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**Development and Evaluation of an Uncertainty Management  
Program for Mothers of Children with Newly Diagnosed Cancer in  
Bangladesh**

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**Development and Evaluation of an Uncertainty Management  
Program for Mothers of Children with Newly Diagnosed Cancer in  
Bangladesh**

A Dissertation Submitted to the  
Department of Nursing,  
the Graduate School, Yonsei University  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

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December 2017

This certifies that the dissertation  
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December 2017

## ACKNOWLEDGEMENTS

Alhamdulillah by the name of Allah, the compassionate and most merciful, praise to the Lord of the universe and blessing to the Prophet Muhammad s.a.w. First of all, thanks to Allah SWT for giving me the strength to complete this project.

This project has been accomplished through the encouragement, guidance, and support of many special people. My biggest thanks and utmost gratitude goes to my dissertation supervisor, Professor Hee Soon Kim, for her constructive guidance, excellent coaching, supportive manner, and compassionate and warm love throughout the research process. I would like to extend my sincere gratitude to the thesis examining committee for providing fruitful suggestions to improve my work. Sincere thanks go to all the mothers of children with cancer who participated in this research. I am grateful to the Government of the People's Republic of Bangladesh, the Directorate General of Nursing Service and Midwifery, and the Korean International Cooperation Agency (KOICA) for giving me a scholarship and technical support to study in Korea.

My greatest thanks go to Professor Tae Wha Lee, Dean, College of Nursing, Director, Graduate School of Nursing, Yonsei University, for her encouragement and

warmth throughout my doctoral program. My special gratitude goes to Emeritus Professor Chung Yul Lee, for assisting in the reliability tests and data analysis.

Special thanks to all the officials and students at Yonsei University for their support during my academic pursuits. I sincerely thank the Dean for the support and the direction provided by the many talented Professors at the CoN. Special thanks also goes to the experts, both in Korea and Bangladesh, for their assistance in commenting on and validating the research materials and questionnaires, translation of the instruments, and editing the dissertation. Special thanks go to So Jeong Lee, coordinator and other supportive officials at KOICA for their assistance. Thanks go to Noh, Dabok RN, PhD for assisting in preparing the research materials and data analysis.

Finally, I recognize the patience, support, and endurance of my family during my PhD program. My husband, Momin, who had the patience of Job with me throughout all the ups and downs and my kids, Adib and Sristy, who inspired me to complete this work, through their innocence and kindheartedness. My mother, who encourage me to finish my studies; I owe you a great debt of gratitude.

*Shanzida*  
*December 2017*

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## ABSTRACT

Development and Evaluation of an Uncertainty Management Program for Mothers of  
Children with Newly Diagnosed Cancer in Bangladesh

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*Purpose:* This study aims to develop an uncertainty management program for mothers of children with newly diagnosed cancer and to evaluate the program's effect of on maternal uncertainty, maternal coping, and maternal quality of life.

*Methods:* A uncertainty management program (UMP) was developed based on "Mishel's Theory of Uncertainty in Illness and needs assessment and the process included content validation, involving expert reviews, focus group interviews, measurement of reliability using Cronbach's alpha, and repeated measures analyses of variance." This Quasi-experimental study used a non-equivalent control group non-synchronized design. Participants recruited from a specialized

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hospital were assessed at prôt-test, post-test 1, and post-test 2. Seventy mothers of children with cancer were assigned into two groups (experimental group = 35, control group = 35).

*Results:* The UMP consisted of four components including three face-to-face sessions conducted by the researcher, three consecutive days after baseline assessment. Repeated measures ANOVA showed significant main time effect, main group effect, and interaction effect by group and time on maternal uncertainty ( $F = 108.593, p < .001$ ;  $F = 125.745, p < .001$ ;  $F = 102.450, p < .001$ , respectively), maternal coping ( $F = 24.293, p < .001$ ;  $F = 40.320, p < .001$ ; and  $F = 6.781, p < .002$ , respectively), and maternal quality of life ( $F = 45.561, p < .001$ ;  $F = 154.822, p < .001$ ; and  $F = 43.685, p < .001$ , respectively).

*Conclusion:* This study has implications relating to the applicability of the theory of uncertainty in illness for the future development of interventions designed to decrease illness uncertainty including bio-behavioral outcome in other populations with different circumstances

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**Key words:** uncertainty, coping, quality of life, cancer, children, mothers, intervention.

## **I. INTRODUCTION**

### **1. Background and Significance of the Problem**

Childhood cancer is an increasingly prevalent chronic disease the world over (Castillo-Martínez, Juárez-Villegas, Palomo-Colli, Medina Sansón, & Zapata-Tarrés, 2009). Cancer is the leading cause of death (Kazak & Noll, 2015) and major cause of morbidity in children in Bangladesh (Government of the People's Republic of Bangladesh, Ministry of Health and Family Welfare, 2008). Between 2011-2014, Bangladesh's rate of pediatric cancer (age 0-18 years) was 7.8 per million person-years (Hossain et al., 2016).

During active medical treatment, parents of children with cancer face many emotional and psychosocial challenges that can cause them uncertainty (Emma Hove'n, Anclair, Samuelsson, Krister, & Boman, 2008). Uncertainty pervades parents' experience of their child's illness throughout treatment, from the time of diagnosis. Mothers of children with cancer have been reported to experience sadness and despaired about their child's treatment, prognosis, and future. Previous studies have reported that, due to the strong impact of religion and social traditions, Bangladeshi mothers of children with cancer often believe that the cancer is a curse

from God (Basher, Karim, Sultana, Hossain, & Kamal, 2012). In such cases, the mothers were reported to believe that the chronic illness was a type of fate or punishment (Eun-Sook, Won-Oak, Min-Hyun, & Young-Mi, 2009).

Mothers of children with cancer face a number of potential stressors including the unpredictable nature of cancer (Dodgson, Garwick, Blozis, Patterson, Bennett, & Blum, 2000; Mishel, 1988), the impact of disease severity (Madeo, O'Brien, Bernhardt, & Biesecker, 2012), treatment regimen and dealing with multiple health care professionals (Mishel, 1988). Uncertainty has been identified as a significant predictor to psychological outcomes and presents significant challenges to the adjustment of mothers of children with cancer.

Studies found that illness uncertainty is associated with parental distress (Holm, Patterson, Rueter, & Wamboldt, 2008; Stewart & Mishel, 2000), maternal coping (He, You, Zheng, & Bi, 2016; Khatun, Kim, & Park, 2016), maternal adjustment or adaptation (Durette, 2013; Grootenhuis & Last, 1997; Madeo et al., 2012), and maternal quality of life (Effendy et al., 2014; Liu & Yeh, 2010; Lai, Lin, & Yeh, 2007; Pai, Drotar, Zebracki, Moore, & Youngstrom, 2006; Yamazaki, Sokejima, Mizoue, Eboshida, & Fukuhara, 2005). Parents of children with cancer (especially mothers) are often socially isolated by stigma and the care-giving burden of their



child's illness. These mothers are at risk of better psychological adjustment. Thus, promoting positive psychosocial outcomes can be considered just as significant as minimizing negative psychological outcomes in mothers of children with cancer.

There is a noticeable gap in the literature regarding the assessment and management of uncertainty in mothers of children with cancer. Of the existing research into parental uncertainty, and only a small portion of the literature is related to the mothers of children with cancer and the majority of studies are conducted among Western participants meaning that culturally diverse populations and fields of research are significantly underrepresented. One study demonstrated that a subset of parents of children with type 1 diabetes experienced significant psychological distress related to their child's diagnosis. The current literature presents conflicting information about the effects of interventions, especially in the management of uncertainty in mothers of children with cancer. Mishel's theory of uncertainty emphasizes elements of the characteristics and definition of uncertainty. Only one-way information giving is insufficient for mothers' cognitive appraisal process to help them cope with their illness-related situations and increase their quality of life.

Studies on uncertainty management are lacking, as are theories and needs assessment templates for mothers managing ill children. Thus, the present study

aimed to develop an uncertainty management program (UMP) based on the construct of Mishel's theory of uncertainty in illness and need assessment, and to evaluate the effects of the UMP on mothers of children with cancer. This study offers an additional contribution by enabling us to evaluate the empirical adequacy of Mishel's theory of uncertainty in illness to reduce uncertainty in Bangladesh, where the culture is different from Western cultures.

## **2. Purpose of the Study**

The purpose of the study was to develop and evaluate the effects of an uncertainty management program for mothers of children with newly diagnosed cancer. The specific purposes were as follows:

- 1) Develop an uncertainty management program for mothers of children with newly diagnosed cancer.
- 2) Evaluate an uncertainty management program for mothers of children with newly diagnosed cancer.

## **3. Hypotheses of the Study**

The specific hypothesis for evaluating an uncertainty management program

was as follows:

Hypothesis 1: There will be decreased maternal uncertainty in mothers of children with newly diagnosed cancer in the experimental group compared to the control group.

Hypothesis 2: There will be increased maternal coping in mothers of children with newly diagnosed cancer in the experimental group compared to the control group.

Hypothesis 3: There will be increased maternal quality of life of mothers of children with newly diagnosed cancer in the experimental group compared to the control group.

#### **4. Definition of the Terms**

##### **1) Maternal uncertainty**

Illness uncertainty has been defined as a cognitive appraisal context that occurs when the meaning of illness related events is unclear, outcomes are unpredictable, and there is a lack of information or cues (Mishel, 1990). In this study, maternal uncertainty refers to the inability of mothers to structure, categorize, and determine the meaning of illness related events adequately because the illness-related

situations are unclear, disease prognosis is unpredictable, and there is a lack of information. Maternal uncertainty was measured using the Parents Perception of Uncertainty Scale (PPUS).

## **2) Maternal coping**

According to Mishel's (1990) theory, parents of children with cancer may try to manage illness-uncertainty through different coping strategies, including emotion-focused coping and problem-focused coping, thus working toward psychological adaptation. In the present study, the definition of maternal coping was adopted from the study of Sterken (1996): individual development of strategic mechanisms whereby the tasks and needs associated with being a mother of a child with cancer are achieved. Maternal coping was measured by the Coping Health Inventory for Parents (CHIP).

## **3) Maternal quality of life**

Quality of life refers to the appraisal of one's satisfaction with one's current level of functioning, as compared to what the person perceives to be possible or ideal (Cella & Cherin, 2001). In the present study, maternal quality of life refers to the mothers' evaluation of her satisfaction with her current level of functioning. Maternal

quality of life was measured using the Caregiver Quality of Life Index-Cancer-Singapore25 (CQOLC-S25).

## **II. LITERATURE REVIEW**

The purpose of this chapter is to review the current literature related to this study. The literature review is an important part of the research process. It guides the researcher from the research question to the data analysis process. The review of the literature related to this study follows.

### **1. Childhood Cancer**

#### **1) Current issues related to childhood cancer**

Childhood cancer is a life-threatening event. Cancer is emerging as a major cause of childhood death in Asia (American Cancer Society, 2015). Globally, approximately 163,300 children develop cancer each year (American Cancer Society, 2015). Among children ages 1 to 14 years in United State, it is estimated that 10,270 will be diagnosed with cancer and 1,190 will die of the disease in 2017 (Siegel, Miller, & Jemal, 2017). The majority of children with cancer (84%) live in developing countries (American Cancer Society, 2012) where nearly 90% of the children have poor access to healthcare (Ferlay et al., 2008). In Malaysia, with a total population of 27.2 million (May 2008, Department of Statistics Malaysia, 2008),

1,500 children are expected to be diagnosed with cancer every year (Othman, Mohamad, Hussin, & Blunden, 2011). Leukemia is the most common form of cancer among children in most parts of the world (American Cancer Society, 2015; Arfa, Zaher, Dowatyv, Moneeb, 2008). Data from the Thai Paediatric Oncology Group indicates that the age-standardized incidence of Leukemia was 3.8 cases per 100,000 with a 5-year survival of 57% for the period of 2003-2005 (Wiangnon, et al., 2011).

In Bangladesh, approximately 16.1 percent of children with cancer were admitted to the pediatric oncology department of the National Institute of Cancer Research & Hospital (NICRH) in 2014 (Government of the People's Republic of Bangladesh, Ministry of Health and Family Welfare, 2016). According to Jabeen, Haque, Islam, and Talukder (2010), there were 28,409 new confirmed cases who attended the outpatient department of the National Institute of Cancer Research and Hospital (NICRH) from 2005-2009 in Bangladesh. The most common types of childhood cancer are lymphoma (24.2%), retinoblastoma (17.4%) and leukemia (14.3%) (Jebeen et al., 2010). Most children (75%) suffering from Acute Lymphoblastic Lymphoma (ALL) (Mullik & Algin, 2010). The incidence of under-5 mortality in Bangladesh is 36 per 1000 live births (Government of the People's Republic of Bangladesh, Ministry of Health and Family Welfare, 2016). Cancer is the

leading cause of child mortality and a major cause of morbidity (Bangladesh Bureau of Statistics, 2009; Hoyert, Freedman, Strobino, & Guyer, 2001; Jemal, Siegel, & Ward, 2010).

## **2) Problems related to childhood cancer**

Children with cancer alter the life situation of their family. Late stage cancer is incurable, and the role of the caregiving increases the physical and an emotional burden on the family (Given, Given, & Sherwood, 2012). The life-threatening nature of cancer and its invasive treatment procedures present numerous challenges, emotional stresses, and social burdens for the children and their parents especially for mothers.

Cancer presents a very difficult challenge for a child who may often be afraid of both the illness and the treatment process (Shelley, 1991). Initially, children do not understand the complexities of their diagnosis and treatment. Therefore, they need more help and support. Psychosocial reactions of children with cancer include fear of rejection, low-self-esteem, fear of restrictions influenced by the situation, and anxiety about how others (especially peer groups) will react to their illness (Marcus, 2006). Children undergoing cancer treatment also experience a number of physical changes such as weight loss related to gastrointestinal effect or weight gain related to use of



steroids (Marcus, 2012), changes of body image (Theofanidis, 2014), behavioral disturbance (Melissa-Chalikiopoulou, 1990), and difficulties with school adjustment (UICC, 2006). According to one report, in Bangladesh, approximately 87.5% children with cancer suffer emotional disturbances, and 34.7% experience behavioral disorders including separation anxiety, and social phobia (Mullick & Algin, 2010). A child with cancer may experience unjustified sorrow due to a belief that their suffering is a punishment for their parent's past sins (Mullick & Algin, 2010). The restrictions a child faces due to illness may lead to feelings of inadequacy and the belief that they are unacceptability different from the others.

It is natural for parents to experience despair and distress on hearing that their child has cancer. Having a child with cancer is one of the most difficult and painful experience for parents (Theofanidis, 2014). Parental identity can be threatened if the parent feels that they were responsible for giving birth to an unhealthy child or that they were not capable of protecting their child from chronic diseases (Theofanidis, 2014). Having a child with cancer can increase parental stress, which can subsequently increase the stress of the child. The child's negative health condition may affect his or her parents' psychological adjustment. Parents of a child with cancer suffer from various stresses (Barrera, D'Agostino, Gibson, Gilbert, Weksberg,

& Malkin, 2004; Klassen et al., 2008) including feelings of hopelessness (Barrera, et al., 2004; Martinson, Kim, Yang, Cho, Lee, & Lee, 1995) and helplessness (Hoven, Anclair, Samuelsson, Kogner, & Boman, 2008); deep despair followed by guilt (Martinson et al., 1995; Mu et al., 2001); fear (Hoven et al., 2008; Martinson et al., 1995); and anxiety and depression (McCaffery, 2006). Loss of work due to commitments related to care giving while struggling to meet substantial treatment costs increase the financial burden of illness on the families of children with cancer (Eiser, Eiser, & Stride, 2005).

Similarly, having a child with cancer can cause a great deal of physical and emotional stress on mothers, as they are generally the primary caregiver for their children (Nelson, Miles, & Belyea, 1997). A study by Pathirana, Goonawardena, and Wijesiriwardane (2015) revealed that caregivers of children with leukemia have impaired quality of life. Mothers reported feelings of helplessness (Grootrnhuis & Last, 1997), depression, loss of control, less confidence, loneliness, sleep disturbance, social isolation, anorexia, weight loss, problems at work, increased relationship conflict, higher rates of divorce, decreased satisfaction (Eun-Sook et al., 2009; Klassen et al., 2008; Martinson et al., 1995), and feelings of inadequacy in the parenting role (Hoven et al., 2008). Due to the strong impact of religion and prevalent

social traditions, most the Bangladeshi mothers are unwilling to tell with others about their child's illness (Basher et al., 2012). Korean and Bangladeshi mothers were reported to believe that chronic illness, like cancer, was a type of fate and punishment or a curse of God (Basher et al., 2012; Eun-Suk et al., 2009). Korean mothers reported feeling of guilt when they did not receive adequate support from their family or relatives (Martinsol et al., 1995).

## **2. Effects of Intervention**

Some psychological interventions have been conducted, including uncertainty management interventions (Hoff, Mullins, Gillaspay, Page, Van Pelt, & Chaney, 2005; Mullins et al., 2012), problem-solving & product ethnography (Morrison, Szulczewski, Strahlendorf, Lane, Mullins, & Pai, 2016), family-level education and support interventions (Svavarsdottir & Sigurdardottir, 2006; Sigurdardottir, Svavarsdottir, Rayens, & Gokun, 2014), psycho-educational, cognitive behavioral technique (Hoekstra-Weebers, Heuvel, Jaspers, Kamps, & Klip, 1998), COPE (Creating Opportunities for Parent Empowerment) intervention (Duffy & Vessey, 2016), and parent empowerment programs (Lamanna, 2012) for parents of children with chronic illness. Studies found that these such interventions were linked with

significantly decreased maternal distress (Hoff et al., 2005; Mullins et al., 2012), improved adjustment (Mullins et al., 2012), and increased overall quality of life (Ghodsbin, Asadi, Fard, & Kamali, 2014). A study by McMillan et al. (2005) found that the patients received coping skill intervention but their caregivers improved their quality of life. A study which aimed to assess the effects of coping interventions to manage advanced cancer patients and their caregivers' quality of life, observed significant group and time interactions in caregivers' quality of life (Northouse et al., 2013).

