CHAPTER 3

Methodology

The purposes of this study were to describe the level of uncertainty in illness among leukemic children receiving chemotherapy and to examine whether or not symptom pattern, information support from health care providers, information support from parents, information support from peers, illness related knowledge, and parental uncertainty can predict uncertainty in illness among leukemic children receiving chemotherapy. This chapter describes the methodology of the study, including the research design, population and sample, research setting, research instruments, data collection, and data analysis.

Research Design

A predictive correlational study was conducted to identify predictors of uncertainty in illness among leukemic children receiving chemotherapy.

Population and Sample

Population

The target population of this study was children with leukemia, aged 10 to 15 years receiving chemotherapy in Bangkok, and their parents.

Sample

The sample of this study was leukemic children aged between 10 and 15 years who were currently receiving chemotherapy in tertiary hospitals and their parents.

Purposive sampling was used to select the children based on the following inclusion criteria: (1) ability to understand and communicate in Thai, and (2) willingness to participate in this study. Meanwhile, the parents of those children with leukemia were recruited based on the following inclusion criteria: (1) ability to

understand and communicate in Thai, (2) willingness to participate in this study, (3) cohabitation with the child and (4) provision of care for their child at the hospital.

The sample size was determined with consideration of the representative sample to reduce type II errors using Cohen's statically analysis (Cohen, 1988) with the following formula:

$$N = \frac{\lambda}{\mathbf{f^2}}$$

To determine the noncentrality parameter (λ), the degree of freedom of the numerator of the F radio (U) which was equal to the number of independent variables (U = 6) and the degree of freedom of the denominator of the F ratio (V=120) were assigned. With six predictor variables, a significance level of .05, a power of .80, and the moderate effect size (f^2) of 0.15 by Cohen (1988), Cohen's Table yielded the λ value of 14.3 (Cohen, 1988). The estimated sample size was 96 children and 96 parents.

Research Setting

This study was conducted at pediatric oncology units of four tertiary hospitals in Bangkok consisting of Ramathibodi Hospital, King Chulalongkorn Memorial Hospital, Queen Sirikit National Institute of Child Health, and Phramongkutklao Hospital.

Research Instruments

The following research instruments were used to collect the data in the study:

Demographic Data Form

The Demographic Data Form was developed by the researcher for gathering the following data: (1) demographic data of children including age, gender, education, time since diagnosis, number of admissions, phases of chemotherapy, types of

chemotherapy drugs, side effects and complications of chemotherapy drugs, and laboratory results and (2) the demographic data of parents including relationships with children, occupation, and family income.

Children's Uncertainty in Illness Scale (CUIS)

The CUIS was originally developed by Mullins and Hartman (1995) and translated into Thai by Kantawang (2007). The CUIS was used to measure the child's perceived illness uncertainty about the course, prognosis, and treatment of his/her illness. It consisted of 23 items with 5 point Likert scale ranging from 1 (very true) to 5 (very false). A CUIS total score was obtained by summing scores across all items, with higher scores indicating higher uncertainty in illness. This score was classified into three levels including low (23 - 53), moderate (54 - 84), and high (85 - 115) using the method of equal class intervals (Polit & Beck, 2004).

Symptom Pattern Scale of Children with Cancer

Symptom Pattern Scale of Children with Cancer was a subscale of the Stimuli Frame of Children with Cancer Scale developed by Tathong et al. (2012) based on the symptom pattern concept of Mishel's Uncertainty in Illness Theory (1988). It consisted of 8 items with a 3-point Likert scale (1= disagree, 2 = agree, and 3 = strongly agree). The total score was obtained by summing up the scores across all items. Higher scores reflected that children perceive a more congruent symptom pattern.

Information Support from Health Care Providers Scale

The Information Support from Health Care Providers Scale was modified from the Information Support Subscale of the Social Support of Children with Cancer Scale developed by Tathong et al. (2012). It was used to assess the perception of children about receiving information support from nurses and physicians. It consisted of 12 items with a 3-point rating scale including 1 (not true), 2 (true), and 3 (very true). The total score was obtained by adding up the scores across all items. High scores indicated high information support from health care providers.

Information Support from Parents Scale

The Information Support from Parents Scale was modified from the Information Support Subscale of the Social Support of Children with Cancer Scale developed by Tathong et al. (2012). It was used to assess the perception of children about receiving information support from parents. It consisted of nine items with a 3-point rating scale including 1 (not true), 2 (true), and 3 (very true). The total score was obtained by adding up the scores across all items. High scores indicated high information support from parents.

