

**THE EFFECTS OF EMPOWERMENT PROGRAM ON  
MATERNAL CARING BEHAVIOR FOR CHILDREN  
WITH LEUKEMIA UNDERGOING CHEMOTHERAPY**



**A THESIS SUBMITTED IN PARTIAL FULFILLMENT  
OF THE REQUIREMENTS FOR  
THE DEGREE OF MASTER OF NURSING SCIENCE  
(PEDIATRIC NURSING)  
FACULTY OF GRADUATE STUDIES  
MAHIDOL UNIVERSITY**

**2006**

**ISBN 974-04-7396-2**

**COPYRIGHT OF MAHIDOL UNIVERSITY**

Thesis  
Entitled

**THE EFFECTS OF EMPOWERMENT PROGRAM ON  
MATERNAL CARING BEHAVIOR FOR CHILDREN  
WITH LEUKEMIA UNDERGOING CHEMOTHERAPY**

*Arunrat Kanjana*

Miss Arunrat Kanjana  
Candidate

*Pornsri Sriussadaporn*

Assoc. Prof. Pornsri Sriussadaporn,  
M.Ed. (Educational Research)  
Major-Advisor

*Chomchuen Somprasert*

Assist. Prof. Chomchuen Somprasert,  
Ph.D.  
Co-Advisor

*Kleebsabai Sanpakit*

Assist. Prof. Kleebsabai Sanpakit, M.D.,  
Dip. American. Board of Pediatric  
Hematology Oncology  
Co-Advisor

*Jisnuson Svasti*

Prof. M.R. Jisnuson Svasti,  
Ph.D.  
Dean  
Faculty of Graduate Studies

*Pornsri Sriussadaporn*

Assoc. Prof. Pornsri Sriussadaporn,  
M.Ed. (Educational Research)  
Chair  
Master of Nursing Science  
Faculty of Nursing

Thesis  
Entitled

**THE EFFECTS OF EMPOWERMENT PROGRAM ON  
MATERNAL CARING BEHAVIOR FOR CHILDREN  
WITH LEUKEMIA UNDERGOING CHEMOTHERAPY**

was submitted to the Faculty of Graduate Studies, Mahidol University for the degree  
of Master of Nursing Science Major in Pediatric Nursing

on  
26 May, 2006

*Arunrat Kanjana*

.....  
Miss Arunrat Kanjana  
Candidate

*Pornsri Sriussadaporn*

.....  
Assoc. Prof. Pornsri Sriussadaporn,  
M.Ed. (Educational Research)  
Chair

*Tassanee Attharos*

.....  
Dr. Tassanee Attharos,  
D.N.S.  
Member

*Chomchuen Somprasert*

.....  
Assist. Prof. Chomchuen Somprasert,  
Ph.D.  
Member

*Fongcum Tilokskulchai*

.....  
Assoc. Prof. Fongcum Tilokskulchai,  
Ph.D. (Nursing)  
Member

*Kleebzabai Sanpakit*

.....  
Assist. Prof. Kleebzabai Sanpakit, M.D.,  
Dip. American. Board of Pediatric  
Hematology Oncology  
Member

*M.R. Jisnuson Svasti*

.....  
Prof. M.R. Jisnuson Svasti,  
Ph.D.  
Dean  
Faculty of Graduate Studies  
Mahidol University

*Kobkul Phanchaoenworakul*

.....  
Assoc. Prof. Kobkul Phanchaoenworakul,  
Ph.D. (Nursing)  
Dean  
Faculty of Nursing  
Mahidol University

## ACKNOWLEDGEMENT

The study has been completed with great kindness, guidance and support from Assoc. Prof. Pornsri Sriussadaporn, major advisor, Assist. Prof. Chomchuen Somprasert and Assist. Prof. Kleesabai Sanpakit, co-advisors. I also would like to thank the thesis committee, Assoc. Prof. Fongcum Tilokskulchai and Dr. Tassanee Attharos, for their valuable recommendations.

I would like to thank the validators for their suggestions and support in validating the research instrument. I deeply thank Prof. Dr. J. Pamela Hellings for her kindness and support in editing this thesis.

I would like to thank the professionals of the pediatric oncology unit, Siriraj Hospital, for their facilitation of the data collection.

Finally, I am grateful to the mothers who were the samples in this study for their participation. The usefulness of this thesis, I dedicate to my parents, teachers, and mothers of children with leukemia and their children.

Arunrat Kanjana

THE EFFECTS OF EMPOWERMENT PROGRAM ON MATERNAL CARING BEHAVIOR FOR CHILDREN WITH LEUKEMIA UNDERGOING CHEMOTHERAPY

ARUNRAT KANJANA 4637788 NSPN/M

M.N.S. (PEDIATRIC NURSING)

THESIS ADVISORS: PORNSRI SRIUSSADAPORN, M.Ed., CHOMCHUEN SOMPRASERT, Ph.D., KLEESABAI SANPAKIT, M.D., DIP. AMERICAN BOARD OF PEDIATRIC HEMATOLOGY/ ONCOLOGY

ABSTRACT

The purpose of this research was to examine the effects of an empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. A quasi-experimental study with a two group pretest-posttest design was used. The samples were 29 mothers of children with leukemia admitted for chemotherapy in the university hospital. The experimental group of 14 mothers and the control group of 15 mothers were selected with these inclusion criteria: they were mothers who had children diagnosed with leukemia, aged between 3-12 years, having received chemotherapy at least one time, having been admitted for chemotherapy, and having had a period of time of care at home. Match paring by age of children was used. The mothers in the experimental group participated in the empowerment program to enhance caring behavior in six sessions. The first four dealt with caring to prevent or lessen the following symptoms from side effects of chemotherapy: infection, bleeding, nausea/vomiting, and mucositis. The fifth session was to promote health and the sixth to support development. The mothers in the control group received usual nursing care. Data were collected by questionnaire assessing maternal caring behavior, and analyzed by using ANCOVA with pretest caring behavior scores as covariate.

The results revealed that the mean scores of maternal caring behavior in the experimental group were statistically significantly higher than those in the control group ( $p < .05$ ). This finding suggests that the empowerment program should be used in nursing care to enhance maternal caring behavior for children with leukemia undergoing chemotherapy, especially for mothers who have children who are newly diagnosed or relapsing.

KEY WORDS: EMPOWERMENT / CARING BEHAVIOR / CHILDREN  
LEUKEMIA / CHEMOTHERAPY

121 P. ISBN 974-04-7396-2

ผลของโปรแกรมการเสริมสร้างพลังใจของมารดาต่อพฤติกรรมการดูแลบุตร โรคมะเร็งเม็ดเลือดขาวที่ได้รับยาเคมีบำบัด (THE EFFECTS OF EMPOWERMENT PROGRAM ON MATERNAL CARING BEHAVIOR FOR CHILDREN WITH LEUKEMIA UNDERGOING CHEMOTHERAPY)

อรุณรัตน์ กาญจนะ 4637788 NSPN/M

พย.ม. (การพยาบาลเด็ก)

คณะกรรมการควบคุมวิทยานิพนธ์: พรศรี ศรีอัญญาพร, M.Ed., ชมชื่น สมประเสริฐ, Ph.D.,  
กليبสไบ สรรพกิจ, M.D., Dip. American Board of Pediatric Hematology/Oncology

#### บทคัดย่อ

การวิจัยครั้งนี้เป็นการวิจัยกึ่งทดลองแบบ 2 กลุ่ม วัดผลก่อนและหลังการทดลอง เพื่อศึกษาผลของโปรแกรมการเสริมสร้างพลังใจต่อพฤติกรรมการดูแลบุตรของมารดาที่มีบุตรเป็นโรคมะเร็งเม็ดเลือดขาวและได้รับยาเคมีบำบัด กลุ่มตัวอย่าง เป็นมารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวที่พาบุตรรับการรักษาด้วยยาเคมีบำบัดในโรงพยาบาลสังกัดของมหาวิทยาลัยจำนวน 29 คน โดยเป็นกลุ่มทดลอง 14 คน และกลุ่มควบคุม 15 คน การเลือกกลุ่มตัวอย่างมีเกณฑ์ที่กำหนด ได้แก่ มารดาที่บุตรได้รับการวินิจฉัยเป็นโรคมะเร็งเม็ดเลือดขาว, โดยบุตรมีอายุ 3- 12 ปี, ได้รับการรักษาด้วยยาเคมีบำบัดอย่างน้อย 1 ครั้ง, เป็นผู้ป่วยในและได้กลับบ้านระยะหนึ่ง มีเกณฑ์ในการจับคู่ คือ อายุของเด็ก กลุ่มทดลองได้รับโปรแกรมการเสริมสร้างพลังใจที่ผู้วิจัยจัดขึ้น จำนวน 6 เรื่อง ในการดูแลเพื่อป้องกันหรือบรรเทาผลข้างเคียงของยาเคมีบำบัด ได้แก่ 1) การติดเชื้อ 2) เลือดออกง่าย 3) เยื่อในช่องปากอักเสบ 4) คลื่นไส้ อาเจียน 5) การดูแลเพื่อส่งเสริมสุขภาพเด็ก 6) การดูแลเด็กให้มีพัฒนาการตามวัย ส่วนกลุ่มควบคุมจะได้รับการพยาบาลตามปกติ เก็บรวบรวมข้อมูลโดยใช้แบบสอบถามพฤติกรรมการดูแลบุตร วิเคราะห์ข้อมูลโดยใช้ ANCOVA โดยมีคะแนนพฤติกรรมการดูแลบุตรก่อนการทดลองเป็นตัวแปรควบคุม

ผลการวิจัยพบว่า มารดาในกลุ่มทดลองมีคะแนนเฉลี่ยพฤติกรรมการดูแลบุตรมากกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ ( $p < .05$ ) จากการวิจัยครั้งนี้มีข้อเสนอแนะว่า ควรสนับสนุนให้มีการนำกระบวนการเสริมสร้างพลังใจมาใช้ในการปฏิบัติกรพยาบาล เพื่อส่งเสริมพฤติกรรมการดูแลบุตรของมารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวที่ได้รับยาเคมีบำบัด โดยเฉพาะในมารดาที่บุตรได้รับการวินิจฉัยเป็นครั้งแรกหรือมีการกลับเป็นซ้ำของโรค

121 หน้า. ISBN 974-04-7396-2

## CONTENTS

	<b>Page</b>
<b>ACKNOWLEDGEMENT</b> .....	<b>iii</b>
<b>ABSTRACT</b> .....	<b>iv</b>
<b>LIST OF TABLES</b> .....	<b>vii</b>
<b>LIST OF FIGURES</b> .....	<b>viii</b>
<b>CHAPTER</b>	
<b>I        INTRODUCTION</b>	<b>1</b>
<b>II       LITERATURE REVIEW</b>	<b>12</b>
1. Children with leukemia	12
2. Concept of empowerment	21
3. The theory of self-care	29
4. Maternal caring behaviors for children with leukemia undergoing chemotherapy	30
5. Empowerment program of maternal caring behavior for children with leukemia undergoing chemotherapy	44
<b>III      MATERIALS AND METHODS</b>	<b>47</b>
<b>IV      RESULTS</b>	<b>60</b>
<b>V       DISCUSSION</b>	<b>67</b>
<b>VI      CONCLUSION</b>	<b>81</b>
<b>REFERENCES</b> .....	<b>84</b>
<b>APPENDIX</b> .....	<b>91</b>
<b>BIOGRAPHY</b> .....	<b>121</b>

## LIST OF TABLES

Table		Page
1	Demographic characteristics of mothers	61
2	Demographic characteristics of children with leukemia	63
3	Pre- and posttest mean scores and standard deviations for two groups of mothers	65
4	Comparison of pretest mean scores for two groups of mothers	66
5	Analysis of covariance of posttest caring behavior scores, with pretest caring behavior scores as covariate	66

## LIST OF FIGURE

Figure		Page
1	The process of data collection	58



## CHAPTER I

### INTRODUCTION

#### **Background and rationale**

Leukemia is the most common pediatric malignancy in Thailand accounting for 39.8% of all children cancers. The incidence is 3.7 per one hundred thousand children (Suvatte, in Intharakamthornchai, ed., 1999). Nowadays, the incidence of disease is increasing; according to the study by Wiangnon et al. (2003), there were 27.9 per 1 million children in 1988-1994, increasing to 36.9 per 1 million children in 1995-1997. Furthermore, statistic report in 1990-1999 showed that 1,530 children were diagnosed with leukemia in Siriraj Hospital (Siriraj Cancer Center, 2001). In Thailand, cancer has been the third ranked cause of child death behind infectious disease and accidents (Saeksan, in Jittinan, ed., 1999). Moreover, there were 620, 640, and 620 cases of children with cancer death in 2001, 2002, and 2003 respectively (Ministry of Public Health, 2003). That is why the children with leukemia are important because of the high risk and the increasing incidence.

Treatment in children with leukemia has improved the cure rate from 30% in 1970 to 76% in 2000. Success in the cure rate is due to both marked improvement of treatment and appropriate care from parents or caregivers (Veerakul & Sanpakit, in Visitsoontorn, ed., 2002). In some types of leukemia, the cure rate can get up to 90% (Hongeng, in Ratanatharatorn, ed., 1998) and 5 years disease free survival were 60-70% (Suvatte, in Intharakamthornchai, ed., 1999). In the present, there are many methods for therapy of leukemia such as chemotherapy, radiation or bone marrow transplantation. Even though chemotherapy is an effective treatment, drug agents will destroy both leukemic cells and normal cells. As a result, there are many systemic side effects of chemotherapy such as bone marrow depression, nausea and vomiting, mucositis, dermatitis, and alopecia (Hockenberry, 2004). Especially fever and neutropenia, it is a life-threatening condition that can cause death within 24 hours if the patient is not receive prompt for treatment (Copstead, 1995).

From past experience in caring for children with leukemia, the researcher found that most of them were readmitted, experienced prolonged hospitalization and related death due to side effects of chemotherapy such as infection, bleeding, and mucositis. This agrees with the study of Riley, Hann, Wheatley, & Stevens (1999) which found that the main cause of death in children with leukemia was infection (65.9%) and bleeding (19.1%). In the researcher's opinion, the cause of problems may come from side effects of chemotherapy that are inevitable as well as children receiving inappropriate or inconsistent caring from their mothers. The causes of inappropriate caring among mothers are varied. The first cause is lack of knowledge or skill. The second is belief and attitude towards the disease i.e. that it is not curable; for example, when mothers observe their children suffering from therapy, they may reject treatment or not take child for the next follow up. The third cause may come from malpractice, for example, allowing the child to eat as they want no matter if the result of this is infectious diarrhea. The final cause may come from lack of social support such as having financial problems that make the mother not able to take the child for follow up.

Children with leukemia demand caring for a long period of treatment due to the life-threatening of the disease and impact of the treatment, especially from chemotherapy. As well as this, children are not able to perform self-care management fully due to limitations of age and developmental stage. Thus, they must rely on their mothers who usually play the key roles in caring. Orem (2001) described the person that performs dependent care as the dependent care agent and classified self care requisites into three aspects: universal, developmental and health deviation. The universal requisite is caring for the child to meet his/her basic needs and promote or maintain health. This requisite consists of: caring for the child so that he/she receives sufficient intake of food, water, air; promoting normal elimination; preventing hazards; balancing activity and rest. The developmental requisite is caring for the child to promote growth and development. The health deviation requisite is caring for the child to prevent or lessen the severity of side effects of chemotherapy such as infection, bleeding, mucositis or nausea and vomiting. Children with leukemia demand close monitoring either in hospital or the home setting. Thus, caring from the health team may be insufficient. The mother should be competent in caring or be able to

problem solve or apply knowledge to care appropriately in their situation. From the reviewed literature, there have been many methods used for enhancing maternal ability to care for children with cancer such as group support (Sinsawang, 1995) and supportive-educative nursing systems (Kranseang, 1996).

In the past, enhancing maternal caring behavior for children with chronic illness focused on health education to increase knowledge and skill. The expertise of caring was professional and the direct goal was compliance (Gibson, 1999; McCarthy, Herbert, Brimacombe, Hansen, Wong, & Zelman, 2002). Nowadays, there are many studies indicating that health education only is insufficient to increase competency. McCarthy et al. proposed that in traditional health education, mothers had a passive role and depended on professionals so that the outcomes were not able to help mothers to meet their own needs in caring. Likewise, Darbyshire & Morrison (1995) stated that in the traditional medical model, mothers always take the passive role and depend on professionals. Similarly, Pellino et al. (1998) proposed that in traditional health education, the problems and needs as well as the solutions came from professionals. The goal was compliance. Therefore, strategies were used for increasing compliance. Furthermore, change behaviors came from extrinsic motivation. That is why this method is not able to help mothers in caring for children with chronic illness and complex demands of care. However, under the concept of empowerment, changing behaviors come from intrinsic motivation. The problems and concerns are explored by patient or caregiver. Gibson (1999) stated that in families of children with chronic illness, the expertise belonged to mothers, not professionals, because they had developed knowledge and practice in caring continuously, as well as knowing their children better than others. Children with leukemia require appropriate and correct as well as consistent caring, and there are many factors that affect mothers in caring such as differences in competency and receiving social support. Thus, traditional health education is not enough to enhance maternal caring behavior for these child. Additionally, traditional methods that provide information are not the appropriate way to help mothers to use their own innate competency in caring. At present, there is change of focus to participatory responsibility for health as well as to promote family centered care; the process of empowerment may be the one nursing intervention to enhance maternal caring behavior for children with leukemia. The role of the nurse is

not as an expert but to facilitate, support or coordinate with the mother for caring continuously either in the hospital or home setting.

In this study, the researcher utilized the concept of empowerment to enhance maternal caring behavior for children with leukemia undergoing chemotherapy (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996). The process of empowerment was divided into 4 steps. The first step is discovering reality, when mothers learn that their children have been diagnosed with leukemia and will require close caring and a long period of care and treatment. The mother responds emotionally, cognitively and behaviorally. Emotional responses include frustration and uncertainty about whether the disease is in remission or progression. Cognitive responses include the need for information about the disease and treatment and guidance for caring. Behavioral responses include wanting to provide the best care for the child. Sometime this response causes mothers to exhibit inappropriate behavior such as over protection or concern. This step is to help the mothers to identify problems and evaluate their experience in caring. The second step is critical reflection. It is the step to help mothers to evaluate and examine their situation critically. When the mothers develop critical reflection, they can enhance their decision-making capabilities and develop a strategic plan for caring. The third step is taking charge. It is the step to help the mothers develop a strategic plan for action. The guidance for caring may come from sharing information and experience or receiving information from professionals. Finally, the last step is holding on. When the mothers perceive their strength and competency, they are able to maintain their power even during a changing situation. Furthermore, Gibson (1995) proposed that the outcomes of empowerment are a sense of control and competency. The indicators reflecting maternal competency are knowledge and competence in caring for their child. Also, Dunst & Trivette (1996) described the outcomes of empowerment as including both the behaviors that are strengthened or learned as a result of participatory experience, and the control appraisals people make about their own capabilities and those pertaining to control over situations.

As mentioned above, empowerment could be one of the nursing interventions to enhance maternal caring behavior for children with leukemia undergoing chemotherapy. In this study, empowerment is represented as a process that contributes to behavior by motivation. Motivation is an urge in an individual to perform goal directed behavior. Therefore, motivation is an intrinsic desire in the mothers to achieve the target goal through behavior. This conceptual framing of empowerment through behavior has been supported by the study of Conger and Kanungo (1988) who proposed that the idea of empowerment is meant to enable, and that it implies a raised level of confidence to successfully execute desired behavior. From the review of the literature, no research related to empowerment among mothers on caring behavior for children with leukemia or cancer was found. However, there is research support in other chronic diseases. Utrarachkij (1997) studied the process of empowerment in mothers of children with encephalitis and the results revealed that when the mothers developed empowerment, they were confident of their own competency and caring. Similarly, McCarthy et al. (2002) studied empowering parents through asthma education and the results showed significant differences regarding sense of control and ability to provide care for parents who participated in the empowering group. Likewise, Hendrickson et al. (2002) studied empowerment in rural Viet Nam for exploring changes in the context of an integrated nutrition project. The result showed that mothers in the intervention group increased knowledge, confidence, and information sharing about child-care and feeding, while non-intervention mothers reported minimal changes in these domains.

In summary, it is concluded that childhood leukemia is a life-threatening disease with increasing incidence. There are many impacts from the disease and its treatment that affect the child and family. Additionally, leukemia is a high cost disease especially in cases of infection. Children with leukemia can be cured but it takes long term treatment to attain a cure. The severity of disease or side effects of chemotherapy is associated with death if children receive inappropriate caring. Therefore, if the mothers have competency to provide care, they would have choices in decision making and find ways to care for their child appropriately in their situation. The result of this would be to prevent or lessen side effects of chemotherapy and to help children receive treatment on schedule. Because of this, the researcher was interested in

studying the effects of an empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. This study utilized the concept of empowerment (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996) and self care theory from Orem (2001) to develop nursing interventions. The results will be advantageous in the development of maternal caring behavior for children with leukemia in the hospital and home setting.

### **Research question**

How does the empowerment program affect caring behavior among mothers of children with leukemia undergoing chemotherapy?

### **Purpose of the study**

To compare the scores of caring behavior among mothers of children with leukemia undergoing chemotherapy between an experimental group and a control group.

### **Conceptual framework**

Treatment in children with leukemia takes a long period of time. Success in curing or controlling the disease has come from advances in treatment and in children receiving correct and consistent caring from their mothers. Children can not fully perform self-care management and must rely on their mothers who always play the key roles in caring. Thus, children are dependent for care from their mothers. Orem (2001) stated that a person who performs dependent care is a dependent care agent and classified self care requisites into three aspects: universal, developmental and health deviation.

Children with leukemia demand three self care requisites during treatment. The first requisite is universal. It is providing health promotion and helping the child to meet basic needs. This requisite consists of helping the child: to receive sufficient intake of food and water; to have fresh air or good ventilation available; to promote normal elimination; to prevent hazards; to provide balance between activity and rest. The second requisite is developmental. It is caring for the child to promote continuing

growth and development. Finally, there is the health deviation self care requisite. It is caring for the child to prevent or lessen the severity of side effects of chemotherapy. Side effects are life-threatening and frequently include infection and bleeding; and side effects cause the child distress and frequently include mucositis and nausea/vomiting. Therefore, if mothers lack information and skill in caring, they would perform inappropriately in caring. It may contribute to the severity of chemotherapy or be related to death of child. Thus, the mother should have competency in caring and know how to care appropriately for their child.

Empowerment is an active process to help mothers enhance their competency to solve their problems and develop the ability to mobilize resources. When the mothers develop a sense of power, they have alternative choices in decision-making and finding ways to solve problems by themselves. The empowered are competent and feel a sense of control and mastery over their situation. Thus, the researcher was interested in using the process of empowerment as a nursing intervention to enhance maternal caring behavior for children with leukemia undergoing chemotherapy. The conceptual framework in this study was based on the concept of empowerment which consists of discovering reality, critical reflection, taking charge and holding on (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996). The foundation of empowerment is the belief that all mothers have existing strengths and capabilities as well as the capability to become more competent. The details of empowerment process are as follows:

1. Discovering reality is the step when the mothers realize that their child has health problems. The mothers respond emotionally, through anxiety and fear; cognitively, through their need for information in order to understand their situation and to help the child; behaviorally through doing everything they can for their child. Through the process of discovering reality, the mothers realize and understand their situation. In this study, the mothers were helped to realize and understand their problems and concerns by sharing their experiences and information. The mothers also had a chance to identify problem and evaluate their experience in caring.

2. Critical reflection. This step was necessary for the mothers to be able to take charge of their situation in a proactive manner to develop a sense of personal power. This is the step for the mothers to evaluate themselves and examine their

situation critically. With the ongoing process of critical reflection, the mothers sometimes became frustrated but this is a catalyst for growth and change for the process of empowerment. As a result, the mothers develop confidence in their knowledge and ability to care for their child. They fully examine reality to understand and determine their situation and also to realize that they are able to take charge in any situation. In this step, the mothers were enhancing their decision-making capabilities and understanding their situation, accepting reality and developing strategies to deal with it and drawing on their experience to search for options and to seek their own solutions. By asking questions and exploring alternatives with mothers, the mothers could make decision which were consistent with their goals. Through the process of critical reflection, the mothers became aware of their strengths, abilities and resources. In this study, the mothers were helped to evaluate and examine their situation critically by discussion of the benefits and limitations of their caring, collaboration and shared decision making. Moreover, the mothers had a chance to analyze their experience and understand their situation. When the mothers developed critical reflection, they would enhance their decision making capabilities and develop strategies and plans to deal with their situation.

3. Taking charge. In this step, the mothers became aware of their strengths and were confident in their knowledge, and able to take action in their situation. Moreover, the mothers learned assertiveness and gained a growing sense of confidence. In this study, the mothers were helped to develop a strategic plan for action. The methods to help mothers in taking action were provision of information needed to make informed choices, and demonstrating and performing practice until they were able to do it correctly and with confidence. In cases of caring correctly, the mothers are motivated by positive feedback to maintain competence.

4. Holding on. As a result of awareness of their strengths, competency and capability, the mothers were able to maintain their sense of power even during changing situations and they were able to develop a sense of control. Moreover, they continued to persist with their efforts to attain a desired outcome. In this study, the mothers were helped to maintain their competency for caring by revising their knowledge and skill until they were confident and correct in the execution of caring practices.

When the mothers become empowered, they would develop confidence in their knowledge of their child and in their decision-making for their child and the decisions were consistent with their goals. An outcomes of the process of empowerment was participatory competence. The indicators reflecting maternal competency were the mothers' developing knowledge, and increasing competence in caring for their children and making decisions. In this study, the outcomes of the empowerment process are aimed at enhancing maternal competence in caring for children with leukemia undergoing chemotherapy in three aspects of self care requisites: universal, developmental, health deviation. The ultimate expected outcomes are positive health for the children, the prevention or lessening of side effects of chemotherapy, and the children receiving treatment on schedule.

### **Hypothesis**

Mothers of children with leukemia undergoing chemotherapy who participate in an empowerment program will have caring behavior scores higher than those who receive the usual nursing care.

### **Scope of the study**

This research was to study the effects of an empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. The samples of this study were the mothers of 3-12 year old children with leukemia who took their children for chemotherapy to the Ananthamahidol building on floor 3<sup>rd</sup>, 4<sup>th</sup>, 5<sup>th</sup> and 6<sup>th</sup> floors at Siriraj Hospital, Bangkok. This study was undertaken from December 2005 to April 2006.

### **Definition of terms**

**Empowerment program** refers to the program arranged by the researcher for enhancing maternal caring behavior for children with leukemia undergoing chemotherapy. The empowering was done through individual discussion. The program was developed based on the concept of empowerment (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996). It was composed of 4 phases of interaction: initial,

action, follow up, and terminating. Contents of caring in the program were developed based on the self care concept of Orem (2001) and divided into three aspects of self-care requisites: universal, developmental and health deviation.

The process of empowerment consisted of 4 steps as follows:

Step 1: discovering reality. This step is to help mothers learn from their experience, and to understand their problems and concerns in caring. In this step, the mothers are encouraged to share their experience and information by using questioning, active listening, and reflective questions for critical thinking.

Step 2: critical reflection. This step is to help mothers evaluate themselves and examine their situation critically. When the mothers develop critical reflection, they have choices in decision making and develop strategies to deal with their situation. In this step, the mothers are encouraged to evaluate and examine their situation critically by discussion of the benefits and limitations of their caring, and by collaboration and shared decision making.

Step 3: taking charge. This step is to help mothers develop a strategic plan for action. The methods to help mothers to take action include providing information needed to make informed choices, and demonstrating and performing practice until caring procedures could be done correctly and with confidence.

Step 4: holding on. This step is to help mothers to maintain caring behavior by revising their knowledge and skill until they could execute caring practices confidently and correctly.

**Maternal caring behavior for children with leukemia** is defined as the action or the performance of mothers in caring for children with leukemia. The caring behaviors were assessed with a questionnaire which researcher constructed by utilizing self-care concept (Orem, 2001) in combination with related textbooks, research papers, and literature. There are three aspects of self-care requisites, and the details are as follows:

1. Universal self-care requisite is defined as the mother's activity to promote or maintain health of their child. Provision of care includes caring for the child to ensure that he/she receives sufficient food and water, has fresh air and good ventilation, has normal processes of elimination, has hazards prevented, and has a balance between activity and rest.