Conversely, a study by Hoeskstra-Weebers et al. (1998) showed that parents had significantly less psychologically distress but there was no effect of psycho-educational intervention. A study by Crespo, Santos, Tavares, and Salvador (2016) found that family-center care was not significantly related with maternal quality of life and parental confidence (Duffy & Vessey, 2016). However, caregivers' perception of their child's treatment experience was shown to influence their perception of quality of care, relationship with health care providers, and thus their ability to manage stress and uncertainty (Morrison et al., 2016). Jiang and He (2012) reported that uncertainty management interventions were effective in decreasing uncertainty, anxiety, and depression, and improving quality of life. Over time, the

experience of uncertainty contributes to increased distress and post-traumatic stress syndrome (PTSS) in parents of children with cancer (Grootenhuis & Last, 1997; Hoff et al., 2005). To date, a considerable body of empirical research supports the silent role of this construct in predicting adjustment outcomes. Illness uncertainty has been shown as a robust predictor of overall distress and anxiety, and depression in parents of children with chronic illness including cancer (Grootenhuis & Last, 1997). A study of Hoff et al. (2005) found that uncertainty focused intervention significantly reduced general psychological distress in parents of children with type 1 diabetes.

In summary, the current literature demonstrates that parents of children with diabetes mellitus type 1 (DM1) experience significant psychological distress related to the diagnosis of their child's illness. There were some interventions related to psychological positive outcomes for family caregivers caring for children with chronic illness which focused on knowledge base, parent empowerment, problem-solving skill, and delivering information about strategies for increasing maternal coping and quality of life. However, there was an absence of a comparison group in these studies, and they used long sessions with group interventions. Furthermore, some studies used one interventionist for both groups who knew the aims of the research and may have introduced bias. Most of the studies had small sample sizes

and a lack of diversity in culture. In addition, there were limited intervention studies on maternal coping and maternal quality of life based on Mishel's theory of uncertainty in illness. According to Mishel's model, the basic needs for parents of chronically ill children include information about the child's condition and plan of treatment; guidance and support as the parents learn about the child's illness; and trust in themselves and the health care professional (Mishel, 1988). Open communication with information giving and support are important for mothers of children with chronic illness' cognitive process during caring for their children. Therefore, it is reasonable that Mishel's model's construct and needs assessment be used to develop and evaluate the effects of an uncertainty management program for mothers of children with cancer in the context of Bangladeshi culture.

### **III. THEORETICAL FRAMEWORK**

#### **1. Conceptual Framework of the Study**

The conceptual framework for this study was Mishel's theory of uncertainty in illness (UIT) (Mishel, 1988). Uncertainty is the central concept in this theory and is defined as "the inability to determine the meaning of illness-related events that occur in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking" (Mishel, 1990). Another concept central to the uncertainty theory is cognitive schema, which is defined as a person's subjective interpretation of illness-related events (See Figure 1, Figure 2). Uncertainty theory is organized around three major themes related to the concepts: (1) antecedents of uncertainty, (2) appraisal of uncertainty, and (3) coping with uncertainty. First, the antecedent theme of the theory includes stimuli frame, cognitive capacity, and structure providers that proceed and influence uncertainty.

The stimuli frame has three components: symptom pattern, event familiarity, and event congruence (Mishel, 1990). In children with cancer, a change in symptom pattern is often needed before patterns are recognized and believed; there is either a

worsening of the condition or an improvement (Santacroce, 2001). Mothers' use of stimuli frame is influenced by two variables: cognitive capacity (the ability to process information) and structure providers (resources available to help interpret meaning of the stimuli). There is less uncertainty when symptom occurs in a pattern. An example of this is a child who becomes irritable, tired, and ill after receiving chemotherapy. Mothers process this information in the context of their own experiences, using cultural and social cues as well as information from healthcare providers. Symptom appraisal can be hindered when symptoms lack prominence.

Event familiarity refers to the repetitive nature of the structure environment. Familiarity is the result of cognitive processes based on experience with the environment. Familiarity is threatened by new and novel symptoms or treatments such as occur at diagnosis or end of life, as the child declines. During treatment, mothers become familiar with the various treatments required for their child.

Event congruence is when there is consistency between what is expected and what occurs. Lack of event congruence creates questions and undermines the predictability established. The four potential sources of uncertainty proposed by Mishel (1988) during an illness experience are ambiguity concerning the state of the



illness, complexity regarding treatment, lack of information about the seriousness of illness and prognosis, and unpredictability of the course (Mishel, 1990).

Cognitive capacity refers to the ability of a person to process information. When the environment is perceived to be a threat, cognitive efficiency is diminished and the ability to further process cues is impaired. For example, a mother who was just told their child has leukemia during an emergency department visit for bruising would be expected to experience decreased cognitive processing and thus require much repeating of information.

Structure providers are the resources available to a person which assist them in the interpretation of the stimuli frame. Structure providers include education, social support, and the credible authority of health care providers. Education has both a direct and indirect effect on perceived uncertainty. Education can improve a parent's knowledge about the stimuli frame which helps provide meaning and understanding. Educational levels also play a role in the parent's ability to modify uncertainty cognitively. Individuals with less education demonstrate higher levels and longer periods of uncertainty due to an inability to understand complex treatments and rationale for care.

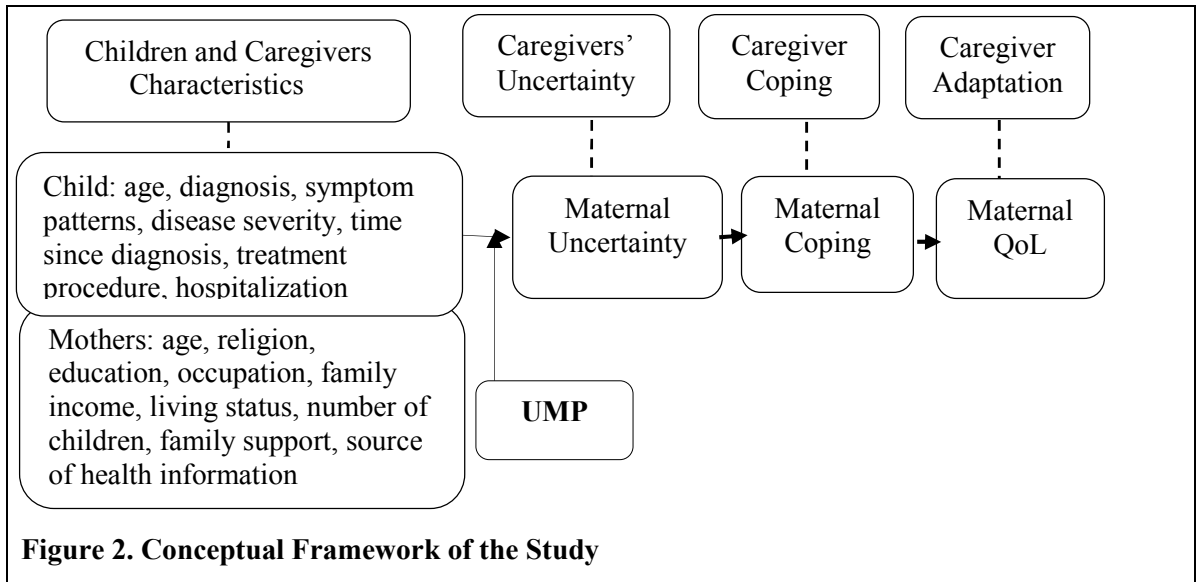
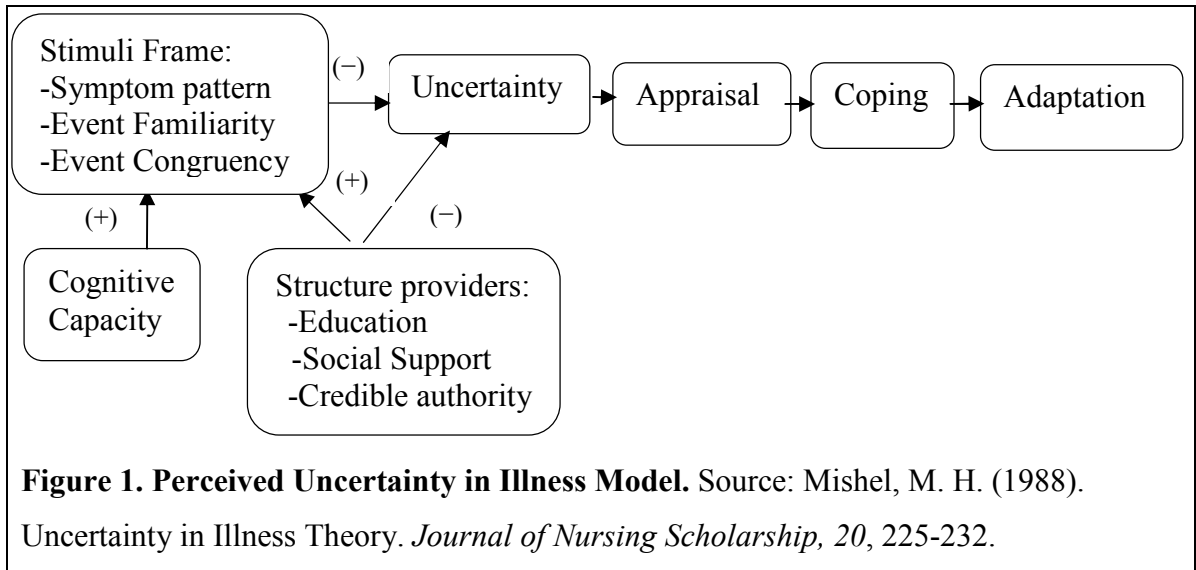
Social support reduces uncertainty by acting as a feedback system to help interpret the meaning of illness-related events. Social support reduces uncertainty by modifying (a) the ambiguity of the illness, (b) the perceived complexity of the treatment and (c) the unpredictability of the future. Social supports are significantly associated with parental stress (Speechley & Noh, 1992). One example of social support is having someone to share information with to assist in the appraisal process (Mishel & Braden, 1988).

Credible authority relates to the amount of trust and confidence patients and caregivers have in the ability of healthcare providers to provide care. Trustworthy consistent information enhances event familiarity, and promotes event congruence. This directly supports the structure of the cognitive schema families build. Nurses have multiple opportunities to be credible authorities to patients and their caregivers. Trusting relationships with healthcare providers have been found to reduce uncertainty (Mishel & Braden, 1987).

Appraisal of uncertainty is the second major theme in the UIT. Appraisal of uncertainty is defined as the process of placing value on the uncertain event or situation. An appraisal will result in uncertainty being viewed as either a danger or an opportunity. The situation is classified as a threat or danger when the event is

perceived to be uncontrollable (Mishel, 1988). Loss or absence of a credible authority can lead to a danger appraisal in which uncertainty stimulates a fight or flight response. When danger is appraised, a coping response is needed so that it can be reframed into a positive illusion. The relationship between appraisal and subsequent adaptation is thought to be mediated by coping strategies (Mishel & Sorenson, 1991).

The third theme in the UIT is coping with uncertainty which includes danger, opportunity, and adaptation. Cohen and Martinsen (1988) have reported that uncertainty is responsible for much of the perceived stress and coping strategies. Coping is the attitudes and behaviors used to manage trust uncertainty. Adaptation is as the ability to maintain functioning within the person's normal range of behavior (Mishel, 1988). The more effective the coping strategies, the better the adaptation are expected to be. When effective, coping strategies lead to adaptation.



According to the model, UIT provides a framework for selecting interventions to improve an individual's psychological outcomes under conditions of uncertainty. For mothers of children with cancer, uncertainty is presented due to the child's medical condition, unpredictable symptoms, disease severity, diagnostic procedures, hospitalization, and multiple care providers (Dodgson et al., 2000; Madeo et al., 2012; Mishel, 1988). Mishel's theory contends that consistent information and effective coping strategies, as well as support from a credible authority, reduce uncertainty by assisting in the understanding of treatment situations (Mishel & Braden, 1988). The components of the present study's uncertainty management program were guided by the construction of Mishel's uncertainty in illness model.

## **VI. DEVELOPMENT OF AN UNCERTAINTY MANAGEMENT PROGRAM**

This chapter describes the development process of an uncertainty management program (UMP).

### **1. Process**

The program's components were developed based on a need assessment by review of the related research and theoretical literature and focus group interviews.

#### **Need assessment**

As a part of the needs assessment, a literature review and focus group interviews were conducted. Initially, related research and theoretical literature on maternal psychological interventions for parents of children with chronic illness were reviewed (Appendix 3). Approximately, 14 related studies and theoretical publications on parental psychological interventions for mothers were selected for review. Data were retrieved from 1983 to 2017 from different databases (CINAHL, MEDLINE, Pubmed, Psyc INFO, and Google Scholars) using the following key words as descriptors and Medical Subject Heading (MESH): interventions, program,

parents/mothers/ caregivers, pediatric/child, cancer/oncology/ malignancy, chronic disease, coping, stress, adjustment, adaptation, quality of life/well-being.

Two focus group interviews (FGI) were conducted; one with mothers of children with cancer and the other with health care team members. The first FGI was conducted with 5 mothers on April 18, 2017. The second FGI was conducted with a health care team including 5 nurses and one medical doctor on April 17, 2017 at a tertiary level hospital in Bangladesh. The criteria for the participants of the mothers were that participants be women participation in the FGI are similar to the participants of the study. “Mothers of children with cancer, between the ages of 2-18, admitted in pediatric oncology units; and agreed to participate.” The inclusion criteria for the participants of the health care team had approximately 4 years working experience in the pediatric oncology department and agreed to participate in the FGI.

The purpose of the FGI was to gather qualitative data to explore the challenges and experiences of mothers caring for their children with cancer, and to gather information about the type and elements of the UMP which would be helpful. First, the researcher and research assistants introduced themselves and briefly explained the purpose and procedures of the FGI. If the participants agreed to participate after hearing and understanding the research purpose and procedure, the

researcher asked the mothers to sign an informed consent form. The participants' consent form and information sheet translated from English into Bengali, by a professional English- Bengali translator and validated by two Bangladeshi doctoral students at Yonsei University, Korea. There was no obligation to participate and participants were assured that they were able to withdraw from the study at any time without any penalty regarding their child's care and that, if they withdrew from the study, their information would be deleted. Confidentiality and anonymity was maintained. Participants were also assured that the information that they were to provide would not be disclose to others and would be kept in secure locked cabinet for three years, and afterward discarded. This study did not use the name or identity of the participants. A lunch box with small gifts was given to the participants of the health care team and a small amount of money (500Taka) equivalent to \$ 6 US dollars was provided to the mothers for refreshment in compensation for their participation. The FGI commenced with leading questions (Table 2, Table 3) related to the mothers' view of my program's content and delivery. Two research assistants were instructed by the researcher to ask for and record the participants' responses to the leading questions.



**Table 2. Leading questions for mothers**

<b>Focus group interview 1</b>	
	Opening question
1.	How are you? Could you give your introduction?
	Introductory question
2.	When was your child diagnosed with cancer?
	Transition question
3.	Are there any troubles with respect to caring for your ill children and what kind of difficulties are you facing during caring for your ill children?
	Key question
4.	Could you tell me about the day when your child was diagnosed with cancer?
5.	What was your reaction or response to learning about the diagnoses?
6.	What would you like to tell to me about parenting after your child was diagnosed with cancer?
7.	What is the greatest challenge you face regarding caring for your ill children now?
8.	When you feel sadness, how do you manage with such feelings?

**Continuation of Table 2.**

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**Focus group interview 1**

---

9. If you think all of the things that happen to you as a parent since your child's diagnosis, what kind of support and advice would be most helpful for other parents who find themselves in your situation?
10. What is helpful for getting support during caring for your ill children?  
Ending question
11. Do you have anything more that you want to talk about regarding caring for your ill children?

---

FGI responses were analyzed by the researcher for themes and elements to be incorporated into the UMP and ways of implementing the program. Data from the FGI was analyzed using content analysis methodology which uses key concepts derived from relevant research findings as coding categories (Creswell, 2009). The categories were determined according to findings from literature review. For the analysis, the FGIs were read repeatedly, highlighting meaningful words and sentences. All highlighted text was categorized on the basis of the literature review coding categories. Information collected from both the literature review and the FGIs were then incorporated into components of the UMP.

**Table 3. Leading questions for health care teams**

---

<b>Focus group interview 2</b>	
1.	What kinds of supports are needed for mothers during caring for their children with cancer?
2.	Is there any way to convey these supports to the mothers during caring for their children with cancer?
3.	Which kinds of programs are helpful for mothers of children with cancer?
4.	Do you have any suggestions or recommendations for successful implementation of the program?

---

## **2. Results**

### **1) Concepts derived from the literature review**

An integrative literature review revealed four individual key concepts: (1) ambiguity, (2) lack of information, (3) complexity or lack of clarity, and (4) unpredictability (Fedele et al., 2013; Hoff et al., 2005; Mishel et al., 1988; Mullins et al., 2012; 2015).

