A STUDY INVESTIGATING THE IMPACT AND COPING OF FAMILIES DURING CANCER CHILDREN'S HOSPITALIZATION

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CERTIFICATE OF ORIGINALITY

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Abstract

Background

Advanced therapy for childhood cancer is often associated with repeated and prolonged hospitalization, which is considered as an immensely stressful experience for the whole family. The whole family experiences great hardships during a cancer child's hospitalization, with negative impact that can put the family into crisis or threaten its integrity. Some families adapt well, while others continue to experience extremely serious problems. Positive family adaptation can be attributed mainly to the dynamic balance between the inherent stressors and coping strategies. Pediatric oncology nurses are the best persons to support families during a cancer child's hospitalization. Family assessment during the interactions with families is the fundamental step for nursing support. In Mainland China, there is a paucity of literature exploring family impact and coping during a child's hospitalization for cancer treatment. Limited attention and care have been given to the entire family, whose needs and stress have been ignored or assessed inaccurately by healthcare providers. The population of families with children hospitalized in pediatric oncology units is a considerable target group demanding special attention in Mainland China. Nurses need broader knowledge and in-depth information pertaining to these families in order to provide better family care services during children's hospitalization for cancer treatment.

Aim

The aim of this study was to understand family adaptation by investigating family impact and coping during a cancer child's hospitalization in Mainland China.

Design

This study employed a mixed method, and pediatric oncology departments in four hospitals in Mainland China were involved. In the quantitative survey, 253 parents from different families with children hospitalized for cancer treatment completed the questionnaires, including a demographics questionnaire, the Family Impact Module of the Pediatric Quality of Life Inventory, the Hospitalization Impact and Coping Scale, and the Coping Health Inventory for Parents. The quantitative data were analyzed using descriptive analysis, multiple linear regression, confirmatory factor analysis and exploratory factor analysis. The qualitative section involved semi-structured individual interviews with 19 parents recruited from those who had completed the quantitative survey. The verbatim transcripts were analyzed using directed content analysis.

Findings

The quantitative survey revealed that families were affected moderately by their children’s hospitalization. Social functioning was affected the most, followed by the extra burden and psychological impact. In terms of family coping, one strategy, ‘effort to maintain positive and active parental care’, was regarded as the most helpful, followed by ‘maximizing quality and quantity of child care’. The identified predictors of family impact were the total number of days of all admissions and the severity of a child’s disease. The predictors of family coping effectiveness were the number of readmissions, family with a religious background, and age of the hospitalized child. To understand family issues in detail, some parents were interviewed. Four themes emerged from the nineteen sets of parents’ interviews: family impact, family coping, family adaptation and unmet family needs. The findings have contributed to the in-depth understanding of family adaptation, while also provided important operational data for guiding the development and improvement of family-centered care in clinical settings in Mainland China.

Conclusion

This study has generated insights into family adaptation by investigating how families were affected by and coped with their cancer children’s hospitalization in

Mainland China. The findings, which delineated the challenges the families had encountered, their coping strategies and the effectiveness of these, the characteristics of mal-adapted and bon-adapted families, and unmet family needs, have provided in-depth information for clinical nurses to support families to achieve bon-adaptation and improve the quality of clinical service. Success in fostering positive family adaptation requires a strengthening of family attributes and synergistic efforts by the healthcare providers, hospitals, the government and other communities.

Publications Arising from the Thesis

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List of abbreviations

ALL	*Acute Lymphoblastic Leukemia*
APGAR	*Adaptability, Partnership, Growth, Affection, and Resolve*
ANOVA	*One-way Analysis of Variance*
CFA	*Confirmatory Factor Analysis*
CFI	*Comparative Fit Index*
CHIP	*Coping Health Inventory for Parents*
EFA	*Exploratory Factor Analysis*
FCC	*Family-centered care*
F-COPES	*Family Crisis-Oriented Personal Evaluation Scales*
FIM	*Family Impact Module*
HICS	*Hospitalization Impact and Coping Scale*
HIS	*Hospitalization impact scale*
HCS	*Hospitalization coping scale*
IOF	*Impact-on-Family*
ITCs	*Tem-to-Total Correlations*
McMaster FAD	*McMaster Family Assessment Device*
MCMQ	*Medical Coping Mode Questionnaire*
NICU	*Neonatal Intensive Care Unit*
PCSI	*Parental Coping Strategy Inventory*
PedsQL FIM	*Family Impact Module of the Pediatric Quality of Life Inventory*

PSS: IH	*Parental Stressor Scale: infant hospitalization*
RMSEA	*Root-Mean-Square Error of Approximation*
SCSQ	*Simplified Coping Style Questionnaire*
SPSS	*Statistical Package for Social Sciences*
SRMR	*Standardized Root Mean square Residual*
TLI	*Tucker-Lewis index*
WLSMV	*Weighted Least Squares Mean and Variance-adjusted estimation*

CHAPTER 1 INTRODUCTION

This chapter first presents the background of the study, followed by the identification of the knowledge gap. The chapter continues to describe the aim and significance of the present study. Finally, it concludes with a brief introduction of the operational definition of related concepts and the thesis organization.

1.1. Background of the study

1.1.1. Incidence of childhood cancer

Among the causes of death in children in developed countries, childhood cancer has been ranked second after accidents (Global Cancer Control, 2012). It is now becoming a public health problem in developing countries as reported by international agency for research on cancer (IARC) (Global Cancer Control, 2016), along with the improvements in the control of communicable diseases and the occurrence of premature delivery (Yaris *et al.*, 2004). Worldwide, the incidence of childhood cancer appears to be rising (Global Cancer Control, 2012). There are more than 175,000 children developing cancer every year globally (Children with Cancer UK, 2012). More than 85% of pediatric cancer cases occur in developing countries (Yaris *et al.*, 2004). In Mainland China, it has been reported that the incidence has increased by 20% since 2003 and is on the rise. The Chinese Anti-Cancer Association indicated more than 32,000 children aged 14 or younger newly diagnosed with cancer every year in Mainland China (Juan, 2011). This accounts for about one fifth of the total new cases around the world.

During the past several decades, with modern advances in combination chemotherapy, survival rates for childhood cancer have increased dramatically. Unfortunately, improved prognoses are often associated with repeated and prolonged hospitalization (Long & Marsland, 2011), which is an immensely stressful experience both for children and their families (Berrios-Rivera *et al.*, 2008; Hallström *et al.*, 2002a). A child’s illness, aggressive treatment, repeated and long-term hospital stays can be a strain for the entire family. Since nowadays, the entire family has to be involved closely in the trajectory of a child's cancer treatment. It is crucial to become more concerned about the situation of the whole family instead of only focusing on the hospitalized child in clinical settings. Considering family as 'merely an extension of a child' is incongruent with the principles of family-centered care (Kuo *et al.,* 2012).

1.1.2. Family impact and coping during a cancer child's hospitalization

Families with children hospitalized for cancer treatment are faced with great challenges, including invasive and painful treatment procedures, altered parent-child relationships, uncertainty about the child's and family's future, insecurity caused by the unfamiliar hospital environment, increased emotional and physical work, and disruption of family routines (Berrios-Rivera *et al.,* 2008; Hopia *et al.,* 2005; Hopia *et al.,* 2004; Yiu & Twinn, 2001). Any of these stressors can put the family into crisis and threaten family integrity, which, in turn, can have a negative effect on the hospitalized child's recovery. This indicated a child's functioning and responses were affected by how his/her family responded to an adversity (Patterson & Garwick, 1994). Nevertheless, some families cope and adapt positively to this stress while others are at risk of numerous difficulties. Studies have shown that family outcomes can vary from bon-adaptation to mal-adaptation (Manning *et al*., 2011; McCubbin *et al.,* 1983).

Family stress theory has been used to illustrate the factors determining how successfully a family manages a stressful event (Lavee & Mccubbin, 1985; McCubbin & Patterson, 1983). The most important factor is family coping. Studies have addressed the crucial role of family coping as a vital interrelated link between daily life stress and family adaptation (Lin *et al*., 2011; McCubbin & McCubbin, 1993). Family coping is a bridging concept containing cognitive and behavioral components, in which family resources, perceptions and behavioral responses work together to contribute to a rebalanced family functioning (McCubbin & Patterson, 1983). Family coping refers to the efforts of the individual family members, subsystems, and the family unit to master, tolerates, or reduces demands that exceed the family's resources and the strategies employed (Dyk & Schvaneveldt, 1987).

McCubbin and Hamilton (1996) indicated that how well a family adapts to a stressful event depends largely on how it copes with the event. Family coping will be most effective if the characteristics of the stressor match with the type of coping strategy applied to the circumstance (Lazarus, 1984; Manning *et al.,* 2011). Effective family coping strategy has the potential to minimize stress and enhance family adjustment (Pakenham *et al.*, 2005; Wartella *et al.,* 2009). Therefore, the level of family adaptation is largely determined by family coping.

1.1.3. Nurses' responsibilities in caring for the families

Nurses are in the best position to support a family during a child's hospitalization (Sanjari *et al.*, 2009). Families with children hospitalized for cancer treatment are separated from their relatives, friends, and neighbors. They spend most of their time at the hospitals to accompany their hospitalized children receiving cancer treatment. Parents rely very much on nurses for their children's daily care. Caring for the hospitalized children and their families tends to be the core of nursing practice in pediatric oncology departments (Ogle, 2006; Kuo *et al.,* 2012).

Family Centered Care (FCC) is perceived as essential in the delivery of care to children and their families and has been receiving rising attention recently (Ogle, 2006; Regan *et al.*, 2006; Kuo *et al.*, 2012). FCC is an approach to the planning, delivery, and evaluation of health care, and is grounded in the mutually beneficial triple partner-ship of health care providers, patients and families. The principles of FCC are respect, information sharing, participation and collaboration (Institute for Family-Centered Care, 2008). A previous study has pointed out that pediatric oncology nursing is based on family-centered care, which is a vehicle that pediatric oncology nurses can use to ensure they provide appropriate care to patients and their families (Ogle, 2006). The children and their families are the heart of pediatric oncology nursing because children live within the context of their families (Ogle, 2006).

The healthcare system has begun to emphasize FCC, as evidenced by the following affairs. In 2010, the Ministry of Health in China proposed a ‘project to develop high-quality nursing care’ to improve the quality of nursing services and patients’ satisfaction (Ma, 2010). In 2013, the pediatric professional committee of the Chinese Nursing Association (CAN) indicated that FCC, as a high-quality nursing care model, should be implemented in all children’s hospitals in China (Family Centered Care in Pediatric Units, 2013). This reflects the fact that the healthcare systems in China emphasize the FCC approach.

Families are supposed to be involved in clinical care, and receiving adequate attention can be a source of constant support to the hospitalized children and enable them to survive the painful cancer treatment journey successfully (MacKay & Gregory, 2011). It is crucial that pediatric oncology nurses can provide supportive care to the entire family instead of only focusing on the hospitalized child. As stated by Cantrell (2007), if family-centered caring presence is stripped from the practice of pediatric oncology, children and their families will surely suffer, and positive treatment outcomes will decline.

Nurses are able to support families by ensuring that information about their children’s conditions is available; helping families to organize their thoughts to achieve sense of control over their lives; encouraging parents to share their feelings; assisting families to identify family strengths and reorganize family life, and providing family-to-family support (Hopia *et al.*, 2004). Thus, the role of the pediatric oncology nurse is multifaceted. Nurses act as facilitators, teachers, supporters, advocators, managers, counselors and sources of knowledge (Graham, 2005; McCullough & Price, 2011).

1.1.4. Assessment of family impact and coping

To enable nurses to carry out their important roles, fundamental concerns can begin with family assessment (Yiu & Twinn, 2001). As indicated in previous studies (Kong, 2010; Smith & Liehr, 2008), whether a family can achieve bon-adaptation during a cancer child’s hospitalization depends on family perceptions of the stressors piling up and their coping strategies (Kong, 2010; Smith & Liehr, 2008). Given the crucial role of family impact and coping in the adaptation process, family assessment should be included as the most important component in a clinical setting. Family assessment should focus mainly on the following questions: What are the impacts of the child's hospitalization on family? How has the family been coping with the child's hospitalization? Nursing supportive interventions should be devised and developed on the basis of the answers to these questions.

As the starting point for the delivery of family care, assessment is based mostly on nurses' observations and interactions with a family (Hopia *et al.*, 2004). After a child is admitted to a hospital, clinical nurses often ask the parents to complete an admission information sheet, including the family background and child's condition. The admission information record is the first point in getting to know the family. It is only when the clinical nurses have interacted with a family for a while that in-depth information pertaining to the family situation is available.

However, in clinical practice, the heavy workload with too many demands involved in stabilizing cancer children's conditions can affect the quality of family assessment and the delivery of timely support. Nurses' skills for assessing family situations are inadequate, as reflected in a few studies which found that nurses and parents had different perceptions about stress. For example, one study found that nursing staff tended to overestimate the parental stress levels and to differ from parents in what they perceived as stressful (Akbarbegloo & Valizadeh, 2009). Nursing staff were found to believe that a child's behavior and appearance would be the most stressful factors for parents, while the parents themselves rated parental role alteration as the most stressful. Another study indicated that parents reported 'low-to-moderate stress' during a child's hospitalization, but staff rated related parental stress as 'moderate-to-high' (Pritchard & Montgomery-Honger, 2014). Both nurses and parents rated 'loss of parental role' as the most stressful experience. Yet, the nurses considered 'staff communication and behaviors', to be the second most stressful aspect while parents rated this as the least.

