

**DEVELOPMENT OF A FAMILY-CENTERED CARE MODEL
FOR THE CHILDREN WITH CANCER IN A PEDIATRIC
CANCER UNIT**



**A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR
THE DEGREE OF DOCTOR OF NURSING SCIENCE
FACULTY OF GRADUATE STUDIES
MAHIDOL UNIVERSITY**

2003

ISBN 974 – 04 – 3820 - 2

COPYRIGHT OF MAHIDOL UNIVERSITY

**Thesis
Entitled**

**DEVELOPMENT OF A FAMILY-CENTERED CARE MODEL
FOR THE CHILDREN WITH CANCER IN A PEDIATRIC
CANCER UNIT**

Tassanee Attharos

Miss. Tassanee Attharos
Candidate

Siriporn Khampalikit

Assoc. Prof. Siriporn Khampalikit, Ph.D.
Major-advisor

Fongcum Tilokskulchai

Assoc. Prof. Fongcum Tilokskulchai, Ph.D.
Co-advisor

Rutja Phuphaibul

Assoc. Prof. Rutja Phuphaibul, D.N.S.
Co- advisor

Rassmidara Hoonsawat

Assoc. Prof. Rassmidara Hoonsawat
Ph.D.
Dean
Faculty of Graduate Studies

Kobkul Phanchaoenworakul

Assoc. Prof. Kobkul Phanchaoenworakul,
Ph.D.
Chair
Doctor of Nursing Science
Faculty of Nursing

Thesis
Entitled

**DEVELOPMENT OF A FAMILY-CENTERED CARE MODEL
FOR THE CHILDREN WITH CANCER IN A PEDIATRIC
CANCER UNIT**

was submitted to the Faculty of Graduate Studies, Mahidol University
for the degree of Doctor of Nursing Science
on
May 23, 2003

Tassanee Attharos

Miss Tassanee Attharos
Candidate

S. Khampalikit

Assoc. Prof. Siriporn Khampalikit, Ph.D.
Chair

Prakin Suchaxaya

Asst. Prof. Prakin Suchaxaya, Ph.D.
Member

Fongcum Tilokskulchai

Assoc. Prof. Fongcum Tilokskulchai, Ph.D.
Member

Kobkul Phanchaoenworakul

Assoc. Prof. Kobkul Phanchaoenworakul,
Ph.D.
Member

Rutja Phuphaibul

Assoc. Prof. Rutja Phuphaibul, D.N.S.
Member

Rassmidara Hoonsawat

Assoc. Prof. Rassmidara Hoonsawat,
Ph.D.
Dean
Faculty of Graduate Studies
Mahidol University

Kobkul Phanchaoenworakul

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

ACKNOWLEDGEMENTS

I would like to express my deep appreciation to my distinguished committee member who have guided me through this learning process. Firstly, I deeply thank Assoc. Prof. Dr. Siriporn Khampalikit, the committee chair, who not only has guided me through this demanding process but also served as a kind and patient mentor. Dr. Siriporn enthusiastically taught me how to conduct research and be a good researcher. Even though her time has been occupied by the deanship task and other roles, she always made time for me. Secondly, I would like to thank Assoc. Prof. Dr. Rutja Phuphaibul and Assoc. Prof. Fongcum Tilokskulchai for their expert suggestions and support. Special thanks go to Asst. Prof. Dr. Prakin Suchaxaya and Assoc. Prof. Dr. Kobkul Phancharoenworakul for their expertise and valuable comments. Their constructive suggestions have been very helpful to improve my dissertation.

I wish to express my gratitude to The Thai Red Cross Society, and The Thai Red Cross College of Nursing for providing me with a good opportunity and financial support to pursue the doctoral degree. I specially thank you to Asst. Prof. Ankana Sriyaporn, the former director of The Thai Red Cross, College of Nursing, and Asst. Prof. Chulepon Chawmathagit, the current director, for their encouragement and support. A special thank also goes to the Collaborative Program, Ministry of University Affairs, for their financial support. I appreciate the generosity of the Pediatric Nurses Society of Thailand for the partial funding of my study. I am also indebted to Dr. Punyarat Lapvongwatana for her constant advice and support. I would like to thank Dr. Punchalee Wasanasomsithi, and Mrs. Jutamas Anyan for their advice the English version of this thesis. Additionally, I would like to thank Dr. Sathja Thato for her support.

My deep appreciation goes to Mrs Chanphen Tatayanond, Miss Sudtinun Jiraprayut, Miss Porntip Maithong, and Mrs. Ouemduen Kongkaew, and all the staff members of the setting for their hard work to improve the quality of care for children with cancer. I am grateful to the children with cancer and their families. Their participation in my study yielded invaluable information to improve quality of life of children with cancer.

I also wish to acknowledge my classmates, especially Dr. Supaporn Duangpaeng, for their friendship, and experience that they have shared with me throughout my long study journey. I would like to thank all the members of Pediatric Nursing Department, The Thai Red Cross College of Nursing, for their supports and concerns during my study. My special thank are also given to Mr. Somchai Brudhthikal for his concern and support. Additionally, I would like to thank Mr. Somyos Chatasingha who help for solving problems related computer.

Lastly, my sincerest gratitude goes to my family, including my mother, my nieces, my nephew, and my brothers for their unconditional love, patience, and continuing support.

DEVELOPMENT OF A FAMILY-CENTERED CARE MODEL FOR CHILDREN WITH CANCER IN A PEDIATRIC CANCER UNIT

TASSANEE ATTHAROS 4137112 NSNS/D

D.N.S.

THESIS ADVISORS: SIRIPORN KHAMPALIKIT, Ph.D. (NURSING CARE OF CHILDREN), FONGCUM TILOKSKULCHAI, Ph.D. (NURSING), RUTJA PHUPHAIBUL, D.N.S.(FAMILY HEALTH)

ABSTRACT

This action research aimed to develop a model of family-centered care for children with cancer in a pediatric cancer unit. The participants included 26 nursing staff, 41 children admitted in a pediatric cancer unit at a university hospital in Bangkok and 45 family members. Data were collected and analyzed by interviewing the participants, conducting focus groups, and directly observing the participants.

This family-centered care model was developed through three cycles, each of which included planning, action and observation, reflection, and re-planning. The first cycle was to promote mutual understanding of the model. The second cycle was to establish an individual practice by applying the model. The third cycle was to conduct a nursing team in practicing the model. In the final expected outcome, the ward would be committed to practice this model together.

The family-centered care model in this study consists in applying family-centered care, assessing the process for influencing factors and evaluating its results. The core components of family-centered care are: a caring and empathetic relationship, mutual learning, partnership, and enhancing strength. The process of care involves three phases: initiation of family-centered care, mutual care, and care directed by family. Nurses' roles, family roles, as well as children's roles in each phase were described. Related factors consist of hospital policy, setting, knowledge and attitude of the nurse, the child's stage of development, the stage of the illness, severity of the child's illness, and the family's coping. Output of care consists of the fact that the nurses provide the nursing care based on the concept of family-centered care as a standard, modify their practice, and increase self-esteem and professionalism. The children are happier. The families openly and continuously communicate with the nurses, being confident in caring for the children and satisfied with the nursing care.

This study illustrated that the family-centered care model could be successfully implemented in the clinical pediatric unit in a large hospital setting. This study could be an example for clinical units to apply the model to fit each particular setting.

KEY WORDS : FAMILY- CENTERED CARE/ ACTION RESEARCH/
CHILDREN WITH CANCER/

220 p. ISBN 974 – 04 – 3820 - 2

การพัฒนาแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลางสำหรับเด็กโรคมะเร็ง ณ หน่วยเด็กโรคมะเร็งแห่งหนึ่ง (DEVELOPMENT OF A FAMILY- CENTERED CARE MODEL FOR THE CHILDREN WITH CANCER IN A PEDIATRIC CANCER UNIT)

ทศนิษฐ์ อรรถารส 4137112 NSNS/D

พย.ค.

คณะกรรมการควบคุมวิทยานิพนธ์ : ศิริพร ชัมภลจิต, Ph.D. (NURSING CARE OF CHILDREN), ฟองคำ ติลกสกุลชัย, Ph.D. (NURSING), รุจา ภูไพบูลย์, D.N.S. (FAMILY HEALTH)

บทคัดย่อ

การวิจัยเชิงปฏิบัติการครั้งนี้มีวัตถุประสงค์เพื่อพัฒนาแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลางสำหรับเด็กโรคมะเร็ง ณ หน่วยเด็กโรคมะเร็งแห่งหนึ่งโดยใช้แนวคิดการดูแลโดยให้ครอบครัวเป็นศูนย์กลางเป็นกรอบแนวคิด กลุ่มผู้มีส่วนร่วมในการศึกษาประกอบด้วยทีมพยาบาลจำนวน 26 คน เด็กที่ป่วยเป็นโรคมะเร็งจำนวน 41 คน และสมาชิกในครอบครัวจำนวน 45 คน ที่เข้ารับการรักษา ณ หน่วยเด็กโรคมะเร็งโรงพยาบาลมหาวิทยาลัยแห่งหนึ่งในกรุงเทพมหานคร เก็บรวบรวมข้อมูลและวิเคราะห์ข้อมูลด้วยวิธีการวิจัยเชิงคุณภาพ จากการสัมภาษณ์รายบุคคล สันทนากลุ่ม และการสังเกต

กระบวนการพัฒนาแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลางในการศึกษานี้ ประกอบด้วย 3 วงจร ซึ่งแต่ละวงจรประกอบด้วย การวางแผน การปฏิบัติและสังเกต การสะท้อนคิด และการวางแผนใหม่ วงจรที่ 1 เป็นการส่งเสริมความเข้าใจร่วมกันของพยาบาลในการพัฒนาแบบการดูแล วงจรที่ 2 เป็นการทำให้เกิดการปฏิบัติในระดับบุคคล วงจรที่ 3 เริ่มทำให้เกิดการปฏิบัติเป็นทีม และผลลัพธ์สุดท้ายคือ การตกลงแบบการดูแลร่วมกันเพื่อนำสู่การปฏิบัติในหน่วยงานนี้

รูปแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลาง ประกอบด้วย แนวคิดหลัก กระบวนการดูแลโดยให้ครอบครัวเป็นศูนย์กลาง ปัจจัยที่เกี่ยวข้อง และผลลัพธ์การดูแล แนวคิดหลัก คือ การสร้างสัมพันธภาพที่เอื้ออาหารและเห็นอกเห็นใจของพยาบาลกับเด็กและครอบครัว การร่วมมือกันระหว่างพยาบาลและครอบครัวในการดูแลเด็ก การเรียนรู้ซึ่งกันและกัน และการเสริมสร้างความเข้มแข็ง กระบวนการดูแลประกอบด้วย 3 ระยะ คือ ระยะเริ่มเข้าสู่กระบวนการดูแล ระยะดูแลร่วมกัน และระยะครอบครัวเป็นผู้กำกับการดูแล ปัจจัยที่เกี่ยวข้อง คือ นโยบาย สถานที่ ความรู้และทัศนคติของพยาบาล พัฒนาการของเด็ก ระยะการเจ็บป่วย ความรุนแรงของความเจ็บป่วย และการเผชิญความเครียดของครอบครัว และผลลัพธ์ที่เกิดขึ้น คือ พยาบาลให้การพยาบาลโดยใช้แนวคิดการดูแลโดยให้ครอบครัวเป็นศูนย์กลางเป็นมาตรฐาน และมีความรู้สึกรับผิดชอบในตนเองและความมีอิสระทางวิชาชีพ เด็กมีความสุขมากขึ้น ครอบครัวมีการสื่อสารกับพยาบาลอย่างเปิดเผยและต่อเนื่อง รู้สึกมั่นใจในการดูแลเด็ก และพึงพอใจในการดูแล

การวิจัยครั้งนี้แสดงให้เห็นว่าการพัฒนาแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลางสามารถปฏิบัติได้ในหน่วยเด็กของโรงพยาบาลขนาดใหญ่ที่มีการบริหารที่ซับซ้อน

CONTENTS

	Page
ACKNOWLEDGEMENT	iii
ABSTRACT (ENGLISH)	iv
ABSTRACT (THAI)	v
LIST OF TABLES	ix
LISTS OF FIGURES	x
CHAPTER	
I INTRODUCTION	
Background and Significance	1
Purpose of the Study	5
Research Question	5
Conceptual Framework	5
Scope of the Study	7
Definition of Terms	7
Expected Outcomes and Benefits	8
II LITERATURE REVIEW	
The Children with Cancer and their Families	9
Concept of Family Centered-Care in Pediatric setting	16
Family-Centered Care of the Children with Cancer	23
III METHODOLOGY	
Research design	31
Participants	31
Research Setting	32
Instruments	32
Research Phase	33
Data Collection	36

CONTENTS (cont.)

	Protection of Human Subject	37
	Data Analysis	38
	Establishment of Trustworthiness	38
IV	FINDINGS	
	Demographic Data of the Participant	41
	Situation in Caring for Children with Cancer	45
	Pediatric Cancer Unit	45
	Perception of Nurses, Children, and Families	47
	Discussion of the Problem	73
	Process of the Family-Centered Care Model Development	76
	Circle One: Promotion of Nurses' Understanding	77
	Circle Two: Promotion of FCC Practice at Individual Level	96
	Circle Three: Becoming a Team	111
	Strategies Used in the Development of the Model	121
	Family-Centered Care Model	127
V	DISCUSSION	158
	Situation in Caring for the Children with Cancer	158
	Process of the Family-Centered Care Model Development	161
	A Family-Centered Care Model	165
VI	CONCLUSION	
	Summary of the Study	170
	Strengths and Limitations of the Study	178
	Implication and Recommendations	180
	Contribution to Nursing Knowledge Development	182
	BIBLIOGRAPHY	184
	APPENDICES	
	APPENDIX A Approval Letter	192
	APPENDIX B Interview Guide	193
	APPENDIX C Consent Form for the participants	197

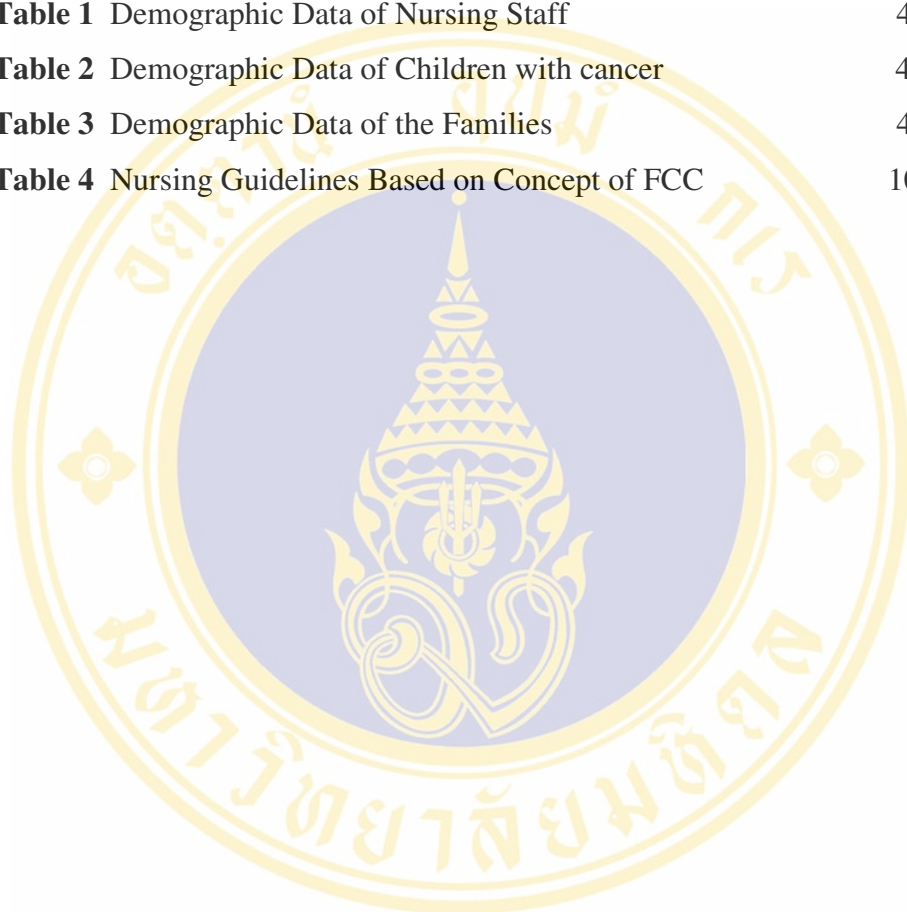
CONTENTS (cont.)

APPENDIX D	Case Study	201
APPENDIX E	Guideline Practice for Family-Centered Care	207
BIOGRAPHY		220



LISTS OF TABLES

	Pages
Table 1 Demographic Data of Nursing Staff	42
Table 2 Demographic Data of Children with cancer	43
Table 3 Demographic Data of the Families	44
Table 4 Nursing Guidelines Based on Concept of FCC	100



LISTS OF FIGURES

	Pages
Figure 1 Circle One : Promotion of Nurses' Understanding	77
Figure 2 Circle Two: Promotion of FCC Practice at Individual Level	96
Figure 3 Circle three: Becoming a Team	111
Figure 4 Action Research Cycle in Developing the Family-Centered Care Model	120
Figure 5 The Process of Development of the Family-Center Care Model for the Children with cancer	126
Figure 6 A Family-Centered Care model for the Children with cancer in a Pediatric Cancer Unit	128

CHAPTER I

INTRODUCTION

Background and Significance of the Study

Cancer is one of the major health care problems affecting both children and their families. In the United States, approximately 9,100 new cases of childhood cancer were reported in 2002 (American Cancer Society, 2002). Cancer is the leading cause of death of all diseases in children aged three to 15 years and the second cause of death of all causes. In Thailand, the Thai Ministry of Public Health reported that the number of death of childhood cancer at all sites by age 0-14 years from 1998 to 2001 were 823, 621, 606, and 620 cases, respectively (Ministry of Public Health Report, 2001: 146).

The diagnosis of cancer has immediate and lasting impacts on children and their families (Hockenberry-Eaton & Minick, 1994: 1025). The children with cancer usually counteract with numerous stressors. These stressors include life-threatening disease, painful procedures, lengthy and intensive treatment, adverse effect of treatment, and changing environment which directly and/or indirectly affect the development of children (Hockenberry, Manteuffel & Bottomley, 1997: 178-179). These children may develop anxiety, depression, and low self-esteem (Hymovich, 1995: 51; Visespanit, 1998). The diagnosis of cancer has not only long lasting effects on the children but also great impact on their families. The whole family members and their family life will be affected. The families confront with a dual dilemma in that the families have to try to meet the physical and psychosocial needs of the children and simultaneously attempt to maintain normal family functions (Shields et al., 1995: 40). Like the children's experiences, families may also face with many stressors throughout the different phases of the children's treatment. Findings from previous studies of the adaptation of families with childhood cancer have consistently demonstrated that families suffer from the burden of coping with their own needs and feelings (Clarke-Steffen, 1997: 278; Davies et al., 1998: 301; Phuphaibul et al, 2000).

Struggling with uncertainty has also been found to be a basic social psychological process in Thai families living with children with cancer in their day-to-day lives (Patoomwan, 2001). Finally, the cost of cancer is high so treatment cost becomes a burden on either patients and their families or by treating hospital (Songnuy, 1999).

It is a responsibility of the pediatric nurse and medical institute to address the care both of the children and their families throughout the therapy because family's response to childhood cancer affects the health care of the ill child and the child's response to illness (Clarke-Steffen, 1993: 146). There is also evidence to support that children's outcomes are partly dependent on their families' abilities to cope with the situation (Melnik, 2000). Nurses not only care for the children with cancer but also enhance the abilities of the families to develop the additional skills needed to meet the demands of the children with cancer and help the children cope with their conditions. There are numerous studies related to the experience of the children with cancer and their families which have demonstrated that the assistance of healthcare providers, family, and friends enables children with cancer to begin to move beyond the cancer experience (Haase & Rostad, 1994: 1483). Families activities are focused on accomplishing tasks necessary for successful therapy (Weekes & Kagan, 1994: 666). Children gain a great deal of emotional strength from their families and the nursing staff (Hockenberry-Eaton & Minick, 1994: 1029). Parents of children with cancer value a good working relationship with nurses and want to participate in their children's care (Romaniuk & Kristjanson, 1995: 88). Moreover, family involvement is now seen as an essential part of the treatment of children with cancer (Hicks, Lavender, 2001: 145). Being involved in care, families have reported that they and their children are able to increase coping ability and confidence (Evans, 1994; Evans, 1996). Thus, caring for the children with cancer need to be coordinated by all individuals such as nurses, children, and families with the goal of developing the best possible plan of care for the children with cancer and their families using the concept of family-centered care.

The family-centered care concept (FCC) is a central element of the holistic nursing care of the children. The foundation of this concept is the recognition that the family is central to the child's life and should be central to participation in planning, implementation, and evaluation of children's care with the profession (Ahmann,

1994a: 113; Ahmann & Johnson, 2000: 88; DePompei, Whitford & Beam, 1994: 119; Evans, 1994: 477; Hutchfield, 1999: 1178; Smith, Coleman & Bradshaw, 2002: 20). The key elements of family-centered care are 1) The families are respected for the knowledge they have of their child and as a constant in a child's life and primary decision maker; 2) Collaboration among patients, families, and professionals occurs in the delivery of care; 3) Professions communicate with and share complete and unbiased information with patients and families in ways that are affirming and useful; 4) The families are treated with dignity and respect; and 5) Nurses recognize and build on family strengths and resources (Hostler, 1991: 1548-1555; Hutchfield, 1999: 1184; Nethercott, 1993, cited in Hutchfield, 1999: 1180; Shelton & Stepanek, 1995: 362-363). Many studies have highlighted benefits to both parents and child when family-centered care practices are implemented in any healthcare setting. Johnson and colleague (1992, cited in Ahmann, 1994b: 52) have reported various benefits of family-centered care as follows: 1) Family experiences about feeling of confidence and competence in caring for their children increase; 2) Family dependence on professional caregiver decreases; 3) Cost of care decreases; 4) Professionals' experience on job satisfaction increases; 5) Both parents and providers are empowered to develop new skills and expertise; and 6) Parents and children's satisfactions increase. There were many examples of family-centered care programs in children hospitals, some of which have been rigorously evaluated and which documented positive outcomes for both children and their families as well as healthcare providers (Curley, 1988; Curley & Wallace, 1992; George & Hancock, 1993; Hostler, 1991; McKlindon & Barnsteiner, 1999; Evans, 1996).

In the hospital setting, the intensive treatment leads the children with cancer to frequent and sometimes long hospitalization with distressing and painful procedures and numerous side effects. This event is stressful to the children with cancer and their families. The families do not have much opportunities to care for their children. They have been excluded from decision making and participation in the children's care from admission until discharge. Within the hospital culture, there may be resistance to incorporate the patient and family into involvement in care. Numerous barriers to integrating FCC principles have been identified. These barriers include constraints on space, time, and the ability to meet physical needs of the patients. When faced with

limited time, staff members priorities' may be focused on the physiologic needs of their patient and technical demands of the environment. Additional barriers to implementing FCC may be the lack of knowledge regarding FCC and lack of strong organizational support for FCC (Galvin, et al., 2000). Yeh et al. (1999) studied the deficiency of psychological and emotional support for parents from healthcare professionals prior to and during cancer treatment. The study showed that six categories of the determinants were associated with parental decisions: suffering from severe pain from medical treatments and adverse side-effects, desire for better and less painful treatments, adverse effects of other patients' experiences, search for possible explanations for disease after prolonged denial of diagnosis, lack of empathy from healthcare professionals, and misinterpretation of improved prognostics.

Despite the widespread formal support family-centered care, there is still inconsistent actualization of the principle of family-centered care in many hospital settings in the United States (Galvin et al. 2000: 625). In Thai hospitals, their formal policy of family-centered care accepts the tenets of this model but fails in its application of the chosen policy (Shields & King, 2001: 209). There is discrepancy between the concept of family-centered care and the practice of the professionals who are responsible for implementing this concept (Ahmann, 1994a: 113; Bruce & Ritchie, 1997: 214). The nurses perceive that the elements of family-centered care are necessary for practice; however, they did not match their perceptions of activities necessary to provide family-centered care in their everyday work (Bruce & Ritchie, 1997: 217; Letourneau & Elliott, 1996: 167). The concept of family-centered care has been implemented in various ways. They are different in the level of collaboration and the focus of care. In addition, the roles of nurses in the family-centered care are not clear (Brown & Ritchie, 1990). There is a lack of consensus among nurses about what form of parental participation should be taken and how far it should extend (Coyne, 1995: 35).

The institutional policies and professionals should collaborate with families to develop the family-centered care model of the children with cancer appropriate in each context. Thus, this study used action research as the methodology to develop a family-centered care model in one oncology pediatric unit in a university hospital.

Purpose of the Study

The purpose of the study is to develop a family-centered care model for the children with cancer and their families.

Research Questions

The research question of this study is:

What is the family-centered care model for the children with cancer and their families?

The model of family-centered care for the children with cancer would describes the following:

1. The process of the development of the family-centered care model
2. The nurses' roles in the family-centered care model
3. The families' roles in the family-centered care model
4. The children' roles in the family-centered care model
5. The factors influencing the model of care

Conceptual Framework

This study used the concept of family-centered care as its theoretical framework and action research as its methodological framework.

The concept of family-centered care

The Association for the Care of Children's Health (ACCH) has recognized that the term family-centered care cannot simply be described by a common definition (Bowden, Dickey & Greenberge, 1998); however, the elements of family-centered care that have emerged from analysis of literature are identified as follows (Ahmann & Johnson, 2000: 88; Hostler, 1991: 1548-1555; Hutchfield, 1999: 1184; Nethercott, 1993, cited in Hutchfield, 1999: 1180; Shelton & Stepanek, 1995: 362-363):

1. The family is respected for the knowledge they have of their child, and as a constant in their child's life.

The parents of the children who is sick care not only for the child's medical problem, but for the totality of the child's well-being, happiness, and progress. The parents care for all the child's needs over each 24-hour period. At the same time, parents must care for themselves, other family members, and a family as a whole. In contrast to parents, professionals care for the child in a brief, circumscribed, problem-focused circumstance. Thus, to keep a focus on family's central role, professionals must begin to understand and respect the family expertise (Ahmann, 1994a: 114).

2. Collaboration among patients, families, and professionals occurs in the delivery of care

A commitment to collaboration represents the mean to achieve the vision of family-centered care (Shelton & Stepanek, 1995: 363). Parents and health professionals share the provision of healthcare to children. Parents are involved in the full range of healthcare delivery as policy makers, planners, and evaluators of services delivered. Parents are fully participatory in the decision making process and share responsibilities, while healthcare professionals serve as coaches, information providers, and enablers of the meaningful participation of parents (Hostler, 1991: 1549).

3. Professionals communicate with and share complete and unbiased information with patients and families in ways that are affirming and useful

Knowledge eliminates parental powerlessness and dependence on the professional staff (Hostler, 1991: 1549). Communication between families and professionals are essential to the family-centered care process. True collaboration demands that families and professionals work with openly exchange information, ideas, and concerns. This type of communication is the cornerstone of quality health and developmental services and supports for children and their families (Shelton & Stepanek, 1995: 21).

4. The family are treated with dignity and respected.

The fundamental idea of family-centered care is that children are best served when they are understood as inextricably linked to a larger living unit the family. Illness can affect any family, crossing all cultural, ethnic, racial, economic, educational, and geographic lines. Family-centered care requires that each family be

approached anew, with a recognition of and respect for such diversity within and across each family (Shelton & Stepanek, 1995: 363).

5. Nurses recognize and build on family strengths and resources

One goal of service provision should be to prepare caregivers for effective dealing with future concerns and needs. Thus, service provision is not just an issue whether or not specific needs are met. Rather, it also involves the manner in which mobilization of resource occurs, and whether or not resource contributes to the enablement and empowerment of families to collaborate fully as equal partners in their children's care teams. The provision of services and supports must therefore be flexible, accessible, and comprehensive in responding to the wide array of family-identified needs (Shelton & Stepanek, 1995: 364).

Scope of the Study

The action research was used to develop a family-centered care model for the children with cancer in a pediatric cancer unit. This study was to develop nursing system that required cooperation of the nursing team.

Definition of Terms

The family-centered care model for the children with cancer and their families refers to the model of care for the children with cancer and their families that is developed through the collaboration of nurses, children with cancer and families, and the researcher. The concept of family-centered care was used as a guideline in developing the model (Ahmann, 1994a: 113; Ahmann & Johnson, 2000: 81; DePompei, Whitford & Beam, 1994: 119; Evans, 1994: 477; Hutchfield, 1999: 178).

The children with cancer refers to the children diagnosed with any type of cancer who were admitted to the hospital.

The families of the children with cancer refers to the families who cared for the children with cancer.

Expected Outcomes and Benefits

1. This study would produce theoretically derived practice of family-centered care which could be a guideline in caring for the children with cancer and their families in a pediatric cancer unit. The model of family-centered care for the children with cancer and their families would describe the nurses' role and the families' roles in caring for the children and their families

2. This study would offer additional knowledge to the theoretical body of "family-centered care." It would help move the translation of the concept into concrete practice indicators.

3. This model has been developed by the collaboration of the nurses, the children with cancer and their families, and the investigator. Thus, it should be useful for nurses who practice in a clinical setting to promote practice with other children.

CHAPTER II

LITERATURE REVIEW

This review of literature is presented in three sections. Firstly, the children with cancer and their families; Secondly, the concept of family-centered care in pediatric setting; Finally, family-centered care of the children with cancer. Literature review in this chapter was conducted to help conceptualize and provide a model of structured, interrelated concept for the formulation of the study.

The children with cancer and their families

The children with cancer

Cancer in children is a stressful event for the children. The impact of cancer has been well documented. Numerous studies have explored the experience of the children, while others have studied about the quality of life.

Impact of cancer on the children

Diagnosis and initiation of treatment

A diagnosis of cancer is traumatic for all children. Cancer affects the children even before diagnosis from multiple physical examinations, blood tests, and courses of antibiotic therapy. During induction, the children are faced with a multitude of stressors that arise from the aggressiveness of treatment and the psychological distress. Stressors related to the actual diagnosis and treatment include pain and invasive procedure, surgery, radiation therapy, and chemotherapy induced side effects. Specific concerns depend on the children's age and developmental level. The young children are concerned about hospitalization, separation from parents, and fear of medical procedures. In the school-aged children, the diagnosis and initiation of therapy arouse many of the same feeling and fears seen in the preschoolers. The major concerns of the school-aged child are separation, an unfamiliar environment, fears of abandonment and punishment, and threats to body integrity. For the

adolescents, illness presents unique issues. Focal concerns about independence, appearance, acceptance, sexuality, and future plans are immediately confronted.

Treatment and Remission

After the induction of therapy, the children often have a period of remission or tumor regression. The children are able to go home for extended periods, returning to the hospital on a scheduled basis to receive chemotherapy or radiation treatment. During this phase, the children may be faced with emergency hospital admissions. Emergent medical situations requiring hospitalization such as fever and neutropenia may reawaken fears faced at diagnosis. The young children may have increased fear of separation or abandonment, whereas the main concern of older children is isolation from peers and disrupted social activities.

Relapse

A relapse of disease causes an intense period of anxiety. The children's focus is on the required treatments which may be very aggressive. The children may react to parental distress and have behavioral changes. The same stress experienced at diagnosis may recur and be even more intense because of negative memories of treatment.

Experience of cancer in children

Numerous studies have examined the experience of cancer in children in different phases (Enskar et al., 1997a; 1997b; Haase & Rostad, 1994; Hockenbery-Eaton & Minick, 1994; Novakovic et al., 1996; Weekes & Kagan, 1994). The children described both negative and positive experiences. They described that disease and treatment influenced their life (Enskar et al., 1997a; 1997b). The children's perceptions of cancer experiences helped them become strong during treatment (Hockenbery-Eaton & Minick, 1994). Furthermore, they changed attitudes about self and life, improved relationship with others, or had better job performance (Novakovic et al., 1996). They also discussed their experience regarding care from their families and nurses who helped them overcome difficult situations (Haase & Rostad, 1994; Hockenbery-Eaton & Minick, 1994; Weekes & Kagan, 1994).

Quality of life of the children with cancer

Very few studies have examined the quality of life of the children with cancer. Only two studies were found (Visespanit, 1998; Wannapong et al., 1997). One was about quality of life in school aged children with leukemia in the area of relationship with other persons, which found that most patients were loved and cared for well by parents and siblings. In the aspect of physical and emotional functions, most of them had delayed growth and decreased ability in performing daily activities. In the area of signs and symptoms and treatment received, all of them had frequent infections, suffered from side effect of chemotherapy, felt bored and worried about the treatment, and feared painful procedures. In the aspect of life satisfaction, all of them felt that the illness was the barrier to performing regular daily activities. Finally, in the area of self-concept, the children's perception of self-value varied according to their illness condition. They felt self-worth when they were free from chemotherapy and were able to perform activities. However, when they had serious complications, they perceived themselves as having low self value (Visespanit, 1998).

The findings of Wannapong, et al. (1998) appeared inconsistent with these findings. The overall quality of life was in a good level. For the four components of quality of life, it was found that life satisfaction was in a very good level, while self concept, health and functioning, as well as socio-economic were in a good level (Wannapong et al., 1997).

The families of the children with cancer

The impact of cancer on the families has been well documented. Numerous studies have described experience, needs, perceptions of quality of life, and the relationship between the nurse and the families.

Impact of childhood cancer on the families

Diagnosis

The time of diagnosis is a very stressful period. Parents typically react with shock, disbelief, guilt, anger, and fear. In response to these emotions, most of the parents struggle toward understanding the diagnosis and recommended treatment. Some parents cope by denying the reality of the diagnosis and seek other opinions in an attempt to reverse it. In addition, parents are faced with numerous other stressors.

While dealing with their own emotions, they must learn about their child's illness and treatment, and manage their family's life outside the hospital.

As the diagnosis is accepted, guilt and anger become significant emotion. Anger may be directed at physicians, nurses, or other staff members. Guilt is expressed in seeking reasons that cancer has occurred in their child.

Treatment and Remission

In the phase of initiation of treatment, the family is faced with the task of reorganizing and the burden of caring. As treatment progresses, frequent trips to the treatment center continue to disrupt the family's daily routine. Families who live in communities without a major treatment center face additional problems: They need to face with traveling long distance for treatment, separation from home and most supports during a stressful and frightening time, and the strain on finances resulting from transportation, child care, and accommodations.

Relapse

Relapse of the disease causes more intense anxiety than the initial diagnosis. After confirmation of a relapse, feeling of shock, anxiety, fear, guilt, anger and sadness are common. Families are faced with reinitiation of treatment with a smaller chance for successful outcome. The new adjustments are also required.

Terminal phase

Parents are faced with acknowledging their child's impending death while maintaining hope. Therefore, they need continuing comfort and support from all members of the professional healthcare team.

Stress and coping of the families having children with cancer

The mothers have nine areas of concern, ranked from the most to the least as follows: health (treatment and outcome), work and finance, uncertainty of illness and impending death of the child, family life, the child's body image, response to questions asked by the child, relationship between the mother and their friends and significant others, traveling, and hospitalizational experiences of the child, respectively (Suwanagood, 1996).

Besides, the parents reported that they used coping strategies as follows: information seeking, problem solving, help seeking, maintenance of emotional

balance, reliance on religion, optimism, denial, and hope (Davies et al., 1998; Mackawon, 1994; Suwanagood, 1996; Will, 1999).

Experience of families having children with cancer

Because childhood cancer affects the entire family, a description of what it is like to live through childhood cancer is needed to gain insight. Numerous studies have described the families' experience at each phase of the illness.

In the diagnosis and initiation of treatment phase, the majority of mothers perceive the illness of their children as very serious and life-threatening at the time of diagnosis. Once the diagnosis sinks in, the mothers report a variety of reactions. Firstly, most mothers react with shock, disbelief, and disruption, followed by the fear of losing their child (Davies et al., 1998; Mackawon, 1994; Martinson & Yi-Hau, 1994). The experience of "waiting and not knowing" immediately surrounds the diagnosis of cancer in the children. Waiting to hear a diagnosis of the result of a test, the meaning of diagnosis, and possibilities for treatment are significantly distressing for parents and siblings of children who have cancer. They become uncertain. Uncertainty leads to worry and preoccupation (inability to think about other facets of life), vulnerability (stemmed from the sudden realization that bad things could happen to them), and helplessness (stemmed from feeling that for the first time the parents are unable to do much to aid and protect the child) (Clarke-Steffen, 1993). The families use strategies of managing the flow of information, reorganizing roles, evaluating and shifting priorities, changing future orientation, assigning meaning to the illness, and managing therapeutic regimen (Clarke-Steffen, 1997).

In the recurrence phase when childhood cancer recurs, the parents describe the coping process as regulating shock, situation monitoring, alternating realizations, and eyeing care limiting decision. This coping process indicates that parents' efforts to overcome shock and despair to make wise decision about treatment while accepting the outcome is beyond their control, and they focus on helping their child have the optimal chance to care while preparing for the child's possible death (Hinds et al., 1996).

In the terminal phase all of the mothers experience poor health conditions after their child's death: insomnia, weight loss, loss of appetite, headache, depression,

and fatigue (Saiki, Martinson & Inano, 1994). Mothers have reported that the most difficult things for them are missing the child's physical presence, dealing with the emotions of grief, and having physical grief responses: insomnia, dizziness (Davies et al., 1998).

Needs of families having children with cancer

When a child was diagnosed with cancer, the family is confronted with meeting both physical and psychosocial needs of the child and maintaining normal family functioning. There were few studies which assessed the psychological needs of families having a child diagnosed with cancer. For the diagnosis phase, the family with a newly diagnosed child expressed a greater need for information (Ohanian, 1990; Shields et al., 1995; Thanustherakul, 1993). Information about the future service and about the child's illness was perceived to be the greatest need by these groups (Ohanian, 1990; Shields et al., 1995). For the treatment phase, Mercer & Ritchie (1997a, 1997b) identified the perceived needs and resources of parents of children undergoing treatment of cancer, and identified any differences in needs between parents when children received all of their care at a tertiary center and parents whose children received at least some of their care in their local community. There were no significant differences between the two groups. Parents reported that their important needs for information were met, but other needs (financial assistance, time rest) were not. During the palliative care phase, James & Johnson (1997: 83-93) reported that the needs of parents of pediatric oncology patients during the palliative care include three needs. the needs to have the child recognized as special while retaining as much normality within the child and family's lives as possible; the needs for caring and connecting with healthcare professionals; and the needs to retain responsibility of parenting their dying child.

The finding from these studies indicated that healthcare providers who care for children with cancer and their families need to perform individual assessments and identify family support early in the diagnosis phase throughout the treatment period.

Parents' perceptions of their quality of life

The children's adjustment to cancer depends on the parents' ability to deal with their own anxiety and stress as well as the children's physical and psychological distress. Both parents' anxiety and distress are linked to the traumatic experience of the diagnosis and treatment of the children's disease. The social, emotional, physical, and financial stressors of the disease affect parents by increasing their vulnerability to the stresses of everyday life, thus affecting their quality of life. There was only one study to assess parents' perceptions of their quality of life after diagnosis and treatment of cancer in their child. Results indicated that the parents perceived their quality of life now as good, but not as good as before their child was diagnosed with cancer. There was a statistically significant difference in parents' perceptions of their quality of life now and before their child was diagnosed with cancer (Wright, 1993: 139-145).

The parents-nurse relationship

Although physical care of childhood cancer is now possible, there is research to indicate that caring of childhood cancer has immediate and long-term implications (both physical and psychological) for the child and family. Thus, supportive family relationships can help the child deal with implications. Family-centered care may promote such supportive relationship.

Romaniuk & Kristjanson (1995: 80-89) explored the parent-nurse relationship when a child with cancer is hospitalized. Using grounded theory methodology, both parents and nurses' care were examined from parents' perspective. Analysis of interview led to development of a framework that described the parent-nurse relationship in care of hospitalized child with cancer. A substantive theory was developed describing parents care (Making it better), nursing care (Going through the motion, caring incompletely, and caring completely), and the parent-nurse relationship (Working together). This study indicated that parents of children with cancer value a good working relationship with nurses and want to participate in their child care. The good parent-nurse relationship is an important component in care of the hospitalized child with cancer, and the development of such a relationship requires that both parents and nurses receive support in their efforts to provide family-centered care.

In-hospital care by parents

Parents of pediatric oncology patients who are in hospital for long periods are usually knowledgeable about their child's treatment and care. They usually attempt to deal with stresses of the disease and treatment by restoring some sense of normality and control. Being involved in their child's care is a way of facilitating their own coping efforts (Evans, 1994). Evans (1996: 138-145) studied the feasibility of parental participation in nursing care of their child (especially the mothers' ability to correctly administer antibiotics) and to identify the mothers' reactions to participating in their child care. All mothers in this study were capable of performing the procedure and all were willing to do so. Mothers emphasized the fact that they often stressed and were out of control because of the impact of disease and treatment. The mothers stated that their coping was facilitated by helping in the care of their child. All parents thought that practical involvement not only gave them something useful to focus on, but also gave them a feeling of control and positivism and alleviated their anxiety. This involvement increased their confidence, helped get the mind function, and enabled them to make more decisions. All mothers emphasized how important it was not to worry about the children, and their anxiety decreased when they performed the procedure. By being involved in care, these parents reported that they and their child were better able to cope.

From this study, it has been established that mothers are the most appropriate persons to care for their children and are willing and able to be involved in the care of their children.

The illness of children with cancer affects both the children and families. It is the responsibility of nurses to care for the children and their families.

Concept of Family-Centered Care in Pediatric Settings

Evolution of the family-centered care

In the mid 19th century, the mission statements of hospitals described as primary goals the medical and surgical treatment of children's diseases, and nurturing was noted as the more important function. Attitudes toward children and families tended to be moralistic and paternalistic (Broom, Knalf, Pridham & Feetham, 1998:

257). However, there were concerns that the hospital staff, including physicians, should avoid spoiling the sick children. Often, parents were reviled for their ignorance and vicious stupidity as the cause of their children's sickness.

At the end of the 19th century, scientists had proved that many diseases were caused by bacteria. Hospital wards were closed to visitors, including families, to prevent infections. In addition, visits by parents caused their child distress. Therefore, parents were prohibited from visiting their hospitalized children to prevent infection and emotional stress (Young, 1992).