During active medical treatment, parents of children with cancer face many emotional and psychosocial challenges that can cause uncertainty (Emma Hove'n,

Anclair, Samuelsson, Krister, & Boman, 2008). Uncertainty pervades parents' experience of a child's illness through treatment, from the time of diagnosis. Mothers were reported to believe that chronic illness was a type of fate or punishment (Eun-Suk et al., 2009). In Bangladesh, mothers of children with cancer reported the belief that chronic illness (like cancer) was a curse from God (Basher et al., 2012). Children with cancer often have uncertain prognosis (Mishel, 1988) that produce stress (Duffy, 2013) which decreases their mothers' ability to cope and results in an altered functioning of the maternal role (Duffy, 2013). Mothers of children with cancer have been reported to experience feelings of helplessness (Grootenhuis, & Last, 1997), emotional fatigue (Houtrow, Yock, Delahaye, & Kuhlthau, 2012; Wakefield et al., 2011), and depression (Barrera et al., 2004). Thus, caring for children with cancer is a role accompanied by extensive mental strain which may heighten maternal uncertainty.

There have been interventions which were designed to decrease illness uncertainty which have been shown to be effective in decreasing psychological distress among adults. Interventions targeting uncertainty among adult cancer patients have been shown to result in decreased negative affective states (Braden, Mishel, & Longman, 1998) and decreased pain and nausea among women with breast cancer

(Badger, Braden, Mishel, 2001). Interventions designed to enhance parental adjustment to pediatric cancer are still relatively few (Hoff et al., 2005). Only one study on an educational program about quality of life for parents of children with leukemia has been published, and it reported increased parental quality of life in the intervention group (Ghodsbin et al., 2014). Kazak (2005) summarized existing empirical reports of psychological intervention for children with cancer and their families and reported positive effects of psychological interventions on distress associated with cancer and its treatment. A study by Hoff et al. (2005) “an intervention to decrease uncertainty and distress among parents of children newly diagnosed with diabetes” and found that there was a significantly decreased level of psychological distress in parents. Another study showed that parents had less psychologically distress following psycho-educational intervention, but no effect of condition was found, nor an interactive effect of time and condition (Hoeskstra-Weebers et al., 1998). Crespo et al. (2016) found that family-centered care was not significantly related with maternal quality of life. Parents of children with cancer, especially mothers, are often socially isolated by stigma and the care-giving burden of their child’s illness.

## **2) Concepts from the focus group interview**

Most of the participants of the health care team participating in the FGI reported that mothers suffered emotional stress concerning caring for their ill children. The mothers from the FGI explained their challenges regarding caring their ill children including difficulties in getting clear messages about their child's condition, prognosis, and treatment protocol; difficulties in interpersonal relationships; difficulties in finding support from health care professionals; difficulties in seeking help; negative thoughts about feelings and emotions; and nervous tension about their child's future. Participants were more likely to describe their experiences negatively rather than positively. The initial components of the program were identified based on the literature review and results from the FGIs as shown in Table 4.

**Table 4. Association between literature review, focus group interview, and the program contents of an uncertainty management program**

S/ N	Literature review		Focus group interview			Program Components	Strategies
	Main Concepts	References	Challenges	Mothers (n = 5)	Health Care Teams (n = 6)		
#1	Ambiguity concerning the state of illness	Bandura (2001) Brasher (2001) Fedele et al. (2013) Mishel (1988)	1. Vagueness about ill child's condition  2. Difficulties in caring 3. Difficulties in interpersonal relationships	√ (4)	√ (4)  √ (4)  √ (5)	1. Building good interpersonal relationship	-Teaching, counseling, discussion, and listening, -Face-to-face - Telephone -Group  -Discussion  -Teaching, counseling, listening, and discussion

**Continuation Table 1**

S/ N	Literature review		Focus group interview			Program Components	Strategies
	Main Concepts	References	Challenges	Mothers (n = 5)	Health Care Teams (n = 6)		
							-Face-to-face, -Telephone - Group
#2	Lack of information about seriousness of illness and prognosis	Bandura (2001) Fedele et al. (2013) Mishel (1988)	1. Difficulties in getting information about seriousness	√ (4)	√ (4)	2.Communication: -Information giving	-Teaching, counseling, listening, and discussion, - Face-to-face, - Telephone -Group
			2. Passive attitude in seeking	√ (4)	√ (4)		- Teaching, counseling, listening, and



**Continuation of Table 4.**

S/N	Literature review		Focus group interview			Program Components	Strategies
	Main Concepts	References	Challenges	Mothers (n = 5)	Health Care Teams (n = 6)		
			information				discussion, - Face-To-Face, -Telephone -Group
#3	Complexity or lack of clarity regarding treatment protocol	Bandura (2001) Fedele, et al. (2013) Mishel (1988)	1. Vague about protocol treatment, medical procedures	√ (4)	√ (4)	3. Coping enhancement	-Learning by doing -Expression
			2. Difficulties interpersonal relationship	√ (3)	√ (3)		-Expression

**Continuation of Table 4.**

S/N	Literature review		Focus group interview		Program Component s	Strategies
	Main Concepts	References	Challenges	Mothers (n = 5)		
#4	Unpredictability about the course of treatment	Bandura (2001) Fedele et al.(2013) Mishel (1988) Mullins et al.(2012)	1. Negative thought about the future of ill child 2. Negative attitude toward self 3. Negative thought feeling and emotions	√ (3)  √ (5)  √ (4)	√ (3)  √ (4)  √ (4)	4. Social support      -Role -Modeling Demonstration    -Discussion   -Discussion

### **3. Final Version of the Program**

The initially developed program outline and manual were revised and modified based on experts' comments. Content #2 and #3 regarding sharing experience (sub-theme of the social support) were revised to increase appropriateness. Such as provide sufficient information about nurse and physician who are taking care of their children and tell mothers about other hospital staffs and environment were revised. Next, the Uncertainty Management Program (UMP) was developed. The fully developed program was ninety minutes long and designed to be completed over three sessions (30 minutes/session). The UMP is a manual written document consisting of four components (Table 5). The main themes of the UMP were (1) rapport building, (2) providing an overview of an uncertainty, (3) communication, (4) enhancing coping, and (3) social support. The sub-themes of the UMP program were "setting goals, building therapeutic relationships, and understanding the program", "giving information, emotional release, and distraction techniques", "sharing experiences and positive reinforcement". The contents and the activities of the final version of the UMP were introductions and getting know each other; introduction of the program; explaining the meaning of illness uncertainty; establishing a caring and warm relationship and mutual trust; providing clear

information to the mothers about caring for their sick children; encouraging the mothers to express their internal feelings and experiences, positive thoughts and emotions; providing information to the mothers about techniques for distraction such as deep breathing, religious/social activities, positive thinking; and facilitating the mothers to share their experience with other parents in the same situation and share the same experiences. The sessions were conducted on three consecutive days, commencing the day after baseline data collection.

#### **4. Validation of the Program**

The content validity of the program was tested and confirmed by expert groups from Korea and Bangladesh. Two experts (professors, RN, PhD) from the College of Nursing, Yonsei University, Korea and two experts (medical doctors) from the pediatric oncology department in Bangladesh. The content validity index (CVI) was tested by the themes of overview of uncertainty, communication, coping enhancement, and social support on a 4-point Likert scale (1) not relevant to (4) definitely relevant. The CVI of the program's contents was higher than 0.80.

**Table 5. Final version of an uncertainty management program (UMP)**

<b>Sessions</b>	<b>Main themes</b>	<b>Sub-themes</b>	<b>Contents &amp; activities</b>
1st (Day1)	Building rapport	① Involving participants in setting goals  ② Therapeutic relationship	① Introducing the program objectives and process.  ② Getting to know each other.  ③ Setting mothers goals.  ① Improving interpersonal relationship & establishing mutual trust with mothers.  ② Establish caring, warmth, and therapeutic relationship with mothers.
	Overview of the uncertainty	① Increasing overall understanding of and uncertainty the program	① Briefly explain about illness uncertainty sources of uncertainty.  ② Sources of uncertainty. Uncertainty management techniques.  ③ Briefly explain about illness uncertainty sources of uncertainty.

**Continuation of Table 5.**

<b>Sessions</b>	<b>Main themes</b>	<b>Sub-themes</b>	<b>Contents &amp; activities</b>
			③ Sources of uncertainty. Uncertainty management techniques.
2nd (Day2)	Communications:	① Giving information	① Actively listen to what the mothers are trying to tell.  ② Ask question about their needs.  ③ Maintain eye contact with mothers during conversation.  ④ Provide adequate information about the standards of cancer treatment.  ⑤ Give clear information about the child's diagnosis procedure and test report.  ⑥ Explain about child's pattern of symptoms such as pain, vomiting, nausea.  ⑦ Ensure other supportive care of their children.

**Continuation of Table 5.**

<b>Sessions</b>	<b>Main themes</b>	<b>Sub-themes</b>	<b>Contents &amp; activities</b>
		② Emotional release	① Encourage to express mother's feelings and experiences ② Talk about mothers own thoughts related to negative feelings ③ Encourage mothers to express positive thoughts and emotions.
	Coping enhancement	① Distraction techniques	① Inform mothers about benefits of different types of distraction technique such as deep breathing, and religious activities. Demonstrate deep breathing by the researcher or research assistants.
3rd (Day3)	Social support	① Sharing experience	① Provide clear explanation about health care system, and purpose of their child's treatment. ② Facilitate mothers to share their experience to other parents who

**Continuation of Table 5.**

Sessions	Main themes	Sub-themes	Contents & activities
			have the same situation and experiences.
		②Positive reinforcement	① Encourage mothers to think positively. ② Encourage mothers to avoid negative thinking. ③ Thank the participants for completing the activities.
	Wrap-up		① Review all three sessions. ② Make contact sheets. ③ Say good bye.



## **V. EVALUATION OF AN UNCERTAINTY MANAGEMENT PROGRAM**

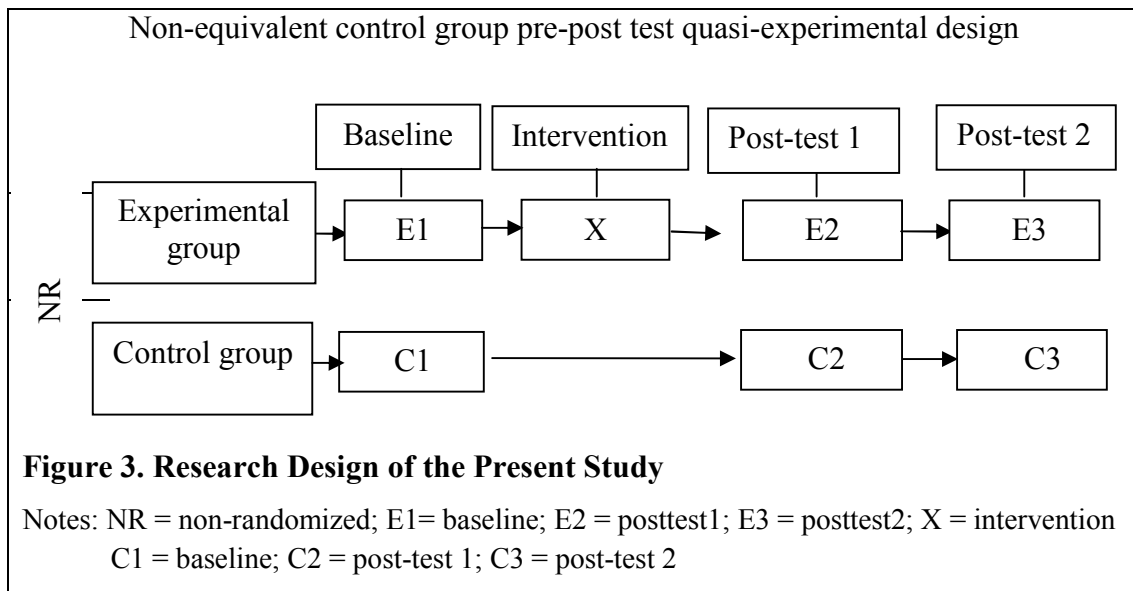
### **1. Study Design**

The study was quasi-experimental with nonequivalent control group non-synchronized design intended to examine the effects of an uncertainty management program (UMP) on maternal uncertainty, maternal coping, and maternal quality of life in mothers of children with newly diagnosed cancer (Figure 3). Using a 2-group repeated measure design, participants were conveniently divided into experimental or control groups. The control group received the standard care and the experimental group received the uncertainty management program. The study took place between May to August 2017.

### **2. Study Population and Sample**

The population of the study was mothers of children with cancer who were hospitalized at Dhaka Medical College Hospital (DMCH) in Bangladesh. DMCH is a 2700 bed hospital. The pediatric oncology unit consists has 20 beds. However, there were other units for pediatric patients where children with cancer could be admitted

due to availability of the beds in the pediatric oncology unit. Every day, around 60-70 children attend as outpatients, among them around 1-2 children come to receive chemotherapy. This is the largest hospital in central Dhaka. A large number of children attend this clinic, and therefore, the subjects drawn from this setting were considered to be an appropriate representation of all mothers of children newly diagnosed with cancer in Bangladesh.



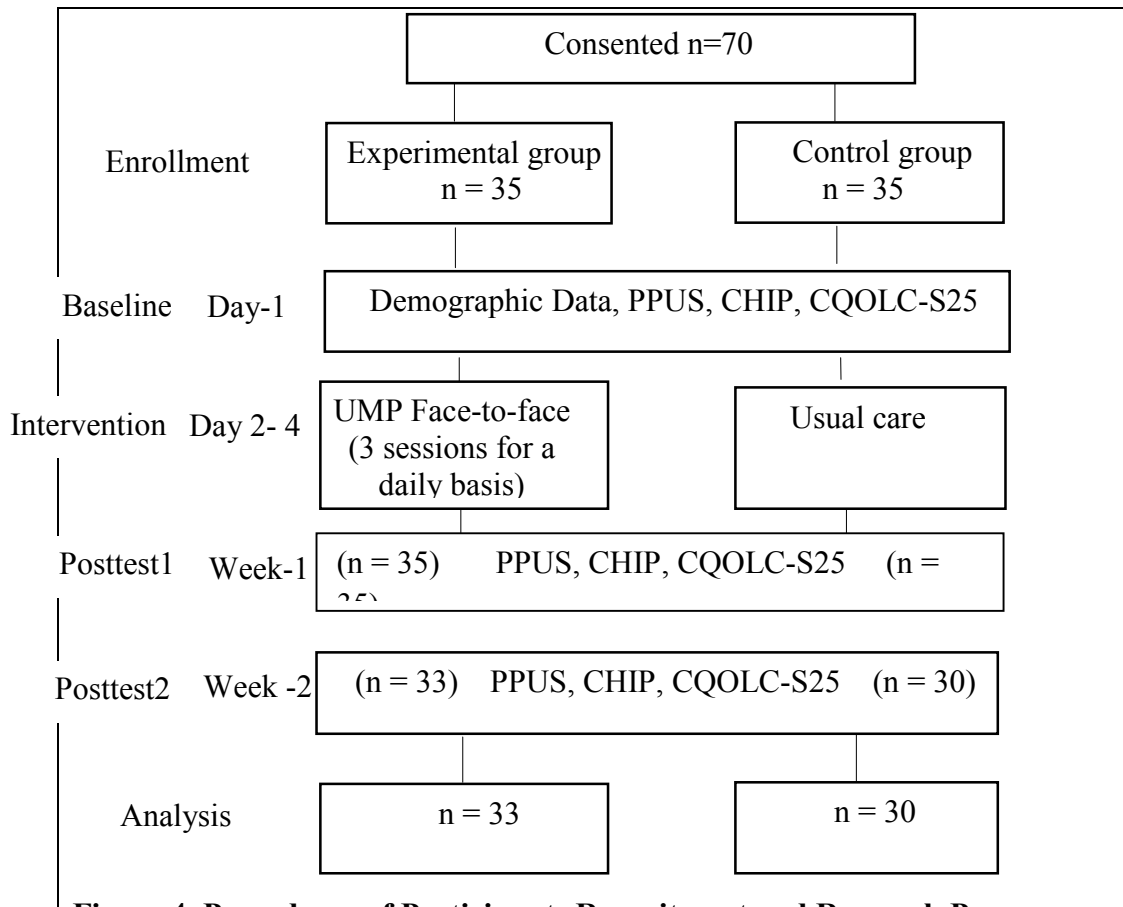
The sample size for the study was calculated using G\*Power analyses for repeated measures ANOVA analysis at the level of significance ( $\alpha$ ) .05, power .80, and an effect size 0.25. It was suggested that 56 subjects were required for two

groups. Considering the rate of attrition as 20%, the total number of participants was  $N = 70$ , 35 participants for each group (Cohen, 1988) (Figure 4).

A convenience sampling method was used to recruit eligible participants. Eligible participants were initially identified by the pediatric oncology nurse from among all the mothers of children with cancer which was newly diagnosed within a 16 week period (Fedele et al., 2013; Mullins et al., 2012). The inclusion criteria was as follows: (1) mother of a child between 2 and 18 years old diagnosed with leukemia or lymphoma, brain tumor (Mullins et al., 2012); (2) mother of a child admitted as an inpatient, (3) agreed to participate after understanding the research purpose. Exclusion criteria were as follows: (1) mothers who were unable to communicate; (2) mothers of a child with a diagnosis that was a secondary malignancy; and (3) mother of a child already receiving chemotherapy/radiation.