2. Developmental self-care requisite is defined as the mother's activity to provide care for development. The content was based on developmental research from Harvighurst (1953 cited in Hurlock, 1975) and Hockenberry (2005).

3. Health-deviation self-care requisite is defined as the mother's activity that provides care to prevent and lessen side effect of chemotherapy such as infection, bleeding, mucositis and nausea/vomiting. It includes practicing skills when the child has fever, epistaxis, bleeding from wound, oral assessment and oral caring.

**Routine nursing care** is defined as nursing care for mothers of children with leukemia undergoing chemotherapy and includes providing information about caring in individual or group settings and giving a handbook which is constructed by ward professionals for review at home.

### **Expected outcomes and benefits**

It is expected that the empowerment program will be able to be used in the construction of discharge planning guidelines for nurses to enhance maternal caring behavior for children with leukemia undergoing chemotherapy both in the hospital and home setting. Moreover, this program could help mothers become more confident, more competent and better able to provide care in the three aspects of self-care requisites: universal, developmental and health deviation. It is expected that there will also be advantages for children in terms of positive gains in health outcomes.

## CHAPTER II

### LITERATURE REVIEW

This research is a study of the effects of an empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. The literature reviewed for this study is presented in sequence as follows:

1. Children with leukemia
2. Concept of empowerment
3. The theory of self-care concept
4. Maternal caring behaviors for children with leukemia undergoing chemotherapy
5. Empowerment program of maternal caring behavior for children with leukemia undergoing chemotherapy

#### **1. Children with leukemia**

Leukemia is a group of malignant diseases in which genetic abnormalities in a hematopoietic cell give rise to a clonal proliferation of cell. The progeny of these cells increase in the rate of proliferation and decrease in the rate of spontaneous apoptosis (Tubergen & Bleyer, in Behrman, Kliegman, & Jenson, eds., 2004).

##### **1.1 Epidemiology**

Leukemia is the most common malignant neoplasm in children, accounting for about 41% of all malignancies. The peak age of incidence is between 2-6 years old and it occurs more frequently in boys than in girls (Tubergen & Bleyer, in Behrman et al., eds., 2004). In Thailand, leukemia was the most common of childhood cancers (38.7%). The most common type of leukemia is acute lymphoblastic leukemia. The ratio of acute lymphoblastic leukemia (ALL) to acute non lymphoblastic leukemia (ANLL) was 4.9: 1 (Wiangnon et al., 2003).

## **1.2 Etiology**

The etiology of leukemia is unknown, although several genetic and environment factors are associated with childhood leukemia. The factors that predispose children to leukemia are (Tubergen & Bleyer, in Behrman et al., eds., 2004):

1.2.1 Genetic conditions: abnormalities of chromosomes such as Down's syndrome, Bloom syndrome, Ataxia-telangiectasia, Fanconi syndrome are found frequently in children with leukemia.

1.2.2 Environmental factors: exposure to radiation both in utero and in childhood, exposure to alkylating agents, benzene exposure, and advanced maternal age.

1.2.3 Epstein-Barr virus in developing countries

## **1.3 Pathogenesis**

Leukemia is due to hematopoietic cells which are uncontrolled and have an increasing rate of proliferation. The result of this is a disruption of normal marrow function and marrow failure ultimately (Tubergen & Bleyer, in Behrman et al., eds., 2004). In children with leukemia, two forms are generally recognized: ALL and ANLL. The classification of ALL depends on characteristic malignant cells to determine morphology, phenotype, cytogenetic and molecular genetics, whereas the classification of ANLL comes from the French-American-British Classification System. ALL is divided into three subtypes: L1, L2, and L3. In the past, L3 (Burkitt cell) was associated with poor prognosis. Since these have been found to respond to a short intensive course of chemotherapy, the result of treatment has improved (Hongeng, in Ratanatharatorn, ed., 1998). Moreover, chromosomal abnormalities are found in most children with leukemia and the abnormality may be related to chromosomal number, translocation, or deletion (Tubergen & Bleyer, in Behrman et al., eds., 2004).

## **1.4 Signs and symptom**

The resulting accumulation of leukemia cells depresses bone marrow production of the formed elements of the blood and diffuses to other organs. These signs and symptoms are the result, as follows:

1.4.1 General systemic effects: fever and fatigue

1.4.2 Bone marrow failure: anemia from decreasing of red blood cells, bleeding tendency due to thrombocytopenia, infection due to abnormal dysfunction of white blood cells

1.4.3 Lymphoid system invasion: enlarged lymphnode, hepatosplenomegaly

1.4.4 Extramedullary invasion: frequently in CNS and invasion to testes and kidneys

The initial presentation is usually non-specific. Anorexia, fatigue and irritability are common presentations while low-grade fever is an intermittent presentation. Also bone or joint pain may present as complaints. When the disease is progressing, signs and symptoms of bone marrow failure are present such as pallor, fatigue, bruising or epistaxis as well as fever associated with infection (Tubergen & Bleyer, in Behrman et al., eds., 2004).

### **1.5 Diagnosis**

Correct diagnosis is crucial and is useful for selecting appropriate treatment in each child and as a guide for predicting prognosis. Leukemia can be diagnosed as described:

1.5.1 Peripheral blood: anemia and thrombocytopenia are seen in most patients. Most children with ALL present with a total leukocyte count of less than 10,000/  $\mu\text{L}$  (Tubergen & Bleyer, in Behrman et al., eds., 2004).

1.5.2 If peripheral blood suggests the possibility of leukemia, bone marrow aspiration should be done for diagnosis and differential diagnosis from other diseases that may be the causes of bone marrow failure (Tubergen & Bleyer, in Behrman et al., eds., 2004). If there are more 25-30% of blast cells in the bone marrow, it indicates acute leukemia.

1.5.3 Detect for extramedullary involvement to predict prognosis. Central nervous system (CNS) involvement of leukemia is one of the poor prognosis factor in the high risk group. Treatments are both in CNS and hematopoietic system.

1.5.4 Differentiate from other malignancy that diseases involve bone marrow such as neuroblastoma, retinoblastoma, Ewing sarcoma, rhabdomyosarcoma, and aplastic anemia. Moreover, differentiation should be done from infectious diseases

such as pertussis, infectious mononucleosis or rheumatoid arthritis (Tubergen & Bleyer, in Behrman et al., eds., 2004).

### **1.6 Treatment**

It is crucial to determine diagnosis before initiating treatment. The economic status of the family as well as intention and co-operation from parents during a long period of treatment should be considered. Furthermore, the prognosis factors should be considered at initial diagnosis and the appropriate protocol for predictive factors selected (Suvatte, in Intharakamthornchai, ed., 1999).

Nowadays, treatments are dependent on risk adapted therapy and are divided into two groups: high risk and low risk of relapsing. In the high risk group, children generally receive several drug agents in order to gain a good result of treatment whereas few drugs are provided in low risk group to decrease toxic effects (Hongeng, in Ratanatharathorn, ed., 1998).

The predictive factors include: the age of the child at first diagnosis, the initial leukocyte count and the speed of response to treatment. Children are divided into two risk groups: average risk and high risk. Children aged between 1-10 years and with a leukocyte count less than 50,000 are defined as average risk whereas, children older than 10 years or less than 1 year with an initial leukocyte count of more than 50,000 are defined as high risk (Tubergen & Bleyer, in Behrman et al., eds., 2004).

Treatment is generally divided into 2 parts: specific and supportive treatment.

1.6.1 Specific treatment: commonly divided into four phases, as follows:

1) Remission induction: the objective of this phase is to eradicate the leukemia cells from the bone marrow as rapidly as possible, to preserve normal hematopoietic cells and to restore normal hematopoiesis quickly. It is taken for 4-6 weeks (Suvatte, in Intharakamthornchai, ed., 1999). In the high risk group, the principle drugs are composed of vincristine, corticosteroid, L-asparaginase and doxorubicine. In cases of CNS involvement, drugs of choice include intrathecal methotrexate combined with cytarabine and hydrocortisone. After receiving induction, 98% of children are in remission which is defined by less than 5% blast cells in the bone marrow and the return of the neutrophil and platelet count to near normal level (Tubergen & Bleyer, in Behrman et al., eds., 2004). In cases of incomplete remission, the same treatments are given until remission is achieved (Suvatte, in

Intharakamthornchai, ed., 1999). On the other hand, after treatment for 12 weeks remission is not achieved, more intensive course of chemotherapy may be considered or supportive treatment should be provided to the child because they are not responding to treatment.

2) Intensification or consolidation therapy: this phase is administered immediately following remission induction due to leukemic cells still remaining in the body. The objective is to diminish residual leukemic cells from sanctuary sites by using many drug agents. Drug agents are selected based on their varying mechanisms of action to cell cycles of leukemia as well as prevention of drug resistance. Commonly used drugs include prednisolone combined with 6-MP, and high doses of methotrexate and cyclophosphamide (Suvatte, in Intharakamthornchai, ed., 1999).

3) CNS prophylaxis: the objective is to prevent later CNS relapse because drug agents rarely pass through the blood brain barrier to CNS (Tubergen & Bleyer, in Behrman et al., eds., 2004), and leukemic cells are resistant from a low concentration of drugs in central nervous system. The standard of CNS prophylaxis is intrathecal chemotherapy. In the high risk group prophylactic cranial radiation (usually a dose of 1800cGy) is used in combination. The radiation dose is divided into 180cGy for each session and given within 2 weeks (Suvatte, in Intharakamthornchai, ed., 1999). Today, radiation mode is reserved for the high risk group. In the low risk group, cranial radiation is not necessary because of the intermittent treatment with intrathecal methotrexate is as effective as cranial radiation. Furthermore, in cases of intermediate risk, alternative treatments are used and the most common drugs are intravenous methotrexate combined with triple intrathecal chemotherapy (Kulapong, 1997).

4) Maintenance phase: the goal of this phase is to eradicate and decrease the drug resistance of leukemic cells as well as decrease the effect of normal hematopoiesis and the immune system. The most common drugs are 6-MP combined with methotrexate and usually intermittent doses of VCR and corticosteroid (Tubergen & Bleyer, in Behrman et al., eds., 2004).

Currently, treatments to attain a cure, such as exploring for new drugs that directly affect malignant cells and decrease the effect on normal cells, are being developed. Furthermore, there are studies at the level of molecular biology and the

genetic basis of cancer. The results could be a guide for developing treatments with biological modalities such as gene therapy, tumor vaccines, antiangiogenic agents, monoclonal antibody therapy and cytokines therapy combined with chemotherapy (Veerakul & Sanpakit, in Visitsoontorn, ed., 2002).

5) Termination of treatment: treatment is terminated when children have been completely in remission for 3-3.5 years. The relapsing present 10-15% of cases and usually present within 1 year after off treatment. Afterward, the relapse rate present 2-3% per year (Suvatte, in Intharakamthornchai, ed., 1999). Relapse of leukemia are rarely presented after 4-5 years of discontinuation of treatment.

#### 1.6.2 Supportive treatment

It is crucial to provide supportive treatment to children with leukemia because they usually have abnormal signs and symptoms before diagnosis. The abnormal signs consist of fever, anemia, pain, bleeding or infection. As children are definitely diagnosed with leukemia and receive chemotherapy, they are always faced with significant suffering from the side effects of chemotherapy. Some complications, such as infection, are associated with death if receiving inappropriate treatment (Suvatte, in Intharakamthornchai, ed., 1999).

#### 1.7 Chemotherapy and side effect

Chemotherapy is the main treatment in pediatric cancer. The action of drugs is aimed to eradicate cancer cell by inhibiting synthesis and functioning of DNA or RNA. The goals are to destroy cancer cells as well as minimize the toxic effect on normal cells (Veerakul & Sanpakit, in Visitsoontorn, ed., 2002).

### 1.7.1 Antineoplastic agents used in pediatric leukemias (Bleyer, in Behrman et al., eds., 2004)

Agent	leukemia			
	ALL(pre-B)	ALL(T-cell)	ALL(B-cell)	AML
<b>Antimetabolites</b>				
Methotrexate-low dose	+	+	+	+/-
Methotrexate-high dose	+	+	+	+/-
Mercaptopurine	+	+	+	+/-
Cytarabine	+	+	+	+
Thioguanine	+	+	+	+
<b>Alkylating agents</b>				
Cyclophosphamide	+	+	+	+
<b>Antitumor Antibiotics</b>				
Doxorubicin(Adriamycin)	+	+	+	+
Daunomycin	+	+	+	+
<b>Vinca Alkaloids</b>				
Vincristine	+	+	+	+
<b>Miscellaneous Agents</b>				
Corticosteroid	+	+	+	+
L-asparaginase	+	+	+	-

+ = commonly used; - = not used or rarely used; +/- = occasionally used as a second-line or substitute agent

### 1.7.2 The side effects of chemotherapy

The most commonly occurring side effects include:

#### 1) GI system

- Nausea and vomiting: this symptom frequently occurs and causes the child suffering (Crom, Boggs, Mandrell, & Norville, 1999). The mechanism comes directly from stimulation of the vomiting center by chemotherapy (Yarbro, Frogge, & Goodman, 2004). The onset is immediate, 5-6 hours after administration, and lasts 48 hours. Experience or anxiety before receiving chemotherapy may stimulate

anticipatory nausea and vomiting. The severity depends on type, dose, frequency and mode of chemotherapy especially intravenous route.

- Mucositis: children present most frequently in distress (Yarbro et al., 2004; Hockenberry, 2005). It occurs within 3-4 days after administration (Ball & Bindler, 2003) especially high doses of methotrexate. The effect of the drugs destroy epithelial cells in the oral cavity. Children have more severe mucositis than adults because of the higher mitotic rate of child's gastric mucosa (Hockenberry, 2004). The consequences of mucositis are pain, burning, bleeding in the oral cavity and infection.

- anorexia: it is a direct effect from chemotherapy and parents are always concerned in this symptom.

- diarrhea: it is the effect of chemotherapy that destroys the intestinal surface and invades to stomach. This also causes abdominal pain (Norradechanont, 2004).

- constipation: some chemotherapeutic agents, particularly vinca alkaloid affect neurogenic intestine function and decrease bowel movement (Hockenberry, 2005).

2) Bone marrow system: bone marrow suppression usually appears 7- 10 days after administration; complete recovery is usually within 3-4 weeks (Ball & Bindler, 2003). The result from bone marrow suppression consists of decreasing the number of white blood cell, red blood cell, and platelet. Children present as follows:

- neutropenia: a short term of neutropenia lasts less than 10 days, whereas a long term exceeds 10-14 days after administration. Infection is a life-threatening condition and is related to morbidity and mortality in children with leukemia (Lehrnbecher et al., 2004). In children with neutropenia, infection may not indicated clearly due to the abnormal defense mechanism when inflamed (Crawford & Lyman, 2004). Thus, it is important for close monitoring and caring to prevent infection both in the hospital and home setting.

- thrombocytopenia: the prevalence of mortality from bleeding is 1%-3% (Yarbro et al., 2004). It commonly occurs 7-21 days after administration. Bleeding tendency is commonly present when platelets are less than  $50,000/\text{mm}^3$ ; spontaneous

bleeding may presents when platelets are less than 20,000/mm<sup>3</sup>; cranial hemorrhage may presents when platelets are less than 10,000/mm<sup>3</sup>.

- anemia: children commonly exhibit fatigue and are easily tired when there is a decrease of RBC.

3) Alopecia: hair loss is a common side effect. It is a temporary symptom and hair begins to regrow in 3-6 months and may be slightly different color or texture such as being darker, thicker or curlier (Hockenberry, 2005).

4) Urinary system: cyclophosphamide is often associated with cystitis (Hockenberry, 2005). The cause of uric acid nephropathy and renal failure may come from inadequate water intake.

5) Nervous and muscular system: the neurotoxic effect may come from vincristine. The child can exhibit peripheral neuropathy and muscle weakness (Hockenberry, 2005).

The Adverse effects of various chemotherapeutic agents (Bleyer, in Behrman et al., eds., 2004)

<b>Drugs</b>	<b>common adverse effect</b>	<b>uncommon adverse effect</b>
<b>Antimetabolite</b>		
Methotrexate	myelosuppressive, mucositis, hepatitis	neurotoxicity
Ara-C	myelosuppressive, nausea/vomiting	mucositis, neurotoxicity with intrathecal
6-TG	myelosuppressive	nausea/vomiting
6-MP	myelosuppressive, nausea/vomiting	mucositis
<b>Alkylating Agents</b>		
Cyclophosphamide	myelosuppressive, hemorrhagic cystitis	mucositis
<b>Antibiotics</b>		
Doxorubicin	myelosuppressive, nausea/vomiting	cardiomyopathy
<b>Vinca Alkaloids</b>		
Vincristine	peripheral neuropathy, jaw pain, constipation, alopecia	obstipation
<b>Miscellaneous Agents</b>		
Corticosteroid	Cushing' s syndrome, diabetes, hypertention	hypokalemia, myopathy, growth delay
L-asparaginase	hypersensitivity reaction, coagulopathy	encephalopathy, pancreatitis

### 1.7.3 Late effects of treatment

1) Secondary malignant neoplasms: children receiving cranial radiation at age 4-5 years or younger are most susceptible to develop brain tumors (Silverman & Sallan, 2003 cited in Hockenberry, 2005). Brain tumors are commonly seen in children with ALL, and are especially associated with cranial irradiation (Whitlock & Gaynon, in Greer et al., eds., 2004).

2) Cardiac toxicity: treatment with anthracycline is associated with cardiomyopathy (Hockenberry, 2005) and development of clinical congestive heart failure (Whitlock & Gaynon, in Greer et al., eds., 2004).

3) Neurocognitive effects: cranial irradiation can produce neurologic dysfunction while spinal irradiation can produce growth retardation (Bleyer, in Behrman et al., eds., 2004). Eighteen-Gy brain irradiation may result in a gradual decline in full scale IQ score of 4 points per year after diagnosis (Whitlock & Gaynon, in Greer et al., eds., 2004).

4) Endocrinologic disturbance: cranial or craniospinal irradiation may lead to short stature and precocious puberty in girls (Whitlock & Gaynon, in Greer et al., eds., 2004).

## 2. Concept of empowerment

Empowerment is widely used for developing individuals, groups, organizations, and communities. It has been used in a variety of fields such as the social, educational, political, psychological, organizational management and health fields. In the health field, the concept of empowerment is commonly used in the aspect of therapeutic or health promotion. Furthermore, it has been used by diverse groups such as patients with chronic illnesses and their caregivers, psychiatric patients, the aging, students, adolescents, drug addicts, nurses, and people in general in the community or an organization.

### 2.1 Definitions of empowerment

Empowerment is difficult to operationalize because it is highly abstract, complex, and multidimensional. It can also be either a process or an outcome (Gibson, 1991; Rodwell, 1996). However, empowerment could be defined based on

characteristics of a group or context. From the reviewed literature, there were many studies defining empowerment. They are listed as follows:

Bishop et al. (1988): empowerment is defined as an active process of educative empowering.

Hawks (1992): empowerment is defined as the interpersonal process of providing the proper tools, resources and environment in order to build, develop and increase the ability and effectiveness of others to set and reach goals for individual and social ends.

Gibson (1995): empowerment is defined as a social process of recognizing, promoting and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize the necessary resources in order to feel in control of their own lives.

Feste & Anderson (1995): empowerment is defined as an educational process to help patients develop knowledge, skill, attitudes, and self-awareness to effectively assume responsibility for their health-related decisions.

Rodwell (1996): empowerment is defined as a helping process; a partnership valuing self and others; mutual decision-making; and freedom to make choices and accept responsibility.

Ryles (1999): empowerment is defined as a positive concept that suggests a growth in competencies in negotiating and expressing, with and to, our fellow human beings as a means of gaining access to scarce resources.

Nyatanga (2002): empowerment represents both a process and an outcome involving the individual or group's ability to pull from within themselves the power to influence or control significant events in their lives. The ultimate goal of empowerment is well-being.

In summary, empowerment is an interpersonal process to help people to draw on their innate competency for solutions. It is the process of helping people to have choices in decision-making and finding ways to solve problems by themselves. The empowered are competent, autonomous, and relate to others. They are also able to control factors that affect them (sense of control).

## 2.2 Defining attributes

The defining attribute of empowerment is embodied in an interpersonal process and mutual decision-making (Gibson, 1991; Hawks 1992; Rodwell, 1996). Gibson (1991) proposed that empowerment can be viewed as a process or as an outcome; it is focused more on solutions than problems; it addresses revolution more than reform; it is a positive and a democratic concept; and it addresses people's strengths, rights and abilities rather than deficits and need. Furthermore, Hawks (1992) described empowerment as an interpersonal process characterized by open communication and mutual goal setting. Moreover, Rodwell (1996) explained empowerment as a helping process, a partnership which values self and others and the freedom to make choices and accept responsibility. Finally, Nyatanga (2002) stated that empowerment can be viewed as a dynamic psychological process characterized by treating people as equals, especially valuing their perceptions and experiences, and by providing individualized care plans and not allowing things to be solely decided by professionals but rather to be owned in partnership with patients.

### 2.2.1 Attribute of empowerer

Gibson (1991) proposed that the nurse can be viewed as a helper, supporter, counselor, educator, resource consultant, resource mobilizer, facilitator, enabler and advocate. Also, Hawks (1992) explained that the nurse who is empowered must possess and use professional skills such as communication and interpersonal skills, be willing to give choices and encouragement to patients and caregivers, and to involve them in decision-making and goal setting. Furthermore, Dunst & Trivette (1996) described the help giver attributes as including beliefs about the help receiver's competencies and the capacity of help receivers to become capable of dealing effectively with situation, concerns, and desires. Moreover, Nyatanga (2002) stated that nurses should learn from patients as much as patients learn from nurses and nurses must use empathic understanding in order to facilitate empowerment for each patient.

### 2.2.2 Attributes of the empowered

Hawks (1992) stated that the attributes of the empowered include a willingness to accept empowering behavior, responsibility, and participation in goal-setting and decision-making.

## 2.3 Factors related to empowerment

### 2.3.1 Antecedents

There have been many studies of antecedents or preconditions of empowerment. The antecedents are love and bonding (Utrarachkij, 1997; Gibson, 1995); commitment (Gibson, 1995; Rodwell, 1996; Ryles, 1999); nurturing and a caring environment (Hawks, 1992; Ryles, 1999); mutual trust and respect (Hawks, 1992; Rodwell, 1996; Ryles, 1999); and participation (Rodwell, 1996; Ryles, 1999). Furthermore, Hawks (1992) described the antecedents included openness, honesty, and acceptance of people as they are. Moreover, Ryles (1999) explained that the primary antecedent to promote empowerment included open communication, honesty, openness and genuineness.

### 2.3.2 Influencing factors

Gibson (1995) proposed that the factors that influence the process of empowerment are both intrapersonal and interpersonal; they are described below:

#### 1) Intrapersonal factors

1.1) value: such as value of the children themselves and their families.

1.2) beliefs: beliefs are influential factors that help mothers to deal with their difficulties. The beliefs include belief in their own ability to care or belief in the ability of a health team to help the child.

1.3) Determination

1.4) Experience: the mother can learn to care from her experience. The source of experience may come from her own learning, her family, or professionals.

2) Interpersonal factor: social support is an interpersonal relation that influences the process of empowerment. The sources of support may include spouse, families, friends, the health team, and other mothers in similar situations.

Jenjob (1999) stated that the influencing factors of empowerment in patients with rheumatoid arthritis consisted of building trust, respect and acceptance, providing a safe environment, participation, belief in competency of other people, and autonomous opinions.

## 2.4 The process of empowerment

Empowerment is a dynamic and learning process. Studies of the process of empowerment are described below:

Bishop et al. (1988) described empowerment in terms of educative empowering based on the principle that learners should be empowered to take control of their own learning which will enable them to seek out and be aware of alternatives and thus to make choices for themselves. They described how learning from experience is crucial because the process of learning from experience is the key for critical thinking. The elements in the educative empowerment, the learning/reflection process, are described as follows:

1) Experience: it is the core of learning. Experience includes everything that they are, do, feel, see and hear. It is the beginning point for learning to be shared within a group.

2) Naming Experience: it is the process of describing and identifying experiences: what happened; the significance of the experience; what they did, said, felt; what others did, said, felt; what things were not understood. Through the process, they are sharing their experiences around the issues and connecting the issues with their lives.

3) Analysis: it is the process of understanding the experience and critically thinking, and of analyzing who has power in this situation, whose voice is heard, who makes the decisions, and what is similar in this situation to others. This helps the learners to understand and clarify problems on their own.

4) Planning: it is the critical stage in the learning process when they begin to develop strategies and plans for action. During this phase, the learners are helped to identify what it is they want to do, how to do it based upon what they have learnt from experience and how to develop strategies for caring action.

5) Doing: it is the stage in which they act as a result of learning, because doing becomes the next concrete experience. Thus, thinking what to learn from the next experience and setting goals for learning are crucial. Moreover, the doing becomes the new experience and one starts around the spiral again.

Although research related to the process of learning and reflection in the mothers of children with chronic illnesses population is limited, the learning and reflection process has been applied and the results have supported its effectiveness in the chronic illness population. Suvanarak (1999) studied the application of empowerment in self-care of diabetic patients and utilized the process of learning and reflection. She found that patients in the intervention group significantly improved their self-care.

Gibson (1995) studied the process of empowerment in mothers of chronically children and divided the process into 4 components:

1. Discovering reality: this is the initial phase when mothers realize that there is something wrong with their children. When mothers discover reality, the responses are as follows:

- 1.1 Emotional responses, such as bewilderment, shock, confusion, fear, anxiety, and anger.

- 1.2 Cognitive responses: following diagnosis, mothers feel unsure and face uncertainty. They seek information about the disease and treatment from books, doctors, nurses, or other mothers in similar situation.

- 1.3 Behavioral responses: because of their responsibility for the health of the child, mothers do everything possible for their child. In some cases, they are overprotective or overly concerned.

Similarly, Utrarachkij (1997) studied the process of empowerment in mothers of chronically ill children. In the phase of discovering reality, mothers felt frustration, anxiety, anger, fear and sadness. The methods that helps mother to decrease fear included confidence in their own competency and commitment to supporting the child.

2. Critical reflection: In this phase, frustration acts as a catalyst for growth and change (Gibson, 1999). Through the process, the mothers fully examine their situation to understand and determine it and they also realize that they are able to take charge in any situation. Consequently, mothers develop an awareness of their strength, rights, and resources.

Likewise, Utrarachkij (1997) revealed that in the phase of critical reflection, even through mothers felt fear and frustration, they learned about everything that can benefit the child by methods such as seeking information for caring and developing their ability to care.

3) Taking charge: in this phase, mothers are aware of their strengths, confident in their knowledge of how to care, and able to take action in their situation. Moreover, mothers learn assertiveness and gain a growing sense of confidence. Gibson (1995) described how taking charge entails advocating for the child, learning the ropes, learning to persist, driving negotiation in the hospital setting, and establishing partnerships.

Likewise, Utrarachkij (1997) explained that in the taking charge phase, mothers were confident in caring, and assertive in negotiations with doctors.

4. Holding on: this is the final phase, when mothers are aware of their strengths, competency and capabilities. They are able to maintain a sense of power even in changing situations. They develop a sense of control, perform other activities and maintain balance in their lives.

Similarly, Utrarachkij (1997) described how in the holding on phase, mothers were able to manage difficult situations such as extubation, and preserve normal daily activities of life in their families.

Dunst & Trivette (1996) described empowerment in terms of ideology and participatory experience. The ideology of empowerment is the belief that all people have existing strengths and capabilities as well as the capacity to become more competent. Participatory experience includes collaboration about the interests and concerns of two or more people who bring collective wisdom and knowledge of solutions to problems and the attainment of desired goals and outcomes. Moreover, they stated that one of the three components of effective help-giving practices is participatory involvement and this includes practices that provide help for the receiver and opportunities to discuss the benefits and limitations of different choices, provision of information for making such choices, collaboration and shared decision making between help receivers and help givers, and that provide for active involvement of help receivers in choosing among options.

