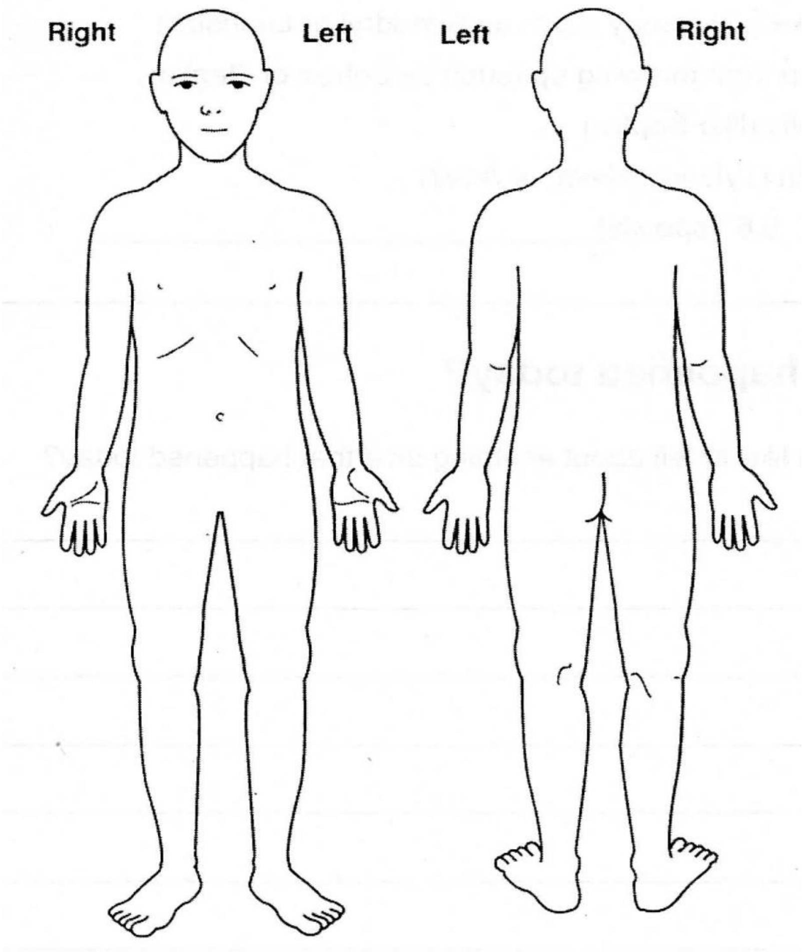
10.2 How much of the time did your child feel this?
☐ A very short time ☐ A medium amount ☐ Almost all the time

10.3 How much of this did your child feel?
☐ A little ☐ A medium amount ☐ Very tried

10.4 How much did this bother or trouble your child?
☐ Not at all ☐ A little ☐ A medium amount ☐ Very much

Body Outline for Location of Pain, Itchy, and Tingling

Instruction: If your child has these symptoms, please make the marks colors as big or small as the places where these symptoms are. Red=Pain; Blue=Itchy; and Yellow=Tingling.



Child Pain

Mark on the line below how much pain your child had during last night?

NoPain☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ A lot of pain
0	1	2	3	4	5	6	7	8	9	10

แบบบันทึกอาการของเด็ก

คำแนะนำ: โปรดบันทึกอาการของลูกที่คุณสังเกตพบในวันนี้

1. อ่อนเพลีย

1.1 ลูกของคุณมีอาการอ่อนเพลียมากกว่าปกติหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี

1.2 มีอาการอ่อนเพลียนานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

1.3 มีอาการอ่อนเพลียมากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

1.4 อาการอ่อนเพลียรบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

2. **หงอยเหงา**

2.1 ลูกของคุณมีอาการหงอยเหงามากกว่าปกติหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ

2.2 มีอาการหงอยเหงานานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

2.3 มีอาการหงอยเหงามากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

2.4 อาการหงอยเหงารบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

3. คันยุบยิบ

3.1 ลูกของคุณมีอาการคันยุบยิบมากกว่าปกติหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ

3.2 มีอาการคันยุบยิบนานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

3.3 มีอาการคันยุบยิบมากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

3.4 อาการคันยุบยิบนี้รบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

4. เจ็บปวด

4.1 ลูกของคุณรู้สึกเจ็บปวดมากกว่าปกติหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ

4.2 รู้สึกเจ็บปวดนานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

4.3 รู้สึกเจ็บปวดมากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

4.4 อาการเจ็บปวดนี้รบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

5. หงุดหงิด

5.1 ลูกของคุณมีอาการหงุดหงิดมากกว่าปกติหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ

5.2 มีอาการหงุดหงิดนานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

5.3 มีอาการหงุดหงิดมากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

5.4 อาการหงุดหงิดรบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

6. ความอยากอาหารหรือเบื่ออาหาร

6.1 ลูกของคุณมีความอยากอาหารผิดปกติหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ ☐ เบื่ออาหาร ☐ อยากอาหารมากขึ้น

6.2 มีอาการนี้เท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

6.3 อาการนี้รบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

7. คลื่นไส้อาเจียน

7.1 ลูกของคุณมีอาการคลื่นไส้อาเจียนหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ

7.2 มีอาการคลื่นไส้อาเจียน นานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

7.3 อาการคลื่นไส้อาเจียนรบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

8. **นอนหลับ**

8.1 ลูกของคุณมีปัญหาการนอนหลับหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี

8.2 ปัญหาการนอนหลับนี้มีผลต่อกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

9. **ชา**

9.1 ลูกของคุณมีอาการชาหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามี ลูกของคุณ

9.2 มีอาการชานานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

9.3 มีอาการชามากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

9.4 อาการชารบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

10. **อาการอื่น ๆ**

10.1 ลูกของท่านมีอาการอื่นๆหรือไม่ ☐ มี ☐ ไม่มี

ถ้ามีโปรดบอกอาการ...

10.2 มีอาการนี้นานเท่าไหร่?

☐ ระยะเวลาสั้นๆ ☐ ระยะเวลาปานกลาง ☐ เกือบตลอดเวลา

10.3 มีอาการนี้มากเท่าไหร่

☐ เล็กน้อย ☐ ปานกลาง ☐ มาก

10.4 อาการนี้รบกวนกิจวัตรประจำวันของลูกมากแค่ไหน

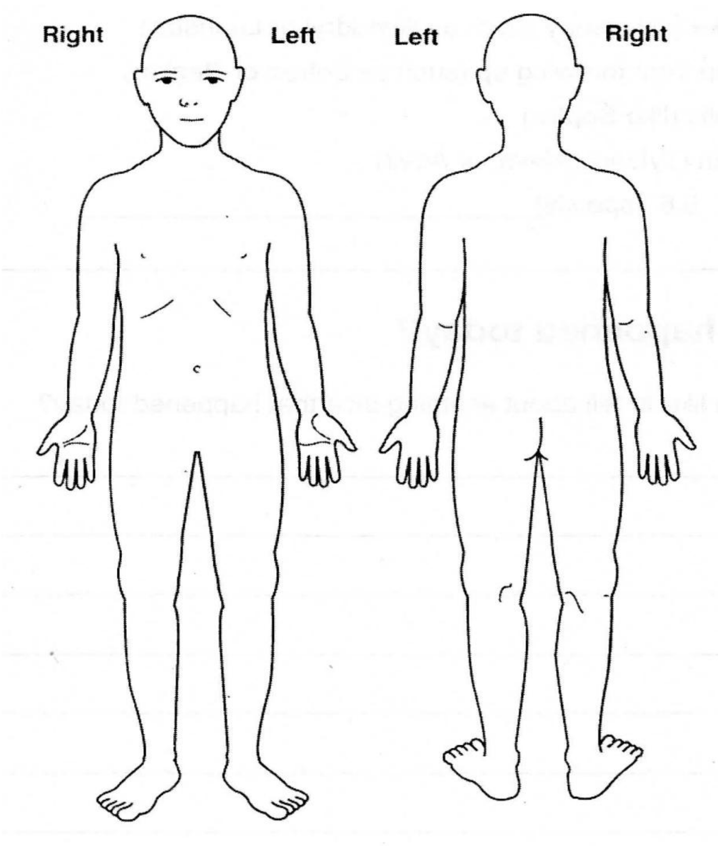
☐ ไม่รบกวนเลย ☐ รบกวนเล็กน้อย ☐ รบกวนปานกลาง ☐ รบกวนมาก

