

CHAPTER 4

Results and Discussion

This chapter is organized into two parts consisting of the results of data analysis and the research findings discussion. A predictive correlational study was conducted to identify predictive factors of uncertainty in illness among leukemic children receiving chemotherapy. The findings of the data analyses were composed of (1) demographic characteristics of the leukemic children and their parents, and clinical characteristics of the leukemic children; (2) descriptive statistics of the variables studied which include uncertainty in illness and correlation coefficients of the study variables and (3) predictability of symptom pattern, information support from health care providers, information support from parents, information support from peers, knowledge of illness, and parental uncertainty on uncertainty of illness among leukemic children receiving chemotherapy.

Results of the Study

Demographic Characteristics of the Leukemic Children and Their Parents

Of the 96 children with leukemia, more than half were male (54.2%), aged between 12 and 15 years (56.25%), and in primary school (55.2%). The majority of parents were mothers (76.0%). Nearly half (49.0%) of all parents were employees. Regarding family income, 33.3% had an income <15,000 baht/month and another 33.3% had an income of 15,000-30,000 baht/month, based on Table 4-1.

Table 4-1 Demographic Characteristics of the Leukemic Children and Their Parents

Demographic Characteristics	Frequency	%
Children's gender		
Male	52	54.2
Female	44	45.8
Children ages		
(Range = 10-15, \bar{X} = 12.28, S.D. = 1.97)		
10	30	31.25
11	12	12.5
12	8	8.33
13	13	13.54
14	13	13.54
15	20	20.84
Children educational level		
Primary school	53	55.2
Secondary school	38	39.6
Vocational education	2	2.1
Parental status		
Mother	73	76.0
Father	23	24.0
Parental occupation		
Employee	47	49.0
Unemployed	26	27.0
Merchant	18	18.8
Farmer	2	2.1
Government officer	3	3.1
Family income (baht)		
(Range = 5,000 – 100,000, \bar{X} =33,468.75 , S.D. = 30,809.76)		
< 15,000	32	33.3
15,000 – 30,000	32	33.3
30,001 – 45,000	10	10.4
> 45,000	22	23.0

Clinical characteristics of the leukemic children

The study sample included 96 leukemic children. Two-thirds of the children (67.7%) had been diagnosed with leukemia >1 year. More than half (58.3%) had been admitted to the hospital 10 times or less. About 66% had undergone the maintenance phase of chemotherapy. During the data collection period, most (91.7%) had side

effects from chemotherapy, 75% had more than one symptom, and 41.7% had complications, including infection, bleeding, and anemia. Forty percent of the children had a hemoglobin count less than 11 g/dL. Of the children, 28.1% had an absolute neutrophil count (ANC) 1000 % or less. In addition, 27.1% had a platelet count 10,000 per microlitre or less (Table 4-2).

Table 4-2 Clinical Characteristics of the Leukemic Children

Clinical Characteristics	Frequency	%
Duration of illness (month)		
(Range =1-96, \bar{X} = 2.43, S.D. = 23.80)		
< 12	31	32.3
12 - 36	41	42.7
36 - 60	17	17.7
> 60	7	7.3
Numbers of admission		
(Range = 1- 60, \bar{X} = 12.71, S.D. = 12.74)		
1 - 10	56	58.3
11 - 20	27	28.1
21 - 30	3	3.1
31 - 40	4	4.2
41 - 50	5	5.2
51 - 60	1	1.1
Phase of chemotherapy		
Induction phase	16	16.7
Consolidation phase	16	16.7
Maintenance phase	64	66.6
Side effects		
None	8	8.3
Having side effects	88	91.7
1 Symptom	16	16.7
2 Symptoms	13	13.6
3 Symptoms	10	10.4
4 Symptoms	12	12.5
5 Symptoms	7	7.1
6 Symptoms	14	14.6
7 Symptoms	7	7.3
8 Symptoms	8	8.3
9 Symptoms	1	1.0
Complications		
None	56	58.3
Having complications	40	41.7
Infection	6	6.3