Therefore, nurses should not simply assume that they understand a family's situation. They may fail to anticipate and attend to a family's need for help. This idea was supported by Maxwell and colleagues (2007), who found a significant difference in nurses' and family members' perceptions of the family needs and the extent to which these needs were met. Moreover, parents were not always fully aware of the help to which they are entitled during their children's hospitalization (Shields & Kristensson-Hallström, 2003). These findings from previous studies revealed that nurses overlooked or did not recognize the negative impact or ineffective coping a family was experiencing. This inadequate assessment of the situation and non-systematic use of interventions can leave the families to struggle and try to cope on their own.

Nurses are responsible for the overall quality of family care delivered during a child's hospitalization (Shields & Kristensson-Hallström, 2003). Supporting the child and his/her family during such a challenging period is a way to promote family health and the achievement of bon-adaptation (Ogle, 2006). Giving constant attention and support to the entire family is an important component of clinical service. Detailed information about family impact and coping will assist clinical nurses to devise and develop supportive interventions tailored for a family's situation and needs.

1.2. Knowledge gap

A substantial body of research has been conducted in western countries to explore families' adaptation when they encountered adversities, like disability, autism, cancer or other chronic disease. Some studies have also been conducted in Asian nations to explore families' experiences of parenting children with cancer, for example in Taiwan (Yeh, 2002; Chao *et al.*, 2003), Hong Kong (Wong & Chan, 2006; Yin & Ywinn, 2004), Korea (Han *et al.*, 2009), and Mainland China (Qi *et al.*, 2008). However, most previous studies have considered the disease as the only stress. The purpose of previous studies was to explore how families integrated the stress into their normal daily lives in their home settings.

In Mainland China, there is a paucity of studies exploring how families adapt to a child's hospitalization for cancer treatment. Family impact and the coping of families with children hospitalized for cancer has been an area of limited research. Considering the differences in socio-cultural background and the medical and assistance systems between Mainland China and western countries, western studies may not be valid in Chinese society. Chinese people live in a multicultural context with multiple views, including Confucianism, Taoism and Familism. This can affect their perception of their stress, their coping strategies, their coping goals and the standards of successful coping, which are all different (Lazarus & Folkman, 1984; Kayser *et al.*, 2014; Strug *et al.*, 2005). For example, one Chinese study revealed that some parents accepted their children's illness as their fate (Wong & Chan, 2006). This was related to a Chinese fatalistic belief, which assumes that life situations are predetermined by external, invisible forces, such as fate or a former life. Because it is fate that cannot be changed, one has to endure it with courage. But in western culture, people may attempt to remove the stressor rather than accept it as a part of life (Long & Oudenhoven, 2012). This reflects the effect of culture on the choice of coping strategies. It is inadvisable to copy the results of western countries completely when exploring family's responses to stress in Mainland China. Studies reflecting the values of western countries will not necessarily describe the Chinese families' adaptation to a cancer child's hospitalization. It is necessary to structure the research basis to be suitable to the native culture and social background in accordance with the Chinese reality and situation.

In pediatric oncology care settings in Mainland China, nursing services have focused primarily on hospitalized children with cancer. Limited attention and care has been given to the whole family, whose needs and stress have been ignored or perceived inaccurately by healthcare providers. The incidence of childhood cancer in Mainland China appears to have been rising in recent years. The population of families with children hospitalized in pediatric oncology units is a considerable target group demanding special attention. Limited availability of information will affect the delivery and quality of care to families in clinical settings. Nurses need broader knowledge and in-depth information pertaining to family impact and coping to provide better family care services to promote bon-adaptation during a child's hospitalization for cancer treatment in Mainland China. During the process of family-centered intervention development, family impact and family coping are supposed to be taken into consideration. All efforts based on the comprehensive assessment can facilitate positive adaptation of families with children hospitalized for cancer treatment.

1.3. Study aims

Based on the background discussed above, the aim of this study was to understand family adaptation by investigating how families are affected by and cope with their children's hospitalization for cancer treatment.

1.4. Significance of study

This study sought to search and deepen understanding family adaptation by shedding light on family impact and family coping during a cancer child's hospitalization in Mainland China. It is expected that the findings will help healthcare providers to gain an in-depth understanding of the impact of a child's hospitalization for cancer treatment on a family and how a family copes. Nurses will gain insight into the family's role that family members are not separate entities from the hospitalized cancer child. The findings will be helpful in planning for the provision of necessary and appropriate family care in pediatric oncology settings. It is hoped that the hospitalized cancer children and their families will benefit ultimately.

The findings from this study are directly relevant to the Chinese context and, hopefully, can provide information to health care professionals and policymakers for necessary practice and care policy planning to support families having children hospitalized for cancer treatment.

This study has also validated the psychometric properties of the Hospitalization Impact and Coping Scale (HICS) for use in a cancer group. It has thus facilitated the instrument's application and the establishment of cutoff point as a screening tool for future research.

1.5. Operational definitions of terms

For the purpose of this study, the following operational definitions were used.

1) Childhood cancer

Childhood cancer is defined as any malignant neoplasm occurring in children under the age of 14 (inclusively) at the time of diagnosis (Bahadur & Hindmarsh, 2000).

2) Hospitalization impact

Impact is defined as the perceived effects on the family from the parents' perspective. Hospitalization impact refers to the perceived effects of a child's hospitalization on the family from the parents' perspective, measured at least 24 hours after admission to the pediatric unit (Kong, 2010). In the present study, this included the impact related to cancer, treatment and hospital stay. The Hospital Impact Subscale was used to assess family impact.

3) Family coping

In the resiliency model, coping refers to specific cognitive and behavioral efforts by which an individual and the family attempt to reduce or manage the demands on the family system (McCubbin & McCubbin, 1993). Family coping refers to the strategies and methods employed by a family member or the family as a whole to overcome the adverse hospitalization impact during a cancer child's hospital stay, and their effectiveness (Kong, 2010). The Hospitalization Coping Subscale was used to assess the effectiveness of family coping.

4) Family adaptation

Family adaptation refers to an outcome as a result of changes in the family system over time. It is a continuum from bon-adaptation (positive end) to mal-adaptation (negative end) (McCubbin *et al.,* 1983).

5) Family assessment

Family assessment is a process for gathering information pertaining to the whole family. It aims for a full understanding of the family. The aim of family assessment in the present study was to achieve a comprehensive understanding of families' perceived impact and coping during children's hospitalization for cancer treatment.

1.6. Organization of thesis

The chapters of the dissertation have been organized as follows:

Chapter 1 Introduction, the current chapter: Chapter 1 provides a review of the relevant literature in order to situate the research in its theoretical framework.

Chapter 2 Hospitalization of a child with cancer: family impact and family coping: This chapter reviews previous studies pertaining to the impact of hospitalization on family and family coping, and describes the gaps in earlier research.

Chapter 3 Theoretical framework and measurements of impact and coping: This chapter states the theoretical framework and measurements related to impact and coping.

Chapter 4 Methods: This chapter states the purpose, design, sampling, data collection, and data analysis procedures.

Chapter 5 Results of quantitative study: This chapter presents the findings from the quantitative survey.

Chapter 6 Results of qualitative study: This chapter presents the findings from the qualitative study.

Chapter 7 Discussion: This brings together the important findings that have emerged from two research phases and discusses their practical implications.

Chapter 8 Conclusion and recommendations: This provides research conclusions drawn from the quantitative and qualitative analyses of data obtained from different stages of the present study. In conclusion, directions are suggested for future research.

CHAPTER 2 LITERATURE REVIEW

Hospitalization of a child with cancer: the impact on family and family coping

This chapter presents the literature relevant to the current study. It first reviews general information related to childhood cancer. It then focuses on the literature regarding to family impact and coping. The chapter ends with a brief summary.

2.1. Search method

An electronic search was conducted in five databases, namely, Pubmed, Springerlink, Scopus, PsycINFO and CAJ (China Academic Journal) Full-text Database. Literature published between January 2004 and November 2014 in English or Chinese was searched. The keywords used in this search were: (‘cancer’ or ‘oncology’ or ‘carcinoma’) AND (‘hospitalization’ or ‘treatment’) AND (‘family’ or ‘parent’ or ‘sibling’ or ‘child’) in article abstracts. Articles discussing the impact, stressor or coping of families with children diagnosed with cancer at the age of 14 or younger were included. Review articles, anecdotal reports and commentaries were excluded. Reference lists of the identified articles were also checked for any potential relevant publications.

2.2. Prevalence and treatment of childhood cancer

More than 175,000 children aged 14 or younger are diagnosed with cancer around the world every year (Global Cancer Control, 2012). As reported by the National Cancer Institute (2008), the most common cancer in children is leukemia, which accounts for one-third of all types of childhood cancer. The second most common type is central nervous system tumors, which accounts for 25%. Lymphoma, accounting for 10% of new cases, is in the third place. The most common solid tumors are brain tumors (e.g. gliomas and medulloblastomas).

Rates of childhood cancer appear to have been rising over the past few decades. Fortunately, owing to the improved treatments, the death rate has decreased for most types of childhood cancer (Arceci, 2006). For instance, the five-year survival rate for acute lymphoblastic leukemia is approaching 80%~85%, while it is above 90% for Hodgkins' disease, 68% for neuroblastoma and 72% for bone cancer (Arceci, 2006). In Mainland China, the most common types of childhood cancer are leukemia, lymphoma, and central nervous system tumors. The 5-year observed survival for all childhood cancers combined is 55.7%. For leukemia, lymphoma, and central nervous system tumors, 5-year survival rates are 52.2%, 58.8%, and 41.2%, respectively. Higher 5-year survival rates have also been observed for epithelial cancer (88.9%), malignant renal tumors (86.7%), germ cell and other gonadal tumors (78.4%), and retinoblastoma (75.0%) (Gao, 2001). These great improvements can be attributed largely to modern advances in a combination of multimodal treatments including surgery, chemotherapy and radiotherapy (Goldman & Hewitt, 2006).

Unavoidably, improved prognoses and survival rates are often associated with repeated and prolonged hospitalization, which is often long and difficult. This creates an immensely stressful situation for the whole family and penetrates every detail of the entire family life. Family members consider their child’s repeated, prolonged and often difficult treatment and hospitalization as a traumatic experience (Long & Marsland, 2011). Therefore, as indicated by Schweitzer and associates (2012), researchers have shifted their foci away from describing how families get through children’s deaths to exploring how they attempt to handle cancer survivors’ long-term treatment and hospitalization.

2.3. Hospitalization of a child with cancer: the impact on family

The hospitalization of a child with cancer, associated with long-term consumption of medication and intensive medical treatments, increases family burden, threatens the balance of the whole family and ultimately affects family functioning. Family functioning is defined as the way in which the family members interact, react to, and treat each other (Winek, 2010). Family functioning has the ability to meet family members’ needs as a unit, like loving and supporting each other, communicating emotionally and sharing responsibilities (Alderfer *et al.*, 2009). It is central to the well-being of children receiving cancer treatment (Barakat *et al.,* 2010). It can facilitate positive outcomes for a sick child (Derstine, 2001). For instance, one study examined family relationships and quality of life (QOL) in children with cancer, and reported a consistent link between quality family relationships and a better QOL, especially within the psychological domain (Orbuch *et al.,* 2005). Similarly, another study identified that children with cancer reported better QOL when their parents remained goal-focused instead of protective in their parenting (Eiser *et al.,* 2004). This indicated that strengthened family functioning may lead to better QOL for children with cancer. A family has to change its usual ways of functioning when faced with a stressful event, a trauma, or an adversity (Olson & Gorall, 2003). Peterson and Green (2009) suggested flexibility in family roles play an extremely important part in healthy family functioning.

Quite a few studies have revealed that a child's hospitalization poses many challenges to the functioning of a family (Panganiban-Corales & Medina, 2011). A cross-sectional study revealed that, of the 90 Filipino family caregivers of children undergoing cancer treatment, nearly half (44.4%) reported their families as being moderately dysfunctional and 11.1% as severely dysfunctional (Panganiban-Corales & Medina, 2011). Families with children having completed treatment were found to function better than those with children undergoing treatment (Streisand *et al.,* 2003; Brown *et al*., 2003). Morris and colleagues (1997) reported that families with children with cancer rated themselves as less cohesive and more conflicted than those with healthy children. The results of a meta-analysis showed that mothers of children with cancer reported higher levels of family conflicts than mothers of healthy children (Pai *et al.*, 2007). Another study indicated that parents of children undergoing active cancer treatment experienced more difficulties in four areas of family functioning (affective responsiveness, affective involvement, behavior control and general functioning) than parents of children who had completed treatment (Streisand *et al.*, 2003). Some families continued to experience poor family functioning when their children's treatments ended and they returned home (Streisand *et al*., 2003).