ตำแหน่งของอาการ

คำแนะนำ: ถ้าลูกของคุณมีอาการ ปวด คัน หรือ ชา ตามร่างกาย

กรุณาใช้ปากกาสี ระบายตามตำแหน่งที่มีอาการ

สีแดง = ปวด; สีน้ำเงิน = คัน; สีเหลือง = ชา



หากลูกของคุณมีอาการปวด กรุณาตอบคำถามด้านล่าง

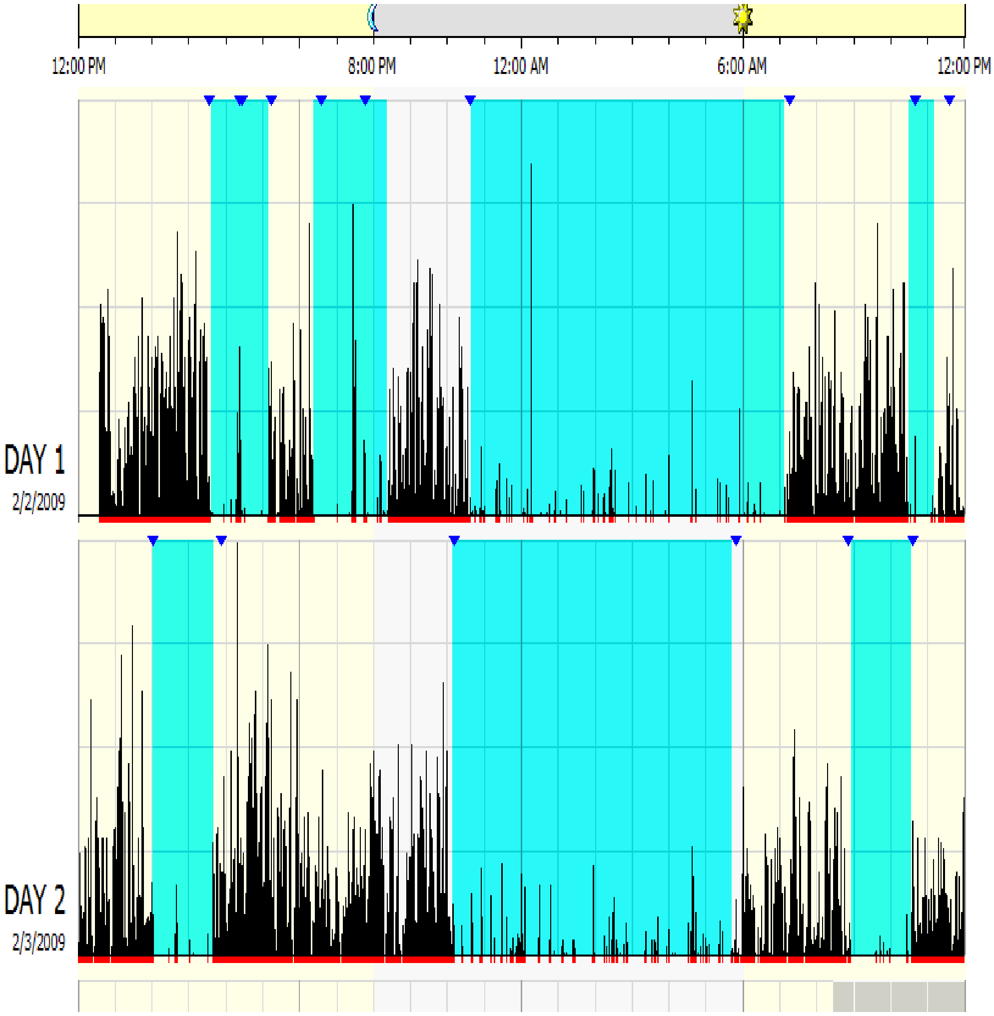
เลือกหมายเลขที่ คุณคิดว่าตรงกับระดับความปวดของลูกในวันนี้ มากที่สุด