In the early to middle 1900s, researchers were aware of the emotional effects of long-term hospitalization and isolation of children from their families. In 1920, James Spence, a British pediatric surgeon, recommended allowing mothers to stay with their hospitalized child. In 1945, Spitz described a condition seen in infants in foundling homes called "hospitalism." Children who developed hospitalism usually received more physical care than psychological care (Broome et al., 1998: 258). In 1953, Bowlby investigated the effects of separation from their parents on children, and as a result new insights were gained into psychological needs (Bradley, 1996:724).

As a result of growing evidence of the emotional impact of illness and hospitalization on children, hospital policies have slowly changed during the late 20th century. Open visiting for parent was proclaimed as vital for the welfare of children in hospital settings, and care by parents was advocated through government report (Bradley, 1996: 724; Broome et al., 1998: 258; Young, 1992).

The American Academy of Pediatrics (AAP, 1960) reported on "the care of children in hospitals" which discussed the importance of protecting the child from emotional distress of hospitalization. This protection began with the child's physician helping the parents prepare the child for hospitalization. In addition, AAP encouraged all children hospitals to implement a liberal policy for family visiting. Rooming-in and family-assisted care for parents were also encouraged. The AAP (1986) also discussed how the design of pediatric environments may need to be changed to accommodate the emerging philosophies of care by parent and family emerged care (Broome et al., 1998: 259).

In 1987, the Association for the Care of Children's Health (ACCH) outlined the essential elements of family-centered care. In 1994, the institute of family-

centered care stated that the involvement of families in every phase of pediatric healthcare would change the care of children and improve pediatric practice for the benefit of the family, the hospital, and the community.

Definition of family-centered care

Historically, the concepts of family-centered care in the pediatric setting have been difficult to define (Letourneau & Elliott, 1996: 158) Darbyshire (1993, cited in Hutchfield, 1999: 1178) described family-centered care as one of pediatric nursing's amorphous terms. However, in literature review, family-centered care was described as 'A philosophy that supports parents in their caring role' (Gill, 1993), 'A basic / fundamental tenet of pediatric nursing' (Evans, 1994), 'To incorporate the family into the plan of care' (DePompei, Whitford & Beam, 1994), 'To recognize the family as central in the child's life and a partnership that supports parents in their central caring role' (Ahmann, 1994a), and the professional support of the child and family through a process of involvement, participation, and partnership underpinned by empowerment and negotiation' (Smith, Coleman & Bradshaw, 2002).

Finally, Ahmann & Johnson (2000: 88) have defined the concept of family-centered care as "an approach to planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare, patients, and families. It has redefined the relationships between and among consumers and healthcare providers.

These definitions seem to reflect two views of family-centered care. Some offer a holistic view of the child and family and represent a description of co-operation with the family (Hutchfield, 1999). Thus, family-centered care is a holistic approach to recognize the family as central in a child's life and to incorporate the family into the plan of care.

Surrogate and related terms

In the literature reviewed, the terminology changed from parental participation, parental involvement, partnership in care, and care by parents finally to family-centered care (Coyne, 1996: 739; Hutchfield, 1999: 1181).

Key Elements of FCC

The concept of FCC has been described by the ACCH as including the following eight equally important elements (Bruce & Ritchie, 1999):

1. Recognition that the family is the constant in the child's life, whereas the service system and personnel within those systems fluctuate.
2. Facilitation of parent/professional collaboration at all levels of healthcare.
3. Recognition of family strengths and individuality and respect for different methods of coping.
4. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
5. Encouragement and facilitation of parent-to-parent support.
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health delivery systems.
7. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
8. Assurance that the design of healthcare delivery systems is flexible, accessible, and responsive to family needs.

The Izaak Walton Killam (IWK) Children's hospital FCC Committee (1992) subsequently modified these to include the ninth element:

9. Implementation of appropriate policies and programs that are comprehensive and provide emotional support to meet the need of staff members.

Nursing strategies to enhance family-centered care

A variety of creative strategies can be employed to fulfill the attributes of family-centered care as follows (Bowden, Dickey & Greenberge, 1998):

1. The family is respected for the knowledge they have of their child, and as a constant in their child's life. Nurses can promote the family's role as primary caregivers for the child as follows: change visiting policies to promote the family at the bedside, be sure there are an adequate number of sleeping cots for parents, encourage family visiting in the post-anesthesia room, use parent questionnaires to understand family needs, involve parents in play room activities, encourage parents to

chart the child's progress, contact with parents to provide care for period of time during the day, and in the acute setting, and provide support services such as laundry and kitchen facilities to families experiencing long hospitalizations.

2. Collaboration among patients, families, and professionals occurs in the delivery of care. Nurses can promote collaboration between families and profession in many ways as follows: Incorporate families in interdisciplinary conferences regarding the child's care, coordinate and record all the child's daily activities on a large calendar visible to everyone, and encourage all family members to participate in home care activities.

3. Professionals communicate with and share complete and unbiased information with patients and families in ways that are affirming and useful. Nurses can promote collaboration between families and professional in many ways as follows: create a parental information and orientation program to familiarize parents with the hospital, provide a brief parent welcome and orientation program, use preoperative videos and tours to ease the child's and family's fear about the pre- and postoperative processes, establish programs to support infant or child's transition to home after a lengthy hospitalization, and create a parents' information board containing community resources and information pamphlets.

4. The family are treated with dignity and respect. For example, recognize and integrate ethnic, racial, and cultural activities as appropriate into the clinical setting (e.g., foods, play items, picture on wall), aim for diversity of healthcare staff, and encourage families to bring in culturally significant items such as food and healing and religious symbols.

5. Nurses recognize and build on family strengths and resources. For example, establish family support groups, placing invitations to attend meetings on each child's bed, develop activities or programs to support families as they make the transition from one unit (intensive care unit) to another (pediatric floor), develop mechanism to support regular contact between the child and out-of-town parents, establish a parent committee or family advisory council to advise the hospital on issue of importance, and provide activities such as picnics, movies, and special events for children and their families to interact with other families who have children with the same chronic or acute condition.

Antecedents

The antecedents that have emerged from the literature appear to be linked with the presence of parents on the ward and their willingness to be involved in the care of the child (Darbyshire, 1993), as well as the willingness of the staff to collaborate with parents (Brown & Ritchie, 1990). Antecedents of family-centered care are explained by Hutchfield (1999) as follows:

- It must be in the child's best interests to have the child's family involved in its care.
- Parents must want to be involved in the care of their sick child.
- Nurses must be willing to share the care of the sick child with his or her family.
- Parents/families must be allowed open access to their children and be residents with them if they wish.
- Nurses must be prepared to develop a relationship with the family and collaborate with them.
- Nurses should be sufficiently skilled and experienced themselves, so they can adequately support, teach, and empower families.
- Sufficient time must be available to identify the concerns of the family.
- The climate of the ward should make families feel welcome.
- Facilities must be available for parents and families staying with or visiting their sick child.

Consequence

When family-centered care is implemented into practice, it has elicited positive feelings from healthcare staff and reports of increased parents and children's satisfaction (DePompei, Whitford & Beam, 1994; Gill, 1987; Heller & McKlinedon, 1996). Families experience greater feeling of confidence and competence in caring for their children, the dependence of families on professional caregivers decreases, costs of care decrease, professionals experience greater job satisfaction, and both parents and care providers are empowered to develop new skills and expertise (Johnson, Jeppson & Redburn, 1992, cited in Ahmann, 1994a: 52).

Family-centered care in practice

Nurses' perceptions and practices of family-centered care

The concept of family-centered care continues to evolve and expand. However, it has been reported that there is discrepancy between the concept of family-centered care and the practice of the professionals who are responsible for implementing this concept (Ahmann, 1994a; Bruce & Ritchie, 1997). Brown & Ritchie (1989) concluded in their studies that nurses did not perceive the care of parents as part of their role. Also, nurses lacked an understanding of the concept of family centered-care or had difficulty using such knowledge in their practice. This finding seems inconsistent with the finding of these studies. The nurses perceived that the elements of family-centered care was necessary for practice; however, they did not match their perceptions of activities necessary to provide family-centered care in their everyday work (Bruce & Ritchie, 1997: 217; Letourneau & Elliott, 1996: 167).

As for factors related to nurses' perceptions and practices, some researchers found that age, nursing position, and education had a relationship with nurses' perceptions. Nurses aged 31-40 years old perceived that the elements of family-centered care were less present in their practices than did nurses who were 41-50 years of age. In addition, nurses in administrative and educative positions rated necessary elements higher than nursing staff in direct care. Nurses whose highest level of education was a bachelor's degree or a master's degree had significantly higher perception scores than post secondary nurses (Bruce & Ritchie, 1997; Gill, 1993: 265-266; Letourneau & Elliott, 1996: 167). Moreover, nurses who were married or were parents had more accepting attitudes than nurses who were never married or were not parents. Finally, as the number of years of experience increased, the attitudes were slightly more accepting (Gill, 1993; 265-266).

In summary, the concept of family-centered care was meaningful to nursing practice; however, the practice did not accompany with the concept which was significant. Personal and professional characteristics affected perceptions of the important family-centered care activities. Thus, the perceptions may contribute to or distract from nurses' practice of family-centered care.

Cancer can be seen as a family disease because it affects the children and the whole families. Thus, nurses not only care for the children but also need to include families in their care.

Family-Centered Care of the Children with Cancer

Family-centered care of the children with cancer comprises of providing clinical care, facilitating psychological support, providing information and communication, establishing a support system, and promoting growth and development.

1. Providing clinical care

Nurses develop plans of care in collaboration with other healthcare professionals to provide direct nursing care. The role of pediatric oncology nurses is managing diseases and treatment-related complications, administering chemotherapy, and preparing the children for procedures.

1.1 Management of disease and treatment-related complications

The management of side effects includes infection prevention, prevention and management of nausea and vomiting, provision of nutritional support, and pain management.

Infection prevention

Children receiving cancer treatment are immunosuppressed and at increased risk for infection, particularly seven to ten days after receiving chemotherapy (Nadir). Prevention is essential during the management of these children.

Prevention and management of nausea and vomiting

Nausea and vomiting may be mild to severe, depending on chemotherapeutic drugs being administered and the tolerance of the child receiving drugs. Even when the administration of chemotherapy agents is preceded by antimetic therapy, nausea and vomiting may still occur. The nurses must monitor intake and output. Nonpharmacologic measures can be used to control nausea and vomiting. Distraction, relaxation, and guided imagery are methods the nurses can employ to help the child.

Nutritional support

Alterations in nutritional status in the child undergoing cancer treatment are common. The disease itself and the side effects of therapy often interfere with caloric intake. Nutrition assessment should include daily weighing, intake output records, caloric count, and laboratory values of element. It is necessary to prevent, alleviate, or minimize the side effects associated with the treatment regimen. When metabolic needs exceed caloric intake, the child may benefit from a nutritional supplement given between meals. Small, frequent meals may be appetizing if the child is suffering from nausea. If increasing oral intake is not possible, the enteral route is the second choice in children whose GI tract is intact and can tolerate it.

Pain management

Children with cancer may experience pain for a variety of reasons. Children may experience pain caused by the disease itself. Pain is also associated with side effects of the various treatment modalities. Both pharmacologic and non-pharmacologic interventions are important in managing pediatric pain. Several nonpharmacologic pain management strategies have been successful in dealing with the pain associated with procedures. These interventions include music therapy, hand-holding, imagery, relaxation, and breathing exercises. A variety of techniques can be taught to the child and the child's family together with the administration of pain medications (Hockenberry-Eaton & Kline, 1997: 1214-1217).

1.2 Chemotherapy Administration

An understanding of the action and side effects of specific chemotherapeutic agents is essential for nurses caring for children with cancer. A potentially fatal complication of certain chemotherapeutic agents is an allergic reaction. Anaphylaxis can occur with L-asparaginase, Bleomycin, and the epipododhyllotoxins. Nurses administering agents that are known to cause anaphylaxis should always assess patients for reaction of the drugs. Nurses should observe patients for signs and symptoms of local reactions. Life-threatening anaphylaxis can lead to hypotention and shock. Nurses should prepare emergency equipment and drugs readily available when administering these chemotherapeutic agents (Hockenberry-Eaton & Kline, 1997: 1219-1221).

1.3 Preparing the children for procedure

Research describes the value of preparing children for invasive healthcare procedures. Preparation is a process in which many members of the healthcare team have a role. Preparing children with cancer for procedures can help decrease their anxiety and help them cope more effectively with the procedure. Preparation often includes medical play, provision of age-appropriate sensory information related to procedure, discussion and practice of coping skills, and emotional support during the procedure. Follow-up with the child after procedure is extremely important. Many tools, such as teaching dolls, videos, and picture books that depict healthcare events, are now available to aid the preparation process (Hicks & Lavender, 2001: 146).

2. Facilitating psychosocial support

Nurses work with the interdisciplinary care team to provide psychosocial support for the children with cancer and their families.

Accept the family's emotional reaction

Diagnosis, treatment, relapse, and terminal illness are crisis events for families who have children with cancer. One of the most supportive interventions is to accept the family emotional reactions to the diagnosis in as non-judgemental a manner as possible. At the time of diagnosis, families experience anxiety, fear, anger, and depression. Nurses help the families to develop new attitudes and coping techniques. Nurses provide support by helping family members work together. During the treatment period, nurses are resources for the family, teaching them about the disease and treatment and providing support during stressful situations. During the recurrent period, it is a particularly difficult time by parents. Nurses must be listeners and must create a caring atmosphere. Adequate time must be spent on counseling and support during the period when the families face with the failure of treatment. At the terminal phase, parents facing the loss of children have found themselves with numerous crises. Nurses help the families accept the terminal status of the children, allow the families to participate in caring for the children as much as possible, encourage expression of emotions and guilt, and plan for the future (Wong, 1995: 953-954).

Assess the family's strengths

Families are faced with direct medical expenses, in combination with out-of-pocket expenses for nonprescription medication, transportation, and so forth, all of which can consume a high percentage of the family's income. Families of children with cancer face the potential for ongoing stress related to factors such as the child's condition and financial concerns. In addition, mothers who are employed outside the home may have to leave their job temporarily or permanently because of the child's health care demands. The cost of pocket expense include travel to the treatment center, child care, on top of loss of income from job absence. Nurses must understand family systems. Family's assessment is an important function during the initial hospitalization and subsequent visits. The nurses consider cultural influence on the children and their families and conduct assessment of family's support system including their strengths and weaknesses. Evaluation of community resources is an integral part of the family assessment (Wong, 1995: 950-952).

Help the family cope

Teaching the family how to cope with having children with cancer can promote positive adaptation. In addition, nurses can assist parents by identifying and building on family strengths, promoting child and family competence, and encouraging the development of a nurturing environment that addresses the needs of parents and the children. Teaching the coping skill and helping families to use or further develop their social support networks and other nursing actions can encourage and empower the parents and promote positive adaptation in the family (Wong, 1995: 954-955).

3. Providing information and communication

Education

When children are diagnosed with cancer, their families are faced with a disease and treatment plan of which they know nothing or very little. A rigorous and complex treatment regimen may require their participation. This new responsibility and uncertain treatment outcome heightens the family's anxiety, which is intensified by lack of knowledge. The literature suggests that helping families understand the meaning of the illness and treatment can facilitate their overall adjustment and coping (Moore, Kramer & Perin, 1986: 63).

Parent/family education refers to any learning experiences which are aimed at positively affecting the knowledge level, skills, and attitudes or other behaviors of the patients and their families (Johnson & Flaherty, cited in Moore, Kramer & Perin, 1986: 63). Information will assist the children and their families to be knowledgeable participants in their health care.

Nurses work with other members of the interdisciplinary team to provide education for the families and their children regarding the diagnosis, treatment, and psychosocial issues of childhood cancer. Education programs for families and patients should include discussion of the pathophysiology of different types of cancer, various treatment options, general side effects of treatment, family concerns, and other issues (Hockenberry-Eaton & Kline, 1997: 1221).

The education program for families includes written materials and handbooks for parents, formal teaching sessions, videotapes, tours of the hospital and clinic, and structured play activities for the child to learn more about the illness and treatment.

Parent and patient education is ongoing and continuing throughout treatment and after completion of therapy. At the initial diagnostic talk, the nurse could be present. During subsequent discussions, the nurse reinforces and reviews information, answers the questions, and clarifies concerns of the patients and their families. At the treatment phase, the nurse educates the children and their families related to disease, plan of treatment, and complications from chemotherapy and radiation. In addition, the nurse informs the families about the resources of financial support because the families must spend much more money in this period. At the remission, nurses give information related to child rearing, and daily living of their child. At the end of therapy, nurses give information regarding complication of treatment, and when children have relapses, nurses support parents with compassion and empathy.

Nurses caring for children with cancer must understand that patient education must be related to the child's developmental stage. Knowledge of growth and development helps the nurse to communicate with children before painful procedures or tests and to understand the child's uncertainty about hospitalization (Hockenberry-Eaton & Kline, 1997: 1221).

Communication

The importance of effective communication has been recognized as an essential element facilitating family coping with childhood cancer. The failure of communication within the family is a key problem in working with childhood cancer patients (Gogan, O'Malley & Foster, cited in Moore, Kramer & Perin, 1986: 64). It is important that the family and treatment team communicate with each other.

Nurses should convey information accurately and clearly. Nurses should encourage the expression of parents' concerns and speak openly about their feelings. Families should be encouraged to share non-illness related problems, as they have the potential to affect the family's overall ability to adapt to the child's illness.

4. Establishing a support system

The diagnosis of a child with cancer is a situational crisis that affects the entire family system. There are several variables influencing the resolution of the crisis such as available support system, perception of the event, coping mechanism, reactions to the child, available resources, and concurrent stresses within the family. The families of children with cancer who have many resources may adjust successfully to the child situation than the families who have few resources. Supports for the children and their families consist of infra-familial resources, social support from friends and relatives, parent-to-parent support, and community resources.

Support systems may be available through a variety of relationships and may consist of one significant other, such as a spouse, or a group of significant others such as the extended family or the healthcare team. The parent-to-parent support is particularly valuable for parents of children with cancer who are likely to experience frequent and lengthy hospitalization, as well as numerous routine clinic visits. Just being with another parent who has shared similar experience is helpful. Nurses can foster participation in parent-to-parent support group by serving as a referral agent, a group advisory board member, a resource person, or an assistant in founding a group.

Numerous studies have demonstrated that support system has an effect on knowledge of the families of the children with cancer (Sinswang, 1995; Kramseang, 1996). There were also some studies which found that support group affected bereaved extended family of children with cancer (Heiney, Well & MDiv, 1993; Heiney, Ruffin & Goon-Johnson, 1995).

5. Promoting growth and development

Cancer therapy has the potential to cause significant developmental and growth delays. The nurse must continually assess the child's growth and development during therapy. Changes in weight or lack of expected growth in height or weight should be followed closely. In particular, specific nutritional interventions should be started immediately once changes in weight occur (Hockenberry-Eaton & Kline, 1997: 1223).

Nurses can facilitate normal development by ensuring that the child is treated at an age appropriate level when visiting the hospital.

Early childhood During infancy, the child achieves basic trust through a satisfying, intimate, and consistent relationship with his or her parents. Nurses must preserve the parent-child relationship when the child is admitted to the hospital. During early childhood, the goal is to achieve separation from the mother, autonomy, and initiative. Young children also need the opportunity to develop independence. Frequently the child is able to learn self-help skills, but the parents continue to perform the act. Therefore, the nurse must guide parents toward the usual milestones expected from the child.

School age For school-aged children, the majority of the tasks are entering into school and achieving a sense of industry. Returning to school is an important milestone for children with cancer. The nurse must be vigilant in attempting to help the child return to school when at all possible.

Adolescence Adolescence can be a particularly difficult period for the teenager and family. A sense of feeling different from peer can lead to loneliness, isolation, and depression. Participation in a group of teenagers with peers who share the same condition can alleviate feeling of isolation and enhance smooth transition to a meaningful relationship with one person in adulthood.

In summary, the diagnosis of cancer has an impact on the children and their families. There is sufficient evidence from research reviewed here that childhood with cancer is an overwhelming and stressful experience for the children and their families. There are many research studies which have described quality of life and experiences of children with cancer, and explored experiences, needs, and quality of life of parents or families of children with cancer. However, little is known about interaction among

nurses, children, and their families. Some studies have indicated that parents of children with cancer value a good working relationship with nurses and want to participate in their child care. The involvement of families increases their confidence, help get the mind to function, and enable them to make more decisions. By being involved in care, these parents reported that they and their child were better able to cope. Therefore, the concept of family-centered care based on the belief that all families are deeply caring and want to nurture their children is considered a central element of the holistic nursing care of the children (Ahmann, 1994a: 113), and it will guide the investigator to develop the family-centered care model for the children with cancer and their families. However, there is a lack of consensus among nurses about what form of parental participation should take place and how far it should extend (Coyne, 1993: 35). In order to develop the model of care for the children with cancer using family-centered care, action research was selected as the research methodology in this study.

CHAPTER III

METHODOLOGY

This chapter includes a description of the research design, participants, research setting, instruments, research phase, data collection, protection of human subjects, data analysis, and establishment of trustworthiness.

Research Design

An action research is used in this study to develop a family-centered care model for the children with cancer in a pediatric cancer unit. Action research is a research method that involves taking action to improve practice and systematically studying the effect of the action taken (Streubert & Carpenter, 1999: 251).

Participants

The participants of this study were children diagnosed with cancer, the parents or primary family caregivers of children with cancer, and nursing staff

The selection criteria of the subjects of the study consisted of the following:

1. The children aged 1 to 15 years diagnosed with cancer who were admitted to the hospital were included. The families were willing to participate in the study. The informed consent was obtained from the children and their families. The number of the children with cancer was 41 children.
2. The parents or primary family caregivers of children with cancer who agreed to take part in the research. The families were approached at the time of admission of the children with cancer to the ward. They had to be able to verbally communicate with the investigator. Forty-five family members agreed to participate in this study, consisting of 38 mothers, four fathers, and three grandmothers.

3. The nursing staff who were willing to participate in the study were also included. Nursing staff consisted of 13 nursing staff, six nurse assistants, and seven nurse aids.

Research Setting

The research setting was a 26-bed oncology pediatric ward providing care for children from aged 0 to 15 years. This hospital provided access to all individuals from every part of Thailand. Approximately 100 new cancer patients were reported annually.

Instruments

1. Instruments for research procedure

The instruments comprised of a tape-recorder for subject interviews and group discussion, and a camera.

2. Instruments for data collection

The instruments for data collection were composed of (1) An Interview Guide of Participant Perceptions (2) General Information Questionnaires.

2.1 An Interview Guide of Participant Perceptions

A concept of family-centered care for understanding the care of the children with cancer and a review of literature regarding caring for children with cancer were used to guide the development of the interview guidelines to explore the perception of children, families, and nurses in this study. It was a semi-structured interview (Appendix B). The interview data were collected for analysis of the current situation. Each interview lasted about one hour. It was audio recorded, and complete written transcriptions were made immediately after the interviews (Appendix B).

2.2 General Information Questionnaires

2.2.1 Child's General Information Questionnaire. It contained a checklist of demographic characteristics of the children. These were age, gender, education level, diagnosis, and chief complaint.

2.2.2 Family's General Information Questionnaire. It contained a checklist of demographic characteristics of the families. These included gender, age, current marital status, education, occupation, monthly income, and relationship to the patient.

2.2.3 Nursing staff's General Information Questionnaire. It contained a checklist of gender, age, marital status, education, employment in nursing, work experience in the oncology ward, and monthly income.

These questionnaires were used to obtain general information of the participants after they agreed to participate in the study.

Research Phase

This study was divided into three phases: 1) Pre-research preparation phase, 2) Action research phase, and 3) Evaluation phase

Pre-Research Preparation Phase

The investigator prepared the research as follows:

1. Selection of the research setting and formation of the action research team

The investigator selected the oncology pediatric ward in a university hospital as the setting for the study. The investigator introduced herself to the nurse director and explained the details of the topic of the research. The investigator informed all the nurses in this ward that an action research project would be implemented. Recruiting subjects and interviews were conducted by the investigator who introduced the action research principles and objectives to the potential participants. A contract was drawn up between the practitioners and the researcher. During this time, the investigator became familiar with the participants by working as a nurse practitioner in this ward. This approach also helped the investigator develop trusting relationship with the nursing staff.

2. Training of the action research team

The investigator shared knowledge about the concept of family-centered care and the action research method with the nurses in the ward. The contents of the concept of the family-centered care comprised of evolution of the

concept, elements of FCC, FCC in practice, and benefits of FCC. The contents of action research was composed of definition, fundamental characteristics, and the process of the action research.

Action Research Phase

This phase was comprised of an analysis of the current situation and identifying of the problem, planning, action and observation, reflection, and replanning.

1. An analysis of the current situation and identification of the problem

1.1 The investigator began to investigate the current situation by (1) interviewing the parents or primary family caregivers of the children with cancer on care received and expectation of the care provided; (2) interviewing the nurses on care given to the children with cancer and their families; (3) interviewing of the children with cancer on perception toward their illness and their needs of care; (4) observing the clinical practice including interactions among the nurses and children and their families during care provision, and nursing management in this ward. In addition, semi-structured interviews guided by the concept of family-centered care were developed. The data were collected through the semi-structured and in-depth interviews, focus groups, and participatory observations, and document data sources.

1.2 The investigator analyzed and summarized the data and met with the nurses to share information and discuss the results of the current situation and to seek agreement of the problem.

1.3 Pilot study. The investigator and nursing staff conducted a pilot study. Four case studies of children with cancer and their families were carried out by the investigator and nursing staff.

2. Planning

The investigator and participants collaborated to create an action plan. An action plan detailed the description of the change process of implementation, reflection, and evaluation plan. The action plan also detailed the roles of each participant including the families, the nurses, and the investigator, as well as specified collecting on of the information to help them evaluate the effects of the actions.

3. Action and observation

Action plan was implemented with the nurses as participants.

The collaborative activities were implemented as follows:

3.1 Nursing staff who were invited to participate in this study engaged in the planned action and collected data on their actions.

3.2 The investigator and nursing staff worked together as follows:

(1) The investigator and the nurses selected the children and their families who met the inclusion criteria of the study to participate in this study with their consents. The investigator and nurses introduced themselves to the children and their families who were interested in the participation in this study.

(2) The investigator and nurses gave a complete verbal explanation about the study to the potential participants. Any questions that the potential participants had were answered by the investigator. The Thai version of a letter of information was read by the potential participants (Appendix C1).

(3) When the potential participants agreed to participate in this study, they were asked to give their consent (Appendix C2). The participants included the children with cancer and their families, and then the nursing staff began to implement the action as planned.

(4) The investigator took no action in the implementation role. The investigator remained during the implementation to guide and facilitate the reflection that might occur.

4. Reflection

Reflection provided an insight into the process of implementation and the effects of the change. Diaries, team meetings, and interviews were used. Data recorded during reflection were an important contribution to the theory from the action research study. Reflection gave the investigator an insight into the implementation and factors influencing the implementation.

During the implementation, there were some factors influencing the implementation. The investigator developed focus group interviews with the nurses and the families in order to discover feelings and opinions about the factors influencing the plan of action. The participants discussed and probed the factors that influenced the implementation of the action plan, and planned for the next stage.

5. Replanning

Action research was described in terms of a cyclical process involving planning, action and observation, and reflection, then planning, and so on.

Participants discussed the practice and decided to adjust the implementation plan. Discussion and probing the problem would give the research team an insight into the factors influencing implementation of the new method. The research team planned the next stage of the research. These were organized throughout the entire process until the participants achieved satisfactory.

Evaluation phase

The investigator and participants collaborated to analyze and summarize the results of this study. The participants engaged in the reflection process about how the new practice would affect them while they were acting.

Data Collection

In this study, data collection included individual interviews, focus group interviews, field-notes, participatory observation, and document data sources. These approaches were used throughout each stage of the action research.

Individual interviews

In order to gain an understanding of the situation and the process of the development of family-centered care model, the investigator conducted in-depth interviews with the key informants. The key informants consisted of the nurses who worked in the ward, the children with cancer, and their families. Interviews were recorded. A semi-structured questionnaire, guided by the concept of family-centered care, was developed for the interview, and data were recorded.

Focus group interviews

Focus group interviews were aimed at discovering feelings and opinions about specific topics of interest or eliciting reaction to proposed solutions. The group consisted of six to eight persons with similar experiences in the topic. This approach was used with the families of the children with cancer and the nurses who worked in this ward.

Field notes

Field notes were used to supplement other forms of data collection. Field notes were written accounting for things that the researcher heard, seen, experienced, and thought during the data collection process. The investigator wrote field-notes after spending several times in the ward.

Participant observation

The purpose of an observation was to observe participants in as natural a setting as possible (Morse & Field, 1996: 86). The investigator spent time in the ward to be familiar with the nurses and other hospital staff in order to perform subsequent observation. Observations were focused on both verbal and nonverbal interactions among nurses, families, and the children, and recorded with field notes. The investigator spent five to six hours on observation each day.

Documentary data source

Documentary data sources were used. Document data sources consisted of nurses' notes and other records of children with cancer.

Protection of human subjects

Approval for involvement of human subjects was sought and obtained from The Committee on Human Rights Related to Human Experimentation at Mahidol University. A complete explanation and written description about the purpose, the method, the potential risk, the benefits of participation, and the protection of confidentiality were given to the potential participants in this study. The potential participants were given opportunities to ask questions and to decline or accept participation in this study. Written consent was obtained once they decided to participate in the study.

As for confidentiality, the code numbers were assigned to each of the participants. The audio-tapes were transcribed by the investigator. All of data records, cassette tapes containing interview data, and other written documents, were kept in a secure file cabinet and destroyed after the data were no longer needed for the purpose of the study.

Data Analysis

Content analysis was used to analyze the qualitative data obtained from the interviews. The audio-tape recordings of interviews were transcribed verbatim and analyzed by the researcher. The transcribed interviews provided the text for interpretation. The investigation made preliminary interpretation. The analysis consisted of the movement from and understanding of the whole text to more specific themes with the text and then back again to the whole.

Establishment of Trustworthiness

The four criteria including credibility, transferability, dependability, and confirmability were used to evaluate the trustworthiness of the qualitative findings in this study (Lincoln and Guba, 1985: 301). The investigator established the trustworthiness of this study by reporting on the following:

Credibility

In this study, the investigator spent enough time to becoming oriented to the situation. The investigator worked together with other nursing staff in order to build trust, to learn the context, and to minimize distortions. In addition, the investigator used the technique of persistent observation for the sake of identifying and assessing salient factors and crucial atypical happenings. The triangulation was used by the investigator. Three modes of data collection were interview, observation, and focus group. The uses of different sources were organized by interviewing parents, children with cancer, and nurses. For peer debriefing, the investigator met the mature advisor to discuss codes, categories, and themes that had emerged from the data. The codes, categories and themes were labeled with the words of nurses, children, and families. Finally, as for member checking, the investigator conducted member checking concurrently with data collection and interpretation in order to verify interpretations with the participants. The categories of data were periodically checked with the participants, and their comments were used in developing the model.

Transferability

Transferability was established by describing the means for applying the research findings to other contexts. Fundamentally, the possibility of applying findings across settings is established through thickly detailed descriptions that enable audiences to identify similarities of the research setting with other contexts (Stringer, 1999: 176). The investigator was responsible for adequately describing the original context of the study so that the readers could possibly make adjustment of transferability.

Dependability and confirmability

Dependability and confirmability were provided through an audit trail that clearly described the processes of collecting and analyzing data and provided the means by which readers may refer to the raw data (Stringer, 1999: 177). In this study, the investigator described the process of data collection clearly. Raw data were recorded completely. Audio-taped and transcripts were classified. Quotations of participants' statements were reported appropriately and adequately to assert that findings were grounded in events rather than the research construction. Another investigator can follow the process.

Summary

In summary, this research utilized an action research design to develop a family-centered care model of the children with cancer. The participants of this study were children diagnosed with cancer, parents or primary caregivers of children, and pediatric nurses. The purposive sampling was used. This study was divided into three phases including 1) pre-research preparation phase, 2) action research phase, and 3) evaluation phase. Informed consent was obtained, and the rights of all participants were protected. Data analysis included the use of content analysis.

CHAPTER IV

FINDINGS

This study was the development of a family-centered care model for the children with cancer in a pediatric cancer unit, using action research. The results of this study are presented in the following order:

1. Demographic data of research participants
2. Situation in caring for children with cancer in a pediatric cancer unit
 - 2.1 Pediatric cancer unit
 - 2.2 The study of nurses, children with cancer, and families' perspectives
 - 1) The nurses' perspective in caring for children with cancer
 - 2) The families' perspective in caring for children with cancer
 - 3) The perception of children with cancer toward their illness and their needs of care
 - 2.3 Discussion of the problems and evaluation of the nursing team requirement in the development of the care model
3. The process of development of the family-centered care model
 - 3.1 The process of development with action research
 - Circle 1 – the promotion of nurses' understanding
 - Circle 2 – the promotion of practice at an individual level
 - Circle 3 - the becoming of team practiceEvaluation- committed to practice the model in the unit
 - 3.2 Strategies used in the development of a family-centered model, and enabling factors and barriers to the development
 - 3.3 The effects of a family-centered care model on participants
4. A family-centered care model in a pediatric cancer unit

1. Demographic data of research participants

The research participants in this study were members of the nursing team, children with cancer, and the families.

1.1 Nursing team

The nursing team was composed of 13 nurses, six nurse assistants and seven nurse aides. The ages ranged from 20 to 49 years. Most nurses were single, whereas the majority of nurse assistants and nurse aides were married. All nurses were graduated with a bachelor's degree; nurse assistants and nurse aides held a diploma and high school certificate, respectively. Most nurses had been working for less than five years, most nurse assistants had been working for longer than 25 years, and nurse aides had been working for six to 25 years. Most members of the nursing team had experience in pediatric cancer unit for longer than five years. The income of the team members ranged between 5,000 and 10,000 baht per month, as shown in Table 1.

1.2 Children with cancer

This study was conducted in 41 children with cancer. Most of the children were boys with similar numbers of pre-school and school-aged children. The number of younger children aged between four and five years was similar to the number of older children aged between six and twelve years. Most children were diagnosed with leukemia and came to the hospital with symptoms of fever, anemia, and abnormal bleeding, as depicted in Table 2.

1.3 The family of children with cancer

Most of the family members participating in this study were patients' mothers, while four participants were the fathers. The parents' ages ranged from 20 to 39 years; all of them were married. Most parents were finished elementary education, and worked as employees. The family incomes ranged from 5,000 to 10,000 baht, and most of them lived in Bangkok, as illustrated in Table 3

Table 1 Demographic Data of Nursing Staff

Characteristics	RN. (n=13)Number	PN. (n=6)	NA.(n=7)
Gender			
Male	–	–	–
Female	13	6	7
Age (years)			
20-29	7	1	1
30-39	3	-	2
40-49	3	5	4
Marital status			
Single	12	1	1
Married	1	5	6
Education			
Secondary Education	–	–	5
College, Diploma	–	6	2
Bachelor's Degree	13	–	–
Employment in Nursing (years)			
< 5	7	1	1
6-15	2	–	3
16-25	3	2	3
> 25	1	3	0
Work experience (years)			
< 1	–	–	1
2-3	1	1	3
4-5	6	–	3
> 5	6	5	0
Monthly income (baht)			
< 5,000	-	1	1
5,001-10,000	8	2	6
10,001- 15,000	2	3	-
15,001- 20,000	3	-	-

Table 2 Demographic Data of the Children with cancer (n=41)

Characteristics	Number
Gender	
Male	22
Female	19
Age (years)	
< 1	4
2-3	8
4-5	14
6-12	13
> 13	2
Education	
No schooling	13
Kindergarten	9
Elementary level	12
Secondary level	7
Medical Diagnosis	
ALL, ANLL	35
Lymphoma	2
Rhabdomyosarcoma	2
Retinoblastoma	1
Hepatoblastoma	1
Chief complaint	
Pale, bleeding, fever or infection	33
Pain	2
Hepatosplenomegaly	3
Others (accident, dog bite, convulsion)	3

Table 3 Demographic data of the Families of the Children with cancer (n=45)

Characteristics	Number
Age (years)	
20-39	37
40-59	4
Current marital status	
Married	37
Divorced	4
Education	
No schooling	4
Elementary level	20
Secondary level	12
College, Diploma	4
Bachelor's Degree	1
Occupation	
Trader	6
Employee	19
Government official	1
Agriculture	4
Housewife	11
Monthly income (Baht)	
< 5,000	10
5,000-10,000	25
10,001-15,000	3
15001-20,000	3
Relationship with patient	
Father	4
Mother	38
Grandmother	3

2. Situations in caring for children with cancer in a pediatric cancer unit

The researcher and participants of this program collaborated in analyzing current situations in caring for children with cancer and their families in order to understand circumstances of caring for children with cancer and their families in a pediatric cancer unit. The contents in this section included a pediatric cancer unit; a study of the perception of people involved in caring for children with cancer consisting of nurses, children with cancer, and their families; and the discussion and evaluation of nursing team requirement in the development of a family-centered care model.

2.1 Pediatric cancer unit

The setting was a pediatric cancer unit which delivered medical care to pediatric patients with low immunity. The total number of beds was 26; among these, 16 beds were for children with cancer, while the other ten were for children with kidney disease.

The nursing staff in this ward consisted of one Head Nurse, 12 registered nurses, six nurse assistants, and seven nurse aides. The working daily cycle was divided into three shifts: the morning shift starting from 7:30 a.m. until 3:30 p.m., the afternoon shift starting from 3:30 p.m. until 11:30 p.m., and the night shift starting from 11:30 p.m. until 7:30 a.m. During the weekdays, the nursing team in the morning shift consisted of the Head Nurse, four registered nurses, and two nurse aides. In both the afternoon shift and the night shift, there were two registered nurses, one nurse assistant, and one nurse aide. On holidays and weekends, there were three registered nurses, one nurse assistant, and one nurse aide for the morning shift, whereas the number of staff in the afternoon and the night shifts remained the same as in the weekdays.

The workloads were assigned with a combination approach. There were task, team, and individual assignments. The Head Nurse acted as the in-charge nurse of the morning shift. For team assignment, the staff were divided into two teams; each team had a registered nurse as a team leader and three other members comprising one registered nurse, one nurse assistant, and one nurse aide. The team leaders assigned a duty for each team member, led pre-conference discussion, and coordinated with doctors about the treatment plan. The team members delivered

nursing care to patients for whom they were assigned to be responsible. Patients were usually categorized into five groups based on severity of illness: (1) patients who were able to help themselves; (2) patients with mild illness; (3) patients with moderate illness; (4) patients with severe illness; and (5) patients who were in a critical condition. The nurse aide was usually assigned to taking care of patients who could help themselves; the nurse assistant took care of patients with mild illness under supervision of the team leader, and the registered nurse delivered care to patients who were moderately ill up to those who were in a critical condition. Each staff was responsible for two to three patients and was also assigned to other ward duties such as giving medication, recording vital signs, or recording water intake and output.

Both male and female children ranging from newborn to 15 years old were admitted in this ward. The number of new patients was approximately 100 cases per year; most of them were referred from other hospitals, both in Bangkok and remote areas. Most children with cancer had leukemia. The children admitted in this ward were ranging from newly diagnosed, receiving chemotherapy, with recurrence of the disease to children at the end stage. For those who were newly diagnosed, the patients may go to the hospital with symptoms related to cancer and they were subsequently admitted to confirm the diagnosis. The diagnosis involved various techniques such as blood test, bone marrow aspiration, or x-ray. After the children were definitely diagnosed with cancer, they would receive medical care as in treatment protocols. The treatment in this unit included chemotherapy, radiotherapy, and palliative treatment. Children who needed surgical treatment would be transferred to surgical units. Patients admitted to this unit included those who had complications such as infection or fever.

The pediatric nursing care in this unit was based on the nursing process. Each nursing team conducted pre-conference before delivering daily care.

Nursing staff provided group teaching and individual teaching to the children and the family. The provided knowledge included general information about the ward, hospital staff, regulation, rights to receive healthcare services, and suggestion for the family. The general information was given on admission. Nurses also provided health education concerning caring for children with low immunity and caring for children receiving chemotherapy. More suggestions about childcare were

given before the child was discharged from the hospital. The nursing team also gave information and answers to any questions from the child and the family.

This unit allowed the family to visit patients from 09:00 a.m. to 8:00 p.m. on weekdays. However, the visiting time was flexible, especially when the children could not sleep. The parents were not usually allowed to stay overnight with the children, except in cases of very small children, who could not help themselves, and those on credit payment. Most families participated in helping the children with their daily activities such as personal hygiene care and eating. The families also participated in the delivery of simple nursing care like tepid sponge or giving oral medications.

The collaboration in childcare between nurses and the family had no definite pattern. Nurses carried out usual nursing process comprising assessment, diagnosis, planning, and providing care. Only nursing staffs attended pre- and post-conference with no participation from the family.

2.2 The perception of nurses, children with cancer, and their families on caring for children with cancer

The researcher was not a member of the ward; therefore, she worked as a nurse in the study site to examine the situation with the participants of the program. The working time was 07:30 a.m.-5:00 p.m. everyday in order to establish a good relationship and familiarity with the participants of the program. The researcher participated in every pediatric care activity including reports of patients information among shifts, pre-conference, post-conference, as well as other activities concerning nursing staff such as monthly staff meeting, and quality development meeting. Data were collected at the same time with triangulation comprising participation observation, in-depth interview, focus groups, and gathering of information from papers and records.

1. Participation observation. This involved observing behaviors of the participants in natural set-up, observing the practice of regular nursing staff, and observing the interaction between nurses, children with cancer, and their families. The researcher recorded the field notes after the observation.

2. In-depth interviews. The researcher interviewed children with cancer and their families about caring for children with cancer and the staff's delivery of care including the expectation of family-centered care. All nurses were interviewed about current nursing care for children with cancer, expectation in caring for children with cancer, and the utilization of the family-centered care concept. The interview questions were open-ended. Family interviews were mostly conducted from morning until afternoon. Nurses were usually interviewed at 4:00 p.m.-5:00 p.m. after the morning shift was over. The interview took place in the ward meeting room, with approximately 30-60 minute time period and was recorded on an audio tape. Every nurse was interviewed twice, but the Head Nurse and the ward supervisor was interviewed once. For the families, seven people were interviewed, six mothers and one father, and one interview involved both the father and the mother. For children with cancer, five cases of school-aged and adolescents were interviewed.