Disruption of daily routines and family life was the theme reported the most frequently by parents with children diagnosed with cancer in previous studies (Bjork *et al*., 2009; Brody & Simmons, 2007; Harrington *et al*., 2009; Nicholas *et al*., 2009; Norberg & Steneby, 2009). Families with children undergoing active cancer treatment must alter their daily lives to accommodate for children's repeated and prolonged hospitalization, although they desire to maintain some level of normalcy. To satisfy the demands of integrating a child's frequent intensive treatment and hospitalization into their daily lives, families struggle with substantial difficulties, including maintaining household jobs, balancing time spent in childcare and employment, and maintaining normal social activities (McGrath *et al*., 2005; Norberg & Steneby, 2009; Ward-Smith *et al*., 2005; Woodgate & Degner, 2003). Other than everyday changes, parents also expressed that they were struggling with the stress of balancing the demands of the sick child and other family members (McGrath *et al*., 2005; Patterson *et al*., 2004; Woodgate & Degner, 2003). The amount of time spent together as a family declined sharply (James *et al*., 2002; Neil-Urban, 2002).

A large number of qualitative studies revealed that adapting the treatment demands of a child with cancer requires family members to reorganize roles and reallocate responsibilities (Jones & Neil-Urban, 2003; Kars *et al*., 2008; Neil-Urban, 2002; Nicholas *et al*., 2009; Wong & Chan, 2006; Yin & Twinn, 2004; Young *et al*., 2002a). The child who is undergoing active treatment becomes the focus of family attention, as indicated by parents and medical staff who work in oncology units (Harrington *et al*., 2009). Families expressed that priority should be given to their ill children both on and off cancer treatment (Norberg & Steneby, 2009). As treatment begins, the family functions as a supportive team, in which members attempt to maintain household equilibrium by undertaking complementary roles and sharing responsibilities (Neil-Urban, 2002; Nicholas *et al*., 2009). The term 'split family' has been used to describe family reorganization, as one or two family members take the responsibility to accompany the hospitalized child receiving cancer treatment in hospital, while others at home are in charge of the household, work, and sibling care (McCubbin *et al*., 2002; Nicholas *et al*., 2009; Woodgate, 2006a; Young *et al*., 2002a). Parents described how they worked together as couples to grapple with the heavy demands family faced during the period of a child's cancer treatment; this has been described as ‘tag team parenting’, with the potential to reduce spousal interaction (Mercer & Ritchie, 1997).

Although a family with a child undergoing cancer treatment experiences substantial strains and challenges, a small body of studies revealed a strengthened family closeness because of the miserable experience (Brody & Simmons, 2007; McGrath *et al*., 2005; Woodgate & Degner, 2003; Woodgate, 2006a). For instance, Brody and Simmons (2007) conducted a study to explore fathers’ perspectives on impact of a child’s diagnosis and treatment on the family. All of the fathers in the study expressed that their relationships with their wives and ill children were strengthened during the challenging period. Another study revealed an increased closeness between healthy siblings and the child with cancer (McGrath *et al*., 2005). However, Quin (2005) discovered that about one-quarter of parents considered the experience of having a child with cancer adversely affected their couple relationship, while a small minority found the strain on their marriage as intense, leading to breakdown or near breakdown. Arabiat and associates (2013) also found that marital conflicts and misunderstandings increased significantly in the process of a child receiving cancer treatment.

At the time of the diagnosis and following difficult inpatient treatment, families will join hands emotionally and practically to support one another and be mobilized for the considerable difficulties resulting from a cancer child’s hospitalization. Changes in family functioning will subsequently influence family’s adaptation to a child’s hospitalization and family members’ health and behaviors (Long & Marsland, 2011). It is necessary to promote a family to reestablish a new family pattern to decrease the negative effects on family functioning. More nursing interventions are necessary to help families with hospitalized children with cancer to maintain and restore healthy family functioning, and to facilitate their return to normal family life.

2.4. Family financial burdens

Given the long-term inpatient treatment of children with cancer, the economic effects can be a substantial strain for the majority of families (Health

&Lintuuran,2006; Harrington *et al*., 2009; McCaffrey, 2006; Mostert *et al.*, 2008; Nicholas *et al.,* 2009; Patterson *et al.,* 2004). A study in Greece indicated that over 50% of families with children undergoing active cancer treatment faced great financial strain (Patistea *et al.*, 2000). Another study conducted with 191 New Zealand families revealed that 37% of them were compelled to borrow money to cover the cost of treatment (Dockerty & Skegg, 2003).

Some studies revealed that families of children with cancer suffered greater financial hardship than those with healthy children (Heath & Lintuuran, 2006). A study of 56 Australian families found that 74% experienced a moderate or great degree of economic hardship in the first year of children's cancer treatment. The most frequently reported extra financial burdens were associated with vehicle and additional food expenses. The highest costs were associated with airfares and childcare or babysitting (Heath & Lintuuran, 2006). Treatment costs and extra expenses during a cancer child's prolonged and repeated hospitalization resulted in financial difficulties and debts, and forced parents to either postpone or withdraw from parts of the child's treatment (Mostert *et al.*, 2008).

Another crucial factor identified to aggravate financial strain is reduced family income resulting from disrupted employment (Mostert *et al.,* 2008). Given that most cancer treatments are delivered during working hours, there is a potential risk for increased loss of family income due to changes in parents' employment status, leading to a decline in family's economic capacity (Heath & Lintuuran, 2006). As an example, a study conducted with 151 families with children undergoing active cancer treatment revealed that 46% of parents resigned from their jobs or dropped to part-time work to care for their ill children (James, 2002). Family income usually decreases since the start of treatment (Health *et al*., 2006). In a study conducted in the United Kingdom, the sum of income lost and out-of-pocket expenses exceeded 50% of the total family income in more than 45% of families during the first week of treatment (Bodkin *et al.*, 1982). Increased loss of income aggravates family financial strain. Other factors identified as contributing to high family financial burden are single parenthood, lower income, and the distance involved in travelling to hospital (Heath & Lintuuran, 2006).

The economic costs of a cancer child’s treatment can be a huge challenge. In Mainland China, very limited research exists to identify the effects of both medical and non-medical costs on families’ financial burden when one member is receiving cancer treatment. In conducting this study, it is necessary and important to include the medical and non-medical costs, since literature has shown that both of them are considerably great for cancer treatment (Bodkin *et al.*, 1982; Longo *et al.*, 2006).

2.5. Impact of a cancer child’s hospitalization on family members

A cancer child’s hospitalization is considered as a disastrous event, and the interactions among family system, environment, and medical professionals affect individual’s adjustment and adaptation constantly (Berrios-Rivera *et al.*, 2008; Kantarciolu *et al.*, 2012; Nedović *et al.*, 2013).Family members experience a great number of impact during a child’s hospitalization for cancer treatment (Berrios-Rivera *et al.*, 2008). Therefore, a child’s hospitalization not only has an impact on the child with cancer himself or herself, but also on family members and, in some cases, may cause family members to suffer as much as the sick child, or even more.

2.5.1. Impact of hospitalization on the sick child

Repeated and prolonged hospitalization has a potential risk to affect the sick child’s emotional functioning, social functioning, and health condition. The following sections outline the possible impact of hospitalization on the children with cancer.

1) Emotional functioning

Admittance to a hospital can be a devastating blow to a cancer child himself or herself. A substantial body of studies demonstrated that hospitalization is often accompanied by emotional adjustment problems in children with cancer (Kantarciolu *et al.*, 2012; McGrath*et al.*, 2004; Nedović *et al.*, 2013). A quantitative study reported that children receiving cancer treatment in hospital demonstrated poorer emotional functioning when compared to healthy children. Significant differences were detected in 2 items (‘I feel angry’ and ‘I worry about what will happen to me’) of the emotional functioning scale (Nedović *et al.,* 2013). Another study revealed that emotional problems in hospitalized children had increased after 6 months of treatment (Kantarciolu *et al.*, 2012).

A majority of qualitative studies using self-report data from children and/or from parents and/or health professionals disclosed the negative emotions that children with cancer may experience during a hospital stay (Berrios-Rivera *et al.,* 2008; Han *et al.,* 2011; McCaffrey, 2006; Moody *et al.,* 2006). Almost all children have been found to have negative emotions and feelings including anger, insecurity, fear, worry, anxiety, depression, uncertainty and helplessness. These negative emotions may result in their worsening conditions and inappropriate behaviors (Sadruddin, 2013). In particular, within the first three months of hospitalization, the children said that ‘the hospital is a shock’ (Han *et al.,* 2011). This feeling was also described clearly in another longitudinal qualitative study in which children reported a range of negative emotions at the beginning of treatment, such as anger, anxiety and depression (McGrath *et al.,* 2004). After three months of hospitalization (the intermediate and later days), some children complained more often as they were compelled to accept the reality that they would stay in the hospital for long-term treatment. When compared with the early stage of hospitalization (3 months or less), although their moods improved, emotional instability was still evident (Han *et al.,* 2011). Some children also expressed feelings of guilt, because they considered themselves to be responsible for the changes taking place within their families, including migrating to unfamiliar cities, separation from significant family members and friends, interruption of healthy siblings’ school attendance and aggravating family financial burden. Some children desired to cease their long-term hospitalized treatment to stop disrupting their family lives (Vindrola-Padros, 2012).

Children reported that being away from their former lives due to inpatient treatment made them feel unlucky and unhappy (Berrios-Rivera *et al.,* 2008). They became annoyed, impatient, and irritable because of the tedium of hospital life and the loss of contact with their peers (Berrios-Rivera *et al.,* 2008; McCaffrey, 2006). Many children with cancer complained that they were fed up with the long-term treatment and of going in and out of hospital, which they described as tiresome (Nedović *et al.*, 2013). One study found that children aged from nine to twelve years became particularly stubborn and argued with their families. Some children even encountered emotional shock, which was demonstrated by numbness, dullness, reticence, and lack of activity (Berrios-Rivera *et al.*, 2008).

2) Social impairment

Hospitalized children with cancer also experience social impairment (Melnyk, 2000). A body of quantitative studies has shown that children with cancer are at great risk of social isolation, possibly related to their physical appearances or functioning, negative moods and disruption of academic and social participation because of long-term hospital stay (Freeman *et al.*, 2003; Kantarciolu *et al.*, 2012; Nedović *et al.*, 2013). One study reported that more than one-third of cancer-affected children reported problems concerning socialization (Freeman *et al.*, 2003). Hospitalized children with cancer experienced a decreased social functioning when compared to healthy children (Nedović *et al.*, 2013). Kantarciolu and colleagues (2012) found increased social/emotional problems, decreased competence, and regressed social development in children after six months' treatment for acute lymphoblastic leukemia. School-aged hospitalized children reported having no one to help them keep up with schoolwork and having difficulties in socializing with friends (Kantarciolu *et al.*, 2012).

Qualitative studies have shown that most children battling with cancer are socially isolated in hospital during treatment. They considered themselves as isolated in the hospital and cut off from the rest of the world (McCaffrey, 2006; Sadruddin, 2013). In one qualitative study, most children's drawings reflected their isolation and emotional detachment from their family members (Sadruddin, 2013). Separation from significant others, such as peers or relatives, caused by hospitalization, is distressing and may influence the development and maintenance of secure attachment.

Appearance change is another factor contributing to social impairment. Children are sensitive to changes in their appearances resulting from disease and treatment, such as hair loss or weight change. They view image changes as emotional trauma, which often results in the destruction of self-image and self-esteem (Berrios-Rivera *et al.,* 2008; Sadruddin, 2013). Consequently, they worry about being rejected by peers due to appearance changes and experience difficulties in transition back to school (Berrios-Rivera *et al*., 2008). Additionally, isolation due to susceptibility to infection seems to have crucial side effects on their social participation. This further worsens the social impairment of sick children; for example, some children become dependent on their parents more than they were prior to hospitalization (Sadruddin, 2013).

3) Physical symptoms

Many hospitalized cancer children have reported somatic symptoms related to disease and treatment, including nausea, loss of appetite, severe fatigue, mouth sores, rashes, infections, sleeping difficulties, weight loss, poor nutrition, decreased appetite and pain (Berrios-Rivera *et al.,* 2008; McCaffrey, 2006; McGrath *et al.,*2004; Miller *et al.,* 2011; Moody *et al.,* 2006; Sadruddin, 2013; Nedović *et al.,* 2013). Side effects of treatment and possible complications make children feel stressed and emerge weaker than they were prior to hospitalization.

Some quantitative studies have found that children hospitalized for cancer treatment demonstrate poorer physical functioning. A significant decrease in all items of the physical health scale has been detected when compared to healthy children (Nedovic *et al.,* 2013). Nausea, pain, and fatigue are the most prevalent symptoms (prevalence greater than 34%) (Miller *et al*., 2011). Fatigue often accompanies sleep disorders (McGrath *et al*., 2004). A longitudinal quantitative descriptive study found that hospitalized children with cancer demonstrated more fatigue and tended to experience more nocturnal awakenings. Factors identified as contributing to sleep disturbance include noise, lights, lack of control, separation from parents, unfamiliar environment, loss of normal routine, anxiety and pain (Hinds *et al*., 2007).

Some qualitative studies have revealed children reporting poor nutrition, caused by their poor appetites, changes in taste and smell sensations, effects of therapy and restrictions in hospital food choices (Moody *et al*., 2006). These studies also revealed that children cited physical problems, such as weight and hair loss, vomiting, stomachache, body swelling, fever, and headache, as traumatic events (Berrios-Rivera *et al*., 2008). In addition, children in all age groups complained about the physical discomfort of needle jabs. Infusion system made the children feel they were stuck because their playing and activities were restricted (Nedović *et al.*, 2013).Children expressed that they did not want to be hampered by needles or infusion system (Moody *et al*., 2006).