## **2.5 Outcome and consequence of empowerment**

Empowerment is a dynamic process with varying dimensions. Thus, the outcomes and consequences of empowerment are difficult to measure (Gibson, 1991). From the review of related literature, there were many documents found indicating the outcomes and consequences of empowerment. They are described below:

### **2.5.1 Outcomes of empowerment**

The outcomes of empowerment are increasing the ability to set and reach goals (Hawks, 1992; Rodwell, 1996), and building relationships or changing in relationships with others (Ryles, 1999; Falk-Rafael, 2001). Furthermore, Gibson (1995) described the outcome of empowerment can be conceptualized as participatory competence and indicators that reflect competence including developed knowledge, developed competence in caring for their child and making decisions, and developed confidence in communication. Besides, Dunst & Trivette (1996) described the outcomes of empowerment as including both the behaviors that are strengthened or learned as a result of participatory experience, and the control appraisals people make above their own capabilities and those pertaining to control over situations. Moreover, Falk-Rafael (2001) explained that the outcomes included changes in self in the aspects of self-esteem and self-confidence, and changes in behavior that they are able to determine for alternative choices of health for themselves and their families.

### **2.5.2 Consequences of empowerment**

A sense of mastery of their situation, self-development, personal satisfaction, purpose and meaning in life are the consequences of empowerment (Gibson, 1995). Besides, Rodwell (1996) proposed that consequences include positive self esteem, ability to set and reach goals, a sense of control over the life and change process and a sense of hope for the future. Furthermore, Dunst & Trivette (1996) described the consequences of empowerment in terms of competency-enhancement rather than dependency-formation. Moreover, Ryles (1999) described how consequences are self-awareness and personal growth.

Nevertheless, Gibson (1995) proposed some negative consequences of empowerment such as rejection from health care professionals due to professional unwillingness to share their power, too much responsibility in caring, and not receiving support as they required.

### 2.5.3 Research related to the outcome of empowerment in caring behavior

Petchtone (2004) studied the effectiveness of an empowerment program on care-giving ability among family caregivers of cerebrovascular disease patients and utilized the process of empowerment from Gibson (1995). The result showed that caregivers in the intervention group significantly increased their knowledge and care-giving ability ( $p < .001$ ).

Sakulnoom (2002) studied the effect of an empowerment program on perceived self-efficacy for self-management among mothers of children with congenital heart disease and utilized the process of empowerment from Gibson (1995). The result revealed that mothers of children in the intervention group significantly increased perceived self -efficacy for self-management over the control group ( $p < .05$ ).

McCarthy et al. (2002) studied empowering parents through asthma education. The result showed that parents in the empowering group significantly increased ability to provide care, ability to make decisions and sense of control than the control group ( $p < .05$ ).

Sathirapanya (2001) studied the effectiveness of empowerment for enhancing quality of life among ischemic stroke patients and their relatives and utilized the process of empowerment from Gibson (1995). The result showed that relatives in the experimental group had significantly improved knowledge and skills for caring.

### 3. The theory of self-care

Self-care is the practice of activity that persons initiate and perform on their own behalf in maintaining life, health, development and well being (Orem, 2001). As a result of pathology and treatment combined with limitations of age and development, children with leukemia are not able to complete their self-care. Thus, they depend on others, particularly on mothers who always play a key role of caring. Orem (2001) described a dependent care agent as a person who accepts and fulfills the responsibility to know and meet the therapeutic self-care demand of relevant others who are socially dependent on them.

Therapeutic self-care demand is the summation of care measures necessary at specific times or over a duration of time for meeting all of an individual's known self-care requisites. The self-care requisites are divided into three types as follow:

1. Universal self-care requisite: the universal requisite is the actions to maintain human structure and functioning. When provided effectively, organized dependent-care fosters positive health and well being. The general set of actions for meeting universal self-care requisites are as follows:

- 1) Maintenance of sufficient intake of air, water, food
- 2) Provision of care associated with eliminative process and excrement
- 3) Maintenance of a balance between activity and rest
- 4) Maintenance of a balance between solitude and social interaction
- 5) Prevention of hazards to life, functioning, and well-being
- 6) Promotion of normalcy

2. Developmental self-care requisite: this requisite is relevant to initial formation of human structure, function, and behavior. Each individual at their own stage of developmental becomes personally involved in his or her development and movement to maturity. The developmental requisite can be met by dependent care agents, parents or others.

3. Health deviation self-care requisite: this requisite exists for persons who are ill, or have pathology from medical diagnosis or treatment.

#### **4. Maternal caring behavior for children with leukemia undergoing chemotherapy**

Children with leukemia must meet the self-care requisites during continuing therapy to attain a cure. The self-care requisites include: universal, developmental, and health deviation. The universal requisite is important because these children demand the basic needs of daily life as well as needing to maintain health in order to receive chemotherapy on schedule. The developmental requisite is essential because in this age there is continuing growth and development in physical and psychosocial aspects. Furthermore, as a result of pathology of leukemia and receiving treatments especially chemotherapy, health deviations usually occur from the toxic effect of drug agents.

Therefore, health deviation self-care requisite is crucial for children. Thus, provision to care these children entails the following:

#### **4.1 Universal self-care requisite**

It is a kind of care that responds to the basic need of children with leukemia, as follows:

4.1.1 Caring for children to receive sufficient intake of food. Hockenberry (2004) stated that children treated for cancer experienced altered nutrition in 8% to 32% of cases. Moreover, adequate nutrition is essential because they demand sufficient food to balance the high metabolic rate and to rebuild body tissue (Peckenpaugh & Poleman, 1999). Furthermore, adequate nutrition provides enhanced immune function to prevent infection (Carter, 1993). Therefore, provision of caring to preserve for sufficient intakes of food are as follows:

- Encouraging the child to eat food such as 1) proteins which come from meat, milk, and peanuts 2) carbohydrate which come from rice or noodles 3) fat which comes from meat and meat products, milk, and vegetable oil 4) vitamins and minerals which come from vegetables such as pumpkin, cucurbit, cabbage and from fruits such as oranges, bananas, and papayas 5) vegetables and fruit (not raw vegetable and wash fruit before eating).
- Providing a diet with fresh fruits, nuts and seeds (especially pumpkin and sunflower seeds), making own juices of fruit or vegetables, avoiding foods such as red meat, saturated fats (substitute soya), smoked and salt cured foods (from Best Practice diets for the cancer patient).
- Avoiding food which may be contaminated with infectious organisms.
- Providing healthy food such as low salt, low fat, and low sugar meals and not provide snacks due to excessive weight gain related to glucocorticoid (Landier, 2001).

4.1.2 Ensuring that children receive sufficient intakes of water. Encouraging the child to drink increased water while receiving chemotherapy especially within 2 days after administration in order to excrete waste products, prevent cystitis, and inhibit the information of uric acid in kidney. Children should be offered at least 6-8

glasses of water per day. When the climate is hot or children are playing or using more energy, water consumption should be increased.

4.1.3 Ensuring that children receive sufficient intake of air. Providing children with a place with fresh air or good ventilation. Avoiding taking children to large crowds such as department stores as well as keeping away from anyone with known or suspected infections such as chickenpox or respiratory tract infection. Encouraging the child to wear a mask when going to large crowds (Ball & Bindler, 2003).

#### 4.1.4 Provision of care for normal elimination and excrement

Constipation is a common problem in children undergoing chemotherapy. Prevent it by encouraging children to toilet at least 1 time per day and providing fluid and fiber such as vegetables and fruit (Landier, 2001; Ball & Bindler, 2003). Encourage them to perform activities if not indicated for limitation in order to increase bowel movement (Norradechanont, 2004). If children have constipation or pain at the anal area, consult doctors immediately.

#### 4.1.5 Provision of care to prevent hazards, as following:

- Keep clean by bathing and brushing teeth with toothpaste twice daily: in the morning and bed time. Keep genitourinary area clean after using toilet.
- Prevent extravascular leakage of chemotherapeutic drugs by immobilizing at intravenous site and observing for abnormal signs such as pain, swelling, redness around the intravenous site while receiving chemotherapy and promptly consult health team when an abnormality is present.
- Provide and arrange for a safe environment

4.1.6 Ensuring that the child a balance between activity and rest. Provide at least 8-10 hours sleep per day and increase rest or sleep for 1-2 hours when children are weak or fatigued.

## 4.2 Developmental self-care requisite

Childhood is the period of life with continuing growth and development. In children with leukemia, there are many factors that affect development such as pathology of disease, impact from treatment and chronic illness and intermittent hospitalization. Thus, provision to promote development is essential in these children.

Harvighurst (1953 cited in Hurlock, 1975) described the developmental task as a task which arises at a certain period in the life of the individual, successful achievement of which leads to his happiness and to success with later tasks, while failure leads to unhappiness and difficulty with later tasks. In this study, the researcher utilized the concept of Harvighurst and literature from Hockenberry to promote development and divided provision of care into 2 groups: preschool age and school age. The details are as follows:

4.2.1 Preschool age: the age criteria came from Erickson's stage of development and Hockenberry (2005) and described the age at this stage as 3-5 years. Developmental tasks during this life span include developing initiative, accomplishment in self-care, initial development for relations in peer group, increasing conceptual thinking, learning to distinguish right and wrong, and learning to give and take with others.

The provision to promote developmental task in preschool age children is as follows (Hurlock, 1975; Hockenberry, 2005):

- Encourage child to perform daily self-care such as bathing, toothbrush, eating, dressing.
- Promote relationship in peer group to prepare for peer group age and living with others.
- Provide play or perform activities appropriate to age and illness such as 1) play which is not harmful or injurious 2) promote creative thought such as block building, drawing or painting. 3) select the television stories that are appropriate for children such as features or animal stories or cartoons 4) provide music or story telling.
- Avoid overprotection. Teach them to learn decision-making and solve easy problems on their own.
- Explain that the cause of illness do not come from the child and do not punish them.
- Monitor for growth continuously.
- Understand emotions in this age that are commonly exhibited such as anger, fear, jealousy, joy, grief, affection.

- Prepare for learning skills such as teaching them to count 1-10, encouraging them to read basic content, and read books to them.
- Promote appropriate behavior such as not saying impolite words, not destroying things when angry, and learning to forgive when doing something wrong, and accepting that they are wrong when they exhibit inappropriate behavior.
- Teaching them to control elimination and clean after using toilet.
- Teaching children to offer toy to others and learn to give and take.

4.2.2 School age: the age criteria are from Erickson's stage of development and Hockenberry (2005) and the age described at this stage is 6-12 years. Developmental tasks during this stage include developing sense of accomplishment and relations in peer group, learning to work or live with peer group, increasing concrete thinking, becoming independent, developing fundamental skills in reading, writing, and calculating.

The provision to promote developmental task in school age children is described as follows (Hurlock, 1975; Hockenberry, 2005):

- Monitoring for growth continuously.
- Encourage the child in self-care because at this age they are able to eat or dress by themselves. Promote the performance of daily activities life if there is no indication for limitation because this age demands independence.
- Promote social skills because at this age they develop in helping others. Thus, encourage them to do homework. Encourage them to perform activities with the family, peer group or others in order to promote learning for adaptation or living with others.
- Promote learning skills such as writing, drawing, painting, singing, reading and performing activities with peers or teachers in the hospital.
- Promote appropriate play given their illness.
- Understand the interest in this age in things such as appearance, clothes, school, health, vacations, and autonomy.
- Teach them to give and take with others.
- Promote the exhibition of emotions or appropriate behavior such as not saying impolite words, not destroying things when angry, and learn to forgive

when they do something wrong, and accept that they are wrong when they exhibit inappropriate behavior.

- Explain disease and treatment and encourage the child to participate in self-care.

### **4.3 Health deviation self-care requisite**

Provision to care correctly, consistently, and continuously to prevent and lessen side effects of chemotherapy. The details of caring are as follows:

#### **4.3.1 Infection**

##### **1) Prevent infection**

- Clean the body by bathing daily, and performing frequent mouth care (Ball & Bindler, 2003; Yarbro et al., 2004; Baggott et al., 2004).
  - Frequent hand washing (Ball & Bindler, 2003; Hockenberry, 2005).
  - Eat low bacterial diet (Landier, 2001; Ball & Bindler, 2003), wash fruit and vegetables before eating (Baggott et al., 2004).
  - Avoid uncooked food (Landier, 2001; Yarbro et al., 2004).
  - Avoid raw vegetables (Yarbro et al., 2004) and processed meats (Landier, 2001).
  - Provide nutritionally complete food to support the body's natural defenses (Hockenberry, 2005).
- Screen all visitors for signs of infection to minimize exposure to infective organisms. Limit visitors if they are suspect for infection (Baggott et al., 2004; Hockenberry, 2005).
  - Administer antibiotics as prescribed such as bactrim to prevent pneumocystic carinii (Landier, 2001; Hockenberry, 2005).
  - Avoid large crowds such as department stores (Ball & Bindler, 2003; Yarbro et al., 2004) and wear a mask when going to these places.
  - Avoid contact with sick people (Landier, 2001; Yarbro et al., 2004).
  - Avoid live attenuated virus vaccines such as measles, mumps, rubella, oral polio virus because these vaccines can result in overwhelming infection (James et al., 2002; Hockenberry, 2005).

- Evaluate the child for any potential sites of infection such as mucosal ulcerations, abrasion wound, and dental problems for early treatment (Hockenberry, 2005).

- Evaluate for fever and signs of infection (Yarbro et al., 2004), and seek prompt help if there are signs of infection such as cough, fever, runny nose, tugging at the ear (Ball & Bindler, 2003).

## 2) Management of children with febrile neutropenia or infection.

Caring for children with febrile neutropenia or infection is the same as for prevention but more strict, especially in cases of severe neutropenia. Protective isolation or limitation of visitors is essential. Hospitalization may be necessary because these children need close observation, monitoring, caring and antibiotic administration. In children prescribed antibiotics for home use, it is essential to take the medication as prescribed.

## 3) Caring for children with fever.

Information source from [www.Joannabriggs.edu.au](http://www.Joannabriggs.edu.au). The finding was best practice “Management of the child with fever” and described management, as follow:

- Single dose of paracetamol can produce a reduction in temperature (level II)

- Increase fluids and remove clothing (Level IV)
- Provide cooling such as a cool bath or tepid sponge, use of fan, and reduction of room temperature.

- The routine use of sponging to reduce fever is not supported (Level II) but this method can help the child feel comfortable. However, there is evidence that paracetamol combined with sponging can reduce temperature 1.3°C - 1.7°C.

### 3.1) Caring for children with fever.

The provision to care for children is taken from best practice “Management of the child with fever”; James et al. (2002); Hockenberry (2005) and the details are as follow:

- Provide tepid bath if no sign of shivering or no indication for limitation.

- Provide tepid sponge combined with administration of acetaminophen.

- The method for tepid sponging includes using tepid water (Water temp between 29-32 °C); wetting the wash cloths and placing them on the child, especially on axillary, neck, face; and placing the wet cloth until it becomes warm then changing it.

- Encourage child to meet adequate hydration by forcing oral fluids.
- Removing thick or excess cloth, and dressing in lightweight clothing.

- Frequent changing if clothing is wet.

- Keep the environment for good ventilation and cooling. Use fans or air conditioner to reduce room temperature in cases of no shivering.

- Administration of acetaminophen as prescribed and then repeated dose every 4 hours if fever is not lessened.

- Consult doctor immediately when children are drowsy or fever is not lessened because it may be the sign of infection.

### 3.2) Assess body temperature (Kozier, Erb, Berman, & Synder, 2004)

The body temperature is frequently measured orally. If children have taken cold or hot food or fluid, assessment should be delayed for 30 minutes before taking the temperature orally to ensure that the temperature of the mouth is not affected by the food or fluid. In children with oral mucositis, axillary method is appropriate for assessment. The procedure for assessing body temperature is as follows:

- Check that thermometer function is normal and shake the glass of thermometer down to below 35°C or shake fluid into the bulb.

- Explain to child what to do or how to for cooperating.

- Wash hands before recording body temperature.

- Thermometer placement: orally by placing the bulb on either side of the frenulum; axillary by placing the bulb in the center of axilla and patting the axilla dry if very moist.

- Wait for the appropriate amount of time: 2 to 3 minutes for orally and 6 to 9 minutes for axillary.

- Remove thermometer and read the temperature. If the temperature is too high, too low, or inconsistent with the child's condition, recheck that the thermometer is functioning properly and repeat measures.
- Consult physician immediately if the temperature is more than 38°C every 4 hour 2 times or more than 38.5°C one time because it may be a warning sign of infection.

#### 4.3.2 Bleeding tendency

##### 1) Prevention of bleeding tendency

- Clean mouth often and gently using soft toothbrush. If platelet levels are low, use swabs instead of toothbrush (Yarbro et al., 2004; Hockenberry, 2005).
- Avoid playing contact sport or performing activities with potential for injury such as football, riding bicycles, or climbing tree (James et al., 2002; Hockenberry, 2005) and encourage children to perform or participate in quiet activities such as reading books, watching videos, or coloring (James et al., 2002).
- Avoid medications that induce prolong bleeding or interfere with platelet function such as aspirin (Yarbro et al., 2004; Hockenberry, 2005).
- Inspect for bleeding such as pethichiae, epistaxis, ecchymosis, melena (Hockenberry, 2005).
- In cases of severe thrombocytopenia, children should restrict activity that could result in accidental injury, and offer the child involvement in responsibility for limitation activity in order to gain compliance (Hockenberry, 2005).
- Arrange home and environment for safety to prevent bleeding tendency from falling or injury.

##### 2) Management for bleeding

###### 2.1) Epistaxis management

- Apply continuous pressure to the nose with thumb and forefinger for at least 10 minutes (Rosdahl & Kowalski., 2003; Hockenberry, 2005). While applying pressure, tell the child to use mouth breathing instead of nose breathing.
- Apply ice, cold cloth or ice bag to bridge of nose (Rosdahl & Kowalski, 2003; Yarbro et al., 2004; Hockenberry, 2005).

- Keep child calm and quiet (Hockenberry, 2005) because crying induces increasing pressure in nasal cavity and the result is more epistaxis or difficulty in stopping bleeding.

- Consult physician immediately if epistaxis does not stop within 5 minutes (Shaffer, 1994).

#### 2.2) Procedure to stop bleeding from wound

- After dressing wound, apply pressure at the site without disturbing clot formation for at least 10-15 minutes (Yarbro et al., 2004; Hockenberry, 2005).

- Apply ice or cold cloth or ice bag compression (Hockenberry, 2005) for at least 5-10 minutes (Yarbro et al., 2004)

- Keep children calm and quiet (Hockenberry, 2005).

- Observe for bleeding. If not stopping, consult physician immediately.

2.2 Inspect for signs of bleeding such as epistaxis, petechiae, ecchymosis, hematuria, melena. If there are signs of abnormality, consult physician immediately (Ball & Bindler, 2003).

### 4.3.3 Nausea and vomiting

#### 1) Prevention of nausea and vomiting

- Eat cracker before chemotherapy administration (Schroeder, in Gulanick et al., eds., 1998; Baggott et al., 2004) or provide soft diet (Baggott et al., 2004).

- Avoid foods that stimulate or induce nausea and vomiting such as fried foods, fatty foods and sweet foods (Schroeder, in Gulanick et al., eds., 1998; Yarbro et al., 2004).

- Provide small and frequent food intake (Schroeder, in Gulanick et al., eds., 1998; Hockenberry, 2005).

- Avoid food with strong odors that induce nausea and vomiting (Paice, 1999; Hockenberry, 2005).

- Clean mouth and teeth often (Baggott et al., 2004; Yarbro et al., 2004).

- Do not lie down after meal (Baggott et al., 2004).

## 2) Lessening nausea and vomiting

- Mouth care after vomiting (Crom et al., in Miaskowski & Buchsel, eds., 1999).
- Offer cool or clear liquids and no eating of fried food, fatty food and sweet food (James et al., 2002).
- Provide quiet environment and fresh air (Paice, in Miaskowski & Buchsel, eds., 1999).
- Offer fruit juice such as orange or lime. Suck on sour candy (Paice, in Miaskowski & Buchsel, eds., 1999).
- After vomiting, offer liquid diet (Norradechanont, 2004) or soft diet (Paice, in Miaskowski & Buchsel, eds., 1999; Baggott et al., 2004).
- Clean and place cool cloth on face and neck (Yarbro et al., 2004).
- Consult physician immediately if children vomit 1 to 2 times per day within 2 days (James et al., 2002) or decrease intake or experience severe weakness.

### 4.3.4 Oral mucositis

From database [www.Joannabriggs.edu.au](http://www.Joannabriggs.edu.au). Finding best practice “Prevention and Treatment of Oral Mucositis in Cancer Patients”. The guidance for caring is as follows:

- Brush teeth after every meal and at bedtime
- Rinse mouth with water consistently
- Avoid food or drink that is hot or highly spicy
- Inspect oral cavity regularly, consult professional if oral cavity is red, painful or sore
- Coat lips with moisturizer, do not allow drying
- Offer glutamine supplement intake to decrease mucositis

Provision of care to prevent or lessen mucositis is drawn from best practice and review literature and the details are as follows:

## 1) Prevent oral mucositis

- Use a soft brush (Ball & Bindler, 2003; Hockenberry, 2005).
- Brush teeth within 30 minutes after eating and at bed time (Yarbro

et al., 2004).

- Provide soft diet, avoid food or drink such as hot or spicy food that irritates epithelial cells (Yarbro et al., 2004; Hockenberry, 2005).
- Rinse mouth every 4 hours and after meals (Hockenberry, 2005). Duration time for rinse should be 1-2 minutes (Yarbro et al., 2004).
- Rinse mouth with NSS (salt solution is mixed by using a half teaspoon of salt in 8 ounces of water) (Yarbro et al., 2004). When NSS is empty, use water instead of NSS.
- Avoid buying commercial mouthwash because it contains alcohol which increases drying of the oral cavity (James et al., 2002; Ball & Bindler, 2003).
- Apply lip balm to keep lips moist and prevent cracks or fissures (Yarbro et al., 2004; Hockenberry, 2005).
- When the mouth is dry, frequently drink water or other fluids (Yarbro et al., 2004).
- Inspect for oral ulcers daily or frequently (Ball & Bindler, 2003; Hockenberry, 2005). Observe for redness, soreness or pain, cracked ulcers, white patches, bleeding, difficulty swallowing, and report evidence of abnormal signs to doctors for early treatment (Yarbro et al., 2004; Hockenberry, 2005).

## 2) Lessen oral mucositis symptoms

- Provide soft or liquid diet (Hockenberry, 2005).
- Avoid food or drink that is hot or spicy due to painful sensations (Hockenberry, 2005).
- Use soft sponge toothbrush and brush carefully; in case of severe inflammation in oral cavity, use cotton tipped applicator or gauze wrapped finger to avoid trauma (Hockenberry, 2005).
- Mouth caring after meals and at bed time (Hockenberry, 2005). If there is severe inflammation, rinse mouth every 1-2 hours because this method could relieve symptoms and help the child to be comfortable (Miller & Kearney, 2001; Yarbro et al., 2004).
- Rinse mouth with NSS for 1-2 minute (Yarbro et al., 2004).
- Provide glutamine supplements such as meat, pork, milk, soy bean,

yogurt.

3) Oral assessment: provision for oral assessment is as follows (Yarbro et al., 2004):

3.1) Oral assessment should be done frequently or at least one time per day.

3.2) Prepare equipment for assessment: good source of light, mirror, non sterile groves, gauze, tongue blade.

3.3) Wash hands or apply non-sterile gloves.

3.4) Systematically perform and use directed light to

- observe the outer lips
- pull down lower lips and raise upper lip to observe the teeth and mucosa.
- instruct the child to open the mouth and observe the hard and soft palates.
- use a finger to displace tongue and examine the mucosa of the inner cheeks.
- examine the top of the tongue and tell the child to curl the tongue up to the roof of the mouth to observe the underside of the tongue.

4) Criteria for evaluating oral cavity (apply from oral assessment of Lertwongpaopun, 2003). The details are as follows:

- swallow: normal swallow, some pain on swallow, unable to swallow.
- lips: smooth and pink and moist, dry or cracked, ulcerated or bleeding.
- mucous membrane: pink and moist, reddened or coated, ulceration with or without bleeding.
- gingiva: pink and stippled and firm, edematous with or without redness.

\* If there are indications of abnormality, care for oral cavity is the same as for mucositis.

4.3.5 Rectal ulceration: wash perianal area after toilet, keep skin dry, use warm sitz bath to promote healing, prevent constipation, avoid rectal temperature or suppositories to prevent rectal trauma (Hockenberry, 2005).

4.3.6 Anemia: provide sufficient sleep and rest, arrange sequence of activities that are important, keep warm, change position slowly to prevent fainting (Schroeder, in Gulanick et al., eds., 1998).

4.3.7 Loss of appetite: when severe anorexia is present, allow the child to intake any food as tolerated, improve the quality of food and selection when appetite increases, serve small snacks, allow the child to select favorite food in daily menu, provide small feeding rather than three meals daily, and provide food with nutrients (Ball & Bindler, 2003; Hockenberry, 2005).

4.3.8 Constipation: prevent by encouraging the child to intake more fluids and fibrous foods (Landier, 2001; Ball & Bindler, 2003; Baggott et al., 2004; Yarbrow et al., 2004), drink more water or at least 8-10 glasses of fluid each day, encourage child to perform activity or exercise in order to increase bowel movement (Baggott et al., 2004; Yarbrow et al., 2004).

4.3.9 Diarrhea: prevent by eating low bacterial diet. When diarrhea occurs, avoid food with high fiber, fatty food or others that increase bowel movement (Yarbrow et al., 2004).

4.3.10 Alopecia: allow children to wear soft cotton cap or wig; offer adequate covering during exposure to sunlight, wind or cold (Hockenberry, 2005); cut hair short; use light shampoo and soft hair comb.

4.3.11 Hemorrhagic cystitis: offer more fluid intake; voiding immediately after feeling the urge, before bedtime and after arising; observe signs of cystitis (burning and painful or bleeding urination); promptly consult a physician if there are abnormal signs (Hockenberry, 2005).

4.3.12 Fatigue: provide balance between activity and rest, get more rest if fatigue symptoms occur, offer sufficient food and drink which contains high calories, provide children with fresh air, encourage exercise or appropriate activity (Baggott et al., 2004).

4.3.13 Tissue inflammation: move children carefully, especially at the intravenous site of chemotherapy administration and inspect for edema, redness, pain frequently. If there are abnormal signs, promptly consult professional team.

4.3.14 Provision for caring for children at the home setting

- Have the child intake medication as prescribed: medication such as bactrim, 6-TG, 6-MP, MTX.
- Take the child for follow up visits on schedule. If not able to take child for follow up, connect with professional before an appointment day.
- Inspect for abnormal signs such as high fever, bleeding, melena, hematuria, painful urination, regular headache, and signs of infection. If abnormal signs are present, consult doctor immediately.

## **5. Empowerment program of maternal caring behavior for children with leukemia undergoing chemotherapy**

The empowerment program is a nursing intervention to enhance maternal caring behavior for children with leukemia undergoing chemotherapy. This program is focused on helping mothers to develop competency in caring. It is comprised of individual discussion between mothers and the researcher to share information and experience, and conduct demonstrations and practice. The program consists of 4 phases, as follows:

Phase 1 Initial phase: it is the phase of building the relationship for trust and providing a safe environment.

Phase 2 Action phase: the program was developed based on the concept of empowerment (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996). The antecedents are love, bonding, commitment, and responsibility. The influencing factors include value of the child, belief in their competency to control side effects of chemotherapy and belief in the ability of the health team to help children become cured, experience in caring, and determination.

Children with leukemia demand close observation, monitoring and caring. As a result of their life threatening disease and the impact of treatment as well as limitations of age and development that make children unable to fully self-care, they

must rely on mother who usually plays the key role in caring. Orem (2001) classified self-care requisites into three aspects: universal, developmental, health deviation. These children demand three self-care requisites during period of treatment. Thus, contents of caring in the program are constructed based on the self-care concept of Orem (2001) and the details are as follow:

1. Universal self-care requisites: promote children to meet basic needs and maintain health to receive chemotherapy on schedule. These requisites consist of ensuring that the child receives sufficient food and nutrients, gets fresh air or good ventilation, receives sufficient water, eliminates normally, has a balance of rest and activity, and that there is prevention of hazards.

2. Developmental self-care requisites: this age has continuing growth and development. Thus, provision to promote development is essential.

3. Health deviation self-care requisites: side effects of chemotherapy are usually causes of problems in health deviation and children are always confronted with a lot of suffering from the toxic effect of chemotherapy. The symptoms that are frequent and life threatening include infection and bleeding. The symptoms that are frequent and cause child distress consist of nausea and vomiting and mucositis.

