

CHAPTER 1

Introduction

Background and Significance of the Research Problem

Leukemia is the most common childhood cancer and a major cause of death among children under 15 years of age (Leukemia & Lymphoma Society, 2013). In the United States, the average incidence of leukemic children in this age group is 53.5: 1,000,000 which accounts for 70% of childhood cancers (National Cancer Institute, 2014). In Thailand, the average incidence of leukemic children in this age group is 38.1: 1,000,000 which accounts for 51% of all cancer in children (Wiangnon et al., 2011). Aschemotherapy is the primary treatment modality for leukemia in children, these incidences indicate that a large number of such children are affected by illness and chemotherapy.

Chemotherapeutic agents are effective because they target cell cycle activities that are increased in malignant cells (American Cancer Society, 2013). The intensity of chemotherapy involves a combination of multiple cytotoxic agents that are administered at their maximum tolerated doses based on the severity of toxicity and non-overlapping toxicity to complete remission (Makin, 2013). As a result, children with leukemia experience many severe side effects including nausea, vomiting, taste changes, fatigue, and mucositis as well as anemia, neutropenia, and thrombocytopenia due to bone marrow suppression (Margolin, Rabin, Steuber, & Poplack, 2011). Moreover, many of them not only suffer from these side effects, but also from common complications of chemotherapy such as infection and bleeding (Brundige, 2010; 2010a).

The years between ages 10 and 15 years, are years of transition from childhood to adolescence (Potts & Mandleco, 2012). Piaget (1973) described cognitive development of children between 10 to 15 years of age as a movement from concrete to abstract thought. For most children, emergence of formal operational

thinking starts at the age of 12 years. This is characterized by systematic and abstract thought including thinking about possibilities and thinking through hypotheses (London, Ladewing, Ball, Bindler, & Cowen, 2011). Therefore, children with leukemia between 10 and 15 years of age would be able to perceive their illness and its impacts. Studies found that children with cancer identified three types of distress they experienced from 4 to 8 weeks after being diagnosed with cancer including physical concerns with side effects and complication of chemotherapy, pain from procedures or treatment, such image changes as hair loss and weight changes, and treatment related worries such as not getting well and missing school (Abu-Saad, Sagherian, & Tamim, 2013; Hedstrom, Liungman, & von Essen, 2005). Moreover, uncertainty in illness has been found to be a major complaint of the cancer experience among children with cancer (Fortier, Batista, Wahi, Kain, Strom, & Sender, 2013; Haase & Rostad, 1994; Weekes & Kagan, 1994).

Potentially life threatening aspects of leukemia, and suffering from side effects of chemotherapy lead to uncertainty in illness among children with cancer during the time from cancer diagnosis through the stages of treatment (Stewart, 2005; Decker, Haase, & Bell, 2007). Previous studies in Thailand demonstrate that children with cancer who are receiving chemotherapy experience moderate to high levels of uncertainty in illness (Silapavitayatorn, Kantawang&Leuviiryakit, 2009; Tathong, Kantawang, & Sripusanapan, 2012).

Therefore, uncertainty in illness is a major concern during the period of cancer treatment among children with cancer. It contributes to children's negative emotional arousal which leads to psychological distress (Lee, 2006). In particular, uncertainty has strong direct effects on anxiety and depressive symptoms, the two most commonly demonstrated psychological distresses in children with cancer (Neville, 1998; Stewart, Mishel, Lynn, & Terhorst, 2010). These lead to poor psychological adjustment which interferes with their ability to cope with illness-related stressors and decrease their ability to take care of themselves (Stewart et al., 2010). Thus, nurses should be aware of the uncertainty in illness among leukemic children receiving chemotherapy and its consequences, and provide nursing interventions to reduce that uncertainty. However, the intervention in any form will be effectively developed only

if factors affecting uncertainty in illness of children with cancer are clearly identified. Therefore, such knowledge is critically needed.