2.5.2. Impact of a cancer child’s hospitalization on parents

Having a child hospitalized for cancer treatment is one of the worst situations parents have to face (Berrios-Rivera *et al.,* 2008; Hallström *et al.,* 2002b). They worry that their child will suffer a lot and that their family life will be disrupted completely (Berrios-Rivera *et al.,* 2008). They carry the fear that they may lose the child, and take the responsibility to contact doctors and cope with household demands, as well as bear financial burden during their child’s hospitalization for cancer treatment (Hallström *et al.,* 2002b; Wray *et al.,* 2011). They also have to cope with various stressors from society, family, career and self-development, and troubles about the child’s education and future development after healing (Mostert *et al.,* 2008; Freeman *et al*., 2003; Nedović *et al*., 2013).

1) Emotional burden

Most studies have found that parents of children hospitalized for cancer treatment perceive a series of negative emotional responses, including obsessive symptoms, depression, anxiety, a sense of frustration, guilt, fear, hostility, bigotry, vigilance and sensitivity to interpersonal relationships (Cai *et al*., 2007; Jackson *et al*., 2007; McCaffrey, 2006; McGrath *et al.,* 2004; Mostert *et al.,* 2008; Shields & Kristensson-Hallström, 2003; Wray *et al.,* 2011), or can even experience severe mental disorders like depressive neurosis (Lin *et al.*, 2002). Some parents expressed that they were on the brink of emotional collapse (McCaffrey, 2006).

A quantitative study conducted with Chinese parents found that the anxiety inventory scores for parents with hospitalized cancer children were significantly higher than that of parents with non-cancer children (Qi, 2008). Parents not only experience the above-mentioned motional symptoms, but also experience self-abasement resulting from social discrimination and isolation from other families because of misunderstandings on their misfortune (Qi, 2008). It is likely that some parents may still experience psychological distress for a long time after their children's healing. Parents demonstrate compulsive thinking, being too alert, and adaptation disorders when they are reminded of their children's treatment experiences (Kazak & Barakat, 1997). One longitudinal study revealed that anxiety, depression and stress in parents increased sharply after a child's hospitalization and continued at a high level even after the child's discharge (Wray *et al*., 2011). It was found that moderate-to-severe psychological symptoms in parents did not improve six months after their children's diagnoses and these symptoms remained high eighteen months after diagnosis (Manne *et al.*, 2001; Sloper, 2000).

Qualitative studies have revealed that unfamiliar and disorganized hospital surroundings often trigger a deep sense of fear and frustration for parents, who may feel insecure (Hallström *et al*., 2002b; Jackson *et al*., 2007). Moreover, clinical professionals are often regarded as complete strangers, who speak medical jargon beyond the parents' comprehension. Hospital staff are in their occupational roles and usually wearing uniforms, which puts them in a more dominant position, while parents feel helpless and unsafe (Callery & Smith, 1991). In particular, a majority of parents explained that their stress appeared to be heightened by lack of familiarity with hospital environment when they were confronted with the overwhelming and confronting situations at the time of their children's first hospitalization (Jackson *et al*., 2007). Other factors contributing to the emotional discomfort are overcrowded rooms, noise, lack of privacy, frightening experiences, uncomfortable beds and inadequate facilities for parents who stay overnight at the hospital (Jackson *et al*., 2007).

Other emotional responses, anger, helplessness and feeling unsafe, have also been expressed by parents when they are talking about medical staff. Parents expressed their concerns about poor communication with medical professionals in the early stage of a child's hospitalization. These problems include confusion, ambiguous answers given by staff, forgetfulness of staff, and poor communication among hospital units (Mostert *et al.,* 2008). Parents reported, in one qualitative study, that they hesitated or did not dare to ask medical staff questions or follow up questions when they felt the medical professionals were working under substantial stress (Nedović *et al.*, 2013). Studies have revealed that improved communication between parents and medical staff has the potential to alleviate the former's negative emotional responses (Turner *et al*., 2014; Wigert *et al*., 2013; Wigert *et al*., 2014).

Moreover, uncertainty about the outcomes of treatment and separation from family members can result in intensive stress-response emotions in parents (McGrath *et al*., 2004; Vindrola-Padros, 2012). Parents experience more anxiety when their children are receiving new medicines or displaying previous symptoms again. When their children feel comfortable, parents' anxiety can be eased (Nedović *et al.,* 2013). Parents not only worry about the hospitalized child, but also that serious problems might occur for healthy siblings who are not given adequate attention due to long periods of separation (Nedović *et al.*, 2013). Another major source of parents' negative emotional responses is separation from their sick children soon after admission. Parents are usually asked to wait in a crowded waiting room endlessly for someone to give them information; there, they deal with emotions such as fear, anger and guilt (Battrick & Glasper, 2004; Dudek-Shriber, 2004; Shields & Kristensson-Hallström, 2003).

2) Social functioning

Several studies have reported parents accepting that their main responsibility was to accompany their children receiving cancer treatment, at the cost of abandoning their social activities (Berrios-Rivera *et al*., 2008; McGrath *et al*., 2004). They abandoned their former daily activities and even gave up their own self-development in order to dedicate themselves completely to childcare (Berrios-Rivera *et al*., 2008). A study of parents with children undergoing treatment revealed that 29% of fathers and 8% of mothers lost their jobs, and 87% of fathers and 100% of mothers stated that this loss of employment was due to their children’s treatment (Mostert *et al.*, 2008). Parents are not able to attend social events because of time constraints (Freeman *et al*., 2003; Nedović *et al*., 2013). They felt that they were in constant demand, and everyday life required lots of planning, which made them tired. As a result, parents may lose interest in participating in social activities or employment because their energy is over-consumed on their hospitalized children. Moreover, one parent explained that sick children were supposed to be given first priority, and constantly kept in mind (Nedović *et al.*, 2013). Thus, hospitalized children become the sole center of family lives, and parents spend most of time and energy in taking care of their sick children. Parents have little time for themselves, together or alone, to attend social events, hence they eventually lose their support networks and feel isolated or lonely (Coyne, 2003; Khamis, 2007).

3) Physical symptoms

Most parents experience decreased physical well-being during their children’s hospitalization for cancer treatment. Patents underwent a variety of symptoms, including sleep-disorder, pain, fatigue and a low level of vigor (Chen & Wang, 2008). Parents, as the primary caregivers, bear the responsibilities to provide food to their children, follow complicated protocols, search for information, communicate with hospital staff and monitor children’s conditions. Parents also worry about prognoses of hospitalized children and deal with the boredom of hospital life. Being overwhelmed by the exhaustion of attending to above mentioned numerous demands has been reported by parents who staying at hospital (Chen & Wang, 2008).

Exhaustion from too many demands, combined with other negative emotions, can leave parents fatigued and sleepless. Fatigue can often be accompanied by loss of appetite, weight loss and sleep difficulties (Chen & Wang, 2008). A study of Chinese-American parents with infants hospitalized in an intensive care unit (ICU) found that parents’ fatigue and sleep disturbance were related closely to parental stress (Lee *et al.*, 2007). In this study, 93% of mothers and 60% of fathers experienced sleeping problems after their children had been admitted to ICU. Mothers experienced much more wakeful time during the night than did fathers (Lee *et al.,* 2007). Another study exploring responses of Chinese families with children hospitalized in general pediatric departments revealed that half of the mothers experienced fatigue, loss of appetite, weight loss and sleep difficulties (Martinson *et al.,* 1995).

2.5.3. Impact of a cancer child's hospitalization on healthy siblings

Significant reorganization of family routine and daily life is required after a child's hospitalization (Newton & Wolgemuth, 2010). This reorganization gives rise to a great number of effects on healthy siblings, including hyper-responsiveness to disrupted family routine, separation anxiety towards parents, feelings of confusion (Craft & Wyatt, 1985), poor academic performance, mood disturbance, and difficulties in social relationships (Woodgate, 2006b).

1) Emotional and physical adjustment

Woodgate (2006b) found that healthy siblings undergo various levels of disruptions, physically and emotionally, during a cancer child's hospitalization for treatment. The emotional problems appear to be the most prominent, as reported in several studies (Packman *et al*., 1997; Sharpe & Rossiter, 2002; Wilkins, 2003). Healthy siblings experience anxiety, withdrawal, jealousy, worry, fear, abandonment, sadness, guilt, anger and loneliness (Freeman *et al*., 2003; McCaffrey, 2006; McGrath *et al.,* 2004; Smardakiewicz & Krukowska, 2004; Vindrola-Padros, 2012; Woodgate, 2006b; Wray *et al.,* 2011). Of these emotional reactions, abandonment and jealousy are the most common. Healthy siblings have complained that they are being ignored and abandoned by parents who devote themselves to the cancer child completely and are absent from home for prolonged periods (Freeman *et al*., 2003; McCaffrey, 2006; McGrath *et al*., 2004; Vindrola-Padros, 2012; Woodgate, 2006b; Wray *et al*., 2011).

Healthy siblings particularly experience adverse emotions due to lack of information concerning disease, worry that their ill siblings might die, difficulties in communication with parents, separation from significant family members and missing the lives they used to have (Freeman *et al*., 2003; Woodgate, 2006b). Inevitably, the above-mentioned emotions will affect their physical functioning adversely. Problems with eating, sleeping, and health are regarded as common complaints of children with siblings suffering from cancer (Freeman *et al.*, 2003).

2) Social and educational development

Qualitative studies have reported that some changes in social functioning took place in healthy siblings during the sick child's hospitalization for cancer treatment. An illustration is the change of family role. Older siblings may be forced to take on adult responsibilities because of their parents' long-term absence from home (Freeman *et al*., 2003; Woodgate, 2006b). Another illustration is behavioral challenges, which are triggered by the negative emotions (Patterson *et al.*, 2004); some healthy siblings lose their tempers easily and show aggressive behaviors. These behaviors can affect their interpersonal communications negatively. Impaired interpersonal communication ability may lead to avoidance of spending time with friends, which may exacerbate feelings of isolation and loneliness in healthy siblings and have adverse effects on their social development (McCaffrey, 2006; Patterson *et al*., 2004). Nevertheless, healthy siblings have been found to experience some positive outcomes, as their miserable experiences may facilitate their psychosocial growth, including increased personal maturation, positive self-perceptions, enhanced social competence, capacity for pro-social behavior, more compassion and caring (Woodgate, 2006b).

The hospitalization of children with cancer can have adverse effects on their healthy siblings' educational success (Vindrola-Padros, 2012). A brother or sister's hospitalization has the potential to distract healthy siblings' concentration and disrupt their sleeping, which can make them unwell (Freeman *et al*., 2003). Moreover, they may have withdraw from school/ kindergarten/day care as a result of moving to another city for the sick child's treatment (Freeman *et al*., 2003;

Lähteenmäki & Sjoblom, 2004; Nedović *et al.*, 2013).

2.6. Pediatric oncology nurses' responsibilities to care for families

A pediatric oncology nurse, as a key member of the multidisciplinary team, undertakes the responsibility to care for the child with cancer and his or her family. Established close, long-standing, therapeutic relationships between clinical nurses and families after children's hospitalization allow nurses to assist families to get through the challenging periods by providing ongoing care and support (Svavarsdottir, 2005; Nuutila & Salantera, 2006). Brody and Simmons (2007) indicated that pediatric oncology nurses are in the best position to support families by using a variety of strategies. These strategies include ensuring that families are being heard, showing empathy, ensuring the availability of psychological assistance, and offering adequate and understandable information related to the child's condition at the moment of admission, as well as giving parents opportunities to speak out their inner feelings. Nurses can also provide families with coping assistance by helping them to identify strengths within the family and to reorganize family life in new ways.

It has been suggested that the fundamental ability of a pediatric oncology nurse is to provide, guide and evaluate nursing practice delivered to individuals diagnosed with cancer and their families (Kaitlyn Antle, 2009). The prime responsibilities of pediatric oncology nurses include administering chemotherapy under physicians' supervision, monitoring pediatric patients, developing care plans for pediatric cancer patients, explaining treatment plans to pediatric cancer patients' families, and assessing the physical and psychological needs of both patients and their families (Kaitlyn Antle, 2009).

The Association of Pediatric Oncology Nurses has developed a scope of practice specifically for nurses. Two aspects of the scope mention that pediatric oncology nurses should care for children with cancer and their families, as well as that their practice should encompass all phases of children and their families' experiences. Nurses should intervene with the family throughout every stage of a child's illness, since nursing interventions are nursing treatments that assist families and their members to promote, attain, or maintain optimal health and functioning (Craft & Willadsen, 1992).

2.7. Family coping during a child's hospitalization for cancer treatment

2.7.1. Definition and categories

Coping is an individual's dynamic cognitive and behavioral endeavor to handle the internal or external demands which are appraised beyond his/her capability (Lazarus & Folkman, 1984). Coping strategy refers to the methods by which individuals are able to meet demands and manage emotional distress (Liang, 2006). Coping aims at eliminating stressors and focuses on the reduction of stress responses. Any particular coping strategy is not 'good' or 'bad' in general; it may be beneficial on one occasion, but ineffective or even harmful in another context (Lazarus, 1999). 'Family coping strategy' is defined as 'a specific effort or an attitude by which an individual family member or the family as a whole attempts to reduce or manage a demand on the family system and bring resources to manage the situation' (McCubbin *et al.*, 2001).