Table 4-2 (continued)

Clinical Characteristics	Frequency	%
Anemia	14	14.5
Infection and anemia	6	6.3
Bleeding and anemia	2	2.1
Infection, anemia, and bleeding	12	12.5
Hemoglobin (g/dL)		
(Range = 6.89 – 15.20, \bar{X} = 11.46, S.D. = 1.90)		
< 9.5	16	16.6
9.5 - 11	23	24.0
>11	57	59.4
ANC (%)		
(Range = 0 - 28272, \bar{X} = 2612.5, S.D. = 306.68)		
< 500	13	13.5
500 - 1000	14	14.6
1001 – 1500	16	16.7
1501 - 2000	7	7.3
> 2000	46	47.9
Platelets (cells/mm ³)		
(Range = 1000- 656000, \bar{X} = 187010, S.D. = 1.22)		
< 50000	16	16.7
50000 - 100000	11	11.4
100001 - 140000	7	7.3
140001 - 400000	58	60.4
> 400000	4	4.2

Descriptions of the Variables

The dependent variable for this study was uncertainty in illness. The independent variables for the study were symptom pattern, information support from health care providers, information support from parents, information support from peers, knowledge of illness, and parental uncertainty. Based on Table 4-3, uncertainty in illness scores of the samples ranged from 48 to 91, with a mean of 70.05 and a standard deviation of 8.52. Symptom pattern scores were between 8 and 24, with a mean 17.63 and a standard deviation of 4.04. The scores of information support from health care providers ranged from 20 to 36, with a mean of 30.94 and a standard deviation of 4.27. The scores of information support from parents ranged from 16 to 27, with a mean of 23.53 and a standard deviation of 2.69, and the information support from peers ranged from 8 to 24, with a mean of 13.38 and a standard

deviation of 4.69 in sequences. Illness related knowledge scores ranged from 14 to 37, with a mean of 28.90, and a standard deviation of 5.23. Furthermore, Parental uncertainty scores ranged from 51 to 125, with a mean of 86.42 and a standard deviation of 14.56.

Table 4-3 Descriptive Statistics of the Variables

Variables	Possible Range	Actual Range	\bar{X}	SD
Uncertainty in illness	23-115	48 – 91	70.05	8.52
Symptom pattern	8 - 24	8 - 24	17.63	4.04
Information support from health care providers	12 – 36	20- 36	30.94	4.27
Information support from parents	9 – 27	16- 27	23.53	2.69
Information support from Peers	8 – 24	8- 24	13.38	4.69
Knowledge of illness	0 – 37	14- 37	28.90	5.23
Parental uncertainty	31 – 155	51- 125	86.42	14.56

Among 96 leukemic children, the majority (94.8%) had uncertainty at moderate level (Table 4-4).

Table 4-4 Uncertainty in illness of leukemic children

Uncertainty in illness	frequency	%
Range= 48 – 91 \bar{X} = 70.05 SD = 8.52		
Low (23 - 53 scores)	1	1.0
Moderate (54 - 84 scores)	91	94.8
High (85 - 115 scores)	4	4.2

Relationships between variables.

Pearson's product moment correlation was used to examine the relationships between the study variables. The magnitude of relationship was determined by the following criteria: $r < .30$ =low, $r = .31 - .50$ = moderate, $r > .50$ = high (Burns & Grove, 2001). Base on the table 4.4. Child uncertainty had a low and positive

relationship with symptom pattern ($r = .232, p < .05$), a moderate and negative relationship with information support from health care providers ($r = -.319, p < .01$), a moderate and negative relationship with illness related knowledge ($r = -.314, p < .01$), and a low and positive relationship with parental uncertainty ($r = .216, p < .05$). There was a non-significant relationship between other independent variables and uncertainty as presented in Table 4-5.