Seventy mothers completed baseline assessments and post-test assessments but 63 mothers ( $n = 30$  control group;  $n = 33$  intervention group) completed the follow-up assessments. Five mothers from the control group and two mothers from the intervention group dropped out during collecting the post-test 2. For the experimental group, the reason for one mother dropping out was that her child died, and the other drop out was due to Ramadan. During Ramadan, most of the Muslim

mothers were fasting. The control data was collected during Ramadan. Therefore, 5 mothers from the control group refused to participate at post-test 2.



**Figure 4. Procedures of Participants Recruitment and Research Process**

Notes: PPUS = Parents Perception of Uncertainty Scale; CHIP = Coping Health Inventory for Parents; CQOLC-S25 = Caregiver Quality of Life Index-Cancer-Singapore25.

### 3. Intervention

The total experimental period for each participant was three sessions with a total of 90 minutes. Three thirty minutes session were implemented on consecutive days 1 day after baseline data collection. All sessions were one-to-one sessions and were conducted at the mother's convenience and took place in a quiet and separate corner of the pediatric oncology unit.

To minimize variability among different researchers, only one research assistant was engaged for the study. In order to obtain accurate data, the researcher trained the research assistant before the study as follows:

- 1) The purpose of the study was explained to the research assistant
- 2) The process of the study was explained to the research assistant
- 3) The researcher directly demonstrated to the research assistant how to use the research tool and gather data from the study participants
- 4) The researcher observed the research assistant's use of the tool and their gathering of data from the study participants and identified any problems related to data collection and corrected or re-explained the procedure. This process was repeated until data collection between researcher and research assistant was demonstrated to be consistent.

- 5) The research assistant had at least 5 years experiences in the pediatric oncology department, a master degree, and research experience.

After obtaining verbal permission from the participants, the written consent form was signed by the researcher or research assistant and the participating mother. The UMP was implemented by the researcher and the research assistant collected data three times at baseline and post-test 1 and 2. After baseline data collection, post-test 1 and post-test 2 were conducted at one week and 2 weeks from baseline. The control group received standard care and did not participate in the UMP. A face-to-face session was conducted individually for mothers in the experimental group after completing the screening, recruitment, and baseline data collection, before the child received chemotherapy. A list of mothers of children admitted in the pediatric oncology units was obtained from the head nurse giving the patient's bed number and diagnosis. Mothers were informed about the purpose and procedures of the study. Initially, the researcher introduced herself and explained the procedure of the intervention. Then, if the mother consented to participate in the intervention, the researcher implemented the UMP at a time convenient to the mother.

The experimental protocol was as follows:

At day 2 after baseline, session 1 was conducted, focusing on an overview of

uncertainty and established a therapeutic relationship and mutual trust with the participant.

At day 3 after baseline, session 2 was conducted, focusing on uncertainty management techniques including communication such as giving information, expressing emotional release/reaction; and strategies for coping enhancement that can help manage uncertainty.

At day 4 after baseline, session 3 was conducted, focusing on social support including seeking someone with the same experience as them to share experiences with, and positive reinforcement. After complementing post-test 1 and post-test 2 data collection, the mothers in both the control group and the intervention group received 300 Bangladeshi Taka (equivalent to approximately 4 US dollars) for dinner, as compensation.

#### **4. Measurements**

Data was collected using the following four sets of self-reported questionnaires: (1) Demographic Questionnaire, (2) Parents Perception of Uncertainty Scale (PPUS), (3) Coping Health Inventory for Parents (CHIP), and (4)

Caregivers Quality of Life Index-Cancer -S25 (CQOLC- S25). The total number of items was 107 and it took approximately 25-30 minutes to complete.

Demographic Questionnaire: The Demographic Questionnaire was designed by the researcher based on the literature reviewed. The questionnaire collected data about the participant's age, education, religion, occupation, monthly family income, housing, number of children, sources of health information; and the characteristics of the participant's child with cancer such as age, gender, siblings, diagnosis, time of since diagnosis, length of receiving treatment, and number of hospital admissions.

Parent Perception of Uncertainty Scale (PPUS): Maternal Uncertainty was measured using the PPUS. The original items of the PPUS (Mishel, 1983) were derived from Mishel's Uncertainty in Illness Scale for Adults (MUIS-A) and it was a 4-point Likert-type scale ranging from strongly disagree (1) to strongly agree (4). The range of possible scores on the 31-item PPUS is 31 to 124, with a higher score indicating greater uncertainty. The coefficient  $\alpha$  for the PPUS was .86 (Mishel et al., 1988). For the present study, the Cronbach's  $\alpha$  score was .89.

Coping Health Inventory for Parent (CHIP): Maternal coping was measured using the CHIP (McCubbin et al., 1983) developed by McCubbin and Colleagues in 1983 to assess parent's appraisal of behaviors used to manage family-life in families



with a child who is seriously and/or chronically ill. It is a 4-point Likert-type scale ranging from strongly disagree (1) to strongly agree (4). The range of possible scores on the 36-item CHIP is 36 to 144, with a higher score indicating a greater degree of coping. The coefficient  $\alpha$  for the PPUS was .88 (McCubbin et al., 1983). In the present study, the Cronbach's alpha coefficient was .80.

Caregivers Quality of Life Index-Cancer -Singapore25 (CQOLC-S25): Maternal quality of life was measured using the Caregivers Quality of Life Index-Cancer-Singapore25 (CQOLC-S25) adopted by Mahendran et al. (2015). It was a 4-point Likert-type scale ranging from strongly disagree (1) to strongly agree (4). The maximum total score for the CQOLC-S25 is 100 and higher scores reflect a better quality of life. The reliability of the CQOLC was .88 (Weizner & Susan, 1999), and .89 (Mahendran, Lim, Chua, Peh, Lim, & Kua, 2015). For the present study, the Cronbach's alpha coefficient was .87.

The original instruments and program manual were developed in English. The English version instruments and program manual were translated into the Bengali language. The method of translation was the back translation technique (Brislin, 1970). Three bilingual translators who were fluent in both English and Bengali translated the instruments (e.g., they were two oncologists and one English editor).

## **5. Data Collection**

The data of the study was collected between May 2017 and August 2017. After obtaining permission from the director of the selected hospital and signing informed consent forms by the participants, the researcher and research assistant first assigned the eligible mothers into the control group (May to June) and next into the experimental group (July to August). Potential study participants were identified from the patients' medical records. The research assistant then monitored the patients to determine the schedule of their first phase of chemotherapy. Mothers were asked to participate in the study and consent was obtained if they agreed to participate in the study. Mothers were informed that they had the right to withdraw from the study at any time. Moreover, mothers were assured that their refusal to participate or withdrawal from the study would not affect the care provided to their children.

To avoid possible contamination of the intervention, the study was designed to have sequential data collection. The data were first collected from the control group followed by the experimental group in the same hospital.

The research assistant then collected baseline data using self-report by the participants. "Mothers who had difficulty reading and writing were helped by the research assistant who read the question to them and marked down their answers".

After that the researcher performed the three face-to-face sessions of UMP for the participants of the experimental group at day 2, day 3, and day 4 after baseline data collection of all pediatric oncology patients. After completing the three face-to-face sessions of the UMP, post-test 1 data was collected by the research assistant at one week from baseline and post-test 2 data was collected at two weeks from baseline. Post-test 2 was conducted before discharge of the participants' children from hospital. It is common procedure for patients to be discharged from hospital 1 week after receiving their first phase of chemotherapy. However, in the hospital where this research was conducted, due to issues such as residential distance from the hospital and financial problems, patients are admitted for around 2 weeks. Therefore, the post-test 2 data was collected at week 2 after baseline data collection.

## **6. Data Analysis**

Data was analyzed using IBM SPSS Statistics for Window Version 20.0. The specific analysis for variables in the study follows.

Differences in the demographic characteristics of the participants and their children, and the study variables between the control and the experimental groups were analyzed using Independent t-test for the continuous variables and chi-squared

test for the categorical variables (to detect whether the participants in the two groups were equal at baseline). Repeated measures analyses of variance (ANOVA) were performed to assess the main effects of group (control or experimental), time, and the interactive effect of group and time on the variables in the study. The Bonferroni approach was used in all analyses to minimize the chance of false positive findings. Reliability of the study instruments was analyzed using Cronbach's  $\alpha$ .

## **7. Ethical Consideration**

This study was approved by two separate institutional review boards (IRB) at the medical college hospital where the study was conducted and the university attended to the investigator. Initial approval was granted on March 24, 2017. However changes to the study (the inclusion of information sheet and consent form for the focus group discussion) required a second submission with revisions approved on April 17, 2017. Study recruitment was conducted during May 2017 to August 2017. Participation in the study was completely voluntary. In accordance with all human subject research, participants signed a consent form to indicate that they voluntarily agreed to participate in the intervention study. Participants were given a verbal and written description of the experimental study. The information

included the intervention purpose, design, three thirty minutes face-to-face intervention on consecutive day, and data collection at baseline and post-test 1 and 2, potential risks and benefits. Participants given the opportunity to ask questions. They were informed of the opportunity to withdraw from the experimental study at any time without consequence or reason. They were also informed that their child would continue to receive the same standard of care as the control group after withdrawal. Risk to participants was minimal and included the risk of experiencing upsetting emotions as result of participating in the study, and a minimal risk of loss of confidentiality. Steps were taken to immediately identify data, and all data was stored in a locked desk. In addition, the confidentiality of the participants responses were also assured by using sample coding. All participants received 300/- BD Taka (equivalent to 4 US dollars) as an acknowledgement of their participation, whether they completed the questionnaire or not.

## VI. RESULTS

A quasi nonequivalent pre-post with a control group experimental design was implemented to evaluate an uncertainty management program for mothers of children with newly diagnosed cancer admitted to the pediatric oncology units of Dhaka Medical College Hospital (DMCH). Participants for this study comprised of a convenience sample of 70 mothers recruited from pediatric oncology units at the DMCH in central Dhaka, from May to August 2017. Mothers were identified through the patient admission registry, based on their child's cancer diagnosis. Once identified, mothers were approached by the researcher and research assistant in consultation with the child's registered nurse to ensure families were not disturbed, and handed a study information sheet and the experimental study was explained. Eligible mothers were confirmed for the study. After providing written informed consent, mothers were given a self-report questionnaire to complete at the hospital.

The same research assistant collected all data including baseline, post-test 1, and post-test 2. On day 2, day 3, and day 4 after baseline data collection, the researcher implemented face-to-face sessions totaling 90 minutes (30 minutes/session) focusing on the overview of uncertainty, communication, coping enhancement, and social support. The research assistant collected post-test 1 data at

one week, and post-test 2 data at two weeks from baseline. All participants received about 300 Bangladeshi Taka (equivalent to US dollar nearly \$ 4) as compensation for their participation in the study. All procedures were approved by the university and target hospital's institutional review board for the protection of human subjects. Baseline group differences in demographic characteristics and study variables were analyzed using Independent t-test and chi-squared test. Repeated measures ANOVA were used to test the effects of an uncertainty management program. The findings of the study are presented as a table (Table 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16) with brief explanations as follows.

## **1. Homogeneity Test**

### **1) Homogeneity test for the demographic characteristics of participants and their children between two groups.**

Chi-squared and Independent t-tests were conducted at baseline to examine differences between the two groups' demographic parameters (maternal age, education, religion, occupation, family income, and child age, gender, diagnosis, time since diagnosis, and the length of time spent receiving treatment). No significant differences were observed between the two groups as shown in Table 6. The mean

age of the participants was  $28.09 \pm 5.62$  years in the control group and  $27.34 \pm 5.95$  years in the experimental group. In both groups, most of the participants were Muslim which is similar to the national demographics in Bangladesh (89% Muslim and 9.6% Hindu) (Government of the People's Republic of Bangladesh, Ministry of Health and family welfare, 2016). Most of the participants were housewives in both groups. The average monthly family income of the participants in the control and experimental groups was  $10057.14 \pm 5880.89$  Taka and  $12485.71 \pm 9882.76$  Taka, respectively which is below the national standard in Bangladesh where the average monthly family income is approximately 31,883 Taka (BDT 100 Taka = USD \$ 0.0125) (PPRC, UNDP, 2016).

There were no statistically significant differences observed between the control and experimental groups regarding the child's characteristics ( $p > .05$ ) (Table 6). The average age of the children was approximately 5 years in both groups ( $p > .05$ ). Most of the children were male in both groups (58.8% experimental group and 65.7% control group). The most common diagnosis was Leukemia in both groups (65.7% control group; 80.0% experimental). The average diagnosis time was  $4.83 \pm 2.61$  weeks in the control group and  $5.29 \pm 3.39$  in the control group. The average length of time spent receiving treatment was 4 weeks in both groups ( $p > .05$ ).



**Table 6. Homogeneity test for demographic characteristics of mothers and their children between two groups**

Characteristics	Categories	Control ( <i>n</i> = 35)		Experimental ( <i>n</i> = 35)		<i>x</i> <sup>2</sup> / <i>t</i>	<i>p</i>
		N (%)	M ± SD	N (%)	M ± SD		
Characteristics of Mothers							
Age (years)			28.09±5.62		27.34±5.95	.537	.593
Education						4.592	.101
	Bellow high school	18 (51.4)		11 (31.4)			
	High school	15 (42.9)		17 (48.6)			
	College or university	2 (5.7)		7 (20.0)			
Religion						3.968	.106*
	Islam	29 (82.9)		34 (97.1)			
	Hindu	6 (17.1)		1 (2.9)			
Occupation						1.429	.232
	Housewife	30 (85.7)		33 (94.3)			
	Employee	5 (14.3)		2 (5.7)			
Family income Taka/month**			10057.14±5880.89		12485.71±9882.76	-1.249	.216

**Continuation of Table 6.**

Characteristics	Categories	Control ( <i>n</i> = 35)		Experimental ( <i>n</i> = 35)		<i>x</i> <sup>2</sup> / <i>t</i>	P
		N (%)	M ± SD	N (%)	M ± SD		
Monthly Taka						1.516	.469
	Adequate	5 (14.3)		3 (8.6)			
	Not adequate	30 (85.7)		31 (88.6)			
Housing						.065	.799
	Monthly rent	12 (34.3)		11 (31.4)			
	Own house	23 (65.7)		24 (68.6)			
Number of children							
	One	12 (50.0)		12 (50.0)			
	2 or more	23 (50.0)		23 (50.0)			
Sources of health information						.215	.643
	Health care provider	32 (91.4)		33 (94.3)			
	Others	3 (8.6)		2 (5.7)			
Characteristics of Children							
Age (years)			5.75±2.95		5.04±2.23	1.121	.266

**Continuation of Table 6.**

Characteristics	Categories	Control ( <i>n</i> = 35)		Experimental ( <i>n</i> = 35)		<i>x</i> <sup>2</sup> / <i>t</i>	P
		N (%)	M ± SD	N (%)	M ± SD		
Sex						.349	.555
	Male	20 (58.8)		23 (65.7)			
	Female	14 (41.2)		12 (34.3)			
Siblings						.065	.799
	Yes	24 (68.6)		23 (65.7)			
	No	11(31.4)		12 (34.3)			
Diagnosis						2.413	.299
	Leukemia	23 (65.7)		28 (80.0)			
	N-H/Lymphoma	3 (8.6)		3 (8.6)			
	Others	9 (25.7)		4 (11.4)			
Time since diagnosis (in week)			4.83±2.61		5.29±3.39	-.632	.529
Length of receiving treatment (in week)			4.40±2.33		4.54±3.05	-.220	.826
Number of hospital admission							
	First time	16 (45.7)		16 (45.7)			
	More than one	19 (54.3)		19 (54.3)			

Notes: M = mean; SD = Standard Deviation; \*Fisher exact test; \*\*BDT 100 = USD (= \$1.21)

**2) Homogeneity test for the dependent variables between two groups.**

All participants' scores for maternal uncertainty, maternal coping, and maternal quality of life, as well as homogeneity between two groups in terms of these variables are presented in Table 7. The maternal uncertainty score of all participants was 85.60 at baseline. The mean scores for maternal coping and maternal quality of life for all participants were 77.00 and 56.40, respectively. The results showed that there was no statistically significant difference between the two groups with respect to maternal uncertainty, maternal coping, and maternal quality of life ( $p > .05$ ).

**Table 7. Homogeneity test for dependent variables at baseline (one day before to the first intervention) between two groups**

Variables	Total (N = 70)	Exp. Group (n = 35)	Cont. Group (n = 35)	t	p
	M ± SD	M ± SD	M ± SD		
Maternal Uncertainty	85.60±5.03	86.51±4.81	84.69±5.15	-1.534	.130
Maternal Coping	77.00±6.91	77.20±7.99	76.80±5.74	-.240	.811
Maternal Quality of Life	56.24±4.08	56.08±4.22	56.40±4.00	.320	.750

Notes: M = mean; SD= standard deviation; Exp.= experimental group; Cont.=control Group

## 2. Hypothesis Test

Repeated measures ANOVA analyses were performed with data from both control and the experimental groups to assess the main effects of group (control or experiment), time, and the interactive effect of group and time on outcome variables. The effect of interaction between time and intervention was also assessed. Partial eta squared values to indicate the percentage of variance in maternal uncertainty, maternal coping, and maternal quality of life attributed to the effect of time, group, or interaction between group and time were calculated. Repeated measures ANOVA showed a significant effect of group, time, and an interactive effect of time and group for all outcome measures including maternal uncertainty, maternal coping, and maternal quality of participants.

### 1) Effect on maternal uncertainty

There was decreased maternal uncertainty in mothers of children with newly diagnosed cancer in the experimental group compared to the control group.”