Mishel (1988) defines cognitive uncertainty as the inability to determine the meaning of an illness event, Uncertainty in illness of individuals is the uncertainty that they experience during the diagnostic and treatment phases in four forms including (1) ambiguity concerning the state of the illness, (2) complexity regarding treatment and system of care, (3) lack of information about the diagnosis and seriousness of the illness, and (4) unpredictability of the course of the disease and prognosis.

Additionally, Mishel (1988) addresses factors influencing uncertainty in illness, predominantly on two of the antecedents of uncertainty, stimuli frame and structure provider. The stimuli frame is the primary antecedent of uncertainty in illness and has three components including symptom pattern, event familiarity, and event congruence (Mishel, 1988; Mishel, 2014). These components of the stimuli frame are inversely related to uncertainty in illness (Mishel & Braden, 1988). Uncertainty of individuals is generated when clear symptoms are absent, on the other hand, their uncertainty is decreased when patterns of the symptoms are consistent with what they have perceived (Mishel, 2014). The secondary antecedent of uncertainty is a structure provider which has two major components: (1) social support which refers to affirmation support from friends, family, and those with similar experiences, and (2) credible authority which refers to support from health care providers who the patient sees as credible information givers (Mishel & Clayton, 2008). Therefore, the selected factors considered as predicting factors of leukemic children's uncertainty were more specific.

Knowledge regarding predicting factors of uncertainty in illness among children with cancer is limited. At present, there have been only two studies examining stimuli frame, including symptom pattern, which influences uncertainty in illness of children with cancer. In one study, the stage of illness as a symptom pattern was not a predicting factor of uncertainty (Stewart et al., 2010). This might be because the stage of illness was not specific enough to identify the characteristics of the symptom pattern. According to Mishel (1988), symptom pattern is the degree to which symptom occurrence was present in terms of number, frequency, intensity,

duration and location of symptoms having enough consistency to be perceived as having a pattern. Without a clarification of the symptom pattern, there is likely to be a high level of uncertainty in illness. The second study found that the stimuli frame could explain only 4.9% of the variance in uncertainty in illness ($R^2=.049$, $\beta =.220$, $p < .05$) (Tathong, Kantawang, & Sripusanapan, 2012). This might be because the scale used to measure the stimuli frame included all three components: symptom pattern, event familiarity, and event congruence; thus, not being sensitive enough to capture the children's perception of the stimuli frame and resulting in lessening its influence on the child's uncertainty. An additional analysis of the study found that symptom pattern was a predictive factor of uncertainty and could explain 9.2% of the variance in uncertainty ($R^2=.092$, $\beta =.303$, $p < .01$) (Kantawang & Tathong, 2013). Thus, in this study, only the symptom pattern from the stimuli frame based on Uncertainty in Illness Theory's antecedent was selected as a predictive factor and employed in the use of the scale used to measure symptom pattern. It would be a complete concept component for the ability to identify the characteristics of the symptom pattern.

Information support, as a dimension of social support, is another major factor influencing uncertainty in illness, and it has been argued that it is more likely than other dimensions to directly affect uncertainty (Mishel, 2014). Mishel (1988) conceptualized social support as affirmation support which is believed to influence uncertainty in illness directly by providing information to modify three types of uncertainty; ambiguity about the illness, treatment complexity, and unpredictability of the future. The indirect influence of social support involves lessening uncertainty by helping individuals in clarifying symptom patterns and promoting event familiarity as well as event congruence (Mishel, 1988). Naruemandecha (2008) studied the relationship between social support including information support and uncertainty in illness among children aged between 10 and 15 years with SLE, and found that there were high negative relationships between overall social support and illness uncertainty ($r = -.746$, $p < .01$). The study of children and adolescents with cancer indicated low to moderate levels of the relationship or influence. Uncertainty in illness of newly diagnosed children and adolescents with cancer had a moderately

negative association with social support ($r = -.30, p < .01$) (Neville, 1998). In addition, the overall social support of Thai children with cancer aged between 8 and 15 years receiving chemotherapy could predict only 4.4% of their uncertainty in illness ($R^2 = .044, p < .05$) (Tathong et al., 2012). These findings might be because while only information support influenced the uncertainty, the social support scale measured several types of social support, including emotional, esteem, information, and tangible support resulting in less influence on the uncertainty. An additional analysis of this study found that only information support from parents, friends, nurses, and physicians was a predictor of uncertainty and could explain 10.4% of variance in uncertainty of these children with cancer ($R^2 = .104, \beta = .326, p < .01$) (Kantawang & Tathong, 2013).