ไม่ปวด ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ปวดมากที่สุด

0 1 2 3 4 5 6 7 8 9 10

Appendix F: Actigraphy


12 6:03PM


12:00 PM
8:00 PM
12:00 AM
6:00 AM
12:00 PM
DAY 1
2/2/2009
DAY 2
2/3/2009

Appendix G: Symptom Management

Care Methods

1. What is the most important symptom your child had?

____

2. What are care methods did you use to relieve your child’s symptoms?

____

3. Mark on the line below how much relief from the symptom your child had after your care.

No	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ A lot
	0	1	2	3	4	5	6	7	8	9	10

การดูแล

1. คุณคิดว่าอาการใดของลูกที่เป็นปัญหามากที่สุด

____

2. กรุณาบอกวิธีที่คุณใช้ในการดูแลลุกเมื่อลูกมีอาการดังกล่าว

____

3. เลือกหมายเลขที่คุณคิดว่าตรงกับอาการของลูกที่รู้สึกดีขึ้น หลังจากคุณดูแลลูกแล้ว

ไม่ดีขึ้น	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	ดีขึ้นมากที่สุด
	0	1	2	3	4	5	6	7	8	9	10	

Appendix H: Semi-structured Interview Questions

Semi-Structured Interview Questions

1. What are your meanings of cancer, chemotherapy treatment and symptom related to chemotherapy treatment?
2. What caused your child symptoms?
3. What role did you play in symptom management?
4. How did you learn to recognize symptoms and act on what you see?
5. What strategies worked best to relieve your child’s symptom?
6. What can doctors or nurses do to better relieve your child’s symptom?
7. What advice would you give to a parent whose child has been recently diagnosed with cancer and has symptoms?
8. How are your child’s symptoms related to each other?
9. Do you think management of your child’s symptom such as pain may have an effect on his/her other symptoms?

Appendix I: Children’s Medical Record

Patients' Data from Chart Review

Children Number____________

1. Diagnosis____
2. Treatment Phase___________________________________
3. Medications
    a. Cancer____

    ____

    b. Symptom Management____

    ____

4. Height ________________Weight______________________
5. Blood Test Results
    a. WBC_______________
    b. Hb ________________
    c. Platelet_____________
    d. Electrolyte__________
    e. Others____
6. Treatment Procedure

    6.1 ____________________When__________________________________

    6.2 ____________________When__________________________________

7. Other problems____

    ____

    ____

Appendix J: Experts for Content Validity

List of Experts for Content Validity

Five experts will validate the content and clarity of items corresponding with theoretical definitions. There are the following:

1. Experts of Research and Pediatric Hematology-Oncology

    1. Dr. Arunothai Meekaewkhunchon, MD. Certificate in Hematology and Oncology
       Hematology Department, Queen Sirikit National Institute of Child Health
    2. Dr. Somjai Kanjanaponkkul, MD. Certificate in Hematology and Oncology
       Hematology Department, Queen Sirikit National Institute of Child Health

2. Experts in pediatric hematology-oncology

    1. Lawan Limniyom, RN. Certificate in Oncology
       Hematology Department, Queen Sirikit Children Institute
    2. Wiriya Dangwisut ,MSN, RN.
       Pediatric Nursing Department, Boromarajonani College of Nursing, Bangkok

3. Expert of Research and Pediatric Nursing and Family Nursing
    1. Dr. Pailin Nukunkit, RN, Ph.D.
       Dean of School of Nursing
       Pratumtani University