Repeated measures ANOVA was calculated to determine whether maternal uncertainty, as measured by the Parent Perception of Uncertainty Scale (PPUS), decreased within the groups (control group and experimental group) as a function of time (baseline, post-test 1, and post-test 2). Sphericity assumption requires that the

variance of the population difference scores for any two groups are the same as the variance of the population difference scores for any other two conditions (Boduszek, n.d.). Mauchly's Test of Sphericity indicated that the assumption of sphericity had not been violated,  $X^2(2) = 747, p .688$ .

As shown in Table 8, time had a significant main effect on maternal uncertainty, indicating that maternal uncertainty decreased over time in both groups ( $F = 108.593, p <.001$ ). The UMP showed a significant main group effect ( $F = 125.745, p <.001$ ) as well as interaction with time ( $F = 102.450, p <.001$ ), indicating that the UMP was effective in decreasing maternal uncertainty and that the effect strengthened over time. Partial eta squared showed that that the UMP accounted for 68% of the variance in the maternal uncertainty of participants, indicating that the UMP had the notable effect on maternal uncertainty. The pattern of mean change of maternal uncertainty over time was observed differently in the two groups (Figure 5.a). In the experimental group, the mean score decreased dramatically across the three time points. Whereas, in the control group, the mean score decreased very slowly at post-test 1, then increased at post-test 2 (Table 9, Table 10- Appendix 2).

As shown in Table 8, time had a significant main effect on ambiguity, indicating that ambiguity experienced by participants decreased over time in both groups ( $F = 26.112, p < .001$ ). The UMP showed a significant main group effect ( $F = 99.031, p < .001$ ) as well as interaction with time ( $F = 111.231, p < .001$ ), indicating that the UMP was effective in decreasing maternal ambiguity concerning the state of the child's condition and that the effect strengthened over time. Partial eta squared showed that the UMP accounted for 62% of the variance in the ambiguity of participants, indicating that the intervention had the considerable effect on ambiguity. The pattern of mean change of ambiguity over time was observed differently in the two groups (Figure 5.b). In the experimental group, the mean score decreased dramatically across the three time points. In contrast, the mean score in the control group increased sharply from post-test 1 to post-test 2 (Table 9, Table 10-Appendix 2).

As shown in Table 8, there was a significant time effect on lack of clarity contributing to maternal uncertainty, indicating that the participants' extralayer of confusion decreased over time in both groups ( $F = 46.681, p < .001$ ). The UMP showed a significant main group effect ( $F = 48.118, p < .001$ ) as well as interaction with time ( $F = 12.687, p < .001$ ), indicating that the UMP was effective in decreasing

mothers' lack of clarity regarding their children's' treatment and that the effect strengthened over time. Partial eta squared showed that the UMP accounted for 44% of the variance in the clarity domain of maternal uncertainty of the participants, indicating that the intervention had the notable effect on the mothers' level of clarity (Table 8). The pattern of mean change of lack of clarity over time was observed differently in the two groups (Figure 5.c). In the experimental group, the mean score decreased sharply from baseline to post-test 1 and remained stable at post-test 2. While in the control group, the mean score changed slowly across the three time points (Table 9, Table 10- Appendix 2).

As shown in Table 8, time had a main effect on lack of information, indicating that the amount of information regarding the child's cancer diagnosis and seriousness of the illness decreased over time ( $F = 37.317, p < .001$ ). The UMP exhibited a significant main group effect ( $F = 116.402, p < .001$ ) as well as interaction with time ( $F = 28.825, p < .001$ ), indicating that the UMP was effective in increasing the amount of information about the seriousness the children's illness and that the effect strengthened over time. Partial eta squared indicated that the intervention accounted for 32% of the variance in the lack of information domain of maternal uncertainty of participants, indicating that the UMP had the remarkable effect on the lack of



information domain of maternal uncertainty. As shown in figure 5.d), the pattern of mean change of lack of information over time was observed differently in the two groups. In the experimental group, the mean score decreased rapidly from baseline to post-test 1 and remained stable at post-test 2. In contrast, in the control group, the mean score slightly decreased from baseline to post-test-1 and then increased at post-test 2 (Table 9, Table 10-Appendix 2).

There was a significant main time effect on unpredictability, indicating that the levels of predictability about the course of treatment increased over time ( $F = 40.129, p < .001$ ). The UMP showed a significant main group effect ( $F = 25.462, p < .001$ ) as well as interaction with time ( $F = 18.416, p < .001$ ), indicating that the UMP was effective in decreasing unpredictability and that the effect strengthened over time. Partial eta squared showed that the UMP accounted for 29% of the variance in the unpredictability experienced by participants, indicating that the intervention had the considerable effect on the unpredictability domain of maternal uncertainty (Table 8). The pattern of mean change of unpredictability over time was observed differently in the two groups (Figure 5.e). In the experimental group, the mean decreased rapidly from baseline to post-test 1 and post-test 2. On the other hand,

in the control group, the mean change was observed very slowly over time (Table 9, Table 10-Appendix 2).

**Table 8. Repeated measures analysis of variance on effects of intervention and time on maternal uncertainty**

N = 63 (Experimental Group = 33, Control Group = 30)

Dependent Variables	Time			Group			Group X Time		
	F	p	Partial Eta Squared	F	p	Partial Eta Squared	F	p	Partial Eta Squared
Total	108.593	<.001	.644	125.745	<.001	.677	102.450	<.001	.631
Ambiguity	26.112	<.001	.300	99.031	<.001	.619	111.231	<.001	.646
Lack of clarity	46.681	<.001	.438	48.118	<.001	.445	12.687	<.001	.175
Lack of information	37.317	<.001	.380	28.825	<.001	.321	58.307	<.001	.489
Unpredictability	40.129	<.001	.397	25.462	<.001	.294	18.416	<.001	.232

**Table 9. Group differences of changes between baseline–post-test 1, post-test 1–post-test 2 for maternal uncertainty**

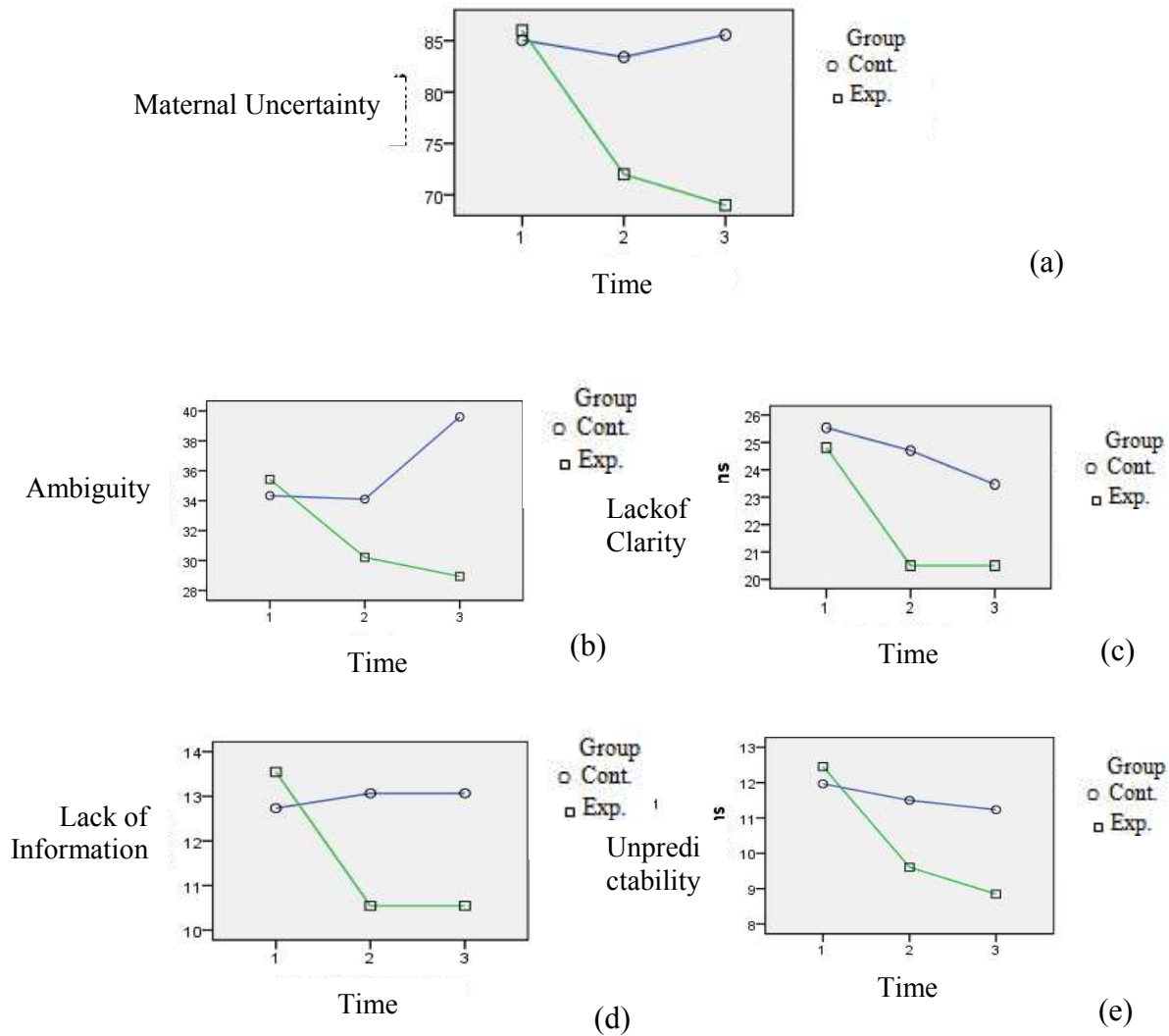
Outcome Variables	Group	Pre –Post 1			Post1- Post 2		
		M±SD	t	p	M±SD	t	p
Maternal uncertainty	Exp. group (n = 33)	14.71±6.78	-1.53	.130	3.00±5.12	12.063	<.001
	Cont. group (n = 30)	1.40±3.31			-2.17±4.62		

Notes: Exp. = experimental group; Cont. = control group; Pre = baseline; Post1 = post-test 1;

Post2 = post-test 2; M = mean; SD= standard deviation

M, SD = differences from paired t-test

t and p = form independent t-test



**Figure 5. Changes in Maternal Uncertainty and it's Sub-domains from Baseline Assessment to Post-test 2 by Groups**

Notes: Exp. = experimental group; Cont. = control group

## 2) Effect on maternal coping

There was increased maternal coping in mothers of children with newly diagnosed cancer in the intervention group compared to the control group.

Repeated measures ANOVA showed a significant time effect, group effect, and group and time effect on maternal coping over time in both groups. As shown in Table 11, a significant main effect of time for maternal coping was observed, indicating that maternal coping increased over time regardless of group ( $F = 24.293$ ,  $p < .001$ ). The intervention showed a significant main effect of group ( $F = 40.320$ ,  $p < .001$ ), indicating that maternal coping was significantly increased in the experimental group. There was a significant interaction effect between group and time ( $F = 6.781$ ,  $p < .002$ ), indicating that the UMP was effective in increasing maternal coping and that the effect strengthened over time. Partial eta squared showed that the UMP accounted for 40% of the variance in the maternal coping of participants, indicating that the UMP had the notable effect on maternal coping. The pattern of mean change of maternal coping over time was observed differently in the two groups (Figure 6.a). In the experimental group, the pattern of mean change increased substantially from baseline to post-test 1, which was followed by a minimal increase from post-test 1 to post-test 2. In the control group, the mean score slightly

increased from baseline to post-test 1, but this was offset by a decrease from post-test 1 to post-test 2 (Table 12, Table13- Appendix2).

There was a significant main time effect on efforts to maintain integration, cooperation and optimistic definition of the situation, indicating that maintaining family integration, cooperation with family, and finding an optimistic definition of the situation for participants increased over time in both groups ( $F = 43.900, p < .001$ ). The UMP showed a significant main group effect ( $F = 11.712, p < .001$ ) as well as interaction with time ( $F = 8.084, p < .001$ ), indicating that the UMP was effective in maintaining family integration, cooperation, and finding an optimistic definition of the situation, and that the effect strengthened over time. Partial eta squared showed that the UMP accounted for 16% of the variance in family integration and cooperation of participants, indicating that the intervention had an effect on maintaining family integration, cooperation and optimistic definition of the situation (Table 11). The pattern of mean change of efforts to maintain integration, cooperation and optimistic definition of the situation over time was observed differently in the two groups (Figure 6.b). In the experimental group, the mean score increased substantially from baseline to post-test 1 as well as from post-test 1 to

post-test 2. Whereas in the control group, the mean score increased slowly from baseline to post-test 1 and post-test 2 (Table 12, Table13-Appendix 2).

Repeated measures ANOVA indicated that there was a significant main effect of time on maintaining social support and emotional stability, indicating that social support and emotional stability increased over time in both the control and experimental groups ( $F = 9.366, p < .001$ ). The UMP showed a significant main group effect ( $F = 16.704, p < .001$ ) as well as interaction with group and time ( $F = 4.082, p < .02$ ), indicating that the UMP was effective in maintaining social support and emotional stability of participants and that the effect strengthened over time (Table 11). Partial eta squared showed that the UMP accounted for 21% of variance in the social support and emotional stability in the participants, indicating that the intervention had an effect on maintaining social support and emotional stability (Table 11). The pattern of mean change of maintaining social support and emotional stability over time was observed differently in the two groups (Figure 6.c). In the experimental group, the mean was increased sharply from baseline to post-tests 1, and remained constant from post-test 1 to post-test 2. In the control group, the mean also increased dramatically from baseline to post-test 1, but this was offset by a substantial decrease from post-test 1 to post-test 2 (Table 12, Table13-Appendix 2).



As shown in Table 11, there was a significant main effect of time on efforts to resolve problems through communication with health care professionals and other parents with the same experiences, indicating that efforts to resolve problems increased over time in both the control and experimental groups ( $F = 5.724$ ,  $p < .004$ ). The UMP showed a significant main effect ( $F = 51.571$ ,  $p < .001$ ) as well as interaction with time ( $F = 8.483$ ,  $p < .001$ ), indicating that the UMP was effective in promoting efforts to resolve problems through communication with health care professionals and other parents with the same experiences mothers and that the effect strengthened over time. Partial eta squared showed that the UMP accounted for 46% of the variance in participants' efforts to resolve problems through communication, indicating that the intervention had an effect on participants' communication with health care professionals and others parents. The pattern of mean change of efforts to resolve problems through communication over time was observed differently in the two groups (Figure 6.d). In the experimental group, the mean score increased dramatically from baseline to post-test 1, but this was compensated by a dramatic decrease from post-test 1 to post-test 2. In the control group, the mean decreased slowly from baseline to post-test 2, but changes from baseline to post-test 1, as well as from post-test 1 to post-test 2 were minimal (Table 12, Table13-Appendix 2).

**Table 11. Repeated measures analysis of variance on effects of intervention and time on maternal coping**

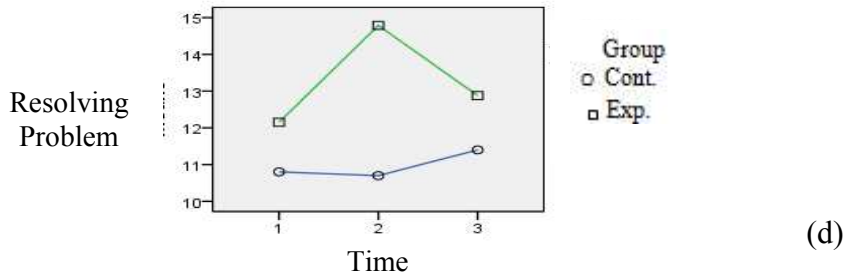
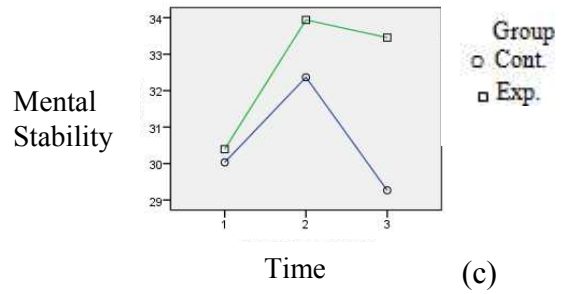
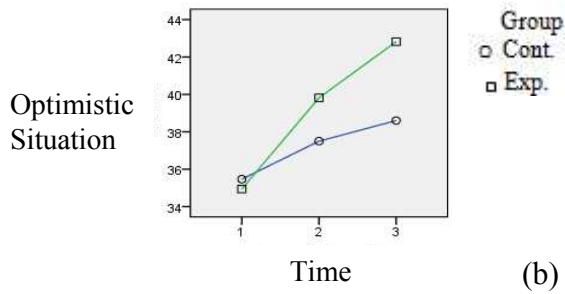
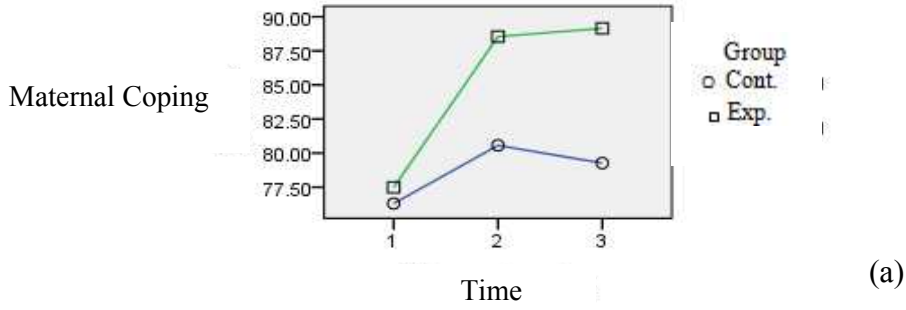
N = 63 (Experimental Group = 33, Control Group = 30)

Dependent Variables	Time			Group			Group X Time		
	F	p	Partial Eta Squared	F	p	Partial Eta Squared	F	p	Partial Eta Squared
Total	24.293	<.001	.285	40.320	<.001	.398	6.781	.002	.100
Effort to maintaining optimistic situation	43.900	<.001	.418	11.712	.001	.161	8.084	<.001	.117
Effort to maintaining mental stability	9.366	<.001	.133	16.704	<.001	.215	4.082	.019	.063
Effort to maintaining resolving the problem	5.724	.004	.086	51.571	<.001	.458	8.483	<.001	.122

**Table 12. Group differences of changes between baseline–post-test 1, post-test 1–post-test 2 for maternal coping**

Outcome Variables	Group	Pre –Post1			Post1- Post2		
		M±SD	t	p	M±SD	t	p
Maternal coping	Exp. group (n = 33)	-10.80±10.44	-.240	.811	-6.1±10.59	-4.762	<.001
	Cont. group (n = 30)	-3.63±7.07			1.30±10.19		

Notes: Exp. = experimental group; Cont. = control group; Pre = baseline; Post1 = post-test 1; Post2 = post-test 2; M = mean; SD= standard deviation  
M, SD = differences from paired t-test  
t and p = form independent t-test



**Figure 6. Changes in Maternal Coping and it's Sub-domains from Baseline Assessment to Post-test 2 by Groups**

Notes: Exp. = experimental group; Cont. = control group

### 3) Effect on maternal quality of life

There was increased maternal quality of life of mothers of children with newly diagnosed cancer in experimental group compared to control group.