3. Focus group. The researcher conducted focus group conversations twice with the nurses and once with the families. The families which participated in the conversation were families of children with different stages of cancer. The group members consisted of three fathers, one mother, one grandfather, and one grandmother lasting approximately 1.5 to 2 hours. The conversation was recorded in an audio tape.

4. Data gatherings from papers and records. The researcher examined documents concerning work such as job assignment chart or nurse records.

The record of in-depth interviews and group conversations was transcribed and analyzed with the content analysis method. The results were co-analyzed with the field record from participative observation. After the data analysis, the researcher presented the results in a meeting with the nursing participants. The participants were then discussed and gave suggestions until they reached a consensus conclusion. The findings of the study of perception of nurses, children with cancer, and their families on caring for children with cancer are presented below.

The nurse perspective in caring for children with cancer

Nurses expressed opinions toward the delivery of nursing care to children with cancer and their families in the following issues: current nursing care for children with cancer, barriers to the delivery of care, expectations about a model of care for children with cancer, and perception of family-centered care model in a pediatric cancer unit. The details of nurse's perspectives are presented below.

1. Current nursing care for children with cancer

Nurses felt that current nursing care for children with cancer consisted of the following: delivery of care according to treatment protocols, focusing on the patients but not involving their families, little participation between families and nurses, and having some family-centered care practices.

1.1 Delivery of care according to treatment protocols

In caring for children with cancer, most nurses felt that the nursing roles were delivering treatment as stated in the protocols and taking care of symptoms concerning complications of chemotherapy, many nurses stated that:

“In addition to giving medications as in doctors' protocols, we also take care of complications from medication treatment that are important, such as hygiene care, prevention of infection, and side effects of the medications.”

“Mostly, I assess the symptoms; I don't take care much how are they doing, vomiting and eating”

1.2 Focusing on patients but not involving their families

Nurses stated that most of the care were focused on children and were not extended to their families. There was no assessment of family requirements and, sometimes, no understanding of differences between individuals. For example:

“We never really talked to each other- -how much they want or how much we want. No, we haven't balanced it yet. We just think...what we are doing today is good but how much the family want...we don't know if (what we do) is enough.”

“Originally, we just take care of the disease, help them feel well. We take care of their body and their mind, but we don't focus on the family. If there are parents helping to support the children, we don't do anything much with them.”

1.3 Nurses providing physical care whereas the families providing mental care

Nurses stated that, in caring for children with cancer, they provided physical care whereas the families delivered mental care, as a nurse explained:

“I don’t give them much mental care because they have parents to take care about that.”

1.4 Little participation of family in the care of children in the hospital

Nurses felt that the care for children with cancer at present was mostly delivered by nurses; the families did not involve in the delivery of care. A nurse reported:

“My (nursing) care is focused on the patients. For parents and relatives, we don’t have them participate in the care very much.”

1.5 Existence of some kind of family-centered care without a definite model

Some nurses stated that families might be cared for, depending on individual nurses’ interests. However, there was no pattern of family-centered care, as can be seen:

“We’ve done something about it depending on each one’s potential. But, we still don’t have any formal patterns that we will follow through to practice standard care for every patient to receive the same thing, to the extent that everybody provides care with the same protocol and every patient is involved and receives in the same kinds of care”

1.6 The nursing practice mainly focused at the tasks

A nurse made a comment that the nursing practice was mainly focused on the task or the nursing activity:

“Originally we focused our practice on physical care. We delivered nursing care as in the old days in which the care was not focused on patients, just concentrated on nursing activities. Hospital accreditation partly made us aware of this patient-centered concept more than before. We think about what should be the best for the patients and we let their family participate with us.”

2. Barriers to the delivery of care to children with cancer

Nurses perceived that the barriers to the utilization of the holistic approach for caring of children with cancer included the large amount of paperwork and frequent turnovers of nursing staff.

2.1 Large amount of paper workload

Nurses felt that they had less time to care for the children due to a large amount of paper workload:

“So much work, especially paper work. We have to finish our work first before we can talk to them.”

“I try to do so, but cannot do much. As I said there are a lot of paper work, so I don't have much time to spend with the patients and that leads to problems. I know the problems only superficially.”

“I feel there are a lot of academic work lately. So, I have less time to spend with the children. I don't know..maybe I think that myself. You know, I have to spend time writing papers, finishing paper work and don't have much time to spend with the children. I just leave them with their mothers. I go to see them when it's medication time or time to do some work, but I don't have time to play or to chat with them anymore. I feel that I don't approach them much lately.”

“Paper work needs to be finished, so I don't have much time to talk to the patients and their relatives.”

2.2 Frequent turnovers of nursing staff

The frequent turnovers of newly graduated nurses caused problems in the continuum of nursing care. Additionally, nursing staff did not have time to train the newly graduated nurses:

“I can't do that very often now because of frequent staff turnovers. I can't train them.”

In conclusion, the study of current situation in caring for children with cancer revealed that nurses delivered care according to treatment protocols in order to help the children recover from the illness. The children's families involved in mental care but there was little participation in the care between the families and the nursing team, and the nursing care was not extended to the families. Nursing practice was focused on doing the task. Perceived barriers to nursing care included paperwork and frequent turnovers of newly appointed staff.

3. Expectations about a model of care for children with cancer and their families

Nurses were not satisfied with current nursing practice. They expected a care model for children with cancer and their families in which nurses had roles in holistic care and family involvement.

3.1 Holistic approach is the nursing approach that covers physical, mental, and social care. Many nurses expressed similar opinions as shown in the following example:

“In providing nursing care, we should cover physical, mental, emotional, and social aspects. We should even take care about of their economics. Everything is important. It must be a holistic care.”

3.2 Family care

Nurses recognized the importance of the children’s families. A nurse said:

“We have to give mental support for both the children and their family. Cancer is a chronic disease, so we have to deliver mental care to the mothers, too.”

3.3 Family involvement in caring for the children

Nurses are aware of the importance of family involvement in caring for the children. A nurse stated:

“Mother is the person that a patient is most familiar with. She has been caring for the child for a long time. For nurses, there are many of them, and they are strangers to the patient. The patient doesn’t trust them, so we should let the mother closely deliver care to her child, too.”

“These children...it is not like we deliver nursing care and they’ll get better. Yes, they are admitted to our ward, and we may...we may deliver half the care as in the treatment plan. We have to let them (parents) participate in the care. How much can the children understand us? How much can we understand them? One nurse here has to deliver care to so many children, but they care for only one child --their child. They are the parents. They love and they are concerned about the child. The child is theirs, so they want to give the best care.”

In conclusion, nurses expected that nursing care for children with cancer should be a holistic nursing care, the care should be extended to the patients’ families and the families should be involved in the delivery of care.

4. Nurses' perception of a family-centered care

Nurses expressed the expectations of a family-centered care model or holistic nursing care in their practice; therefore, the researcher conducted in-depth interviews with nurses to investigate their definition, attitudes, and guidelines for the family-centered care model, including factors related to the model.

4.1 Definition of a family-centered care

Nurses defined a family-centered care as the participation of patients' relatives in delivering care, decision making, exchanging information, and provision of education.

"Nursing care with the children's relatives participating in the care, and in decision-making of medical care. Children, nurses, and family collaborate in delivery of care, focusing at the children as the center of care. We emphasize the holistic nursing and we let the family participate in this."

"We encourage the relatives to participate in caring for the children. But we have to educate them with the knowledge that can improve the child's symptoms, not just cleansing the child's bottoms. They should know about the symptoms, take care of the child, and participate in decision making."

"Body and mind -- we talk about everything. We give them mental support, do what they want, and allow them to ask questions. We share with each other, and talk about what we want. We have to ask how they feel and how we can respond to them. About the financial problems, we ask what the problem is. We help each other more in caring for the children, pay more attention, and try to understand more about the disease. We make them aware of the importance of how to give appropriate care to their baby so that the disease does not get worse."

"In our practice, we provide physical care. For mental care we have to let the parents participate with us. The children are not very close to us; they feel closer to their mothers. We need to get information from their mothers to know the children's background and adjust the treatment to suit them. So information from parents is quite important. Family has roles in some aspects of treatment; if they don't understand, they may do something without knowing that it's wrong, such as giving the child unhygienic food. If the relatives don't understand or don't learn anything about it, but let the children eat as they used to do before, some complications may occur. Collaborating, learning from each other, giving or sharing information to each other--these will lead to balanced adjustment of the treatment. So, family should participate in taking care of the children."

In conclusion, nurses perceived family-centered care model as a nursing care with family participation in caring for the children, in making decision, and in exchanging information.

4.2 Attitude toward a family-centered care model

Nurses were aware of the importance of a family-centered care model. They explained that the children who had diseases needed continuous care from their families who understood them and could respond to their needs. The families could learn about caring for the children from nurses so that the children could stay with the persons whom they loved and trusted. Family care was seen as essential for children with chronic diseases.

1) Children with chronic diseases should receive care from their families

Children with cancer were ill with a chronic disease that required a continuous care from the families. The children should be provided with the best care from healthcare professionals and their families:

“Because they have a chronic illness. People who take care of them for the rest of their life, all the time that they have this disease, are their family. Thus, the relatives’ participation by being aware of the children’s disease, treatment and nursing activities and in delivery of appropriate care will lead to the best care for the patients from healthcare staff and their family, so they will be happy in the last stage of their life.”

2) The families could respond to the children’s needs.

Children with cancer needed close care from the families who could appropriately serve their needs:

“Our patients--they are chronic cases. They are unhappy and badly need their family need people that will stay with them. We know, naturally, this is a chronic disease and patients need mental support. They should be happy. They need their family, so we bring the family in. Family plays an important role in medical care, so I think it’s important to think about them.”

3). The families understood the children.

The families were familiar with their children; hence, they could understand the children both mentally and physically. Family involvement, therefore, was highly beneficial for the children:

“People who know the children are their family. We understand about the disease, but their family knows about their daily routines, their personalities, and habits. So, if we can have them participate, it will be very useful for the children in both mental and physical aspects.”

4) The families could learn about caring for the children from nurses.

“They are important. They take good care of their children. They understand what we are doing now and how we care for their children. They try to understand and follow our suggestions. Then their children will not have complications and can go back home straight after the chemotherapy. Family that does not involve much or does not understand much may have to bring the child back quite often, and the child’s symptoms are not good.”

5) The children could stay with the person whom they love and trust.

The families had been close with their children; hence, care from family would make the children happy as they had the persons whom they loved and trusted ground:

“It’s the end stage of a chronic disease. The family should involve more when the patients are at the end stage. So, they can have times with the people they love most, and be happy at the last stage of their life. Being with the family must be something that they want the most. We are fine and we still want to be with our family. These children are ill, so they must be longing for their parents.”

“The children have been living with their family all the time, so they highly trust their family.”

In conclusion, nurses felt that a family-centered care was important. Moreover, the families could respond to the children’s needs and they could learn about caring for their children from nurses. The families also understood the children while the children would be happier to stay with the person whom they loved and trusted the most

4.3 Suggestions for nursing practice in a family-centered care as recommended by nurses

Nurses recommended the practice for a family-centered care approach as follows: encouragement of close care from family, collaboration between nurses and families in caring for the children, information exchange, establishment of relationship, enhancement of family potency, and collaboration between doctors and nurses.

4.3.1 Encouragement of a close care from the family

Most children with cancer suffered from pain and side-effects of chemotherapy. A close care from the families could console them. Conversation with close relatives should relieve their pain and sufferings:

“The relatives should stay with them because the children walked in and we made them sick, or we hurt them. Something like this, if the relatives can share with them, they will feel much better.”

“With this disease, the children need somebody they can trust to stay with them, to take care of them when they are in pain. The best persons are the ones in their family.”

“They can help talk the children into cooperate with medical care, and comfort them not to be afraid of the treatment. For example, when we need to deliver a nursing procedure, the relatives will console the children and engage them with their talk.”

4.3.2 Collaboration between nurses and families in caring for the children

Nurses would like to see family participation in assessment of symptoms, planning, and caring for the children.

1) Encourage family participation in assessment of symptoms as well as report of symptom changes

Nurses taught the families on how to assess children's symptoms and let them participate in the assessment of symptoms:

“The relatives should observe the symptoms and inform nurses. At the same time, nurses should ensure that mothers know about this too. If nurses don't frequently ask, mothers observe the symptoms and inform nurses. Mothers should know what symptoms they should observe.”

2) Encourage mothers to participate in drawing the nursing care plan

Nurses should allow the families to participate in a discussion about the children's problems, to investigate children's problems with nurses, and to be involved in the nursing care planning:

"Actually, if there is a case conference for nurse education and we really want the relatives to participate in caring for the patients, we should let the mothers join in the conference, to learn the management plan for their children, and let them know about the children's problems. We should let the mothers say how they feel, so it's like they are involved in planning for the management for their children. It's like collaboration with the staff to see how much we can do for the patients. Nurses may see the problems in different points of view from the patients' relatives. "

3) Encourage family participation in the delivery of care

Nurses encouraged the family to deliver care to the children in aspects of daily routine care, basic nursing care, prevention of risks and complications, encouragement of children's cooperation, and being the children's advocacy.

a. Participation in daily routine care

The families were encouraged to participate in daily routine care:

"Allow the relatives to participate in nursing care within the limit that they can do like bed bath. But we should supervise them. If they can do it, we'll let them do it. Then they'll have the feeling that they can do something for the children and that will generate the bonding with their children."

b. Participate in basic nursing care

Nurses felt that the families could deliver basic nursing care such as doing a tepid sponge bath or giving an oral medication:

"If the mother is there, I'll let her do it, and I can observe if she does it correctly. I also teach the mother how to do a tepid sponge bath.

c. Prevention of risks and complications

The families could participate in the prevention of risks and complications:

‘Mothers have roles in the prevention of complications and risks that are likely to occur.

d. Encourage the children to cooperate in the treatment and nursing care

The families could participate in encouraging the children to cooperate with the medical treatment and nursing care by consoling them and talking them out of their fear:

‘The families can talk to the children to cooperate with the treatment, comfort them, and talk them out of their fear. During a procedure, the relatives can talk to the children and calm them down.’

e. Being the children’s advocacy

The families could act as the children’s representatives in following nurses’ suggestions.

‘When giving medications, the mother has to tell her child. The child may not follow nurses’ suggestions. We teach mothers to give support, to console the child. Giving medications and moral support at the same time may make the child cooperate more.’

4) Encouraging the parents to participate in decision- making

Nurses encouraged the parents to participate in decision-making.

‘I’d like them to participate but they should have information before making a decision. We should give them sufficient information such as treatment plan and side effects. We should let them discuss with doctors.’

‘They should be able to decide whether they accept the treatment. Some patients requiring chemotherapy may need a high dosage and parents should know about it most: ‘what are the effects?’ ‘should they accept it?’ ‘They should be able to decide in this aspect.’

‘Their rights or not? If we give high dose of chemotherapy, we should tell them. They should participate in decision-making. The relatives should know that their children need a treatment protocol of high dosage. What are the symptoms after the treatment? What is the chance of recovery? Even if the relatives have little schooling, they should know and they should decide whether to take the treatment or to go back home. If they don’t want to take the treatment and want to go home, it’s our responsibility to explain the possible outcomes to them.’

4.3.3 Information exchange

Nurses perceived the importance of information exchange between the patients' families and them. Information exchange was composed of the provision of information from nurses to the patients and their families or vice versa.

1) Providing information to patients and their families

The information provided included information at admission, information about the disease and its treatment, and information provided before hospital discharge:

Information at admission

"Mostly, I give information at admission, telling them what they should do when they are in the hospital"

Information about the disease and its treatment

"In every medical care, and every nursing care, they should know how the treatment will really be or to which direction the treatment will go."

Information before hospital discharge

"What should they do at home? It depends on health education. The care is not only at the hospital. When the patients go home, parents should know that their children still have low white blood cell count, when they should take about their children to a hospital."

"They should know about abnormal symptoms, the symptoms that need hospital visit. Another thing is we should tell them if the disease is untreatable so that they can prepare themselves. They may want to get treatment from some other places or want to go home. They should know about that."

2) Encouraging mothers to give information about their children

Nurses felt that information through the children receiving from mothers enabled them to deliver effective care to the children.

"Getting the information is important. Information from mother is even more important. Because parents are the persons that have been raising the children so they can understand the children more than us. Moreover, they stay close to the children so they will notice any changes and tell us; the children, therefore, will be timely helped."

"Another role of mothers is an informer. They will come and tell us how we should talk to the children. If not so, we have to find out ourselves."

4.3.4 Having conversations and establishing relationship with patients' families

Nurses felt that having conversations and establishing relationship with the patients' families is a component of a family-centered care. Relationships could be developed from having conversations with the families frequently, generating sense of trust and allowing them time to ask questions.

1) Having conversations with the families frequently

Nurses might learn the problems in patients' families from a conversation with relatives who were despondents.

2) Generating sense of trust

The sense of trust could be generated from friendly manners and showing interests in the children's symptoms; the families, then, had courage to ask questions:

"Firstly we should build up a sense of trust with them... Every time we deliver nursing care... give an injection or something... we may ask questions, ask how they are, or greet them. It's like approaching psychiatric patients; we need to have interactions with them."

"They will trust us when we show interests in their children, often go to see them, smile, and are friendly with them. Then they'll be nice with us. Just greet them while we are changing shifts, try to approach them frequently, and then they will trust us and have courage to ask questions. If we don't say anything, or don't ask questions, they will be afraid of us, and they won't dare to ask questions or to do anything with us."

3) Allowing times for parents to ask questions

When patients' families had opportunities to ask questions, they would trust nurses and would be more comfortable to ask questions when they needed to know something.

"I tell them if there's any questions or if they don't understand anything, they can ask me. Or if I have any questions, I'll ask them too. If there's anything that worries them, they can tell me. If I can help them, I will do."

4.3.5 Enhancing parents' potency

Nurses could help parents to enhance their abilities by encouraging them to participate in decision-making and identifying choices of treatment, informing them about family rights, being the adviser, and setting up support groups among patients' families.

1) Encouraging patients' families to participate in decision-making and identifying choices of treatment

Patients' families could participate in treatment planning by receiving information from doctors and nurses. They should be allowed to make a decision and select the choice of treatment.

"Mostly we play roles in caring for the children and don't let parents make a decision. But actually we should let parents exercise their rights to choose. For example, they can choose if they want their child to receive chemotherapy. We give them information first, and then the parents have to choose."

2) Informing about family rights

Patients and their parents should be informed about their rights upon admission.

"Firstly, tell them about their rights. They should be told before we do anything with their children."

"Actually, it should be given from the admission date, when they arrive. They should know their rights concerning hospital stay every time."

3) Being an adviser

Nurses could be an adviser for patients' families. They could ask nurses questions when they were in doubts.

"We should act as their adviser and let the families be the caregivers. When they have a problem, they should be able to solve the problem if we have taught them how to do it. Once they have found that the problem is not solved they can come to us, seeking advice and we give them support, and help"

4) Setting up a support group among patients' families

A group of families with similar problems could talk to each other, exchange their experience and their opinions, and express their feelings. This support group could give moral support to the group members:

“It’s quite good to let parents talk to other parents. They are like friends with similar experience, and they can give moral support to each other”

“We should let parents of children with the same disease talk to each other. They can express their feeling, and talk about how they care for their children. It will be nice if we can have parents of a recovered child talk to them.”

4.3.6 Collaboration between doctors and nurses

Nurses were aware of the importance of collaboration with doctors in the delivery of care:

“Nurses and doctors should collaborate. It’s not like..that’s all you know, you think that’s all I know. Yes, actually, we don’t know as much as them, but if we can collaborate, all benefits will go to the patients.”

In conclusion, nurses suggested that nursing practice in family-centered care model should consist of the following activities: encouraging mothers to give close care to their children, encouraging families’ to participate in nursing activities, and enhancing families’ potency and collaboration between doctors and nurses.

4.4 Nurses’ perception on factors related to family-centered care

Nurses perceived that factors affecting the development of a family-centered care model involved two aspects: nursing and administration.

4.4.1 Nursing factors

Nurses pointed out that factors leading to the success of family-centered care included setting the mutual goals, increasing time spent with children and their families, modifying work style, and enhancing mutual understanding among health care staff.

1) Setting mutual goals

Nurses believed that mutual goals would lead to success in family-centered care:

“If we believe that it’s really important, and we strictly follow it as a guideline of practice, this guideline will stay with us, and will not be easily changed.”

2) Increasing the time spent with children and their families

Nurses stated that the mental care would be more effective if they could spend more time with the children and their families:

“If we have more time for relatives, spending more time with children and their relatives, it will be better. But we don’t do that. We just spend time talking among staff.”

3) Be flexible in working

Nurses felt that some modifications might improve their delivery of care:

“Why do we have to strictly follow the same style when doing the routine job? We may turn left or turn right and it should be alright if we could reach the same final result. We should not fix our idea. Like some work that we have to do at a certain time, we may delay it and do something else first.

4) Mutual understanding among health care staff

Nurses suggested that all staff should understand the concept of family-centered care and should follow the same model of practice in order to be fully collaborative:

“We may have to start with the staff because everybody should understand the concept to change their idea and their behavior. It is important that they understand differences between individuals. We need to enhance their knowledge and understanding.”

4.2.2 Administration factor

Nurses believed that frequent encouragement from administrators could lead to family-centered care practice:

“Sometimes we already know how good it is. But will we do it or not? It may need being emphasized. Administrators should frequently emphasize the importance of this practice to the staff.”

In conclusion, most nurses perceived the importance of health care staff in developing a family-centered care model. They suggested that the staff should have mutual goals, spend more time with children and their families, modify their working style, have mutual understanding about the practice, and receive encouragement from administrators.

4.5 Nurses' expectation of the outcomes of family-centered care

Nurses believed that family-centered care would have positive effects on children and their families, including nursing staff.

4.5.1 Beneficial outcomes for children

Nurses stated that family-centered care would have positive effects on children, resulting in improved outcomes of treatment and good mental health.

“If the families participate, the treatment outcomes should be better and the complications may be reduced.”

“Another thing is the children are happy when they are in hospital with their parents. If their families understand them, they will have the feeling that they can go home quickly if they follow the suggestion. They are happy and do not feel discouraged. When it's time to go to the hospital, they are eager to go, because they feel let's finish it quickly, so do I can go back home quickly.”

4.5.2 Beneficial outcomes for the families

Nurses expected that the family-centered care would have positive effect on the children; hence, the families would be satisfied with the care and ability to adjust to their children's illness:

“The best thing is the patients, who will receive good care, and the families will be satisfied most. I cannot see any negative point, but only nurses will be more tired.”

“I think the families will be in a mental state that can accept the illness.”

4.5.3 Beneficial outcomes for nursing staff

Nurses stated that if the family-centered care was undertaken in tangible patterns, nurses would have better perception of the importance of their job:

“If the care is more tangible, nurses may use less time, understand it more, and see the point more clearly.”

The family 's perspective in caring for children with cancer

Families' opinions about the current circumstances in the delivery of care to children with cancer are presented in the following order:

1. the importance of participation in the delivery of care
2. the family's needs when their children are admitted to a hospital
3. the delivery of care from families to children with cancer during hospitalization

1. The importance of participation in the delivery of care

Families saw the importance of participating in caring for children with cancer because they could give their children moral support, they could respond to the children needs, and they could be the children's representatives. In addition, families could monitor the children's symptoms and would feel less worried. They could also learn how to deliver care from nurses.

1) Giving the children moral support

The children would feel warm, spiritually uplifted and content if they had their parents stay close to them. These would have positive effects on physical health and they would be able to eat and rest more properly:

"When I am with him, he receives emotional support. If I am not here, he does not sleep much. When I arrive here in the morning, he sleeps all the time."

"My child will be lonely if he's alone. But if I stay with him he will recover from the sufferings faster. He is content when I do things for him and stay with him"

2) Giving response to the children's needs

Parents could answer to the children's requirement if they stayed with the children. They could respond to both physical and psychological needs, as well as play with their children.

Giving response to physical and psychological needs

When the families stayed with them, the children would be able to eat more and had proper rest:

"If I sneak out and he wakes up, he will not sleep anymore. Even if he is very sleepy, he wouldn't sleep. But he'll sleep when I come back to see him."

"He wants me to stay with him at night. If I am here, he would not have fever and can sleep well."

“He seems so lonely when his mom is not here. He may want to eat something but he could not get it.”

Families could respond to the children’s psychological requirement if they stayed with the children.

“If the parents are allowed to stay overnight, we will know what the children want because the parents have been taking care of them, so they know their children quite well.”

Taking care to make sure that the children enjoy themselves

Families had been taking care of their children for a long time; hence, they know what to play with the children.

“It will be good if parents can stay with their children. They can play with their children. They may have some small toys that they can use to play with the children.”

3) Being the children’s representatives

When parents could take care of their children closely, they could be the persons that informed nurses about the children’s needs and provided information about the children’s illness to health care staff.

“Sometimes my child may want something but he dose not dare to ask for it from nurses.”

“When my child has a fever or abdominal pain, he wants us to stay with him at night. He doesn’t have courage to tell nurses about the problems. He’s afraid of nurses. When they ask, he doesn’t tell them.”

“Sometimes my child does not have courage to talk to doctors. We listen to our child and tell doctors he has these symptoms.”

4) Monitoring children’s symptoms

Families believed they would be able to monitor the children’s symptoms and closely care for them if they could stay with their children.

“We will observe the symptoms and know how to care for our child. If we are not here regularly we will not know our child’s symptoms today. What’s the symptom? How did he urinate or defecate?”

5) Being less worried

Parents felt less worried when they could deliver close care to their children:

“I am worried about my child when I go back home. It’s not comfortable sleeping in the chair here. I am content any way because my child is happy.”

‘If I don’t see my child, I’ll miss him like when I am at work. My child used to call for me at home when I was asleep.’

6) Opportunity to learning from nurses

Families felt that participation in nursing care is beneficial because they can learn how to care for their children from nurses and follow the nurses’ practice:

‘We observe what nurses do with our child and we’ll do it like that. So our child will not get infected so easily.’

2. Families’ requests for hospitalized children

The families stated that when their children were admitted to the hospital, they would like to request for hospital stay with their children, effective communication and good relationship with health care staff, information, and acceptance from health care staff.

2.1 Hospital stay with the children

Parents wanted to stay with their children to closely take care of them and to support them when they underwent a painful procedure.

‘I think parents should be allowed to stay with their children. Children feel supported when they see their parents. Children are very scared when admitted to a hospital and I think the best thing is parents staying close to them. Then the children will be happy, and morally supported. Sometimes they don’t know what’s gone wrong, what these things are for or how. I think this is important, the most important.’

‘People are different. The most important thing is the children can see their parents. I ask for that..let parents stay with their children.’

2.2 Effective communication and good relationship with healthcare staff

Families felt that they would like to have good relationship with nurses and develop acquaintance so that they would have courage to ask questions:

‘I hope nurses come to talk with me, talk to relatives and others, so that we will be closer and we will have courage to talk, or to consult them. We can develop acquaintance with each other.’

2.3 Receiving information from nurses

Families needed information about the disease and its treatment:

‘Doctors said we need record. After a blood test, we’d like to know about Hb, WBC, Platelet. Lately we go to directly ask from Pee A. When we get the information, we promptly know our child is

improved. When nurses are transferring the shift, we listen to them, too. Sometimes we understand, sometimes we don't.”
 “We look at the results of blood test and we know whether it decreases or increases. We give our child close observation and listen to doctors' comment during a ward round.”

2.4 Nurses as a family substitute

Families wanted nurses to take care of their child when they were not available:

“Take care – like often come to see my child, more often than usual so that my child will be alright and I would not get worried.”
 “Taking care of my child when I am busy..If I am at work, I cannot come, so I 'd like nurses to take care of him for me.”

2.5 Nurses' acceptance of family uniqueness

Families wanted acceptance from nurses:

“At the beginning they asked why the father didn't go to work or ..go find a job. They should not say things like that. Each family is different. It could be the mother or the father who works. I felt that, at first, I felt uncomfortable.”

2.6 Family being with the child in pain

“I'd like to give my child support – stay close to him. If you tell the parents to leave the child alone with doctors, the child will be very scared. At least when my child is in pain, he would like me to be with him. I'd like to hold him and give him moral support. I want to be with him when he is in pain.”

3. Perspectives on families' roles

Families with hospitalized children expected the following roles: taking close care of their children (during the visiting time), participating with nurses in caring for the children, and seeking information.

3.1. Taking care of the children during the visiting time

The children's families came in the morning and went back home when the visiting time was over. They indicated that they accepted hospital regulations; however, they might ask for an extension of their stay if the children's symptoms changed. Families wanted to stay overnight to take care of their children:

“I have to accept it. I want to be with my child but the regulation is like that. So, I have to follow it.”
 “I'd like to stay at night. But there is a regulation. If they allow me to stay, I will.”

Request for extension of visiting time when the children's symptoms worsen

Despite an acceptance of hospital regulations, families still wanted to stay close to their children when there were changes in their children's symptoms or the children's condition became worse. They might ask for a special permission to stay with their children for a longer time:

‘Sometimes when my child is not very well, like having pneumonia, cough, rashes or cannot help himself, I'll ask nurses if I can stay with him. Sometimes they allow me to, sometimes they do not. If my child is fine, they will not allow me to stay.’

3.2 Participating with nurses in caring for the children

Families have roles in participating with nurses in caring for their children. The participation involved delivering daily routine cares as well as giving love and moral support.

a. Delivering daily routine cares

Families had opportunities to deliver care to their children in aspects of daily activities and some basic care such as giving tepid sponge:

‘I'll give my child tepid sponge, if he has a fever. Or tell nurses when the (IV) medication nearly finishes.’

b. Giving love and moral support

Families realized that another very important role was expressing love toward their children. Showing their love by hugging or having physical contact could relieve the children's pain.

‘Very important. The way we look at our child or our feeling can make our child feel like we are not sincere with him. We have to build up the trust. When my child is in pain, he wants his dad to hug him. So, I give him a hug. Hug him so that he can forget everything.’

‘Doctors and nurses provide physical care. I give warmth and moral support. We need to give the child moral support.’

3.3 Seeking information

Families sought information by reading announcements, listening to staff discussion, and talking to relatives of other children:

‘When we are here, we try to observe if there's any announcement.’

‘We try to listen. Sometimes we can understand it, but sometimes we can't.’

“I can observe my child closer from listening to the doctors during the ward round.”

“Our child has these symptoms. Are these similar to their children? If their children are getting better and our child has the same symptoms, then we’ll be glad that our child will be better, too.”

Children’s perceptions about their illness and needs of care

Children with cancer perceived their illness and their requirements of care as discussed below:

1. Perception of illness

Older children perceived that there was no cure for the disease and they would die from the disease. They also perceived that chemotherapy would bring them a lot of sufferings.

1. 1 There was no cure for the disease.

The children had experience from listening to other people and from their own experiences. As a result, they lacked confidence in the outcomes of treatment, they perceived the disease as an incurable disease, and some of them believed that they would die from this disease:

“If it can be treated, it would have gone a long time ago, not come back again and again like this.”

“I received medications for a year and a half, and it disappeared for five years. Then it comes back again. It might disappear, but it would come back again and again”

“I am scared that I might die. They said there’s no cure for it. Those relatives said there have been many people dying here. They talked to each other, and I overheard it.”

1.2 Chemotherapy would bring them a lot of sufferings.

Chemotherapy has many side effects such as abdominal pain, vomiting and headache. The children felt severely suffered from these symptoms:

“I vomit, both before and after receiving the medications. I have received drugs to stop vomiting; I still vomit anyway. Sometimes there’s blood in my vomit.”

“I am scared. It’s very painful. Sometimes I can’t sleep, and sometimes I feel the soaring pain in my stomach. And after vomiting for many times, I’ll get a headache.”

2. Children's needs

Children with cancer wanted to have their mothers stay with them or frequently visit them. They also needed moral support from their mothers when they felt unwell or in pain and wanted nurses to participate in their activities. If possible, however, they did not want to stay at the hospital at all and would rather stay home.

2.1. Needs to be with or receive frequent visits from their mothers

The children wanted to stay close to their mothers; however, they understood that their parents had to work. They requested for frequent visits from their parents. Some stated that they could sleep well when their mothers were with them:

“I want my mother to be with me. She doesn't have to do anything, just keep my company.”

2.2 Needs for moral support from mothers when feeling unwell or having pain

When the children felt unwell or were suffered from medical procedures such as lumbar puncture or from the side effects of chemotherapy, they wanted moral support from their mothers:

“I want to have my mother with me when I have lumbar puncture. I want her to be near me. When I am tired I want my mother to be with me. When I feel sick, feel like vomiting or have stomach pain I want to see her. Also, when I am breathless, I want my mother's support. I also want her to work.”

2.3 Need for nurses to interact with them

When their mothers were not with them, the children would like nurses to frequently visit them and play with them:

“I would like all nurses to come and talk to me, talking to me every day.”

Children stated that they wanted nurses to speak to them with gentle manners:

“I don't want nurses to do anything else, just talk to me nicely.”

2.4 Need to go back home

Children still wanted to go home even if their mothers were staying with them at the hospital. They felt that they had more freedom and they could enjoy themselves at home.

Summary of the study of perceptions of nurses, children with cancer, and their families

The study of children's perceptions revealed that the subjects perceived the disease as an incurable disease and the side effects of chemotherapy caused them a lot of sufferings. The children required care from both their families and nurses. They wanted their families to give them close care and frequently visit them. They needed moral support from their families, especially when they were in pain or felt unwell. At the same time, the children would like to receive care from nurses and wanted nurses to participate in their activities. As for the families, they wanted to closely take care of their children. They mostly wanted to be with their children during hospitalization. They wanted to be with their children during a medical procedure and wanted nurses to provide close care to their children in their absence. Most families recognized the importance of participating with nurses in caring for the children for the following reasons: giving the children moral support, responding to the children's physical and psychological requirements, representing the children in expressing their needs, closely monitoring the children's symptoms and being less worried about the children's illness. As for nurses, most of them felt that their roles involved providing medical care as stated in treatment protocols and delivering physical care whereas families delivered mental care. Nurses also felt that there was no tangible model for family-centered care and the delivery of care was mostly focused on the children, not extended to their families. There was not much collaboration between nurses and children's families and the communication was mostly one-way. Additionally, nurses felt that there was too much paperwork; hence, they had less time to spend with patients. Nurses expected a holistic nursing care that covered physical, psychological, and family care, and they also expected collaboration among the children, their families, and nursing staff for the improvement in caring for children with cancer. Finally nurses expressed positive attitudes toward the family-centered care model and recommended family-centered care for nursing practice.

2.3 Discussion of problems and assessment of nurses' requirements in the development of family-centered care model

After the researcher and the participants had summarized the findings from the analysis of current situations in caring for children with cancer, the researcher presented the results to the participants, the Head Nurse, and the nurse supervisors and led a discussion about current situations in caring for children with cancer, specifically from the perceptions of the children and their families. The discussion was opened for comments and queries. The requirement for changes in nursing practice for the development of family-centered care model for children with cancer was subsequently assessed.

During the discussion, nurses expressed their opinions toward the development of family-centered care model in three different ways: being supportive, having uncertainty, and keeping a status quo.

1. Support to the development of a family-centered care model

Most nurses agreed that there should be the development of a family-centered care model because it would be beneficial to the children and their families.

‘I’ve seen the importance of this from the beginning and I think this model should be developed. We have spent very limited time with them. Do I want to do it? Yes, if there’s a proper model that is beneficial to the children and their families.’

2. Uncertainty about the development of a family-centered care model

Some nurses stated that they felt uncertain about the development of a family-centered care model. They gave reasons that the model could be difficult in actual clinical practice due to overloaded paperwork and lack of standard.

A nurse pointed out that there was already a lot of work for nurses, including paper work and various other tasks. She felt that the development of a family-centered care mode would be difficult, as one nurse stated:

‘We cannot even provide health education sometimes. We have so much paperwork, routine work, and others. I can see the benefits, but can we really do it? Will it be a failure?’

A nurse raised a question about how a care model for children with cancer could be standardized. She stated that children are different, as well as their families.

‘How could there be a standard for the care model? Individuals have their characteristics. How can we find the middle point?’

3. Keep a status quo

A nurse commented that there was no need to develop the model as the existing nursing care was already family-centered. She said:

‘I don’t see any problem. We don’t need to develop it. It is fine as it already is.’

4. Administrators’ perception of the importance of the development of a family-centered care model

The nurse supervisor observed that the concept of family-centered care model was consistent with the organization commitment to the concept of patient-centered service. She commented that there should be the development of a family centered care model:

‘I agreed with Ajarn about our hospital’s commitment to patient-centered service. If we develop this model, we will achieve (the goal) number 3, which focuses on patients receiving continuous care.’

The discussion resulted in different opinions toward the development of a family-centered care model as follows: most nurses agreed with and supported the development of a family-centered care model because they felt the model would be beneficial for the children and their families. However, some nurses were not certain about the development of the model, and one nurse did not support the development of the model as she felt the present practice was already family-centered. Further discussion was ensued to find the conclusion about the development of the model. Finally, there was an agreement that a family-centered care model would be developed with the researcher acting as a principal developer so that participants of the study, could improve their knowledge and understanding and could continuously work for the development of the program. Nurses who felt uncertain and the one who did not support the development of the model did not refuse to participate in the study, nevertheless they would be an observer at the beginning of the program and would later participate in the program. In conclusion, the participants of the meeting agreed to develop a family-centered care model for children with cancer.

After the participants had an agreement on the importance of the development of a family-centered care model and agreed to develop the model together, there was a

brainstorming session to generate ideas about the development process of a family-centered care model. The main problem was nurses did not know how to initiate this practice. The researcher and members of the nursing team then agreed to follow the process of action research. At the beginning, the researcher would lead the development of a family-centered care model.



Process of the Family-Centered Care Model Development

The development process of a family-centered care model for children with cancer in a pediatric cancer unit involved the process of development with action research, strategies used in the care model development, and enabling factors and barriers to the model development.

Process of the development

The development process of a family-centered care model for children with cancer in a pediatric cancer unit with action research is a continuous circle of actions carried out with the collaboration of nurses, children with cancer, and their families. Each circle of actions was composed of planning, action and observation, reflection, and re-planning. These actions were continuously carried out until the family-centered care model for children with cancer in a pediatric cancer unit was established. The process of development consisted of the following circles:

Circle 1 The promotion of nurses' understanding

Circle 2 The promotion of individual practice

Circle 3 Becoming a team

Circle 1. Promotion of Nurses' Understanding

After having collaboratively analyzed current situations of care for children with cancer and their families, the research participants, comprising children with cancer, their families, and staff nurses, developed the family-centered care model for children with cancer in the pediatric cancer unit together with the researcher.

Circle 1
Promotion of nurses' understanding

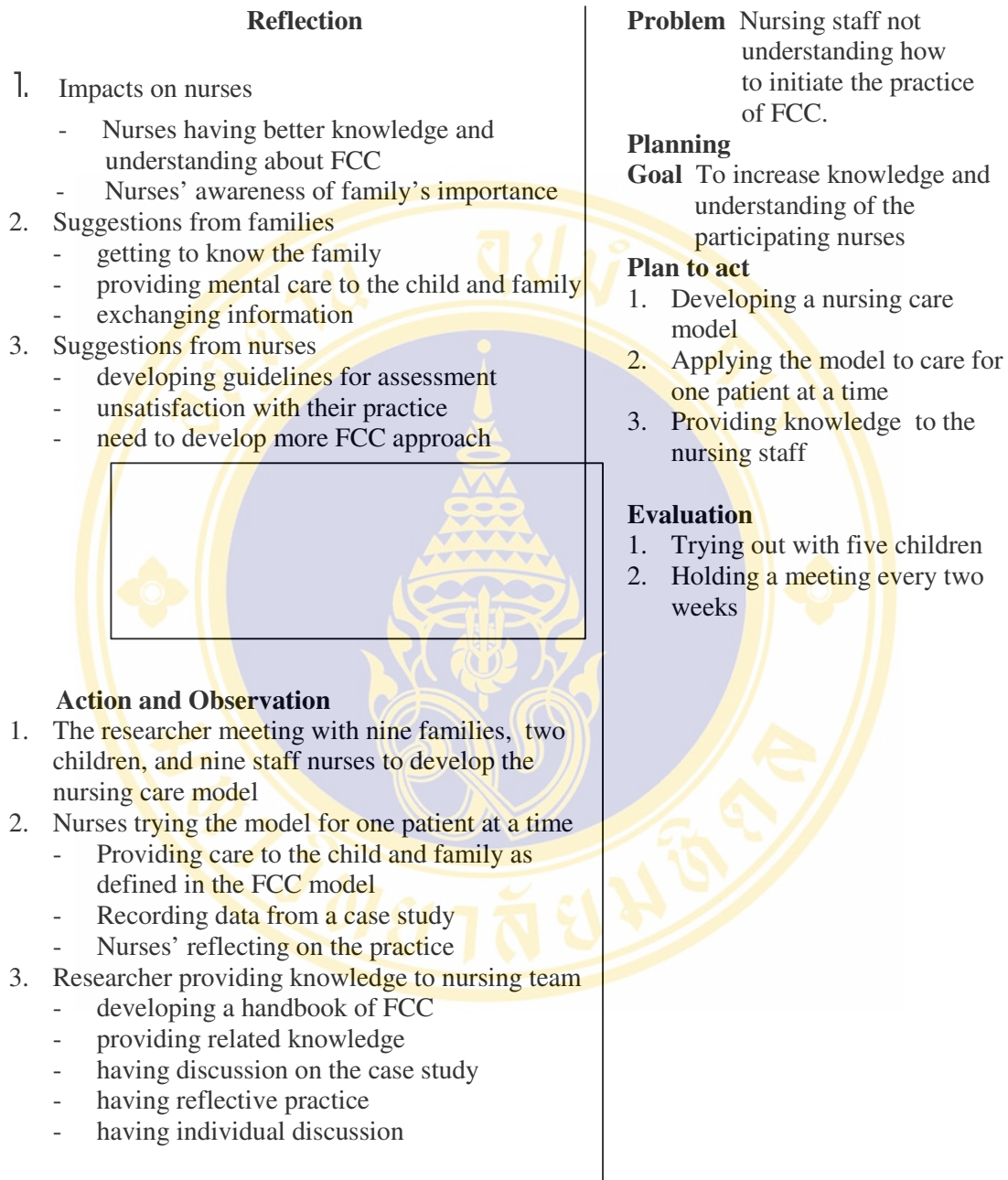


Figure 1 Circle 1: Promotion of nurses' understanding

1. Identifying the problems

The researcher and participating nurses held a meeting to identify problems in caring for the children with cancer. The participants agreed that current problems included: new nursing care model having not yet been developed and nursing staff not understanding how to initiate the practice of a family-centered care. Hence, they needed suggestions from the researcher.