Thus, content in the program is constructed from three self-care requisites and divided into 6 sessions, as follows:

Session 1 caring for children to prevent or lessen symptoms from side effects of chemotherapy: infection, and when children get fever.

Session 2 caring for children to prevent or lessen symptoms from side effects of chemotherapy: bleeding tendency, epistaxis, and bleeding from wounds.

Session 3 caring for children to prevent or lessen symptoms from side effects of chemotherapy: mucositis, oral assessment, and oral caring.

Session 4 caring for children to prevent or lessen symptoms from side effects of chemotherapy: nausea and vomiting.

Session 5 caring for children to promote health.

Session 6 caring for children to support development.

In each session the following 4 steps are included:

Step 1 Discovering reality: this is the step to help mothers understand their situation and face reality.

Step 2 Critical reflection: this is the step to help mothers to evaluate and examine their situation critically.

Step 3 Taking charge: this is the step to help mothers to take action in their situation.

Step 4 Holding on: this is the step to help mothers to maintain their competence and caring behavior.

Phase 3: Follow up phase: it is the phase to boost maternal caring behavior by telephone support to reinforce their caring, to evaluate progression of caring and to follow-up the child's health.

Phase 4: Terminate phase: this phase is to help mothers to maintain competence and caring behavior by revising their caring. Afterwards, the essential issues of caring were summarized.

The outcomes of the empowerment program were expected to be enhancing maternal caring behavior for children with leukemia undergoing chemotherapy in three aspects of self-care requisites: universal, developmental, and health deviation. When the mothers develop a sense of power, they would have alternative choice in decision-making and finding ways to care appropriately in their situation by themselves. As a result, children would receive appropriate care in the hospital and home setting and the consequence would be prevention or lessening of the side effects of chemotherapy and the receiving of treatment on schedule.

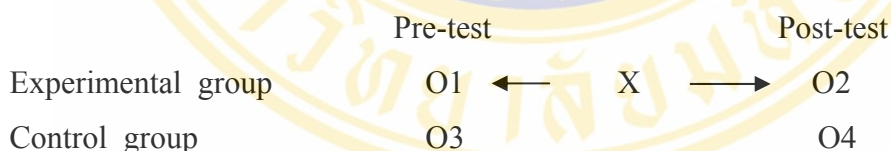
## CHAPTER III

### MATERIALS AND METHODS

This chapter presents the research design, population and sampling, research setting, research instruments, data collection, protection of human rights, and statistics for data analysis.

#### Research Design

This study was a quasi-experimental design, untreated control group design with dependent pretest and posttest samples (Shadish, Cook, & Campbell, 2002), which consisted of experimental and control groups. The purpose of this study was to determine the effects of an empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. The samples in the experimental group participated in an empowerment program developed by the researcher, whereas samples in the control group received the usual nursing care. The research design is shown below:



O1: refers to the scores for maternal caring behavior of the experimental group before participating in the empowerment program

X: refers to the empowerment program in the experimental group

O2: refers to the scores for maternal caring behavior of the experimental group after participating in the empowerment program

O3: refers to the scores for maternal caring behavior of the control group before receiving the usual nursing care

O4: refers to the scores for maternal caring behavior of the control group after receiving the usual nursing care

## Population and Sampling

The population of this study were the mothers who had children with leukemia undergoing chemotherapy and who had been admitted in the general ward of Arnanthamahidol building floor 3<sup>rd</sup>, 4<sup>th</sup>, 5<sup>th</sup> and 6<sup>th</sup> floors at Siriraj Hospital.

### Inclusion criteria

The mothers were recruited by the following criteria:

1. The mothers had children diagnosed with acute lymphoblastic leukemia or acute non-lymphoblastic leukemia.
2. Their children with leukemia were aged between 3-12 years.
3. Their children had received chemotherapy at least one time (induction phase).
4. The mothers were the primary caregivers of the children.
5. Their children had been admitted to hospital to receive chemotherapy as a treatment and had a period of time being cared for at home.

### Exclusion criteria

The mothers were excluded from this study:

1. Mothers who were not able to participate in the 4 day empowerment process intervention.
2. Mothers who were not able to be called for follow ups at the home setting.

The samples in this study were two groups: experimental and control. Gaffney & Moore (1996) indicated that age of child was a predictor for dependent care ability among mothers. Thus, age of child was used for match pairs in this study, as below:

Pre school age (age between 3-5 years) matched with Pre school age (age between 3-5 years)

School age (age between 6-12 years) matched with School age (age between 6-12 years)

### Sample size

This was a quasi-experimental research design to compare means between two groups that were independent of each other. Therefore, sample size was calculated by using power analysis and the formula was taken from Polit & Beck (2004) and is shown below:

$$\gamma = \frac{\mu_1 - \mu_2}{\sigma}$$

$\gamma$  = effect size

$\mu_1$  = mean of the first sample group

$\mu_2$  = mean of the second sample group

$\sigma$  = population standard deviation

From a previous study of McCarthy et al. (2002) it was found that the mean of maternal caring ability in the empowering group was 9.24 and the traditional group was 8.55. The population standard deviation was .84

$$\begin{aligned} \gamma &= \frac{9.24 - 8.55}{.84} \\ &= 0.82 \end{aligned}$$

This study needed a significance level at .05 and 80% power of test. Also, the effect size was 0.82 (large effect size). Thus, using a table of approximate sample sizes from Polit & Beck (2004), the sample size indicated in each group was 25 cases.

The number of patients did not increase during collection data from December, 2005 to April, 2006. Therefore, the sample in this study was 15 cases in each group.

### Setting

This study was conducted at the Arnanthamahidol Building, Department of Pediatrics, Faculty of Medicine, Siriraj Hospital, Mahidol University. The Hematology/Oncology inpatient unit is located in the Arnanthamahidol building, 6th floor. The unit has a capacity of 25 patients' beds and children who are newly diagnosed or who have infections are admitted to other appropriate units for their

conditions. In this study, the samples included mothers of children with leukemia who were admitted for chemotherapy. On admission, children usually receive the service of health assessment from pediatric oncologist and a blood test investigation to evaluate bone marrow, liver or kidney function such as CBC, BUN, Cr, and LFT. If children were healthy enough to receive chemotherapy, no abnormal sign and symptom were detected and blood test was within normal limits, chemotherapy would be started on the next day. In hospital, mothers were permitted to stay with the child in the day, but not at night. The usual activity to develop knowledge and skill on caring includes health education and giving handbooks. Contents for health education were general and not focused on their problems and did not promote mothers to find the solutions on their own. Also there is no session for follow up in order to evaluate progression of care in the home setting.

### **Instruments**

The instruments of this study were comprised of:

#### **1. The empowerment program**

This study used an empowerment program as the nursing intervention. The program was developed based on the concept of empowerment (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996) in combination with a review of the literature from textbooks, journals, and related research.

Prior to starting the program, researcher explained the objectives of the study, the roles of the mother and researcher in the program, the benefits for child and mother, the steps of intervention, and protection of human rights. The program was started after the mother indicated her willingness to participate.

The main characteristic of the program was that it used individual discussions between the mothers and the researcher to enhance maternal competency for caring children with leukemia. This program was focused on helping the mother by sharing experience and providing information needed to make informed choices, demonstrating, and performing practice until correctly and confidently. Provision of program in the hospital lasted for 4 days. The intervention was approximately 1-2 hours each session with 1-2 sessions per day. The time of the sessions was between 9.00-10.00 a.m. and 13.30-14.30 p.m. Additionally, the time of the schedule was

adjusted depending on the mother. The intervention was divided into 4 phases, as follows:

Phase 1 Initial phase: it is the phase for the foundation of the relationship with the mother and provides a safe environment for trust.

Phase 2 Action phase: it is the phase of following through the program. Contents of caring in the program are developed based on the self-care concept of Orem (2001) and divided self-care requisites in three aspects: universal, developmental, health deviation. Children with leukemia demand three self-care requisites during their period of treatment. Thus, the program was constructed from the three requisites and divided into 6 sessions as described following:

Session 1 caring for children to prevent or lessen symptoms from side effects of chemotherapy: infection, and when the child has fever.

Session 2 caring for children to prevent or lessen symptoms from side effects of chemotherapy: bleeding tendency, epistaxis, and caring for bleeding from wounds.

Session 3 caring for children to prevent or lessen symptoms from side effects of chemotherapy: mucositis, oral assessment, and oral caring.

Session 4 caring for children to prevent or lessen symptom from side effects of chemotherapy: nausea and vomiting

Session 5 caring for children to promote and maintain health

Session 6 caring for children to support development

In each session, there were 4 steps as follows:

Step 1: discovering reality: this was an initial step when the mothers realized and understand their situation. This step was to help the mothers to identify problem and evaluate their experience in caring.

Step 2: critical reflection: this was the step to help the mothers to evaluate and examine their situation critically.

Step 3: taking charge: this was the step to help the mother develop strategic plan for action.

Step 4: holding on: this was the step to help the mother maintain their competency for caring.

Contents in the program in each session are shown in Appendix B.

The termination of program in each session was as follows:

- Letting mothers summarize essential information in sharing discussion.
- Allowing mothers to ask their questions and express concern.
- Making an appointment for the next meeting, which included date, time, place, and the next topic to discuss.
- Saying thanks to the mother for her attention and cooperation.

Phase 3 Follow up phase: it is the phase to boost the mother to maintain caring behavior by telephone support at home one time per week after the children had been discharged from hospital until the next follow up visit 4 weeks later. The objectives of calling were to reinforce their caring, to evaluate progression of caring, and to ask about problems and concerns. In cases of caring correctly, the mothers were motivated by positive feedback in order to maintain competence and caring behavior. In addition, mothers were able to call the researcher to ask about problems and concerns about caring from 7.00 a.m. to 20.00 p.m. everyday during the period of the program.

Phase 4 Termination phase: the time in this phase was the follow up day. The researcher met the mother and allowed her to ask questions and provided information as she needed. Then, essential issues of caring were summarized. Finally, the researcher informed mothers that the study was finished and said thanks for their participation.

## **2. The instruments of collecting data**

In this study, a self report questionnaire was used for data collection which was comprised of two parts as follows:

### **2.1 Demographic information: data from children and mothers**

- Personal data of child were comprised of type of leukemia, age, sex, birth order, length of time of receiving chemotherapy, the side effects of chemotherapy experienced, phase of chemotherapy, and chemotherapy schedule.
- Personal data of mother were comprised of age, education level, marital status, occupation, income of family, number of children, time spent in caring for the child per day, type of burden in caring, the person supporting her in caring for

the child at home, co-morbidity, and source of information for caring.

## 2.2 Maternal caring behavior questionnaire

This questionnaire was constructed based on the self-care concept of Orem (Orem, 2001) and reviewed literatures. It was comprised of three parts as follows:

- Universal self-care requisites consisted of 15 items; 1 – 15
- Health deviation self-care requisites consisted of 30 items; 16 - 45
- Developmental self-care requisites consisted of 6 items; 46 - 51

The questions were developed on a “Rating Scale” and classified into 4 levels, with each question requiring only one answer, as follows:

“Always” means the mother performed the activity every day of the week. If the situation did not occur everyday but occurred at least 5 times, the mother performed the activity every time.

“Often” means the mother performed the activity 4-6 days per week. If the situation did not occur everyday but occurred 5 times, the mother performed the activity 3-4 times.

“Sometimes” means the mother performed the activity 1-3 days per week. If the situation did not occur everyday but occurred 5 times, the mother performed the activity 1-2 times.

“Never” means the mother never performed the activity

No situation means the mother never performed the activity due to the situation not occurring.

The questionnaire was evaluated for frequency of caring and there were closed-end questions including positive (correct) and negative (incorrect) question statements.

The positive statements were comprised of 45 items; 1-2, 4, 6-15, 17-20, 22-28, 30-39, 41-51

The negative statements were comprised of 6 items; 3, 5, 16, 21, 29, 40

### Scoring criteria

	The positive question	The negative question
Never	1	4
Seldom	2	3
Often	3	2
Always	4	1

### Criteria for interpretation of scores

The interpretation of the meaning of maternal caring behavior scores is subsequently shown. The high average scores show that the mothers have high correctness of caring behavior. The low average scores show that the mothers have partly correct caring behavior.

### Validity

#### 1. The empowerment program

The program used in this study has been tested for content validity, sequence, and language suitability by five experts in relevant fields; an oncologist, a nursing instructor with expertise in caring for children with leukemia undergoing chemotherapy, a nursing instructor specializing in pediatric oncology and Orem's theory, a nurse specializing in the empowerment concept, and a nurse clinician specializing in pediatric oncology. Afterwards, the program was modified according to the suggestions of these experts, and it was pilot tested with mothers of children with leukemia of the same characteristics to evaluate it and test it for simplicity of language.

#### 2. The questionnaire of maternal caring behavior

The questionnaire was tested for content validity, language suitability, and the criteria of measurement by five experts in the relevant fields (the same group who validated the empowerment program). Suggestions from the experts contributed to refinement of the questionnaire of maternal caring behavior.

### **Reliability**

The researcher tried out the revised questionnaire with mothers of children with leukemia who had similar inclusion criteria as the sample in this study. Twenty mothers were used to test the reliability and clarity of the questionnaire. The setting used for data collection for reliability was Chaofa Maha Chakri Building, 1st floor, hematology/oncology unit, Department of Pediatrics, Faculty of Medicine, Siriraj Hospital, Mahidol University. The reliability was tested by using Cronbach's Alpha Coefficient. The result of reliability for the instrument was 0.87

### **Data collection**

The data was collected by the researcher after approval of the research proposal by the Faculty of Medicine, Siriraj Hospital, Mahidol University. The process of data collecting was as follows:

1. A permission letter from the Faculty of Graduate Studies, Mahidol University was presented and submitted to the Director of Siriraj Hospital and the Ethical Committee on Research Involving Human Subjects, Faculty of Medicine, Siriraj Hospital, Mahidol University.
2. After receiving permission, the researcher met with the supervisor nurse and head nurse of the department of pediatrics ward to explain the objectives of the study and steps to collect data.
3. The researcher selected mothers of children with leukemia undergoing chemotherapy based on the inclusion criteria.
4. The medical chart was reviewed.
5. For protection of human rights, the ward nurse introduced the researcher to the mothers. Then, the mother was invited to participate in the study, the researcher introduced herself, explained the research objectives and benefits, the steps in data collection and assured the mother of confidentiality, autonomy, and freedom of withdrawal from the study at any time. The mothers who agreed to participate were requested to sign a consent form.
6. A private area, a quite place or room without any disturbances, was provided for data collection.

7. Demographic data and a pre-test of maternal caring behavior was collected on the first day of admission. While answering the questionnaire, the mother was assisted by the researcher for any problems. After the mother had answered the questions, the questionnaire was checked for the completeness of the answers. If there were any questions unanswered, the researcher asked the mother to complete the questionnaire. The time used to complete the questionnaire was approximately 20-30 minutes.

#### **The control group**

1. The control group received routine nursing care during the study period.
2. On the day of discharge, an appointment was made for post-test in the next follow up visit.
3. In the next follow up visit, 4 weeks after receiving routine nursing care, the questionnaire of maternal caring behavior was collected as a post-test. The time used for completing the questionnaire was approximately 15-20 minutes.
4. After the post test had been completed, the researcher asked the mother about their problems and concerns about caring. Then, the researcher provided answers or information as she needed. After that, the researcher informed the mother that the study was finished and said thanks for her participation.

Because of the low number of patients and the limitations of time of the study, the researcher needed to recruit some mothers who took their children to receiving chemotherapy either intravenously or by the intrathecal route during 8.00-18.00; these children did not have an order for admission. However, these mothers were selected for the similarity of their characteristics to those in the experimental group. They also received routine nursing care from the health team during chemotherapy administration.

#### **The experiment group**

After data collection was completed in the control group, collection of data in the experimental group began, as follows:

1. The experimental group participated in an empowerment program from the researcher. Contents in the program are shown in Appendix B.

2. The appointment for telephone support at home setting was made before children were discharged from hospital. The purpose of telephone support was to reinforce their caring, to evaluate progression of caring and to ask about problems and concerns with caring and then to provide help. The first appointment was scheduled after children had been discharged from hospital for 1 week, then follow up calls were made every week until the next follow up visit. In addition, the researcher gave her personal telephone number to the mothers for asking questions or information about caring. The time to call for asking was from 7.00 a.m. to 20.00 p.m. in the period of the study.

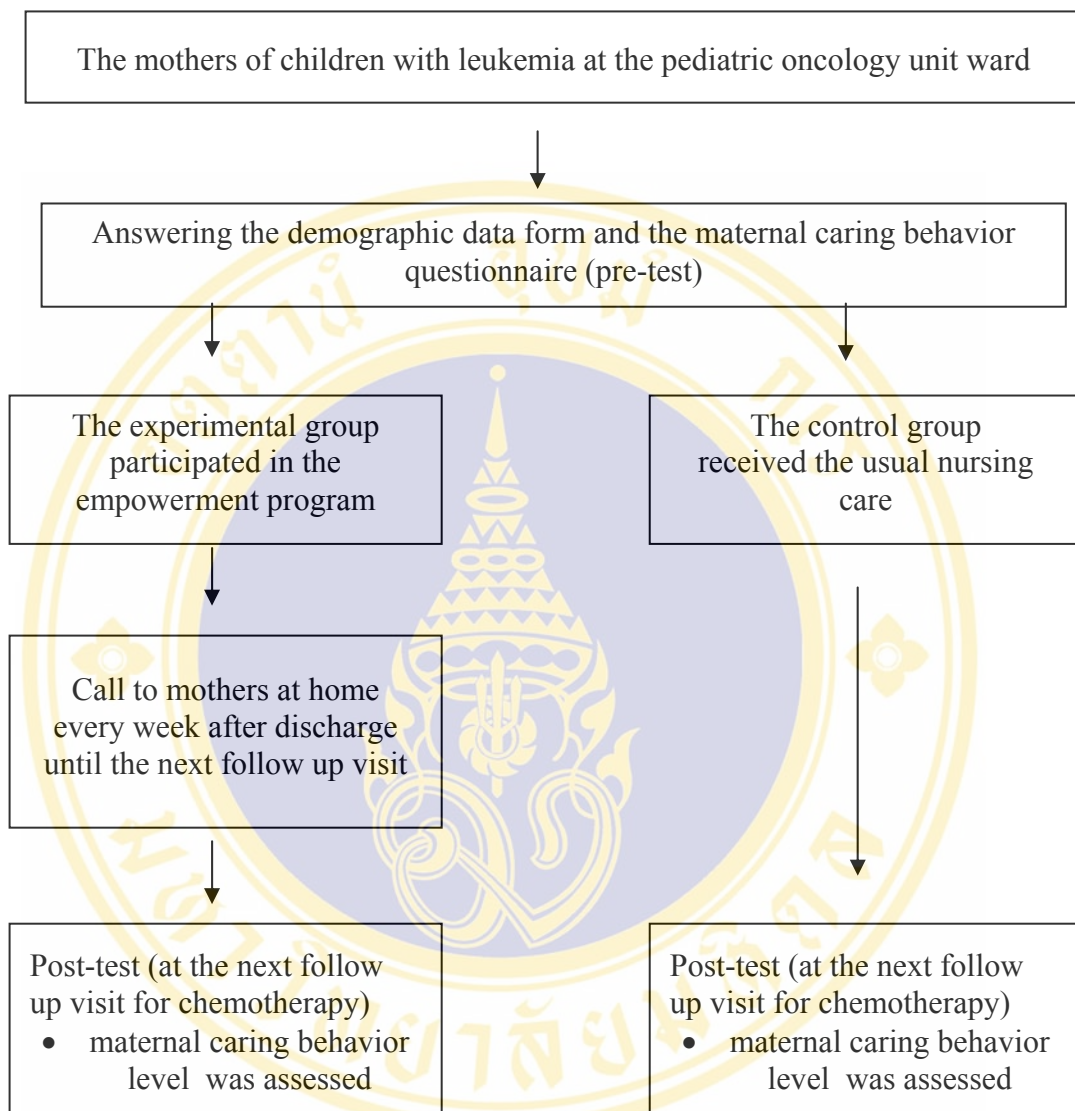
3. Afterwards, an appointment for post test was made in the next follow up visit.

4. In the next follow up visit, 4 weeks after intervention, the questionnaire of maternal caring behavior was administered as a post-test. The time used to complete the questionnaire was approximately 15-20 minutes.

5. After the post test had been completed, the researcher asked if there were questions to ask about caring, and provided the answers or information as she needed. Finally, the researcher informed the mothers that the study was finished and said thanks for their participation.

The criteria for termination from the study included children developing symptoms from side effects of chemotherapy such as severe infection and bleeding in vital organs. In this study, one mother was terminated from this study because her child developed severe symptoms from as a result of chemotherapy and required prolonged admission to the hospital. As a result, this mother did not have the follow up session in the program. Therefore, the samples in the experimental group were 14 mothers.

The process of data collection is summarized in the following diagram and shown in figure 1



**Figure 1** The process of data collection

**Protection of human subjects**

The research was undertaken by permission of the committee on human rights related to research that involves human subject from the Faculty of Medicine, Siriraj Hospital, Mahidol University. The mothers were invited to participate in the study. The researcher explained the purpose of the research, the research process, benefits, and the right to refuse to participate in the study. The mothers who agreed to participate were asked to sign a consent form and were assured that the data would be kept confidential and presented as a group report.

**Data analysis**

The data was analyzed with descriptive and inferential statistics using the Computerized Statistical Program, as follows:

1. Demographic data were analyzed with descriptive statistics: frequency and percentage.
2. The pre test and post test scores of maternal caring behavior were analyzed by means and standard deviations.
3. The scores of maternal caring behavior before and after the intervention were compared for the experimental and the control groups by using the ANCOVA and using the pre test scores as a covariate variable.

## CHAPTER IV

### RESULTS

The purpose of this quasi-experimental was to study the effects of empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. Purposive sampling was used to select mothers of children with leukemia. They were divided into two groups: experimental (n=14) and control (n=15) by matching. The study was conducted on the Arnanthamahidol building floor 3<sup>rd</sup>, 4<sup>th</sup>, 5<sup>th</sup> and 6<sup>th</sup> floors at Siriraj Hospital. The results of this study were presented in the tables as the followings:

**Part I** Characteristics of the samples (Table 1- 2)

**Part II** The score of maternal caring behavior for children with leukemia before and after the empowerment program (Table 3)

**Part III** The comparison of the mean scores of maternal caring behavior for children with leukemia (Table 4-5)

**Part I Characteristics of the samples**

**1.1 Characteristics of the mothers**

**Table 1** Demographic characteristics of mothers

Characteristics	Experimental group (n=14)		Control group (n=15)	
	n	%	n	%
<b>Age (years)</b>				
20 – 30	4	28.6	2	13.3
31 – 40	7	50.0	6	40.0
41- 50	3	21.4	7	46.7
Range 24-46, $\bar{x}$ = 34.07, SD = 5.82    Range 28-48, $\bar{x}$ = 36.55, SD = 6.69				
<b>Education (years)</b>				
Non attended school	1	7.1	0	0
Primary school	6	42.9	9	60.0
Secondary school	6	42.9	1	6.7
Diploma	1	7.1	1	6.7
Bachelor’s degree	0	0	4	26.6
<b>Marital status</b>				
Married	12	85.7	14	93.3
Divorced/widow	2	14.3	1	6.7
<b>Occupation</b>				
Housewife	2	14.3	4	26.7
Employee	5	35.7	5	33.3
Private business	4	28.6	3	20.0
Agriculture	3	21.4	2	13.3
Government officer	0	0	1	6.7
<b>Family income(bath/month)</b>				
< 5000	2	14.3	0	0
5000 – 10000	10	71.4	6	40.0
> 10000	2	14.3	9	60.0
Range 3,000-20,000, $\bar{x}$ =9,214, SD=5,041    Range 5,000-100,000, $\bar{x}$ =25,100, SD=27,000				
<b>Number of children</b>				
1	0	0	3	20.0
2	12	85.7	7	46.7
≥ 3	2	14.3	5	33.3
<b>Type of burden from caring (can answer more than 1)</b>				
Cost	14	100	10	66.7
Working	13	92.9	11	73.3
Time for rest or sleep	5	35.7	5	33.3

**Table 1** Demographic characteristics of mothers (continued)

Characteristics	Experimental group (n=14)		Control group (n=15)	
	n	%	n	%
<b>Having support for caring children with leukemia</b>				
None	3	21.4	5	33.3
Have	11	78.6	10	66.7
<b>Co-morbidity</b>				
None	9	64.3	8	53.3
Have	5	35.7	7	46.7
<b>Perceived time used in caring per day</b>				
Less	2	14.3	1	6.7
Moderate	9	64.3	9	60.0
More	3	21.4	5	33.3
<b>Source of information for caring (can answer more than 1)</b>				
Doctors / Nurses	14	100	15	100
Other mothers or caregivers	11	78.6	14	93.3
Books	12	85.7	14	93.3
Television	1	7.1	5	33.3
Relatives	0	0	2	13.3
Internet	0	0	2	13.3

**Table 1** shows that in the experimental group, the mean age of mothers was 34.07 years (SD=5.82). The most common educational levels were primary and secondary school (42.9% in each level), most were married (85.7%), and most were employees (35.7%), The mean of family income was 9,214 bath/month (SD=5,041). Most of them had two children (85.7%) and met burdens in the category of costs and working (more than 90%). They also had support for caring (78.6%), did not have co-morbidity (64.3%), perceived the time used on caring per day in the moderate level (64.3%), and their sources of information for caring were doctors, nurses and other mothers, and books.

In the control group, the mean age of mothers was 36.55 years (SD=6.69). Most of them were educated to primary school level (60%), most were married (93.3%), and most were employees (33.3%). The mean of family income was 25,100

bath/month (SD=27,000). Most of them had two children (46.7%) and met burdens in the category of costs and working (more than 50%). Most also had support for caring(66.7%), did not have co-morbidity (53.3%), and perceived time used in caring per day in the moderate level (60.0%). For most, the sources of information for caring were doctors, nurses and other mothers, and books.

### 1.2 Characteristics of children with leukemia

**Table 2** Demographic characteristics of children with leukemia

Characteristics	Experimental group (n=14)		Control group (n=15)	
	n	%	n	%
<b>Age (years)</b>				
3 – 6	3	21.4	4	26.7
7 – 9	6	42.9	6	40.0
10 – 12	5	35.7	5	33.3
	Range 3-12, $\bar{x}$ =7.85, SD=3.13 Range 3-12, $\bar{x}$ =7.66, SD=2.89			
<b>Type of leukemia</b>				
ALL	8	57.1	15	100
ANLL	6	42.9	0	0
<b>Phase of chemotherapy</b>				
Intensification	2	14.3	2	13.3
Consolidation	5	35.7	1	6.7
Maintenance	6	42.9	12	80.0
Re-induction	1	7.1	0	0
<b>Times of receiving chemotherapy (months)</b>				
< 12	5	35.7	3	20.0
12 – 24	3	21.4	5	33.3
> 24	6	42.9	7	46.7
	Range 3-52, $\bar{x}$ =21.57, SD=16.47 Range 2-46, $\bar{x}$ =24.66, SD=13.05			
<b>Gender</b>				
Male	7	50.0	8	53.3
Female	7	50.0	7	46.7
<b>Birth order</b>				
First child/only child	7	50.0	7	46.7
Middle child	0	0	2	13.3
Last child	7	50.0	6	40.0

**Table 2** Demographic characteristics of children with leukemia (continued)

Characteristics	Experimental group		Control group	
	(n=14)		(n=15)	
	n	%	n	%
<b>Experienced the side effect of chemotherapy (can answer more than 1)</b>				
Fever	14	100	13	86.7
Alopecia	14	100	15	100
Mucositis	13	92.9	11	73.3
Nausea/vomiting	11	78.6	13	86.7
Anorexia	11	78.6	12	80.0
Diarrhea	7	50.0	4	26.7
Constipation	5	35.7	5	33.3
Bleeding	4	28.6	5	35.3
<b>Received chemotherapy in a schedule</b>				
No	7	50.0	10	66.7
Yes	7	50.0	5	33.3

**Table 2** shows that in the experimental group, the mean child age was 7.85 years (SD=3.13). Most of them were diagnosed with ALL (57.1%), nearly half received chemotherapy in phase of maintenance (42.9%), and the average time of undergoing chemotherapy was 21.57 months (SD= 16.47). There were equal numbers of males and females. The most common birth orders were the first or only child (50%) and last child (50%). Most of them had experienced the following side effect of chemotherapy: fever (100%), alopecia (100%), mucositis (92.9%), nausea/vomiting (78.6%). There were 50% of children who did not receive chemotherapy on schedule.