Sharing information with persons in their social network assists the individual to properly appraise symptoms, which results in lower uncertainty (Mishel, 1988). Important sources of information support of children with cancer are parents and friends who are having the same diagnosis and treatment (Brown, Madan-Swain, & Lambert, 2003; Enskär, 1997; Haluska, Jessee, & Nagy, 2002; Trask, Paterson, Trask, Bares, Birt, & Maan, 2003; Gibson Aldiss, Horstman, Kumpunen, & Richardson, 2010). Children with cancer need information about their diagnosis, treatment and side effects, and care practices from health care providers (Miller, 2012). They need information for problem solving and modifying their uncertainty (Mishel, 2014). Information support from health care providers has been proposed to influence uncertainty by helping patients to interpret their illness related events, clarify symptom patterns, and promote event familiarity and event congruence (Mishel, 1988; Mishel & Clayton, 2008). However those studies did not investigate whether the support from each separate source was related to uncertainty. As information supports can be from various sources depending on the children's perception and preferences, it is worthwhile to identify the source. Information supports from parents, peers, and health care provider were proposed to have association with the children's uncertainty in this study.

Illness related knowledge is another factor associated with uncertainty of chronically ill children. Naruemandecha (2008) found that there was a moderately negative relationship between knowledge regarding illness and illness uncertainty of children between 10 to 15 years of age with SLE ($r = -.467, p < .01$). However, cancer knowledge of Thai children with cancer who are between 8 and 15 years old and are receiving chemotherapy could not predict their uncertainty in illness (Tathong et al., 2012). Stewart's and colleague's study (2010) indicated that children's cancer knowledge negatively predicted their level of uncertainty ($\beta = -2.65, t = -2.31, p = .02$) when age was held constant, such that lower cancer knowledge was associated with higher uncertainty. This empirical evidence of the relationship between illness related knowledge and uncertainty in illness are inconsistent. Thus, illness related knowledge will be included in this study for determining its predictability on children's uncertainty.

Parental uncertainty regarding their child's illness is another factor that has been described as an influencing factor of uncertainty of children and adolescents with cancer (Stewart & Mishel, 2000). Evidence has shown that parental uncertainty demonstrated a significant effect on uncertainty among children between 8 and 18 years old who were currently undergoing treatment for any form of cancer (Stewart et al., 2010). Additionally, child uncertainty was a predictive factor of maternal uncertainty in those children between 8 and 12 years of age with chronic illness (Page, Fedele, & Pai, 2011). Parental uncertainty leads to perception of insecurity about caring for their sick children both at present and in the future (Stewart & Mishel, 2000). Parents of children with cancer reported diminished confidence in their ability to accurately assess their children's health, difficulty in managing the children's behaviors, and uncertainty about the best ways to maintain normalcy for their families (Cohen, 1995; Hinds et al., 1996). According to uncertainty in illness theory (Mishel, 2014), parents' uncertainty can interfere with their capacity to provide the information support for their child's illness schema formation, thereby increasing the children's uncertainty. Therefore, parental uncertainty is proposed to influence uncertainty in illness among leukemic children receiving chemotherapy.

In conclusion, to date knowledge regarding predicting factors of uncertainty in illness among children with cancer could insufficiently explain the variation in illness uncertainty. There have been only two studies (Tathong et al., 2012; Stewart et al., 2010). The findings from the two studies did not well support Mishel's Uncertainty in Illness Theory. As children's level of cognitive development could differently affect their ability to determine the meaning of illness-related events, younger children might have had difficulty understanding the abstract nature of the stimuli frame and vice versa. In addition, various types of cancer and different treatment modalities – i.e. chemotherapy, radiation and surgery – would result in different illness-related events, and thus different experiences. Therefore, previous studies of factors predicting uncertainty in illness which were done in a heterogeneous sample might yield different result from that done in homogenous ones. This finding needs to be confirmed in a homogenous sample of children with similar cognitive development levels.