The repeated measures (ANOVA) showed that time had a significant main effect on maternal quality of life, indicating that maternal quality of life increased over time in both groups ( $F = 45.561, p < .001$ ). The UMP showed a significant main group effect ( $F = 154.822, p < .001$ ) as well as interaction with time ( $F = 43.685, p < .001$ ), indicating that the UMP was effective in increasing maternal quality of life and that the effect strengthened over time (Table 14). Partial eta squared showed that the UMP accounted for 68% of the variance in the maternal quality of life of participants, indicating that the UMP had the remarkable effect on maternal quality of life (Table 14). The pattern of mean change of quality of life over time was observed differently in the two groups (Figure 7.a). In the experimental group, the mean score increased dramatically from baseline to post-test 1, followed by a minimal decrease from post-test 1 to post-test 2. Whereas in the control group, the mean score increased slowly from baseline to post-test 1, followed by a minimal decrease from post-test 1 to post-test 2 (Table 15, Table 16-Appendix 2).

As shown in Table 14, a statistically significant effect of time on burden over time was noted in both groups ( $F = 46.336, p < .001$ ), of group ( $F = 134.918, p < .001$ ), and of interaction of group and time ( $F = 23.647, p < .001$ ), indicating that frustration experienced by mothers regarding their child's cancer diagnosis and future was decreased after intervention in the experimental group compared with the control group. The UMP accounted for 69% of the variance in the burden domains of maternal quality of life of participants. The pattern of mean change of burden over time was observed differently in the two groups (Figure 7.b). In the experimental group, the mean score increased sharply from baseline to post-test 1 and post-test 2. However, in the control group, the mean score increased gradually from baseline to post-test 2, but changes from baselines to post-test 1 and from post-test 1 to post-test 2 were minimal (Table 15, Table16-Appendix2).

Repeated measures ANOVA indicated that time had a statistically significant effect on the physical/practical concerns of participants by group ( $F = 24.874, p < .001$ ). The UMP showed a significant main group effect ( $F = 15.443, p < .001$ ) as well as interaction with time ( $F = 8.306, p < .001$ ), indicating that the UMP was effective in creasing maternal worry regarding mothers' physical health and that the effect strengthened over time. The UMP accounted for 20% of the variance in the

physical/practical concern of participants (Table 14). The pattern of mean change of physical/practical concerns over time was observed differently in the two groups (Figure 7.c). The mean score of the experimental group increased sharply from baseline to post-test 1, but minimally increased from post-test 1 to post-test 2. Whereas, in the control group, the mean score increased slowly from baseline to post-test 1, and post-test 1 to post-test 2 (Table 15, Table16 Appendix 2).

The results of the repeated measures ANOVA showed that time had a statistically significant effect on emotional reactivity, indicating that mothers' positive feelings regarding their children's condition increased over time in both groups ( $F = 83.161, p < .001$ ). The UMP showed a significant main group effect ( $F = 42.340, p < .001$ ) as well as interaction with time ( $F = 12.047, p < .02$ ), indicating that the UMP was effective in decreasing the mothers' negative emotions of relating to their children's conditions and that the effect strengthened over time. The UMP accounted for 41% of the variance in the emotional reactivity of participants (Table 14). The pattern of mean change of emotional reactivity over time was observed differently in the two groups (Figure 7.d). In the experimental group, the mean score decreased minimally from baseline to post-test 1, but this was offset by a dramatic increase from post-test 1 to post-test 2. In the control group, the mean score decreased

dramatically from baseline to post-test 1, but this was also increased rapidly from post-test 1 to post-test 2 (Table 15, Table 16-Appendix 2).

Repeated measures ANOVA showed a significant effect of time on maternal self-need, indicating that mothers' personal need decreased over time ( $F = 9.118$ ,  $p < .001$ ). No effect of group was found ( $F = 2.397$ ,  $p = .127$ ). There was a significant interaction effect of group and time ( $F = 25.040$ ,  $p < .001$ ). Partial eta squared showed that the UMP accounted for 4% of the variance in the self-need of participants, indicating that the UMP had a medium effect on the self-need of maternal quality of life (Table 14). The pattern of mean change of maternal self-need over time was observed differently in the two groups (Figure 7. e). In the experimental group, the mean score increased rapidly from baseline to post-test 1, but this was followed by a minimal increase from post-test 1 to post-test 2. On the other hand, in the control group, the mean score did not change across the three time points (Table 15, Table 16- Appendix 2).

Repeated measures ANOVA indicated that, in both groups, time had a statistically significant effect on the social support that mothers received from their family ( $F = 7.333$ ,  $p = .001$ ). There was a significant effect of group ( $F = 48.548$ ,  $p < .001$ ) as well as interaction of group and time ( $F = 5.200$ ,  $p = .02$ ), indicating



that the UMP was effective in increasing family support and communication and that the effect strengthened over time. The UMP accounted for 44% of the variance in the social support of participants and that the effect strengthened over time (Table14). The pattern of mean change of social support over time was observed differently in the two groups (Figure 7.f). In the experimental group, the mean social support score increased considerably from baseline to post-test 1, but this was compensated by a minimal decrease from post-test 1 to post-test 2. On the other hand, in the control group, the mean score decreased from baseline to post-test 1 and post-test 2 (Table 15, Table16-Appendix 2).

**Table 14. Repeated measures analysis of variance on effects of intervention and time on maternal quality of life**

N = 63 (Experimental Group = 33, Control Group = 30)

Dependent Variables	Time			Group			Group X Time		
	F	p	Partial Eta Squared	F	p	Partial Eta Squared	F	p	Partial Eta Squared
Total	45.561	<.001	.428	154.822	<.001	.717	43.685	<.001	.417
Burden	46.336	<.001	.432	134.918	<.001	.689	23.647	<.001	.92135
Physical concern	24.874	<.001	.290	15.443	<.001	.202	8.306	<.001	.120
Emotional reactivity	83.16	<.001	.577	12.05	<.001	.165	42.34	<.001	.410
Self-need	9.11	<.001	.130	2.40	.127	.038	25.04	<.001	.291
Social support	7.333	.001	.107	48.548	<.001	.443	5.299	.001	.821

**Table 15. Group differences of changes between baseline–post-test 1, post-test 1–post-test 2 for maternal quality of life**

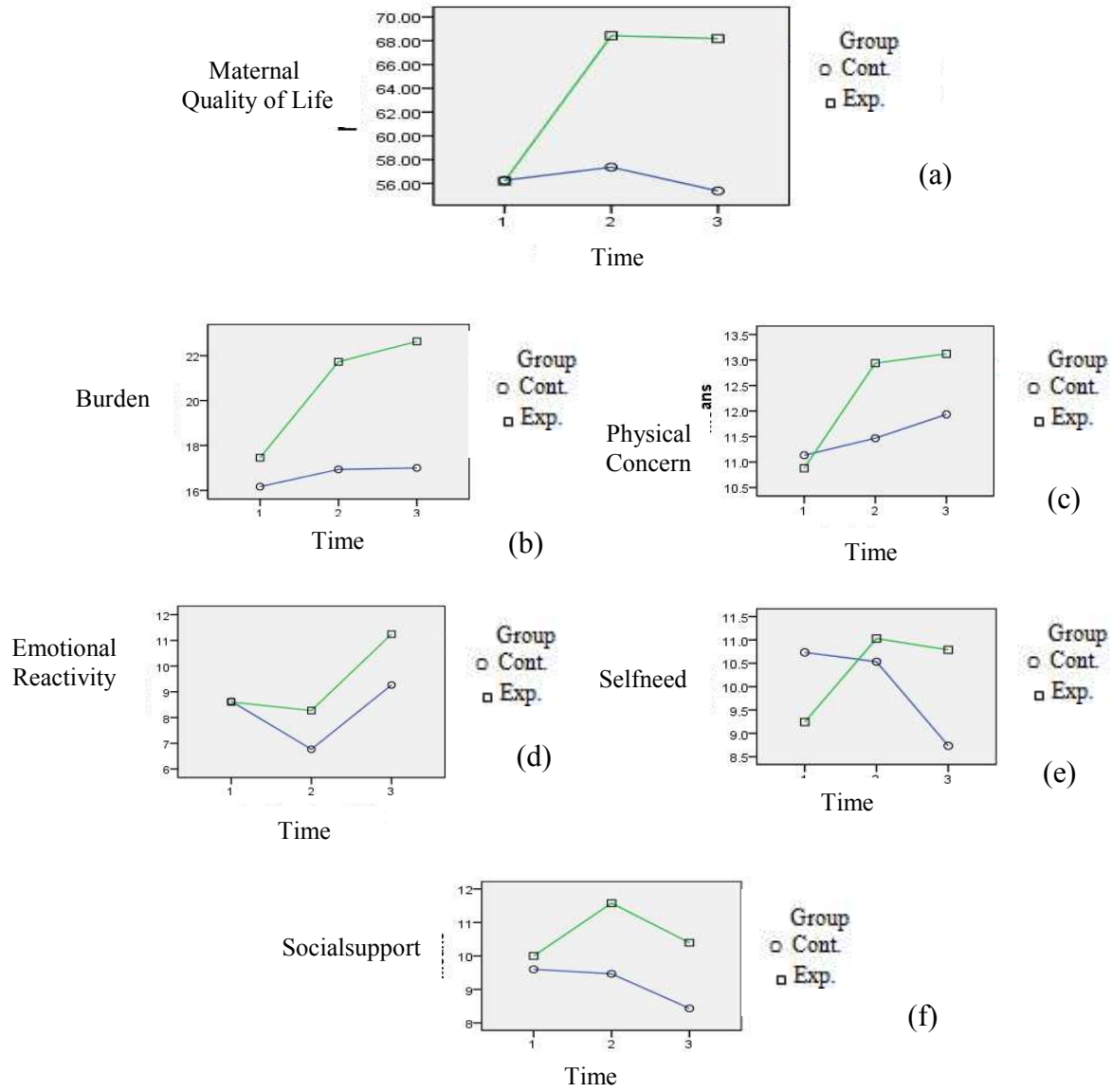
Outcome Variables	Group	Pre –Post1			Post1- Post2		
		M±SD	t	p	M±SD	t	p
Maternal Quality of life	Exp. group (n = 33)	-12.26±6.07	.320	.750	.24±3.89	-10.889	<.001
	Cont. group (n = 30)	-.97±5.38			2.00±6.87		

Notes: Exp. = experimental group; Cont. = control group; Pre = baseline; Post1 = post-test 1;

Post2 = post-test 2; M = mean; SD= standard deviation

M, SD = differences from paired t-test

t and p = form independent t-test



**Figure 7. Changes in Maternal Quality of Life and it's Sub-domains from Baseline Assessment to Post-test 2 by Groups**

Notes: Exp.= experimental group; Cont. = control group

## VII. DISCUSSIONS

This study was designed to develop and evaluate the effect of an uncertainty management program (UMP) on uncertainty, coping, and quality of life for mothers of children with newly diagnosed cancer using Mishel's theory of uncertainty in illness as a framework. The choice of uncertainty theory as a framework for the present study is supported by previous studies including skills-based modules addressing the nature of uncertainty, acquisition of coping skills, communication with medical teams, and eliciting social support. In addition, the contents of the UMP were identified based on a needs assessment as well as a literature reviewed that were important for the Bangladeshi mothers who have a different culture and religion. In the present study, most mothers accepted enrollment in both groups, successfully completed their participation, and participants in the experimental group provided positive feedback after intervention. In the present study, around 88% of mothers were Muslim and others Hindu which somewhat reflects the general Bangladeshi population. According to the Government of the Bangladesh, Ministry of Health and Family Welfare (2016), in Bangladesh, around 89% of people Muslim and 9.9% Hindu.

For maternal uncertainty, maternal coping, and maternal quality of life, consistently significant effects or trends in favor of the experimental group were found from baseline to post-test 1 (1 week after baseline) and post-test 2 (2 weeks after baseline). Mothers in the experimental group continued to exhibit ongoing improvements across all domains after the intervention ended. These findings suggest that the intervention indeed reduced maternal uncertainty, improved maternal coping and increased maternal quality of life. A previous study reported that participants in the treatment as usual (TAU) group showed worsening scores over time, but this pattern was not observed in the intervention group (Hoff et al., 2005). It can be assumed that the UMP had has the potential to decrease uncertainty, improve maternal emotional status, and increase the quality of life of mothers of children with cancer in Bangladesh.

Although a significant effect on maternal uncertainty was found in the group who underwent the UMP, a different trend of mean change was observed in the ambiguity domain of maternal uncertainty in both groups. The mean ambiguity scores in the control group increased dramatically from post-test 1 to post-test 2, which indicate that mothers' ambiguity about the state of their children's illness and the difficulties they faced in caring for their ill children increased with the passing of

time. This may be due to a lack of information about the causes of the illness and how to take care of the children after discharge from hospital. In Bangladesh, there is an ongoing acute shortage of nurses with the number of nurses below the international standard. There are an estimated 2.90 nurses per 10,000 people (Government of the People's Republic of Bangladesh, Ministry of Health and Family Welfare, 2016). In Bangladesh, nurses spend 5.3% (Hadley et al., 2007) of their time on direct patient care (Westbrook, Duffield, Li, & Crewick, 2011). This contrasts Western countries, such as Australia and the United States of America, where nurses spend 20% and 19.3% of their time with patients, respectively (Hendrich, Chow, Skierczynski, & Lu, 2008). Hossain (2012) studied the 'information needs of rural women in Bangladesh' and found that 75% of the respondents were housewives. In Bangladeshi traditional culture and custom, mothers undertake household work and take care of their children and family members. Therefore, mothers do not often encounter situations where they need to communicate in an official capacity. Most of the mothers (85.7%) in this study were housewives. When mothers come to the hospital with their ill children, they ultimately faced difficulties communicating effectively with health care professionals in order to learn about their child's condition and care needs. Francis et al. (2011) found that mothers required specific information to assess the severity of

their child's symptoms. Another qualitative study reported mothers' difficulties in communicating their children's condition to medical staff (Ueki, Takao, Komai, Fujiwara, & Ohashi, 2017).

Maternal coping was significantly increased over time regardless of group. The pattern of mean change of the emotional stability domain of maternal coping in both groups showed the same trend over time. Mothers in both groups had less emotional stability at post-test 2 than post-test 1, but there was a statistically significant difference between the two groups over time. These findings suggest that the UMP initially increased emotional stability among mothers, but the improvement was shown to be transient at post-test 2, which is consistent with another interventional study which report that initial effects were observed, but the effects were not maintained over time (Mishel et al., 2002). The present study's findings suggest that the initial empowerment that was acquired during the intervention tended to diminish over time. To maintain the empowering effects of similar interventions, "booster sessions" have been effectively employed to ongoing empowerment (Ball et al., 2002). Thus, continued encouragement and reinforcement of the UMP by nurses may be necessary for mothers of children with cancer to ensure that they continue to benefit from the program over time.