In the control group, the mean child age was 7.66 years (SD=2.89). All of them had been diagnosed with ALL. Most of them received chemotherapy in the phase of maintenance (80.0%), the average time of undergoing chemotherapy was 24.66 months (SD= 13.05). Again the numbers of males and females were equal and just under half were the first or only child birth order (46.7%). Most of them had experienced the following side effects of chemotherapy: alopecia (100%), fever (86.7%), nausea/vomiting (86.7%), anorexia (80%). Most of children did not receive chemotherapy on schedule (66.7%).

**Part II** The scores of caring behavior for children with leukemia in pretest and posttest

**Table 3** Pre- and posttest mean scores and standard deviations for two groups of mothers

Requisites of caring behavior	Experimental group				Control group			
	Pre test		Post test		Pre test		Post test	
	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD	$\bar{x}$	SD
Universal	3.39	.33	3.57	.28	3.18	.42	3.34	.33
Developmental	3.55	.32	3.64	.42	3.41	.34	3.33	.43
Health deviation	3.29	.34	3.59	.24	3.09	.34	3.16	.41
Infection	3.63	.26	3.7	.24	3.48	.31	3.51	.35
Bleeding	3.03	.42	3.55	.46	2.73	.50	2.93	.46
Nausea/ vomiting	3.33	.51	3.51	.44	3.28	.60	3.38	.51
Mucositis	3.17	.71	3.58	.43	2.89	.53	2.82	.67
<b>Total</b>	<b>3.41</b>	<b>.26</b>	<b>3.60</b>	<b>.27</b>	<b>3.23</b>	<b>.26</b>	<b>3.28</b>	<b>.30</b>

**Table 3** shows the caring behavior in three aspects of requisites: universal, developmental and health deviation. In post test scores, the experimental group had an increase in mean scores of caring behavior in every aspect, and especially an increase in the aspect of health deviation: bleeding and mucositis. In contrast, the control group had similar mean scores of pretest and posttest, and had a decrease in mean scores of caring behavior in some aspects such as developmental and health deviation: mucositis

**Part III** The comparison of the mean scores of caring behavior for children with leukemia

**Table 4** Comparison of pretest mean scores for two groups of mothers

Group	Pretest		t
	$\bar{x}$	SD	
The experimental group	3.41	.26	1.890 <sup>ns</sup>
The control group	3.23	.26	

<sup>ns</sup> = non significant,  $p > .05$

**Table 4** shows that the mean scores of caring behavior for children with leukemia at pre test in the experimental and the control group were not statistically significantly different ( $p > .05$ ).

**Table 5** Analysis of covariance of posttest caring behavior scores, with pretest caring behavior scores as covariate

Source	df	SS	MS	F
Covariate	1	.656	.656	10.3138*
Between group	1	.290	.290	4.558*
Error	26	1.655	.064	
Corrected total	28	3.060		

\*  $p < .05$ , Adjusted  $R^2 = .418$

**Table 5** shows that the mean scores of caring behavior for children with leukemia at post test in the experimental and the control group were statistically significantly different ( $p < .05$ ).

## CHAPTER V

### DISCUSSION

The purpose of this study was to study the effects of an empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy. The results of the study are discussed in terms of the findings related to the research hypothesis.

**Hypothesis:** mothers of children with leukemia who participated in an empowerment program would have caring behavior scores higher than those who received usual nursing care.

The results of this study demonstrated that after the experimental group participated in the empowerment program on maternal caring behavior for 4 weeks, the mean scores of caring behavior for children with leukemia were higher than the scores of caring behavior for children in the control group with statistical significance ( $p < .05$ ). The results for these findings are discussed below.

In the control group, the mothers received the usual nursing care such as advice for caring before discharge or routine health education. In health education sessions, the mothers always had a passive role and were dependent on the professional; this is passive learning. They were not provided with the opportunity to share information and experiences. They did not have a chance to identify, to analyze, and to develop a plan to care by themselves. So they did not have a chance to learn from their experience and to pull their innate competency for caring. Moreover, information for discussion was general and did not motivate mothers to participate in caring. As a result, even though mothers in the control group had the power to care, they did not receive factors to motivate empowered behavior.

In the experimental group, the mothers participated in the empowerment program to enhance caring behavior for children with leukemia undergoing chemotherapy. In this study, empowerment is represented as a process that contributes to behavior by motivation. Motivation is an urge in an individual to perform goal directed behavior. Therefore, motivation is an intrinsic desire in the mothers to achieve the target goal through behavior. This conceptual framing of empowerment through behavior is supported by the study of Conger and Kanungo (1988) who proposed that the idea of empowerment is meant to enable, and implies a raised level of confidence to successfully execute desired behavior. It is also supported by the study of Locke & Latham (1990) who stated that humans can motivate themselves by setting future goals and that these goals affect behavior by directing attention, mobilizing effort to the task, encouraging persistence, and facilitating the development of strategies (Locke & Latham, in Franken, ed., 1998).

In this study, the empowerment program was developed based on the concept of empowerment (Bishop et al., 1988; Gibson, 1995; Dunst & Trivette, 1996).

Prior to starting the empowerment program, the mothers were informed of the objectives of the study, the roles of the mothers and the researcher, the benefits and steps of the program, and protection of human rights. The program was started after the mothers indicated their willingness to participate. Hawks (1992) proposed that an attribute of empowerment is a willingness to accept empowering behavior.

The empowerment program was divided into 4 phases and the advantages of the program were discussed as follows:

**Phase 1** Initial phase. This was the phase in which the mothers developed trust in researcher. The researcher contacted the mothers to establish and build relationships, and provide a nurturing and caring environment. It was essential to form relationships because a good relationship led mothers to have trust in the researcher. To form relationships, the researcher reviewed the medical chart before contact, because this was the basic data to guide the discussion. Afterwards, the researcher called her name and there was some small talk about general topics to indicate an acceptance and respect for her individuality. These activities helped the mothers to relax and feel that they were in a friendly atmosphere and nurturing and caring

environment. Moreover, the mothers were provided with a safe environment by discussion in a private area, a quiet place without any disturbance.

From observation and conversation in this phase, it was found that most of the mothers were willing to participate in the empowerment program, and were open to sharing their experience as well as expressing their ideas. This indicated that they had trust in the researcher. As a result, the process of empowerment program proceeded well. Likewise, Ryles (1999) proposed that the antecedent of the process of empowerment is trust, nurturing and a caring environment. Even so, there were some mothers who were not open for conversation. This might be due to their not being clear on the objectives of the study, the benefits of the program, and the concern for their rights. The researcher continued to form relationships and informed the mothers again so that they would clearly understand what they were not sure of. Afterwards, the empowerment program progressed well. Additionally, some mothers could not start the program on the first day. They were not prompt in participating in the empowerment program due to tiredness from their journey, a desire to go back to working after taking the child to hospital, or the fact that the child was irritable and demanded care. Thus, the time in schedule was adjusted depending on the mothers' readiness for learning. Orem (2001) proposed that the learning process may not take place when the learners are not in a state of readiness.

**Phase 2** Action phase. This was the phase in which the mothers in the experimental group were developed learning from their experience. Experience is the core of learning (Bishop et al., 1988), and it is one of the intrapersonal factors that influences the process of empowerment (Gibson, 1995). In this phase, the mothers were provided with the opportunity to enhance competency in caring by individual discussion, performing practice and having demonstrations of the skills of caring for children with leukemia undergoing chemotherapy in three aspects of self-care requisites: universal, developmental, and health deviation. In the individual discussions, the mothers had a chance to share information and experiences of caring, to develop to identify and analyze their caring and to develop a strategic plan to care appropriately in their situation on their own. From the discussions, the mothers and researcher could learn together and this was the learning process from interaction

between the researcher and the mothers. Moreover, the mothers had a chance to practice skills and return demonstration until they were able to perform them correctly and confidently. These activities assisted the mothers to learn from real action and helped them become able to apply the skill to care appropriately for their child. Additionally, the role of researcher was not as an expert but as a facilitator and supporter; the mothers were encouraged to be partners and participants in caring as well.

In this study, content in the empowerment program was developed based on the three self-care requisites of Orem (2001): universal, developmental and health deviation. These requisites were divided into 6 sessions: caring to prevent or lessen infection, and when the child had fever; caring to prevent or lessen bleeding tendency, epistaxis, and bleeding from wounds; caring to prevent or lessen mucositis, oral assessment and oral caring; caring to prevent or lessen nausea and vomiting; caring to promote health; and caring to support development. In each session 4 steps are included as follows:

Step 1 discovering reality. This was the step in which the mothers in the experimental group learned to develop to evaluate their experience and identify their problems in caring. Sternberg (2005) stated that problem recognition, problem definition, and evaluation of problem solving were the metacognitive skills for developing competency (Sternberg, in Elliot & Dweck, eds., 2005). In this step, the mothers were provided with opportunities to find their problems of caring, causes of problem, and methods of management of care that were used in the past and the results of those methods. The mothers were motivated by questioning, active listening, and reflecting. Moreover, they were encouraged in critical thinking.

From observations and discussions in this step, it was found that most of the mothers could find out their problems of child health. They understood and had an awareness of the problems: infection, bleeding, nausea and vomiting, mucositis. They also understood the need to promote health and support development. The examples reflecting their on-going process of discovering reality were:

- Caring to prevent or lessen infection

“There is a sick person who has fever and common cold in my home and my daughter is in contact with him. Thus, she may get fever from being near this sick person.”

“Before starting chemotherapy, if my son was stressed from vein puncture or an open vein, he was liable to get fever.”

“It takes 6 hours to get to hospital. So, my daughter was tired and weak from the journey. She was not healthy enough for chemotherapy, and sometime she gets fever in hospital.”

- Caring to prevent or lessen from bleeding

“If my daughter collides with the edge of something, she may get ecchymosis from the collision.”

“My son does not brush his teeth gently; sometimes he has bleeding gums from brushing.”

“My son is naughty, sometimes from playing he falls and has bleeding from a wound ”

- Caring to prevent or lessen nausea/vomiting

“If my son eats some food and receives sedation before intrathecal chemotherapy, he usually has nausea and vomiting.”

“If my son eats more food before receiving intrathecal chemotherapy, he sometimes has nausea and vomiting.”

- Caring to prevent or lessen mucositis

“My son has had many cases of dental caries, because he dislikes brushing his teeth especially at bedtime.”

“My son does not brush his teeth carefully; sometime he has oral ulcers from brushing.”

- Caring to promote health

“Because of eating less food and not liking to drink milk, my son was underweight and did not look healthy.”

“My daughter dislikes eating vegetables; sometime she gets constipation.”

“My son eats food that he likes such as *mama* [instant noodles], so he looks thin.”

- Caring to support development.

“After being diagnosed with ALL and receiving treatment, my son became amoodly child”

“My daughter did not increase her weight gain while undergoing chemotherapy; this may be due to eating less food in hospital.”

These quotes suggest that the mothers were able to find out about the health problems of their children, and achieve understanding and awareness of the problems in caring. It is congruent with the study of Jenjob (1999) who studied the process of empowerment in rheumatoid arthritis patients utilizing concepts of Gibson (1995). The results revealed that the mean scores of understanding the problem and situation in posttest at 1 month, 2 month and 3 month were significantly higher than in the pretest.

Even so, through this on going process there were some mothers who did not share their experience and request information. This may have been because they lacked information or skill to share, were not confident of their own competency, and were frustrated about the problems of caring during the step of discovering reality. The mothers were encouraged to discover their problems as well as understand their reality.

In contrast, the mothers in the control group received the usual nursing care such as health education. In health education, the mothers did not have a chance to develop their evaluating of their experience and identifying their problem in caring. Thus, they could not find out the children’s health problems. Darbyshire & Caledonian (1995) proposed that because, in the medical model the professionals are the experts who own the knowledge and are necessary to identify and define the problem and to prescribe and evaluate solutions, the parent’s role is a passive one of providing the information requested and complying with any information and advice given. Thus, the caring behavior scores of mothers in the control group were similar in pretest and posttest (table 3) and significantly different from the mothers in the empowerment group (table 5).

Step 2 critical reflection. In this step, the mothers learned from their experience. They had the opportunity to clarify and analyze their experience as well as understand their problems and concerns. The mothers were encouraged to evaluate and examine their situation critically by discussing the benefits and limitation of their

caring through collaboration and shared decision making. Sternberg (2005) stated that analyzing, critiquing, evaluating and assessing were the critical thinking skills for developing competency (Sternberg, in Elliot & Dweck, Eds., 2005). As a result, when the mothers developed critical reflection, they would have choices for decision making and developing a strategic plan to solve infection, bleeding, nausea/vomiting, and mucositis and to promote health and support development appropriately in their situation on their own.

From observation and discussion in this step, it was found that most of the mothers could learn from their experience. They could analyze and understand their experience of care as well as develop a strategic plan to care appropriately for their child. The following quotes reflect maternal involvement in the on-going process of critical reflection:

- Caring to prevent or lessen infection

“My son wants to eat papaya salad but I am concerned about diarrhea. Thus, I search for the clean food store or tell him to eat at home”

“When my son has a common cold, I take him early to a nearby hospital for treatment. As a result, he is healthy for chemotherapy on schedule.”

“My daughter had experience of neutropenia. From observation, when my daughter drank goat’s milk, her white blood count test was in the normal limit. Thus, I always encourage her to drink goat’s milk for preventing neutropenia.”

- Caring to prevent or lessen bleeding

“My son likes to ride a bicycle. I permit him to ride slowly or ride in the area that is sure for safety.”

- Caring to prevent or lessen nausea/vomiting

“My son sometime has nausea/vomiting after intrathecal chemotherapy. Thus, before treatment I allow him to have some drink, but do not allow to eat more food.”

- Caring to prevent or lessen mucositis

“My son dislikes brushing his teeth or mouth care. I told him to look at another child who has mucositis. Afterwards, he increased his teeth brushing and mouth care.”

- Caring to promote and maintain health

“I want my daughter to eat more vegetables but she does not like to eat them. If I cook Sukiyaki for her, she likes to eat vegetable in Sukiyaki. Thus, I usually cook Sukiyaki for her.”

“I am concerned that my daughter will get diarrhea. Thus, when I buy food or kitchen equipment I would like to make sure that the food that I buy is clean or not having an expired date and I choose to buy in department stores or twenty hour mini mart instead of the retail store”

“When my daughter eats less food or gets weakness, I encourage her to have supplementary food such as milk.”

- Caring to support development.

“My son has fun when he goes to the department store, but I am concerned about the large crowds. Thus, I take him on ordinary days when the crowd is small not on holidays or in the afternoon”

“My daughter likes drawing. Thus, I encourage and support her in drawing”

These quotes suggest that the mothers could learn from their experience. They examined their situation critically, and developed their decision making capabilities and a strategic plan to solve problems of infection, bleeding, nausea and vomiting, mucositis, and they developed a plan to promote health and support development. They also understood and realized that they were able to take charge in their situation. This is congruent with the study of Gibson (1999) who proposed that through cycles of critical reflection, the mothers realize that they have learned from their experience and acquired knowledge and skill as well as becoming able to take charge of their situation and develop a sense of personal power. Likewise, Utrarachkij (1997) studied the process of empowerment in mothers of chronically ill children utilizing the empowerment concepts of Gibson (1995). The result revealed that in the phase of critical reflection, the mothers learned everything that benefited the child and they developed the ability to provide care. Similarly, Jenjob (1999) studied the process of empowerment in rheumatoid arthritis patients and utilized the concepts of Gibson (1995). The result revealed that the mean scores in the category of critical reflection in the posttest at 1 month, 2 month and 3 month were significantly higher than in the pretest.

However, some mothers passed through the process of critical reflection with difficulty. This might have been due to lack of information or skill or little experience of sharing. The mothers were provided with the opportunity to examine their situation critically and develop a strategic plan of caring.

In contrast, the mothers in the control group received routine nursing care. They did not have a chance to develop their skills of analyzing and understanding their experience of care as well as developing a strategic plan to care for their child. Therefore, they were not able to enhance decision making capabilities and develop strategies and plans to deal with their situation. As a result, the caring behavior scores were similar in pretest and posttest (table3) and significantly different from the mothers in the empowerment group (table5).

Step 3: Taking charge. This was the phase in which the mothers developed a strategic plan for action. The mothers were provided with the opportunity to have choices in decision making and develop a strategic caring plan as well as to achieve goal directed behavior. The motivating methods included sharing and providing information needed to make informed choices, and demonstrations and performing of practice until they were able to execute skills confidently and correctly. These were the strategies to develop the process of empowerment (Feste & Anderson, 1995; Falk-Rafael, 2001). Likewise, Sternberg (2005) proposed that metacognitive skill, learning skill, thinking skill, knowledge and motivation are the five elements for developing competency (Sternberg, in Elliot & Dweck, eds., 2005). Moreover, the mothers who care correctly were motivated by positive feedback. Positive feedback tends to increase intrinsic motivation by enhancing perceived competency (Deci & Moller, in Elliot & Dweck, eds., 2005). Through the process of taking charge, the mothers became aware of their strengths and became confident in their knowledge, and able to take action in their situation, and also achieve their goal directed behavior for caring.

Referring to the data of this study, it was found that some mothers did do malpractice in caring such as allowing the child to eat snack, not protecting the child from playing contact sports or potential injuries, and not coating the lips with moisturizer. This may have been due to lack of information or lack of concern for the side effects of chemotherapy. The mothers were provided with information about the advantages and disadvantages of their caring. As a result, on comparison of the caring

behavior scores in pretest and posttest in the empowerment group, there were increases in mean scores in three aspect of self-care requisites in the posttest and also higher scores than in the control group (table 3). The increasing mean scores may have come from the fact that the mothers had enough information for decision making and chose the right choice to provide care, and awareness of their caring. This is congruent with the study of Wallerstein & Bernstein (1988 cited in Krobthong, 1999) who proposed that knowledge is gained from sharing of experience and understanding the social influences surrounding their lives by using the tools of the empowerment process. Similarly, Jantacumma (2004) studied the effect of empowerment program on self-care behavior in the elderly utilizing the empowerment concept of Gibson (1995). The result revealed that the elderly in the empowerment group significantly increased knowledge and self-care in the aspect of universal self-care requisites for food, water, air, elimination process and excrements, balance between activity and rest, prevention of hazards, and promotion of human function and development than did the control group. Likewise, Krobthong (1999) studied the effect of the empowerment process on knowledge and self-care practice in the essential hypertension patients utilizing the empowerment concepts of Gibson (1995). The result revealed that the mean scores of knowledge and self-care practice in the empowerment group were significantly higher than those in the control group ( $p < .001$ ). Besides, Wong, Harker, Lau, Shatzel, and Port (2004) studied the effectiveness of the Spanish arthritis empowerment program on knowledge and self-care behavior. The result showed significant improvement from pretest to 6-month follow up in knowledge and self-care behavior ( $p < .001$ ). Additionally research supported the effect of motivation on caring behavior. There was a study of Keawkan (1990) who studied the effect of motivation on relatives' behaviors in caring for stroke patients. The result showed that relatives of stroke patient increased their knowledge and skill in taking care of patients after motivation.

Moreover, some mothers lacked the skill to provide care in areas such as caring to prevent or lessen bleeding; in this area, the mothers disturbed clot blood formation from wound bleeding; and in the area of caring to prevent or lessen mucositis, the mothers did not use cotton tipped buds for oral care to avoid trauma from mucositis, and never practiced or only sometime practiced inspecting the mucous membrane and tongue in the oral cavity. This might have been due to lack of

confidence, experience, knowledge and skill in performing these tasks. The mothers were provided with opportunities to improve their skill in caring by demonstrations and training in the skill until they could do it confidently and correctly. When the mothers had an opportunity to perform practice, they could learn from real action. As a result, the mothers gained competency for caring and also became autonomous in setting goal directed caring behavior for bleeding and mucositis. Additionally, some mothers had questions about caring such as how to clean hands when traveling or what to do when there was no water to wash with. The researcher motivated the mothers to set directed goals for caring to prevent infection and mutual participation to find ways to solve problems.

This finding suggested that the mothers became autonomous in setting the goal directed caring behavior to prevent infection, bleeding, nausea/vomiting, mucositis; and to promote health and development. They also found their competency to solve the problems of their child. For these reasons, when comparing the mean scores of caring behavior in the posttest, it was found that the mothers in the experimental group achieved higher scores of caring behavior than the mothers in the control group (table 5). This is congruent with the study of Gibson (1995) who proposed that in the process of taking charge, the mothers were confident in their knowledge of their child and took charge of the situation. Similarly, Utrarachkij (1997) studied the process of empowerment in mothers of chronically ill children. The result revealed that in the step of taking charge, the mothers were confident in caring. Likewise, Jenjob (2542) studied the process of empowerment in rheumatoid arthritis patients utilizing the empowerment concepts of Gibson (1995). The result revealed that the patients increased their knowledge of self-care in the posttest scores at 1 month, 2 months and 3 months than did the pretest scores.

Step 4: Holding on. This was the step in which the mothers gained awareness of their strengths, competency and capability and developed a sense of control and also continued to persist with their efforts to attain a desired outcome. The mothers were provided with the opportunity to maintain their competence in caring by revising their knowledge and skill. Through the process of holding on, the mothers became autonomous and competent in caring in the three aspects of self-care requisites.

From observation and discussion in this step, most of the mothers reported that they knew how to provide care for their child. The example reflecting the ongoing maternal process of holding on were things such as the mothers having a choice to provide care for preventing infection and finding ways to care appropriately for their child on their own. This finding suggested that the mothers had competency and autonomy in caring. It is congruent with the study of Gibson (1995) who proposed that in the process of holding on mothers were aware of their competency, and capabilities. Similarly, Utrarachkij (1997) stated that in the step of holding on, the mother was able to deal with and manage her situation when difficulties such as extubation occurred. Likewise, Jenjob (2542) studied the process of empowerment in rheumatoid arthritis patients utilizing the empowerment concepts of Gibson (1995). The result revealed that after empowering, the scores of self management and sense of mastery were increased in the posttest at 1 month, 2 months and 3 months compared to the pretest scores.

In contrast, the mothers in the control group did not have a chance to develop or boost their competence for caring. Therefore, the caring behavior score in the control group were similar in pretest and posttest (table3) and significantly different from the mothers in the empowerment group (table5).

**Phase 3** Follow up phase: this was the phase in which the mothers maintain competency and autonomy in caring. The mothers were provided with the opportunity to boost their competency by telephone support to reinforce their caring, to evaluate the progression of caring, and to follow the child's health. They also had the opportunity to ask about their problems and concerns about health problems and promote health and support development. From conversation, it was found that most of the mothers reported that they could perform caring activities by themselves and that they know how to care for their child so that child did not have increased severity of side effects of chemotherapy after discharge. In case of caring correctly, the mothers were motivated to maintain their potential behavior by positive feedback. The positive feedback tends to increase intrinsic motivation by enhancing perceived competency. Additionally some children had problems before discharge such as dental caries, failure to thrive, mild mucositis, and chronic bronchitis. The researcher followed through to evaluate these problems and provide support. Orem (2001) stated

that providing support is the method of helping the mothers to have choice, and became able to perform the activity. Moreover, the mothers had the opportunity to call the researcher to ask about problems of caring. For example, a mother called to ask when her child had fever with diarrhea. This mother was encouraged to find the cause of problem and develop a strategic plan to care. Some mothers called to ask about using tear eye drops or when his child got a rash, the mothers were provided with information needed to make informed choices. As a result, the mothers were autonomous, competent and maintained caring behavior. The result from telephone support was consistent with the study of McCarthy et al. (2002) who studied empowering parents through asthma education. The result revealed that the phone calls, which were part of the empowering intervention, had reinforced the parents' confidence in their decision skills.

In contrast, the mothers in the control group did not have the opportunity to develop or boost their competence and autonomy for caring because in routine nursing care there were not session for follow up child health or asking for problems about caring at home. Therefore, the caring behavior score in the control group were similar in pretest and posttest (Table3) and significantly different from the mothers in the empowerment group (Table5).

**Phase 4 Termination phase:** this was the phase in which the mothers maintain competence and caring behavior. The mothers had the opportunity to revise or ask about problems of their caring. From the conversation in this phase, most of the mothers reported that they could perform caring activity by themselves. This indicated for the mothers were autonomous and competent in caring. Then, essential issues of caring were summarized.

In summary, when the mothers felt empowered, they felt competence and autonomous in performing relevant caring behavior for their child. The result of this study demonstrated that the mothers who participated in the empowerment program achieved their goal directed caring behavior significantly more than the control group. The achievement score might be mainly due to the effects of empowerment program. The result from this study suggests that empowerment program might be one of the nursing interventions to enhance maternal caring behavior for children with leukemia undergoing chemotherapy. This finding was congruent with the study of Gibson

(1995) who studied the process of empowerment in mothers of chronically ill children. The result demonstrated that the mothers who attained participatory competence had developed sound knowledge of their child health and were competent in caring. Besides, Dunst & Trivette (1996) proposed that the empowerment outcomes are behaviors that are strengthened or learned as a result of participatory experience. Similarly, Utrarachkij (1997) studied the process of empowerment in mothers of chronically ill children. The result showed that when the mothers of children with encephalitis developed empowerment, they were confident in their own competency and caring. Likewise, McCarthy et al. (2002) studied empowering parents through asthma education. The result showed that parents in the empowering group significantly increased ability to provide care, ability to make decisions, and sense of control compared to the control group ( $p < .05$ ). Moreover, Hendrickson et al (2002) studied empowerment in rural Viet Nam for exploring changes in the context of an integrated nutrition project. The result showed that mothers in the intervention increased knowledge, confidence, and information sharing about child-care and feeding, while non-intervention mothers reported minimal changes in these domains. Additionally, these finding were similar with previous research of Sathirapanya (2001) and Petchtone (2004), using the process of empowerment from Gibson (1995). The result showed that the empowerment process increased knowledge and skill in caring.

## CHAPTER VI

### CONCLUSION

#### Summary of the study

This research was a quasi-experimental study with two group pretest-posttest design aiming to study the effects of empowerment program on maternal caring behavior for children with leukemia undergoing chemotherapy.

The samples of this study were mothers of children with leukemia aged 3-12 years who took their children for chemotherapy at Siriraj hospital. The samples were composed of 29 mothers who were divided into two groups: the experimental group (n=14) and the control group (n=15). The mothers in the experimental group participated in an empowerment program, while the mothers in the control group received the usual nursing care.

The research instruments were the intervention instrument and the data collection instruments. The intervention instrument was an empowerment program. The data collection instruments consisted of a demographic data questionnaire and maternal caring behavior for children with leukemia questionnaire, with a pretest on the first day and posttest on 4-weeks follow up. The study was conducted from December 2005 to April 2006. Descriptive statistics were used to analyze the demographic data. ANCOVA were used to test the research hypothesis.

The results of this study were summarized as follow:

1. Characteristics of the samples

The general characteristics of the experimental group and the control group were similar in many categories and there were a few exceptions. For the characteristics of mothers, most of the mothers in both the experimental and control groups were employees, were married, had support for caring, and their source of information for caring were doctors, nurses, other mothers and books. The mean of maternal age was 34.07 years in the experimental group, and 36.55 years in the control group. The few exceptions with different characteristics for mothers in both groups

were education and family income. For education level, most of the mothers in the experimental group had primary and secondary, while most of the mothers in the control group were primary level. In terms of family income, the mothers in the experimental group had family income of 9,214 bath/per/month, while the mothers in the control group had family income 25,100 bath/per/month. For characteristics of children, most of the children in both the experimental group and the control group were aged between 7-9 years, were diagnosed with ALL, received chemotherapy in phase of maintenance and received more than 24 months. In terms of the experiencing of side effects of chemotherapy, most of the children in the experimental group had fever (100%), alopecia (100%), mucositis (92.9%), and nausea/vomiting (78.6%) while most of the children in the control group had alopecia (100%), fever (86.7%), nausea/vomiting (86.7%), and mucositis (73.3%).

2. Hypothesis: mothers of children with leukemia who participated in an empowerment program would have caring behavior scores higher than those who received usual nursing care.