2 Planning

On account of no existence of a new care model and lack of understanding among the nurses, the participants agreed with the planning of actions. The plan included goals, plan to act, duration of the invention, and evaluation.

2.1 Goal

The goals set in this meeting were to establish the tentative nursing care model and to increase knowledge and understanding of participating nurses.

2.2 Plan to act

Activities for goal attainment included the development of a nursing care model, applying the model to care for the children with cancer, as well as the promotion of knowledge and understanding among the participating nurses.

1) Development of a nursing care model

The researcher, children with cancer, the children's families and nursing staff planned to develop a model of care. In an initial research meeting, participating nurses made a comment that they were not sufficiently confident to have a meeting with all concerning groups. Hence, the research group agreed to delineate a nursing care model together first and delineated it again in a meeting with all research participants.

2) Nurses applied the model to care for one patient at a time

Nurses agreed that the family-centered care model should be applied to one patient at a time, starting from the patient who was newly diagnosed. The application of family-centered care model would begin on the admission day and finish on the discharge day.

During the utilization of the family-centered care model, nurses recorded the child's and the family's responses, as well as the utilization of the care model, in the ward diary that was previously prepared for this purpose.

3) Researcher providing knowledge to the nursing staff

It was agreed that the researcher would prepare participating nurses about the care model. In addition to the discussion about the care model application in pre-meeting every morning, knowledge concerning the family-centered care model for the children with cancer was given to the staff nurses every Wednesday from 2:00 p.m. to 3:00 p.m.

2.3 Evaluation

The researcher and participating nurses planned to try out the care model with five children and to revise the model after an evaluation. A meeting was held every two weeks to discuss problems concerning the application of the care model and to follow the progression of the invention. The nurses were interviewed to evaluate their understanding about the care model. The nursing care model was evaluated from interviews with children and their families and from group discussions with children, their families, participating nurses, and the researcher.

3. Action and observation

Action included developing care model, applying the care model for the children with cancer, and promoting understanding about the development of care model among participating nurses.

3.1 The development of a nursing care model

The development of a family-centered care model comprised of two stages. In stage 1, the researcher and eight staff nurses participated in the meeting and had an agreement on the care model. In stage 2, the participants of this meeting comprised of nine mothers of children with cancer at various stages, one preschool-aged child, one school-aged child, nurses, and the researcher. The meeting, which was about an hour long and was recorded on audio-tape, was held to discuss the development of a family-centered care model. Participants of the meeting agreed on a tentative care model for children and their families, in which the roles of family and nurses were stated as detailed below:

Nurses' role in caring for the children with cancer

1) Giving support for family to participate in caring for the children

Nurses allowed the family to participate in caring for the child and in answering to the child's requirements in physical, mental, emotional and social aspects. A nursing care plan was made in collaboration with the children and their families every morning and during the shift report as well as other opportunities arisen. Nurses provided information, taught families to evaluate the children's symptoms and to deliver childcare, and evaluated the parents' performance.

2) Information Exchanging

Nurses gave information at admission and provided knowledge about the children's condition as well as proper child care. They also taught the parents about chemotherapy, adverse effects, and care. Information was given before hospital discharge and the parents were encouraged to provide nurses with information about their children.

3) Accepting family differences

Nurses assessed children and their families, provided supportive care, and allowed the parents to express their feelings. Nurses had a conversation with the children's mother at any available time.

4) Promoting family's ability and the use of available resources

Nurses took a role in evaluating the family's requirements. They promoted the set-up of support groups for mothers, allowed mothers to make a decision, and gave the family suggestions about available resources.

5) Providing the family with considerate and attentive care

Children's family asked for sympathy, as well as gentle and polite manners, from nursing staff. A mother said:

'I'd like the staff--the nurses, to speak nicely and be considerate. Some may speak to us with a quieter voice.'

Family role

The family closely participated in caring for the child with nurses and gave the child mental support when he or she underwent medical procedures.

1) Providing a close care in participation with nurses

Participating mothers commented that hospital regulation did not allow them to stay with their children. They asked for flexibility regarding visiting hours in some cases, e.g. very small children, severely ill children, children that could not help themselves, or older children who needed the mother's company. A mother of a child with liver cancer expressed her desire:

"Just allow me to stay with my child, as other things are less important."

"I know the hospital has its regulation; still, I want to stay with my child sometimes."

The preschool aged child, sitting on his mother's lap, spoke loudly:

"I want my mother to stay with me."

Another child who had leukemia lamented:

"I want my mother to be with me when I am tired, sick, or have a stomachache. I want her with me when I am exhausted. I want her support."

Thus, there was an agreement that mothers could stay with their children to provide close care, particularly in case of small children, severely ill children, children who could not help themselves, or older children requiring the mothers' company.'

2) Participating in the delivery of care when the children were suffered from medical procedures

Children with cancer frequently experienced physical pain from medical procedures such as taking blood sample or administering chemotherapy. Their mothers were usually told to wait outside the operating room during the procedure. Participating families expressed their desire to stay with their children during these medical procedures. A mother of a child with leukemia complained:

'I'd like to stay near my child to give him support. When you tell the parents to leave, the child will be in the room on his own and he may be scared. Children want to see us when they are in pain. I'd like to hug my child. I want to give him mental support and to stay close to him when he is in pain.'

3) Participating in non-complicated activities

Mothers expressed their desire to help nurses care for their children with non-complicated activities. For instance, they could help monitor

intravenous fluid infusion and make sure that the children did not move too much. A mother said:

‘Nurses can teach me what I should do when my child is having intravenous fluid. Then, they can leave us and do some other works.’

Nurses added that mothers should be taught about symptom assessment and caring skills first. Then they might practice the skills under nurses’ supervision before delivering care to their children.

3.2 Nurses trying our the model for one patient at a time

For the implementation of the care model, research participants applied the care model to the delivery of care to hospitalized children with cancer. The model was tried out with one child at a time, starting from the admission day until the day the child was discharged from the hospital.

Nurses’ action

Participating nurses utilized the model in the following the manners:

- 1) Nurses delivered care to the children and their families following the nurse role defined in the family-centered care model.
- 2) Nurses recorded responses from the children and their families and the care outcomes.
- 3) Nurses reflected on their nursing practice.

1. Providing care to the child and the family on the basis of nurses’ role as defined in the family-centered care model

The delivery of care based on the nurses’ role was organized into three phases: admission phase, hospitalization phase, and pre-discharge phase.

Admission phase

Nurses conducted the following activities after a child was admitted into the hospital:

1. Assessing the problems

Nurses assessed the child’s condition and made the nursing care plan according to the child’s problems and his or her responses to the illness based on the priority of the problems. Nurse recorded the results of assessment and the child’s history in the hospital record form.

2. Establishing rapport

The nursing team comprising nurses, nurse assistants, and nurse aides established rapport with the child and his or her family by welcoming them with friendly manners. The rapport was continuously maintained from the day of admission until hospital discharge.

3. Giving general information

The nursing team gave advice and information to the family and the older child. The given information included information about the place, personnel, and the patients' rights. The family could ask questions and ask for more details should they were in doubt.

Hospitalization

Nurses applied the family-centered care model to care for the patient as follows:

1) Accepting family importance

a) Nurses were aware of the family's importance in caring for their child. The ward regulation was flexible so that a child's family could take care of the child at night, as well as in the daytime.

b) Nurses had time for the child's family and maintained continuous rapport with the family.

2) Exchanging information

Nurses continuously exchanged information with the child's family and supplied more information to the family. Information about the child's disorders was given after doctors informed the family of the diagnosis. Nurses and the family also exchanged information about the child's condition, childcare during chemotherapy, and the prevention of possible complications.

3) Collaborating in caring for the child

Nurses collaborated with the child's family in all caring activities delivered to the child. The activities included caring for basic needs, symptoms assessment, and delivery of medical care.

a) Basic needs care: Nurses and the family collaboratively helped the child perform daily activities including general hygiene care, feeding, and care of physical and mental well-being.

b) Symptoms assessment and delivery of medical care:

Nurses gave information and taught the family about simple nursing skills. Nursing staff demonstrated simple nursing procedures such as taking temperature, giving a tepid sponge bath, giving oral medication and applying medications on skin. The family then practiced and delivered these simple practices to the child.

4) Promoting the family's potential and supporting the utilization of resources

Nurses assessed the family's and the resources' needs of help and assisted them accordingly. Nurses helped the family get over the period of distress and provided them with mental support while delivering care to the child. A support group for families of children with cancer was set up and scheduled for a meeting once a month.

5) Giving considerate and attentive care

Nurses expressed the feeling of love and kindness toward the child and his or her family with gentle manners and polite speaking. Intention to help the family was clearly shown, and nursing care was provided in response to the family's needs.

Pre-discharge phase

1) Discussion about home care: Nurses discussed with the family about caring for the child at home and how to monitor abnormal symptoms that requiring hospital visits.

2) Utilization of resources. Nurses explained how to access the resources, including telephone call counseling, and how to obtain services from resources in the neighborhood when the child had abnormal symptoms.

2. Record of data from a case study

The researcher and participating nurses collected data obtained from each case into the record book. When a new patient was admitted and was recruited as a case study, the researcher would record natural history, family history and all information obtained from the interaction with the patient and his or her family. Nurses assigned to care for the case continued the recording everyday regarding the child's condition, the child's and his or her family's responses , and the nursing practice. For the morning shift, the nurse who was assigned to take care of the

case-study child was responsible for the record. For the evening and the night shifts, the nurses whose team had the case-study child were responsible for the record.

3. Nurses' reflection on the practice

The researcher and participating nurses collaboratively set guidelines to reflect on nursing practice from the case study in order to connect the theoretical concept with the practical aspect. The following questions were reflection points of nursing care for children with cancer and their families:

- 1) How did mothers and children respond to the caring activities?
- 2) How did caring activities connect with the concept of family-centered care?
- 3) Was there any problems during the performance of caring activities?
- 4) Was there any conflict with the performance of other staff and, if there was, what was the conflict?
- 5) How were the caring activities beneficial to the children, their families, and other people? (as observed from their behaviors and verbal expressions)

3.3 Researcher providing knowledge to nursing staff

The researcher's role was providing knowledge and promoting understanding among participating nurses. The researcher enhanced knowledge and understanding among participating nurses by developing a handbook of family-centered nursing care, having discussions about related knowledge and case study, having reflective practice, and encouraging individual discussions with staff nurses. Thus, the researcher acted as a model who provided knowledge to participating nurses at the same time.

1) Developing a handbook of family-centered nursing care

The researcher developed a nursing handbook entitled 'The Development of Family-Centered Care Model for Children with Cancer.' The main objective of this handbook was to promote knowledge and understanding of nurses' role in caring for children with cancer and their families. The contents of this handbook comprised concepts of family-centered care model, the methodology of action research, and family-centered care for children with cancer. Four copies of this

handbook were placed on the ward document shelf, available for interested staff nurses.

2) Providing related knowledge

The researcher gave lessons concerning the development of the care model every Wednesday from 2:00 p.m. to 3:00 p.m. The lesson contents involved the concept of family-centered care and nursing care for the children with cancer and their families. The lesson attendants included the morning-shift nurses and other interested persons.

3) Having discussion on the case study

The researcher and participating nurses discussed the case studies in the monthly staff meeting. Theoretical knowledge was discussed along with the practical nursing care given to the children and their families. The discussions concerning nursing care for the children were based on the concept of family-centered care. The researcher would present the case study regarding natural history, family history, condition of illness from hospital admission until discharge, and treatment plan. The nursing staff discussed the role of the nursing team in caring for the child and his or her family based on the family-centered care model.

4) Having reflective practice

Pre-meeting, which focused on nursing care, was usually held in the morning before nursing teams started their work. The discussion group in pre-meeting was composed of the head nurse, six staff nurses (four morning-shift nurses and two night-shift nurses), three nurse assistants, and two nurse aides. During this time, a topic concerning family-centered care was discussed in the pre-meeting everyday. The queries concerning childcare were raised and discussed among staff and the researcher. Participating nurses talked about problems and appropriate care for the children and their families. Meanwhile, the researcher raised questions that encouraged nurses to reflect on their practice for the children and their families. In addition, the researcher shared her experience as a nurse with the group. The interview with the case-study child and his or her family was also shared with the group to reveal data concerning the child's and the family's responses. The discussion was related to the concept of family-centered care. The record from the ward diary was sometimes referred to during the discussion for reflection of whether the nursing practice was family-centered or not and of the practice that was consistent with the

family-centered care concept. Other team members would express their opinions. The discussion took approximately 20 to 30 minutes everyday.

5) Individual discussion

The researcher and participating staff had conversations, discussing on nursing care based on the family-centered care model. Individual discussion was conducted as an informal talk with a nurse, a nurse assistant or a nurse aide. The topic being discussed varied, depending on the situation at that time.

The researcher conducted a case study in collaboration with staff nurses from the admission until the discharge day. At the beginning of the study, the model was not applied to all hospitalized children with cancer. The invention was conducted in newly diagnosed children, children with recurring symptoms and children at the terminal stage. The total number of nine cases was studied. Among these, five children were newly diagnosed with cancer, one of them was in the recurring stage, and the other three children were at the terminal stage. After finishing the study with nine cases, the research participants nurses, the researcher, the children, and their families reached the process of reflection.

4. Reflection

The reflection was conducted after the invention, which was the trial of the tentative model by applying to the delivery of care for children and their families. The objectives of reflection included developing a well-refined model and promoting the practice with understanding among the participating nurses. The nursing practice was reflected in the following manners:

When the child was hospitalized, the researcher and nurses shared their ideas with the family to analyze whether the care was family-centered and in which way that it was so. The researcher and nurses had conversations and exchanged opinions with the family about the nursing care. Before the child was discharged from the hospital, the researcher interviewed the family about the care they received, using the questionnaire based on the family-centered care concept. The researcher noted the answer and also recorded the interview on audio-tape with permission from the family.

In addition, reflection was conducted in a focus group. The focus group participants comprised nurses and the researcher and it was held when the families took the children back for treatment at the maintenance phase. Some families might participate in the meeting all together.

Results of Reflection

The reflection on nursing practice based on the care model was focused on nurses' understanding about the family-centered care model, positive features of the care model that should be maintained, suggestions for the development of family-centered care model.

The results of reflection were presented regarding the impact on nurses, family, nurses and families' role in the family-centered care model, and suggestions of the nurse and family:

1. Impacts on nurses

Nurses reported better knowledge and understanding about nursing care based on the family-centered care model and more awareness of the importance of the family:

1) Nurses had better knowledge and understanding about nursing practice based on the family-centered care model.

The information indicating nurses' knowledge and understanding about the nursing practice based on family-centered care model was obtained from the interviews with nurses and the interpretation of nurses' notes in the diary. Nurses commented that their understanding about the family-centered care model increased from the meeting and lessons from the researcher, as stated:

‘The pre-conference or pre-meeting helps me understand more.’

‘I could not figure it out at first. After the case study, there was shift report with the relatives joining in, and we read the information out for them, I started to know how we can give information, can catch up more. I am not totally clear now but better than before, and I started to vaguely see the benefits of this model.’

One of the nurses' notes that indicated better understanding about the family-centered care model is as follows:

‘The patient had very bad stomach pain and received 3 mg. of Morphine intravenously. The nurse asked the mother how she could help her child. She answered that warm compress on the child abdomen should reduce his pain. The mother understood that the pain

was caused by the tumor in the abdomen. The nurse gave her mental support, continued observing the symptoms, and made contact with doctors for further management on the child's severe pain.

2) Nurses had increased awareness of the family's importance.

Nurses realized the importance of the family in caring for children with cancer. Therefore, they established rapport with the family, gave them information and focused on family care more than before. An interview that reflected more awareness of family importance is exemplified below:

“When they come, everybody would see that the recognition of family's importance and having good relationship with the family has good effects on the treatment. It is a mental aspect that everybody realizes. Nursing staff should give more information to the family, giving more care to the relatives. It needs to be known that being aware of the family's importance is a must, and more conversation to relatives is needed.”

2. Family's and nurses' role in the family-centered care model

The trial of the care model with nine patients resulted in the reflection on family's and nurses' role in the family-centered care model as detailed below.

- Establishing good relationships among nurse, children, and families

The children and their families were not familiar with the hospital staff at first and they just started to get to know each staff. At the beginning of the hospitalization, they felt more comfortable with friendly staff and talked to these staff first. The relationship with other staff was developed later on. The families commented that it was good that nurses talked and was close to the children as the children would become more familiar with nurses:

“I like nurses to speak nicely or to joke with children sometimes so the children will feel familiar with and closer to nurses.”

- Exchanging information

The families felt that information from nurses, both general information about the place and the staff, and childcare information concerning chemotherapy and low immunity, was useful.

- General information

The provision of general information at admission regarding the place and hospital staff helped the families learn about the place and get to know each staff.

- Information about childcare during chemotherapy and care for children with low immunity

The families reviewed family's role and nurses' role when the children were receiving chemotherapy. Nurses gave advice about childcare and abnormal symptoms monitoring. The families then observed the children's symptoms and abnormalities such as ecchymosis or bruises. They also helped care for the children such as caring for personal hygiene, monitoring carefully while the children had activities, and encouraging the children to follow nurses' suggestions.

- Collaborating in caring for the children

The families would like to help care for the children in aspects of daily activities and giving support during medical procedures.

- Helping with daily activities

The families expressed desires to closely care for the children, to help them do daily activities, and to do anything as suggested by nurses.

- Giving the children mental support during medical procedures

Some families would like to give their children mental support during medical procedures. They would like to comfort the children by talking to them or by hugging them and being with them during medical procedures.

“I'd like to give my child mental support, telling him to fight with the illness, and to be patient.”

3. Suggestions from families and nurses

Suggestions for the development of a care model that was closer to the family-centered model from families and nurses are presented below:

3.1 Suggestions from the families

A father expressed an opinion that nurses should focus on family care more than before, starting from getting to know the family, exchanging information, and delivering considerate and attentive care to the family.

a. Getting to know the family

The families suggested that nurses should assess the family's environment for appropriate care in each case. In addition, they should spend more time talking to the family:

“They should assess the environment at home what the environment and the situation at home are like, so that they can give care that is appropriate for each family. If they have time, they should have a conversation with children's parents for 10 or 15 minutes.”

b. Exchanging information

A father suggested that nurses should give information to the families, either in-group or individually, after obtaining information about the family:

“They should ask for information from each individual and think about how to give the information, in group or for each individual. The time should be considered, too. If they have time, they can have a conversation with the children's parents, asking how they are. Everybody has problems other than medical treatment. Mental condition is also very important. Everybody is mentally suffered.”

c. Providing mental care and delivering considerate and attentive care to the children and the family

The families made remarks that the children's hospitalization demanded adjustment, in addition to worry about the children's illness. The staff's considerate and attentive care would help them feel better. The families considered their mental condition very important as they were suffered from the children's illness. Therefore, they needed to express their feelings and needed sympathy and support from nurses:

‘It's good when the nurses that we just know are friendly with us. Letting us express our feelings is good. Giving us notebook to write down our feeling is a good idea because we can write anything down if there are any problems. The father-in-law is dying or the mother-in law is sick, and we can write them all down. The word cancer is serious for common people. They should give us mental support.’

‘To be in the hospital we have to adjust--adjust to our child's illness and adjust to the hospital staff. Some little talk can make us feel better: how are you?; are you all right?; or is there anything I can do for you? Parents get in here feeling so lonely sometimes. We are so worried and our mind is not clear as it used to be.’

d. Giving suggestions about the social insurance card

The families thought nurses should know about the insurance card and they could explain the usage of the card to patients and relatives.

‘Nurses should know about social welfare, so they can explain it to patients.’

3.2 Suggestions from nurses

Nurses did not have guidelines for the assessment of family requirements and the outcomes of care delivered to the family.

Some nurses commented that there was no framework or guideline to initiate a conversation with the families, as well as no list for the evaluation of care delivered to the families. Suggestions from nurses are as follows:

1. Guidelines for the assessment of family’s requirement and assessment of outcomes should be set up.
2. Nurses were not satisfied their practice because the nurses’ role was more of a giver and the family-centered care was not regularly conducted. They wanted to develop more family-centered care.

Enabling factors and barriers to the development of the family-centered care model

The reflection on enabling factors and barriers to the development of family-centered care model with nurses revealed the following enabling factors and barriers:

Enabling factors

The enabling factors for the development of the family-centered care model comprised having a good commitment, being encouraged from the researcher, and the hospital quality accreditation.

1. Having a good commitment

Nurses commented that the patient-centered care model required staff’s willingness to put their mind into the work. They were aware of the importance of having a good mind, as stated:

“It was already in our mind, and it became clearer when you (the researcher) came. We see the development of our work.”

‘It’s a personal factor...about my mind. I have a child. Being a mother makes me realize the importance of mother-child bonding. This maternal role is connected with caring for the children with cancer here.’

2. Encouragement from the researcher

Nurses had an opinion that, in addition to enhancing an awareness of the family’s importance, the researcher also taught related knowledge and held group discussions. As a result, they developed knowledge and understanding about the care model and were able to continue developing the model:

‘The researcher gave knowledge in reflecting our mind.’

‘I didn’t understand something about the family-centered care model, and the researcher gave me knowledge so I could understand it better now.’

‘The researcher played an important role in encouraging me to feel, and to be aware of the importance and in teaching me during the pre-conference, making me understand more.’

3. Hospital policy

The hospital accreditation program led to the patient-centered policy, which had an effect on nurses’ desire for nursing care improvement :

‘Hospital accreditation is another reason. We now have a patient-centered policy which should involve family participation. The hospital policy leads to improvement in staff quality.’

4. Learning from case studies

The discussion on case studies led to extensive exchanges of opinions among nursing staff; as a result, the staff were more aware of the family’s importance:

‘The case study allows us to express various opinions and enables us to perceive the importance of family role. The small children, as we all know, are living dependently on their mothers.’

Barriers

The barriers to the development of the family-centered care model were heavy workload and tiredness and limited knowledge about the child and the illness.

1. Workload.

Nurses reported that the heavy workload reduced the time to interact with patients.

‘I don’t have time, too much work. It’s not so much that I cannot do it at all but I cannot do it completely.’

‘So much work so I did not have much interaction with the patients.’

‘Sometimes we have to work with other patients. There are many patients and I have a heavy workload. Sometimes it’s urgent, so the care is interrupted.’

2. Tiredness

The feeling of tiredness resulted in less care for patients:

‘Sometimes it’s emotional reaction. Today I feel mentally tired. I’d like to do it, but I cannot do it very well. I feel guilty sometimes.’

‘When I am tired, I will not do it. No, it’s not that I don’t do it at all. I just do it more slowly and the care is slower.’

3. Limitation knowledge about the child and the illness

Nurses reported that the limited knowledge regarding the child and the illness could be barriers to the development of the care model:

‘Sometimes I don’t know about the case and the illness.’

In conclusion, in circle 1, research participants collaboratively reflected on problems concerning childcare in a pediatric cancer unit and found that there was no family-centered care model and nurses did not understand how to initiate the practice of family-centered care. Thus, nurses agreed to develop a family-centered care model and planned to promote knowledge and understanding about the care among participating nurses. A tentative model was then developed and was subsequently tried out with one patient at a time for the total number of nine patients. During the implementation of care model, the researcher set up activities to enhance knowledge and understanding among participating staff. The reflection on the practice comprised the reflection of the researcher and nurses in daily pre-meeting, the reflection of the researcher and the families through interviews before the children were discharged from the hospital, and the reflection of nurses, the researcher, and the family. In summary, nurses understood the practice with the family-centered care model.

Nevertheless, there were problems that required solution for further practice. For instance, nurses were not satisfied with their practice because the nurses' role was more of a giver and the family-centered care was not regularly conducted. However, they wanted to develop more family-centered care.



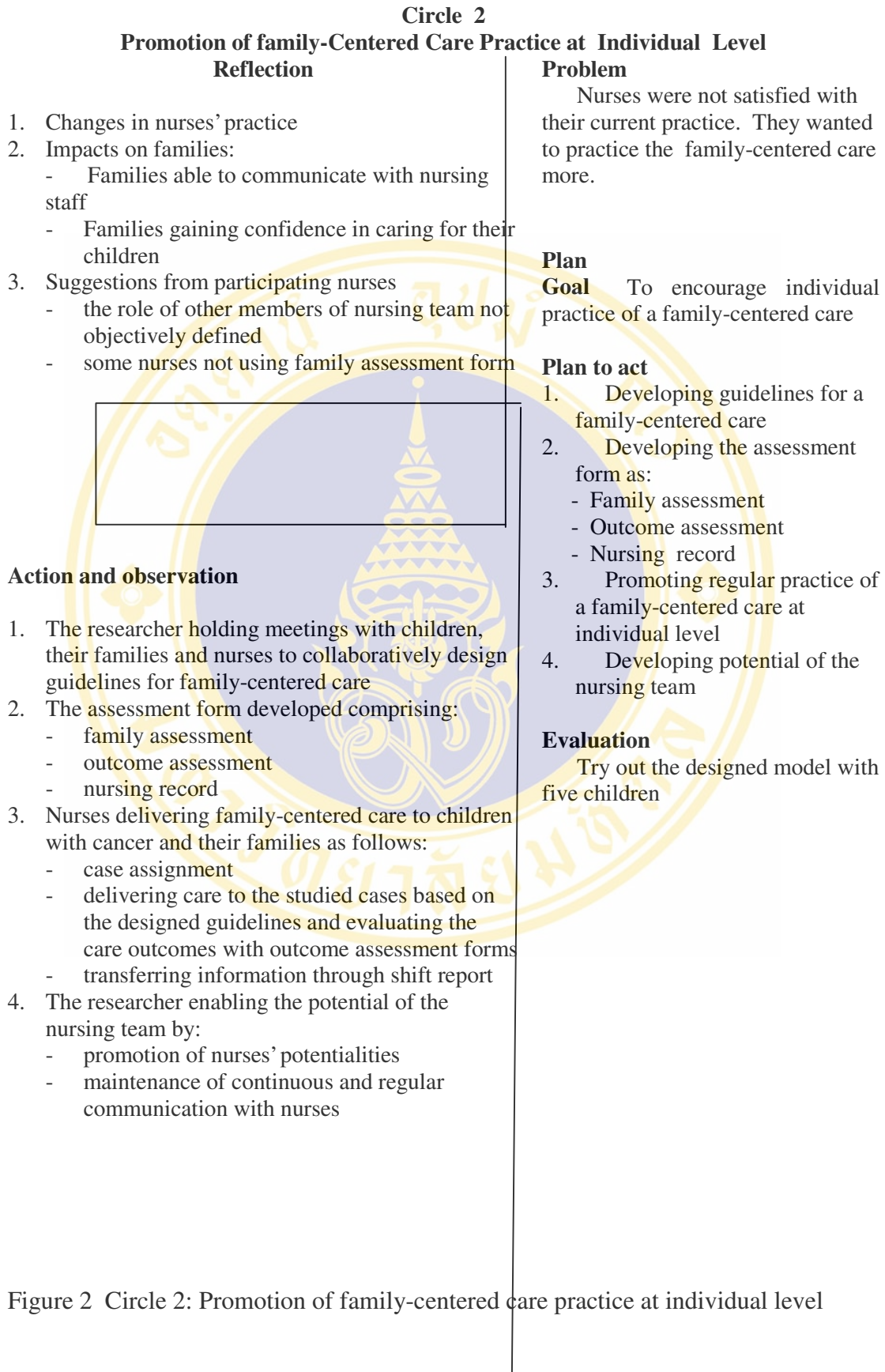


Figure 2 Circle 2: Promotion of family-centered care practice at individual level

1. Identifying problems

Discussion with participants was ensued to identify problems for further development of the family-centered care model. The identified problems for Circle 2 were that the nurses had a more giving role in this care model, when compared to the family and nurses who did not regularly practice family-centered care. They were not satisfied with their current practice, and they wanted to develop more on a family-centered care.

2. Planning

Information from the reflection in the previous circle was utilized to set up goals, plan to act, and evaluation.

2.1 Goal

The researcher, nurses, and children's families had a meeting to set up the goals together. The goals were to encourage individual practice of family-centered care.

2.2 Plan to act

The planned activities included developing guidelines of a family-centered care, developing the assessment form, promoting regular practice of family-centered care at the individual level, and improving potential of the nursing team.

1) Developing the guidelines of family-centered care

The trial of the family-centered care model with nine children, including five children at the beginning stage of cancer, one child at the recurring stage, and three children at the terminal stage, resulted in the improvement of nurses' understanding of the children's and families' responses, as well as nurses and families' roles, in an objective way. Thus, the meeting would be held to develop a guideline for a family-centered care.

2) Developing the assessment form

The research participants planned to develop the assessment form which was composed of a family assessment, an outcome assessment, and a record form.

a) Family assessment form

The research participants comprising the families and nurses had a consistent opinion about a family assessment. The nurses suggested that a family assessment form should be provided as guidelines for the nurses to obtain more knowledge about the family. The families suggested that the nurses should learn about the family, environment, and other situations for delivery of appropriate care. Thus, the research participants agreed upon development of a family assessment form.

b) Outcome assessment

The participating nurses suggested that the family should evaluate the outcomes of delivery of care with the family-centered care model. Thus, the research participants planned to develop a form for the evaluation of the care model and care outcomes.

c) Record form

As nurses understood the care provision with the family-centered care model, research participants proposed that there should be a convenient record form for a common use. The researcher, then, planned to design the record form to accommodate nursing practice with a family-centered care.

3) Promoting regular practice of a family-centered care at the individual level

The participating nurses commented that staff nurses did not regularly conduct family-centered care practice. The research participants, therefore, planned to encourage regular practice of the care model at the individual level. Research participants planned to try out the care model in caring for children with cancer at every stage of the illness. The trial would be conducted with five children, and outcome of care would be evaluated for further development.

4) Developing potential of nurses, nurse assistants, and nurse aides to encourage practical use of the model

There were three nurses who demonstrated good understanding about the application of the family-centered care model in their practice and who were able to communicate with members of the nursing team very well. These nurses had been working for approximately 15–20 years. The researcher, therefore, improved the potential of these three nurses for the management of this research program. For example, they would lead a discussion during pre-meeting, and they would be a model

in conducting a pre-conference with family participation. The researcher acted as a team member who participated in the discussion and proposed some issues of interest for further discussion.

2.3 Evaluation

Research participants agreed to try out the designed model with five children. The evaluation would be conducted between nurses and the families and in a meeting of nurses, families, and the researcher.

3. Action and Observation

The goals set in the planning stage included encouraging individual practice of the family-centered care. The action plan comprised developing guidelines for family-centered care, developing the assessment form, promoting regular practice of family-centered care at the individual level, and improving potential of the nursing team. The plan was then implemented in the following manners:

3.1 Meeting to collaborate design guidelines for family-centered care

Children with cancer and their families had a meeting with nurses to express opinions about their common responses. The meeting participants also determined nurses' and family's roles according to the results of the invention based on family-centered care concept. Guidelines of the family-centered care for children with cancer at every stage of the illness were developed as shown in Table 4 and detail was in appendix E.

Nursing guidelines based on the family-centered care model

Child's and family's responses	Family role	Nurse role	Responsible person	Family-centered care	Evaluation
The child and the family were not familiar with the hospital.	1. Maintaining parental role 2. Developing understanding, giving information to the nurses	1. Establishing a rapport with the child and their family 2. Assessing the child and the family 3. Encouraging the family to participate in caring for the child with nurses 4. Giving orientation at admission	-all nursing staff -the assigned nurses - the assigned nurse assistants -the assigned nurses	-Establishing rapport - Collaboration -Information exchange -Acceptance of differences	-The child's and the family's responses -The family's decision -The family's understanding
The child was ill	1. Participating in the assessment, planning, implementing and evaluating care. 2. Exchanging and sharing experience in childcare and anxiety with nurses	1. Taking care of the child, following a family-centered care, practicing with the family participating in assessment, planning, implementing and evaluating 2. Giving information	-the assigned nurses	-Collaboration -Information exchange -Delivery of care with consideration of family differences	- Understanding about the child's illness - Participation -The child's and the family's responses

Child's and family's responses	Family role	Nurse role	Responsible person	Family-centered care	Evaluation
The child was suffered from intrusive procedures.	1. Participating in the delivery of care 2. Providing mental support	1. Giving information about the procedures to the family 2. Encouraging the family to participate in caring for the child	-the assigned nurses	-Information provision -Participation	-Family's responses: -verbal -behavioral
The family felt distressed after being informed about the diagnosis.	1. Expressing the feelings toward the child's illness	1. Observing the family's responses and delivering care according to individual differences e.g. - listening - giving support	- the assigned nurses	- Acceptance of individual differences -Promotion of family strength	Family's responses

Child's and family's responses	Family role	Nurse role	Responsible person	Family-centered care	Evaluation
The family did not understand about disease, illness, and its treatment.	1. Exchanging information about the disease and the treatment plan	1. Assessing the family's knowledge about the disease, the treatment, and childcare 2. Exchanging information about the illness and impacts 3. Coordinating with doctors	-the assigned nurses	-Provision of information	The family's understanding
The family was worried about having a chronically ill child and related problems such as the child's disorders, livings, and expenses	1. Exchanging information with the staff 2. Developing abilities in caring for the child 3. developing self care ability of the child	1. Assessing the needs for help and available resources 2. Discussing about the family's anxiety 3. Assessing the family's abilities and promoting their abilities and skills in caring for the child	-the assigned nurses -All nursing staff	-Promotion of family strength -Provision of care with consideration of individual differences -Provision of information -Promotion of an ability to deliver care, based on individual differences	- The family's access to available resources - The family's caring skills and the child's skills of self-care.

3.2 Designing the assessment form

The assessment form was developed comprising family assessment, outcome assessment, and nursing record.

1) Family assessment form

The researcher reviewed related literature and designed the family assessment form following the Calgary Family Assessment Model (CFAM). The researcher outlined the form and presented the outline in a meeting for discussion. Nurses agreed to use this form for family assessment.

2) Outcome assessment

The outcome assessment questionnaire was developed to assess the outcome of care prior to the patients' discharge. The questionnaire was composed of open-ended questions.

3) Record form

The researcher and nurses collaborated to develop the record form.

3.3 Nurses delivered family-centered care to children with cancer

Nurses delivered family-centered care to children with cancer consisting of case assignment, nursing care delivery, transferring information through shift report, and meeting for reflection.

1) Case assignment

In applying the care model to the delivery of care for the children with cancer and their families, a nurse was assigned to take care of the selected case child in the morning shift. For the evening and the night shifts, in which nurses are assigned to deliver care in a team for a group of patients, the nurses caring for the case-study child were those who were responsible for the team delivering care to that child.

2) Nursing care delivery

The assigned nurses delivered care to the case study child with the designed nursing care model. The family-centered care concept was applied to every activity in the delivery of care to children with cancer and their families, starting from hospital admission until discharge.

On the admission day, Nursing staff conducted the following activities when a child was admitted into the hospital.

a. Establishing rapport with the ill child and his or her family

All staff established relationships with the family since the child was admitted into the hospital.

b. Assessing the child and the family

Nursing staff assessed the child and the family with the assessment form.

c. Initiation of family participation in caring for the child

Nurse and the family started their collaboration in child care. Mutual goals were set regarding suitability for each family. The family then participate in child care.

From the hospitalization until hospital discharge, nurses who were assigned to take care of the case delivered care with the family-centered care concept. For example, in caring for the child's illness, nurses encouraged the family to participate in the discussion about illness problems and provided the nursing team with information about the child. At the same time, nurses gave information to the child and the family, promoting their understanding about the condition of illness. Nurses also assessed the family's knowledge about childcare and gave them information concerning childcare. Additionally, nurses assessed the family's anxiety about the child's illness and gave them mental support. Another example is when blood sample was drawn for an examination, nurses explained the reasons to the family. In case of an older child, both the child and the family would be informed about the procedure, and the family was encouraged to participate in caring for the child during the procedure.

The designed assessment forms, both family assessment and outcome assessment, were utilized after the delivery of care. The outcomes would be evaluated prior to hospital discharge.

Nurses recorded the progression of responses from the child and the family, family's and nurses' roles, and the assessment results onto the record forms. The nursing record forms were both the usual nurses' notes and the newly developed form.

3) Transferring information through shift report

The in-charge nurses reported the progression of the child's and the family's responses and caring activities as recorded in the record forms. Nursing staff then learned about the health condition of the child and the family's responses during shift report. The next staff taking care of the case were on able to provide continuous care accordingly.

4) Meeting for reflection in the nursing team

In everyday pre-meeting, the nursing team comprising nurses, nurse assistants, and nurse aides exchanged their opinions and experiences concerning the delivery of care to the case study child. The group leader led the discussion and encouraged the participation in discussion and sharing of experience among nursing staff.

The case study was conducted with 10 children with cancer. Among these, two children were newly diagnosed, six children were receiving treatment, one child was at the recurring stage, and the other child was at the terminal stage.

3.4 The researcher enabling the potential of the nursing team: the researcher's role

The researcher reduced her role as a model and took the supporting role. She played a significant role in promoting nurses' potentialities, maintaining continuous and regular communication.

3.4.1 Promotion of nurses' potentialities

The researcher encouraged nurses who understood the family-centered care concept well to be group leaders in child's care. For instance, at the beginning of the implementation of this circle, the researcher led group discussions. Later, experienced nurses who demonstrated good understanding about the care model were encouraged to lead the discussion and followed the outcomes of nursing practice themselves.

3.4.2 Maintenance of continuous and regular communication

The researcher communicated with nursing staff for continuous understanding. She worked as a staff nurse and studied the case study child with other nurses. The researcher shared her experience concerning the case study with other

staff and expressed opinions in group discussion. She also attended monthly staff meetings and reported the progress of the research project to the meeting participants with some handouts to clarify the process of research invention. The meeting participants contributed their ideas and making plans for further development of the program.

4. Reflection

Reflection was conducted between nurses and the families before each child was discharged. The researcher worked as a staff nurse in the unit and recorded the observation of interactions between nurses and families regarding participation, information exchange and promoting strength and resources.

The results of reflection indicated changes the nursing practice, effect on families, and suggestion from participating nurses.

1. Changes in nurses practice

Nurses demonstrated changes in the delivery of care to the family. The changes included accepting the family's importance, collaborating with the family in caring for the child, exchanging information, and having rapport with the family and changing in communication of the nursing team.

1.1 Accepting family importance

Nurses were aware of the family's importance in the delivery of nursing care. Information from the observation showed that nurses were more flexible with the family in terms of visiting hours and they allowed the family to stay with the child at night, as well as in the daytime.

1.2 Collaborating with the family in caring for the child

Nurses collaborated with the family in providing care to the child. The observation revealed that during the pre-conference, nurses asked the family about the child's symptoms in attentive manners. Nurses and the family developed a nursing care plan for the child together after the family told nurses about the child's symptoms. Moreover, data from the interviews with nurses showed that nurses collaborated in caring for the child with the family more than before, as one nurse said:

'I think about it during the shift report and listen to the family more than before during the pre-conference, giving them chances to speak. I think everybody does it the same way. It's like an automatic process.'

Nurses also followed the child's symptoms and evaluated the child's condition in collaboration with the family, as one stated:

'When we work together with the family, we follow up the outcomes, evaluating the results after care provision, more than before. An example is giving the child tepid sponge. Before (the utilization of this model), we let the parents give the child tepid sponge and never followed up the results. Now we check if the mother does it correctly and we monitor the child's symptoms, checking if his or her temperature decreases.'

1.3 Exchanging information with the family

The information exchange between nurses and the family increased. Nurses provided information about the child's illness and observation of symptoms and told the family to report nurses when observing abnormal symptoms. The family provided nurses with information about the child's symptoms.

'Asking questions about their home is like information exchange, too. During the hospitalization, we teach mothers to observe this symptom or that symptom, and they will tell us when they notice changes or anything abnormal. If we tell them, they will be able to do it.'

Nurses observed the family's behaviors and found that the family developed behaviors of providing information about the child to nurses with no need of nurses' initiation. A nurse said:

'I don't have to ask the mother now. She reports the symptoms to me promptly. When it's time, B's mother will report today the child is like this and that...'

'Before this we had to ask the mother 'how is your child?', 'how does the symptoms change?' Now, the mother report it to us herself. If there's any change in the child's symptoms, she will come to report on us promptly.'

1.4 Having rapport with the family

Nursing staff at all levels frequently interacted with children with cancer and their families, as observed during shift report and clinical practice:

'We approach them more and think about talking to them more than before. We have had more conversation with the children and the families since this program started. When they come to us, we greet them – can I help you? We talk to them more than before.'

Information from the record of information stated:

'The atmosphere in the unit has noticeably changed. The families greeted nurses and had conversation in friendly, informal manners.'

1.5 Change in communication in the nursing team

The changes in the communication of the nursing team were present in shift report, pre-and post conference, Kardex note, and nursing records. Nurses' behavior in shift report was modified. Nurses informed the colleagues about the child's and the family's responses, as well as nursing care delivered to them, more than before. During pre- and post-conferences, nurses exchanged information with the family. The nursing record was significantly changed. The record included the care delivered to the family. For instance, in a record in the Kardex note about a child with a nursing diagnosis as being at risks for complications due to the treatment with chemotherapy, a nurse's note stated, *'Teach the patient and the relatives to observe complications from chemotherapy such as nausea, vomiting, fever, or oral ulcers.'* This note indicated an increase in family care in nursing practice.

2. Impacts on families

Information from interviews with the families and observation indicated that the families felt confident in caring for their children, they also expressed their feelings and opinions to nurses. For example, the families reported that the participation in caring for their children made them feel that they could trust them and they had the courage to let nurses know their feelings and their needs.

3. Suggestions from participating nurses

3.1 Nursing staff's roles in family-centered care

Some nurses commented that nursing care was delivered in team practice, which was composed of nurses, nurse assistants, and nurse aides. Nevertheless, the development of family-centered care model did not have definite roles of nurse assistants and nurse aides.

3.2 Some nurses not using family assessment form

Some nurses made a remark that the family assessment form was complicated and inconvenient in clinical practice and improvement was needed to simplify the utilization of the form. Discussion was ensued about the revision of the assessment form. Nurses asked the researcher to revision the assessment form.