In the present study, there was a significant increase in maternal quality of life over time. However, the self-need domain of maternal quality of life did not show any change in the experimental group after intervention and failed to approach significant difference between two groups. But in the control group, the mean was increased from baseline to post-test 1 and it was decreased at post-test 2. The findings of the current study are similar to those reported by Yamazaki (2005), who found that mean scores were poor in mental and physical performances of QoL. In the present study, the average age of mothers was similar and there were no significant differences between both groups: in the control group the percentage of mothers aged > 30 years as 61.9%, with an age range of 19-37 years; and in the experimental group the percentage of mothers aged > 30 years was 38.1%, with an age range of 20-40 years. Walsh (2017) reported that in Bangladesh, mothers who experience childbirth for the first time in their thirties have more compassions and less behavioral, social, and emotional difficulties than their younger counterparts. In the present study most of the mothers in the control groups' ages were > 30 years. This may have given the mothers more physical and psychological strength to overcome their situations. Furthermore, in the control group, out of 35 participants, 24 (66.7%) responded 'disagreed' and 2 (5.6%) responded 'strongly disagreed' with the item number "18"

(it bothers me that my priorities have changed) and 23 (63%) responded disagreed and 2 (5.6%) responded strongly disagreed with the item number “19” (The need to protect my loved one bothers me). In Bangladesh, most of the mothers are primarily responsible for taking care of their children who are quite close to them. It is natural for mothers to increase their parenting role and attachment when taking care of and touching their ill children (Miller & Commons, 2010). One study revealed that the kind of touching and holding emphasized by attachment parenting can either reduce the effect of stressful experiences, or result in more positive reactions to stress (Miller & Commons, 2010). Blass and Barr (2000) found that the presence of a caregiver can moderate the negative physiological effects of a stressful medical procedure in human infants. Moreover, Al-Quran and the authentic traditions of Prophet Muhammad may the mercy and blessings of God be upon him, speak clearly about the responsibility that comes with raising a child (Stacey, 2010). It is an obligation upon Muslims to raise and care for their children by bringing them up as moral, righteous human beings (Stacey, 2010). In the present study, 98.6% of participants in both groups were Muslim. Equally these mothers may have been more conscious about their responsibility regarding caring for their children instead of their own personal needs. Thus, another program for Muslim mothers may be needed based on the self-need

domain of the quality of life for mothers of children with cancer. The findings of the present study demonstrate the importance of examining UMP variables in addition to bio-behavioral outcomes among diverse populations with chronic illness.

There were several limitations in the present study. First, this study has a non-randomized controlled design and emphasized non-equivalent time limited participation in the program, due to ethical issues. Thus, further studies in the form of RCTs are needed for rigorous evaluation of the intervention. Second, the sample size was conveniently selected from one setting, but future studies considering sampling characteristics of different settings are needed. Third, the UMP manual was developed and evaluated for the first time with Bangladeshi mothers and focused on the effects of a version of the program using a face-to-face individual format. Thus, need to develop group intervention/online tools/booklets etc. in future studies. Fourth, the follow-up period was relatively short which prevented the researcher from determining the long-term effect of the intervention program on the dependent variables. In addition, the present study sample focused only on mothers of children with cancer, thus results from the present study may be different from similar studies conducted with other family members of children with cancer. Because, fathers often serve as primary wage earners, securing health benefits, as well as acting in the role

of main caregivers for siblings, especially during the ill child's hospitalization, they often experience distress when their child is diagnosed and could also profit from intervention. Finally, the follow-up period was limited to 2 weeks and participants were selected from only one tertiary specialized hospital situated in the central city of Dhaka. Thus, the results may not be applicable and generalizable to the mothers of children with cancer admitted at secondary and primary level hospitals.

## VIII. CONCLUSION AND RECOMMENDATIONS

This study developed an uncertainty management program (UMP) focusing on the construct of Mishel's theory of uncertainty in illness. The results indicate that a UMP targeting mothers' illness uncertainty may directly impact maternal outcomes by producing long-term effects on uncertainty, coping, and quality of life for mothers of children hospitalized with newly diagnosed cancer. The UMP supports prior research about mothers of children with chronic health conditions. This study provides the first evidence that uncertainty management can improve the emotional status and quality of life of mothers of children with cancer.

### **Recommendations**

The theory originated in response to specific nursing interventions aimed at decreasing mothers' uncertainty and improve coping and quality of life. This could support mothers to take care of their children diagnosed with cancer. Based on the results of the present study, the following recommendations are suggested.

### **1) Application aspects of UMP**

The present study was guided by Uncertainty in Illness Theory (UIT) (Mishel, 1988) and the UMP components were developed based on the construct of the UIT and need assessment. The UMP yielded significant reductions in maternal uncertainty, and improvements in maternal coping and maternal quality of life for mothers of children newly diagnosed with cancer. The intervention resulted in ongoing significant reductions in psychological distress for mothers and showed that it is possible for uncertainty related distress to be managed even when the uncertainty itself persists. Mothers of children with cancer need interventions that improve their levels of uncertainty and enhance their physical, social, and emotional wellbeing, with a view to facilitating a possible reduction in caregivers' care burden and the maintenance of QoL. Several issues heightened some of the mothers' sense of uncertainty including a lack of information about their children's medical condition and treatment protocol, confusion and complexity about caring for their ill children, and multiple health care providers. In this study, mothers living with the uncertainty of their children's illness could find information about their children's care with the help of nurses and other health care providers. Nurses can play an important role in

helping patients as well as caregivers by providing support, information, and education, on disease and treatment options (Ghodsbin et al., 2014).

## **2) Aspects of health policy**

This study has implications for the theory of uncertainty in illness' applicability for the development of an uncertainty management programs for mothers of children with cancer. There is a need for establishing support system for hospitals and community based training by nurses. Faculty based training has also emerged for preparing nursing students studying in university. Family participation should be encouraged in the context of patients with chronic illness in Bangladesh.

## **3) Future study**

Future studies which adhere to ethical guidelines are needed to further determine the efficacy of the UMP. The effects of a version of the program using an open-group format should also be evaluated. Replicated studies based on populations with diverse chronic illness are needed to verify the validity and reliability of the present study and to determine whether these effects generalize across diverse groups, and determine the applicability of results in real situations. Multi-site studies on UMP variables in addition to bio-behavioral outcomes for diverse populations with chronic illness are also recommended. Finally, research is needed in the form of a path

analysis on Mishel's model to evaluate causal models that can estimate the magnitude and significance of causal connections between variables. In terms of generalizability, future studies should be conducted in diverse settings with diverse populations.



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## APPENDICES

## Appendix 1: Cover Letter and Questionnaire

ID

--	--	--

Date: \_\_\_\_\_

Dear Sir /Madam,

I am Shanzida Khatun, Nursing Supervisor, 500 beded General Hospital, Mugda, Dhaka, Bangladesh. I am a doctoral student in nursing at Yonsei University Graduate School, Seoul, Korea.

The purpose of this study is to develop and examine the effect of uncertainty management program for mothers of children with cancer. The finding of the study will contribute to the pediatric oncology nurses help to intervene to support mothers of children with cancer in reducing cancer related stress. The questionnaire is divided into four sections. Section 1 of your personal data related questions. Section 2 is related to parents perception of uncertainty scale section 3 is related to coping health inventory for parents section 4 maternal quality of life-cancer,

Thank you for your participation.

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## QUESTIONNAIRE

### Section 1: The Demographic Data Questionnaire

Direction: This questionnaire consists of 15 Items regarding mother's and child's demographic characteristics. Please listen the questions and give answers as accurate as possible. This questionnaire will be answered by the mothers. The researcher assistant will complete the questions by asking answers from the mothers.

#### Characteristics of Mother

- 1 Age \_\_\_\_\_ Years
  - 2 Education
    - 1. Less than high school       2. High school
    - 3. Vocational                       4. College
    - 4. University                         5. Illiterate
  - 3 Religion
    - 1. Muslim                               2. Hindu
    - 3. Christian                             4. Buddhist
    - 5. Others
  - 4 Occupation
    - 1. Housewife                       2. Government service
    - 3. Private service                       4. Labor
    - 5. Others (please specify \_\_\_\_\_ )
-



5 Family income (Taka/month)

\_\_\_\_\_ (Please specify)

6  1. Adequate  2. Adequate

7 Housing

1. Monthly rent  2. Leasing house

3. Own house

8 Number of children

1. One  2. Two- three

3. > Three

9 Source of health information

1. Health care provider  2. Relatives

3. Friends  4. Internet

5. Others (Please specify.....)

#### Characteristics of Child

1 Age (years)

2 Sex

1. Male  2. Female

3 Sibling

1. Yes  2. No

4 Diagnosis

1. Leukemia  2. Neuroblastoma

3. Lymphoma  4. Brain tumor

5. Others

---

- 5 Time of since diagnosis  
(.....) Week      (.....) Month
- 6 Length of receiving treatment  
\_\_\_\_\_ (please specify)
- 7 Number of hospital admission  
[ ] First time  
[ ] more than one time
-

**Section 2: Parent’s Perception of Uncertainty Scale (PPUS)**

Direction: This questionnaire consists of 31 items including four subscales regarding ambiguity (13 item), lack of clarity (9 item), lack of information (5 item), and unpredictability (4 item). As accurately as possible, please give your opinion in each statement. Please tell or indicate this by selecting one of the five numbers next to each statement that best describes your opinion. There is no right or wrong answers.

The rating scales are as follows:

- Strongly disagree (1) = do not really agree with the statement
- Disagree (2) = I do not agree with the statement
- Agree (3) = I agree with the statement
- Strongly agree (4) = I really agree with the statement

For example:

Items	Strongly disagree	Disagree	Agree	Strongly agree
	①	②	③	④
1. I know that what’s right with my child	√			

---

Note: I do not really know that what’s right with my child

S/N	Items	Strong disagree	Disagree	Agree	Strongly agree
		①	②	③	④
Ambiguity:-					
1	I am unsure if my child's illness getting better or worse	①	②	③	④
2	It is unclear how bad my child's pain will be	①	②	③	④
3	My child's symptoms continue to change unpredictably	①	②	③	④
4	It is difficult to know if the treatment or medications my child getting are helping	①	②	③	④
5	Because of the unpredictability of my child's illness, I cannot plan for the future	①	②	③	④
6	The course of my child's illness keeps changing. He/she has good and bad days	①	②	③	④
7	It's vague to me how I will manage the care of my child after he/she leaves the hospital	①	②	③	④

S/N	Items	Strong disagree	Disagree	Agree	Strongly agree
		①	②	③	④
8	It is not clear what is going to happen to my child	①	②	③	④
9	The results of my child's tests are inconsistent	①	②	③	④
10	The effectiveness of the treatment is undetermined	①	②	③	④
11	It is difficult to determine how long it will before I can care for my child by myself	①	②	③	④
12	Because of the treatment, what my child can do and cannot do keeps changing	①	②	③	④
13*	I'm certain they will not find anything else wrong with my child	①	②	③	④
Lack of Clarity:-					
14	I have a lot of questions without answers	①	②	③	④
15	The explanations they give about my child seem hazy to me	①	②	③	④

S/N	Items	Strong disagree	Disagree	Agree	Strongly agree
		①	②	③	④
16*	The purpose of each treatment for my child is clear to me	①	②	③	④
17	I don't know when to expect things will be done to my child	①	②	③	④
18*	I understand everything explained to me	①	②	③	④
19	The doctors say things to me that could have many meanings	①	②	③	④
20	There are so many different types of staffs; it's unclear who is responsible for what	①	②	③	④
21*	I can depend on the nurse to be there when I need them	①	②	③	④
22*	The doctors and nurses use everyday language so I can understand what they are saying	①	②	③	④
Lack of Information:-					
23	I don't know what's wrong with my child	①	②	③	④

S/N	Items	Strong disagree	Disagree	Agree	Strongly agree
		①	②	③	④
24	My child's treatment is too complex to figure out	①	②	③	④
25	They have not given my child a specific diagnosis	①	②	③	④
26*	My child's diagnosis has defined and will not change	①	②	③	④
27*	The seriousness of my child's illness has been determined	①	②	③	④
Unpredictability:-					
28*	I can predict how long my child's illness will last	①	②	③	④
29*	I usually know if my child is going to have a good or bad day	①	②	③	④
30*	I can generally predict the course of my child's illness	①	②	③	④
31*	My child's physical distress is predictable; I know when it is going to get better or worse	①	②	③	④

Note: \* Items will be reversed score

### Section 3: Coping Health Inventory for Parents (CHIP)

Direction: This questionnaire consists of 36-items regarding maternal coping including optimistic definition about the situation (16 item), efforts for emotional stability (15 item), and effort for resolving the problem (5 item). As accurately as possible, please give your opinion in each statement. Please tell or indicate this by selecting one of the five numbers next to each statement that best describes your opinion. There is no right or wrong answers. The rating scales are as follows:

Strongly disagree (1) = I do not really agree with the statement

Disagree (2) = I do not agree with the statement

Agree (3) = I am agree with the statement

Strongly agree (4) = I am really agree with the statement

For example:

Items	Strongly disagree	Disagree	Agree	Strongly agree
	①	②	③	④
1. Finding someone to talk about the truth	√			

Note: I do not really find someone to talk about the truth



S/N	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
Efforts for maintaining integration, cooperation, and optimistic definition of the situation					
1.	Believing that my children will get better	①	②	③	④
2.	Doing things with my children	①	②	③	④
3.	Believing that things will always work out	①	②	③	④
4.	Telling myself that I have many things I should be thankful for	①	②	③	④
5.	Building a closer relationship with my spouse	①	②	③	④
6.	Talking over personal feelings and concerns with spouse	①	②	③	④
7.	Doing things with family relatives	①	②	③	④
8.	Believing in God	①		③	④

S/N	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
9.	Believing that my child is getting the best medical care possible	①	②	③	④
10.	Trying to maintain family stability	①		③	④
11.	Doing things together as a family (involving all members of the family)	①	②	③	④
12.	Trusting my spouse (for former spouse) to help support me and my child(ren)	①	②	③	④
13.	Showing that I am strong	①	②	③	④
14.	Getting other members of the family to help with chores and tasks at home	①	②	③	④
15.	Believing that the medical center/hospital has my family's best interest in mind	①	②	③	④

S/N	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
16.	Encouraging child(ren) with medical condition to be more independent	①	②	③	④
Efforts for maintaining social support and emotional stability					
17	Involvement in social activities (parties, etc.) with friends	①	②	③	④
18.	Being able to get away from the home care tasks and responsibilities for some relief	①	②	③	④
19.	Getting away by myself	①	②	③	④
20.	Eating	①	②	③	④
21.	Sleeping	①	②	③	④
22.	Allowing myself to get angry	①	②	③	④
23.	Purchasing gifts for myself	①	②	③	④

S/N	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
	and /or other family members				
24.	Concerning on hobbies (art. Music, jogging, etc.)	①	②	③	④
25.	Becoming more self-reliant and independent	①	②	③	④
26.	Keeping myself in shape and well-groomed	①	②	③	④
27.	Talking to someone (not professional counselor/ doctor) about how I feel	①	②	③	④
28.	Engaging in relationship and friendships which help me to feel important and appreciated	①	②	③	④
29.	Investigating time and energy in my job	①	②	③	④
30.	Going out with my spouse on a regular basis	①	②	③	④

S/N	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
31.	Building close relationship with people Efforts for communication with professionals and other parents	①	②	③	④
32.	Talking with other parents in the same type of situation and learning about their experiences	①	②		④
33.	Reading more about the medical problem which concerns me	①	②	③	④
34.	Explaining our family situation to friends and neighbors so they will understand us	①	②	③	④
35.	Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	①	②	③	④
36.	Talking with the doctor	①	③	④	⑤

S/N	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
	about my concerns about my child(ren) with the medical condition				

**Section 4: Caregiver Quality of Life Cancer-S25 (CQOLC-S25)**

Direction: This questionnaire consists of 25-items regarding maternal quality of life including burden (8-item), physical/practical concerns (5-item), emotional reactivity (4-item), self need (4-item), and social support (4-item). As accurately as possible, please give your opinion in each statement. Please tell or indicate this by selecting one of the five numbers next to each statement that best describes your opinion.

There is no right or wrong answers. The rating scales are as follows:

- Strongly disagree (1) = I do not really agree with the statement  
 Disagree (2) = I do not agree with the statement  
 Agree (3) = I am agree with the statement  
 Strongly agree (4) = I am really agree with the statement

For example:

Items	Strongly disagree	Disagree	Agree	Strongly agree
	①	②	③	④
1. I feel happy	√			

Note: I do not really happy

Item #	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
<b>Burden</b>					
1.	I feel nervous	①	②	③	④
2.	I feel frustrated	①	②	③	④
3.	I feel guilty	①	②	③	④
4.	I worry about the impact my loved one's illness has had on my children or other family members	①	②	③	④
5.	I feel under increased mental strain	①	②	③	④
6.	I am discouraged about the future	①	②	③	④
7.	I have difficulty dealing with my love one's changing eating habits	①	②	③	④



Item #	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
8.	It bothers me, limiting my focus to day-to-day	①	②	③	④
	Physical/practical concerns				
9.	My daily life is imposed upon	①	②	③	④
10.	My sleep is less restful				
11.	It bothers me, that my daily routine is altered	①	②	③	④
12.	It is a challenge to maintain my outside interests	①	②	③	④
13.	I am under a financial strain	①	②	③	④
	Emotional reactivity				
14.	It upsets me to see my loved one deteriorate	①	②	③	④

Item #	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
15.	I fear my loved one will die	①	②	③	④
16.	The need to manage my loved one's pain is overwhelming	①	②	③	④
17.	I fear the adverse effects of treatment on my loved one	①	②	③	④
Self-needs					
18.	It bothers me that my priorities have changed	①	②	③	④
19.	The need to protect my loved one bothers me		②		④
20.	It bothers me that I need to be available to chauffeur my loved one to appointments	①	②	③	④

Item #	Items	Strongly disagree	Disagree	Agree	Strongly agree
		①	②	③	④
21.	The responsibility I have for my loved one's care at home is overwhelming	①	②	③	④
Social Support					
22.	*I have developed a closer relationship with my loved one	①	①	④	⑤
23.	I feel adequately informed about my loved one's illness	①	②	③	④
24.	*Family communication has increased	①	②	③	④
25.	*I am satisfied with support I get from my family	①	②	③	④

Note: All items will be reversed score except \*items.