Table 4-5 Correlation Matrix of the Study Variables

	Unc	SymP	IHCP	IPar	IPeer	Know	PUnc
CUnc	1						
SymP	.232*	1					
IHCP	-.319**	.253*	1				
IPar	-.148	.250*	.386**	1			
IPeer	.083	.089	.229*	.081	1		
Know	-.314**	.391**	.438**	.416**	.114	1	
PUnc	.216*	-.008	-.033	-.211*	.090	-.007	1

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

CUnc = Child uncertainty in illness

SymP = Symptom pattern

IHCP = Information support from health care providers

IPar = Information support from parents

IPeer = Information support from peers

Know = Knowledge related illness

PUnc = Parental uncertainty

Predictability of Variables

Multiple regression analysis revealed that symptom pattern, information support from health care providers, parental uncertainty, and illness-related knowledge were the predictive factors of uncertainty in illness among children with leukemia undergoing chemotherapy and accounted for 34.8% of the variances in uncertainty in illness, as shown in Table 4-6.

As described in Table 4-6, the symptom pattern was the strongest predictive factor of uncertainty in illness ($\beta = 0.445$, $p < .001$) followed by illness related knowledge ($\beta = -0.371$, $p < .001$), information from health care providers ($\beta = -0.262$, $p < .01$), and parental uncertainty ($\beta = 0.209$, $p < .05$), respectively.

The final regression model from the analysis was as follows:

Standardized regression coefficient model

$$Z_{\text{Unc}} = -0.262 Z_{\text{IHCP}} + 0.445 Z_{\text{SymP}} - 0.371 Z_{\text{Know}} + 0.209 Z_{\text{PUnc}}$$

Table 4-6 Predictor of Uncertainty in illness by Using Stepwise Regression Analysis

Variables	β	R^2	R^2 Change	t	p
Constant				10.54	.000***
IHCP	-.262	.102	.102	-2.77	.007**
SymP	.445	.206	.104	4.82	.000***
Know	-.371	.305	.099	-3.74	.000***
PUnc	.209	.348	.043	2.46	.016*

SE^{est} = 7.025 F = 12.166 p-value = .000

* $p < .05$ ** $p < .01$ *** $p < .001$

IHCP = Information support from health care providers

SymP = Symptom pattern

Know = Knowledge of illness

PUnc = Parental uncertainty

Discussion

The results of this study are discussed in relation to each of the research objectives of the study as follows:

Research Objective 1

To describe the level of uncertainty in illness among leukemic children receiving chemotherapy.

Most leukemic children receiving chemotherapy (94.8%) reported at a moderate level of uncertainty in illness. This finding was congruent with the previous study of Silapavitayatorn (2008) which showed that most of the children with cancer receiving chemotherapy, aged between 8 and 15 years, reported having uncertainty in illness at a moderate level (93.3%). Similarly, another recent study on uncertainty in illness among children with leukemia and lymphoma receiving chemotherapy (Tathong et al., 2012) found that the majority reported having uncertainty in illness at a moderate level (85.2%).

The finding that the majority of leukemic children receiving chemotherapy had a moderate level of uncertainty in illness which could be explained by two reasons. Firstly, the majority of children (64%) were in the maintenance phase. The chemotherapy maintenance phase aims to prevent remission of leukemia. The children received a combination chemotherapy formula for about two and a half to three years (Margolin et al., 2011). During the maintenance phase, these children received the chemotherapy several times; and they had a lot of experience regarding disease manifestation, procedures of chemotherapy, and its side effects as well as complications (Cicogna, Nascimento, & Lima, 2010). Thus, they were familiar with these illness related events, knew what to anticipate, and understood illness events. Finally, they could give meaning of illness events themselves (Gibson et al., 2010). Therefore, receiving the chemotherapy maintenance phase led to moderate levels of uncertainty among the majority of these leukemic children.

The second reason had to do with duration of illness and number of admissions. Two-thirds of these leukemic children (67.7%) had been diagnosed with leukemia for more than one year. About forty percent of the children were admitted to

the hospital more than 10 times. Long illness duration and several hospital admissions would increase opportunities for these children to receive more information from health care providers which helps them understand their illness related events. This results in moderate level of uncertainty in illness.