Information Support from Peers Scale

The Information Support from Peers Scale was modified from the Information Support Subscale of the Social Support of Children with Cancer Scale developed by Tathong et al. (2012). It was used to assess the perception of children about receiving information support from friends who were leukemic children. It consisted of eight items with a 3-point rating scale including 1 (not true), 2 (true), and 3 (very true). The total score was obtained by adding up the scores across all items. The high scores indicated high information support from peers.

Illness Knowledge Scale

The Illness Knowledge Scale was modified from the Illness Knowledge of Children with Cancer Scale of Tathong et al. (2012). It was used to assess knowledge regarding leukemia, side effects and complications of chemotherapy, and care practices. The scale consisted of 37 true-false questions, with a 2-point rating scale including 0 (not true, not sure) and 1 (true). The total score was obtained by adding up the scores across all items. High scores indicated a high illness related knowledge possessed by children.

Parent Perception of Uncertainty Scale (PPUS)

The PPUS was developed by Mishel (1983) and translated into Thai by Suwanna-o-sod (2004). It was used to assess the parents' perceived illness uncertainty about their child's illness. It consisted of 31 items with 5-point Likert scale (strongly

disagree to strongly agree). Subscale scores and total scores were summed across items with high scores indicating high levels of uncertainty in illness.

Testing for Quality of Research Instruments

The instruments of this study were tested for their psychometric properties including content validity for the modified instruments and reliability for all instruments.

Content Validity Testing

The Illness Knowledge Scale, Information Support from Health Care Providers Scale, Information Support from Parents Scale and Information Support from Peers Scale were examined for their content validity by five experts. The panel of experts was composed of three nurse instructors who had expertise in caring for children with cancer, one pediatric oncology physician, and one advanced practice nurse in pediatric oncology. All experts were asked to judge the specific items in terms of their sufficiency and clarity in representing the concepts underlying the questionnaire's development. In addition, the experts were asked to rate the relevance of each item to the objective using a 4-point rating scale: (1) not relevant, (2) somewhat relevant, (3) quite relevant, and (4) very relevant (Waltz, Strickland, & Lenz, 2005). For this study, the questionnaires were judged as having acceptable content validity, if it had the item-level content validity index (I-CVI) of .80 and the scale-level content validity index (S-CVI) of .90 or above (Polit, Beck, & Owen, 2007).The average scores of S-CVI of the Illness Knowledge Scale, Information Support from Health Care Providers Scale, Information Support from Parents Scale and Information Support from Peers Scale were .99, 1.00, 1.00, and 1.00, respectively. All instruments had the average I-CVI score of 1.00 (see Appendix E).

Reliability Testing

All the research instruments used in this study were tested for their reliability by conducting a study among 10 leukemic children who met the inclusion criteria like the sample of the study. The internal consistency reliability of each instrument was

calculated by using Cronbach's alpha reliability coefficient. The lowest acceptable value of the reliability coefficients in the standard measurement was 80(Burns & Grove, 2005). Cronbach'salpha coefficients of the research instruments were between .80 and .94, indicating acceptable reliability (see Appendix D).

Preparation of Research Assistant

A research assistant, an advanced practice nurse in pediatric oncology who had experience in clinical research, of this study was trained for data collection. The researcher gave information about the study regarding the objectives of study, the inclusion criteria of the participants, protection of the rights of participants, and data collection procedure activities. The inter-rater reliability was tested with three leukemic children by the percentage of agreement between the researcher and the research assistant to examine confirmatory understanding of each item and was reported to be 1.00.

Human Rights Protection of Research Subjects

The study proposal was approved by the Research Ethical Committee of Faculty of Nursing, Chiang Mai University and the four data collecting hospitals. Prior to the study initiation, the eligible participants, leukemic children receiving chemotherapy and the parents, were informed about the study objectives, methods, time for participation, and protection of confidentiality of the participants. The children and their parents had the right to participate or refuse to participate in the study at any time without affecting their treatment or health care services. Their information provided during the study was kept confidential and used for the purpose of statistical analysis only. The children had to have permission to participate in this study from their parents and they were provided with assent. They were able to ask questions regarding the study and to withdraw from the study at any time without having any effect on their treatment or the services provided to them.