Previous studies have usually classified 'coping' as problem-focused and emotion-focused (Folkman, 2010; Lazarus, 1984). Problem-focused coping involves doing something to tackle the problem causing distress by adopting strategies including information gathering and decision-making. Emotion-focused coping helps to regulate overwhelming emotions by using strategies such as distancing, seeking emotional support, and escaping avoidance (Folkman, 2010). Problem-solving efforts are commonly considered particularly useful for handling controllable stressors, while emotion-focused strategies are expected to be more adaptive for handling uncontrollable stressors (Taylor, 1991).

Another unique and useful way to handle a stressful situation is 'meaning-focused' coping, in which cognitive strategies are employed to manage the meaning of a transaction. Meaning-focused coping strategies emphasize that the positive emotions occur alongside negative ones throughout the intensely stressful periods (Park & Folkman, 1997). Meaning-focused coping regulates positive emotions and draws on deeply held values and beliefs in the form of strategies such as goal revision, focusing on strengths gained from life experience, searching for meaning in adversity, making causal attributions and reordering priorities (Folkman, 2010; Folkman & Moskowitz, 2004).

Kong identified four patterns of coping strategies: effort to maintain positive and active parental care, attempts to readjust mental stability, utilizing internal and external resources, and maximizing of the quality and quantity of childcare (Kong, 2010). These four coping strategies illustrated how a family copes with a child's hospitalization.

2.7.2. Significance of family coping

Although families whose children are hospitalized with cancer are facing great challenges, many families are capable of adapting to the presence and care of a chronically ill child and demonstrate healthy adaptation when facing increased demands and strains (Patterson & Garwick, 1994). McCubbin (1996) indicated that how a family copes influences how well it adapts. Family coping has the function of actively changing the situation and handling the subjective stress-related emotions (Jones, 2004; Perry *et al*., 2005). A good balance between inherent stressors and coping strategies can promote positive family adaptation, which allows a family to achieve and maintain its optimal level of functioning (Manning *et al.*, 2011).

Studies have addressed the important role of coping as a vital interrelated link between life stress and family adaptation (Lin *et al.,* 2011; McCubbin & McCubbin, 1993). Manning and associates understood coping as a mechanism that facilitates the rebalance of family functioning (Manning *et al*., 2011). McCubbin and Patterson (1983) described it as a bridging concept that has both cognitive and behavioral components, in which family resources, perceptions, and behavioral responses work together to contribute to a rebalanced family functioning. A study conducted among families with children with autism found that family coping could affect both family functioning and parental distress significantly (Manning *et al.,* 2011). Similar findings were discovered in another study, in which a significant negative association between coping and the level of strain on the family system was detected (Sivberg, 2002). Coping is most effective when the characteristics of the stressor match with the type of coping strategy employed to the circumstance (Lazarus, 1984; Manning *et al.,* 2011). Effective coping strategy has the potential to minimize stress and enhance family adjustment (Pakenham *et al.,* 2005; Wartella *et al.,* 2009), which can help families to survive the challenging experience of their cancer child's hospitalization. Otherwise, ineffective coping strategies are often associated with increased distress because they do not include active attempts to deal with the problem (Sloper, 2000).

Families who adjust well seem to adopt multiple active coping strategies including family integration, family cooperation, optimism, seeking social support, maintaining self-esteem and psychological stability (Tak & McCubbin, 2002). Decreased anxiety and depression in parents of children with cancer has been associated with more frequent use of active problem-focused strategies and less frequent use of escape behaviors and negative response patterns. Families can acquire new skills or alternative methods to solve problems through positive coping styles, which also counteract the perceived greater feelings of helplessness and distress (Sahler *et al*., 2005).

Families who do not cope well, otherwise, have been noted to have adopted passive coping strategies, such as negative appraisal, escape or avoidance (Hastings *et al*., 2005). In the short run, a passive coping strategy can serve as a stress reduction mechanism, yet it is bound to be detrimental or may eventually lead to family mal-adaption through distancing the problem instead of tackling the stressful event directly. A great number of studies have revealed parents' perceptions of distress; mental and physical health can be affected adversely by the long-term application of escape-coping strategies (Hastings *et al*., 2005; Pakenham, 1999). Emotional-focused coping strategies are often closely related to high parental anxiety and depression throughout a child's treatment trajectory (Phipps & Dunavant, 2005; Sloper, 2000). Parents who do not cope well appear to have low self-esteem and marital unhappiness, high anxiety, isolation and depression (Dunn & Burbine, 2001; Forde *et al.,* 2004; Oelofsen & Richardson, 2006). A significant association between passive coping strategies and emotional distress has been detected in another study (Norberg *et al.,* 2005). There is a need to strengthen the coping capacity of families who frequently use passive coping strategies once a child hospitalized for cancer treatment.

2.7.3. Coping and adjustment

Coping is regarded as a process that varies with the situation and evolves over time (Kupst *et al.,* 1995, Moos & Holahan, 2003; Vrijmoet-Wiersma *et al*., 2008). As indicated by Lazarus (1999), family coping strategies may change according to the diversity of contexts, for example, some strategies may be functional for handling everyday hassles, while quite different strategies may be suitable for tackling seriously threatening situations. In the context of coping with a cancer child's hospitalization, what a family first needs to cope with is the trauma of diagnosis and an unfamiliar hospital environment. Avoidance seems to be functional in the early phase of childhood cancer when parents are overwhelmed with stressors. Then they cope with the subsequent demands of treatment, such as repeated and prolonged hospitalization, reduction of working time, frequent traveling, distressing side effects, and their children's physical and mental responses to treatment, as well as the family's ability to make changes associated with the long-term adjustments (Kazak *et al*., 2003; Maurice-Stam *et al*., 2008).

A family usually utilizes multiple strategies to handle a stressful situation. A large body of work has suggested that a family with a sick child tends to employ multiple strategies to handle the piling up demands successfully (Kandel & Merrick, 2007; Raina *et al.,* 2005). Walsh (2003) indicated that the most successful adaptation can probably not be achieved with a single coping strategy or with invariable responses, and a variety of strategies appears to be helpful in handling new challenges that unfold over time. A family experiences a series of adaptive paths over time, from the crisis, through the disruptive transition, and subsequent shock waves in the immediate aftermath and beyond. A family's rigidity in dealing with the changing demands of the illness may lead to dysfunctional coping strategies that can eventually put the family in a crisis (Walsh, 2003).

Given the important role of family coping in contributing to positive family adaptation, it is strongly suggested that the former should be included in family assessment in clinical settings. Assessment of family coping is essential for a good nursing service (Hashemi *et al.,* 2007).

2.8. Culture in Mainland China

Under different cultural circumstances, individual perceptions of stress, coping strategy, adjustment processes, the goal of coping and the standard of successful coping are different (Kayser *et al.*, 2014; Lazarus & Folkman, 1984; Strug *et al.*, 2005). Chinese people live in a multicultural context with multiple views, including Confucianism (emphasizes the personal growth that occurs after coping with pressure, and the harmony) (Shi, 2013), Taoism (emphasizes wu-wei, which means nonintervention or doing nothing but following whatever is given in life, Balance of Yin and Yang) (Cheng *et al.,* 2010), Familism (emphasizes the importance of family bonds) (Yang, 2004), fatalistic view (emphasizes life situations are predetermined by external, invisible forces, such as fate or a former life) (Lee, 1995), and face culture (feelings of gaining or losing face because of positive or negative social evaluation) (Yang, 2004). Even in modern society, Chinese culture still affects the perceptions and behaviors of Chinese people (Shi, 2013).

2.9. Summary

Due to the advanced development of medical technology, a diagnosis of childhood cancer no longer implies a certain death sentence. However, repeated and prolonged hospitalization and follow-up may develop a catastrophic crisis and threaten the stability and adaptive functioning of the whole family (MacKay & Gregory, 2011). Studies have shifted in foci from describing families' experiences of losing a child with cancer to understanding how they manage the long-term effects or consequences (Woodgate & Degner, 2003).

As discussed in the literature review, in recent decades a substantial body of studies has emphasized the emotional and behavioral impact of disease on sick children, their parents (Cordaro & Veneroni, 2012) and their healthy siblings (Buchbinder *et al.*, 2011; Sharpe & Rossiter, 2002). However, most of these studies have focused on how families live with chronic disease in home settings, and few have covered family adaptation to hospitalization and its effects on families. Studies relating to childhood cancer have only focused on the effects of disease. A special characteristic of childhood cancer treatment is the repeated and prolonged hospitalization. Children with cancer will experience about one or two months of initial treatment. Even if they have smooth and satisfactory progress, they still need to stay in hospital for short courses of chemotherapy and/or radiation therapy, and for treating side effects and complications. Family members have to spend a lot of time at the hospital. Nurses must not only focus on stabilizing a cancer child's condition, but also must pay special attention to the whole family.

In Mainland China, few studies have focused on the psychological distress of children and their parents after diagnosis with cancer (Lin *et al.,*2004; Zhao & Wang, 2006). There is a lack of research investigating how a family responds to a child's repeated and prolonged hospitalization for cancer treatment. The lack of studies for this population shows the dearth of information regarding this problem in Mainland China. It indicates that clinicians, researchers, and the Chinese government seem to have ignored this special population.

The population of families with children hospitalized in pediatric oncology units is a considerable target group demanding special attention. Of the new cases of childhood cancer around the world, one fifth occurred in Mainland China and with an upward trend of increasing incidence (Juan, 2011). Limited availability of information related to families with children hospitalized for cancer treatment may affect the assessment of healthcare demands of this population, as well as the delivery of timely and effective family care. Nurses need a broader knowledge and in-depth understanding about families to provide better service to them during their children’s hospitalization for cancer treatment.

Chinese culture and policy could have an effect on a family’s response to stress. This prompted the author to explore family impact and coping during a cancer child’s hospitalization, based on the Chinese native culture and policy. Considering the differences in ethnic and socio-cultural backgrounds, medical systems and assistance systems between eastern and western countries, western studies may not be valid in Chinese society. Researchers cannot copy the results of western countries entirely when exploring people’s responses to stress in Mainland China. Studies reflecting the values of western countries cannot fully describe Chinese families’ adjustment to stress. It was necessary, therefore, that the research was suitable to the reality of the Chinese culture and social background.

This study aimed to understand family adaptation by investigating family impact and coping during a cancer child’s hospitalization in Mainland China. The knowledge gained from this study will assist pediatric oncology nurses to develop effective nursing interventions to help families go through their crises.

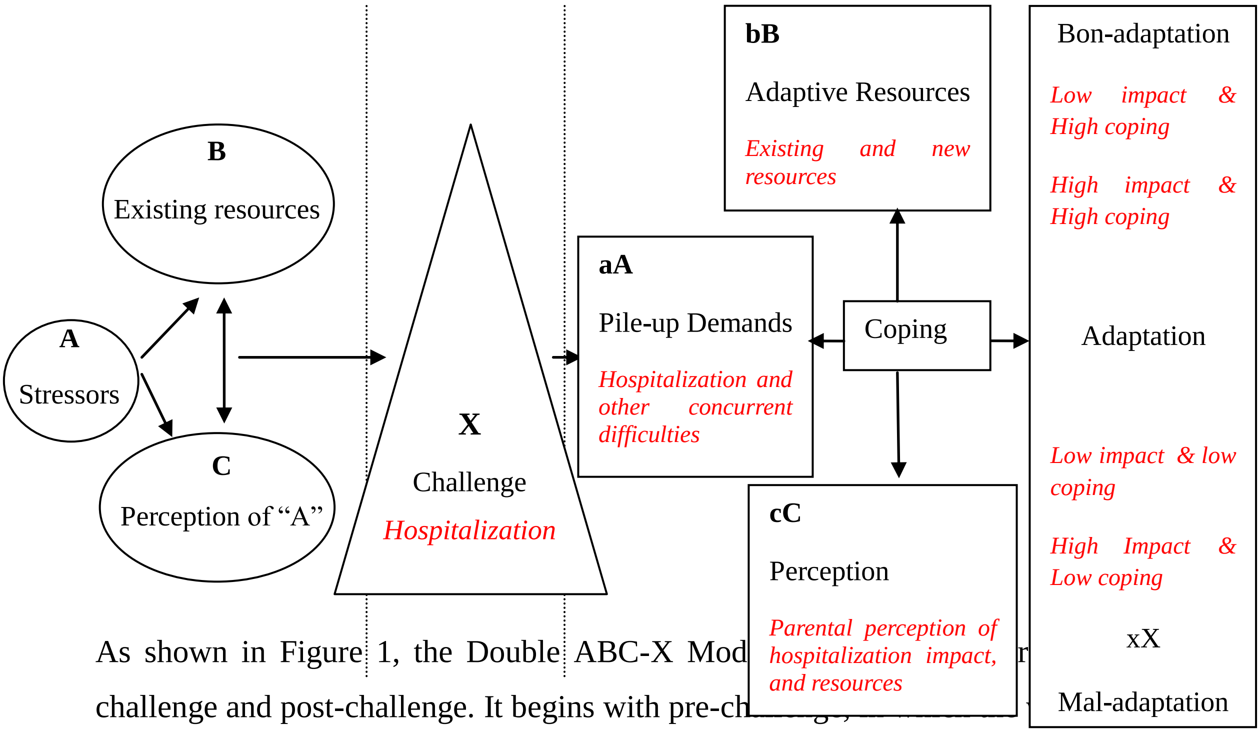
CHAPTER 3 THEORETICAL FRAMEWORK AND MEASUREMENTS OF IMPACTAND COPING

This chapter firstly introduces the theoretical framework used in the current study. It then focuses on the measurements related to coping and impact.