The hypothesis postulated in this study was accepted. After the experimental group participated in the empowerment program on maternal caring behavior for 4 weeks, the mean scores of caring behavior for children with leukemia were statistically significantly higher than the scores of caring behavior for children in the control group ( $p < .05$ ).

In conclusion, this study suggests that the empowerment program is an effective intervention to enhance maternal caring behavior for children with leukemia undergoing chemotherapy.

## **Implications and Recommendations**

Referring to the findings of this study, the implementation and recommendations are as follows:

### **1. Implication for nursing practice**

1.1 This empowerment program should be encouraged to be utilized in routine nursing care for enhancing maternal caring behavior for children with leukemia.

1.2 The empowerment program should be applied to use for the mothers who have newly diagnosed or relapsing children because these mothers may confront many problems and feel frustration as well as having low empowerment level in caring behavior.

1.3 The empowerment program should be suitable for use with mothers of children with other malignancies or chronic illnesses.

1.4 For a more effective empowerment program, nurses should provide the program with group discussion and better individual discussion to enhance caring behavior.

1.5 Telephone support should be provided to facilitate the mothers in expressing their problems or concerns in caring at the home setting.

## **2. Recommendations for further study**

2.1 The effect of the empowerment program should be followed over the long term in order to assess its sustainability. Thus, future research should be followed up at 3 months and 6 months.

2.2 This research dealt with the effect of an empowerment program in contributing to caring behavior. Caring behavior is predicated on intrinsic motivation. Therefore, future study should examine the effect of the empowerment process on motivation.

2.3 In this study, the empowerment program was provided by individual discussion; future research should study the effect of empowerment on group discussion.

2.4 Future research should use a larger sample size of mothers of children with leukemia, and randomized sampling is recommended for more representation and better generalization of study.

2.5 The study should be modified to study the caring behavior of other mothers of children with chronic illnesses using this model of empowerment.

## REFERENCES

- Baggott, C., Beale, I.L., Dodd, M.J., & Kato, P.M. (2004). A survey of self-care and dependent-care advice given by pediatric oncology nurse. *Journal of Pediatric Oncology Nursing, 21*(4), 214-222.
- Ball, J.W., & Bindler, R.C. (2003). *Pediatric Nursing: Alterations in cellular growth* (3<sup>rd</sup> ed.). New Jersey: Pearson Education.
- Best practice' diets for the cancer patient.* (n.d.). Retrieved July 13, 2005, from <http://www.iconmag.co.uk> 2003.
- Bishop, A., Huntly, A., Isaac, S., & Jonson, M. (1988). *Basics and tools: A collection of popular education resources and activities.* Ontario: CUSO Education Department.
- Bleyer, A. (2004). Principle of treatment. In R.E. Behrman, R.M. Kliegman & H.B. Jenson(Eds.), *Nelson textbook of pediatrics* (17<sup>th</sup> ed., pp. 1688-1694). Philadelphia, PA: Elsevier Science.
- Carter, L.W. (1993). Influencing of nutrition and stress on people at risk for neutropenia: nursing implication. *Oncology Nursing Forum, 20*(8), 1241-1250.
- Conger, J.A., & Kanungo, R.N. (1988). The empowerment process: integrating theory and practice. *Academy of Management Review, 13*(3), 471-482.
- Copstead, L.C. (1995). *Perspectives on pathophysiology.* Philadelphia, PA: W.B. Saunders.
- Crawford, J., Dale, D.C., & Lyman, G.H. (2004). Chemotherapy-induced neutropenia: risks, consequences, and new directions of its management. *Cancer, 100*(2), 228-237.
- Crom, D.B., Boggs, T.B., Mandrell, B.N., & Norville, R. (1999). Pediatric cancers. In C. Miaskowski & P. Buchsel(Eds.), *Oncology Nursing: assessment and clinical care* (pp. 1525-1580). St. Louis, MO: Mosby.
- Darbyshire, P., & Morrison, H. (1995). Empowering parents of children with special needs. *Nursing Times, 91*(32), 26-30.

- Deci, E.L., & Moller, A.C. (2005). The concept of competence. In A.J. Elliot & C.S. Dweck (Eds), *Handbook of competence and motivation* (pp. 579-597). New York: Guilford Press.
- Dunst, C.J., & Trivette, C.M. (1996). Empowerment, effective helpgiving practices and family-centered care. *Pediatric Nursing*, 22(4), 334-337.
- Falk-Rafael, A.R. (2001). Empowerment as a process of evolving consciousness: a model of empowered caring. *Adv Nurs Sci*, 24, 1-16.
- Feste, C., & Anderson, R.M. (1995). Empowerment: from philosophy to practice. *Patient Education and Counseling*, 26, 139-144.
- Franken, R.E. (1998). *Human Motivation*. California: Brooks/Cole.
- Gaffney, K.F., & Moore, J.B. (1996). Testing Orem's theory of self-care deficit: dependent care agent performance for children. *Nursing Science Quarterly*, 9(4), 160-164.
- Gibson, C.H. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing*, 16, 354-361.
- Gibson, C.H. (1995). The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing*, 21, 1201-1210.
- Gibson, C.H. (1999). Facilitating critical reflection in mothers of chronically ill children. *Journal of Clinical Nursing*, 8, 305-312.
- Hawks, J.H. (1992). Empowerment in nursing education: concept analysis and application to philosophy, learning and instruction. *Journal of Advanced Nursing*, 17, 609-61.
- Hendrickson, J.L., Dearden, K., Pachon, H., An NH., Schroeder, D.G., & Marsh, D.R. (2004). Empowerment in rural Viet Nam: exploring changes in mothers and health volunteers in the context of an integrated nutrition project. *Food Nutr Bull*, 23(4), 86-94.
- Hockenberry, M.J. (2004). Symptom management research in children with cancer. *Journal of Pediatric Oncology Nursing*, 21(3), 132-136.
- Hockenberry, M.J. (2005). *Wong's essentials of pediatric nursing* (7<sup>th</sup> ed.). St. Louis, MO: Mosby.

- Hurlock, E.B. (1975). *Developmental psychology* (4<sup>th</sup> ed.). New York: McGraw-Hill.
- James, S.R., Ashwill, J.W., & Droske, S.C. (2002). *Nursing care of children: Principle & practice*. Pennsylvania: W.B. Saunders.
- Jantacumma, N. (2003). *Effects of the empowerment program on self-care behaviors of elderly in Nongpailom community, Nakhonratchasima Province*. Master of science, Mahidol University, Bangkok, Thailand.
- Kozier, B., Erb, G., Berman, A., & Snyder, S.J. (2004). *Fundamentals of nursing: Concepts, process, and practice*. New Jersey: Pearson Education.
- Krobthong, V. (1999). *The effects of the empowerment process on the self-esteem development for hypertension control*. Doctoral dissertation, Mahidol University, Bangkok, Thailand.
- Landier, W. (2001). Children acute lymphoblastic leukemia: Current perspectives. *Oncology Nursing Forum*, 28(5), 823-833.
- Lehrnbecher, T., Varwig, D., Kaiser, J., Reinhardt, D., Klingebiel, T., & Creutzig, U. (2004). Infectious complications in pediatric acute myeloid leukemia: Analysis of the prospective multi-institutional clinical trial AML-BFM 93. *Leukemia*, 18(1), 72-77
- Lertwongpaopun, W. (2003). *The effects of an oral care program on stomatitis in acute myeloidleukemia patients undergoing chemotherapy*. Master of nursing science, Mahidol University, Bangkok, Thailand.
- Management of the child with fever*. (n.d.). Retrieved July 13, 2005, from The Joannabriggs Institute. <http://www.Joannabriggs.edu.au>.
- McCarthy, M.J., Herbert, R., Brimacombe, M., Hansen, J., Wong, D., & Zelman, M. (2002). Empowering parents through asthma education. *Pediatric nursing*, 28(5), 465-473.
- Miller, M. & Kearney, N. (2001). Oral care for patients with cancer: A review literature. *Cancer Nursing*, 24(4), 241-254.
- Munro, B.H. (2001). *Statistical methods for health care research* (4<sup>th</sup> ed). Philadelphia, PA: Lippincott Williams & Wilkins.
- Nyatanga, L., & Dann, K.L. (2002). Empowerment in nursing: the role of philosophical and psychological factors. *Nursing Philosophy*, 3, 234-239.
- Orem, D.E. (2001). *Nursing: concepts of practice* (6<sup>th</sup> ed.). St. Louis, MO: Mosby.

- Paice, J.A. (1999). Symptom management. In C. Miaskowski & P. Buchsel (Eds.), *Oncology Nursing: Assessment and clinical care* (pp. 275-301). St. Louis, MO: Mosby.
- Peckenpaugh, N.J., & Poleman, C.M. (1999). *Nutrition essentials and diet therapy: Cancer: nutrition prevention and treatment*. Pennsylvania: W.B. Saunders.
- Pellino, T., Tluczek, A., Collins, M., Trimborn, S., Norwick, H., Engelke, Z.K., et al. (1998). Increasing self-efficacy through empowerment: preoperative education for orthopaedic patients. *Orthopaedic Nursing*, 17(4), 48-59.
- Petchtone, P. (2004). *The effectiveness of empowerment program on care –giving ability, self- efficacy and self-esteem among family caregivers of cerebrovascular disease patients*. Master of science, Mahidol University, Bangkok, Thailand.
- Polit, D.F., & Beck, C.T. (2004). *Nursing research: principles and methods* (7<sup>th</sup> ed). Philadelphia, PA: Lippincott Williams & Wilkins.
- Prevention and treatment of oral mucositis in cancer patients*. (n.d.). Retrieved July 13, 2005, from The Joannabriggs Institute. [http://www. Joannabriggs. edu.au](http://www.Joannabriggs.edu.au).
- Riley, L.C., Hann, I.M., Wheatley, K., & Stevens, R.F. (1999) Treatment-related deaths during induction and first remission of acute myeloid leukaemia in children treated on the Tenth Medical Research Council Acute Myeloid Leukaemia Trial. *British Journal of Haematology*, 106(2), 436-444.
- Rodwell, C.M. (1996). An analysis of the concept of empowerment. *Journal of Advanced Nursing*, 23, 305-313.
- Rosdahl, C.B., & Kowalski, M.T. (2003). *Textbook of Basic Nursing* (8<sup>th</sup> ed). Philadelphia, PA: Lippincott Williams & Wilkins.
- Ryles, S.M. (1999). A concept analysis of empowerment: its relationship to mental health nursing. *Journal of Advanced Nursing*, 29(3), 600-607.
- Sakulnoom, K. (2002). *Effect of an Empowerment Program on perceived Self – Efficacy for Self - Management among mothers of children with Congenital Heart Disease*. Master of nursing science, Mahidol University, Bangkok, Thailand.

- Sathirapanya, C. (2001). *The effectiveness of empowerment for enhancing quality of life among ischemic stroke patients attending Songkhla Neuropsychiatric Hospital*. Doctoral dissertation, Mahidol University, Bangkok, Thailand.
- Schroeder, C.M. (1998). Cancer chemotherapy. In M. Gulanick, A. Klopp, S. Galanes, D. Gradishar & M.K. Puzas(Eds.), *Nursing care plans*(4<sup>th</sup> ed., pp. 906-918). St. Louis, MO: Mosby.
- Shadish, W.R., Cook, T.D., & Campbell, D.T. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. New York: Houghton Mifflin.
- Siriraj Cancer Center. (2001). *Cancer Registry: Statistical Report 1990-1999*. Faculty of Medicine, Siriraj Hospital, Mahidol University .
- Sternberg, R.J. (2005). Intelligence, competence, and expertise. In A.J. Elliot & C.S. Dweck(Eds.), *Handbook of competence and motivation*(pp. 15-28). New York: Guilford Press.
- Tubergen, D.G., & Bleyer, A. (2004). The Leukemias. In R.E. Behrma, R.M. Kliegman & H.B. Jenson(Eds.), *Nelson textbook of pediatrics* (17<sup>th</sup> ed. pp. 1694-1698). Philadelphia, PA: Elsevier Science.
- Whitlock, J.M. & Gaynon, P.S. (2004). Acute lymphoblastic leukemia in children. In J.P.Greer, G.M. Rodgers, J. Foerster, F. Paraskevas, J.N. Lukens & B. Glader(Eds.), *Wintrrobe's clinical hematology*(11<sup>th</sup> ed., pp. 2143-2168). Philadelphia, PA: Lippincott Williams & Wilkins.
- Wiangnon, S., Kamsa-ard, S., Jetsrisuparb, A., Sriplung, H., Sontipong, S., Sumitsawan, Y., & Martin, N. (2003). Childhood Cancer in Thailand: 1995-1997. *Asian Pacific Journal of Cancer Prevention*, 4, 337-343.
- Wong, A.L., Harker, J.O., Lau, V.P., Shatzel, S., & Port, L.H. (2004). Spanish arthritis empowerment program: a dissemination and effectiveness study. *Arthritis Rheum*, 51(3), 332-336.
- Yarbro, C.H., Frogge, M.H., & Goodman, M.G. (2004). *Cancer Symptom Management* (3<sup>rd</sup> ed). Sudbery, MA: Jones and Bartlett.

- กระทรวงสาธารณสุข. (2546). (Ministry of Public Health, 2003). *สถิติสาธารณสุข พ.ศ. 2546*. กรุงเทพมหานคร: องค์การสงเคราะห์ทหารผ่านศึก.
- กวีวัฒน์ วีรกุล และ กลีบสไบ สรรพกิจ. (2545). (Veerakul, G & Sanpakit, K., 2002). โรคมะเร็งในเด็กรักษาให้หายได้. ในนวนลองค์ วิศิษฎสุนทร(บรรณาธิการ), *เวชปฏิบัติทางกุมารเวชศาสตร์* (หน้า 387-405). กรุงเทพมหานคร: โรงพิมพ์ชวนพิมพ์.
- กฤษณา ครามแสง. (2539). (Kranseang, K., 1996). *ผลของการพยาบาลระบบสนับสนุน และให้ความรู้ต่อการลดความพร่องของผู้ดูแลเด็กป่วยโรคมะเร็งที่ได้รับเคมีบำบัด*. วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต, มหาวิทยาลัยมหิดล.
- จรงค์ อุตราชต์กิจ. (1997). (Utrarachkij, J., 1997). กระบวนการสร้างพลังอำนาจในมารดาที่ต้องดูแลบุตรป่วยเรื้อรัง: กรณีศึกษา. *Rama Nurs J*, 3(3), 321-327.
- ชวนพิศ นรเดชนนท์. (2547). (Norradechanont, C., 2004). *เคมีบำบัด: หลักการพยาบาล*. กรุงเทพมหานคร: คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล.
- นภาพรณ แก้วกรรณ์. (2533). (Keawkan, N., 1990). *ผลของการสนใจญาติต่อพฤติกรรมดูแลผู้ป่วยโรคหลอดเลือดสมองในระยะพักฟื้น*. วิทยานิพนธ์ปริญญาวิทยาศาสตรมหาบัณฑิต, มหาวิทยาลัยมหิดล.
- ปัญญา กุลพงษ์. (2540). (Kulapong, P., 1997). *โรคมะเร็งในเด็ก*. เชียงใหม่: ภาควิชากุมารเวชศาสตร์ คณะแพทยศาสตร์ มหาวิทยาลัยเชียงใหม่.
- ปัญญา เสกสรรค์. (2542). (Saesan, P., 1999). มะเร็งในเด็ก. ในสำหรี จิตตินันท์. (บรรณาธิการ). *ตำรากุมารเวชศาสตร์ เล่ม3* (หน้า1710-1727). กรุงเทพมหานคร: เรือนแก้วการพิมพ์.
- ประดิษฐา สิ้นสว่าง. (2538). (Sinsawang, P., 1995). *ผลของการสนับสนุนภายในกลุ่มของมารดาเด็กโรคมะเร็งเม็ดเลือดขาวต่อความวิตกกังวลและพฤติกรรมดูแลบุตรของมารดา*. วิทยานิพนธ์ปริญญาวิทยาศาสตรมหาบัณฑิต, มหาวิทยาลัยมหิดล.
- พนารัตน์ เจนจบ. (2542). (Jenjob, P., 1999). *การเสริมสร้างพลังอำนาจในผู้ป่วยโรคข้ออักเสบรูมาตอยด์*. วิทยานิพนธ์ปริญญาพยาบาลศาสตรมหาบัณฑิต, มหาวิทยาลัยเชียงใหม่.
- วินัย สุวัตถิ. (2542). (Suvatte, V., 1999). Acute Leukemia in Children. ในธานีรินทร์ อินทรกำจรชัย (บรรณาธิการ), *โลหิตวิทยาในเวชปฏิบัติ* (หน้า 334-351). กรุงเทพมหานคร: บริษัท ปียอนด์เอ็นเตอร์ไพรซ์ จำกัด.
- สุรเดช หงส์อิง. (2541). (Hongeng, S., 1998). Childhood leukemia. ในวรชัย รัตนธรรช (บรรณาธิการ), *ตำราการรักษาโรคมะเร็ง 2* (หน้า 449-458). กรุงเทพมหานคร: โฮลิสติก.

อุรา สุวรรณรักษ์. (2542). (Suvanarak, U., 1999). การเพิ่มพลังอำนาจต่อการดูแลสุขภาพตนเองของผู้ป่วยโรคเบาหวาน โรงพยาบาลสภิงพระ จังหวัดสงขลา.

วิทยานิพนธ์ปริญญาวิทยาศาสตรมหาบัณฑิต, มหาวิทยาลัยมหิดล





## APPENDIX A

### Content validators

The content validity of the research instruments were determined by these experts as below:

1. Dr. Tassanee Attharos  
Department of Pediatric Nursing  
The Thai Red Cross  
College of Nursing.
2. Miss Chukwan Pinsakol  
Nursing Division  
Faculty of Medicine, Siriraj Hospital  
Mahidol University.
3. Dr. Autchareeya Patoomwan  
Nursing Department  
Faculty of Medicine, Ramathibodi Hospital  
Mahidol University.
4. Assist. Prof. Suradej Hongeng  
Department of Pediatric  
Faculty of Medicine, Ramathibodi Hospital  
Mahidol University.
5. Dr. Daranee Jamjuree  
Nursing Technical officer  
Division of Nursing  
Ministry of Public Health

## APPENDIX B

### Empowerment program for mothers on caring children with leukemia undergoing chemotherapy

#### โปรแกรมการเสริมสร้างพลังใจของมารดาในการดูแลบุตรที่เฝ้าไข้ยามบำบัด

**วัตถุประสงค์** เพื่อให้มารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาว มีความสามารถในด้าน

1. การปฏิบัติในการดูแลบุตรในการส่งเสริมสุขภาพบุตร ให้มีสุขภาพแข็งแรง
2. การปฏิบัติในการดูแลบุตรตามระยะพัฒนาการให้มีพัฒนาการตามขั้นตอนประจำวัย
3. การปฏิบัติในการดูแลบุตรเมื่อมีภาวะเบี่ยงเบนสุขภาพ จากผลข้างเคียงของยาเคมีบำบัด

**ย่ำบ้ำด**

**กลุ่มเป้าหมาย**

มารดาที่มีบุตรอายุ 3-12 ปี ที่ป่วยด้วยโรคมะเร็งเม็ดเลือดขาวชนิดเฉียบพลัน รับการร้กษาที่หอผู้ป่วยภาควิชากุมารเวชศาสตร์ที่มีผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวเข้ารับการร้กษาด้วยยาเคมีบำบัด คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล

**ลักษณะของโปรแกรม**

โปรแกรมการเสริมสร้างพลังใจในการดูแลบุตรที่ป่วยด้วยโรคมะเร็งเม็ดเลือดขาวที่ไ้รับยาเคมีบำบัด เป็นโปรแกรมที่จัดกระทำไ้กับมารดาเป็นรายบุคคล โดยเป็นการสนทนาพูดคุยเพื่อแลกเปลี่ยนความรู้และประสบการณ์ในการดูแลบุตรร่วมกันระหว่างผู้วิจัยและมารดาเด็ก (Individual discussion) รวมทั้งฝึกทักษะการดูแลที่สำคัญในเด็กที่ไ้รับยาเคมีบำบัด โดยพบกับมารดาจำนวน 4 วัน วันละ 1-2 ชั่วโมง แบ่งเป็น 1-2 ช่วง ไ้แก่ ช่วงเช้า เวลา 9.00-10.00 น. และช่วงบ่าย เวลา 13.30-14.30 น. ทั้งนี้เวลาในการดำเนินการตามโปรแกรม ขึ้นอยู่กับความสะดวกและความพร้อมของมารดา รายละเอียดของหัวข้อเรื่องในแต่ละวันดังนี้

วันที่ 1 เรื่องการดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด: การติดเชื้อและเมื่อมีไข้; อาการเลือดออกง่าย มีเลือดกำเดาไหล และเมื่อเกิดบาดแผล

วันที่ 2 เรื่องการดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด: เชื้อในช่องปากอักเสบ การประเมินสภาพช่องปาก และการดูแลในช่องปาก; คลื่นไส้อาเจียน

วันที่ 3 เรื่อง การดูแลที่จำเป็นโดยทั่วไปเพื่อส่งเสริมสุขภาพผู้ป่วยเด็ก

วันที่ 4 เรื่องการดูแลผู้ป่วยเด็กตามระยะพัฒนาการให้มีพัฒนาการตามขั้นตอนประจำวัย

### วิธีดำเนินการ

ก่อนที่จะเริ่มดำเนินการตามโปรแกรม ผู้วิจัยบอกวัตถุประสงค์ของการศึกษา บทบาทของมารดาและผู้วิจัย ประโยชน์ที่มารดาและเด็กจะได้รับ ขั้นตอนการดำเนินการวิจัย รวมทั้งการพิทักษ์สิทธิ์ของมารดา เมื่อมารดายินดียินดีสมัครใจเข้าร่วมโปรแกรม จึงเริ่มดำเนินการตามโปรแกรม ขั้นตอนการดำเนินการ ประกอบด้วย 4 ระยะ ดังนี้

**ระยะที่ 1** ระยะเริ่มแรก (Initial phase) เป็นระยะของการสร้างสัมพันธภาพ และจัดสิ่งแวดล้อมให้มารดารู้สึกปลอดภัย โดยมีการปฏิบัติดังนี้

1. ศึกษาข้อมูลและการรักษาที่เด็กได้รับ จากแฟ้มรายงานก่อนเข้าพบมารดา
2. เข้าพบมารดาเป็นรายบุคคล ทักทายเรียกชื่อมารดาและบุตรด้วยความเป็นมิตร ยิ้มแย้ม สบตา แสดงท่าที่เป็นกันเองขณะพูดคุย รับฟังในสิ่งที่มารดาพูดหรือแสดงความคิดเห็น
3. พูดคุยทักทายในเรื่องทั่วไป (small talk) เพื่อให้มารดารู้สึกผ่อนคลาย และเกิดความไว้วางใจ
4. จัดสิ่งแวดล้อมในการพูดคุยให้เงียบสงบ เป็นสัดส่วน

**ระยะที่ 2** ระยะดำเนินการ (Action phase) โดยปฏิบัติตามโปรแกรมการเสริมสร้างพลังใจ เพื่อเสริมสร้างความรู้และทักษะของมารดาในการดูแลบุตร โรคเมธีเร็งเม็ดเลือดขาวสาระสำคัญของการดูแลบุตรในโปรแกรม ใช้แนวคิดการดูแลตนเองและบุคคลที่ต้องพึ่งพาของ Orem (2001) โดยมีประเด็นการดูแลบุตรที่จำเป็นใน 3 ด้าน ได้แก่ การดูแลที่จำเป็นโดยทั่วไป เพื่อให้มีสุขภาพแข็งแรงพร้อมที่จะรับยาเคมีบำบัดได้อย่างต่อเนื่อง การดูแลตามระยะพัฒนาการ เพื่อให้มีพัฒนาการตามขั้นตอนประจำวัย และการดูแลเมื่อมีภาวะเบี่ยงเบนสุขภาพจากผลข้างเคียงของยาเคมีบำบัด โดยนำประเด็นการดูแลที่จำเป็นทั้ง 3 ด้าน มาแบ่งออกเป็น 6 ครั้ง ได้แก่

ครั้งที่ 1 การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด: การติดเชื้อ และมีไข้

ครั้งที่ 2 การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด: อาการเลือดออกง่าย มีเลือดกำเดาไหล และเมื่อเกิดบาดแผล

ครั้งที่ 3 การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด: อาการเชื่อบุในช่องปากอักเสบ การประเมินสภาพช่องปาก และการดูแลในช่องปาก

ครั้งที่ 4 การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด:  
อาการคลื่นไส้อาเจียน

ครั้งที่ 5 การดูแลที่จำเป็นโดยทั่วไป เพื่อส่งเสริมสุขภาพผู้ป่วยเด็ก

ครั้งที่ 6 การดูแลผู้ป่วยเด็กตามระยะพัฒนาการ ให้มีพัฒนาการตามขั้นตอนประจำวัย

การดำเนินการแต่ละครั้ง ประกอบด้วย 4 ขั้นตอน ดังนี้

**ขั้นตอนที่ 1** การค้นพบความเป็นจริง (Discovering reality) เป็นการช่วยให้มารดาได้สำรวจและประเมินตนเองเกี่ยวกับประสบการณ์ในการดูแลบุตรที่ได้ปฏิบัติหรือได้กระทำอยู่ ด้านการดูแลที่จำเป็นโดยทั่วไป การดูแลตามระยะพัฒนาการ และการดูแลเมื่อมีภาวะเบี่ยงเบนสุขภาพ ค้นหาปัญหาและความต้องการของตนเองในการดูแลบุตร การดำเนินการในขั้นตอนนี้ ได้แก่ การพูดคุยแลกเปลี่ยนความคิดเห็นระหว่างผู้วิจัยและมารดา การให้มารดาระบุประสบการณ์ในการดูแลที่ได้กระทำ การถามเพื่อประเมินความรู้ความเข้าใจที่ถูกต้อง การถามให้มารดาได้สะท้อนคิด เพื่อช่วยในการค้นพบความเป็นจริง

**ขั้นตอนที่ 2** การพิจารณาไตร่ตรอง (Critical reflection) เป็นการช่วยให้มารดาได้วิเคราะห์ประสบการณ์ในการดูแลบุตรที่เคยทำว่าเป็นอย่างไร วิเคราะห์สาเหตุของปัญหาในการดูแลว่าเกิดจากอะไรได้บ้างเพื่อป้องกันไม่ให้เกิด ได้ทบทวนทำความเข้าใจกับสิ่งที่เกิดขึ้นกับตนเองอย่างทุกแง่มุม ได้พิจารณาว่าการดูแลที่ก่อให้เกิดผลดีกับบุตรมากน้อยเพียงใด ต้องการปรับปรุงแก้ไขหรือเพิ่มเติมวิธีการดูแลอะไรบ้าง ซึ่งเมื่อมารดามีการพิจารณาไตร่ตรองแล้ว จะช่วยให้มีทางเลือกในการตัดสินใจ มีแนวทางในการดูแลบุตรได้อย่างเหมาะสมในสถานการณ์ของตนเอง

**ขั้นตอนที่ 3** การทำให้เกิดความสามารถในการดำเนินการ (Taking charge) ในขั้นตอนนี้เป็นการพัฒนาให้มารดามีความรู้และทักษะในการดูแลบุตร สามารถดำเนินการต่างๆ ด้วยตนเอง ตัดสินใจเลือกวิธีที่เหมาะสมและปรับวิธีการการดูแลให้เหมาะสมกับสถานการณ์ของตนเอง การดำเนินการในขั้นตอนนี้ ได้แก่ การพูดคุยแลกเปลี่ยนความรู้และประสบการณ์ในการดูแลเด็กระหว่างผู้วิจัยและมารดา การให้ความรู้ หรือข้อมูล ให้คำแนะนำ ให้คำปรึกษา เพื่อให้มีทางเลือกในการตัดสินใจ รวมทั้งสอนสาธิตและให้ฝึกปฏิบัติทักษะการดูแลที่สำคัญในเด็กที่ได้เคมีบำบัด เช่น การดูแลเมื่อมีไข้ เมื่อมีเลือดกำเดาไหล ประเมินสภาพช่องปากและการดูแลในช่องปาก จนมีความมั่นใจและสามารถดูแลหรือปฏิบัติได้จริง หรือหากมารดามีการดูแลที่ถูกต้องอยู่แล้ว จะให้ข้อมูลย้อนกลับในทางบวก (positive feedback) เพื่อที่จะดูแลบุตรได้อย่างต่อเนื่อง

**ขั้นตอนที่ 4** การคงไว้ซึ่งความมั่นใจในการควบคุมสถานการณ์ (Holding on) เมื่อมารดามีการรับรู้ความเข้มแข็งและความสามารถของตนเอง จะสามารถรักษาพลังของตนเองไว้ได้ แม้มีเหตุการณ์ใดๆเข้ามา มีความมั่นใจในการควบคุมสถานการณ์และจัดการกับสิ่งต่างๆได้ ซึ่งจะ

ทำให้มีการพัฒนาวิธีการดูแลบุตรให้มีประสิทธิภาพได้อย่างต่อเนื่อง การดำเนินการในขั้นตอนนี้ เพื่อช่วยให้มารดามีความมั่นใจและมีความสามารถในการดูแลบุตรได้อย่างถูกต้องและต่อเนื่อง โดยการซักถาม เพื่อให้มารดาได้ทบทวนวิธีการดูแลของตนเอง จนเกิดความมั่นใจ หรือการให้มารดาปฏิบัติให้ดู (return demonstrate) จนสามารถทำได้จริง

การยุติดำเนินการแต่ละเรื่อง ก่อนจะเลิกดำเนินการ ผู้วิจัยมีการปฏิบัติดังนี้

- ให้มารดาสรุปประเด็นสำคัญที่พูดคุยกัน
- เปิดโอกาสให้มารดาได้ซักถามข้อสงสัยเพิ่มเติม
- นัดหมายวัน เวลา และสถานที่ในการพูดคุยในเรื่องต่อไป บอกหัวข้อที่จะพูดคุยและ

บอกจำนวนวันที่เหลือในการพบกัน

- กล่าวขอบคุณมารดาที่ให้ความสนใจและความร่วมมือ

**ระยะที่ 3** ระยะติดตามผล (Follow up phase) เป็นระยะที่ช่วยให้มารดา มีการคงไว้ซึ่งความมั่นใจในการควบคุมสถานการณ์ (Holding on) โดยการสนับสนุนหรือช่วยให้มารดามีความสามารถในการดูแลบุตรได้อย่างต่อเนื่อง โดยโทรศัพท์ติดต่อพูดคุยกับมารดาที่บ้าน เพื่อประเมินความก้าวหน้าในการดูแล ซักถามปัญหาและอุปสรรคในการดูแล ให้คำแนะนำเพิ่มเติมตามความต้องการ หรือหากมารดามีการดูแลบุตรที่ถูกต้องอยู่แล้ว จะชมเชยและให้ความมั่นใจให้ดูแลบุตรต่อไป การติดตามจะโทรศัพท์ติดต่อกับมารดาหลังจากออกจากโรงพยาบาล สัปดาห์ละ 1 ครั้ง จนกว่าจะพบบุตรมารับยาเคมีบำบัดตามนัด และผู้วิจัยให้เบอร์โทรศัพท์แก่มารดาเพื่อติดต่อสอบถามการดูแลเพิ่มเติมในช่วงเวลา 7.00-20.00น. ได้ตลอดระยะเวลาที่เข้าร่วมโปรแกรม

**ระยะที่ 4** ระยะสิ้นสุดโปรแกรม (Termination phase) เมื่อมารดาพบบุตรมารับยาเคมีบำบัดอีกครั้ง ซึ่งเป็นช่วงของการมารับยาเคมีบำบัดต่อจากครั้งที่เข้าโปรแกรม โดยสรุปประเด็นสำคัญการดูแลผู้ป่วยเด็กที่ได้รับยาเคมีบำบัด ซักถามและให้ข้อมูลเพื่อให้มารดามีการดูแลบุตรอย่างต่อเนื่อง กล่าวขอบคุณและบอกการสิ้นสุดของโปรแกรม

### ครั้งที่ 1

การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด

...การติดเชื้อ...เมื่อมีไข้...