Enabling Factors and Barriers

Enabling factors

The factors that enabled the practice of family-centered care at the individual level comprised staff's understanding, awareness of importance, and appreciation of the value.

1. Staff's understanding

Nurses commented that better understanding enabled them to practice with family-centered care:

‘Staff's understanding about the family-centered care.’

2. Awareness of importance

Nurses suggested that an awareness of the importance of family-centered care contributed to good practice:

‘A factor that contributes to the practice is the staff's awareness of the importance.’

3. Appreciation of value

The nursing staff felt that the practice with family-centered care had positive effects on the children and their families; hence, they felt mentally encouraged to continue family-centered care:

‘We've done it, and the patients think it's good, so we'd like to continue, having mental support. There is also support from the researcher. We have frequent talk with the researcher... This is good.. All right...let's continue.’

In conclusion, research participants comprising nurses, children with cancer, and their families identified the problems together and found problems that nurses had more of a giving role and the family-centered care was not regularly practiced. The participants then developed a plan and modified the tentative care model to increase equality between nurses' and family's roles and to promote regular practice at the individual level. Nurses collaborated with families in delivering care to children according to the roles previously defined. The researcher accommodated their practice by improving nurses' potential and having continuous and regular communication with them, as well as conducting reflecting analysis. The plan was tried out with ten children with cancer comprising two newly diagnosed children, six children receiving treatment, one child at the recurring stage and one child at the terminal stage. The reflection

among nurses, the researcher, children and the families revealed that nurses had changed their practice behaviors.

The clients' behaviors also changed as they were more likely to exchange information with nurses. Promoting factors for the practice of family-centered care included a understanding and awareness of the importance of family-centered care and appreciation of the value of nursing practice. A problem found in this circle included indefinite roles of other nursing staff.



Circle 3 Becoming a team

Reflection

1. Nursing team able practice FCC as planned
2. The application of FCC approach having positive effect, but required continuous development by:
 - self development
 - cooperation in problem solving
 - utilization of the management system
3. Having a meeting to conclude the FCC model for application to nursing practice in the unit
4. Planning for continuous application of the model

Problem The family-centered approach was not practiced as a team

Plan

Goal To encourage the application of family-centered care to team practice

Plan to act

1. Assessing understanding among members of the nursing team
2. Proposing family-centered care guidelines to the nursing team
3. Planning of family-centered activities for the team practice

Evaluation

Holding a meeting after one month of action

Action and observation

1. Setting up a meeting to determine the family-centered approach in a team practice by:
 - 1.1 Evaluating the understanding about FCC of the nursing team
 - 1.2 Proposing a family-centered care model to the participants
 - 1.3 Defining the roles of nursing team
 - 1.4 Determining team practice
2. Applying the guidelines to the delivery of care for every children with cancer admitted into the hospital
3. Improving knowledge, understanding, and awareness
 - conference
 - teaching
 - reflection
 - academic conference

Figure 3 Circle 3: Becoming a team

Circle 3 Becoming a team

Referring to Circle 2, in which the application of the family-centered approach in caring for children with cancer and their families was aimed to enhance individual practice, the reflection indicated that nurses changed in practice. Then, research participants continued to Circle Three.

1. Identifying the problem

Research participants identified problems for further development of the care model. The reflection of circle two indicated that some nurses could not regularly delivery care with family-centered care approach. In addition, the roles of other members of the nursing team did not objectively define. Hence, the research participants agreed that the family-centered approach should be applied to nursing team practice.

2. Planning

A meeting of children with cancer and their families, nurses and the researcher was held to set the goals, to plan to act, and to determine the duration and evaluation of the invention.

2.1 Goal

The goal was to encourage the application of the family-centered care model to team practice.

2.2 Plan to act

The action plan for the development of teamwork in applying the family-centered approach to nursing care was composed of the assessing understanding among member of the nursing team, the proposing family-centered care to the nursing team, and the planning of family-centered care activities for the team practice.

2.3 Evaluation

The researcher and the nursing team held a meeting after one month of action to evaluate the progress of the research and the research outcomes.

3. Action & Observation

Research participants implemented the plan for teamwork development as detailed below:

3.1. Setting up a meeting to determine team practice with the family-centered approach

The nursing team and the researcher held a meeting to determine the utilization of the family-centered approach in team practice as detailed below:

1) Evaluating the understanding about the family-centered approach of the nursing team.

Nurses had a discussion with members of the nursing team about the importance and meaning of family-centered approach, as well as the outcomes of previously conducted activities. Most staff were aware of the importance of the family-centered approach and understood the meaning of family-centered care.

2) Proposing a family-centered care model

Participating nurses and the researcher proposed the model of family-centered care to the meeting participants. The participants then had a discussion about the model.

3) Defining the roles of nurse assistants and nurse aides

- Delivering considerate care by establishing rapport with the children and their families, greeting and being available
- Exchanging information by giving instruction for simple procedure such as temperature measurement or tepid sponge
- Cooperating with the family in caring for the child
- Coordinating the communication between the family and nurses

4) Determining team practice

Team practice involved shift report, pre-meeting, pre and post-conference, nursing practice.

a. Shift report

The nursing team modified the shift report from describing physical disorders to reporting the progression of illness and children's and families'

responses in the past shift, including the delivery of family-centered care in order to maintain the continuity of care.

b. Pre-meeting

After the shift report, the nursing team had pre-meeting to discuss experience in caring for the children, as well as the issues concerning family-centered care focusing on the participation of nurse assistants and nurse aides. The team collaboratively observed children's and families' behaviors and shared the experience with other team members in pre-meeting every morning. Every member also participated in a discussion before daily nursing activities.

c. Pre and post-conference

Nursing staff were divided into two teams for the pre-conference. The pre-conference was modified from including only nursing staff to including the children's families for discussion about children's problems. Nurses exchanged information with the families, listened to them, and gave additional information. Nurses and the families then collaboratively made a care plan for the children.

d. Nursing practice

After the pre-conference, members of each nursing team delivered nursing care based on the family-centered approach. The performance of nursing care was integrally conducted with the family-centered approach comprising accepting the family, exchanging information, encouraging family's participation, and promoting family's strength and capacity. Nursing staff were assigned to be responsible for caring for every child with cancer at any stage, starting from hospital admission until discharge.

3.2 Promoting knowledge, understanding, and awareness of importance in caring with the family-centered approach

In the process of family-centered care model development, some nurses understood the application of the model. These nurses and the researcher had a role in improving the knowledge and understanding about the family-centered approach and in promoting an awareness of family-centered care among other staff in the nursing team as detailed below:

3.2.1 Conference

The nursing team had a discussion about caring for children and their families in pre-meeting everyday and in monthly staff meeting. The discussion was led by senior nurses who understood about the family-centered approach.

3.2.2 Teaching

Nurses played an important role in giving instruction to members of the nursing team in order to help them practice with the family-centered approach. The lessons were usually based on real situations occurring in the ward. For example, a boy with leukemia refused to take a shower and eat his food. He told nurse aides that he would like to wait for his father before doing these activities, and the nurse aides were uncertain about proper nursing care for him. During the discussion about this case, a nurse stated:

‘I understand that you have good intention to care for the child’s hygiene. However, we have to consider whether his action is harmful to his condition. If he is happy to wait for his father, we have to be flexible, wait and try to understand him. Nevertheless, we need to talk to the father so that we can deliver proper care to the child with participation from his father.’

3.2.3 Analytical reflection

Nurses who understood the application of the family-centered approach led discussions to encourage analytical thinking among nursing staff. For instant, a nurse assistant found that a mother inquired about nursing practice so much that she felt bothered. The group had a discussion about this issue and pointed out positive aspects of such behavior to nursing care. A nurse explained:

‘Having questions from a patient could be considered as a success in the delivery of care. In P’s case, his mother is well educated. She already knows something, and she asks for more information from us. If every patient is like this, we can consider that our care is successful.’

To raise an awareness of the family-centered approach among members of the nursing team, nurses presented examples in a practical aspect. A nurse elaborated:

‘When relatives ask questions, we should ask ourselves every time: they ask because we did something wrong to them, because they are fussy, or because we are not doing it the same way as they know.’

3.2.4 Academic conference

To promote understanding about and raised an awareness of the family-centered approach among members of the nursing team, workshop in caring for the family of children with cancer was set up with the coordination between the researcher and Head of Pediatric Nursing Department, College of Nursing. The workshop entitled 'Chronically ill children: Caring for the family' was held on 2 July 2002 with 31 participants comprising nursing staff and pediatric nurses. The content of the workshop included the concept of family, impacts of illness on children and their family, stress and coping with stress, and the role of nursing teams.

4. Reflection

Activities in Circle 3 were aimed to promote teamwork on the basis of the family-centered approach. Outcomes of the invention in this circle were reflected in the following manners.

1. Nurses reflected the outcomes of care with the family

Nurses evaluated the outcomes of nursing care during the provision of care and before hospital discharge, using the framework of reflection point which was previously prepared.

2. The researcher reflected on the outcomes of care with nurses and the family.

The researcher, the family, and the nursing team had a meeting together to evaluate family-centered nursing care.

3. The researcher observed the outcome from participation action.

The researcher participated in nursing activities, observed and recorded the outcomes of nursing care, particularly in aspects of interaction between nurses and the family and the delivery of care.

Results of reflection

1. Nursing teams could practice family-centered care as planned.

Data from the observation and the record demonstrate that some nurses could conduct nursing care for the children with cancer and their families as planned. Nurses gave more suggestions to family and demonstrated simple nursing procedures such as taking temperature and giving tepid sponge to the family during nursing practice. In team practice, nurses could present the children's and their

families' responses during the shift report. In pre-meeting nurse assistants and nurse aides had more participation in the discussion about the patients. Nursing staff had more discussion with families in the pre-conference. Nurses' record also showed that nurses could note the nursing care that covered family care. However, the post-conference was not regularly conducted due to the amount of work; for example, nurses might be busy with patient admission. An application of family-centered care is exemplified in the following researcher's field record:

'During pre-conference this morning, a nurse asked a mother about her child's symptoms and also talked to the child. The mother was enthusiastic to talk about the child's symptoms. The nurses also asked how the mother cared for the child, and the mother explained it to her. The nurse said that the mother could talk in details with T. who was taking care of the case on that day.'

Nurses remarked that the care model was applied as planned; however nurses did not use the designed family assessment form as they thought that the hospital assessment form is sufficient for assessment. During a group discussion, nurses commented that the hospital assessment form was sufficient:

2. The application of the family-centered approach had positive effects, but required continuous development.

Nurses felt that the activities based on family-centered care had positive effects on children with cancer and their families. However, improvement was needed including self-development to be equal with other staff, cooperation in problem solving, and utilization of the management system.

'It was good as we expected but there may be some faults. I felt that it's good and the family expects that everybody would be the same, so we need continuous development.'

2.1 Self-development

Nurses made a remark that some people could not quickly change themselves and their actions might have impact on the overall teamwork. Thus, members of the nursing team agreed that all members should develop their capacity to be able to conduct nursing practice as well as other people:

'We may gradually help the others. Sometimes we cannot suddenly change. Each individual is unique but it is work so we have to gradually pull each other up. Because when we finally reach the point, the discontinuous of our work will be obvious if one person does not do it. Everybody needs to improve herself to be as good as the others, and can do it gradually.'

2.2 Cooperation in problem solving

Nurses had a discussion that family-centered nursing care was a working system; hence, it required cooperation. The working system should encourage compromise among staff; for example, senior nurses warning junior nurses or a colleague to help another colleague. The nursing team members should collaboratively improve the nursing practice:

It's good now. Someone may not be a hundred percent good, but each individual has different capacity. We have to accept and pull them up when they become too relaxed.'

2.3 Utilization of the management system

Nurses proposed that the application of family-centered care should have administrators to follow up the activities:

'Family-centered care is like our regular work. Somebody makes mistakes, somebody is lazy, and somebody is poor. It's natural, and the head nurse should take care of the practice, too.'

3. Having a meeting to conclude a family-centered care model for application to nursing practice in the unit

The meeting participants agreed that the family-centered care model was regularly and continuously developed and the nursing team subsequently had improved knowledge, skills, and capacity to the level that the team members understood the concept of family-centered care. Thus, the researcher, nurses, children with cancer and the family collaboratively concluded the family-centered care model that could be continuously applied to clinical practice in the unit.

4. Planning for continuous application of the model

The researcher, nurses, children with cancer, and the family had a meeting to establish the process of family-centered care for continuous practice as presented below:

4.1 Improving a handbook of family-centered care for nursing practice in the unit

After an appropriate family-centered care model was established, the researcher wrote an overview of the family-centered care model as a handbook for the application of family-centered care to nursing practice in the unit.

4.2 Sustaining the meeting of nurses, children with cancer, and the families for continuous development

The family-centered care model had been continuously developed and should be carried out in the future. The unit should sustain the meeting of nurses, children, and the family to assess the care requirement of the children and the family and for periodical evaluation of care outcomes. The results of evaluation should be used as guidelines for modification of caring behaviors among nursing staff and for further development of the unit.

4.3 Providing an orientation to new staff

The meeting participants planned to provide the new staff of the unit with an orientation about the concept of family-centered care. The new staff should also read the handbook of family-centered care to gain understanding and to develop skills for practical use of the model.

4.4 Promoting effective team practice

The meeting participants had a discussion concerning effective teamwork in the nursing team. It was agreed that effective team practice should consist of the following components: self-development, collaboration of team members, information exchanges, and sharing of experience and opinions in the pre-meeting every morning. The team leader should provide team members with support and compliment; the members should also support each other. The department administrators should also follow up the application of the family-centered care model in the unit.

In summary, the process development of family-centered care model for the children with cancer in a pediatric cancer unit involved the process of development with action research. Process of development consists of three circle. Each of which was composed of planning, action and observation, reflection, and re-planning. Circle one is to develop of nurse's understanding. Circle two is to promote of individual practice. Circle three is to initiate the team. finally, participants collaborated to committed the model to practice the model together (Figure 4).

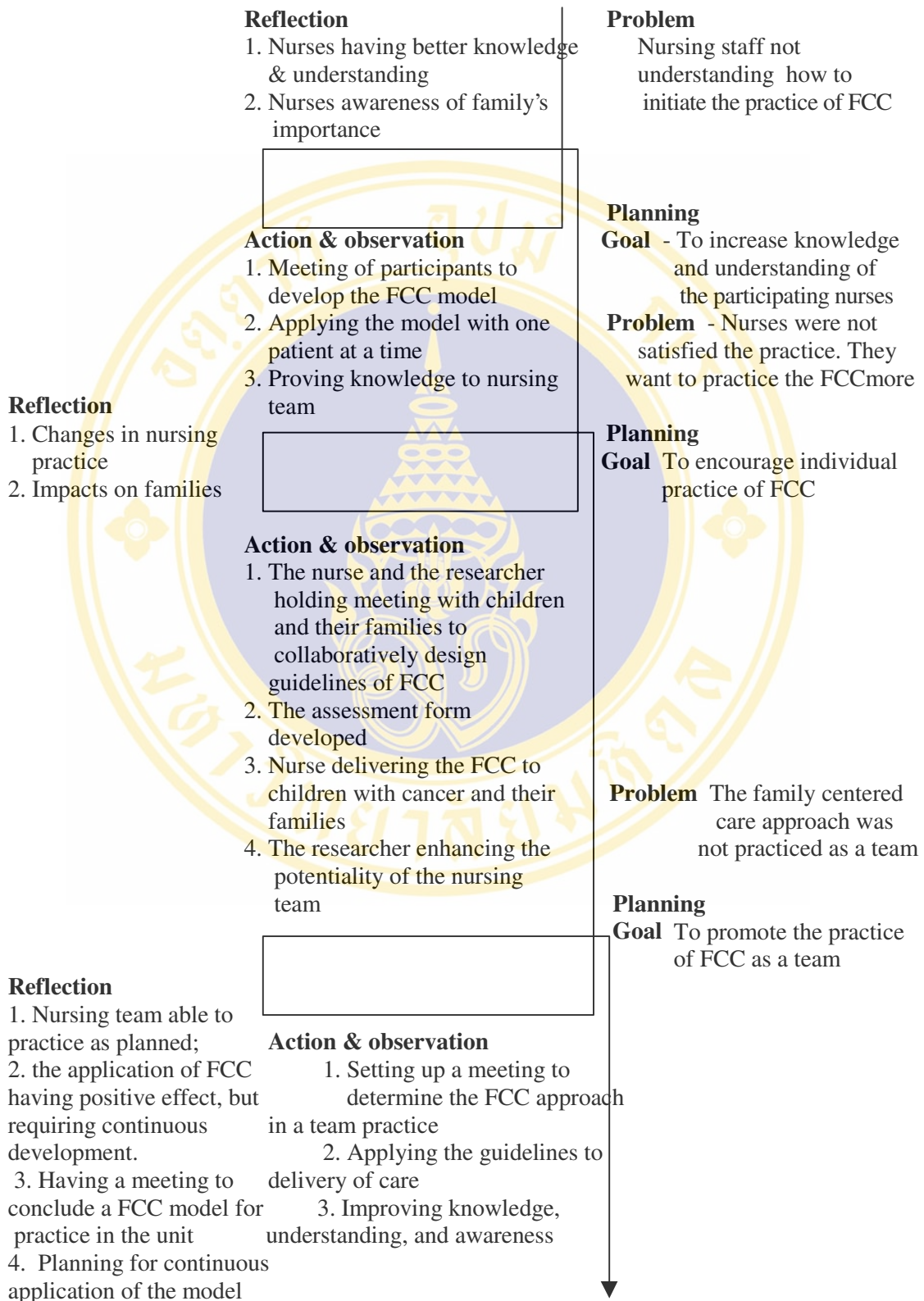


Figure 4 Action Research Cycle in Developing the Family-Centered Care Model

Strategies used in the development of the family-centered care model, enabling factors, and barriers

The strategies used in the development of the family-centered care model in the Pediatric Cancer Unit and related factors were discussed below:

1. Strategies used in the development of the family-centered care model

Referring to the researcher's record and the reflection with research participants, strategies used in the development of the family-centered care model comprised commitment, communication, collaboration, promotion of knowledge and understanding, raising awareness, role modelling, and reinforcement.

1) Commitment

The researcher and research participants had an agreement to collaboratively develop a well-defined nursing care model for application to nursing practice in the unit. The decision for model development was made in staff meeting after an analysis of the situation in caring for children with cancer and the family was conducted. A nurse stated that:

‘We work together and we are determined to really do it, to get a good result out of it. At the beginning we might not be certain if it would work but after we have seen that it really works, we cooperate and coordinate this project not only among the staff but also with the relatives.’

2) Communication

The communication with research participants was an essential activity that the researcher continuously and regularly conducted in both the verbal channel and the written form. The researcher verbally communicated in either morning pre-meetings or monthly staff meetings. The communication in the written form was presented in the record of important issues during the meeting to provide information for staff who did not attend the meeting or record in meeting agendas. A nurse commented on the researcher's communication as follows:

‘The researcher always updates the information. She always asks us if we have any problem and we can discuss the problem with her. She keeps encouraging us. At the beginning, I didn't see the importance of the model and she reviewed it for me. I understand the concept later...understand why she needs to talk to us. I recall it and can do it. I feel good after doing it.’

3) Collaboration

Research participants commented that the participants collaboration contributed to success in the development of the care model. The collaboration included having the meeting to make plans together, trying out the planned action and evaluating the plan together. Therefore, the participants considered collaboration as an essential strategy for the success of model development. A nurse pointed out:

‘Our collaboration, sharing opinion about what we should do or what should be good, in this program makes it successful.’

4) Promotion of knowledge and understanding

The researcher continuously and regularly promoted knowledge and understanding among research participants with various techniques including workshops, lectures, discussions such as case-study discussion or discussion of related topics. Most lectures and discussions were led by the researcher. The workshop entitled ‘‘Chronically ill children: Caring for the family’’ was held. Lectures and discussions were held several times with topics including the concept of family-centered care, family-centered care for children with cancer, and provision of mental care for children undergoing medical procedures. The discussion of case studies among research participants involved significant issues concerning clinical practice. Moreover, the researcher developed a handbook of family-centered care for children with cancer to enhance knowledge and understanding in the development of the care model among nurses. A folder collecting all papers concerning the research program such as articles or research literatures was also available for all staff in the ward bookshelf.

A nurse commented on the researcher’s provision of knowledge:

‘She gives a lot of knowledge and makes me understand about family-centered care. We can talk with her when I have problems. She is the source of knowledge, providing us lessons. She is enthusiastic to give us knowledge, so I feel encouraged to learn and to follow her.’

5) Raising awareness

The researcher and participating nurses collaboratively raised self-awareness among research participants to make them recognize the importance of family-centered care. The awareness was raised through the process of reflection during pre-meeting every morning and monthly staff meeting. Queries were raised to

encourage self-analysis among the participants as well as the analysis of nursing care for the children and the family and collaborative analysis in the meeting group.

6) Role modeling

Role modeling is another technique used as an instrument for the development of the care model. The researcher acted as a model for research participants. Later on, some participants understood and were interested in making an attempt until they were able to apply the model into their practice. These participants subsequently acted as models for other research participants until most participants could apply the model into their practice. For example, in the initiation of family participation during pre-conference, the researcher acted as a model by asking parents questions and encouraging them to participate in the discussion for the development of communication with nurses and collaboration in making a nursing care plan. After the first few sessions, some nurses were able to lead the family to participate in the discussion and, later, the activity was regularly conducted in the unit.

7) Reinforcement

The researcher and research participants applied reinforcement techniques to the development of the care model, aiming to increase spiritual strength for continuous development of the model. The reinforcement comprised reflection on nursing quality such as improved conditions of the children and their families and increased communication between the family and staff. The researcher also gave the participants compliments when they appropriately delivered family-centered care.

Factors related to the development of the family-centered care model

The factors related to the development of the family centered care model could be divided into enabling factors and barriers to the development.

Enabling factors

The factors that promoted success in the development of the family-centered care model were hospital accreditation, desires for patients' improved condition, and encouragement from administrators.

1. Hospital accreditation

Participating nurses commented that the hospital quality appraisal encouraged hospital staff to improve their work units. A nurse stated:

‘In the process of Hospital Accreditation, authorities frequently come to evaluate our performance, so we have to evaluate ourselves and our work. It encourages us to improve our workplace as best as we can.’

2. Desires for children’s improved condition

Participating nurses stated that they would like to see children with improved condition and with no need for frequent hospitalization. A nurse explained:

‘Everybody wants the children to go back home early and to have no problems. They may have to be hospitalized for one or two months, which is a very long time. We hope the children will not have problems that require hospital visits. We hope they would just receive the medications and go back home, not having any complications.’

3. Encouragement from the administrators

Participating nurses remarked that administrators played an important role in supporting the development of the family-centered care model:

‘The support from administrators encourages us to develop the program, so everybody agrees to do it.’

Barriers

Barriers to the development of the family-centered care model included the lack of time for meeting, individual differences, lack of understanding, and disagreement among some staff at the beginning of the program.

1. Lack of time for the meeting

Participating nurses commented that meetings were very important for the development of the model; however, there was not enough time for the meetings.

‘It’s difficult to have a meeting. We don’t have time.’

2. Individual differences

Participating nurses stated that staff were different in terms of knowledge, attitude, and practice. The differences were barriers to the development of the model:

‘Each individual has different restrictions. It’s human nature, sometimes good and sometimes bad. So, the key is human. We don’t need any instruments just human.’

3. Lack of coordination with other professionals

The development of the family-centered care model was a nursing activity; however, the nursing practice involved the multidisciplinary team. Lack of common understanding, therefore, was a barrier to the development of the model:

‘Our work involves multidisciplinary teams such as sharing information with the patients. Sometimes healthcare professionals still think they are more important than patients and do not feel very good when receiving suggestions from us or from the relatives. We have to work together. We need to have common understanding first.’

4. Disagreement with the program at the beginning

Participating nurses commented that at the beginning of the research program some staff expressed uncooperative attitudes toward the program; thus, disagreement was a barrier to the development of the care model at the beginning:

‘At the beginning, it looked like we already had it. Then, why did we have to do it again? When I actually did it, I realized that it does not increase our work as we can do it while we are working.’

‘It feels like we’ve done it. So why do we have to make it more formal? It may look like I was against the practice. However, when I really do it, I’ve found that I can adjust it to myself. I can arrange time to do it.’

In summary, this action research aimed to develop the family centered care model in a pediatric cancer unit. Action research process comprised of 1) an analysis of the situation of caring for the children with cancer; 2) process of family-centered care development. The process development was a continuous circle with the collaboration of children with cancer and their families and nurses. The process of the family-centered care model for children with cancer in a pediatric cancer unit involved the process of development with action research. Process of development consisted of three circle. Each of which was composed of planning, action and observation, reflection, and re-planning. Circle one was to develop nurses’ understanding. Circle two was to promote individual practice. Circle three was to initiate the team. Finally, participants collaborated to commit the model to practice the model together. Strategies used in development of the family-center care model comprised of commitment, collaboration, communication, promotion of knowledge and understanding, raising awareness, role modeling, and reinforcement. The factors that promote success in developing of the model were hospital accreditation, desires

for patients' improved condition, and encouragement of administrators. Barriers is lack of time for the meeting, lack of coordination with other professionals, and disagreement with the project at the beginning. (Figure 5).

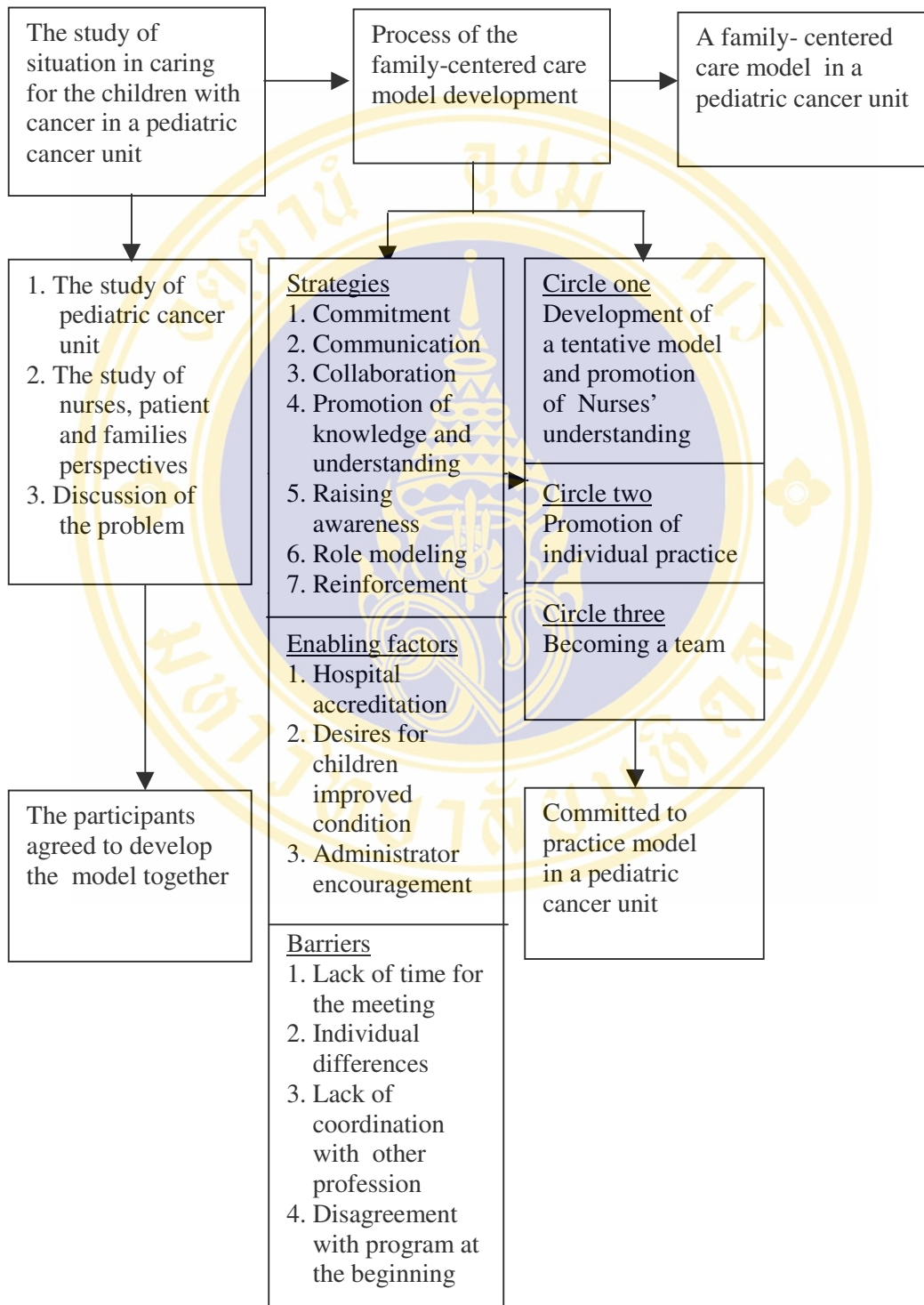
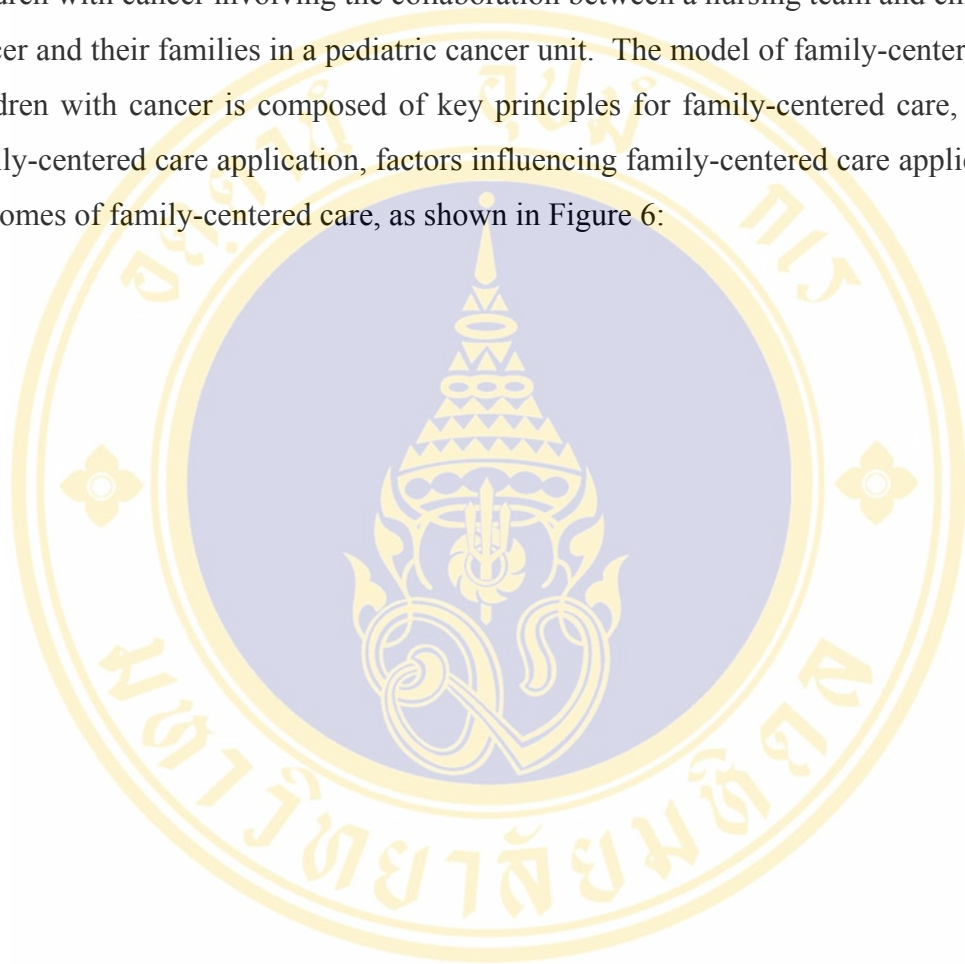


Figure 5 The process of development of a family-centered care model for the children with cancer

A family-centered care model for children with cancer in a pediatric cancer unit

A family-centered care model for children with cancer is a process of caring for children with cancer involving the collaboration between a nursing team and children with cancer and their families in a pediatric cancer unit. The model of family-centered care for children with cancer is composed of key principles for family-centered care, process of family-centered care application, factors influencing family-centered care application, and outcomes of family-centered care, as shown in Figure 6:



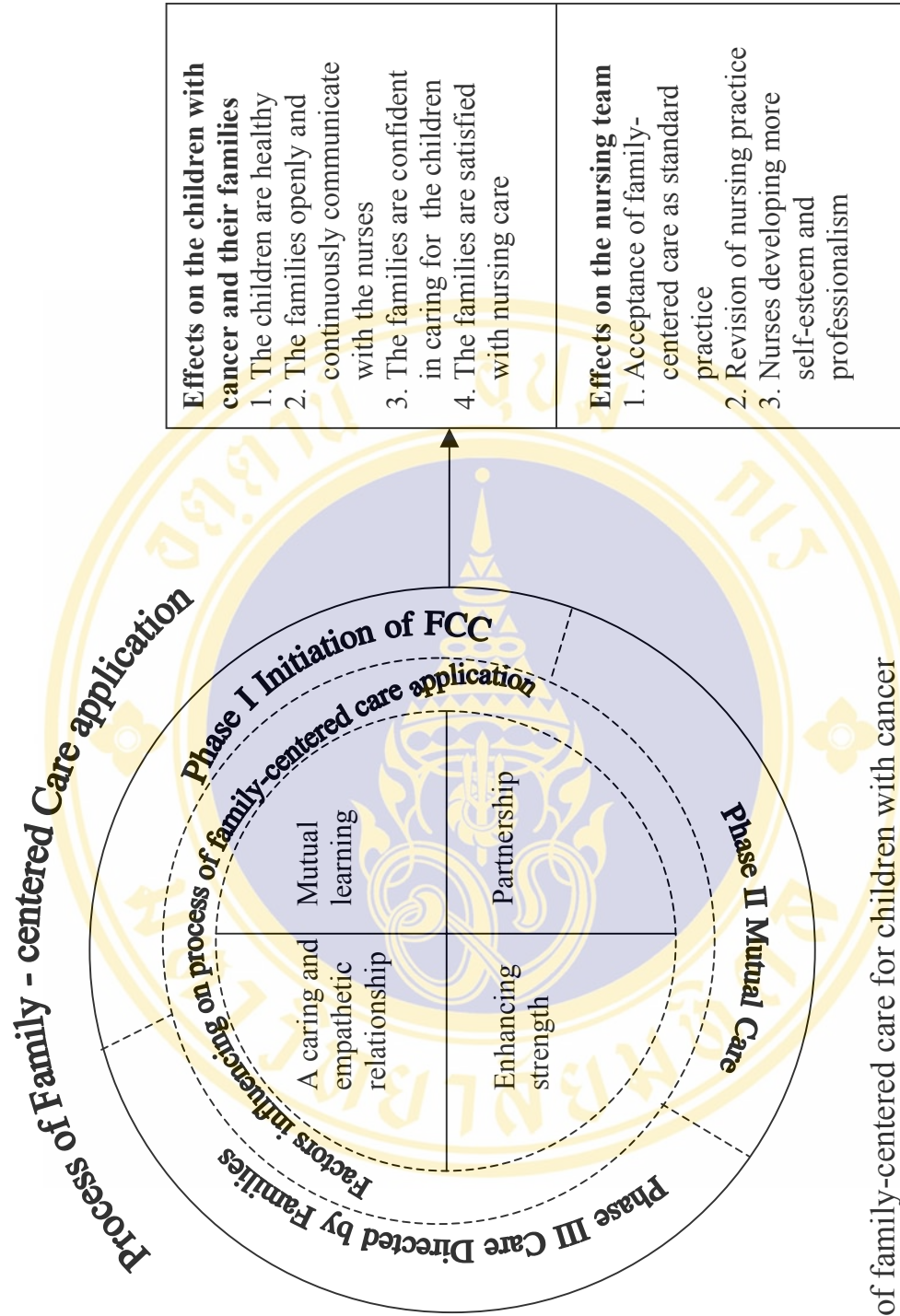


Figure 6 A model of family-centered care for children with cancer in a pediatric cancer unit

The following discussion of family-centered care is presented in the following order: key principles for family-centered care, process of family-centered care application, factors influencing family-centered care application, and outcomes of family-centered care.

Key principles for family-centered care

The practice of family-centered care is primarily based on the following four principles: a caring and empathetic relationship, mutual learning, partnership and enhancing strength.

1. A caring and empathetic relationship

A caring and empathetic relationship is the interaction between the nursing team and children with cancer and their families that involves spending time together, caring manner, having empathy, and having respect.

A caring and empathetic relationship is initiated when the nursing team, the children, and their family to establish rapport with each other and to have some time together. Consequently, their relationship is continually developed until a caring and empathetic relationship is established.

1.1 Caring manner

Caring manner is the interaction with care and thoughtfulness between the nursing team and children with cancer and their families.

Nursing staff express their caring manner toward the children and their families through facial expressions and body language as well as the use of polite and gentle language that indicates willingness to help. The delivery of nursing care is primarily based on the children's and the families' needs.

The families establish rapport with the nursing team by talking about their children's illness. They may start having a conversation with friendly nursing staff at first, before extending to other staff.

1.2 Empathy

Empathy is the interaction between the nursing team and the children and their families with understanding of each other's feelings.

The nursing team expresses empathy for children and the family by observing their expressions, listening to their feelings and having facial expressions that indicate enthusiasm to respond to the families' needs such as having eye contact or nodding.

1.3 Spending time together

Spending time together refers to the nursing team's spending time on interacting with the children and their families using both verbal and nonverbal communication.

Nursing staff spend time with the children and their families beginning from hospital admission until hospital discharge. They spend time having a conversation, getting to know the children and their families, and listening to the families attentively, as well as other family members. They allow times for the families to ask questions and to give information without rushing the families.

Also, the nursing team spends time talking to the children with the language appropriate to the children's development and with gentle language. Nursing staff may establish a relationship with the children by having a conversation or playing with them.

At the same time, the families become familiar with the nursing team by talking to a friendly staff member first and get to know other members of the nursing team later.

1.4 Respect

Respect refers to the nursing team and the children and their families showing respect towards each other. They show respect for the others' comments and opinions, regarding each other as a person, making no judgment and criticism, and accepting them as they are.

2. Mutual learning

Mutual learning refers to the nursing team's giving and taking information with children with cancer and their families, leading to mutual learning.

Mutual learning is developed from receiving information, giving advice and information, and giving feedback

2.1 Receiving information

Receiving information refers to nursing staff's listening to the information about children's illness from the families and vice versa.

The nursing team listens to information about the children and their family from hospital admission until discharge. The families listen to information and suggestion from nurses.

2.2 Giving advice and information

Giving advice and information refers to the nursing team gives information to children and their families and vice versa, thus they learn from each other.

The nursing team gives information to the children and their families regarding the place and the staff at the beginning of hospital admission. When physicians informed the families about the children's diagnosis, nurses give information about the illness; when the children receive chemotherapy, nurses advice the families about caring for children receiving chemotherapy; and when the children are discharged from the hospital nurses give advice about childcare such as oral hygiene care, dietary and assessment of abnormal symptoms. The nursing team also gives information to older children who can look after themselves.

The families give information to nursing staff, mostly about the children's illness as well as general information about the families. They also inform nurses about their experience in caring for the children.

2.3 Giving feedback

The nursing team gives feedback on ideas, feelings and behaviors from background knowledge and previous experience of the families. Nursing staffs also give new information in combination with existing knowledge to enhance the families' understanding and to modify their attitudes, as well as behaviors, in caring for the children.

Nursing staff observe and inquire the families about their caring practice after receiving advice and information from nurses. For children who had received

chemotherapy and had stayed at home, their families have experience in caring for them at home and may have some questions about childcare such as monitoring of abnormal symptoms or selection of appropriate food. Nurses give feedback about the families' practice and review knowledge; they then have a discussion with the families about the application of knowledge to caring practice.

Nursing staff also review the knowledge previously given to the children after an observation and a conversation about their self-care activities at home. While having conversation with the children, nurses repeat information for further practice.

The families inquire for more information, which may be the information already given but they have forgotten. The families might be confused and are not ready to receive any information in the period of emotional distress from the news about the children's illness. Nevertheless, after having cared for the children at home for a period of time, the families may have questions and need more information. They raise the questions to nurses and have a discussion about their problems.

3. Partnership

Partnership refers to the children with cancer and their families being allowed to take part in delivering care to the children with cancer and to make decision in nursing care.

The nursing team enters into partnership with children with cancers and their families in the provision of care to meet the children's needs. Partnership consists of participation in caring, mutual decision-making, and coordination with the family.

3.1 Participation in caring

Participation in caring refers to the children with cancer and their families' being allowed to take part in the delivery of care to the children.

Participation in caring comprises participation in the assessment of children and their families, participation in medical procedures, and participation in the delivery of care.

1) Participation in the assessment of children and their families

The nursing team conducts child and family assessment with participation from the families.

The nursing team has a discussion, which includes the assessment of children and their families, with the families before delivering nursing care. During the pre-conference discussion, nurses listen to information from the families, as well as their feelings. Problems concerning the children's illness are discussed and nurses respond to the families' expressions. The children with prolonged problems will receive continual care from the nursing team being responsible for them.

Family participation in discussion with the nursing team leads to information exchange and assessment of the children's illness and needs, in addition to the families' feelings and desires.

The nursing team inquires older children about their illness and has a discussion on nursing care appropriate to them. For small children, the discussion is conducted with their families.

The families give information to nurses, mainly about the children's illness and their responses to the illness such as insomnia, loss of appetite. The families also ask for more information about the illness when they are in doubts.

2) Participation in medical procedures

The nursing team, children with cancer, and their families collaborate in caring for the children during medical procedure.

When the children are scheduled for a medical procedure, nurses inform the children and their families about the pre-care and post-care practice, as well as the appropriate care during the procedure. The mothers can participate in preparing the children for the procedure if they are willing to. They are then prepared to stay with and to give the children comfort during the procedure and after the procedure is finished.

The families participate in caring for the children before, during and after a medical procedure by embracing the children, holding their hands, stroking their back and talking with them to distract them from the operation. The family caring can relieve the children's fear and can reduce their resistance during the operation.

Most small children cry and struggle to escape during a medical procedure even if they are informed about the procedure in advance. Thus, the procedure operator needs to finish it in the shortest time. Older children tend to be more cooperative; however, some of them may cry loudly and struggle to escape the procedure as well.