To overcome the limitations in previous studies regarding age, cancer types and treatment modalities, this study examined the level of uncertainty in illness and its more specific predictive factors among children with leukemia between 10 and 15 years of age undergoing chemotherapy. The findings of this study can be used to develop an effective intervention to reduce the uncertainty of these children, thereby increasing their well-being.

Research Objectives

The objectives of this study were as follows:

1. To describe the level of uncertainty in illness among leukemic children receiving chemotherapy.
2. To examine whether or not symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness related knowledge can predict uncertainty in illness among leukemic children receiving chemotherapy.

Research Questions

The study had the subsequent research questions as follows:

1. What is the level of uncertainty in illness among leukemic children receiving chemotherapy?
2. How much can the variability in uncertainty in illness among leukemic children receiving chemotherapy, be explained by symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty and illness related knowledge?

Research Hypotheses

Symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness related knowledge can predict uncertainty in illness among leukemic children receiving chemotherapy.

Definition of Terms

Uncertainty in illness refers to the children's perception of their inability to determine the meaning of their illness-related events. It is composed of 4 dimensions (1) ambiguity concerning the state of the illness, (2) complexity regarding treatment and system of care, (3) lack of information about the diagnosis and seriousness of the illness and (4) unpredictability of the course of the disease and its prognosis. It was measured by the Children's Uncertainty in Illness Scale of Mullins and Hartman (1995) translated into Thai by Kantawang (2007).

Predictive factors of uncertainty in illness refers to factors influencing uncertainty in illness among leukemic children receiving chemotherapy, including symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness related knowledge.

Symptom pattern refers to the child's perception of the degree to which symptom occurrence was present in terms of number, frequency, intensity, duration and location of symptoms having enough consistency to be perceived as having a pattern. It was measured by the Symptoms Pattern Scale of Children with Cancer developed by Tathong, and Kantawang (2007).

Information support from health care providers refers to the children's perception of receiving information and advice regarding their illness, side effects and complications of chemotherapy and care practices from health care providers including nurses and physicians. It was measured by the Information Support Scale modified from Information Support Subscale of Social Support of Children with Cancer Scale of Tathong et al. (2012).

Information support from parents refers to the children's perception of receiving information and advice regarding their illness, side effects and complications of chemotherapy and care practices from parents when these children face leukemia and chemotherapy. It was measured by the Information Support Scale modified from Information Support Subscale of Social Support of Children with Cancer Scale of Tathong et al. (2012).

Information support from peers refers to the children's perception of receiving information and advices regarding their illness, side effects and complications of chemotherapy and care practices from friends who are leukemic children. It was measured by the Information Support Scale modified from Information Support Subscale of Social Support of Children with Cancer Scale of Tathong et al. (2012).

Parental uncertainty refers to parents' perception of the inability to determine the meaning of their child's illness in four dimensions: (1) ambiguity about the illness state, (2) lack of information about the illness, its treatment, side effect, and management, (3) complexity of the system of care, and (4) unpredictability of a child's prognosis. It was measured using the Parent Perception of Uncertainty Scale of Mishel, (1983) which had been translated into Thai by Suwanna-o-sod (2004).

Illness related knowledge refers to the children's understanding regarding leukemia, side effects and complications of chemotherapy and care practices. It was measured using the Illness Related Knowledge Scale modified from Illness Knowledge of Children with Cancer Scale of Tathong et al. (2012).

Leukemic children receiving chemotherapy refer to children aged 10 to 15 years diagnosed with leukemia and currently undergoing chemotherapy in pediatric oncology wards of tertiary hospitals.

Parents refer to the mothers and/or fathers of the leukemic children who take care of the children in hospitals.



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