#### วัตถุประสงค์

1. เพื่อสร้างสัมพันธภาพและความคุ้นเคย
2. เพื่อให้มารดามีความรู้ความเข้าใจในวิธีการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาการติดเชื้อและเมื่อมีไข้
3. เพื่อให้มารดามีพฤติกรรมในการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาการติดเชื้อและเมื่อมีไข้ได้อย่างถูกต้อง

### ครั้งที่ 2

การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด

...อาการเลือดออกง่าย... มีเลือดกำเดาไหล...เมื่อเกิดบาดแผล

#### วัตถุประสงค์

1. เพื่อให้มารดามีความรู้ความเข้าใจในวิธีการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาอาการเลือดออกง่าย มีเลือดกำเดาไหล หรือเมื่อเกิดบาดแผล
2. เพื่อให้มารดามีพฤติกรรมในการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาอาการเลือดออกง่าย มีเลือดกำเดาไหล หรือเมื่อเกิดบาดแผล ได้อย่างถูกต้อง

### ครั้งที่ 3

การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด

...อาการเยื่อในช่องปากอักเสบ...การประเมินสภาพช่องปาก...การดูแลในช่องปาก...

#### วัตถุประสงค์

1. เพื่อให้มารดามีความรู้ความเข้าใจในวิธีการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาอาการเยื่อในช่องปากอักเสบ
2. เพื่อให้มารดามีความรู้ความเข้าใจเกี่ยวกับการประเมินสภาพช่องปาก และการดูแลในช่องปาก
3. เพื่อให้มารดามีพฤติกรรมในการดูแลบุตร เพื่อป้องกันและ/หรือบรรเทาอาการเยื่อในช่องปากอักเสบ การประเมินสภาพช่องปากและการดูแลในช่องปาก ได้อย่างถูกต้อง

## ครั้งที่ 4

การดูแลผู้ป่วยเด็กเพื่อป้องกันและ/หรือบรรเทาผลข้างเคียงของยาเคมีบำบัด

.....อาการคลื่นไส้อาเจียน.....

## วัตถุประสงค์

1. เพื่อให้มารดามีความรู้ความเข้าใจในวิธีการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาอาการคลื่นไส้อาเจียน
2. เพื่อให้มารดามีพฤติกรรมการดูแลบุตรเพื่อป้องกันและ/หรือบรรเทาอาการคลื่นไส้อาเจียนได้อย่างถูกต้อง

## ครั้งที่ 5

“การดูแลที่จำเป็นโดยทั่วไปเพื่อส่งเสริมสุขภาพผู้ป่วยเด็ก”

## วัตถุประสงค์

1. เพื่อให้มารดามีความรู้ความเข้าใจในการดูแลที่จำเป็นโดยทั่วไปเพื่อส่งเสริมสุขภาพผู้ป่วยเด็ก
2. เพื่อให้มารดามีพฤติกรรมการดูแลบุตรที่จำเป็นโดยทั่วไปเพื่อส่งเสริมสุขภาพผู้ป่วยเด็กได้อย่างถูกต้อง

## ครั้งที่ 6

การดูแลผู้ป่วยเด็กตามระยะพัฒนาการ...ให้มีพัฒนาการตามขั้นตอนประจำวัย...

## วัตถุประสงค์

1. เพื่อให้มารดามีความรู้ความเข้าใจในการดูแลผู้ป่วยเด็ก ให้มีพัฒนาการตามขั้นตอนประจำวัย
2. เพื่อให้มารดามีพฤติกรรมการดูแลผู้ป่วยเด็ก ให้มีพัฒนาการตามขั้นตอนประจำวัย

### แนวทางการพูดคุยทางโทรศัพท์เพื่อติดตามประเมินผลการดูแลของมารดา

เมื่อถึงวันที่และเวลาที่ผู้วิจัยนัดกับมารดา หลังจากที่เด็กออกจากโรงพยาบาล ผู้วิจัยโทรศัพท์ไปหามารดาสัปดาห์ละ 1 ครั้ง จนกว่ามารดาจะพบบุตรมาตรวจตามนัด โดยมีวิธีดำเนินการตามขั้นตอน ดังต่อไปนี้

1. สร้างสัมพันธภาพต่อเนื่อง
2. ติดตามผลการดูแล โดยซักถามวิธีการดูแลที่มารดาได้ปฏิบัติให้กับบุตรหลังจากออกจากโรงพยาบาล เพื่อช่วยให้มารดามีความมั่นใจและสามารถดูแลบุตรได้จริงและต่อเนื่อง โดยให้ข้อมูลคำแนะนำ คำปรึกษา ตามความต้องการของมารดาหรือตามปัญหาที่พบ จนมารดามีความมั่นใจและสามารถดูแลบุตรได้อย่างถูกต้องอย่างต่อเนื่อง หรือหากมารดามีการปฏิบัติที่ถูกต้องอยู่แล้ว จะชมเชยและให้กำลังใจเพื่อให้มารดาดูแลบุตรต่อไป
3. การยุติการพูดคุยโทรศัพท์ในแต่ละครั้ง โดยกล่าวขอบคุณในความร่วมมือและนัดหมายวันที่และเวลาในการพูดคุยโทรศัพท์ครั้งต่อไป โดยผู้วิจัยจะโทรศัพท์เพื่อติดตามผลเป็นระยะ ทุกสัปดาห์หลังจากออกจากโรงพยาบาลจนกว่าจะมาตรวจตามนัดในครั้งต่อไป หรือหากมารดาต้องการปรึกษาหรือขอคำแนะนำเพิ่มเติม ก็สามารถโทรศัพท์ติดต่อได้ ในช่วงเวลา 7.00-20.00 น.ตลอดระยะเวลาที่อยู่ในโปรแกรม

## APPENDIX C

### Questionnaires

#### เครื่องมือที่ใช้ในการวิจัย

#### แบบบันทึกข้อมูลส่วนบุคคล

คำชี้แจง กรุณาตอบแบบสอบถามเกี่ยวกับตัวท่าน โดยทำเครื่องหมาย / ลงหน้าข้อความที่ตรงกับตัวท่าน หรือเติมคำในช่องว่าง

#### ส่วนที่ 1 ข้อมูลส่วนบุคคลของมารดา

1. อายุ.....ปี
2. ระดับการศึกษา
  - .....ไม่ได้เรียนหนังสือ
  - .....ประถมศึกษา
  - .....มัธยมศึกษา
  - .....อนุปริญญา/ ปวช./ ปวส.
  - .....ปริญญาตรีขึ้นไป
3. สถานภาพสมรส
  - .....คู่
  - .....ม่าย
  - .....หย่า หรือแยกกันอยู่
4. อาชีพ
  - .....แม่บ้าน
  - .....รับราชการ/รัฐวิสาหกิจ/บริษัทเอกชน โปรตระนู.....
  - .....รับจ้าง โปรตระนู.....
  - .....ค้าขาย โปรตระนู.....
  - .....อื่นๆ โปรตระนู.....
5. รายได้รวมของครอบครัว .....บาท/ เดือน

6. ภาวะในการดูแลบุตรเจ็บป่วยคนนี้มีหรือไม่มี  
 .....ไม่มี  
 .....มี ในเรื่องอะไรบ้าง (ตอบได้มากกว่า 1 ข้อ)  
 .....ค่าใช้จ่าย  
 .....หน้าที่การงานอาชีพ  
 .....เวลาพักผ่อน
7. จำนวนบุตร.....คน ผู้ป่วยเป็นบุตรคนที่.....
8. การดูแลบุตรเจ็บป่วยที่บ้าน มีผู้ช่วยเหลือในการดูแลหรือไม่  
 .....ไม่มี  
 .....มี คือ..... (โปรดระบุความสัมพันธ์กับเด็ก)
9. ระยะเวลาในการดูแลบุตรในแต่ละวัน. ....ชั่วโมง
10. ท่านมีโรคประจำตัวหรือไม่  
 .....ไม่มี  
 .....มี คือโรค.....
11. ท่านเคยได้รับทราบข้อมูลเกี่ยวกับยาเคมีบำบัด และการดูแลบุตรในขณะที่ได้รับยาเคมีบำบัดเพิ่มเติมหรือไม่  
 .....ไม่เคย (ข้ามไปตอบส่วนที่ 2) .....เคย  
 ถ้าเคยได้รับทราบข้อมูล ได้รับจากที่ใด (ตอบได้มากกว่า 1 ข้อ)  
 ..... แพทย์ / พยาบาล  
 ..... มารดา / ผู้ดูแลเด็กรายอื่น  
 ..... วิทยุ/โทรทัศน์/หนังสือ  
 ..... ญาติพี่น้อง/ เพื่อน/ผู้ร่วมงาน  
 ..... อื่นๆ ระบุ.....

## ส่วนที่ 2 ข้อมูลส่วนบุคคลของผู้ป่วยเด็กโรคมะเร็ง

1. อายุ.....ปี.....เดือน
2. เพศ .....ชาย.....หญิง
3. เริ่มตรวจพบว่าเป็นบุตรป่วยเป็นโรคนี้นี้ตั้งแต่อายุ....ปี .....เดือน
4. ได้รับการรักษาด้วยเคมีบำบัดนาน.....ปี.....เดือน
5. เมื่อเด็กได้รับเคมีบำบัด มีอาการใดเกิดขึ้นบ้าง (ตอบได้มากกว่า 1 ข้อ)  
 .....คลื่นไส้ อาเจียน  
 .....แผลในปาก  
 .....ติดเชื้อง่าย เช่น มีไข้ เป็นหวัดบ่อย  
 .....เลือดออกง่าย เช่น มีเลือดกำเดาออก มีจุดจ้ำเลือด  
 .....ท้องผูกบ่อยๆ  
 .....ท้องเสียบ่อยๆ หรือเป็นๆ หายๆ  
 .....เบื่ออาหาร  
 .....ผมร่วง  
 .....อื่นๆ..... (โปรดระบุ).....

## ส่วนที่ 3 ข้อมูลทางการแพทย์ (สำหรับผู้วิจัย)

1. ชนิดของ protocol ที่ใช้รักษา.....
2. ชนิดของยาเคมีบำบัดที่ได้รับในครั้งนี้อย่างไร.....
3. ปัญหาที่เคยเกิดขึ้นระหว่างการรักษา.....
4. ได้รับยาครบตามกำหนดนัด  
 .....ครบทุกครั้ง  
 .....ไม่ครบ เพราะ.....

**แบบสอบถาม****พฤติกรรมกรดูแลบุตรของมารดาเด็ก โรคมะเร็งเม็ดเลือดขาว****คำชี้แจง**

แบบสอบถามนี้มีวัตถุประสงค์เพื่อสอบถามว่า ท่านปฏิบัติกรดูแลบุตรในขณะที่ได้รับยาเคมีบำบัดหรือหลังออกจากโรงพยาบาลไปอยู่บ้านอย่างไร

โปรดตอบข้อความโดยพิจารณาข้อความนั้นๆว่าท่านมีการปฏิบัติหรือการกระทำตรงกับข้อความแต่ละข้อบ่อยครั้งเพียงใด โดยตอบตามสภาพความเป็นจริง และเลือกเพียงคำตอบเดียวที่ตรงกับเหตุการณ์จริงมากที่สุด ในแต่ละข้อจะมีคำตอบให้เลือก 4 ระดับ ดังนี้คือ

**ปฏิบัติเป็นประจำ** หมายถึง ท่านปฏิบัติตามข้อความนั้นทุกวันใน 1 สัปดาห์ หรือหากเป็นเหตุการณ์ที่ไม่เกิดทุกวัน แต่เมื่อมีเหตุการณ์เกิดขึ้น 5 ครั้ง ท่านปฏิบัติทุกครั้ง

**ปฏิบัติเป็นส่วนใหญ่** หมายถึงท่านปฏิบัติตามข้อความนั้น 4-6 วันใน 1 สัปดาห์ หรือหากเป็นเหตุการณ์ที่ไม่เกิดทุกวัน แต่เมื่อมีเหตุการณ์เกิดขึ้น 5 ครั้ง ท่านปฏิบัติ 3-4 ครั้ง

**ปฏิบัติเป็นบางครั้ง** หมายถึง ท่านปฏิบัติตามข้อความนั้นเป็นบางครั้ง 1-3 วัน ใน 1 สัปดาห์ หรือหากเป็นเหตุการณ์ที่ไม่เกิดทุกวัน แต่เมื่อมีเหตุการณ์เกิดขึ้น 5 ครั้ง ท่านปฏิบัติ 1-2 ครั้ง

**ไม่ได้ปฏิบัติ** หมายถึง ท่านไม่ได้ปฏิบัติตามข้อความนั้นเลย หรือหากเป็นเหตุการณ์ที่ไม่เกิดทุกวัน แต่ถ้ามีเหตุการณ์เกิดขึ้น ท่านไม่ได้ปฏิบัติเลย

**ไม่มีเหตุการณ์นั้น** หมายถึง ท่านไม่ได้กระทำพฤติกรรมในการดูแลบุตรเนื่องจากไม่มีเหตุการณ์นั้นเกิดขึ้นกับบุตรของท่าน

## ตัวอย่างการตอบ

1. เป็นเหตุการณ์ที่เกิดทุกวัน ท่านปฏิบัติบ่อยครั้งเพียงไร

กิจกรรมที่ท่านได้กระทำกับบุตร	ปฏิบัติเป็นประจำ	ปฏิบัติเป็นส่วนใหญ่	ปฏิบัติเป็นบางครั้ง	ไม่ได้ปฏิบัติ	ไม่มีเหตุการณ์นั้น
1. ท่านให้ลูกรับประทานอาหารประเภทข้าวเนื้อสัตว์ นม ไข่ ผักและผลไม้	/				

หากท่านทำเครื่องหมาย / ในช่องปฏิบัติเป็นประจำ หมายความว่า ท่านปฏิบัติตามข้อความนั้น ทุกวันใน 1 สัปดาห์

2. เป็นเหตุการณ์ที่ไม่ได้เกิดขึ้นทุกวัน แต่เมื่อมีเหตุการณ์เกิดขึ้น ท่านปฏิบัติบ่อยครั้งเพียงไร

กิจกรรมที่ท่านได้กระทำกับบุตร	ปฏิบัติเป็นประจำ	ปฏิบัติเป็นส่วนใหญ่	ปฏิบัติเป็นบางครั้ง	ไม่ได้ปฏิบัติ	ไม่มีเหตุการณ์นั้น
1. ท่านให้ยาลดไข้ตามแพทย์สั่ง เมื่อลูกมีไข้สูง	/				

เหตุการณ์เมื่อลูกมีไข้สูง เป็นเหตุการณ์ที่ไม่ได้เกิดขึ้นทุกวัน หากท่านทำเครื่องหมาย / ในช่องปฏิบัติเป็นส่วนใหญ่ หมายความว่า ที่ผ่านมา เมื่อลูกมีไข้สูง 5 ครั้ง ท่านปฏิบัติให้ยาลดไข้ตามแพทย์สั่ง 3-4 ครั้ง

**ตัวอย่างแบบสอบถาม** พฤติกรรมการดูแลบุตรของมารดาเด็กโรคมะเร็งเม็ดเลือดขาว (เด็กวัยก่อนเรียน)

กิจกรรมที่ท่านได้กระทำกับบุตร	ปฏิบัติเป็นประจำ	ปฏิบัติเป็นส่วนใหญ่	ปฏิบัติเป็นบางครั้ง	ไม่ได้ปฏิบัติ	ไม่มีเหตุการณ์นั้น
1. ท่านให้ลูกรับประทานอาหารประเภทข้าวเนื้อสัตว์ นม ไข่ ผักและผลไม้					
2. ท่านให้ลูกรับประทานอาหารว่าง เช่น นม น้ำหวาน ขนมปัง หรือ ผลไม้ ระหว่างมื้ออาหารและก่อนนอน					
3. ท่านให้ลูกรับประทานขนมขบเคี้ยวที่มีรสเค็ม					
.....					
.....					
.....					
50. ท่านสอนให้ลูกรู้จักรับผิดชอบหรือขอโทษ เมื่อแสดงกริยาไม่เหมาะสม					
51. ท่านติดตามประเมินการเจริญเติบโตของลูก เช่น น้ำหนักและส่วนสูง					

**ตัวอย่างแบบสอบถาม พฤติกรรมการดูแลบุตรของมารดาเด็กโรคมะเร็งเม็ดเลือดขาว (เด็กวัยเรียน)**

กิจกรรมที่ท่านได้กระทำให้กับบุตร	ปฏิบัติเป็นประจำ	ปฏิบัติเป็นส่วนใหญ่	ปฏิบัติเป็นบางครั้ง	ไม่ได้ปฏิบัติ	ไม่มีเหตุการณ์นั้น
1. ท่านให้ลูกรับประทานอาหารประเภทข้าวเนื้อสัตว์ นม ไข่ ผักและผลไม้					
2. ท่านให้ลูกรับประทานอาหารว่าง เช่น นม น้ำหวาน ขนมปัง หรือผลไม้ ระหว่างมื้ออาหารและก่อนนอน					
3. ท่านให้ลูกรับประทานขนมขบเคี้ยวที่มีรสเค็ม					
.....					
.....					
.....					
50.ท่านส่งเสริมให้ลูกมีส่วนร่วมในการดูแลตนเองเมื่อเจ็บป่วย เช่น สังเกตอาการผิดปกติต่างๆ					
51. ท่านติดตามประเมินการเจริญเติบโตของลูก เช่น น้ำหนักและส่วนสูง					

## APPENDIX D

### Human rights and the informed consent



## Participant information sheet (reliability group)

เอกสารหมายเลข 3 ก

### เอกสารชี้แจงผู้เข้าร่วมการวิจัย สำหรับกลุ่มทดสอบเครื่องมือ (Participant Information Sheet)

ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ โปรดสอบถามหัวหน้าโครงการวิจัย หรือผู้แทนให้ช่วยอธิบาย  
จนกว่าจะเข้าใจดี ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษาหารือกับญาติพี่น้อง เพื่อนสนิท แพทย์  
ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย

ชื่อโครงการ(ภาษาไทย) ผลของโปรแกรมการเสริมสร้างพลังใจของมารดาต่อพฤติกรรมการดูแลบุตรโรคมะเร็ง  
เม็ดเลือดขาวที่ได้รับยาเคมีบำบัด

ชื่อผู้วิจัย นางสาวอรุณรัตน์ กาญจนะ

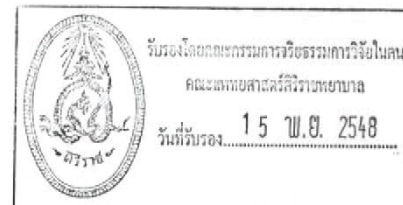
สถานที่วิจัย คลินิกโรคเลือด แผนกผู้ป่วยนอก ตึกเจ้าฟ้าจักรี 1 ภาควิชากุมารเวชศาสตร์ คณะแพทยศาสตร์ศิริราช  
พยาบาล

สถานที่ติดต่อผู้วิจัย คือ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล เบอร์โทรศัพท์ ที่ติดต่อได้ทั้งในและนอกเวลา  
ราชการ คือ 01-6815121

โครงการวิจัยนี้ทำขึ้นเพื่อ ศึกษาผลของโปรแกรมการเสริมสร้างพลังใจสำหรับมารดาที่บุตรเป็น โรคมะเร็ง  
เม็ดเลือดขาวและได้รับยาเคมีบำบัด ซึ่งจะมีประโยชน์ที่คาดว่าจะได้รับ คือ ข้อมูลที่ได้จากท่านจะเป็นข้อมูลพื้นฐาน  
ในการพัฒนาคุณภาพของเครื่องมือในการทำการวิจัย เพื่อช่วยเหลือมารดาผู้ป่วยเด็ก โรคมะเร็งเม็ดเลือดขาวที่ได้รับ  
การรักษาด้วยยาเคมีบำบัด ให้สามารถดูแลบุตรได้อย่างถูกต้องและต่อเนื่องต่อไป

ท่านได้รับเชิญให้เข้าร่วมการวิจัยนี้ เพราะ เป็นมารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวที่ได้รับการรักษาด้วย  
ยาเคมีบำบัด

จะมีผู้เข้าร่วมการวิจัยทั้งสิ้น 20 คน ระยะเวลาที่จะทำการวิจัยทั้งสิ้น 2-3 สัปดาห์



เมื่อท่านเข้าร่วมการวิจัยแล้ว สิ่งที่ท่านจะต้องปฏิบัติ คือ ตอบแบบสอบถามพฤติกรรมการดูแลบุตรที่ได้รับยาเคมีบำบัด ซึ่งจะใช้เวลาในการตอบประมาณ 15-20 นาที หลังจากนั้นหากท่านมีข้อสงสัยหรือต้องการคำแนะนำเกี่ยวกับการดูแลบุตรที่ได้รับเคมีบำบัด ผู้วิจัยจะให้ข้อมูลหรือคำแนะนำในการดูแลบุตรที่ได้รับเคมีบำบัดตามที่ท่านต้องการ

หากท่านไม่เข้าร่วมในการวิจัยนี้ ท่านก็ยังคงได้รับการรักษาพยาบาลตามปกติจากเจ้าหน้าที่ในคลินิกโรคเลือดที่บุตรของท่านเข้ารับการรักษา

ถ้าเกิดเหตุการณ์ไม่พึงประสงค์ หรือมีข้อข้องใจที่จะสอบถามเกี่ยวข้องกับกรวิจัย ท่านสามารถติดต่อกับนางสาวอรุณรัตน์ กาญจนะ ที่คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล โทรศัพท์ที่ติดต่อได้ 24 ชั่วโมง ที่เบอร์ 01-6815121

การเข้าร่วมการวิจัยนี้ ท่านไม่ต้องเสียค่าใช้จ่ายทั้งสิ้น หากมีข้อมูลเพิ่มเติมทั้งด้านประโยชน์และโทษที่เกี่ยวข้องกับการวิจัยนี้ ผู้วิจัยจะแจ้งให้ทราบโดยรวดเร็วไม่ปิดบัง

ข้อมูลส่วนตัวของท่านจะถูกเก็บรักษาไว้ ไม่เปิดเผยต่อสาธารณะเป็นรายบุคคล แต่จะรายงานผลการวิจัยเป็นข้อมูลส่วนรวม ข้อมูลของท่านเป็นรายบุคคลอาจมีคณะบุคคลบางกลุ่มเข้ามาตรวจสอบได้ เช่น คณะกรรมการจริยธรรมฯ เป็นต้น

ท่านมีสิทธิถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้า และการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้จะไม่มีผลกระทบต่อการบริหารและการรักษาที่สมควรจะได้รับแต่ประการใด

หากท่านได้รับการปฏิบัติที่ไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงนี้ ท่านจะสามารถแจ้งให้ประธานคณะกรรมการจริยธรรมฯ ทราบได้ที่ สำนักงานคณะกรรมการจริยธรรมการวิจัยในคน ตึกอศุลยเวชวิกรม ชั้น 5 ร.พ.ศิริราช เบอร์โทร. (02)419-7000 ต่อ 6405

**ข้าพเจ้าได้อ่านรายละเอียดในเอกสารนี้ครบถ้วนแล้ว**

	รับรองโดยคณะกรรมการจริยธรรมการวิจัยในคน คณะแพทยศาสตร์ศิริราชพยาบาล
	วันที่รับรอง <b>15 พ.ย. 2548</b>
	(.....)

ลงชื่อ...../วันที่.....  
(.....)