Research Objective 2

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

In this study, the selected six variables were proposed in a hypothesized conceptual framework of uncertainty in illness among leukemic children receiving chemotherapy. Four variables including symptom pattern, information support from health care providers, parental uncertainty, and illness related knowledge were found to be the predictive factors of uncertainty in illness, accounting for 34.8% of the variance in uncertainty in illness among leukemic children receiving chemotherapy ($R^2=.348$, $p < .01$). Therefore, the result partially supported the theoretical framework. This finding appears to be quite similar to the result of study in American children with cancer aged between 8 and 18 years, in which parental uncertainty, age, and cancer knowledge significantly predicted children's uncertainty and explained 21% of the variance in child uncertainty (Stewart et al., 2010). However, the results from this study showed much higher predictability on the uncertainty than the previous study did. This finding was confirmed in a homogenous sample of children with similar cognitive development level. Meanwhile, the previous study was conducted in children with a wide range of ages and various types of cancer. Younger children might have had difficulty understanding the meaning of illness-related events. In addition, various types of cancer and treatment would result in different experiences leading to predictability on uncertainty in illness.

Information support from health care providers was found to be the first predictive factor of the uncertainty of children with leukemia ($\beta = - 0.262$, $p < .01$) and accounted for 10.2% of the total variation of uncertainty in illness. The children who reported higher information support from health care providers were less likely

to have uncertainty. This might be because two-thirds of the children (67.7%) had been diagnosed with leukemia longer than one year and 42.7% had been admitted to hospitals more than 10 times. The children who experienced complex illness-related events may have gotten more information from nurses and physicians. The long duration of illness and frequent hospitalization led to a high probability of illness-related information. Moreover, patients who develop a strong alliance with health care provider have been found to maintain a higher level of well-being and greater perceived health care provider support (Trevino, Fasciano, & Prigerson, 2013). The information helped them reduce the ambiguities and complexities, increased their understanding, reduced their unpredictability and made it simpler to clarify symptom patterns, leading to low uncertainty (Mishel, 1988; Mishel & Clayton, 2008). Unfortunately, there is no evidence from prior studies that is specific to the information support from health care providers. However, this finding was similar to the results from several studies that showed the association between social support and uncertainty in children who were diagnosed with cancer. Neville (1998) showed that there was a significantly negative relationship between perceived social support and uncertainty ($r = -.30, p < .01$). Naruemandecha (2008) revealed that social support was significantly negative related to uncertainty of illness ($r = -.746, p < .01$) and information support ($r = -.733, p < .01$). Health care providers such as doctors and nurses impulsively hold professional authority that most people trust, respect, and credibility based on their knowledge and education that are utilized to help people with illness (Mishel, 2014; Kraus & Keltner, 2013). This research finding showed that the information support from health care providers can predict uncertainty in illness among leukemic children.

Symptom pattern as the predictive factor of uncertainty in illness among children with leukemia receiving chemotherapy ($\beta = 0.445, p < .001$) accounted for 10.4% of the total variation of uncertainty in illness. The children who perceived high symptom pattern had high uncertainty. Theoretically, when the children perceive symptoms as having consistency in frequency, intensity, and duration, their uncertainty is low. This might be because the majority of these children (66.6%) had undergone treatment in the maintenance phase, during which children receive low doses of chemotherapy. They had a long intermission period of two to three years