**Appendix 2: Means/Standard Deviations of Maternal Uncertainty, Maternal Coping and Maternal Quality of Life**

**Table 10. Mean/Standard Deviations of maternal uncertainty and its sub-domains**

Variables	Experimental Group ( <i>n</i> = 33)			Control Group ( <i>n</i> = 30)		
	Pre-test	Post-test 1	Post-test 2	Pre-test	Post-test 1	Post-test 2
	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD
Maternal uncertainty	86.00±4.66	72.00±3.23	69.00±3.59	85.03±5.25	83.40±4.95	85.57±3.50
Ambiguity	35.42±3.04	30.21±2.42	28.94±2.49	34.33±2.63	34.10±2.45	39.60±2.09
Lack of clarity	24.81±2.36	20.50±1.83	20.50±1.81	25.53±2.54	24.70±2.57	23.47±1.83
Lack of information	13.55±1.78	10.55±1.30	10.55±1.30	12.73±1.14	13.07±1.11	13.07±1.11
Unpredictability	12.45±1.22	9.61±1.54	8.84±1.71	11.97±1.67	11.50±1.68	11.23±1.23

**Table 13. Mean/Standard Deviations of maternal coping and its sub-domains**

Variables	Experimental Group ( <i>n</i> = 33)			Control Group ( <i>n</i> = 30)		
	Pre-test	Post-test 1	Post-test 2	Pre-test	Post-test 1	Post-test 2
	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD
Maternal coping	77.48±7.99	88.54±6.31	89.15±6.80	76.30±5.85	80.57±6.61	79.27±7.74
Effort to maintaining optimistic definition of situation	34.94±3.68	39.82±3.41	42.82±3.52	35.47±3.48	37.50±3.61	38.60±3.73
Effort to maintaining emotional stability	30.39± 3.97	33.94± 3.49	33.45± 4.05	30.03±3.67	32.37±3.36	29.27±3.98
Effort to maintaining problem solving	12.15±2.75	14.79±1.9	12.88±2.32	10.80±1.77	10.70±1.64	11.40±2.14

**Table 16. Mean/Standard Deviations of maternal quality of life and its sub-domains**

Variables	Experimental Group ( <i>n</i> = 33)			Control Group ( <i>n</i> = 30)		
	Pre-test	Post-test 1	Post-test 2	Pre-test	Post-test 1	Post-test 2
	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD	M ± SD
Maternal quality of life	56.18±4.32	68.42±3.95	68.07±4.85	56.67±4.24	57.37±4.10	55.37±3.96
Burden	17.45±2.19	21.72±1.53	22.64±2.32	16.17±2.27	16.93±1.84	17.00±1.91
Physical/practical concerns	10.88±1.19	12.94±1.33	13.12± 1.24	11.13±1.48	11.47±1.17	11.93±1.48
Emotional reactivity	8.61±1.66	8.27±1.00	11.24±.83	8.63±1.38	6.77±.93	9.27±1.20
Self-needs	9.24±1.32	11.03±1.38	10.79±1.49	10.73±1.41	10.53±1.81	8.73±1.31
Social support	10.00±1.69	11.57±1.64	10.39±1.63	9.60±1.61	9.47±1.59	8.43±1.30

### Appendix 3: Literature Review

**Table 1. Analysis of the relevant interventional literatures**

S/No	Author (year) *unpublished work	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participants	Miscellaneous (limitations of the study, critique etc)
#1.	Mullins et al (2012)	-Skills for managing maladaptive cognition -12-week format - Nature of uncertainty, communication with medical staff, cognitive coping, problem- solving skills, and social support.	-Group -Six sessions - face to face (45m-60 m) -Telephone call (15-30 m)	-Manual -6-distinct modules. - written handout -Homework assignment.	UIT	-Mothers - child (2- 18years) -Newly diagnosed cancer.	-small sample -supportive individuals may have an improvement in adjustment -Uncertainty will be the best conceptualized as a stressor <b>Crt:</b> Future intervention with large sample in pediatric cancer settings.

**Continuation of Table 1.**

S/No	Author (year) <b>*unpublished work</b>	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participants	Miscellaneous (limitations of the study, critique etc)
#2.	Fedele et al. (2013)	-Coping Intervention - (1) Nature of uncertainty, communication with medical staff, cognitive coping, problem-solving, social support, and consolidation	-Group -12 sessions -Alternating weekly/ phone call -45 min to 1 hr -15-30 min phone call	-Manual -Six module -Handout, home work assignment	UIT	-Mothers - Child's age 2-18years and newly diagnosed with cancer	
#3.	Hoff et al. (2005)	-Uncertainty management intervention -Sources of uncertainty and appraisals (Session/1) -Uncertainty	-Group format -Two sessions two consequence weekends.	-Manual - PPT presentation -Manuals, handouts for parents.	UIT	-Parents -Child > 18yrs and newly diagnosed with.	-Question for homogeneity by different ethnicity and socio-economical. - Sampling bias (68% allocated rate) due to Low retention rate.



**Continuation of Table 1.**

S/No	Author (year) <b>*unpublished work</b>	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participants	Miscellaneous (limitations of the study, critique etc)
		management technique (information resources, problem-solving skills, communication skills, and role clarification).	-2.5-hr /session	-		diabetes.	- Not measure of uncertainty management skills that limit the ability to interpret the lack of change. <b>Crt:</b> Future studies should include uncertainty measure. The implications for development of intervention in the context of chronic illness.
#4.	Nicholas et al (2012)	-Web-based intervention For social support and coping skills	-Closed online semi- structured a synchronous forum		Not mentioned	-Fathers of children with brain tumor	

**Continuation of Table 1.**

S/No	Author (year) *unpublished work	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participant s	Miscellaneous (limitations of the study, critique etc)
			facilitated by trained facilitator				
#5.	Hoeskstra- Weebers et al (1998)	-Manual-guided intervention -Psycho-educational, cognitive-behavioral techniques. - Expression of emotions, identification of negative thoughts, encouragement of problem focused coping skills, communication and assertiveness skills, and information about the	-Group -90 minute session - 8 sessions -3 week interval between sessions.	-Manual		-Parents -childs' X age 6.4yrs; newly diagnosed with cancer.	

**Continuation of Table 1.**

<b>S/No</b>	<b>Author (year) *unpublished work</b>	<b>Intervention program</b>	<b>Intervention methods</b>	<b>Intervention component</b>	<b>Theoretical constructs</b>	<b>Participants</b>	<b>Miscellaneous (limitations of the study, critique etc)</b>
		consequences of the treatment for the ill child and whole family.				-	
#6.	Duffy & Vessey (2016)	-COPE intervention -Enhance coping Phase 1: information; Phase II: help parents anticipate and to behavior changes of their child; Phase III: parent-child activity: therapeutic play therapy during medical procedures and hospitalization.	-Group -3 phase -Telephone call	-Workbook	COPE (Creating Opportunities for Parent Empowerment)	-Parent -Child 2-6yrs; chronic neurological and cancer.	

**Continuation of Table 1.**

<b>S/No</b>	<b>Author (year)</b> <b>*unpublished</b> <b>work</b>	<b>Intervention program</b>	<b>Intervention</b> <b>methods</b>	<b>Intervention</b> <b>component</b>	<b>Theoretical</b> <b>constructs</b>	<b>Participants</b>	<b>Miscellaneous</b> (limitations of the study, critique etc)
#7.	Konradsdottir & Svavarsdottir (2011)	-Educational and support intervention -(1) group education for families, adolescents, parents on impact of chronic illness, (2) single support with the parents: engage parents in dialogue about their illness experience, assess impact of the illness on family, comment on the family's strengths, identify possible resources, (3) For	-Group - 3sessions - 1.45 min lecture, 2. 60- 90 min support interview for parents, 3. 60 min for adolescents	-Not mentioned	-CFAM & CFIM (The Calgary Family Assessment Model & the Calgary Family Intervention Model)	-Parents -Adolescents with type 1diabetes	

Continuation of Table 1.

S/No	Author (year) *unpublished work	Intervention program	Intervention methods	Intervention component	Theoretic al construct s	Particip ants	Miscellaneous (limitations of the study, critique etc)
		adolescents: reflect experience each others, give one another support.					
#8.	Svavarsdottir & Sigurdardottir, (2006)	-Family-level educational and support intervention 1. Educational & informational website 2. Siblings and parents experiences, 3. Practical issues regarding cancer treatment, management, medical side effects, 4. Support interview: parents engage in therapeutic relationship, information related to coping,	-Three phases -4-5months/ parents -60-90 minute	-Web-based intervention	Calgary Family Interventi on Model (CFIM).	-Parents (90% mothers) -Mean age of childs' 10.88yea rs and diagnose d with cancer.	Small sample; no comparison grp; <b>Crti</b> : follow-up intervention focusing on ongoing psychological health of parents might be helpful long-term for families who are adapting to childhood cancer.

**Continuation of Table 1.**

S/No	Author (year) *unpublished work	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participants	Miscellaneous (limitations of the study, critique etc)
		resiliency, and adaptation dealing with cancer.					
#9.	Ghodsbin, Asadi, Fard, & Kamali, (2014).	-Education - Information about leukemia remedy, effects of disease, way to cope, care for sick children.	-Group (4-6/group) -3 session -45-60 minutes	-Educational Booklets Poster	Not mentioned	-Parent -Child 7-10 yrs, leukemia	- Convenience sampling
#10	Shahlar et al. (2005)	-PBS training (Bright IDEAS) -Coping skill. IDEAS stand for I, (identify the problem), D, (determine the option), E, (evaluate options and choose the best), A, (act), S, (see if it worked) signify the 5 steps	-Individual session -8 session -1 hr	-Protocol -Treatment manual, - Bright IDEAS booklet	Cognitive-behavioral	-Parents -Child with leukemia	

**Continuation of Table 1.**

S/No	Author (year) <b>*unpublished work</b>	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participants	Miscellaneous (limitations of the study, critique etc)
		of problem solving.					
#11.	*Lamanna, 2012	-Parent Empowerment Program: A. problem identification B. problem orientation (5 steps): (1) background information, (2) problem definition & formulation, (3) develop possible solution (4) decision making, and (5) evaluating your solution.	-Group -two support session (control) -session one received problem-solving intervention & follow-up session -General support for control group	-Parent empowerment manual; Parent packet handout; index card with problem-solving therapy reminders pen	Problem-solving Model of Stress (Nezu, 2004)	-Primary caregiver -Child with cancer	-small sample - failure to detect sig effect - generalization due to only one hospital - One interventionist for both groups who knew the aims that may have introduced bias. - Treatment fidelity for the control sessions were vague, making consistent ratings difficult to achieve. <b>Crt:</b> Number of

**Continuation of Table 1.**

S/No	Author (year) *unpublished work	Intervention program	Intervention methods	Intervention component	Theoretical constructs	Participant s	Miscellaneous (limitations of the study, critique etc)
				-			session should be extended (2 sessions not enough).
#12.	Pateraki et al (2015)	-Stress management program -Deep breathing and progressive muscle relaxation (DB-PMR) -Taking deep diaphragmatic inspirations followed by slow prolonged expirations.	-8 Weeks follow-up -112 sessions -Telephone call at the end of each week and recorded by self-reported checklist -Twice/day at home.	- Audio CD consisting -10 minute RB & 15 minute of	N/A	-Parents -Child with -Child with type 1 diabetes	



**Continuation of Table 1.**

<b>S/No</b>	<b>Author (year)</b> <b>*unpublished</b> <b>work</b>	<b>Intervention program</b>	<b>Intervention methods</b>	<b>Intervention component</b>	<b>Theoretical constructs</b>	<b>Participants</b>	<b>Miscellaneous</b> (limitations of the study, critique etc)
#13.	Othman et al (2010)	-PeP for PoCwC (psycho-education program for parents.	-Group -4 sessions, 50minutes/ session		Self-regulation and TPB	-Parents -Children, cancer	
#14.	Morrison et al (2016)	Part of RCTs	Uncertainty, Stress	-semi structured -	-Intervention helpful for decreasing uncertainty	Parent (13). 77% (9) mothers	-small sample, limited to use advanced analysis, lack of diversity in culture, only English speaker,

Notes: Crt = critique, RCTs = Randomized control trials, UIT = uncertainty in illness theory

**Appendix 4: Institutional Review Board Approval Letter**
**Report of Institutional Review Board**

<b>IRB No.</b>	YUCON-IRB 2017-0006-2		<b>Date of Report</b>	Mar 24, 2017
<b>Type of Review</b>	<input type="checkbox"/> New review <input type="checkbox"/> Continuation <input type="checkbox"/> Final report	<input type="checkbox"/> Subsequent review <input type="checkbox"/> Exempt research	<input type="checkbox"/> Change of protocol <input checked="" type="checkbox"/> Other (Minor revision)	
<b>Title of Proposal</b>	Development and Evaluation of Uncertainty Management Program for Mothers of Children Newly Diagnosed with Cancer in Bangladesh.			
<b>Investigator</b>	<b>P.I.</b>	Shanzida Khatun	Doctorial Student , CON, Yonsei University	
	<b>Co-I.</b>	Hee Soon Kim	Prof. CON, Yonsei University	
<b>Type of Research</b>	<input checked="" type="checkbox"/> Survey <input type="checkbox"/> Experimental study	<input checked="" type="checkbox"/> Interview <input type="checkbox"/> Other: Secondary analysis	<input type="checkbox"/> Observational study	
<b>Proposed period of study</b>	IRB Approved date ~ Dec 31, 2017			
<b>Approved period of study</b>	Mar 24, 2017 ~ Dec 31, 2017			

<b>Contents of Review</b>	<input type="checkbox"/> IRB Request Form <input checked="" type="checkbox"/> Response Form <input checked="" type="checkbox"/> Revised Research proposal <input checked="" type="checkbox"/> Information Sheet & Consent Form <input type="checkbox"/> Research Instruments <input type="checkbox"/> Curriculum Vitae of Principal Investigator
<b>Date of IRB Action</b>	Mar 24, 2017
<b>Decision</b>	<input checked="" type="checkbox"/> Approved <input type="checkbox"/> Approve after minor revision <input type="checkbox"/> Required to be re-reviewed <input type="checkbox"/> Committee review after major revision <input type="checkbox"/> Disapproved
<p>[Requirements]</p> <p>With your modified ethnical consideration for the research participants we have regarded that your protocol has followed the IRB guide line.</p>	

Sue Kim  Mar 24, 2017

Signature of the IRB Chair or Designee

Date

Yonsei University College of Nursing IRB

College of Nursing, Yonsei University, 50-1 Yonsei-ro, Seodaemun-gu, Seoul, Korea

120-752 / E-mail : [nursingirb@yuhs.ac](mailto:nursingirb@yuhs.ac) Fax : 822-392-5440

## Appendix 6: Permission Letter for Using Tools

### 1. Parents Perception of Uncertainty Scale (PPUS)

Request letter for using PPUS scale (3)

On Wed, 10/15/14, [Mishel Merle <mishel@email.unc.edu>](mailto:mishel@email.unc.edu) wrote:

Subject: RE: Request letter for using PPUS scale  
To: "Sanzida Khatun" <[sanzidaadib@yahoo.com](mailto:sanzidaadib@yahoo.com)>  
Date: Wednesday, October 15, 2014, 9:52 PM

you have my permission to  
adapt the uncertainty scale as needed.  
Dr.  
Mishel

### 2. Coping Health Inventory for Parents (CHIP)

Request letter for using CHIP (4)

Per

On Thu, 10/16/14, [Hamilton McCubbin <hamiltonmccubbin@earthlink.net>](mailto:hamiltonmccubbin@earthlink.net) wrote:

From: Hamilton McCubbin <[hamiltonmccubbin@earthlink.net](mailto:hamiltonmccubbin@earthlink.net)>

Subject: Re: Request letter for using CHIP

To: "Sanzida Khatun" <[sanzidaadib@yahoo.com](mailto:sanzidaadib@yahoo.com)>  
Cc: "McCubbin, Laurie Dawn" <[mccubbin@wsu.edu](mailto:mccubbin@wsu.edu)>, "Sievers, Jason Allen" <[jasievers@wsu.edu](mailto:jasievers@wsu.edu)>  
Date: Thursday, October 16, 2014, 12:53 AM

Dear Sanzida Khatun:

We are pleased to learn of study and your academic work in South Korea.

Greetings to Dr. Hee Soon Kim.

WE would recommend you review the web page for ordering permissions, measures, psychometrics, scoring, norms for CHIP and other measures. See attachment. After reviewing, let us know if we can be of assistance.

sie

Laurie "Lali" McCubbin, PhD.

Director

Jason A. Sievers, PhD, Associate

Director

Hamilton I McCubbin PhD, Scientist

### 3. The Caregivers Quality of Life Index-Cancer (CQOLC)

Request for using tool (3)

People

**McMillan, Susan** <smcmilla@health.usf.edu>

11/04/16 at 11:33 PM \*

To: Sanzida Khatun

**boxbe** McMillan, Susan (smcmilla@health.usf.edu) is not on your [Guest List](#) | [Approve sender](#) | [Approve domain](#)

Dear Sanzida:

Attached you will find the Caregiver QOL- Cancer tool. You have permission to translate and use it in your study. Dr. Weitzner give the tool to me to provide it to others who wish to use it. Please note that this version is marked to indicate which items are reverse-scored. That means you score them in the opposite direction from the other items.

I wish you the best with your project. I hope you will share your abstract and a copy of the translated tool when you have finished your project.

Sincerely,

Susan C. McMillan

Susan C. McMillan, PhD, ARNP, FAAN  
Distinguished University Health Professor  
Thompson Professor of Oncology Nursing  
University of South Florida  
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