3) Participation in the delivery of care

The nursing team, children with cancer, and their families collaborate in delivering care to the children.

In their collaboration in the delivery of care to the children, nursing staff and the families provide care depending on the children's and the families' needs as well as the families' availability. The care is delivered in response to the children's physical and psychological needs; for example, caring of illness symptoms, helping in daily activities or recreational activities, or expressing love and care towards the children and helping them make contact with other family members.

3.2 Mutual decision-making

Mutual decision-making refers to the children with cancer and their families and nurses' collecting and sharing information and judgement with each other. Mutual decision-making results from opinions and information exchange between the nursing team and children with cancer and their families, followed by the study of information together.

3.3 Coordination with the family

Coordination with the family refers to the nursing team's making regular contact with children with cancer and their families to appropriately respond to the children's needs.

Nursing staff coordinate with the families in caring for the children during hospitalization, especially in cases that the families cannot stay with the children. Nurses give information to the families when they visit the children and allow them to make inquiries about the children's symptoms via telephone calls. Nurses also make contact with the families when the children express the needs to see their families.

4. Enhancing strength

Enhancing strength refers to the nursing team's collaborating with the families in developing assets, abilities, and resource of the children with cancer and their families to enhance their strength for coping with stress from having children with cancer, having ability in caring for children, and mobilizing the resource in caring for the children with cancer. The families may develop the strength themselves or with support from the nursing team.

The enhancement of family's strength comprises the enhancement of spiritual needs, promotion of family's ability, and development of the support system.

4.1 Enhancement of spiritual needs

Enhancement of spiritual needs refers to the nursing team's collaborating with the families to promote power within the children and to enhance belief and faith in self and others of the children with cancer and their families to be willing to live and develop themselves.

The enhancement of spiritual needs may derive from the families' self-development or the support from the nursing team in maintaining the families' spirit despite having children with cancer.

The enhancement of spiritual needs comprises the raising of hope and spirit and the sharing of feelings.

1) Raising hope and spirits

The nursing team understands the children's and the family's hope for recovery from the illness and provide them with appropriate care accordingly.

In raising hope and spirit, the nursing team skillfully cares for the children to increase the families' confidence in care. Nursing staff also raise the families' spirit by giving them verbal support, giving additional information, and encouraging them to talk to other people.

2) Sharing the feelings

The families express their feelings of sorrow on account of the children's illness. They may share their feeling with nursing staff or with other families of children with cancer.

In sharing their feelings, the families may have conversation or may have emotional expressions such as crying or being depressed. The nursing team consistently assesses the families' feelings, comprehends their expressions, and gives them appropriate mental support.

4.2 Promotion of family's ability in caring for children

Promotion of family's ability refers to nursing team's promoting family's skill in caring for the children with cancer. The nursing team promotes the families' ability in caring for children with cancer by enhancing the families' childcare skills that have existed before the occurrence of the illness. These existing skills can be developed to caring skills for children with cancer. The families also need to develop their abilities in caring for ill children.

The promotion of family's ability consists of child-caring skill development and resource-accessing skill development.

1) Development of child-caring skills

The nursing team enhances the families' skills in caring for an ill child; at the same time, the families develop their abilities in child caring with help and support from the nursing team to gain confidence in caring for the ill child at home.

In the development of child-caring skills, the nursing team assesses the families' ability in caring for children and provides them with suggestion and demonstration for trying out the practice. If the families cannot properly perform childcare, nurses will repeat the information and follow up on the families' practice.

2) Development of resource-accessing skills

The nursing team promotes the families' confidence in selecting health care resources when their children are ill.

For the development of resource-accessing skills, the nursing team gives advice to the families both during hospitalization and when they have returned home after the discharge. The families receive detailed information about health care resources from nursing staff and reflect ideas with nurses about the accessibility of the resources.

4.3 Development of support system

Development of support system refers to the nursing team's collaborating with family to identify and mobilize the resource to enable families to cope with stress. The families and nurses collaboratively survey available health care resources that could be of the highest use for the families. The resources may provide either mental support or financial support to the families.

The nursing team assesses the support system with the families; for example, having a discussion with the families about their health care insurance. Nurses also coordinate with other related professionals to facilitate the families in activating their rights. The nursing team also sets up a support group for the families to exchange experience with each other.

Process of Family-Centered Care application

Process of family-centered care application is a practice continuum of caring for children with cancer with collaboration between children with cancer and their families and the nursing team. The caring is divided into three stages and is based on key principles of family-centered care as detailed below.

Stage 1: Initiation of family-centered care

Hospitalized children with cancer are in various phases of illness. There are children newly diagnosed with cancer as well as those who are in maintenance, relapse, or terminal phase.

Children who are newly diagnosed with cancer are usually hospitalized with acute symptoms. Most of them are admitted to the hospital with infection, thrombocytopenia, and anemia. The children receive symptomatic treatment according to their symptoms; for instance, receiving treatment for infection or receiving blood transfusion in case of severe anemia. At the same time, these children undergo multiple procedures studies such as blood examination, lumbar puncture, bone marrow aspiration, or radiogram. The children are usually scared of medical and nursing procedures, especially small children who always cry in every procedure. The diagnosis will be confirmed after a period of time and the physician will inform the families before an initiation of treatment. Most

families realize that their children have severe illness and are in sorrow. Their emotional responses to the news vary. Some families talk to other families in the same ward. Some families relieve stress and keep their hope by praying for the blessing from sacred images in the hospitals or the ones of their respect. Some families seek more information by reading hospital announcement or asking nurses. Nevertheless, most families start learning about their children's illness.

Some children are in the maintenance, relapse, or terminal phase and are transferred to the hospital for further management. Children in the maintenance phase are normally in an improved condition as they have received treatment from the previous hospital. The families have adjusted to their children's illness and have developed child-caring skills. Children in the relapse phase also have received treatment from the previous hospital. They are transferred for further management because of the recurrence of symptoms and their families have a feeling of sorrow again. They keep their hope by praying to the sacred images, either the ones in the hospital or the images of their respect. The families of children in the relapse phase are able to interpret the children's symptoms and have developed skills in caring for ill children.

When children with cancer are admitted to the hospital – a place that they are not familiar with, they would like to have their families staying close to them. The families want to see their children recover from the illness. They are aware of the importance of participation in caring for children and want to closely care for their children. The families also want information, want to have good relationship with nursing staff, want to be accepted, and want nurses to look after their children when they are not available. On the other hand, nurses want to deliver care to the children with holistic approach, covering physical, psychological, emotional and social aspects. They are also aware of the importance of family participation in caring for the children.

The process of family-centered care for children with cancer starts since the children are admitted to the hospital until they are discharged. The nursing team, children with cancer, and their families have roles in family-centered care as detailed below.

Nurse Roles

The nursing team, which is composed of nurses, nurse assistants, and nurse aides, has roles in establishing rapport with the families, initiating family participation in childcare, learning about the families, and enhancing family's strength.

1. Establishing rapport with the families.

The nursing team establishes a caring and empathetic relationship with the children and their families by talking to them in a friendly manner, expressing willingness to help, starting a conversation in general topics and listening to the families. Nursing staff encourage the families to express their needs. They observe the children's and the families' feeling, listen to them, and are prepared to respond to their needs. The nursing team establishes a good relationship with the children and their families while delivering care.

2. Initiating family participation in childcare

The nursing team gives the families opportunities to participate in caring for the children by assessing their needs in caring for the children and compromising on some hospital regulations to accommodate the families in staying with their children. The nursing team and the families set goals of caring together and collaborate in caring for the children. The families are encouraged to participate in the assessment of children and families, in caring for children receiving medical procedures, and in the delivery of care. The families can also help in the administration of medical treatment and in the prevention of complications from side effects of medications.

At the beginning of hospitalization, the nursing team assesses the families' desires for participation in caring for their children by having a conversation with them. Hospital regulations are eased to allow the families to stay with their children. Nurses and the families set mutual goals of caring together.

The nursing team encourages the families to participate in the assessment and making plans for childcare in pre-conference discussion. Nurses inquire the families about the children and childcare, and at the same time, give information about the illness and appropriate childcare to the families. The nursing team also encourages the families to express their feelings and their needs.

Nursing staff collaborate with the families in caring for the children. When the children undergo medical procedures or medical treatment, the families are allowed to participate in the delivery of care. Nurses give instructions and suggestions about childcare to the families such as, assessment of abnormal symptoms, prevention of complications for illness or treatment, and caring for children receiving intravenous fluid infusion.

3. Learning about the family

The nursing team and the families start learning about each other. At the beginning of hospitalization, the nursing team provides the families with information about the place, the staff and hospital regulations. At the same time, the nursing team listens for information about the children in addition to general information about the families. Nursing staff get to know the children and their families from the assessment with the hospital assessment form, which contains personal information about the child and the family, the child's history of illness, and data about the family regarding income, number of family members, economic status, and financial support. The assessment is conducted by interviewing with the families and observing; data are then collected for making a care plan.

At this stage, the nursing team plays significant roles in giving information to the families as they have not received any information before. The families later receive information about diagnostic investigation and, when the treatment starts, they receive information about medical treatment usually chemotherapy or radiotherapy. Nurses provide the families with information about the illness, caring for children receiving chemotherapy, and caring for children with low immunity. They also give the families brochures about these issues and give times for the families to talk and to ask questions. Most families are interested in the illness, its treatment and the progression. Apart from giving advice to the families, nursing staff also coordinate with physicians about the treatment

For the families of children in the maintenance, relapse, or terminal phase, nurses assess their existing knowledge about the illness and management of illness. They also have conversations with the families to learn about the families' background knowledge for further provision of information to the families.

4. Enhancing family's strength

The nursing team helps the families in keeping and enhancing their strength to overcome the feeling of sorrow. Nursing staff consistently give help and support to the families, listen to them, and understand their emotional expressions and feelings. They provide the parents with mental support and help the parents to adjust to the sorrowful situation. They listen to the parents' talk about hope and belief. The nursing team set a support group for the families to share their feelings. For the families of children in the maintenance, relapse, or terminal phases, nurses observe their expressions and feelings of distress and give them mental support accordingly.

The nursing team assesses the families' resources of financial support and their health care insurance to assist them in activating their rights for health care service.

Nurses promote the families' abilities in childcare after observing their performance of caring activities. The families are usually able to perform basic caring activities when their children have symptoms of complications from the illness or from side effects of the medications. When the children are scheduled for hospital discharge, the nursing team develops a discharge plan in collaboration with the families and reviews all instructions and suggestions previously given to them. More information regarding abnormal symptoms that require physicians' visits is also given to the families. For the families of children in the maintenance, relapse, or terminal phase, the nursing team observes their abilities in caring for the children and gives instructions and suggestions to them when an incorrect or inappropriate performance is observed.

Family Roles

The family roles are having interaction with nursing staff, comprehending instructions from nurses and inducing understanding in children and their families among nursing staff, and participating in caring for the children.

1. Having interaction with nursing staff

The families of children newly admitted to the hospital start having interaction with nursing staff.

2. Comprehending instructions from nurses and inducing understanding in children and their families among nursing staff

The families study general information and specific information about the children's illness. They also give information about their children to the nursing team.

3. Participating in caring for the children

The families play significant roles in providing close care to their children. The provision of care varies in each family. Most families have a family member, which may be the mother, the father, or the grandmother but mostly the mother, stay at the hospital with their children. This family member may leave a full-time job to specifically care for the ill child. Some families of older children may come to visit in the morning and go back home in the evening. The families mostly collaborate with the nursing team in the delivery of care in response to basic physical and psychological needs; for example, caring for the children's daily activities such as personal hygiene care or dietary or giving simple nursing care such as giving oral medication, caring of nausea and vomiting symptoms. The families also report nurses about symptoms of complications from the side effects of treatment or the changes in children's symptoms.

Child Roles

Children's roles consist of adhering to treatment plans, receiving care from nurses and the family, performing self-care, and playing.

1. Adhering to treatment plan

The children's key role is adherence to treatment plans as they are hospitalized on account of severe illness. The children need to undergo various investigations and receive medical treatment such as chemotherapy or radiotherapy.

2. Coordinating care among nurses, children, and the families

The treatment may induce complications; thus, the children require collaborative care from the nursing team and their families. The diagnostic investigations

and side effects of medical treatment also contribute to the requirement of care and mental support, especially among small children.

3. Performing self-care

Older children strictly follow nurses' suggestions. They observe their symptoms and inform the families about abnormal symptoms. They can perform daily activities by themselves with help from the families.

4. Playing

Children with improved symptoms may play with their families in bed or may leave their bed to play in the play area.

At this stage, the families and the nursing team have established a good relationship with each other. The families are satisfied that they can stay with their children to closely care for them. They try to learn about the children's illness and are able to care for their children as advised by nurses. They ask questions when they feel uncertain about their performance. The families feel relieved when their children have improved symptoms and become relaxed. They get familiar with the nursing staff and have gained courage in exchanging information with the nursing team.

Stage 2: Mutual caring

At this stage, the children are usually in the maintenance phase. They have improved symptoms after receiving treatment during the newly diagnosed phase. The children have stayed at home for a while before coming back to the hospital for continuous treatment with either chemotherapy or radiotherapy. Some children are hospitalized for the management of complications such as infection, anemia, or bleeding tendency.

The families are familiar with the ward, the staff and hospital regulations at this stage. They also have knowledge and understanding about the illness, the treatment plan, and childcare and are able to assess the children's abnormal symptoms. They feel less distressed as the children are in an improved condition. Most families are able to comprehend the children's illness and symptoms; however, some families may not understand some issues and have questions about the illness.

Nurse Roles

1. Maintaining a good relationship with family

The nursing team continues establishing a good relationship with the families. The families and the nursing team exchange more knowledge and information at this stage. The families have courage to ask for more information from nursing staff.

2. Collaboration in childcare

The nursing team and the families collaborate in assessment of children and in making plans for childcare. The nursing team conducted pre-conference discussion with family participation. The families have obtained skills in the interpretation of children's symptoms and are able to perform childcare as suggested by the nursing team. Some families may inquire the nursing team about childcare when they feel uncertain about their performance.

3. Enhancing family's abilities in childcare

The nursing team observes the families' performance and inquires them for more information to assess their knowledge and abilities in childcare. The results of assessment are subsequently used for continuous development of child-caring skills by the review of knowledge and demonstration. When a child is scheduled for hospital discharge, the nursing team gives feedback to the family for the review of previously given knowledge. The information that is forgotten will be repeated and new information is given, as well as suggestions for the child's compliance with treatment.

Family Roles

1. Asking questions and giving reports about childcare

The families have experience and have learned information previously given to them; thus, they have better understanding about the children's illness, are able to assess the children's abnormal symptoms, and are able to interpret symptoms of illness. For example, when a child has fever and coughs, the family knows that the child has respiratory tract infection. Nevertheless, the families still have questions and are uncertain about caring for their children; therefore, they are likely to give nurses information and ask for more knowledge. The family's learning about illness varies.

Some families learn about the numbers and functions of different red cells, illness problems, and how to care for the child accordingly. For instance, the families who learn that a reduction in numbers of white blood cells makes the child susceptible to infection will make sure that the child receives good hygiene care and clean food. The families play important roles in assessing and giving nurses reports about the children's abnormal symptoms based on their interpretation e.g. children have oral ulcers and can eat less food; the families, therefore, can also prevent the children from possible complications.

2. Providing childcare that is appropriate for the illness

The families deliver appropriate childcare in children's daily activities with relevance to their physical illness and psychological condition. For instance, when a child has thrombocytopenia, the family asks the child to use mouth wash for oral care instead of toothbrush.

3. Giving complicated nursing care

The families deliver more complicated care to the children such as caring for bottom wet-compress, management of complications from side effects of chemotherapy, and oral hygiene care.

Child Roles

1. Monitoring and taking care of one's self

The children play roles in caring for themselves; for instance, they observe their symptoms, personal hygiene care, or diet, depending on the severity of symptoms of complications from side effects of chemotherapy.

2. Playing

The children who are not too tired may play in the play area. The very small children and very tired children may play with their families in bed.

At this stage, the children and their families are familiar with nursing staff. The families have courage to exchange information with the nursing team, are able to interpret and understand the children's illness, and have developed child-caring skills. Some families go back to work as usual.

Stage 3: Care directed by the family

At this stage, the families have gained knowledge and have developed child-caring skills to the extent that they have expertise in caring for their children. Some families have children in the maintenance phase, just prior to the discontinuation of treatment; some families have children at the beginning of the relapse phase; and others have children in the terminal phase.

The families of children in the maintenance phase, prior to the discontinuation of treatment, feel uncertain and are worried about the recurrence of illness. In addition, they do not understand proper childcare after the treatment is completed.

The children in the relapse phase are usually depressed, do not talk much, and are highly annoyed with any medical procedure as they have been receiving treatment and they think they have recovered from the illness. The families of these children sense the feeling of sorrow again. Some families seek alternative treatment such as herbal medicines or Chinese traditional medications as they find the medications help improve the children's symptoms.

As for the children who are in the terminal phase, in this phase, the children are usually faced with severe illness such as severe infection, brain metastasis of malignant cells, or dyspnea. The children always express needs of care from the family as shown in their behaviors such as clinging on the family or not letting the family leave their side. The children whose family cannot stay with them will frequently call for nurses. The children in this phase need to be close with their family, and when their family is unavailable, need close care from nursing staff.

Nurse Roles

1. Establishing a caring and empathetic relationship

At this stage, the nursing team, the children, and the families have known and are familiar with each other for a while. The nursing team maintains a caring and empathetic relationship with the families and accepts them as they are.

2. Being a facilitator

The roles of the nursing team and the families in caring for the children tend to be more collaborative as the families have gained experience and have expertise in caring for their children. The nursing team plays roles of an adviser and a listener. Nursing staff observe the families' performance, give help, and facilitate them in caring for the children, as the families may not be able to stay with the children all the time.

3. Maintaining consistent communication

The families are able to care for the children by themselves as they have expertise and have developed child-caring skills. They can interpret the children's abnormal symptoms. The nursing team consistently monitors the families' performance and regularly communicates with them about the condition of illness. For a child with many relatives, nursing staff give consistent information to all relatives.

4. Maintaining hope

The families of children reaching the phase of discontinuation of treatment usually feel uncertain and are worried about the recurrence of illness. The families of children in the terminal phase are in distress with fear of losing their children. Nurses give them mental support by assessing their feelings, comprehending, and accepting their emotional expressions. Nursing staff deliver skillful care to ensure the families, give mental support verbally, and provide them with more information, as well as have a discussion about their beliefs.

5. Supporting positive coping behavior

Nurses understand family differences and deliver care accordingly. For example, in the aspect of emotional expression, some families may be very quiet and not verbal whereas other families openly express the feelings of confusion and cry out loud. In response, nurses accept either behavior, understand them, and, at the same time, give them mental support to enhance their abilities to cope with stress.

Family Roles

1. Giving care to the child

The families are familiar with the place, the staff and the hospital regulations. They are able to care for the child by themselves, either in the performance of daily activities, nursing care, or in the management of complications from the illness

and the treatment. The families communicate their needs and the children's needs of help for the activities that they are unable to perform themselves.

2. Express their needs

The families have expertise in caring for the children; however, they may be psychologically disturbed since their children are in the relapse or terminal phase. The families may lose their confidence in caring for the children and require help from the nursing team.

Child Roles

1. Cooperation in care

Nurses and the families have to give them symptoms management and mental support to help them overcome the sufferings while children with severe symptoms receive care from the nursing team.

2. Negotiation in care

Older children in a relapse phase commonly feel annoyed with painful medical procedures. They may ask for the physician to postpone the procedures. Nurses and physician may be flexible.

At this stage, the families have gained strength and have accepted the illness. They have adapted themselves to the children's illness and can live a normal life. They have gained expertise in childcare and are able to care for the children on their own with appropriate response to the children's needs. They can also communicate with nurses to express their needs. However, some families are mentally weak because their children are in the terminal phase, and they need help and support from the nursing team.

Factors affecting family-centered care application

Factors affecting family-centered care process of practice consist of child developmental stage; stage of child's illness; severity of illness; family's coping; policy, philosophy, and regulation; setting; and nurses' attitudes and knowledge.

1. Child developmental stage

Children have different needs, depending on their age. Child developmental stage influences family-centered care application. Younger children like to be close to

their families; they are not familiar with strangers. Hence, this affects the relationship with nurses who care for them. In addition, developmental stage affects mutual learning and collaboration among the children and nursing staff. Younger children cannot participate in care for themselves; they need care from their families.

The child's age needs to be taken into consideration in information sharing between nurses and the family. For small children, information should be given to the mothers who can teach the children later. For school children, nurses should directly share information with the children, using simple and logical language. For teenagers, nurses should give them opportunities to participate in decision-making.

2. Stage of child's illness

Stage of illness affects mutual learning. At the beginning of the diagnosis, the parents do not have much knowledge and experience about the child's illness and disorders. Nurses play a major role in teaching and giving advice. Each family is interested in different topics of information; nevertheless, most of them want to know about the treatment and progress of the disease. Nurses provide information about abnormal symptoms, childcare, and monitor of symptom changes. At the maintenance stage, the parents have gained more knowledge as they have experience in caring for the child at home; therefore, they have combined their experience with the knowledge and they can interpret the child's symptoms. Information sharing at this stage tends to be the provision of feedback so that the family could apply the feedback to their practice. For children at the relapse stage and terminal stage, nurses should spend time with the family to listen, answer questions, and give them mental support.

In addition, the stage of illness has effects on nurse-family collaboration. For children newly diagnosed with cancer, nurses usually provide care concerning condition of illness, whereas the mothers give mental support to induce the sense of warmth and security. The mothers also help the children by expressing love, giving them consolation, and answering to their basic needs. For children at maintenance, relapse, and terminal stages, the families already have some experience in caring for their children; hence, the level of collaboration is different from the families of children at earlier stages. At the later stages of illness, the families are able to assess and observe abnormal symptoms and

they can interpret the illness condition, as well as being able to deliver simple nursing care to their children.

3. Severity of child's illness

Condition of illness has effects on the level of collaboration as severe illness has strong impacts on the family and may alter the family's abilities in caring for the child. Mothers who used to be able to deliver some nursing care may not be able to maintain their capacity when their children are severely ill. Thus, in collaborating with the family, nurses should assess and observe the care requirements of the family. They should also give the family opportunities to participate in the delivery of care for the family's improvement of capacity in caring for the child.

4. Family coping

Families have different behaviors in coping with stress. Some families may openly express their feelings whereas other families may not explicitly show their feelings. Some families may like to ask for information whereas some may wait for nurses to give them information. Hence, nurses should assess the family's requirements of information and should give complete answer to the family with no presence of annoyance. For the families not having an inquiry, nurses should observe their delivery of childcare to find out any misunderstanding or incorrect practice so that appropriate knowledge could be given for improved practice. Moreover, nurses should also assess family differences to adjust the contents and method of information sharing. The family's stress has an effect on the relationship with the nursing team. In addition, family's stress affects participation of the family. Sometimes, they need help from the nursing team in caring for their children. Furthermore, they may not learn new information from the nursing team.

5. Policy, Philosophy and Regulations

The study site of this research has the philosophy of care that emphasizes patient-centered care. Despite lack of written evidence for the support of family-centered care, during the discussion about caring problems in the unit, the administrators of the workplace pointed out that the philosophy of patient-centered care includes family care. The administrators and the nursing team are aware of the philosophy of caring and

subsequently participate in the development of family-centered care model for children with cancer.

Although the study site unit emphasizes patient-centered care, a hospital regulation indicates visiting hours at 8.00 a.m. to 8.00 p.m.; thus, nursing practice is affected as nurses feel that they should follow the regulation. Some nurses are uncertain, and others do not have the courage to allow the families to stay with their children beyond visiting hours. Hence, the regulation has an impact on the families' opportunities to deliver close care to their children.

6. Setting

The ward does not prepare facilities, such as beds, toilets, rooms, or laundry services, for the families to stay with their children; hence, it is not convenient for the families to stay at the hospital. This, therefore, has effects on the family's participation in caring for their children.

7. Nurses' attitudes

Nurses express positive attitudes towards family-centered care. They are aware of family importance, hence having motivation for the application of family-centered care in their practice. If nurses have negative attitudes towards family-centered care, the application will certainly be affected. In this study, nurses were aware of the importance of family's participation; as a result, they were motivated to participate with the families and succeeded in developing the family-centered care model.

8. Nurses' knowledge

Nurses who have knowledge about the concept of family-centered care play an important part in the application of knowledge to clinical practice. In this study, most nurses have positive attitudes but they were not certain whether their nursing practice was based on the family-centered care concept. The enhancement of their knowledge and understanding proved helpful in the development of family-centered care model.

The effects of the family-centered care model development on nursing staff

The effects of the care model development on nurses were evaluated through in-depth interviews and focus group discussions. The in-depth interviews and focus group

discussions were recorded on tape cassettes and were subsequently transcribed to obtain detailed data. The data were subsequently analyzed, in addition to data from field-study record of observation during participation action. The effects of care model development on nurses comprised the adoption of family-centered care as standard practice, the revision of nursing practice, and developing more self-esteem and professionalism.

1. Acceptance of family-centered care as standard practice

Most nurses adopted family-centered care as their standard nursing practice. They applied family-centered care in every nursing activity; the application of the model was natural.

1.1 Applying family-centered care in every nursing activity

Nurses were aware of the importance of family-centered care and applied the care in every nursing activity they delivered to children with cancer and the family. For example, in an assessment of a child's symptoms with the family, nurses also assessed the family's capacity and enhanced their ability in caring for the child, as reported in the following statements:

'I can do it in a way that is quite harmonious to our work now. Everybody thinks about the family, not just the patient, all the time. We always think about the family.'

1.2 Applying family-centered care naturally

Nurses naturally delivered family-centered care to children with cancer:

'I've changed. I might do it without thinking before, and I might do it or might not do it at all. But now, it's good to conduct this practice, so it comes naturally with our work. I don't have to force myself to do it. It just happens. The others feel the same.'

2. Revision of nursing practice

Nurses commented that the delivery of nursing care to children with cancer and the family had changed from previous practice as there were more communication and constant sharing of information, leading to increased care for the family, assessment of children's and family's needs, and more opportunities for children and the family to participate in the delivery of care.

2.1 Increased communication and constant sharing of information

Nurses remarked that they always had a conversation with children and the family while giving nursing care and always asked them questions during the shift report. Nurses continuously communicated with the family by integrating it into their routine work:

‘We share information all the time. When they come to see me, I’ll ask if I can help, if they are alright, or if there is any problem. Since in the morning we can ask about the problem. We may not help them during the transfer of shifts, but we’ll do it later. They may suggest something or give me some information, and I’ll adjust the work accordingly, in response to them.’

2.2 Increased care for the family

Nurses commented that in addition to caring for the child, they also assessed the family’s problems and delivered care to both the child and the family. Two nurses shared the sentiments:

‘Instead of just caring for the child, we care for the family too. Do they have any anxiety? We saw that they were worried before, but we didn’t think much about it. Now, when we see the problems, we transfer them to the next shift, using Kardex and the nursing care plan.’

2.3 Assessment of the child’s and the family’s needs

Nurses remarked that they asked for more information from the family by inquiring about the child’s and the family’s requirements. They also gave the family more opportunities to inform them about the child’s needs:

‘It has changed. In the past we delivered care to the patient and we thought we did our best, but we never asked what the children liked, what they liked to do, what they liked to eat, or what could make them live happily or we may have asked the children, but we never talked to the family.’

2.4 Provision of more opportunities for the family to express their opinion

Nurses gave more opportunities for the family to express their opinion:

‘I thought it was good enough in the past but, actually, it was not as good as we thought because we assumed it on our own. We did not let the family think, and did not ask them what they thought or what they wanted. We did things for them and we thought that it was good. Now, we ask what they want first or if they actually need it. At this point we ask them.

They can tell us what they want and can give suggestion. We've changed our way of thinking.'

3. Nurses developing more self-esteem and professionalism

Nurses' attitudes towards themselves changed as they developed understanding about nursing autonomy; had self-development regarding knowledge, thoughts, and practice; and were proud of themselves.

3.1 Understanding about nursing autonomy

Nurses felt that they were important and they recognized independent roles that they could perform for benefits of the child and the family:

'I feel that I am more important. Our role is not to follow other people or follow somebody's order. We have an independent role that we can perform and it is beneficial for the patient within the scope of our profession. The unit becomes better, too.'

3.2 Feeling of self-development

Nurses reported that the participation in the development of the care model was beneficial for them as they improved their knowledge, thoughts, and practice.

Improved knowledge

Nurses commented that they were more enthusiastic in seeking knowledge by reading and asking other people:

'What we don't know, we won't dare telling the patients so we need to read or ask the doctors. It encourages me to learn and to search for more information from reading and asking others'

Improved thoughts

Nurses felt that their way of thinking was improved as they did not only think about the child but also the family. Moreover, the improved thoughts led to improved practice:

'I think I have improved my thinking, changing myself and accepting other people, including the child and the family, more than before. We have all improved. It's noticeable.'

Improved practice

Nurses reported that the participation in the development of care model led to improvement in their practice as they learned the child's and the family's behaviors:

'I've really improved myself. I did not talk with the patients much before this, but lately I talk a lot more, not only joking with them. Sometimes we don't need to speak, but we can use our expression and manners. We smile, communicate about something else, show them that we care and make them feel that they are participating in our nursing care. We accept their opinions and make it clear. Patients' relatives may have some little problems and would like to talk to us; we can respond to them.'

3.3 Delivery of nursing care with principle

Nurses reported that the development of the care model provided them with more principles for the nursing practice:

'What we are doing now, compared with what we did before, is more structured and has some points. We now have the concept and we follow this concept. Then we have our nursing practice based on this concept, which we understand now.'

3.4 Being proud of one's self

Nurses were proud that they could provide quality care to children and their families and were proud of their practice. A nurse said:

'I am quite proud. I feel that I've offered quite quality work.'

Effects of family-centered care on the child and the family

The effects of family-centered care on the child and the family were evaluated via in-depth interviews with the family before the child was discharged from the hospital. The effect of the care model on the children and their families comprised of the children were healthy, The family is openly and continuously to communicate with nurses, families were confident in caring their children, and families being satisfied with the nursing care.

1. The child being healthy

Information from in-depth interviews with the family revealed that most families thought the family-centered care resulted in healthy condition of the children, in both

physical and mental aspects. In this study, the children receiving care from their families were happy, could eat and could sleep well. They received care with constant observation of symptoms and quick detection of abnormal symptoms. This partly contributed to healthy condition and prevention of complication. A mother of a child with leukemia reflected on her observation:

‘My child is lively, has friends and is much better now. He’s healthy and cheerful, likes reading and can get along well with others.’

2. The family openly and continuously communicating with nurses

It is evident that the families receiving family centered care have courage to ask the nursing team for more information and express their opinions as well as their feelings with the nursing team. Nurses observed that most families had changed their communication behaviors as they gained courage to inform nurses about the child, to ask about the child and to exchange information about caring for the child. A nurse said:

‘The relatives are enthusiastic to talk to us. Their child’s symptoms change a little bit and they come to tell us. I guess they were afraid before. I don’t know. They did not come to us unless we asked ‘How’s your child?’ Then, they told us. Now they come directly to us to talk about their child. They have enough courage to give us information.’

‘The patients have courage to ask more questions. In the past, they just had a blank face when they were in doubt, did not dare to ask any questions, or did not know what to ask. Now we talk to them more often, so they feel more comfortable to ask and to tell us about the child’s symptoms.’

‘The family has a lot they can do. They know a lot more about the disease. They have some ideas: ‘Does this happen because of this thing or that thing?’ They have opinions and they’ll tell us. They may say ‘my child has an oral ulcer,’ which sometimes we don’t know.’

3. Family being confident in caring for children with cancer

In this study, the families gained confidence in caring for their children at home as they have received suggestions and feedback from nurses. As a result, they developed skills in caring for the children and were confident in their abilities to care for the children. Nurses observed the family’s behaviors in caring for the child and found that they were able to deliver appropriate care to the child, as one nurse point out:

‘In the past, the family were not confident in caring for the child and kept calling us for help. Now, they try to help the child first, like giving the child tepid sponge. They did not have the courage to do it before, or they did not dare touching the child at all. We have taught them to give tepid sponge and explained to them that it relieves heat from the body. Now they ask to measure the child’s temperature and can do this activity correctly.’

4. Families being satisfied with the nursing care

Evaluating their conversations with families, nurses felt that the families were satisfied with the nursing care:

‘It’s good for the patient and the family. We don’t get the result in the form of scores, but we can tell from having conversations with the families. They said nurses are good here. They have been to many places and have ended up coming to us. This could be an answer. We put ourselves in their places. They said we are good, and it is not the same elsewhere.’

CHAPTER V

DISCUSSION

The study results are compared to previous relevant theories and studies. The purpose of the comparison is to find their similarities and differences and identify specific contribution of the current study. These discussions are divided into three sections. They are the situation in caring for the children with cancer, a process of development of family-centered care model, and a family-centered care model in a pediatric cancer unit.

Situation in caring for children with cancer

The study of the perception of the children with cancer and their families, and nurses revealed that nurses pay attention to caring children with medical treatment plan and parents take care of mental treatment. Nurses expect to delivery care to the children with holistic approach that means a family-centered care. This system consists of closed caring by family, creating relationship, sharing information, incorporating in childcare, and encouraging parental abilities. As for the family's need for caring children, the most important need is to stay with and care for children at all times. The following needs are to communicate and create relationship, to have information, to be accepted, and to have nurses take care of the child when the family is absent. For children, they require close mother's care, nurse talking to them with tender words, and taking part in fun activities.

The results of this study are compared to those of the study of Enskar and Essen. Enskar and Essen (2000) examined aspects of care and assistance that are important for 8–12-year-old children with cancer through interviewing children, parents and nurses. The identified important caring aspects were amusement, clinical competence, continuity, family participation, honest communication, information, participation in decision making, satisfaction of basic needs, and social competence, and time.

Children most frequently mentioned the importance of social competence, amusement, and satisfaction of basic needs. Parents and nurses most frequently mentioned the important of information, social competence and participation in decision making.

The results of this study are in accordance with the study of Enskar and Essen in the case of the nursing need of children that amuses them. The need of children for close relationship with parents in this study was nearly compatible with the case of child satisfaction of basic need in the study of Enskar and Essen. Staying with parents is basic necessity for all children because children will obtain essential responses. Moreover, the children need tender communication from nurses which requires social ability of nurses to use an effective communication technique with children.

The study of family care need found that parents want to take care of their children closely, to communicate and create relationship, and to have necessary information. This study was different from the study of Enskar and Essen (2000), that found that parents wanted to take charge of information. This can explain that in this office paid attention mainly to information. Thus, parents needed less information. The parents, who paid attention to staying and taking care of their child closely in the hospital, would encourage their child. This may be due to Thai culture that recognize the significance of staying together when sickness occurs in the family, especially in children who rely on parents. The study of nurses' care perception on a child and parents revealed that nurses were in charge of child caring according to medical treatment plan and parents were in charge of mental caring. This finding differed from the study of Enskar and Essen (2000) that pointed out that nurses paid attention to sharing information, social ability and participation on making decision.

The study of nurses' attitudes toward a family-centered care found that nurses perceived that child caring was a holistic care covering physical, mental, and social aspects. The holistic care approach was in agreement with the concept of a family-centered care, but its application was not complete in practice. This study result was compatible with many studies that indicated nurses' perception on the importance of the entire concept of a family-centered care. However, nurses did not take all caring activities into daily practice. Bruce and Ritchie (1977) and Letourneau (1996) found that a caring application with family-centered approach was difficult to practice. It was

opposed to allow family to participate in decision making and treatment (Galvin et al., 2000). Moreover, Shield and King (2001) conducted a study in England, Australia, Indonesia and Thailand and found that although some hospitals had their policy in a family-centered care, it was unable to practice this in reality.

The roles of nurses and parents in the family-centered care model according to the perceptions of children with cancer, family and nurses in the present situation have been investigated. The majority of parents proposed that the most important role of family was to be there with children with cancer. This role is compatible with the study of Shield and Kings (2001) which found that some Thai parents were prepared to lose their job because they felt it was more important to stay with their sick child.

This study, moreover, found that parents were able to stay and take care of their child from 09.00 a.m. to 08.00 p.m. For very young children, infants and seriously ill children, nurses were flexible to let parents stay with them. However, in general, Thai staff thought that the mother should go home and leave the child for the staff to look after. They gave the reason for allowing parents to stay with the children that the parents would help with mental care. Allowing parents to stay with the children must follow the hospital regulations. This finding was congruent with the study of Shield and Kings (2001). They suggested that Thai parents were not allowed to stay with the children all the time unless the children were seriously ill.

This study also found that parents wanted to participate in looking after the children. The most important option was to stay with the children in order to help do daily activities, entertain them, and was hold them when they were getting hurt from medical treatment. Moreover, the parents were able to support nurses' task, such as giving medication and caring for children receiving intravenous fluid infusion. This study agreed with the studies of the need for parents to stay, encourage, and respond to the basic child requirements (Mc.Donald, 1969, cited in Darbyshire, 1993), child comfort and entertainment (Hill, 1975, cited in Darbyshire, 1993), and unwanted participation in nursing technique (Hawthorn, 1974, cited in Darbyshire, 1993).

Nurses also suggested that parents should participate in the child's symptom examination, provide information to nurses, cooperate in planning, and share child caring. The suggestion included daily child caring, preliminary nursing practice, risk and intervened symptom prevention, and child cooperation in treatment. Moreover,

nurses proposed that parents should participate in caring and treatment decision. This study differed from the study of Shield and King (2000), citing that the officers did not pay attention to child caring participation. Nurses also perceived least importance of nurses and parent cooperation (Bruce, et al, 2002).

The process of the family-centered care development

In this study, the nurses acknowledged that caring for the children with cancer and their families was part of their roles based on the concept of family-centered care. The results described that the nursing participants received appropriate education opportunities, and conflict management practice during reflective practice. Guidelines describing the role of the families on the unit helped nursing participants to understand the roles of the nurse and the families according to the concept of family-centered care. They practiced in an environment that supported and enabled them to empower family-centered care. In addition, they received the continued support from management to keep them practicing the skill. The gain in these skills could change their personal views toward parents, and these skill could be transferred into day-to-day practice.

The process of development of the family-centered care model is supported by various concepts, theories, and previous studies as follows:

The development process of a family-centered care supported Bandura's Social Learning Theory in the context of knowledge and perception development of nurses. According to Bandura's Social Learning Theory, a complex repertoire of behaviors can be learned by watching and emulating the action of others (Bandura, 1969). The theory suggests that a diversity of possible actions, based upon direct or vicarious experiences with actual or symbolic models, can be used. Coding into images or words (or that which permits retrieval and reproduction) facilitates the imitation of discrete response demonstrated by a model, and adding verbal equivalents of the modeled stimuli results in more closely matched responses.

The literatures explain the method of social learning in order to increase skills of clinical settings. The explanation includes role modeling and reflective practices.

Role modeling is defined as a process through which persons take on the values and behaviors of another through identification (Bidwell and Brasler, 1989, cited in

Tomlinson et al, 2002). The role modeling incorporates knowledge gained through observation of clinical role model and emphasizes the artistic rather than the scientific aspect of practice. Thus, what is done is stressed rather than the theoretical underpinnings of the action (Davies 1993, cited in Tomlinson et al, 2002). At the first stage of this study, the researcher performed as a role modeling for nurses. After that, experienced, knowledgeable and skillful nurses in a family-centered care repeated the practice as the role models for other nurses to simulate it further. Establishing the importance of a family-centered care of the researcher and senior nurses gave rise to the suggestion of family care behavior, learning value, repeating action, observation, and prizing to a corporate nursing team. This made the nursing team learn complex behavior of the family.

Reflective practice is a method to integrate theory with application. Schon (1987 cited in Tomlinson et al, 2002) suggested persons learn to reflect-in-action by (a) recognizing and applying standard, rule, facts, and operation; (b) reasoning from general rules to specific cases; and then (c) developing and testing new form of understanding and activities when familiar arrangements fail. In this study, the researcher made use of the technique of reflective practice to advocate nurses to understand and practice the knowledge. This technique was conducted through contributing a family-centered care and its components, taking its concept into action, reflecting practice among nurses within a team during taking action, and organizing the meeting every morning.

Reflective practice includes reflection when occurs when a practitioner is engaged in a situation (reflect in action) while the other includes reflection following practice (reflection-on-action). Both types of reflection have significant strength for developing a plan to help change practice in a given setting. Regardless of the type and the time of reflection, the process is necessary for practitioner to rationally analyze their action and to develop their own practice theories that can guide future actions.

From various learning techniques, being mentor, role model and reflective practitioner helps generating learning environment within the office. This also develops abilities of nurses in family caring. Finally, nurses are able to learn from demonstration and develop themselves in family caring. The gain in knowledge and

practice expertise with families by nurses could be transferred into their ongoing day-to-day practice.

The development of a family-centered care model in this study supports the concept of Bloom (1956). Bloom divided the aims of education into three aspects, namely, cognitive domain, affective domain, and psychomotor domain. He ranged five stages of learning. The first stage is receiving or attending, meaning the learner perceives psychomotor cognition. The second stage is responding, meaning the learner gains cognition, is interested in its value, and has opportunity to respond to one characteristic. The next stage is valuing, meaning the learner gains experiences in that value, realizes its value, and has positive attitudes of that value. The fourth stage is organization, meaning the learner takes the valuable value into his/her values. The final stage is characterization, meaning the learner performs according to gained values frequently until it becomes a habit. This study arranged a case study of child caring, starting from admitting a child into the hospital until allowing him/her to go back home. During treatment, there was a case study discussion every morning, analyzing information for the child and parents, and planning for a family-centered care. This is to help nurses realize the value of a family-centered care. During meetings, the study allowed nurses to express their ideas of caring and practice it. When nurses realized the practical value that was useful for the child and parents, they developed the positive attitudes of a family-centered care treatment and practiced it regularly. The researcher and the nursing team followed up the results together, feedbacks, and encouraged the nurses and their team time to time until they were able to practice it regularly.