Data Collection

After getting approval from the Research Ethical Committee of Faculty of Nursing, Chiang Mai University, King Chulalongkorn Memorial Hospital, Ramathibodi Hospital, Queen Sirikit National Institute of Child Health, and Phramongkutklao Hospital, the researcher collected the data using the following steps:

1. Asking for permission to collect the data at four research setting hospitals, King Chulalongkorn Memorial Hospital, Ramathibodi Hospital, Queen Sirikit National Institute of Child Health, and Phramongkutklao Hospital, by sending the letters of the Dean of the Faculty of Nursing, Chiang Mai University to the directors of these hospitals.

2. Before collecting the data, the researcher recruited and trained a pediatric oncology nurse at Ramathibodi Hospital who had experience in conducting research in hospital settings to be a research assistant to collect data at Ramathibodi Hospital. The researcher collected data at three hospitals.

3. The researcher informed head nurses of the four pediatric oncology units about the study objectives and data collection procedures.

4. The researcher and the research assistant screened the eligible participants who met the inclusion criteria from the medical records. Then, the researcher or the research assistant gave a brief description of the study to the child participants and their parents, and asked for their willingness to participate in the study. After that the researcher and the research assistant introduced themselves and informed the child and his or her parents about the overall purposes of the study and time required for participation as well as the human rights protection issues. The children and their parents were assured of confidentiality and their freedom to withdraw from the study.

5. The children and their parents who were willing to participate in the study were asked to sign the assent and consent forms, respectively.

6. The researcher and research assistant collected the data using the questionnaires according to the following steps:

6.1 The demographic data form was used to collect the demographic data from children and their parents. The demographic data from children were collected using by the medical records and interviews. The demographic data from parents were collected using the interviews.

6.2 The other data pertaining to variables were collected using the six questionnaires, CUIS, Symptom Pattern Scale of Children with Cancer, Information Support from Health Care Providers Scale, Information Support from Parents Scale, Information Support from Peers Scale, and Illness Knowledge Scale, respectively.

6.3 The children completed six questionnaires by answering each item read to them over a 20 minute period, with a 5-minute intermission period. At the same time, the parents completed the PPUS by themselves.

6.4 After the children and their parents completedthe questionnaires, the researcher and the research assistant examined the questionnaires for completeness of the data.

Data Analysis

Preliminary data analysis was performed to examine the accuracy of the data and to test underlying assumptions of multiple regression analysis. The procedures of data analysis followed these steps:

1. The demographic data of the children and their parents were analyzed using descriptive statistics including frequency and percentage.

2. The uncertainty in illness of children was analyzed using descriptive statistics including frequency and percentage.

3. Predictability of the symptoms pattern, information support from health care providers, information support from parents, information support from peers, illness related knowledge, and parental uncertainty on uncertainty in illness of the leukemic children were analyzed using Stepwise Multiple Regression Analysis. The assumptions of Multiple Regression Analysis were tested including normality, linearity, homoscedasticity, and multicollinearity, the results showed that the assumptions were all met.

3.1 The normal distribution of all variables in the study was utilized to test by the Kolmogorov-Smirnov test. The result showed the assumption was met for all variables including uncertainty in illness (Z = .784, p = .570), symptom pattern (Z = 1.204, p = .110), information support from health care providers (Z = 1.282, p = 075), information support from parents (Z = 1.290, p = .072), information support from peers (Z = 1.263, p = .082), illness related knowledge (Z = 1.329, p = .058), and parental uncertainty (Z = .568, p = .903).

3.2 The linearity assumption was tested by using the Normal P-P plots that were drawn by using uncertainty in illness on the Y axis against symptom pattern, information support from health care providers, information support from parents, information support from peers, illness related knowledge, and parental uncertainty on the X axis. The results showed that they were all straight lines. If the assumption of linearity is met, the standardized residual should scatter randomly abouta horizontal line (Hair, Black, Babin, Anderson, & Tatham, 2006) (Appendix H).

3.3 The homoscedasticity assumption was tested by using a scatter plot that was illustrated by using raw scores of uncertainty in illness on the X axis against standardized predicted scores of uncertainty in illness on the Y axis. The result showed the line was straight from left lower corner to right upper corner (Appendix H).

3.4 The multicollinearity assumption was met due to the strength of association between all independent variables being less than 0.7 (Munro, 2005). Also, the various steps to create the predictive regression model and the tolerance scores of the same independent variables in the model were not changed much compared to the prior model (Appendix H, Table H-1). For example, the tolerance scores of the Information support from health care providers in the second model (0.936) were closely related to the tolerance scores from the first model (1.000).