3.1. Double ABC-X Model

The Double ABC-X Model was developed by McCubbin and colleagues (1983) on the basis of Hill's (1958) ABC-X Formula. This model is an important research foundation for exploring family adaptation. It can be used to explore how a family responds to a stressful event. Previous studies of families with children with special needs have employed it as a theoretical guide, including Drummond (2002) and Bristol (1987). The Double ABC-X model has been shown to be helpful in exploring family adaptation to a stressful event. Kong (2010) modified this model by using 'challenge' to replace 'crisis' and to apply the model in the context of family impact and coping during the hospitalization of a sick child.

Figure 1 Double ABC-X Model (Kong, 2010; McCubbin & Patternson, 1983)



As shown in Figure 1, the Double ABC-X Mod r

challenge and post-challenge. It begins with pre-ch

B, C) are the same as those included in the ABC-X formula up to the crisis. Variables included in the Double ABC-X Model in the post-challenge are pileup stressors or demands (aA), existing and new resources (bB), perceptions of the initial stressor, pile up demands, and existing and new resources (cC), coping and family adaption.

The Double A factor is defined as family pile-up stressors, resulting from an accumulation of the unresolved initial stressor, the occurrence of stressful changes and events other than the initial stressor, and secondary stressors coming from the families' behaviors to manage the hardships (McCubbin *et al*., 1983).

The Double B factor refers to family resources, including two parts: one is resources that are already available to the family (e.g. personal education, family economic status), and the other part is the new resources coming from families' responses to stress by strengthening and developing personal, family and social resources (McCubbin *et al*., 1983).

Double C describes families' perceptions of stressful situations or challenges. It is essential for clinical nurses to understand a family's definition of an event, since the definition determines how stressful the challenge is for a family and how a family will response to it. Usually, instead of responding directly to the reality of stressful events, families prefer to react to their own appraisals or definitions.

Family coping is a bridging concept containing cognitive and behavioral components, in which family resources, perceptions and behavioral responses work together to contribute to family adaptation (McCubbin & Patterson, 1983).

The outcome is family adaptation, which is a continuum from bon-adaptation (positive end) to mal-adaptation (negative end). Bon-adaption implies families could maintain or strengthen family integrity and family members' sense of well-being. Mal-adaptation implies families are experiencing deterioration of family integrity and family members' sense of well-being (McCubbin & Patterson, 1983). Disruptions or changes created by pile-up stressors are more likely to end up with family mal-adaptation or a crisis (xX). In particular, families who perceive stressors or hardships as crisis producing and lack adequate family resources are more susceptible to crises (McCubbin *et al.*, 1983).

3.2. Theoretical Framework

Pile-up stressors (aA) are the starting point of the framework during the hospitalization of a child with cancer. In this study, the ‘aA’ component of the model was the impact caused by a cancer child’s hospitalization on his or her family. The immediate outcome for most families undergoing a child’s hospitalization due to cancer is likely to be negative. It has been well documented that the diagnosis of cancer in a child puts the family into crisis or great challenge (Noll *et al.,* 1995). Therefore, families with children hospitalized for cancer treatment move quickly into the accumulation of stressors, which can be attributed to disease, hospitalization, and other family life changes. All disruption in various areas of family life (e.g. length of hospitalization, times of readmissions, unemployment, divorce……) can be considered and depicted as likely to increase a family's vulnerability and contribute to the pileup stressors.

Family system resources (bB) are important factors facilitating the achievement of family bon-adaptation. Family system resources are the combination of each family member’s knowledge and skills, the skills of the family as a unit and the resources of external systems (Patterson & Garwick, 1994). Family members’ individualized resources include economic status, education received, physical functioning, self-esteem, active coping styles and other psychological resources (McCubbin & McCubbin, 1993). Variations in family background are associated with successful family adaptation (Park *et al*., 2002). Family resources refer to the skills of a family as a unit, such as family hardiness, resilience, and cohesiveness. External resources refer to support from extended families, social and medical systems (Kaakinen *et al.,* 2014). Social support has received the most attention in the study of family adaptation to illness (Kaakinen *et al.,* 2014). It is comprised of informal (originating from relatives and friends) and formal support (from the medical system and professionals). Seeking both kinds of support is supposed to be one of the most effective coping strategies adopted by individuals to deal with a stressful event.

Parents with sick children have expressed the need for social support since it alleviates their stress by enabling them with the opportunities to share their miserable stories, feelings of frustration and expectations (Carter *et al*., 2004). The demand for social support can increase sharply when the family is experiencing an unpredictable change or stressful event (Norbeck, 1988). In this study, demographic variables, such as the education level of parents, family structure, religion, and family monthly income reflects the adaptive resources.

Perception (cC) describes how family members define their current situation during a child's hospitalization for cancer treatment. Families tend to respond to the stressors based on their perceptions, including the perceptions of the hospitalization, other concurrent difficulties and family resources. When a family perceives the current situation to be positive, family members are better able to cope. For example, if families give positive meanings to their children's hospitalization, such as 'an opportunity for family growth', then they are more likely to adapt to their children's hospitalization successfully.

Coping is a concept with cognitive and behavioral components and it plays a crucial role in bridging resources, perception and behavioral responses as families endeavor to maintain or restore a balanced functioning (McCubbin & Patterson, 1983). According to McCubbin (1996), whether a family can adjust to stressful situations successfully depends largely on its coping behaviors. Quite a few studies have discovered that lower scores on a family coping index were likened with higher levels of stress and lower parental quality of life (Frey, 1989; Saloviita *et al.*, 2003). Effective coping strategies could buffer family members' functions physically and mentally (Lazarus, 1984). If a family adopts active coping strategies, like family members cooperating with each other, it will have more possibilities to overcome the rough time successfully (Shin, 2002). Maintaining family integration and an optimistic outlook for the situation has been considered as the most helpful coping strategy used by Korean mothers with children with cancer (Han *et al.,* 2009). Several studies have also identified the protective role of religion/spirituality in children's and their parents' psychosocial adjustment to cancer (Brody & Simmons, 2007; Rabinea *et al.,* 2008). Otherwise, parents may suffer higher-level anxiety and depression, and lower marital well-being and self-esteem (Forde *et al.*, 2004; Oelofsen & Richardson, 2006). Therefore, healthy coping is necessary to maintain and restore the higher-level quality of life for family members and the integrity of family functioning (Forde *et al.*, 2004).

Family adaptation is viewed as the outcome of family coping. It is a continuum from bon-adaptation to mal-adaptation (McCubbin, 1993). For the family with a child hospitalized for cancer treatment, the goal of the adaptation is to achieve a new level of balance, harmony, coherence, and functioning or to acquire significant growth as a family. Families need to establish new patterns to assist them to overcome the active treatment phase (McCubbin, 2002).

Family adaptation is associated with family impact, existing and new family resources, a family's perception on impact and resources, and family coping. According to the Kong (2010), whether a family's adaptation is successful or not depends largely on family coping and family impact. Families who perceive lower coping effectiveness are more likely to be at risk of being in mal-adaptation in spite of the level of family impact. Family adaptation is a dynamic state in which, if the pile-up demands increase (e.g. marital conflict or unemployment, disruption of family functioning), the family will adopt corresponding coping strategies such as seeking external help. Depending on the effectiveness of the coping strategies, the outcome may be mal-adapted or bon-adapted. The present study focused on the core concepts of the family adaptation through studying the family impact and coping during the hospitalization of a child with cancer.

3.3. Measurements of impact and coping

Studies of stress and coping conducted to date have been mainly in the fields of psychology, sociology and medical science. Researchers in these areas have developed instruments to measure stress and coping.

3.3.1. Measurements of impact

A recent review of the literature revealed discussions of several frequently-used assessments, such as the Impact-on-Family (IOF) scale (Stein & Riessman, 1980; Williams *et al.*, 2006), the Parental Stressor Scale: infant hospitalization (PSS: IH) (Miles & Brunssen, 2003), the Family Adaptability, Partnership, Growth, Affection, and Resolve (APGAR) (Smilkstein, 1978), the McMaster Family Assessment Device(FAD) (Epstein *et al.*, 1983) and the Family Impact Module (FIM) of the Pediatric Quality of Life Inventory (Chen *et al.*, 2011).

The IOF scale has been used in many studies concerned with family impact associated with a range of chronic childhood illnesses. However, the Chinese version of the IOF is unavailable now and does not cover families' hospitalization experiences (Boudas *et al.*, 2013; Kolk *et al.*, 2000; Stein & Riessman, 1980).

The PSS: IH measures parental perceptions of stressors involved in having infants admitted to hospital. These potential stressors are parental role alterations, the sights and sounds of the unit, and infant behavior and appearance. The instrument serves as a clinical measure to evaluate stressors experienced by parents with infants in a neonatal intensive care unit (NICU) (Miles & Brunssen, 2003). It focuses on parents with critically sick infants hospitalized for intensive care treatment, rather than the family as a whole in an oncology unit.

The Family APGAR and McMaster FAD are two instruments used commonly to measure family functioning. The Family APGAR contains five items measuring family dissatisfaction or problems concerning family functioning (Smilkstein, 1978). The McMaster FAD is a 60-item self-report instrument developed to assess six dimensions and overall family functioning (Kabacoff *et al.*, 1990). It focuses on the interactions among family members. Both of these tools can be applied in many different types of situations. The non-specific nature of the measurement may not be suitable or sensitive enough for hospitalization situations.

Another frequently-used tool is the FIM (Family Impact Module), which is a parent self-report measure of the impact of pediatric chronic health conditions on parents' health-related quality of life and family functioning (Varni *et al.*, 2004). It covers a comprehensive range of impact on the family caused by a child's disease. However, it ignores the financial burden and hospital adaptation, which are crucial components of family experience during a child’s long-term hospitalization for cancer treatment.

3.3.2. Measurements of coping

The tools related to family coping include the Medical Coping Mode Questionnaire (MCMQ) (Feifel & Nagy, 1987), the Simplified Coping Style Questionnaire (SCSQ) (Xie, 1998), the COPE inventory (Carver *et al.*, 1989; Hastings *et al.*, 2005), the Coping Health Inventory for Parents (CHIP) (Li, 2008; McCubbin *et al.*, 1983), the Parental Coping Strategy Inventory (PCSI) (Yeh, 2001), and the Family Crisis-Oriented Personal Evaluation Scales (F-COPES) (McCubbin *et al.*, 2000). These tools have been used to assess individual or family coping in healthcare settings. However, they may not be appropriate for use in families with children hospitalized for cancer treatment, since they measure various foci.

The MCMQ, SCSQ and COPE inventories were designed to measure a single individual’s coping strategies when encountering life stress. They cannot be used to measure how a family as a whole copes with a child’s hospitalization for cancer treatment.

Another instrument used to measure parents’ coping strategies is the PCSI. It was developed on the basis of previous qualitative studies of the Taiwanese parental adaptation process when caring for children with cancer. It consists of 12 sub-scales (Yeh, 2001). The applicability of items related to healthy siblings and spiritual beliefs may not be relevant in the Chinese mainland where religion is not a strong cultural factor and few families have multiple children (siblings).Also, the PCSI is not specifically designed for hospitalization experiences and cannot be applied for this study. Another tool, the F-COPES, was designed to measure family coping strategies used during difficult or stressful circumstances (McCubbin, 1996). An advantage of the F-COPES is that it measures family unit coping rather than single individual coping. It was designed for use in practice for different types of stressful situations (McCubbin, 1996), yet the non-specific nature of the measurement may not be suitable or sensitive enough for hospitalization situations.

Another commonly used coping instrument is the CHIP, which was designed specifically to assess the coping patterns of parents caring for chronically ill children within the framework of the Resiliency Model (McCubbin, 1984). It is organized into three sub-scales identified as coping patterns: (1) maintaining family integration, cooperation, and an optimistic definition of the situation; (2) maintaining social support, self-esteem, and psychological stability; and (3) understanding the medical situation through communication with other parents and consultation with medical staff (McCubbin *et al.,* 1983). This instrument may not be appropriate to assess how a family copes with a cancer child's hospitalization, considering it was designed to identify coping patterns that parents find helpful in the management of family life and the medical care of children with chronic diseases in home settings (McCubbin *et al.,* 1983).