The process of a family-centered care development supports the concept of the change process outlined by Lewin (1947, 1951, cited in Huber, 2000: 297-298). A successful change involves three elements: unfreezing, moving, and refreezing. Lewin's theory of change uses ideas of equilibrium within systems. Unfreezing, the first stage of change, can be characterized as a process of thawing out the system and creating the motivation or readiness for change. An awareness of the need for change occurs. This first stage is cognitive exposure to the change idea, diagnosis of the problem, and work to generate alternative solutions. The unfreezing stage is complete when those involved understand and accept the necessity of change. The second

change stage is moving. This means proceeding to a new level of behavior, which implies that the actual visible change occurs in this stage. When the individuals involved collect adequate information to clarify and identify the problem, the change itself can be planned and initiated. Lewin observed that a process of “cognitive redefinition,” or looking at the problem from a new perspective, occurs. In the moving stage, the change can be pretested and a transition period launched. The final change stage is refreezing. In this stage, new changes are integrated and stabilized. Reinforcement of behavior is crucial as individuals integrate the change into their own value systems. Techniques of positive feedback, encouragement, and constructive criticism reinforce new behavior.

This study is in the stage of situation reflection and problem identification. The researcher interviewed nurses about caring for children with cancer and parents, and found that nurses’ care did not cover all aspects. However, they expected the care to cover physical, mental, emotional, and family aspects. After that, the researcher summarized information analysis from the study of present situation and proposed the results to the meeting. The information analysis revealed that there were three answers from nurses: certain support, uncertain support, and no support. This means that there was an incentive to change from the current practice at this stage, but it did not cover all aspects of a family-centered care. When passing to the second stage: the response to new change, the researcher proposed the meaning of new change: the concept of a family-centered care. The objective of this proposal was to create belief and value, as well as learning attention by imitation. This research named cognitive redefinition through positive identification. The researcher did not use administrative position to force them. The nurses gradually learned information of a family-centered care from a case study. They were able to exercise caring according to the family-centered care concept. When passing through the third stage, the nurses combined their personal manner with the responding behavior of a family-centered care to be a natural practice with social reinforcement and encouragement from the researcher and the participating nursing team. The nurses were finally trained to develop personal professional manner.

A Family-Centered Care Model in a Pediatric Cancer Unit

A family-centered care model in a pediatric cancer unit is a theoretical nursing conduct and theoretical approach in practice. This model decreases a gap between theory and application. The solution of the theory practice gap is the practitioners to become directly involved in nursing research with relevance to their own practice to enter into collaboration with the trained researcher in action research projects (Gary, 1996: 3).

This model reflects the holistic nursing care, including children's physical, psychological, and spiritual aspects. The model consist of four concepts: a caring and empathetic relationship, mutual knowing, partnership, and enhancing strength. The caring model that is developed to be family-centered care realizes a child's essence. Parent partnership is a component of family-centered care. The children receive care from their families. Horizontal relationship with parents is an essential component of spirituality. In addition, activities such as holding and comforting in childcare result in outcome that will assist in nurturing the child and family's spiritual life (Hart & Schneider, 1997: 263).

Key principle of family-centered care

Components of a family-centered care structure from this study are consistent with the Elements of the Family-Centered Care of Shelton and Stepanek (1995). The elements are those of:

- recognizing that the family is the constant in a child's life;
- facilitating parental/professional collaboration;
- recognizing family strengths and individuality;
- respecting different methods of coping;
- sharing information;
- encouraging and facilitating parents to parental support;
- understanding and incorporating the developmental needs of children;
- implementing appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of the families;
- assuring that the design of the health care delivery system is flexible and responsive to family needs.

Partnership reflects the component of facilitating parental/professional collaboration, and mutual knowing indicates evidently the ingredients of a family-centered care concept of sharing information. Enhanced strength reflects the components of recognizing family is strengths and individuality. A family members' accepting component reflects the ingredient of different family backgrounds in needs encounter with stress.

A caring and empathetic relationship is one component of a family-centered care developed in this study that is different from those of Shelton and Stepanek (1995). However, this component is compatible with those of Hutchfield (1999). Hutchfield, in attribute of the concept of family-centered care, pointed out that a relationship exists between family and professional that is not judgmental and based on honest and open communication.

Comparing a family-centered care model to the previous one reveals that in this study a nurse team had passed the process of knowledge and skill care development before developing care with the family. This study was congruent with the work of Coleman, 1998 (cited in Smith, Coleman, and Bradshaw, 2002) that offered an empowerment model for family-centered care. Coleman's model suggested that nurses need to empower themselves to be able to empower families in practice. Nurses are empowered by education to develop skill to empower others. The nurse, child, and family formulate partnership and build up a caring and empathetic relationship. Activities include critical consciousness raising, discovering reality, connecting with reality, mutual knowing, mutual goal setting, collaboration and partnership, learning and skill development, increasing responsibilities, and participation experiences. Their concurrence is a model development for family-centered care. Both studies began with nurses' ability development before entering the process of participating between nurse and the family. Moreover, the components of a family-centered care model were consistent with activities of mutual knowing and partnership proposed by Coleman.

Process of family-centered care model application

According to this study, it was found that the process of family-centered care for the children with cancer comprised of three stages: initiation of family-centered care, mutual caring, and care directed by the family. This study was congruent with the hierarchy of family-centered care which consisted of parental involvement, parental participation, partnership with parents, and family-centered care (Hutchfield, 1999: 1185).

Initiation of family-centered care is similar to parental involvement. Relationship is likely to be nurse led; communication is emphasis on information giving; parental role is emotion support for the child; nurse's role is gives nursing, help parents give normal care; involvement in care is parents help to provide emotional support and care for their child.

Mutual care is similar to parental participation. Rapport is established; sharing of knowledge take place; parents' role is under nursing care if they wish; and nurses' role is to teach parents how to give care.

Care directed by the family is similar to partnership with parents. Relationship is equal status; communication is negotiation of role; parents' role is that of primary caregivers including nursing care; parented are empowered to give care; nurses' role is that of supporters or facilitator; partnership acknowledges parents' equal status as caregivers and parents as knowledgeable and skillful.

As a result of this study, there has been an increased awareness regarding the importance of integrating the principle of family-centered care into practice. The nurses have incorporated the major component of the concept of family-centered care. The nurses' families and children's role in the model of family-centered care demonstrated that nurses have incorporated the key elements of family-centered care in their practice. The nurses' role included initiating family participants in childcare by compromising on some hospital regulation to accommodate the family who wished to stay with their children and giving families the option to stay with their children during treatment procedures. Their practice indicated the principle of family-centered care concept regarding the collaboration of families and nurses in child care. The encouragement provided to the families to participate in pre-conference with the nursing team indicated the element of mutual knowing in this study and the sharing of

unbiased and complete information with parents (Shelton & Stepanek, 1995). In addition, the participation of family in pre-conference reflected the principle of enhancing the strength of the families. Furthermore, the nursing team provided the information about hospitalization, and caring for the children when receiving chemotherapy. This role reflected the elements of sharing of unbiased information with the families.

Majority of the parents proposed that the most important role of the family is to be there with children with cancer. This role is compatible with the study of Shield and Kings (2001) stating that some Thai parents were prepared to quit their job because they felt it was more important to stay with their sick child.

In summary, the nurses' role in the family-centered care reflected the key elements of family-centered care that was found in this study and that was described by the scholars.

Factors influencing process of family-centered care

This study found that the factors influencing the process of family-centered care comprised of child's developmental stage, stage of child's illness, severity of child's illness, family coping, policy, setting, and nurses' attitudes and knowledge

The institutional policy was a factor in nurses' involvement with families. In this study, there was no policy of family-centered care in the ward. There were only purpose statements that focused on care which was patient-centered. In addition, the nursing team gave attention to caring for the children based on holistic nursing care. Thus, they were committed to practice with the concept of family-centered care. However, Shields & Kings (2001) conducted study in England, Australia, Indonesia, and Thailand and found that some hospitals had their policy in a family-centered care, so it was unable to practice this in reality.

The attitude of families had effects on the relationship between families and nurses and further influenced the kind of nursing care that the families received in the hospital. In this study, nurses had positive attitudes towards the family-centered care concept, so their practice was based on the family-centered care concept. This study was in contrast to the studies of Bruce & Ritchie (1997) and Letourneau & Elliott (1996) that found that a caring application with family-centered care was difficult to practice. The educational preparation for working with families had an influence on

the care of the family. This study found that nurses had positive attitudes towards family-centered care application and have further developed the knowledge and practiced the skills. They could practice based on the concept of FCC with the family.

Effects of a family-centered care practice on the research participants

The development process of a family-centered care with the participation of the nursing team, children with cancer and parents benefited the participants as follows:

As for the effects on the nursing team, family-centered care standard means an individual nurse and all nursing staff practiced activities that were generated under naturally mental practice. Moreover, they consisted of increases in the occurrence of change in family communication, caring for the family, cooperating with the family, and obtaining self-satisfaction. Owing to the understanding of their independent duty, the nurses felt proud and satisfied to develop themselves.

The outcomes of this operation research are beneficial for both personal and professional development. As for the presentation of Selenner (1997), the outcomes of action research consist of process outcome and final outcome. Process outcomes are changes that take place during the various stages of the project. Final outcomes include organization change and development, personal and professional development and generation of new knowledge.

The findings of nurses' realization of a family-centered care practice and feelings of self-satisfaction in independent duty are consistent with the outcomes of empowerment creation that consists of autonomous decision making, self determination, and feeling of self-worth (Carlson-Catalano, 1992; Gibson, 1995). They are also in agreement with the outcome of empowerment that consists of collegiality, communication, autonomy, and accountability (Worrell et al, 1996).

The effects on children with cancer and their family are having better health, eagerness of the family to communicate with nurses, service satisfaction, and confidence in caring for children.. These outcomes are family's empowerment creation, consisting of collegiality, communication, autonomy, and accountability (Worrell et al, 1996).

CHAPTER VII

CONCLUSION

This chapter summarizes the findings from this research and discusses the strengths and limitations of the study. Then, the contribution to nursing knowledge development is presented. The final parts include the implementations and recommendations for development of nursing knowledge, clinical practice, health policy and suggestions for future research.

Summary of the study

This action research aimed to develop the model of family-centered care for the children with cancer in a pediatric cancer unit. Specifically, this research would describe the process of development of the family-centered care model, as well as the nurses, families, and children's roles in the model, and the factors influencing the model of care.

The participants of 26 nursing staff, 41 children with cancer, and 45 family members were recruited according to the predetermined criteria. The research setting was a 26-bed oncology pediatric ward in a university hospital.

The research process was divided into three phases: 1) Pre-research preparation 2) Action phases 3) Evaluation phases. The investigator prepared the pre-research as follows: selection of the research setting and formulation of the research team and training of the research team. The action research phase was comprised of an analysis of the current situation and a definition of the problem, planning, action and observation, reflection, and re-plan. Finally, in the evaluation phase, the investigator and participants collaborated to analyze and summarize the results of this study. The participants engaged in the reflection process about how the new practice would affect them while they were practicing it.

The research outcomes are presented in three sections comprising situation in caring for children with cancer in a pediatric cancer unit, the process of family-centered care model development, and the model of family-centered care for the children with cancer.

Situations in caring for children with cancer in a pediatric cancer unit

Situations in caring for children with cancer in a pediatric cancer unit was composed of the study of pediatric cancer unit, perception of nurses, children with cancer, and their families on caring for the children with cancer and discussion of problems and assessment of nurses' requirements in the development of family-centered care model.

1. Pediatric cancer unit

The pediatric cancer unit provides medical care to both male and female patients with low immune, ranging from newborn babies to 15-year-old teenagers. The purpose statement of the unit is "to delivery care to patients with low immunity according to nursing standard. The delivery of care is based on the patient-centered approach, aiming to reduce complications. The unit practice is focused on knowledge, love, and unity among nursing staff at al levels.

2. Perceptions of nurses, children with cancer, and the families on caring for children with cancer

Nurses' perceptions

In current clinical practice, nurses deliver care to children in regard with medical treatment plans, whereas the family delivered mental care. There was little collaboration between nurses and the family, and the nursing care are not extended to family care. Nurses reported perceived barriers from overload paperwork and frequent turn of nursing staff. They expressed hope for improvement in the delivery of care.

Nurses had an expectation that the care for children with cancer would be holistic nursing care that involves family care and family participation. The concept of holistic nursing care is consistent with family-centered care; therefore, the researcher conducted in-depth interviews with nurses to investigate their definitions, attitudes and practices of family-centered care, including the relating factors.

The family-centered care, as defined by nurses' perception, is the care provision with participation from the family in caring and decision making. The care also involves information sharing and provision of knowledge to the family.

Nurses' attitudes toward the family-centered care included the awareness of family's importance in caring for the child, which was due to the fact that the family could respond to the child's needs and understand the child. In addition, the family could learn to care for the child with nurses and the child could stay with the persons they love and trust.

Nurses proposed the concept of practice with family-centered care comprising supporting the mothers to deliver close care to their child, collaboration between nurses and family, sharing of information, establishing relationships, and increasing the family's capacity and coordination between nurses and physicians.

Nurses expected that family-centered care would induce outcomes to children and family. The positive outcomes of the model on children increased efficiency of treatment and children's well-being. The positive outcomes on families included the family's satisfaction and increased ability to adjust to the child's illness. For nurses, the model development could induce awareness of their work.

Factors that led to family-centered care included mutual goal setting, time spending with the child and family, modification of practice, common understanding, and the encouragement of administrators.

Family's perception

The family perceived the importance of collaboration with nurses in caring for children with cancer as they saw the benefits for children and the family. The benefit of family participation to the children include provision of mental support, answers to the children's needs, representation in communicating with nurses, and provision of information about the children to nurses. For the family, the collaboration with nurses was beneficial as they would be able to monitor the children's symptoms and to learn how to care for their children. In addition, parents felt less worried when they could deliver close care to their children.

The family's requests when their child was hospitalized included staying with the child; having communication and good relationship with nurses; receiving information about the disease, its treatment and care; being accepted; and nurse's care for the child when they could not stay in the hospital

During the child's hospitalization, the family delivered care by providing close care and accepting the hospital regulations; however, they may ask for over-night stay when the child became severely ill. The family could provide both physical and mental care to the child, and at the same time, they sought information to apply in childcare.

Children's perception of illness and care

Older children with cancer were usually aware that the disease was incurable, they would be dead, and chemotherapy treatment induced suffering. The children wanted to stay with their family and needed mental support from their mothers when they were in pain. They expressed the desires for polite and comforting words from nurses, as well as having activities with them. The children always wanted to return home and did not want to stay in the hospital.

3. Discussion of problems and assessment of nurses' s requirements in the development of family-centered care model

The researcher, participating nurses, and administrators comprising a supervisor and a head nurse needed a meeting to discuss the results of the study of current situation in order to assess the needs of nursing team in transition from current nursing care to family-centered care. The discussion revealed that most nurses supported the development of family-centered care. Nurses felt uncertain about the model development due to anticipation of overloaded paperwork and an opinion about no standardized of the care model. Very few nurses disagreed with the development of the care model. Nurse administrators saw the importance of care model development. In conclusion, the meeting agreed to develop a family-centered care model, using action research.

Process of family-centered care model development

The process of family-centered care model development in a pediatric cancer unit comprised three circles as follows:

Circle 1 – Promotion of nurses' understanding

The pediatric cancer unit did not have a family-centered care model, and nurses did not understand the initiation of care model development. The researcher, then, held a meeting with nurses, children with cancer, and the family to set up the goal of this circle. The goal was to develop knowledge and understanding about family-centered care among participating nurses. The following actions were planned: nursing meetings of nurses, children with cancer and the family and the researcher; trying out family-centered care with one patient at a time; and provision of knowledge and understanding to nurses by the researcher.

Action and observation consisted of the meeting of children with cancer and the family, nurses, and the researcher to define the delivery of family-centered care to children with cancer. The researcher and nurses then tried the model out with a child and recorded responses of the child and the family, as well as the outcomes of care to induce continuous understanding about the care model. The research participants then reflected on ideas about the care among themselves and with the family. The researcher then provided knowledge to nursing staff by developing a handbook of family-centered care for children with cancer. In addition, there were discussion on related topics, case studies and reflective practice, as well as individual discussion.

Nurses reflected on the ideas after trying out the model with children and their family. The reflections demonstrated improved knowledge and understanding among nurses and increased awareness of family importance. The family suggested that nurses should provide mental support and express empathy to the child and the family. On the other hand, nurses expressed dissatisfaction with the practice and felt that delivery of care was still nurse-centered. They suggested an increase in family-centered practice. However, both nurses and family reflected a consistent opinion that there should be family assessment.

Enabling factors of the model development in this cycle included nurses' willingness to deliver care, encouragement from the researcher, and the hospital accreditation policy. Barriers of the model development were overloaded work and nurses' tiredness.

Circle 2 – Promotion of family-centered care at individual practice

The reflection of participating nurses in circle 1 was discussed and was used in planning further development. Problems found in circle 1 included the fact that nurses were not satisfied with their practice and would like to increase family-centered care.

For this circle the goal was to encourage individual practice of family-centered care. The planned actions included meetings of nurses, children with cancer, the family, and the researcher to develop guidelines of family-centered care and an assessment form. Nurses were to try out the family-centered care model and the researcher would promote knowledge and ability of the nursing team.

Action and observation consisted of meeting of research participants to determine practice guidelines of family-centered care, to develop a family assessment form and evaluation form, and to make a record form. The model was tried out by assigning care for family-centered care from admission to discharge. The in-charge nurses of each shift reported the progression in the child's and the family's responses, as well as the delivery of care, during the shift report. The researcher gave support by helping with nurses' empowerment, having continuous and regular communication with nurses.

The delivery of family-centered care was reflected in the meeting of the researcher, nurses, children and the family, and from the researcher's observation in participation with nurses. It was found that nurses changed their practice. The nursing practice reflected an increased acceptance of family's importance. Nurses and the family collaborated in caring for the child; they shared information and had developed goal relationship. The communication among nurses was changed as the child's and the family's responses and the delivery of care were reported during the transfer of shifts. The family participated in pre-and post conference to have a discussion about the child

with nurses. Nurses' notes had more records of family care. During reflection, nurses commented that the roles of other nursing staff were unclear in the family-centered care.

Enabling factors in cycle two were improved knowledge and understanding of family-centered care among nursing staff, which led to an awareness of and appreciation in the value of family-centered care.

Circle 3 - Becoming a team

The practice in circle 2 aimed to promote individual practice of family-centered care. The reflection revealed problems including unclear role of other staff in the nursing team and lack of team practice in the application of the care model. A meeting of the researcher, nurses, children, and the family was held to set up goal and action plan for cycle three. It was agreed that the goal was to promote team practice among nursing staff. The planned action included the development of family-centered care in team practice. The research participants evaluated the outcomes together after a month's trial.

In action and observation, the research participants had meetings to determine team practice of family-centered care by evaluating nurses' understanding about the process of the research program. The practice guidelines were proposed and the meeting participants collaboratively determined the model of family-centered care. Team practice involved shift report, pre-post conference, and nursing practice. The researcher and nurses who well understood family-centered care practice raised understanding and awareness of the family-centered care concept among members of the nursing team by conference, teaching, analytical reflection, and setting up an academic conference.

Reflection revealed that some nursing staff could conduct family-centered care practice as planned, while others still needed further development, as observed from the performance of usual tasks with the application of family-centered care, including the shift report, pre and post-conferences, nursing activities, and nurses' notes. The transfer of shifts had reports of children's and family's responses. The pre- and post-conferences had family participation. Nurses reflected the idea that the family-centered care would be beneficial and effective; however, the leaders needed to continuously develop the nursing team capacity. For continuous development, the participants proposed self-development,

collaboration in problem-solving, and utilization of management system. Nursing team conducted a meeting to conclude a family-centered care model to be applied in the nursing practice in the unit, and planned for further development.

A Family-centered care model in a pediatric cancer unit

A family-centered care model for the children with cancer in a pediatric cancer unit is a model of care for the children involving cancer with the collaboration between a nursing team and children with cancer and their families. The model is composed of key elements for family-centered care, process of family-centered care application, factors affecting family-centered care, and outcomes of family-centered care.

The model of family-centered care is primary based on four elements: a caring relationship, mutual knowing, partnership, and enhancing strength. A caring and empathetic relationship is the interaction between the nursing team and children with cancer and their families that involves spending time together, caring, being empathic, and showing respect. Mutual knowing is developed from receiving information, giving advice and information, and giving feedback. Partnership and participation experience consist of participation in caring, mutual decision, and coordination with the families. Enhancing strength of the family comprises the enhancement of spiritual needs, promotion of family's abilities, and development of the support system.

The process of family-centered care application for the children with cancer is a continuous practice of caring for children with cancer and their families and the nursing team. The care divided into the three stages. The stages is based on key elements of family-centered care.

Stage I Initiation of family-centered care

The nursing team which is composed of nurses, nurse assistants, and nurse aides has roles in establishing rapport with the families, initiating family participation in childcare, learning about the families, and enhancing the family's strength. The family's roles were having interaction with nursing staffs, comprehending instructions from nurses, and inducing understanding in children and their families among nursing staff,

and participating in caring for the children. The children's role is adherence to treatment plan, receiving care from nurses and their families, performing self care, and playing.

Stages II Mutual care

Nurses' roles comprises of maintaining a good relationship with children and their families, collaboration in childcare and enhancing family's abilities in childcare. Families' roles include asking questions and giving reports about childcare, providing childcare that is appropriate for the illness, and giving complicated nursing care. Finally, children's roles are composed of taking care of themselves, and playing.

Stage III Care directed by the family

Nurses' roles include establishing a caring empathetic relationship, being a facilitator, maintaining consistent communication, maintaining hope, and supporting coping behaviors. On the other hand, families' roles are giving care to the child expressing their needs. Finally, children's role is mainly receiving care.

Factors affecting family-centered care practice consist of policy, setting, nurses' attitudes and knowledge, the child developmental stage, the stage of the illness, and the family coping.

The effects of care model on nursing staff comprise of nurses' acceptance of family-centered care as standard practice, revision of nursing practice, and development of more self-esteem and professionalism. The effects of the care model on the children and their families comprise of the children's improved healthy, the families' open and continuous communication with nurses, families' confidence in caring for the children, and families' satisfied with the nursing care.

Strengths and limitations of the study

This study utilized the action research. In practice, its restriction occurred within the specific context. This limitation could be solved by adjusting the limitations to correspond with the context and the corporation of the authentic participants. The participants' ideas and opinions were taken into consideration to form a new action of knowledge or to make use of family-centered care knowledge in action. This outcome

contributed to new knowledge, was suitable for the context, and became the strength of this research.

Procedure strategies enlarged strength of the research findings. Triangulation of data were obtained from two data collection techniques. The first techniques were interviews, focus groups and field-notes. The second was to collect primary data from varieties of samples within determined context, such as the nursing team and children with cancer and their parents, other family members, grandparents and grand-mother.

Besides the knowledge resulting from this research, another strength was a change in the organization and good attitudes of the research participants. Nurses realized consciousness, were confident and developed self-concept. The family and nurses created more communication, decision making, cooperation, family empowerment, and family satisfaction.

The researcher also shared research reports with the research participants. While the results were compiled, nurses helped read and comment on the outcomes.

In conclusion, the strengths of this research are just like those of other action research with cooperation of authentic participants: triangulation of data collection among children, parents, and family and nurses; and sharing of reports with the participants.

Implications and recommendations

The research findings suggest several directions for clinical practice, future research, and health policy as follows:

Implication for clinical practice

The study findings could enhance health care providers, especially nurses, to understand the development of a family-centered care model in a pediatric setting. It is recommended that the study findings should be applied in nursing practice, including developing family-centered care in other settings and developing nurses' ability in family-centered care.

1. Developing a family-centered care in other settings

In developing a family-centered care, policy changes are needed within the institution such as flexibility of visiting hours. For the nursing team to care for the

children, they need to enhance their knowledge and skills in the area of the family-centered care approach. Seminars, conferences, and continuing education courses which will enable the nursing team to gain needed the competencies to conduct family-centered care practice are also required. Furthermore, better facilities are needed to provide and to accommodate for the families of the sick children.

2. Development of clinical nurses' competency in practicing the skill necessary for family-centered care

In order to create a family-centered care, nurses should obtain skill development in communication, relationship building, participation facilitating, and family empowerment.

1.1 Communication: Nurses should acquire communication skills such as how to acknowledge recommendations, reflective thinking, and good listening skills.

1.2 Relationship building: Creating trustworthy relationships between nurses and the sick children's family may lead to the family's reliance on nurses and willingness to share their inner thoughts and feelings. Thus, nurses should undergo skill development in therapeutic relationship in order to better understand the children and their family.

1.3 Participation facilitating: Nurses should be trained in how to encourage the family to participate in child care.

1.4 Family empowerment: Nurses should develop knowledge to understand the family, family care, and family empowerment.

Implications for health care policy

The recommendations for health care policies based on the research findings are as follows:

1. Formulating policy and philosophy in a family-centered care

The research findings indicated that nurses are essential in a family-centered care, but they are not able to take this action because there is no policy implementation. Thus, policy makers should pay attention to the aspect of a family-centered care in all levels of child health care. Policy and philosophy of a family-centered care should be

determined in all levels of child health care services. This is ensure that involve personnel develop activities to perform a family-centered care.

2. Providing facility for the family

The research findings revealed that the family was not encouraged to stay with the sick child because there is no room and facility available. Thus, child health care services should provide facilities for the family. This is to encourage a family-centered care by arranging beds for the family to stay overnight with the child. Moreover, it is important to prepare rooms for family members to use for waiting, conversation, resting and having a exchanging ideas and feelings. Other provisions include arranging a library, rest rooms, and accommodation for family.

3. Establishing family representatives

This study gave the families opportunity to giving suggestion on childcare, and the families were able to propose recommendation to improve the profession. Thus, the administrators should organize activities in which the sick children's family could give advice on family-centered care to concerned personnel.

4. Developing personnel's knowledge and skills

This research helped develop a pattern of a family-centered care from transforming untrained staff to trained one who are equipped with necessary knowledge and skills. Thus, a project of knowledge and skill development in a family-centered care. should be organized to staff.

Implications for educational policy

Based on the research findings, the following recommendations for education policy are proposed:

1. Family-centered care as a content in education

Educational courses should comprise concepts and theories of a family-centered care. In practice, teachers should equip skills and ability necessary in performing a family-centered care.

2. Training program

Training of knowledge and skills which are necessary for a family-centered care should be included in training programs such as therapeutic relationship, family empowerment and conflict management.

Implications for future research

Based on the research findings, the recommendations for future research could be made as follows:

1. A family-centered care approach should be developed appropriately in other child health care services in each context.
2. A family-centered care model should be tested to confirm its efficacy by using the experimental research method.
3. This research methodology basically consists of observation assessment, in-depth interviews, and qualitative data collection methods since the quantitative tools are inappropriate for the context. Thus, the quantitative tools to assess knowledge and practices more appropriate in the context should be specifically developed and utilized.

Contribution to nursing knowledge development

This research was a creation of nursing knowledge concerning family-centered care for children with cancer which was developed through the process of action research. The knowledge resulting from this study is a local theory, as it is focused on nursing situations and reflects clinical practices with certain population in a specific field of nursing. It also represents the contest and concepts of care (Melies, 1997; Im & Melies, 1997). The family-centered care model for children with cancer can be applied with hospitalized children with cancer. In addition to direction for nursing practice, the results of this research also indicate family's roles in the practice.

The development of the family-centered care model for children with cancer through the process of action research is a combination of experience and reflection of nurses and the researcher. Therefore, the family-centered care model is an outcome of the

integration of theory, research, and practice which results in a comprehensive care model for application in a pediatric cancer unit (Im & Melies, 1999).

The knowledge resulting from this research is congruent with the domain of nursing as it produces nursing intervention for children with cancer and the family which is a subject under nursing discipline designed by Donaldson and Crawley (1978). The nursing discipline states that nursing science is composed of: 1) concern with principles and law that govern the life processes, well-beings, and optimal function of the human being; 2) concern with the patterning of human behavior in interaction with the environment in critical life situation; 3) concern with the process by which positive changes in health status are affected. In analyzing the results of this research with the nursing discipline, it is evident that the family-centered care model for children with cancer involves lifestyle, well-being, and functioning of children with cancer and the family. It is a behavioral pattern for nurses' and family's practice, which is an interaction with stress due to cancer. Moreover, the family-centered care model is a process that leads to improvement in the health condition of children with cancer.

BIBLIOGRAPHY

- American Cancer Society. (2002). Cancer facts & figures. Atlanta: American Cancer Society.
- Ahmann, E. (1994a). Family-centered care: Shifting orientation. Pediatric Nursing, 20 (2), 113-117.
- Ahmann, E. (1994b). Family-centered care: The time has come. Pediatric Nursing, 20 (1), 52-53.
- Ahmann, E. & Johnson, B.H. (2000). Family-centered care: Facing the new millennium. Pediatric Nursing, 26(1), 87-90.
- Bowden, V.R., Dickey, S.B. & Greenberge, C.S. (1998). Children and their family: The continuum of care. Philadelphia: W.B. Saunders Co., pp. 20-22.
- Bradley, S.F. (1996). Process in the creation and diffusion of nursing knowledge: An examination of the developing concept of family-centered care. Journal of Advanced Nursing, 23, 722-727.
- Broome, M.E., Knafl, K., Pridham, K. & Feetham, S. (1998). Children and Families in Health and Illness. Thousand Oaks: SAGE Publications.
- Brown, J. & Ritchie, J. (1989). Nurses' perceptions of their relationships with parents. Maternal-Child Nursing Journal, 18(2), 79-96.
- Brown, J. & Ritchie, J. (1990). Nurses' perceptions of parent and nurse roles in caring for hospitalized children. Children's Health Care, 19(1), 28-36.
- Bruce, B. & Ritchie, J. (1997). Nurses' practices and perceptions of family-centered care. Journal of Pediatric Nursing, 12 (4), 214-222.
- Bruce, B., et al. (2002). A multisite study of health professionals' perceptions and practices of family-centered care. Journal of Family Nursing, 8(4), 408-429.
- Carlson-Catalano, J. (1992). Empowering nurses for professional practice. Nursing Outlook, 40(3), 139-142.
- Clarke-Steffen, L. (1993). Waiting and not knowing: the diagnosis of cancer in a child. Journal of Pediatric Oncology, 10(4), 146-153.

- Clarke-Steffen, L. (1997). Reconstructing reality: Family Strategies for managing childhood cancer. Journal of Pediatric Nursing, 12(5), 278-287.
- Coyne, I.T. (1995). Parental participation in care: A critical review of the literature. Journal of Advanced Nursing, 21, 716-722.
- Coyne, I.T. (1996). Parent participation: A concept analysis. Journal of Advanced Nursing, 23, 733-740.
- Curley, M.A. (1988). Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit. Heart & Lung, 17(6), 682-688.
- Curley, M.A. & Wallace, J. (1992). Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit – A Replication. Journal of Pediatric Nursing, 7(6), 377-385.
- Darbyshire, P. (1993). Parents, nurses and paediatric nursing: A critical review. Journal of Advanced Nursing, 18, 1670-1680.
- Davies, B. et. al. (1998). Experiences of mothers in five countries whose child died of cancer. Cancer Nursing, 21(5), 301-311.
- DePompei, P.M., Whitford, K.M. & Beam, P.H. (1994). One institution's effort to implement family-centered care. Pediatric Nursing, 20(2), 119-121.
- Elden, M. & Chisholm, R.F. (1993). Emerging varieties of action research: Introduction to the special issue. Human Relations, 46(2), 121-142.
- Enskar, K. & Essen, L.V. (2000). Important aspects of care and assistance for children with cancer. Journal of Pediatric Oncology Nursing, 17(4), 239-249.
- Enskar, K, et. al. (1997a). Life situation and problems as reported by children with cancer and their parents. Journal of Pediatric Oncology, 14(1), 18-26.
- Enskar, K. et. al. (1997b). Symptom distress and life situation in adolescents with cancer. Cancer Nursing, 20(1), 23-33.
- Evans, M. (1996). A pilot study to evaluate in-hospital care by mothers. Journal of Pediatric Oncology Nursing, 13(3), 138-145.
- Evans, M.A. (1994). An investigation into the feasibility of parental participation in the nursing care of their children. Journal of Advanced Nursing, 20, 447-482.
- Galvin, E. et al., (2000). Challenging the precepts of family-centered care: Testing a philosophy. Pediatric Nursing, 26(6), 625-632.

- Gary, R. (1996). Going to extremes: Action research, grounded practice and the theory-practice gap in nursing. Journal of Advanced Nursing, 24(6), 1315-1320.
- George, A. & Hancock, J. (1993). Reducing pediatric burn pain with parent participation. Journal of Burn Care & Rehabilitation, 14(1), 104-107.
- Gibson, C.H. (1995). The process of empowerment in mothers of chronically ill children. Journal of Advanced nursing, 21, 1201-1210.
- Gill, K.M. (1987). Parent participation with a family health focus: Nurses' attitudes. Pediatric Nursing, 13(2), 94-96.
- Gill, K.M. (1993). Health professionals' attitudes toward parent participation in hospitalized children's care. Children's Health Care, 22(4), 257-271.
- Haase, J.E. & Rostad, M. (1994). Experiences of completing cancer therapy: Children's perspectives. Oncology Nursing Forum, 21(9), 1483-1494.
- Hart, E. & Bond, M. (1996). Action Research for Health and Social Care: A Guide to Practice. Buckingham: Open University Press.
- Hart, D. & Schneider, D. (1997). Spiritual care for children with cancer. Seminars in Oncology Nursing, 13(4), 263-270.
- Heiney, S.P., Ruffin, J.R. & Goon-Johnson, K. (1995). The effects of support group on selected psychosocial outcomes of bereaved parents whose child died from cancer. Journal of Pediatric Oncology Nursing, 12(2), 51-58.
- Heiney, S.P., Well, L.M. & MDiv, J.G. (1993). The effect of group therapy on bereaved extended family of children with cancer. Journal of Pediatric Oncology Nursing, 10(3), 99-104.
- Heller, R. & McKlindon, D. (1996). Families as "Faculty": Parent educating caregivers about family-centered care. Pediatric Nursing, 22(5), 428-431.
- Hicks, M.D. & Lavender, R. (2001). Psychosocial practice trends in pediatric oncology. Journal of Pediatric Oncology Nursing, 18(4), 143-153.
- Hinds, P.S., et al. (1996). Coming to terms: Parents' response to a first cancer recurrence in their child. Nursing Research, 45(3), 148-153.
- Hockenberry-Eaton, M., & Kline, N.E. (1997). Nursing support of the child with cancer. In P.A. Pizzo & D.G. Poplack (eds.), Principle and Practice of Pediatric Oncology (p.p.1209-1228). Philadelphia: Lippincott-Raven Publishers.

- Hockenberry-Eaton, M., Manteuffel, B. & Bottomley, S. (1997). Development of two instruments examining stress and adjustment in children with cancer. Journal of Pediatric Oncology Nursing, 14(3), 178-185.
- Hockenberry-Eaton, M. & Minick, P. (1994). Living with cancer: Children with extraordinary courage. Oncology Nursing Forum, 21 (6), 1025-1031.
- Holter, I.M. & Kim, H.S. (1995). Methodology for critical theory: Critical action research. In A. Omery, C.E. Kasper & G.G. Page (eds.), In search of Nursing Science (p.p.220-232). Thousand Oaks: SAGE Publication.
- Holter, I.M. & Schwartz-Barcott, D. (1993). Action research: What is it? How has it been used and how can it be used in nursing? Journal of Advanced Nursing, 18, 298-304.
- Hostler, S.L. (1991). Family-centered care. Pediatric clinics of North America, 38(6), 1545-1559.
- Huber, D. (2000). Leadership and Nursing Care Management. Philadelphia: W.B. SAUNDERS COMPANY.
- Hutchfield, K. (1999). Family centred care: A concept analysis. Journal of Advanced Nursing, 29(5), 1178-1187.
- Hymovich, D.P. (1995). The meaning of cancer to children. Seminars in Oncology Nursing, 11(1), 51-58.
- Im, E. & Meleis, A.I. (1999). Situation-specific theories: Philosophical roots, properties, and approach. Advances in Nursing Science, 22(2), 11-24.
- James, L. & Johnson, B. (1997). The needs of parents of pediatric oncology patients during the palliative care phase. Journal of Pediatric Oncology Nursing, 14(2), 83-95.
- Kemmis, S & Mc. Taggart, R. (1990). The Action Research Planner. 3rd ed. Victoria: Deakin University.
- Kramseang, K. (1996). The effect of supportive-educative nursing system on dependent care deficit of the child with cancer receiving chemotherapy. Master Thesis, Master of Nursing Science (Pediatric Nursing), Faculty of Graduate studies, Mahidol University, Thailand.
- Letourneau, N.L. & Elliott, R. (1996). Pediatric health care professionals' perceptions and practices of family-centered care. Children's Health Care, 25(3), 157-174.

- Lincoln, Y.S. & Guba, E. (1985). Naturalistic Inquiry. Beverly Hills: SAGE Publication.
- Mackawon, P. (1994). Coping behaviors of families with children having acute lymphoblastic leukemia. Master Thesis, Master of Nursing Science in Family Nursing, Graduate School, Khon Kaen University, Thailand.
- Martinson, I.M. & Yi-Hau, L. (1994). The reaction of Chinese parents to a terminally ill child with cancer. Cancer Nursing, 17(1), 72-76.
- McKlindon, D. & Barnsteiner, J.H. (1999). Therapeutic relationships: Evolution of the Children's Hospital of Philadelphia Model. MCN, 24(5), 237-243.
- Meleis, A.I. (1997). Theoretical Nursing: Development and Process. (3rd ed.) Philadelphia: Lippincott.
- Melnyk, B.M. (2000). Intervention studies involving parent of hospitalized young children: An analysis of the past and future recommendations. Journal of Pediatric Nursing, 15(1), 4-13.
- Mercer, M. & Ritchie, J.A. (1997a). Home community cancer care: Parents' perspectives. Journal of Pediatric Nursing, 12(3), 133-141.
- Mercer, M. & Ritchie, J.A. (1997b). Tag team parenting of children with cancer. Journal of Pediatric Nursing, 12(6), 331-341.
- Meyer, J.E. (1993). New paradigm research in practice: The trials and tribulations of action research. Journal of Advanced Nursing, 18, 1066-1072.
- Ministry of Public Health. (2001). Public Health Statistics A.D. 2001. Bureau of Health Policy and Planning Office of the permanent Secretary Ministry of Public Health.
- Moore, I.M., Kramer, R.F. & Perrin, G.(1986). Care of the family with a child with cancer: Diagnosis and early stages of treatment. Oncology Nursing Forum, 13 (5), 60-66.
- Morse, I.M. & Field, P.A. (1996). Nursing Research: The Application of Qualitative Approaches. London: Chapman & Hall.
- Novakovic, B., et. al. (1996). Experiences of cancer in children and adolescents. Cancer Nursing, 19(1), 54-59.

- Ohanian, N.A. (1990). Information needs of child and adolescent cancer patients and their parents. Conference Proceeding. Association of Pediatric Oncology Nurses.
- Patoomwan, A. (2001). Living with Childhood Cancer in Thai Families: Stories of Struggling with Uncertainty. Dissertation Submitted in partial satisfaction of the requirement for the degree of Doctor of Philosophy in Nursing in the Graduate Division of University of California San Francisco.
- Peter, M. & Robinson, V. (1984). The origins and status of Action research. The Journal of Applied Behavioral Science, 20 (2), 113-124.
- Phuphaibul, R. et al. (2000). The impacts of childhood cancer on families. Mahidol University.
- Romaniuk, D.K.& Kristjanson, L.J. (1995). The parent-nurse relationship from the perspective of parents of children with cancer. Journal of Pediatric Oncology Nursing, 12(2), 80-89.
- Saiki, S.D., Martinson, I.M. & Inano, M. (1994). Japanese families who have lost Children to cancer: A primary study. Journal of Pediatric Nursing, 9(4), 239-250.
- Selener, D.L. (1998). Participatory Action Research and Social Change. New York: The Cornell Participatory Action Research Network.
- Shelton, T.L & Stepanek, J.S. (1995). Excerpts from family-centered care for children needing specialized health and development services. Pediatric Nursing, 21(4), 362-364.
- Shields, G., et. al. (1995). Social work in pediatric oncology: A family needs assessment. Social Work in Pediatrics, 21(1), 39-52.
- Shields, L. & King, S.L. (2001). Qualitative analysis of the care of children in hospital in four countries-Part I. Journal of Pediatric Nursing, 16(2), 137-145.
- Sinswang, P. (1995). The effect of group support on anxiety and care behavior in mothers with leukemic children. Master Thesis, Master of Science (Nursing), Faculty of Graduate studies, Mahidol University, Thailand.
- Small, S.A. (1995). Action-oriented research: models and methods. Journal of Marriage and the Family, 57(November) 941-955.

- Smith, L., Coleman, V. & Bradshaw, M. (2002). Family-Centred Care: Concept, Theory and Practice. Houndmills: PALGRAVE.
- Songnuy, T. (1999). Cost analysis for treatment of children acute lymphoblastic leukemia. A thesis submitted in partial fulfillment of the requirements for the diploma of Thai board of pediatrics of Medical Council. Chulalongkorn University.
- Streubert, H.J. & Carpenter, D.R. (1999). Qualitative Research in Nursing: Advancing the Humanistic Imperative. (2nd ed.) Philadelphia: Lippincott.
- Stringer, E.T. (1999). Action Research. (2nd ed.). Thousand Oaks: SAGE Publications.
- Suwanagood, J. (1996). Concern, coping and vulnerability in mother of children with cancer. Master Thesis, Master of Science (Nursing), Faculty of Graduate studies, Mahidol University, Thailand.
- Thanattherakul, (1993). The relationship between selected factors and needs of parents who care for children with acute lymphoblastic leukemia. Master Thesis, Master of Nursing Science in Family Nursing, Graduate School, Khon Kaen University, Thailand.
- Tomlinson, P.S., Tomlinson, E., Peden-McAlpine, C & Kirschbaum, M. (2002). Clinical innovation for promoting family care in paediatric intensive care: Demonstration, role modeling and reflective practice. Journal of Advanced Nursing, 38 (2), 161-170.
- Visespanit, P. (1998). Quality of life in school-age children with leukemia. Master of Nursing Science (Maternal and Child Nursing), Faculty of Graduate Studies, Chiangmai University, Thailand.
- Webb, C., Turton, P. & Pontin, D. (1998). Action Research: the data move on. Research and Development in Clinical Nursing. London: Whurr Publishes.
- Weekes, D.P. & Kagan, S.H. (1994). Adolescents completing cancer therapy: Meaning, perception, and coping. Oncology Nursing Forum, 21(4), 663-670.
- Whyte, W.F. (1990). Participation Action Research. Newbury Park: SAGE PUBLICATIONS.
- Wills, B.S.H. (1999). The experiences of Hong Kong Chinese parents of children with acute lymphocytic leukemia. Journal of Pediatric Nursing, 14 (4), 231-238.