(TPOG, 2006) resulting in having symptoms with side effects that were consistent enough that the children could perceive them as having a pattern (Pui et al., 2012). In general, during the maintenance phase, the children receive low doses of chemotherapy and should have fewer side effects and complications related to chemotherapy (Pizzo & Poplack, 2011). However, most children in this study (91.7%) had side effects from chemotherapy: 75% had more than one symptom, and 41.7% had complications from chemotherapy that led them to experience complex illness-related events which resulted in high uncertainty (Fortier et al., 2013). Moreover, children who had cancer one to four years after diagnosis still remained uncertain about the meaning of any pain, the unpredictability of physical distress, and the changing course of the illness (Decker et al., 2007). Therefore, despite the fact that these children perceived a high symptom pattern in the maintenance phase, they might still have high uncertainty. Another possibility may be associated with the research instrument. The symptom pattern scale of children with cancer was developed based on illness events that occur during the induction phase. For example, they say, “I suffered from mouth sores and could not eat,” or “I had to be placed in an isolated room after I received chemotherapy.” Most of the questions/events in this instrument would not occur while experiencing the maintenance phase of chemotherapy.

Furthermore, parental uncertainty was found to be a predictive factor of childhood leukemia uncertainty ($\beta = 0.209$ $p < .05$) and accounted for 4.3% of the total variation of uncertainty in illness, such that as parental uncertainty increased, child uncertainty in illness also increased. Parental uncertainty has a negative impact on interactions with the children (Lin, Yeh, & Mishel, 2010). Parental uncertainty about their child’s illness can interfere with their capacity to provide information to support their child’s illness schema formation, resulting in child uncertainty. Typically, the incidence of children with cancer may strengthen the link between a parent’s and child’s psychological functioning (Okado et al., 2014). The findings were congruent with a previous study (Page et al., 2011; Stewart et al., 2010) that found parental uncertainty to be a predictive factor of child uncertainty ($\beta = .24$, $p < .05$, $\beta = .38$, $p < .001$, respectively). In addition, the majority of parents were mothers (76.0%), which was consistent with the study of Page et al. which showed that maternal uncertainty was a predictive factor of child uncertainty in illness.

The last predictor, illness related knowledge was found to be a predictor of childhood leukemia uncertainty ($\beta = - 0.371, p < .001$) which accounted for 9.9% of the total variation of uncertainty in illness, such that as illness-related knowledge increased, child uncertainty in illness decreased. This might be because the majority of children with leukemia had undergone the maintenance phase (66.6%) and may possibly have learned about their illness. Illness related knowledge including leukemia, side effects and complications of chemotherapy, and care practices assist children in interpreting their symptoms and illness-related events, resulting in low uncertainty. Similarly, uncertainty can be reduced by knowledge (Mishel, 2014). The findings were congruent with previous studies in which illness related knowledge had a negative relationship with child uncertainty (Naruemandecha, 2008; Lee, Wang, Li, Shiao, & Tu, 2014).

Information support from parents and peers did not predict the uncertainty experienced by the children with leukemia. However, these two variables had a significantly positive correlation with information support from health care providers ($r = .386, p < .01$; $r = .229, p < .05$; respectively). The children receiving more information support from health care providers also got more information support from parents and peers. A possible explanation could be that information support from parents and peers alone may not be strong enough to directly affect a child's uncertainty in illness. In addition to illness-related information, parents also rely on their relationship with health care providers when their children are seriously ill (Hinds & Kelly, 2010). However, the children might lack opportunities to meet and talk to other hospitalized children who also have cancer, resulting in suffering from the side effects and complications of chemotherapy (Cicogna et al., 2010). They mentioned a strong desire to rest indicating fatigue. Therefore, to address uncertainty in illness, children may request explicit information that could affect their ability to determine the meaning of their illness-related events, while the information from parents or peers were not clear enough for understanding.

The four variables of symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty could explain 34.8% of the variance in uncertainty in illness among children with leukemia undergoing chemotherapy. Further research, using the theoretical framework of this study may be

needed to examine key predictive factors associated with child uncertainty which were not addressed in this study. There might be another predictive factor of child uncertainty, which concerns emotional support. Children with cancer reported that emotional support was an area of unmet need (Michell, Clark, & Sloper, 2006) and particularly as a previous study (Naruemandecha, 2008) in children with SLE indicated that emotional support had a negative relationship with illness uncertainty. Thus, emotional support may influence child uncertainty.



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