3.3.3. Hospitalization Impact and Coping Scale (HICS)

Nearly all of the above-described measuring tools were developed in the western world, so their applicability to different cultures, such as the Chinese context, is questionable (Teng *et al.*, 2010). Even when using a similar assessment tool recently developed in Taiwan, the applicability of some items needs to be considered because of cultural diversity (Liu *et al.,* 2014; Wong *et al.,* 2009). Furthermore, most of the instruments have narrowed their focus on individual family members, and few have addressed family issues as a whole. Of these family-specific instruments, the majority do not cover issues related to hospitalization (e.g. traveling or lodging issues) (Epstein *et al.,* 1983; Kabacoff *et al.,* 1990, Smilkstein, 1978; Williams *et al.,* 2006) or measure different types of stressful situations (McCubbin *et al.,* 1996). Compared with other measuring tools as mentioned above, the Hospitalization Impact and Coping Scale (HICS) is the only hospitalization-specific instrument developed in China. It is the most suitable tool to assess family impact and family coping during a child's hospitalization for cancer treatment in Mainland China.

The HICS was developed by Kong (2010), based on the Double ABC-X model, for families with children hospitalized in general pediatric units in China. It measures both impact and coping of families with hospitalized children using two subscales (hospitalization impact scale, hospitalization coping scale). It has potential to provide a valid and reliable assessment of families at risk for nursing attention in pediatric settings. It could be useful to assist frontline nursing staff to identify the families who are at greatest risk of developing adverse impact and ineffective coping during their children's hospitalization, after which the nurses could respond to those who are in need of special attention. The HICS could be used as an instrument to assess and identify families with the potential to cope well and serve as a support group in clinical practice. Furthermore, through using the HICS, hospitalization impact and family coping could be reassessed over the course of service. Practitioners could administer the instrument at the beginning and at the end of a program or intervention.

In present study, the FIM was employed to examine the concurrent validity of the Hospitalization Impact Scale (HIS), in which the respondents were asked to recall the impact of the current hospitalization. The FIM has been adapted cross-culturally to assess the impact of chronic medical conditions on the pediatric health-related quality of life of the parents and family functioning in the preceding 4 weeks, and the Chinese version demonstrates sound psychometric properties (Chen *et al.*, 2011; Varni *et al.*, 2004). Another study conducted on families of children with cancer in active therapy revealed that the FIM was reliable and valid for assessing the impact of a chronic pediatric condition on the families (Scarpelli *et al.*, 2008).

Additionally, CHIP was used to examine the concurrent validity of the Hospitalization Coping Scale (HCS) in the current study. CHIP has been validated with parents in the care of children suffering from cancer (Birenbaum, 1990; Goldbeck, 2001). The Chinese version of the CHIP also demonstrates sound psychometric properties (Li, 2008).

CHAPTER 4 METHODOLOGY

This chapter first discusses the considerations and rationale for choosing a mixed method as the research approach in this study. Then information related to the research design is presented, which includes the study setting, sampling, instruments, data collection, data analysis and ethical considerations.

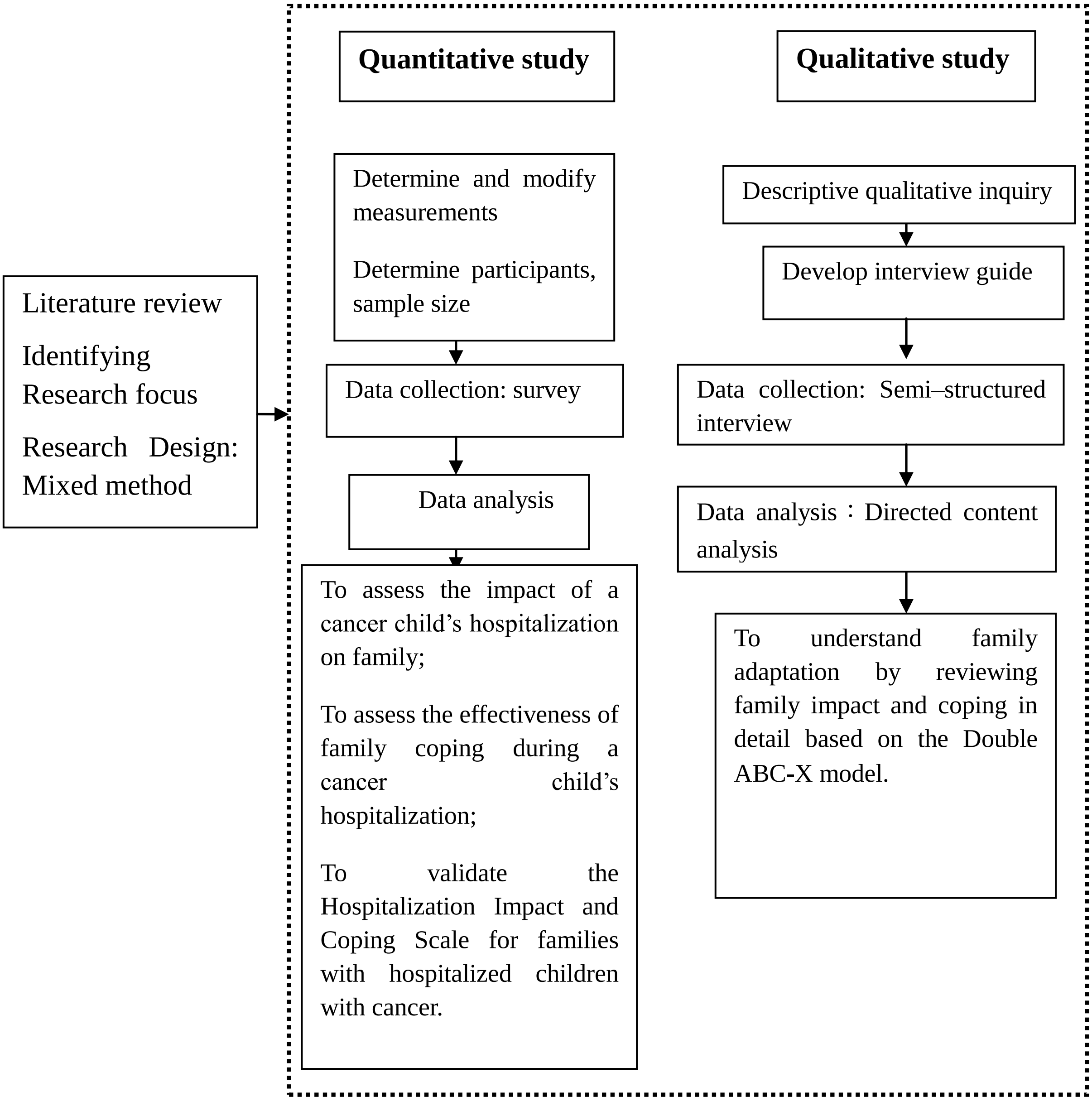
4.1. Research design

Mixed method research is an approach that employs both qualitative and quantitative research paradigms for two separate phases of the one study. The objective of mixed method research is to use different data collection methods to add to the understandings of a research question (Williamson, 2005). Quantitative methodology addresses the generalizability of a study, while qualitative methodology is applied for the exploration of phenomena (Creswell, 2002). The combination provides an improved approach over using a single method, and complements the strengths of each and reduces the effects of their weaknesses (Creswell, 2002). For example, quantitative methods can reduce complex human experiences to numbers and thus fail to capture the full and detailed context of a situation. This shortcoming can be supplemented by a qualitative method that allows greater flexibility and obtains in-depth information about complex phenomena under investigation. Therefore, an advantage of conducting mixed method research is to reveal some important information that would have been overlooked if a solely quantitative or qualitative approach were applied. Tashakkori and Teddlie (2003) indicated that mixed method research allows superior evidence to emerge by employing various approaches focusing on the same phenomenon and providing the same results.

In the present study, the quantitative portion provided a way to quantify the impact of a cancer child’s hospitalization on the family, and the effectiveness of family coping strategies during a cancer child’s hospitalization. Quantitative metrics also addressed the questionnaire’s reliability in a quantitative manner. The qualitative section sought to explore more deeply how a family was affected by and coped with the stressful event. For instance, in the quantitative study, only one item was designed to measure family financial burden, which is one of the major family stressors. The qualitative section was able to provide in-depth information about family financial issues, including the contributing factors, financial support resources, and even problems related to social health insurance. This is necessary and will be helpful in developing targeted interventions and making beneficial policies. Furthermore, this study design has allowed the results to be triangulated, that is gaining different perspectives from the data and using them to give a fuller picture, which enhances the sophistication and rigor of the research (Williamson, 2005).

The use of both quantitative and qualitative methods in the same study can thus prevent the limitations of a single approach and allows a wider, or more complete picture to emerge than that presented by single method (Williamson, 2005). The mixed method employed in the present study facilitated exploration and allowed a better understanding of family impact and coping from quantitative and qualitative perspectives, which provides valuable guidance for interpretation of the findings (See Fig. 2).

Figure 2 Flowchart of the study



Literature review

Identifying Research focus

Research Design: Mixed method

Quantitative study

Determine and modify measurements

Determine participants, sample size

Data collection: survey

Data analysis

To assess the impact of a cancer child’s hospitalization on family;

To assess the effectiveness of family coping during a cancer child’s hospitalization;

To validate the Hospitalization Impact and Coping Scale for families with hospitalized children with cancer.

Qualitative study

Descriptive qualitative inquiry

Develop interview guide

Data collection: Semi–structured interview

Data analysis：Directed content analysis

To understand family adaptation by reviewing family impact and coping in detail based on the Double ABC-X model.

4.2. Phase I: Quantitative survey

4.2.1. Objectives

1) To assess the impact of cancer children's hospitalization on their families;
2) To assess the effectiveness of family coping during a cancer child's hospitalization.

4.2.2. Study field and participants

Settings

The study took place in four pediatric hematology/oncology departments in four class III grade A hospitals in Mainland China from September 2013 to March 2014.

Participants

Childhood cancer has a tremendous impact on a child's family, especially on his or her parents (Wong, 2006). Parents are usually the ones who can perceive deeply every change happening within their family during a child's hospitalization. The researcher recruited the participants with the assistance of a nurse from each department. One of the parents from each family was invited as a proxy if she or he met the following sample inclusion criteria: 1) had a child diagnosed with childhood cancer and hospitalized for treatment; 2) was primarily responsible for childcare during the hospital stay; 3) lived together with the child before hospitalization. The following were exclusion criteria: 1) the length of hospitalization was less than 24 hours; 2) the child was undergoing an emergency (e.g. massivehemorrhage); and (3) the parents were illiterate.

Sample size and sampling

Fang (2001) pointed out that the sample size should be at least 15-20 times the highest number of dimensions of the variables. The impact subscale of the Hospitalization Impact and Coping Scale (HICS) contains six domains; the coping subscale contains four domains. The Family Impact Module (FIM) of the Pediatric

Quality of Life Inventory consists of eight domains. The Coping Health Inventory for Parents (CHIP) includes three domains. Thus, the FIM contains the highest number of dimensions and, with 10% added for non-response, [N= (the highest number of dimensions) $\times 20 \times (1+10\%) = 8 \times 20 \times (1+10\%) = 176$]. Therefore, the sample size was 176.

Additionally, according to the requirements of factor analysis, a minimum participant-to-item ratio of at least 5:1 is recommended (Hatcher, 1994). Thus, for the Hospitalization Impact Scale (HIS) with 36 items, the desired sample size is at least 180. Adding 10% for non-response, a minimum sample of 198 was needed. Convenience sampling was applied to recruit parents to participate in this study.

4.2.3. Measurements

Four instruments were used to collect the quantitative data. The demographic questionnaire was used to address the characteristics related to families, parents and hospitalized children. The Hospitalization Impact and Coping Scale (HICS) was employed to evaluate family impact and coping. The Family Impact Module of the Pediatric Quality of Life Inventory and the Coping Health Inventory for Parents were used to examine the concurrent validity of the HICS.

1) Demographic Questionnaire

The demographic questionnaire is comprised of two parts.

One part addresses the characteristics related to the family, parents and healthy siblings, such as family monthly income, religion, number of family members, number of siblings, siblings’ ages, and the responding parent’s age, education level, gender, and employment status.

The other part was used to collect information related to the hospitalized child, including age, gender, education status, diagnosis and severity, treatment effectiveness, and total days and the number of readmissions until the moment of the assessment.

2) Hospitalization Impact and Coping Scale (HICS) (Kong, 2010)

The HICS was developed by Kong (2010) in China. The original HICS includes two versions, one in simplified Chinese and the other in English. It contains two subscales, the Hospitalization Impact Scale (HIS) and the Hospitalization Coping Scale (HCS). The HIS contains 36 closed questions rated on a five-point Likert scale, ranging from 0 (no impact) to 4 (extreme impact). ‘Not applicable’ (N/A) is used for items that are not relevant to the families’ experiences. The HIS also measures six aspects of impact that the family may experience: psychological impact (5,7,8,13,9,10,11,15,16) social impact (12,14,17,18,19,20,24,25,26) physical impact (1,2,3,4,6), health service utilization impact (31,32,33,34,35,36), family functioning impact (21,22,23,30), and extra burden (27, 28, 29). A high total score suggests that the family is experiencing high-level impact. The HIS has excellent internal consistency for use with families having children hospitalized in general pediatric settings (Cronbach’s alpha value = 0.94).