- Worrell, J.D. et al. (1996). The RN-BSN Student: Developing a model of Empowerment. Journal of Nursing Education, 35 (3), 127-130.
- Wright, P.S. (1993). Parents' perceptionS of their quality of life. Journal of Pediatric. Oncology Nursing, 10 (4), 139-145.
- Wong, D. L. (1995). Whaley & Wong' s Nursing Care of Infant and Children. 5th ed. St Louis: Mosby.
- Yeh, C. et. al. (1999). Determinants of parental decisions on 'drop out' from cancer treatment for childhood cancer patients. Journal of Advanced Nursing, 30 (1), 193-199.
- Young, J. (1992). Changing attitudes towards families of hospitalized children from 1935 to 1975: A case study. Journal of Advanced Nursing, 17, 1422-1429.
- ศศิธร วรรณพงษ์ และ คณะ. (2540). (Wannapong, et al., 1997). คุณภาพชีวิตผู้ป่วยเด็กโรคมะเร็งเม็ดเลือดขาว. คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล





No. 48/2001

Documentary Proof of Ethical Clearance

The Committee on Human Rights Related to

Human Experimentation

Mahidol University, Bangkok

Title of Project : Development of a Family-Centered Care Model for the
Children with Cancer and their Families in a Pediatric
Cancer Unit

Principal Investigator : Miss Tassanee Attharos

Name of Institution : Faculty of Nursing

Approved by the Committee on Human Rights Related to Human Experimentation

Signature of Chairman : S. Danchaivijitr
(Professor Dr. Somwang Danchaivijitr)

Signature of Head of Institute : P. M. Matangkasombut
(Professor Dr. Pornchai Matangkasombut)

Date of Approval : 28 DEC 2001



Appendix B: Families Interviewing Guideline

Interview question for families

1. What is your child diagnosis ?
2. How do you feel about this diagnosis ?
3. How do you think about caring for the children with cancer especially in hospital setting ?
4. What do you expect about nursing care for your children ?
5. Do you think the nursing care for your children is correspondent with your expectation ? Please describe.
6. What participation do you have in caring for your children?
7. What comments do you have in participation with nurses in caring for the children with cancer?
8. What does the family participation mean to you ?
9. What should be the pattern of family-centered care or family participation in your understanding ? What are the nurses' role in the pattern of family-centered care? What are the families' role in the pattern of family-centered care? What are the response of the children ? What are the factors interfering and supporting the pattern of family-centered care?

Appendix B: แนวคำถามสำหรับสัมภาษณ์ครอบครัว

คำถามสัมภาษณ์ครอบครัว

1. ท่านคิดว่าบุตรของท่านป่วยเป็นโรคอะไร?
2. ท่านรู้สึกอย่างไรที่ถูกป่วยด้วยโรคนี้ ?
3. ท่านคิดว่าจะดูแลบุตรของท่านอย่างไร
4. ท่านคาดหวังอย่างไรในการดูแลบุตรของท่านในโรงพยาบาล
5. การดูแลบุตรของท่านเป็นไปตามความคาดหวังของท่านหรือไม่ อย่างไร?
6. ท่านคิดว่าท่านมีส่วนร่วมกับพยาบาลในการดูแลบุตรของท่านอย่างไร
7. ท่านมีความเห็นอย่างไรกับการดูแลที่ให้ท่านเข้ามาดูแลร่วมกับพยาบาล?
8. ท่านคิดว่าการให้พ่อแม่เข้ามามีส่วนร่วมในการดูแลเด็กท่านคิดว่ามีความหมายอย่างไร?
9. ท่านคิดว่าลักษณะของการดูแลโดยให้ครอบครัวมีส่วนร่วมควรเป็นอย่างไร? ท่านจะมีส่วนร่วมในการดูแลบุตรของท่านอย่างไร พยาบาลจะมีบทบาทอะไร

Appendix B: Nurses Interviewing guideline

Interview question for nurses

1. How do you care for the children with cancer?
2. What care do the children and their families need from you? Do you think that the care you give to the children and their families can meet the needed of them?
3. What do you think that the children and families need more care from you ? nursing care should give them more ?
4. Do you think the practice you provided fit with the family-centered care concept ? How ?
5. What is the family-centered care mean to you ?
6. What do you think about allowing the family to involve in caring for their children ?
7. What is the characteristics of the family-centered care for the children with cancer? What is the nurses' role in the model of the family-centered care for the children with cancer? What is the families' role in the model? What are the response of the children ? What are the factors interfering and supporting the pattern of family-centered care?

Appendix B: แนวคำถามสำหรับสัมภาษณ์พยาบาล

คำถามสำหรับพยาบาล

1. ท่านคิดว่าท่านดูแลเด็กที่ป่วยเป็นโรคมะเร็งอย่างไร?
2. ท่านคิดว่าครอบครัวเขาต้องการอย่างไร และการดูแลเด็กที่ท่านให้กับเด็กและครอบครัวสามารถตอบสนองความต้องการของเด็กและครอบครัวหรือไม่?
3. การพยาบาลที่ท่านคิดว่าเด็กและครอบครัวควรได้มากกว่านี้มีหรือไม่ อย่างไร?
4. ท่านคิดว่าการดูแลเด็กโรคมะเร็งที่ปฏิบัติอยู่นี้เป็นปฏิบัติที่ให้ครอบครัวเป็นศูนย์กลางหรือไม่ อย่างไร?
5. ท่านมีความเห็นอย่างไรที่จะให้ครอบครัวมาดูแลบุตรร่วมกับพยาบาล?
6. ท่านจะให้ความหมายของการให้การดูแลโดยให้ครอบครัวเป็นศูนย์กลางการดูแลอย่างไร?
7. ท่านคิดว่าลักษณะการดูแลโดยให้ครอบครัวเป็นศูนย์กลางการดูแลควรเป็นอย่างไร? ท่านและครอบครัวควรทำอย่างไร



Appendix C

คำชี้แจงเกี่ยวกับโครงการวิจัย

ดิฉัน นางสาวทัศนีย์ อรรถารส นักศึกษาหลักสูตรพยาบาลศาสตรดุษฎีบัณฑิต คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล กำลังศึกษาวิจัยเรื่อง “ การพัฒนารูปแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลางในเด็กโรคมะเร็งในหน่วยเด็กโรคมะเร็ง ” มีวัตถุประสงค์เพื่อพัฒนารูปแบบการดูแลเด็กโรคมะเร็งและครอบครัว

วิธีดำเนินการวิจัย ประกอบด้วย การสะท้อนสถานการณ์และการกำหนดปัญหา การวางแผนการปฏิบัติ การปฏิบัติตามแผน การสะท้อนคิด และการประเมินผล ในการวิจัย ท่านมีส่วนในการปฏิบัติดังนี้

1. ให้สัมภาษณ์เกี่ยวกับการรับรู้การดูแลในเด็กโรคมะเร็ง เพื่อประเมินสถานการณ์ และให้ข้อมูลส่วนบุคคล ซึ่งใช้เวลาประมาณ 30-60 นาที
2. ประชุมกลุ่มร่วมกับผู้ร่วมโครงการคนอื่นๆ ในการวางแผน ปฏิบัติตามแผน สะท้อนคิด การปฏิบัติ และติดตามประเมินผลการปฏิบัติ
3. ให้สัมภาษณ์เกี่ยวกับความพึงพอใจต่อการดูแลโดยให้ครอบครัวเป็นศูนย์กลางในเด็กโรคมะเร็งเพื่อประเมินผล ใช้เวลาประมาณ 30 นาที

ประโยชน์ที่จะได้รับจากการวิจัยในครั้งนี้ คือรูปแบบการดูแลที่พยาบาลและบุคลากรที่ให้ บริการทางสุขภาพสามารถให้การดูแลเด็กที่ป่วยเป็นโรคมะเร็งและครอบครัวได้ดีขึ้น โดยรูปแบบที่ได้จะตอบสนองความต้องการของเด็กและครอบครัวและพยาบาลจะได้รับประโยชน์ในการพัฒนาตนเองทั้งความรู้และทักษะการวิจัยเชิงปฏิบัติการอันจะนำไปสู่การพัฒนาคุณภาพการพยาบาลด้านอื่นๆต่อไป

การศึกษานี้จะไม่ส่งผลกระทบในด้านความเสียหายใดๆต่อท่าน ไม่มีความเสี่ยงทางด้านร่างกายเนื่องจากไม่ได้ให้ยาหรือทำหัตถการใดๆ ความเสี่ยงทางจิตใจมีความเสี่ยงน้อย ผู้วิจัยจะปฏิบัติตามแนวทางปฏิบัติจรรยาบรรณนักวิจัย กล่าวคือดำเนินการวิจัยด้วยความรอบคอบ ระมัดระวัง โดยมีจิตสำนึกที่ไม่ก่อให้เกิดความเสียหายแก่กลุ่มตัวอย่าง มีความรับผิดชอบ และเคารพในศักดิ์ศรีของความเป็นมนุษย์ที่ใช้เป็นตัวอย่างในการวิจัย

ในกระบวนการพัฒนารูปแบบครั้งนี้ ดิฉันขออนุญาตบันทึกเทประหว่างการสัมภาษณ์และการประชุมกลุ่ม และบางครั้งอาจถ่ายภาพเพื่อประกอบการศึกษาโดยให้ท่านพิจารณาก่อนนำภาพไปใช้ ข้อมูลที่ท่านให้จะเก็บเป็นความลับ ชื่อของท่านจะไม่ปรากฏบนแบบฟอร์มใดๆของการสัมภาษณ์ หรือเชื่อมโยงถึงเทปบันทึกการสัมภาษณ์ ชื่อของท่านจะแทนด้วยรหัสที่เป็นตัวเลขซึ่งดิฉันจะเป็นผู้เดียวที่ทราบข้อมูลที่บ่งชี้ถึงตัวท่าน บันทึกการสัมภาษณ์จะเก็บไว้ในตู้และลบทำลายเมื่อสิ้นสุดการวิจัย ผลการวิจัยจะเสนอในลักษณะภาพรวมของกลุ่มและไม่มีข้อมูลใดบ่งชี้ถึงตัวบุคคล

ในการเข้าร่วมการวิจัยครั้งนี้ จะเป็นความสมัครใจของท่าน และไม่มีผลตอบแทนใดๆแก่ท่าน ท่านมีสิทธิ์ที่จะตอบรับหรือปฏิเสธการเข้าร่วมศึกษา และถึงแม้ว่าท่านจะเข้าร่วมการศึกษาแล้วท่านสามารถยกเลิกได้ตลอดเวลาตามที่ท่านต้องการโดยไม่มีผลกระทบใดๆต่อการรักษาพยาบาลหรือบริการต่างๆที่ผู้ป่วยและท่านจะได้รับ หากท่านมีข้อสงสัยประการใดเกี่ยวกับการศึกษานี้ ดิฉันยินดีให้ความกระจ่างเพิ่มเติม และหากท่านมีข้อสงสัยในภายหลัง กรุณาติดต่อดิฉันตามที่อยู่ข้างล่างนี้ ดิฉันยินดีตอบคำถามของท่านเพื่อความกระจ่าง

นางสาวทัศนีย์ อรรถารส

คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล

2 ถนนพราณนก บางกอกน้อย

กรุงเทพฯ 10700

โทรศัพท์ 02-9811046 (บ้าน)

แบบฟอร์มใบยินยอมการวิจัยในมนุษย์

การวิจัยเรื่อง การพัฒนารูปแบบการดูแลโดยให้ครอบครัวเป็นศูนย์กลางในเด็กโรคมะเร็งใน
หน่วยเด็กโรคมะเร็ง

วันที่ให้คำยินยอม วันที่.....เดือน.....พ.ศ.....

ก่อนที่จะลงนามใบยินยอมในการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจากผู้วิจัยถึงวัตถุประสงค์ วิธี
การวิจัย อันตราย รวมทั้งประโยชน์ที่จะเกิดขึ้นจากการวิจัยโดยละเอียด และมีความเข้าใจดีแล้ว

ผู้วิจัยรับรองว่าจะตอบคำถามต่างๆที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบัง ซ่อนเร้น จน
ข้าพเจ้าพอใจ

ข้าพเจ้ามีสิทธิ์ที่จะบอกเลิกการเข้าร่วมในโครงการวิจัยเมื่อใดก็ได้ และเข้าร่วมโครงการนี้ด้วย
ความสมัครใจ และการบอกเลิกการวิจัยนี้จะไม่ผลต่อการรักษาโรคที่ข้าพเจ้าพึงได้รับต่อไป

ผู้วิจัยรับรองว่าจะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะในรูปแบบ
ที่เป็นสรุปผลการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่างๆที่เกี่ยวข้อง กระทำได้
เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ผู้วิจัยรับรองว่าหากเกิดอันตรายใดๆอันเนื่องมาจากการวิจัยดังกล่าว ข้าพเจ้าจะได้รับการรักษา
พยาบาลโดยไม่คิดมูลค่าตามมาตรฐานวิชาชีพ และจะได้รับการชดเชยรายได้ที่สูญเสียไปใน
ระหว่างการรักษาพยาบาลดังกล่าว ตลอดจนเงินทดแทนความพิการที่อาจเกิดขึ้น

ผู้วิจัยรับรองว่าหากมีข้อมูลเพิ่มเติมที่ส่งผลกระทบต่อการศึกษา ข้าพเจ้าจะได้รับการแจ้งให้ทราบ
โดยไม่ปิดบัง ซ่อนเร้น

ข้าพเจ้าได้อ่านข้อความข้างต้นแล้ว และมีความเข้าใจดีทุกประการ และได้ลงนามในใบยินยอม
นี้ด้วยความเต็มใจ

ลงนาม.....ผู้ยินยอม

ลงนาม.....พยาน

ลงนาม.....พยาน

ข้าพเจ้าไม่สามารถอ่านหนังสือได้ แต่ผู้วิจัยได้อ่านข้อความในใบยินยอมนี้ให้แก่ข้าพเจ้าฟังจนเข้าใจดีแล้ว และข้าพเจ้าจึงลงนามหรือประทับลายนิ้วมือขวาของข้าพเจ้าในใบยินยอมนี้ด้วยความเต็มใจ

ลงนาม.....ผู้ยินยอม

ลงนาม.....พยาน

ลงนาม.....พยาน

ในกรณีที่ผู้ถูกทดลองยังไม่บรรลุนิติภาวะ จะต้องได้รับการยินยอมจากผู้ปกครองหรือผู้อุปการะโดยชอบด้วยกฎหมาย

ลงนาม.....ผู้ปกครอง / ผู้อุปการะโดยชอบด้วยกฎหมาย

ลงนาม.....พยาน

ลงนาม.....พยาน

ในกรณีที่ผู้ถูกทดลองไม่สามารถตัดสินใจเองได้ (เช่น กรณีผู้ถูกทดลองเป็นโรคจิต/หรืออยู่ในภาวะหมดสติ) ให้ผู้แทนโดยชอบด้วยกฎหมาย หรือผู้ปกครอง หรือญาติที่ใกล้ชิดที่สุดเป็นผู้ลงนามยินยอม

ลงนาม.....ผู้แทน / ผู้ปกครอง / ญาติ

ลงนาม.....พยาน

ลงนาม.....พยาน



Appendix D : Case Study

The following is an example of a case study presented to demonstrate the activities of nurses, the family, and the researcher for better understanding of the process of plan implementation. Nurses and the researcher studied each case from admission until discharge.

History of illness and family history

The patient was a twelve-year-old boy admitted into the hospital for the first time. The boy was referred from a private hospital for further management with a history of anemia, tiredness, and ecchymosis on arms and legs. Physical examination on admission at the private hospital revealed spleen enlargement and hepatomegaly. Blood examination resulted in a high number of white blood cells.

The patient was the second child in a family of two children and was currently studying in Prathom 6. The mother was an operator for a private company, and the father was unemployed. The family received financial support from the mother's older sister and the father's relatives.

On the first day of hospitalization, blood sample was taken for complete blood count (CBC), liver function test, and renal function test (LFT, BUN, Cr, Uric acid, albumin, globulin). The patient also received special investigations for the assessment of body function in preparation for chemotherapy. The special investigations involved the heart and lung examination such as chest X-ray and electrocardiogram. Other investigations included tuberculin test and stool exam for parasite. The results of blood test indicated anemia (Hb 7gm%), thrombocytopenia (Platelet 2000 c.c.ml.), and hyperleukocytosis (WBC 484320 c.c.ml.).

The treatment at the beginning of hospitalization was mainly supportive. The patient received platelets and Pack Red Cell (PRC) for the treatment of thrombocytopenia and anemia. Complications from hyperviscosity were closely monitored as the patient had a large number of white cells, as well as hyperleukocytosis of more than 30%. Specific treatment was given later with chemotherapy following intravenous fluid infusion.

The patient had fever during chemotherapy treatment. Blood samples were taken for CBC and hemoculture, and feces were also collected for stool culture. Antibiotic treatment was given. The child still had anemia and thrombocytopenia during the hospitalization; thus, he received supportive treatment with PRC and platelets.

The patient was hospitalized for 24 days. After the chemotherapy was completed and blood examination indicated remission of the disease, the child was discharged from the hospital.

The child's and the family's responses to the illness

The child's responses

1. The child was tired. Observation of the child's activities revealed that at the beginning of hospitalization the child always stayed under a blanket in bed. The mother said he was tired and slept all the time. She did not know what was wrong with the child.

2. The child was upset about being hurt from nurses' taking blood samples. The conversation with the mother and the observation showed that the child was bored with frequent blood examinations. He complained that the procedure was painful and he did not want to stay in the hospital.

3. The child was worried about being absent from school. According to the father, a doctor informed the child about the long duration of treatment when he was playing at the play area and the child promptly returned to bed without saying anything. When the father asked, he complained that he had not been to school for two weeks and would be certainly expelled from the school.

The family's responses

1. The family felt distressed. The mother accepted the fact that the child was ill with leukemia. She said, with tears in her eyes, *"I am shocked and confused, but I will fight."*

An observation during a conversation indicated that the father expressed his sadness in his saying, *"when I was told that my child had cancer, I felt tight in the chest and confused. I could not sleep for quite a few nights. I feel a bit better now."*

2. The family did not understand the child's condition of illness. In her report of the child's symptoms to a nurse, the mother said that the child felt tired and slept all day and she did not understand what went wrong with the child. When the nurse asked how she cared for the child, the mother said she did not know how to.

3. The family did not understand how to use the social insurance card. During a conversation with a nurse, the mother showed a social insurance card for another hospital service. She did not know what the card was for.

4. The father was worried about the costs of treatment and hospitalization. He consulted a nurse about the duration of hospitalization and expenses. The worry was related to his unemployment. In addition, he was also worried about financial impacts on the first child.

Staff nurses and the researcher delivered care to this child in collaboration with his family. The following activities were conducted: asking for the family's consent for participation in the research program, providing care to the child with the role stated in the family-centered care model, recording the child's and the family's responses to the care in the diary, and reflecting on the practice personally, with the researcher and with the child's family.

Admission phase

After receiving consent from the family to conduct the study, a nurse gave general information about the ward, the staff and hospital regulations. The nursing team established rapport with the child and his family.

Hospitalization phase

Nurses, the researcher, and the family conducted caring activities as detailed below:

1) Nurses acknowledged the importance of the family by allowing the parents to maintain their roles during hospitalization. The child's requirement of care was assessed and the hospital regulation was adjusted to accommodate the parents' visits. In this case, the mother worked full time; hence, she came to see the child in the morning, in the evening, on holidays, and during weekends. The father could stay with the child during daytime everyday.

2) The family collaborated with the nurses in caring for the child, including responding to his basic needs, giving mental support during medical procedures and answering to developmental needs.

2.1) Responding to basic needs: The basic needs involved the child's daily activities. For example, the parents would come to the hospital together in the morning, bringing food for the child. Then, they would help him with having a shower, having breakfast, and taking medications.

2.2) Giving mental support during medical procedures: The child was usually upset from medical procedures. The father could participate by staying with him and holding his hand to calm him down. An interview with the child revealed that he liked to have his father stay with him and hold his hand. He reported feeling less pain with his father was around.

2.3) Answering to developmental requirements. The family also participated in responding to requirements concerning the child's physical and mental development. The child expressed his concern about being absent from school, thus the father comforted and explained the situation to him. Moreover, the father could also make contact with the school about the child's illness.

3) The nurses exchanged information with the family: At the beginning of hospitalization, the child had to undergo several medical procedures and investigations. The nurses gave information about these procedures and investigations to the parents. Moreover, the mothers demonstrated lack of understanding about the child's illness, so an explanation about the condition of illness and appropriate care was also given. During the course of chemotherapy, nurses also gave advice on childcare for children receiving chemotherapy and for children with low immunity to infection. The family also received brochures about how to care for the children receiving chemotherapy and children with low immunity to infection. In addition, nurses gave suggestions about making contact with insurance affiliates as the mother did not understand how to use the social insurance card. Nurses also coordinated with doctors for the production of medical reports, which the mother needed to activate her rights in receiving welfare support.

4) Nurses promoted the family is strength and sought healthcare resources for the family.

Activities for the promotion of family's strength and the search for healthcare resources comprised of helping the family overcome the feeling of distress, supporting the search for resources, giving advice and mental support, and promoting knowledge and understanding in caring for the child.

4.1) Helping the family to overcome the feeling of distress. Both parents expressed the feeling of distress when their child was diagnosed with cancer; however, they demonstrated the potential to cope with the problems and strength in dealing with the sense of loss, as the mother said, 'We have to fight anyway.' Nurses assessed the family's feelings, expressed care and concern about their feelings, and provided them with mental support.

4.2) Supporting the search for healthcare resources: The mother was a holder of a social insurance card of another hospital; hence, the nurses gave suggestions about the family's rights and advised the mother to make contact with the affiliated hospital. When the affiliated hospital asked for a medical report, nurses coordinated with the doctor to arrange the medical report so that the mother could claim her rights in receiving service from the affiliated hospital.

4.3) Giving suggestions and mental support: The father consulted a nurse about the family's financial problems as he was unemployed and the other child was still in school. Moreover, the treatment of the ill child was costly. The nurse listened to the father with interest and gave him mental support. The parents were suggested to reflect on their existing financial resources. Fortunately, in the end they could seek financial support from the mother's older sister.

4.4) Promoting knowledge and understanding about childcare: During the hospitalization, the child had thrombocytopenia. He frequently scratched or picked at blood clots or scabs on his skin. Nurses emphasized the care for children with thrombocytopenia with the parents.

In conclusion, case studies demonstrated the connection between nurses and family's roles. Nurses delivered care to the children and their families in response to their care requirement on the basis of the role indicated in the family-centered care model. The responses from the children and their families were recorded in the diary, and nurses reflected on their practice. The reflection comprised personal reflection, reflection with the family, and reflection with the researcher. Personal reflection was

conducted by considering the nursing care delivered to the children and their families in connection with the family-centered care model and observing the patients' and the families' responses to the nursing care. The reflection with the researcher was conducted everyday in pre-meeting. The researcher might add information about the case, and the information would be discussed with opinion exchanges among participating nurses.





Appendix E

Nursing guidelines based on family-centered care concept

Responses of children with cancer and their families

Children and families had different responses to the illness and hospitalization. Nurses and family's roles were determined according to their common responses as presented below.

1. Children's responses

Children's responses involved the feeling of unfamiliarity with hospital environment, sufferings from illness and complications, fear of being hurt from medical procedures, anxiety from being separated from their family, and distress from side effects of medications.

1.1 The children were not familiar with the hospital.

Most preschool children were attached to their mothers and they usually cried and clung on the mothers when they were hospitalized. The children cried almost all the time after their mothers went back home, and they refused to do daily activities such as sleeping or eating. Older children tended to stay still and did not talk to health care professionals. They only had conversations with their family.

Nurses' role

1) Establishing rapport

Nurses and the nursing team established rapport with the children and their families to develop the feeling of trust. The development of trusting feeling required regular and continuous action, starting from the patient's admission until discharge. The activities to establish a good relationship with children and their families included greeting in friendly manners, asking about the children's condition, expressing concern and care with sincerity, and showing readiness to help.

2) Exchanging information

Nurses asked children and their families about the symptoms and gave them information about the ward; they also introduced children and families to

hospital staff to help them feel familiar with the environment .in the world The parents would then give information about the children and the family.

3) Developing an agreement in caring for the children

Nurses and children's family established an agreement in caring for the hospitalized children with cancer. Mothers were to maintain the maternal role during the children's hospitalization, and they would participate with nurses in caring for the children. Nurses and mothers also shared information about the children.

4) Assessing children and their families

Nurses inquired children and their families about illness symptoms. Families were assessed with the family assessment form. The assessment was performed on the admission date.

Family's role

1) Sustaining parental role

The family could continue delivering care, which included physical and mental care, to their child as when the child was not ill. The maintenance of parental role was composed of the following activities: being there, participating in childcare as a caregiver, providing the child with comfort and enjoyment, and assisting the child in making contact with other family members.

2) Understanding

The family developed knowledge and familiarity with people, places and hospital regulations.

3) Providing information

The family provided nurses with information during the assessment.

1.2 The children were ill from symptoms and complications of the disease.

Children with cancer usually felt ill from a variety of symptoms such as bleeding, anemia, or infection. Moreover, they may develop extensive illness from complications caused by chemotherapy e.g. mouth ulcers or nausea and vomiting. These ill conditions usually require medical treatment such as pharmacotherapy or blood transfusion. The children's responses to illness depended on their development and severity of the illness. For example, older children may be present in quietness

and have depressed expression, whereas children with young age may be on the bout of crying, cling on the mothers and crying while receiving medical procedures.

Nurse role

Nurse delivered care on the basis of the family-centered care approach at every step of care comprising assessment, plan-making, delivery of care, and evaluation.

1) Participating in the assessment of illness

Nursing team assessed the child's disorders together during the pre-conference. Nurses inquired the child and the family about symptoms of illness and provided them with additional information about the illness. In addition, nurses helped the family to investigate the child's problems and made plan for collaborative care.

2) Participating in nursing care

Nurses assessed the child's condition in collaboration with the family by inquiring the mother about the symptoms. The pre-conference allowed nurses and the family to gain information concerning the child's condition at the same time and they could make plan to care for the child together. Family participation in the delivery of care was flexible, depending on the child's and the family's requirements, as well as the family's convenience in staying with the child. The family's delivery of care included caring for the child's daily activities such as food intake or personal hygiene care. The nurses role was the administration of medical treatment such as intravenous fluid infusion or coordinating with other units. Nurses also allowed mothers to deliver simple nursing procedures such as taking temperature, giving tepid sponge, or applying skin cream, after the demonstration from nurses or nurse assistants. Mothers would conduct these procedures under nurses' or nurse assistants' supervision.

3) Following the progress of illness with the family

The condition of the child's illness was regularly followed during pre- and post-conferences or at any available time.

5) Providing mental support

The changes in symptoms of the ill child usually had effects on the family's mental. Hence, nurses gave mental support to help the family overcome the feeling of distress.

Family role

1) Participating in the assessment of illness and monitoring abnormal symptoms

The illness is usually present with symptoms such as anemia, infection, or tendency to bleeding. The child's family could participate in observing abnormal symptoms and talking with their child about the symptoms; then, they could exchange the information with the nursing team. This information exchange provided nurses with more information that they might not be able to obtain unless the child spoke up. Moreover, the family could learn more about the illness from participating in pre- and post-conferences, in which they could inquire for extensive information should they have any doubts.

2) Encouraging the child to cooperate in nursing care and medical treatment

The family participated in encouraging their child to cooperate in medical care. For instance, when the child was receiving intravenous fluid infusion or blood transfusion, the family could comfort the child, assist him or her in doing activities, and deliver special care for the prevention of intravenous fluid leakage. Moreover, the family could also deliver simple nursing care, depending on their ability. Nursing staff would assess the family's ability and would teach them how to conduct simple nursing procedures such as temperature measurement or tepid sponge. The family would be able to deliver care to their child after hospital discharge and would be able to screen the child's abnormal symptoms before taking him or her to consult the physician.

3) Exchanging experience in caring for the child and expressing the feeling of anxiety with nursing staff

The family shared experience in caring for the child, as well as the feeling of anxiety and worry, with nurses. The nursing team would then work together to relieve the family's anxiety.

1.3 Children were suffered from a variety of medical procedures.

Children with cancer have to undergo several medical procedures, either the procedures for diagnosis or treatment. Diagnostic procedures include taking blood samples and bone marrow aspiration. Treatment procedures include the

administration of antibiotics, intravenous fluid infusion, blood transfusion and chemotherapy. In this study, small children always cried out loudly during a procedure. Many children were scared of the presence of doctors and nurses and developed avoidance behavior; some children cried when a hospital staff member approached them. For instance, a preschool child cried loudly after undergoing lumbar puncture:

‘I want to go home, go home, go home. There are only needles here; they hurt me. I want to go home, go home, go home.’

For older children, they responded with stiffness during medical procedures. The interviews with a number of children revealed that they would like to have their family stay with them. A child said:

‘I would like to have my mom stay with me during lumbar puncture.’

During medical procedures, most families were waiting outside the operating room or in the nearby area. Many families expressed desires to stay with their children. A mother of a child with leukemia said:

‘I want to give my child mental support. You send the parents out, then the child is left alone with doctors; he will be scared. At least my child should see me. He always wants to see his mother when he is in pain. I want to be with him, hug him, and give him mental support when he is in pain.’

Nurses’ role

1. Giving information about medical procedures to the family

When a child was scheduled for medical procedures, nurses gave information about the procedures to the family and the older child. Appropriate care before and after the procedure should also be explained, as well as the care during the procedure.

2) Allowing parents to care for a child during medical procedures

Nurses asked mothers about their willingness to stay with their children during medical procedures. Mothers participated in preparing their children for the procedures, giving support during the procedures and comforting the children after the procedure was finished.

1.4 Children were suffered from adverse effects of chemotherapy and from other complications.

Most children received chemotherapy for initial management of their illness. Some children may have complications from adverse effects of the treatment such as nausea, vomiting, mouth ulcers, and loss of appetite.

Nurses' role

1) Providing both mental and physical care

Nurses encouraged the family to participate in the prevention of complications and to observe and provide care to the child during the treatment with chemotherapy.

2) Providing knowledge about the adverse effects of chemotherapy and appropriate care

When doctors made a decision to start chemotherapy, nurses taught the child and the family about the illness, chemotherapy, and possible complications. The family also received the brochures 'Caring for Patients Receiving Chemotherapy' and 'Caring for a Child with Low Immunity' to develop their capacity in caring for the child.

Family's role

1) Participating in caring for children receiving chemotherapy

The family observed abnormal symptoms and provided care accordingly.

2) Exchanging information and experience in childcare with nurses

2. Family's responses to the child's illness

When the family was informed of the diagnosis of the child's illness, they felt distressed and were interested in the disease and its treatment. Each family had different ways to cope with distressed feeling and express their anxiety.

2.1 The family felt distressed when they were informed about the diagnosis.

When diagnostic investigation confirmed the diagnosis of cancer, the doctor would inform the family accordingly. As a result, the family would be shocked. A father of an eleven-year-old boy said:

'When I knew it, my brain went numb. I felt blurred.'

Most families initially responded with denial and disbelief; just like one mother of a child with leukemia:

‘I was thinking how my child would be but I never thought he would have this disease. When it is certain that he’s ill from this disease, I didn’t want to meet anybody on that day. I didn’t want to be with anybody, didn’t want to do anything. I just wanted to sit still, feeling sorry. I couldn’t talk, and didn’t want to answer any questions.’

Each family expressed their sadness differently. The feeling was shown in depressed expression and quietness. Some families expressed their sadness when nurses asked them about the children’s symptoms. Some parents had with sad eyes and lowered their head without saying anything; other spoke in a shaky voice with tears in their eyes. A mother described::

‘When I first knew it, I was in sorrow. I almost fainted. If my child cannot survive...I’d rather lie down. I did not want to hear anybody.’

Nurses’ role

1) Helping the family to overcome distressed feeling

Nurses continuously observed the family’s sadness and provided them with mental support at each stage of sadness, depending on the family’s requirement. For example, nurses prepared a private room for the doctor to inform parents of the diagnosis and waited until both parents were together before telling them. A nurse was also in the room to get information about what the doctors said to the parents. After the diagnosis was informed, parents had times to express their feelings and nurses accepted their responses without making judgments regardless of different responses from each family. Nurses acted as a good listener, expressed understanding, allowed parents to ask questions, and gave clear answers to their questions in warm and friendly manners. Nurses also ensured the parents that they could perceive nursing staff as their resources.

2.2 The family was interested in the disease and its treatment.

At the beginning of the diagnosis, most families were interested in the treatment plan and wondered whether their children’s illness was curable, how long the treatment would last, and how much the cost of treatment would be. A mother said:

‘I’d like the nurses to explain everything to me and explain about each medication.’

Nurses’ role

1) Exchanging information about the disease and related disorders

At the beginning of the diagnosis, the family did not know how they should care for their children. Thus, information exchange at this stage was aimed to develop the family's knowledge and understanding about the disease. After an assessment of family's knowledge about the disease, nurses provided the family with the information including pathological disorders, types of blood cells, the abnormalities and disease management. Nurses occasionally reviewed the information and childcare skills and they might repeat the provision of knowledge once they found that the family did not understand about the disease.

2) Exchanging information about the condition of illness

When the child's condition altered, nurses gave information and had a discussion about the changes in illness condition. The discussion with the family was conducted soon after the child's condition deteriorated. In addition, nurses regularly had a discussion with the family about the child's condition in pre- and post-conferences everyday.

The family of a child who was in the process of treatment already had experience in caring for the child; hence, nurses assessed the mother's existing knowledge and skills, observed the family's practice, and provided additional information regarding their insufficient knowledge. Nurses listened to the family's experience in caring for the child, answered the family's queries, and exchanged information concerning the current stage of illness. Some information might be repeated; such as how to care for the child receiving chemotherapy, prevention of possible dangers resulting from complications such as bleeding tendency, anemia, and low immunity caused by the treatment that suppressed bone marrow functioning leading to abnormal blood cells.

3) Coordinating with doctors in the provision of care

The family usually needed information about the treatment and progression of illness at the beginning of the diagnosis. Nurses represented the family in making contact with doctors and other healthcare professionals. In addition, nurses assessed the family's ability in communicating with doctors and other professionals. They gave the family suggestion and instruction for appropriate management and encouraged the family to practice communicating with other professionals. Nurses

then evaluated the family's performance and reflected on the outcomes with the family, aiming to improve the efficiency of their communication.

2.3 The family had different coping behaviors.

Families conducted various behaviors in coping with stress from the children illness. The family might keep their hope, talk with other families whose children were ill with the same disease, rely on supernatural power or seek more information.

Keeping hope

When a doctor informed the family of the diagnosis and progression of illness, the possibility of the child being cured was also mentioned. In addition, the initiation of chemotherapy, as well as supportive treatment such as blood transfusion for anemia, might improve the child's symptoms. These conditions contributed to the family's relief from the feeling of distress and provided them with hope that the illness would be cured.

'When I first knew that it was blood cell cancer, I cried. I could not sleep all night – I was afraid that I would lose my child, afraid that it wouldn't be cured. When the doctor said he had 60 percent chance, I was glad. I still have some hope.'

Talking with people who had the same feeling

In addition to the treatment plan that could improve the child's condition, talking with other families whose children also had cancer gave the family some hope and mental support. The family felt less distressed as they found that other families experienced the same problems. Some mothers said:

'When I saw other parents, knowing what's wrong with their children, I could stand it. I think there are chances that my child would be treated. The doctor said 60 percent so I can take it.'
'I can accept it after that day I talked to other parents and they said it could be cured. So I can accept it. I leave it to fate. If my child is lucky enough, he may survive and be able to take care of his parents later.'

Relying on religious beliefs and supernatural power

Many parents held on to religious belief and kept praying for their children's safety. Some parents asked sacred images for the protection of their children in the crisis stage. A mother said:

'I went to the spirit house yesterday, praying for my child. This morning I took garlands to the spirit house, asking all spirits to help my child.
I just prayed for my child.'

Seeking information

Families sought information in different ways. Some families sought information from books; others read brochures, pamphlet written and announcements. However, some families mentioned that they could not receive much information as they were shocked. However, most families wanted to know about the treatment and progression of illness.

Nurse role

1) Supporting the family to cope with stress appropriately

- Encouraging the feeling of hope and giving mental support

Nurses understood the feelings of anxiety, fear, and uncertainty of the child and the family; they helped the family to relieve those feelings by exchanging information, giving information concerning the unknown issues, and correcting misunderstood information. Nurses also sought resources for the family, as well as other resources that could provide them with more hope and could improve their interpersonal relationships.

- Providing care concerning financial problems

Most families had financial problems. Nurses assessed the family's rights to receive healthcare service and their financial requirements. Discussion between nurses and the family was held and nurses requested for social welfare support for the family if necessary. They also coordinated with doctors in accommodating the family's contact with other concerning organizations.

2) Encouraging the family to participate in expressing ideas and the in process of decision making

Nurses initiated mothers to participate in decision-making by assisting them to identify the problem and to seek information. Nurses encouraged mothers to consider all choices, pointed out advantages and disadvantages of each option and let mothers choose to do what they thought most beneficial for them.

3) Setting up group discussions with families of other children with cancer

Nurses set up a group consisting of mothers of children with cancer for exchanging and sharing experiences in illness management and in caring for ill children. The discussion group was led by social welfare officers in collaboration with nurses. Mothers had chances to express their feelings about having children with

cancer, dealing with critical situations, and caring for the children. In addition, mothers had chances to give and receive support to and from each other, leading to the reduction of stress and increased calmness as well as strength. As a result, the mothers were prepared to cope with stress and were able to continue caring for their ill children. This support group was held regularly every month.

2.4 The family was concerned about caring for the ill child.

Each family had different concerns about the child's illness. For example, some families may be concerned about the treatment and progression of the illness, while others may be worried about their living and the family's expenses.

- Treatment and progression of illness

Most families expressed their concerns about the treatment, progression of the illness, and childcare. Some mothers said:

'I keep thinking...when my child goes back home and has some food...I am afraid that he may be infected. I am really scared. People may come close to him, gathering around and asking him questions and I don't know if they are alright. Or if they have any infection.'
'Actually, I don't want to go home. Doctors said going back nine days, ten days - see if he will be better. Doctors wants us to leave so we have to leave. I don't know whether it's good or bad inside my child. They said the white cells decreases to 60,000. To be honest, I don't want my child to leave the hospital now, he may get infected.'

- The child's and the family's living

Some families expressed concern about their living condition when the child was discharged from the hospital.

'I am afraid that he may not act like when he is in the hospital. When we are all at the hospital, the medication comes and he just takes it. At home, it was always very difficult to make him take oral medications. He wouldn't take a medication or took it very late, not on time. I will have to be with him to be certain that he had everything as the doctor prescribed. He, himself, is quite absent-minded.'

Family expenses

Almost all families had concern about the expenses, either the expenses related to treatment or not.

'Money... if we need the treatment for a long time, we'll have to pay for the transportation, the medications. We are only farmers. Now the mother comes to stay with the child. Our expenses are not only for this younger child but the older one needs money too. I feel sorry for the big one as the mother spends all money on the ill one. We both think about it.'

'I've been thinking a lot. The oldest child is having an examination. We still don't know where he will study. I don't have much money and, now, one of my children is in the hospital and the other one needs education.'

Some families did not express much concern and were confident in caring for their children at home. These families were mostly the families of children who were severely ill prior to the treatment and chemotherapy significantly improved their symptoms. Thus the mothers felt confident and were not much worried much, as stated:

'I am not worried. I can care for my child as you taught me.'
'I'll try. Whatever happens we can solve the problems later.'

For children, they were delighted to go home.

Nurse role

1) Assessing help requirement and available resources

Nurses assessed the family's requirement of help and available resources, using the assessment form previously designed.

2) Discussing about the family's feeling of anxiety

During the pre-conference or at any available time, nurses had a conversation with the child or the family to assess their anxiety and provided them with help.

3) Discussing about childcare at home

Nurses discussed with the family about caring for the child at home. The discussion covered topics concerning the importance of continuous care, understanding about the child's condition, physical and developmental requirements, childcare and observation of abnormal symptoms requiring hospital visits. Nurses also emphasized the importance of caring for children with cancer with consideration of the children natural growth and development. At the same time, children and their families were encouraged to express their feelings and their concerns; in response, nurses listened to them attentively and answered their questions sincerely and clearly.

4) Promoting confidence in seeking for healthcare resources

Nurses discussed with the parents about the access to resources and encouraged them to reflect on healthcare services that would be appropriate for the child's condition. For example, for the follow-up of treatment outcomes, parents should take their child to the hospital for continuity of the treatment. For mild illness, the access to healthcare service from the healthcare center in the neighborhood could be more convenient and more appropriate. Nurses also gave parents cards containing

telephone numbers that they could contact to get counseling services form the hospital.

Family role

During the pre-discharge phase, when the child felt better and was ready to return home, the family exchanged opinions with healthcare professionals about the knowledge concerning the illness, childcare, and observation of symptoms in addition to raising questions concerning the delivery of care at home. Moreover, they also learned about the access to resources with suggestions from the nursing team about continuous treatment and pediatric health services.



BIOGRAPHY

NAME	Miss Tassanee Attharos
DATE OF BIRTH	5 May 1958
PLACE OF BIRTH	Ayutthaya, Thailand
INSTITUTION ATTEND	The Thai Red Cross, College of Nursing, 1976-1979 Bachelor of Nursing (B.N.) Mahidol University, 1992-1995: Master of Nursing Science (Maternal and Child Nursing) (M.N.S) Mahidol University, 1998-2003: Doctor of Nursing Science (D.N.S)
SCHOLARSHIP AND RESEARCH GRANT	Doctor Collaborative Program, Ministry of University Affairs The Thai Red Cross Society Pediatric Nurse Society of Thailand
POSITION HELD	1980-1982, Nursing Staff, Emergency Unit, Chulalongkorn Memorial Hospital 1982-1991, Nursing Staff, Department of Pediatric, Chulalongkorn Memorial Hospital 1991-Present, Academic Nursing Staff, The Thai Red Cross, College of Nursing
OFFICE ADDRESS	Department of Pediatric Nursing The Thai Red Cross, College of Nursing