## Participant information sheet (control group)

เอกสารหมายเลข 3 ก

เอกสารแจ้งผู้เข้าร่วมการวิจัย สำหรับกลุ่มควบคุม  
(Participant Information Sheet)

ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ โปรดสอบถามหัวหน้าโครงการวิจัย หรือผู้แทนให้ช่วยอธิบาย  
จนกว่าจะเข้าใจดี ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษาหารือกับญาติพี่น้อง เพื่อนสนิท แพทย์  
ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย

ชื่อโครงการ(ภาษาไทย) ผลของโปรแกรมการเสริมสร้างพลังจิตใจของมารดาต่อพฤติกรรมการดูแลบุตรโรคมะเร็ง  
เม็ดเลือดขาวที่ได้รับยาเคมีบำบัด

ชื่อผู้วิจัย นางสาวอรุณรัตน์ กาญจนะ

สถานที่วิจัย หอผู้ป่วยภาควิชากุมารเวชศาสตร์ที่มีผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวเข้ารับการรักษาด้วยยาเคมีบำบัด  
ได้แก่ ตึกอำนวยการ 3, 4, 5, 6 คณะแพทยศาสตร์ศิริราชพยาบาล และที่บ้าน

สถานที่ติดต่อผู้วิจัย คือ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล เบอร์โทรศัพท์ ที่ติดต่อได้ทั้งในและนอกเวลา  
ราชการ คือ 01-6815121

โครงการวิจัยนี้ทำขึ้นเพื่อ ศึกษาผลของโปรแกรมการเสริมสร้างพลังจิตใจสำหรับมารดาที่บุตรเป็นโรคมะเร็ง  
เม็ดเลือดขาวและได้รับยาเคมีบำบัด ซึ่งจะมีประโยชน์ที่คาดว่าจะได้รับ คือ ข้อมูลที่ได้จากการศึกษานี้จะเป็น  
ประโยชน์ในการวางแผนการช่วยเหลือมารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวที่ได้รับการรักษาด้วยยาเคมีบำบัด ให้  
สามารถดูแลบุตรได้อย่างถูกต้องและต่อเนื่องต่อไป

ท่านได้รับเชิญให้เข้าร่วมการวิจัยนี้ เพราะ เป็นมารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวที่ได้รับการรักษาด้วย  
ยาเคมีบำบัด และจะมีผู้เข้าร่วมการวิจัยนี้ทั้งสิ้นประมาณ 50 คน ระยะเวลาที่จะทำวิจัยสำหรับมารดาแต่ละราย  
ประมาณ 1 เดือน และระยะเวลาที่ทำวิจัยสำหรับมารดา 50 คน ใช้เวลาทั้งสิ้นประมาณ 4-5 เดือน

	รับรองโดยคณะกรรมการวิจัยรวมการวิจัยในคน คณะแพทยศาสตร์ศิริราชพยาบาล
	วันที่รับรอง 15 พ.ย. 2548

เมื่อท่านเข้าร่วมการวิจัยแล้ว สิ่งที่ท่านจะต้องปฏิบัติ แบ่งออกเป็น 2 ช่วง คือ

- ช่วงที่ 1 เป็นช่วงที่บุตรของท่านอยู่ในโรงพยาบาล ให้ท่านตอบแบบสอบถาม 2 ฉบับ ได้แก่ แบบสอบถามข้อมูลส่วนบุคคล และพฤติกรรมกรดูแลบุตรที่ได้รับเคมีบำบัด (ตอบแบบสอบถามครั้งที่ 1) ใช้เวลาในการตอบ ประมาณ 20 นาที หลังจากนั้นท่านจะได้รับการพยาบาลตามปกติจากเจ้าหน้าที่ในหอผู้ป่วย และในวันที่แพทย์อนุญาตให้บุตรกลับบ้าน ผู้วิจัยจะนัดหมายวันที่และเวลากับท่าน(ตรงกับวันนัดครั้งต่อไป) เพื่อตอบแบบสอบถามครั้งที่ 2

- ช่วงที่ 2 ในวันที่พาบุตรมาตรวจตามนัด ให้ท่านตอบแบบสอบถามพฤติกรรมกรดูแลบุตรที่ได้รับเคมีบำบัด (ตอบแบบสอบถามครั้งที่ 2) ใช้เวลาในการตอบแบบสอบถามประมาณ 15- 20 นาที หลังจากนั้นหากท่านมีข้อสงสัยหรือต้องการคำแนะนำเกี่ยวกับการดูแลบุตรที่ได้รับเคมีบำบัด ผู้วิจัยจะให้ข้อมูลหรือคำแนะนำในการดูแลบุตรที่ได้รับเคมีบำบัดตามที่ท่านต้องการ

หากท่านไม่เข้าร่วมในการวิจัยนี้ ท่านก็ยังคงได้รับการรักษาพยาบาลตามปกติจากเจ้าหน้าที่ในหอผู้ป่วย ถ้าเกิดเหตุการณ์ไม่พึงประสงค์ หรือมีข้อข้องใจที่จะสอบถามเกี่ยวข้องกับการวิจัย ท่านสามารถติดต่อกับนางสาวอรุณรัตน์ กาญจนะ ที่คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล โทรศัพท์ที่ติดต่อได้ 24 ชั่วโมง ที่เบอร์ 01-6815121

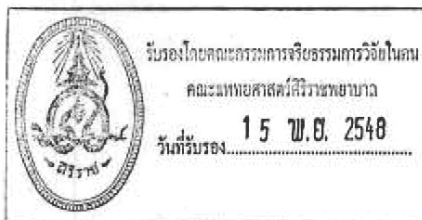
การเข้าร่วมการวิจัยนี้ ท่านไม่ต้องเสียค่าใช้จ่ายใดๆทั้งสิ้น หากมีข้อมูลเพิ่มเติมทั้งด้านประโยชน์และโทษที่เกี่ยวข้องกับการวิจัยนี้ ผู้วิจัยจะแจ้งให้ทราบโดยรวดเร็วไม่ปิดบัง

ข้อมูลส่วนตัวของท่านจะถูกเก็บรักษาไว้ ไม่เปิดเผยต่อสาธารณะเป็นรายบุคคล แต่จะรายงานผลการวิจัยเป็นข้อมูลส่วนรวม ข้อมูลของท่านเป็นรายบุคคลอาจมีคณะบุคคลบางกลุ่มเข้ามาตรวจสอบได้ เช่น คณะกรรมการจริยธรรมฯ เป็นต้น

ท่านมีสิทธิถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้า และการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้จะไม่มีผลกระทบต่อกรบริการและการรักษาที่สมควรจะได้รับแต่ประการใด

หากท่านได้รับการปฏิบัติที่ไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงนี้ ท่านจะสามารถแจ้งให้ประธานคณะกรรมการจริยธรรมฯ ทราบได้ที่ สำนักงานคณะกรรมการจริยธรรมการวิจัยในคน ตึกอตุลยเวชวิกรม ชั้น 5 ร.พ.ศิริราช เบอร์โทร. (02)419-7000 คอ 6405

ข้าพเจ้าได้อ่านรายละเอียดในเอกสารนี้ครบถ้วนแล้ว



ลงชื่อ...../วันที่.....  
(.....)

## Participant information sheet (experimental group)

เอกสารหมายเลข 3 ก

### เอกสารชี้แจงผู้เข้าร่วมการวิจัย สำหรับกลุ่มทดลอง (Participant Information Sheet)

ในเอกสารนี้อาจมีข้อความที่ท่านอ่านแล้วยังไม่เข้าใจ โปรดสอบถามหัวหน้าโครงการวิจัย หรือผู้แทนให้ช่วยอธิบาย จนกว่าจะเข้าใจดี ท่านอาจจะขอเอกสารนี้กลับไปอ่านที่บ้านเพื่อปรึกษาหารือกับญาติพี่น้อง เพื่อนสนิท แพทย์ประจำตัวของท่าน หรือแพทย์ท่านอื่น เพื่อช่วยในการตัดสินใจเข้าร่วมการวิจัย

ชื่อโครงการ(ภาษาไทย) ผลของโปรแกรมการเสริมสร้างพลังใจของมารดาต่อพฤติกรรมการดูแลบุตรโรคมะเร็งเม็ดเลือดขาวที่ได้รับยาเคมีบำบัด

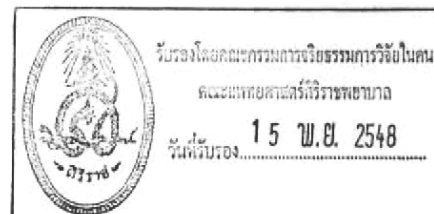
ชื่อผู้วิจัย นางสาวอรุณรัตน์ กาญจนะ

สถานที่วิจัย หอผู้ป่วยภาควิชากุมารเวชศาสตร์ที่มีผู้ป่วยเด็ก โรคมะเร็งเม็ดเลือดขาวเข้ารับการรักษาด้วยยาเคมีบำบัด ได้แก่ ตึกอำนวยการ 3, 4, 5, 6 คณะแพทยศาสตร์ศิริราชพยาบาล และที่บ้าน

สถานที่ติดต่อผู้วิจัย คือ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล เบอร์โทรศัพท์ ที่ติดต่อได้ทั้งในและนอกเวลาราชการ คือ 01-6815121

โครงการวิจัยนี้ทำขึ้นเพื่อ ศึกษาผลของโปรแกรมการเสริมสร้างพลังใจสำหรับมารดาที่บุตรเป็นโรคมะเร็งเม็ดเลือดขาวและได้รับยาเคมีบำบัด เป็นโปรแกรมที่ผู้วิจัยจัดทำขึ้น เพื่อช่วยมารดาให้มีความรู้และมีความสามารถในการดูแลบุตรได้อย่างถูกต้อง ทั้งในขณะที่อยู่โรงพยาบาลและเมื่อกลับไปอยู่บ้าน

ซึ่งจะมีประโยชน์ที่คาดว่าจะได้รับ คือ มารดามีความรู้และสามารถดูแลบุตรเพื่อป้องกันหรือบรรเทาจากผลข้างเคียงของยาเคมีบำบัด เช่น การติดเชื้อ การมีเลือดออกง่าย การอักเสบในช่องปาก คลื่นไส้อาเจียน รวมทั้งได้ฝึกปฏิบัติ เช่น การดูแลความสะอาดในช่องปาก การดูแลเมื่อบุตรมีไข้ และสามารถดูแลบุตรเพื่อส่งเสริมสุขภาพให้แข็งแรง ดูแลให้มีพัฒนาการตามวัย ซึ่งเมื่อมารดามีความรู้และสามารถดูแลบุตรได้อย่างถูกต้องและต่อเนื่อง จะช่วยบุตรให้มีสุขภาพแข็งแรงพร้อมจะรับยาเคมีบำบัดตามแผนการรักษา มีพัฒนาการตามวัย อาจช่วยลดหรือบรรเทาความรุนแรงจากผลข้างเคียงของยาเคมีบำบัดได้



ท่านได้รับเชิญให้เข้าร่วมการวิจัยนี้ เพราะ เป็นมารดาผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาวที่ได้รับการรักษาด้วยยาเคมีบำบัด และการวิจัยนี้ทำขึ้นเพื่อช่วยท่านให้มีแนวทางในการดูแลบุตรหรือปรับวิธีการดูแลบุตรได้อย่างถูกต้องและเหมาะสม มีข้อดีที่ต่างจากการสอนตามปกติที่ท่านได้รับ คือ การพูดคุยเพื่อแลกเปลี่ยนความรู้และประสบการณ์ จะช่วยให้ท่านมีทางเลือกในการตัดสินใจดูแลบุตร ท่านสามารถนำวิธีการที่ได้ไปปรับใช้หรือหาแนวทางแก้ไขปัญหาได้อย่างเหมาะสมกับบุตรและครอบครัวของท่าน

จะมีผู้เข้าร่วมการวิจัยนี้ทั้งสิ้นประมาณ 50 คน ระยะเวลาที่จะทำวิจัยสำหรับมารดาแต่ละราย ประมาณ 1 เดือน และระยะเวลาที่ทำวิจัยสำหรับมารดา 50 คน ใช้เวลาทั้งสิ้นประมาณ 4-5 เดือน

เมื่อท่านเข้าร่วมการวิจัยแล้ว สิ่งที่ท่านจะต้องปฏิบัติ แบ่งออกเป็น 3 ช่วง คือ

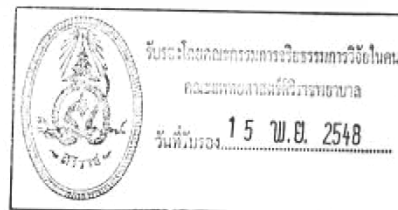
- ช่วงที่ 1 เป็นช่วงที่บุตรของท่านอยู่ในโรงพยาบาล ให้ท่านตอบแบบสอบถาม 2 ฉบับ ได้แก่ แบบสอบถามข้อมูลส่วนบุคคล และพฤติกรรมการดูแลบุตรที่ได้รับยาเคมีบำบัด (ตอบแบบสอบถามครั้งที่1) ใช้เวลาในการตอบ ประมาณ 20 นาที หลังจากนั้นจะเป็นการพูดคุยเพื่อแลกเปลี่ยนความรู้และประสบการณ์ในการดูแลเด็กที่ได้รับยาเคมีบำบัด เช่น การดูแลเพื่อป้องกันการติดเชื้อ การมีเลือดออกง่าย การอักเสบในช่องปาก คลื่นไส้อาเจียน การดูแลให้บุตรมีสุขภาพแข็งแรง การดูแลให้บุตรมีพัฒนาการตามวัย และฝึกปฏิบัติ เช่น การดูแลในช่องปาก การเช็ดตัวลดไข้ โดยจะพบกัน ทุกวันๆ ละ 1-2 ชั่วโมง เป็นเวลานาน 4 วัน โดยพบกันทั้งหมด 6 ครั้ง

- ช่วงที่2 ในวันที่แพทย์อนุญาตให้บุตรกลับบ้าน ผู้วิจัยจะนัดหมายวันที่และเวลากับท่าน เพื่อโทรศัพท์ซักถามปัญหาในการดูแลและให้คำแนะนำการดูแลบุตรตามที่ท่านต้องการ โดยโทรศัพท์ติดต่อกับท่านที่บ้าน สัปดาห์ละ 1 ครั้ง จะติดต่อกันครั้งแรกในวันที่ 7 หลังจากบุตรจำหน่ายออกจากโรงพยาบาล หลังจากนั้นจะโทรศัพท์ทุก 1 สัปดาห์ จนกว่าท่านจะพบบุตรมาตรวจตามนัด นอกจากนี้ท่านยังสามารถโทรศัพท์ติดต่อผู้วิจัย เพื่อซักถามวิธีการดูแลบุตรเพิ่มเติมได้ในช่วงเวลา 7.00-20.00 น. ตลอดระยะเวลาที่อยู่ในโปรแกรม

- ช่วงที่3 ในวันที่พบบุตรมาตรวจตามนัด ให้ท่านตอบแบบสอบถามพฤติกรรมการดูแลบุตรที่ได้รับยาเคมีบำบัด (ตอบแบบสอบถามครั้งที่2) ใช้เวลาในการตอบแบบสอบถาม 15- 20 นาที

ในขณะที่ท่านได้รับโปรแกรมการเสริมสร้างพลังใจ ท่านก็จะได้รับการพยาบาลตามปกติจากเจ้าหน้าที่ในหอผู้ป่วยร่วมด้วย ในการเข้าร่วมการวิจัยนี้ไม่มีความเสี่ยงที่อาจจะเกิดขึ้น เนื่องจากการพูดคุยเพื่อแลกเปลี่ยนความรู้และประสบการณ์ในการดูแลเด็ก และฝึกปฏิบัติ เช่น การดูแลในช่องปาก และให้ท่านตอบสอบถาม ไม่ได้มีกิจกรรมที่อาจก่อให้เกิดอันตรายหรือความเจ็บปวดแต่อย่างใด

หากท่านไม่เข้าร่วมในการวิจัยนี้ ท่านก็ยังได้รับการรักษาพยาบาลตามปกติจากเจ้าหน้าที่ในหอผู้ป่วย



ถ้าเกิดเหตุการณ์ไม่พึงประสงค์ หรือมีข้อข้องใจที่จะสอบถามเกี่ยวข้องกับการวิจัย ท่านสามารถติดต่อกับนางสาวอรุณรัตน์ กาญจนะ ที่คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล โทรศัพท์ที่ติดต่อได้ 24 ชั่วโมง ที่เบอร์ 01-6815121 หรือเมื่อท่านรู้สึกกังวลใจหรือไม่พร้อมที่จะเข้าร่วมโปรแกรม ผู้วิจัยจะพักการดำเนินโปรแกรมไว้ก่อน และจะให้การดูแลท่าน และเมื่อท่านพร้อมและยินดีที่จะเข้าร่วมโปรแกรม ผู้วิจัยจึงจะดำเนินโปรแกรมต่อไป แต่หากท่านยังรู้สึกกังวลใจหรือไม่พร้อมที่จะเข้าร่วมโปรแกรม ผู้วิจัยจะหยุดโปรแกรม และจะปรึกษากับแพทย์หรือพยาบาลประจำหอผู้ป่วยที่ดูแลรักษาบุตรท่านได้ทราบ เพื่อให้การดูแลช่วยเหลือท่านต่อไป

การเข้าร่วมการวิจัยนี้ ท่านไม่ต้องเสียค่าใช้จ่ายใดๆทั้งสิ้น หากมีข้อมูลเพิ่มเติมทั้งด้านประโยชน์และโทษที่เกี่ยวข้องกับการวิจัยนี้ ผู้วิจัยจะแจ้งให้ทราบโดยรวดเร็วไม่ปิดบัง

ข้อมูลส่วนตัวของท่านจะถูกเก็บรักษาไว้ ไม่เปิดเผยต่อสาธารณะเป็นรายบุคคล แต่จะรายงานผลการวิจัยเป็นข้อมูลส่วนรวม ข้อมูลของท่านเป็นรายบุคคลอาจมีคณะบุคคลบางกลุ่มเข้ามาตรวจสอบได้ เช่น คณะกรรมการจริยธรรมฯ เป็นต้น

ท่านมีสิทธิถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้า และการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้จะไม่มีผลกระทบต่อค่าบริการและการรักษาที่สมควรจะได้รับแต่ประการใด

หากท่านได้รับการปฏิบัติที่ไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงนี้ ท่านจะสามารถแจ้งให้ประธานคณะกรรมการจริยธรรมฯ ทราบได้ที่ สำนักงานคณะกรรมการจริยธรรมการวิจัยในคน ตึกอำนวยการ ชั้น 5 ร.พ.ศิริราช เบอร์โทร. (02)419-7000 ต่อ 6405

ข้าพเจ้าได้อ่านรายละเอียดในเอกสารนี้ครบถ้วนแล้ว

	รับรองโดยคณะกรรมการจริยธรรมการวิจัยในคน คณะพยาบาลศาสตร์ศิริราชพยาบาล	ลงชื่อ...../วันที่..... (.....)
	วันที่รับรอง..... 15 พ.ย. 2548	

**Informed consent form**

เอกสารหมายเลข 3 ข

หนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัย

วันที่..... เดือน..... พ.ศ.....

ข้าพเจ้า .....อายุ.....ปี อาศัยอยู่บ้านเลขที่.....

ถนน..... ตำบล..... อำเภอ.....

จังหวัด..... รหัสไปรษณีย์..... โทรศัพท์.....

ขอแสดงเจตนายินยอมเข้าร่วมโครงการวิจัย เรื่อง ผลของโปรแกรมการเสริมสร้างพลังใจของมารดาต่อพฤติกรรมการดูแลบุตรโรคมะเร็งเม็ดเลือดขาวที่ได้รับยาเคมีบำบัด โดยข้าพเจ้าได้รับทราบรายละเอียดเกี่ยวกับที่มาและจุดมุ่งหมายในการทำวิจัยรายละเอียดขั้นตอนต่างๆ ที่จะต้องปฏิบัติหรือได้รับการปฏิบัติ ประโยชน์ที่คาดว่าจะได้รับของการวิจัย โดยข้าพเจ้าไม่ต้องเสียค่าใช้จ่ายใดๆทั้งสิ้น โดยได้อ่านข้อความที่มีรายละเอียดอยู่ในเอกสารชี้แจงผู้เข้าร่วมการวิจัยโดยตลอด อีกทั้งยังได้รับคำอธิบายและตอบข้อสงสัยจากหัวหน้าโครงการวิจัยเป็นที่เรียบร้อยแล้ว

ข้าพเจ้าจึงสมัครใจเข้าร่วมในโครงการวิจัยนี้

หากข้าพเจ้ามีข้อข้องใจเกี่ยวกับขั้นตอนของการวิจัย หรือหากเกิดผลข้างเคียงที่ไม่พึงประสงค์จากการวิจัยขึ้นกับข้าพเจ้า ข้าพเจ้าจะสามารถติดต่อกับนางสาวอรุณรัตน์ กาญจนะ ที่ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล โทรศัพท์ ที่ติดต่อได้ 24 ชม. 01-6815121

หากข้าพเจ้า ได้รับการปฏิบัติไม่ตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมการวิจัย ข้าพเจ้าจะสามารถติดต่อกับประธานคณะกรรมการจริยธรรมการวิจัยในคน หรือผู้แทน ได้ที่ สำนักงานคณะกรรมการจริยธรรมการวิจัยในคน ตึกอคูหลยเคชวิกรม ชั้น 5 ร.พ.ศิริราช โทร (02) 419-7000 ต่อ 6405

ข้าพเจ้าได้ทราบถึงสิทธิที่ข้าพเจ้าจะได้รับข้อมูลเพิ่มเติมทั้งทางด้านประโยชน์และโทษจากการเข้าร่วมการวิจัย และสามารถถอนตัวหรืองดเข้าร่วมการวิจัยได้ทุกเมื่อ โดยจะไม่มีผลกระทบต่อค่าบริการและการรักษาพยาบาลที่ข้าพเจ้าจะได้รับต่อไปในอนาคต และยินยอมให้ผู้วิจัยใช้ข้อมูลส่วนตัวของข้าพเจ้าที่ได้รับจากการวิจัย แต่จะไม่เผยแพร่ต่อสาธารณะเป็นรายบุคคล โดยจะนำเสนอเป็นข้อมูลโดยรวมจากการวิจัยเท่านั้น

ข้าพเจ้าได้เข้าใจข้อความในเอกสารชี้แจงผู้เข้าร่วมการวิจัย และหนังสือแสดงเจตนายินยอมนี้โดยตลอดแล้ว จึงลงลายมือชื่อไว้

ลงชื่อ.....ผู้เข้าร่วมการวิจัย/ผู้แทนโดยชอบธรรม/ วันที่ .....

(.....)



ลงชื่อ.....ผู้ให้ข้อมูลและขอความยินยอม/วันที่.....  
(.....)

ในกรณีผู้เข้าร่วมการวิจัยอ่านหนังสือไม่ออก ผู้ที่อ่านข้อความทั้งหมดแทนผู้เข้าร่วมการวิจัยคือ.....จึงได้ลงลายมือชื่อไว้เป็นพยาน

ลงชื่อ..... พยาน/ วันที่.....  
(.....)





## บันทึกข้อความ

ส่วนราชการ คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล โทร. 0 2419 9407-9

ที่ ศธ 0517.07/ **22578** วันที่ ๑๙ พฤศจิกายน 2548

เรื่อง ยินดีให้ความอนุเคราะห์ข้อมูลประกอบการทำวิทยานิพนธ์

เรียน คณบดีบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

ตามที่ บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล ได้ขอความอนุเคราะห์ให้ นางสาวอรุณรัตน์ กาญจนะ นักศึกษา บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล หลักสูตรปริญญาโท สาขาวิชาการพยาบาลเด็ก คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล เข้าเก็บข้อมูลด้วยแบบสอบถาม Pre-test และ Post-test จากมารดาที่มีบุตรเป็นโรคมะเร็งเม็ดเลือดขาว ที่เข้ารับการรักษาด้วยเคมีบำบัด ที่ตึกเจ้าฟ้าจุฬาภรณาสถาปัตยกรรมศาสตร์ โรงพยาบาลศิริราช เพื่อเป็นข้อมูลประกอบการทำวิทยานิพนธ์ เรื่อง "ผลของโปรแกรมการเสริมสร้างพลังจิตใจของมารดาต่อพฤติกรรมการดูแลบุตร โรคมะเร็งเม็ดเลือดขาวที่ได้รับยาเคมีบำบัด" ความละเอียดแจ้งแล้วนั้น

คณะแพทยศาสตร์ศิริราชพยาบาล มหาวิทยาลัยมหิดล พิจารณาแล้วยินดียินยอมให้ นางสาวอรุณรัตน์ กาญจนะ ทำการเก็บข้อมูลตามที่ขอความอนุเคราะห์มา ตามสำเนาผลการรับรองโครงการวิจัย จากคณะกรรมการจริยธรรมการวิจัยในคน คณะแพทยศาสตร์ศิริราชพยาบาล เมื่อวันที่ 15 พฤศจิกายน 2548 ที่แนบมา

จึงเรียนมาเพื่อโปรดทราบ

(ศาสตราจารย์นายแพทย์อรุณ นานา)  
รองคณบดีฝ่ายบริหาร ปฏิบัติราชการแทน  
คณบดีคณะแพทยศาสตร์ศิริราชพยาบาล

2 ถนนพหลโยธิน 2 PRANNOK Rd.  
 บางกอกน้อย BANGKOKNOI  
 กรุงเทพฯ 10700 BANGKOK 10700



Tel. (662) 4197000 ต่อ 6405-6  
 FAX (662) 4197000 ต่อ 6405

Siriraj Ethics Committee

Certificate of Approval		COA no.Si 255/2005
<b>Protocol Title</b>	: The effects of empowerment program on mother's caring behavior of children with leukemia undergoing chemotherapy	
<b>SiEC number</b>	: 263/2548	
<b>Principal Investigator/Affiliation</b>	: Miss Arunrat Kanjana, Faculty of Nursing, / Mahidol University	
<b>Research site</b>	: Siriraj Hospital	
<b>Approval includes</b>	:	
	1. EC Submission form	
	2. Protocol	
	3. Participant information sheet	
	4. Informed consent form	
<b>Approval date</b>	: November 15, 2005	
<b>Expired date</b>	: November 14, 2006	
<p>This is to certify that Siriraj Ethics Committee is in full Compliance with International Guidelines For Human Research Protection such as Declaration of Helsinki, The Belmont Report, CIOMS Guidelines and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP)</p>		
 (Prof. Sumalee Nimmannit, M.D.) Chair Person	November 16, 2005 date	
 (Clin. Prof. Piyasakol Sakolsathayadorn) Dean of Faculty of Medicine Siriraj Hospital	November 17, 2005 date	
Page: 1 of 2		

## APPENDIX E

### Statistical assumption test for ANCOVA

Before using ANCOVA in the data analysis the assumption were checked (Munro, 2001). The covariate was pretest score. The independent variable was the intervention. The dependent variable was posttest scores.

First, the researcher checked the assumption of homogeneity of regression. The output is showed in table 7.1. Researcher tested for an interaction between the covariate (pretest score) and the independent variable (the intervention). Because the interaction was not significant ( $p = .280$ ). The assumption was met.

**Table 7.1** Test of the assumption of homogeneity of regression

#### Tests of Between-Subjects Effects

Dependent Variable: POST

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1.484(a)	3	.495	7.829	.001
Intercept	.382	1	.382	6.041	.021
GROUP	.103	1	.103	1.625	.214
PRE	.650	1	.650	10.289	.004
<b>GROUP * PRE</b>	<b>.077</b>	<b>1</b>	<b>.077</b>	<b>1.220</b>	<b>.280</b>
Error	1.580	25	.063		
Total	345.322	29			
Corrected Total	3.064	28			

a R Squared = .484 (Adjusted R Squared = .423)

Next, the researcher ran analysis of covariance. The output is showed in table 7.2. In the table of descriptive statistic, the results showed that the experimental group had higher in mean scores on caring behavior than the control group. The assumption of homogeneity of variance was met ( $p = .801$ ).

**Table 7.2** Analysis of covariance (continued)

**Descriptive Statistics**

<b>GROUP</b>	<b>Mean</b>	<b>Std. Deviation</b>	<b>N</b>
experimental	3.6021	.27566	14
control	3.2798	.30745	15
Total	3.4354	.33078	29

**Levene's Test of Equality of Error Variances(a)**

Dependent Variable: POST

<b>F</b>	<b>df1</b>	<b>df2</b>	<b>Sig.</b>
.065	1	27	.801

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a Design: Intercept+GROUP+PRE+GROUP \* PRE

## BIOGRAPHY



<b>NAME</b>	Miss Arunrat Kanjana
<b>DATE OF BIRTH</b>	July 28, 1966
<b>PLACE OF BIRTH</b>	Uthaithani, Thailand
<b>INSTITUTIONS ATTENDED</b>	Chiang Mai University, 1988 : Bachelor of Science (Nursing and Midwifery) Chiang Mai University, 2002 : Master of Education (Health promotion) Mahidol University, 2006 : Master of Nursing Science (Pediatric Nursing)
<b>POSITION AND OFFICE</b>	110 Maharaj Nakorn Chiang Mai Hospital, Chiang Mai, Thailand Position : Nurse