The HCS includes 16 items rated on a five-point Likert scale ranging from zero (no effect) to four (extreme effect). For items with strategies that are not applied by the families, respondents can indicate ‘No attempt’. There are four patterns of coping strategies: Pattern I--effort to maintain positive and active parental care (3, 4, 5, 9, 13); Pattern II--attempts to readjust mental stability (1, 6, 8, 10); Pattern III—utilizing internal and external resources (2, 7, 11, 12, 16); and Pattern IV--maximizing of the quality and quantity of childcare (14, 15). The total score is 64. A high total score suggests that the family has the potential to handle the stressful situation successfully. The HCS demonstrated satisfactory to good internal reliability with Cronbach’s alpha value ranging from 0.62-0.71.

3) Family Impact Module of the Pediatric Quality of Life Inventory (PedsQL) (FIM) (Jastrowski & Khan, 2011; Varni & Seid, 1999; Varni & Sherman, 2004)

The FIM is a parent self-report measure of the impact of pediatric chronic health conditions on parents’ health-related quality of life and family functioning. This 36-item instrument consists of eight subscales, namely physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning

(5 items), communication (3 items), worry (5 items), daily activities (3 items) and family relationships (5 items). The former 6 subscales measure parent self-reported functioning, whilst the latter 2 subscales measure parent-reported family functioning. Each item has five Likert response options which are 0 (never a problem), 1 (almost never a problem), 2 (sometimes a problem), 3 (often a problem) and 4 (almost always a problem). The items are then transformed linearly to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better health-related quality of life (less negative impact). The Chinese version of the FIM appears to be a reliable (Cronbach's α value＞0.90) measure of the impact of pediatric chronic health conditions on parents' health related quality of life and family functioning (Chen *et al.*, 2011; Varni *et al.,* 2004). It was employed to examine the concurrent validity of the HIS in the present study.

4) Coping Health Inventory for Parents (CHIP) (Mccubbin *et al.*, 1983)

The CHIP provides self-reported information about how parents perceive their overall responses to the management of their family life. This is a widely used measurement in studies of children with chronic illnesses or disabilities. The 45-item checklist consists of three subscales identified as coping patterns: 'maintaining family integration, cooperation, and an optimistic definition of the situation; maintaining social support, self-esteem, and psychological stability; and understanding the medical situation through communication with other parents and consultation with medical staff'. The Cronbach's alpha values for the 3 subscales are 0.79, 0.79, and 0.71. Coping scale scores are also computed for each of the sums of a parents' helpfulness ratings (0= not helpful; 1= minimally helpful; 2= moderately helpful; 3= extremely helpful) across behavior items within each pattern (McCubbin, 1984). The Chinese version of the CHIP has good internal reliability, with a Cronbach's alpha value of 0.91 (Li, 2008). The CHIP was used to examine the concurrent validity of the HCS in the present study.

4.2.4. Data collection

The data collection took place in the pediatric oncology units. First, the researcher asked permission from the hospital manager. Given that nurses would have established rapport with the families, one or two nurses in each unit were invited to help the researcher to communicate with the children's parents. The issues involved in the discussion included introducing the purpose of the study, and explaining the voluntary nature of the participation and the confidentiality of information. The parents were then asked to sign the statement of informed consent if they were willing to participate in the survey. It took 15–20 minutes to complete the questionnaires.

4.2.5. Data Analysis

The Statistical Package for Social Sciences (SPSS) 20.0 (IBM, New York) and Mplus5.1 (Muthe ́n & Muthe ́n, Los Angeles, California) were employed to analyze the quantitative data. A significance level of 0.05 (2-sided test) was used. Specifically, the following statistics were computed:

1) Mean, Standard Deviation, Median, and Range to analyze the demographic data, overall information about family impact and coping;

2) T-test, one-way analysis of variance (ANOVA), and stepwise multiple liner regression to identify predictors of family impact and coping;

3) Confirmatory Factor Analysis (CFA), Exploratory Factor Analysis (FEA), Pearson correlationanalysis and Cronbach's α coefficients to examine the psychometric properties of the HICS.

The t-test is used to compare the means of two groups, while one-way ANOVA can be used to compare more than two groups. Multiple liner regression attempts to model the relationship between two or more explanatory variables and a response variable by fitting a linear equation to the observed data. The stepwise multiple linear regression approach is a method of regressing multiple variables while simultaneously removing those that are not important. The stepwise approach combines the advantages of forward and backward approaches.

CFA is used to test the hypothesis that a relationship exists between observed variables and their underlying latent constructs (Pett *et al.*, 2003). EFA is a statistical technique used to explore the possible underlying factor structure of a set of observed variables without imposing a preconceived structure on the outcome. By performing EFA, the underlying factor structure is identified (Sass & Schmitt, 2010).

4.3. Phase II: Qualitative interview

4.3.1. Objectives

This section describes the qualitative part of the study that aimed to gain an understanding about family adaptation by exploring family impact and coping in detail.

4.3.2. Study design

Descriptive qualitative inquiry was employed in Phase II of the study. This is a ‘vast’ and ‘open’ descriptive approach to answering qualitative research questions. A descriptive qualitative study fits many human situations (including health and illness experiences) that may require a qualitative perspective to research for better and in-depth understanding (Sandelowski, 2010).

4.3.3. Study field and participants

Settings

The settings for the qualitative study were the pediatric oncology departments of the selected hospitals in Mainland China. An interview room was provided in each of the settings. The researcher asked the participants about their preferences for the interview place. One rule of thumb was that the interviewee should feel comfortable and secure during the interview.

Sample size and sampling

Purposeful sampling was employed to select parents according to the coping sub-score in the quantitative data. During the data collection, I calculated the coping score after I finished every 3-5 days of surveying with 10-15 questionnaires. Then I invited the typical cases according to the coping score to participate into the interview. This sampling approach enlarged the diversity inherent in the research topic and facilitated the generation of more fruitful information. The data collection and data analysis were carried out simultaneously. The data collection process was continued until data saturation–when adding further data showed no new information and the extra collected data were redundant (Morse, 2000).

4.3.4. Data collection

Semi-structured in-depth interviews were employed to collect data from September 2013 to March 2014 in the pediatric oncology units of four hospitals in Mainland China.

<u>Development of interview guide</u>

Based on an extensive review of literature regarding family impact and coping, as well as the Double ABC-X model, the researcher adopted a set of semi-structured interview prompts, comprised of open-ended questions to allow respondents to explain their own experiences fully. The prompts provided a clear set of instructions for the interviewer. Two independent, experienced qualitative nursing researchers provided critical comments to help modify them. A pilot study (4 face-to-face interviews) was conducted, following which the interview guide was modified further. The final set of interview prompts is presented below.

1) How is your child's illness and hospitalization affecting you and your family? (Probe for effects on work, finances, and family activities.)

   孩子的疾病和住院对您和您的家庭有什么影响？试从家庭生活、工作或经济等方面举例说明。

2) How is having a child in hospital affecting your family relationships? (Probe for effects on spousal, parent-child, sibling, relatives, and friends relationships.)

孩子住院如何影响您的家庭关系？试从夫妻、子女、兄弟姐妹、亲戚、邻居及朋友关系举例说明。

3) How have you and your family responded to these things?

您及您的家人是如何应对这些事情的？

4) What have you found to be the most helpful to you and your family since the time of your child’s hospitalization?

孩子住院以后, 您认为对您及您的家庭帮助最大的因素是什么？

5) What do the nurses do that is helpful to you and your family when you are distressed?

在孩子住院期间，护士给您提供了哪些帮助？请举例说明。

6) What would you like the nurses to do when you and your family are distressed?

您认为护士怎么做才可以更好的帮助您的家庭渡过难关？

7) What are some of the things that have happened in the hospital that have been distressing/ upsetting/stressful to you and your family?

在医院陪伴孩子的过程中，有什么发生在医院的事情，让您及您的家人感到担心、不快和压力。请举例说明。

8) Is there anything else that you would like to tell me about your child’s hospital experience?

关于孩子住院的经历，您还有什么想告诉我吗？

Preparation for in-depth interview and transcription process

Before the main study, four face-to-face interviews were conducted to complete the interview preparation. The qualitative data were analyzed by the researcher who achieved an excellent grade in the subject “Advanced Methods in Nursing Research” in The Hong Kong Polytechnic University. Advanced Methods in Nursing Research is a subject aimed at developing students’ skills to use qualitative methods in healthcare research.

The interview

The researcher explained the objectives and significance of the present study to the parents and asked them to sign the statement of informed consent if they agreed to participate in the interview. Most of the interviews took place in the wards at the children’s bedsides since they wanted to keep an eye on their children all the time. The interview schedule started with general questions and then moved on to questions related to the family impact and coping. All the participants were proficient in Mandarin, so the interviews were all conducted in this language. Each interview lasted between 45 and 90 minutes. All participants agreed to have their interviews audio taped on a digital recorder.

4.3.5. Data analysis

Qualitative content analysis is the analysis strategy of choice in qualitative descriptive studies (Sandelowski, 2010). Qualitative content analysis includes three approaches, namely conventional content analysis, directed content analysis, and summative content analysis (Hsieh & Shannon, 2005). Directed content analysis is employed to analyze the qualitative data if there is a theory or framework about a phenomenon. Directed content analysis starts with a theory or framework. Key themes or categories are defined before or during the data analysis according to the theory (Hsieh & Shannon, 2005). Directed content analysis has been described as a deductive use of theory based on the distinctions on the role of theory (Elo &Kyngäs, 2008; Potter & Levine-Donnerstein, 1999). Existing theory or research can help focus the research question and it can help researchers begin by identifying key concepts or variables as initial coding categories (Sabzmakan *et al.,* 2014). The result of a directed content analysis validates or extends a theoretical framework conceptually (Hsieh & Shannon, 2005).

Directed content analysis was applied in this study to analyze the qualitative data based on the Double ABC-X Model. The tape recordings of the interview were transcribed verbatim, and then the researcher and the supervisor read and re-read the data in order to become familiar with them. All codes identified in this study were categorized initially according to pre-determined themes based on the Double ABC-X Model. All content analyses began with identifying ‘units of meaning’ (Elo & Kyngäs, 2008), recognizing important components in the data and encoding them. In the next phase, these similar meaning units (codes) were placed initially in categories of the Double ABC-X Model and then into its three main themes (family impact, family coping, family adaptation). Any texts that could not be categorized with the initial coding scheme were given a new code.

4.3.6. Achieving trustworthiness

In order to ensure the rigor of this study, trustworthiness was achieved through credibility, confirmability, dependability and transferability, as suggested by Holloway and Wheeler (2002).

The term ‘credibility’ is related to internal validity, which refers to the ‘truth’ of findings (Polit & Beck, 2010). Credibility was established in this study by using multiple strategies. First, a comfortable space was used for the interview and the participants were informed in advance that their personal information would be treated with confidentiality. Second, prolonged engagement in the field from September 2013 to March 2014 helped establish some trust and rapport with respondents (Lincoln & Guba, 1986). Thirdly, a member-check strategy was employed to ensure that the findings were true to the informants’ expressed meanings (Lincoln & Guba, 1986; Morse & Field, 1996), and confirm that the informants recognized that the interpretation of their expressed experience. The researcher restated or summarized the information and then asked the participant to determine its accuracy at the end of each interview. Third, the researcher and supervisor coded the transcript independently. Subsequent meetings were arranged to discuss the codes. Eighty percent of the codes were agreed upon easily; in cases where disagreement arose, further discussions ensued to reach a consensus about the code. Some codes were revised during subsequent meetings with three supervisors. With regard to the quotes, to guarantee the validity of translation from Chinese to English, two editors who are bilingual in English and Chinese were invited to audit the transcripts.

Confirmability is a process criterion to illustrate as clearly as possible the evidence and thought processes that lead to the conclusion. It is similar to reliability in quantitative research (Speziale & Carpenter, 2007). Confirmability was established by an audit trail, which provided evidence that the recorded raw data had gone through a process of analysis, reduction and synthesis that lead to the findings (Lincoln & Guba, 1986). Dependability refers to the stability of the data over time and over conditions (Graneheim & Lundman, 2004; Polit & Beck, 2010). It was accomplished in this study by the supervisor’s audit procedure and by referring to the information from questionnaires. Furthermore, to confirm dependability and confirmability of the data and results of the analyses, the supervisor was invited to audit the initial codes, subcategories and the categories.

Transferability describes the probability that the present findings have meaning in other similar contexts (Speziale & Carpenter, 2007). This criterion is similar to the concept of generalizability in quantitative research. Although the goal of qualitative research is not to produce generalizations, the transferability criterion focused on general similarities of findings under similar contexts or circumstances. Detailed data were provided to permit others to evaluate the transferability and applicability of the data to other contexts (Lincoln & Guba, 1986).

4.4. Ethical considerations

The project received ethical approval from the Human Ethics Committee of The Hong Kong Polytechnic University and Sun Yat-Sen University, as well as the four hospitals. Strict compliance with basic ethical principles, including voluntary participation, informed consent, confidentiality and anonymity, was ensured.

Parents who were primarily responsible for the children’s care during their hospital stay were invited to participate in the study. The data collection took place when the child was settled into hospital.

The researcher explained the aims and contents of the project, as well as the potential risks and benefits, in a language that was understandable to the parents.

The parents were given an information sheet that provided a written summary of the study. Their participation was voluntary. They were asked to sign a consent form indicating their agreement to participate in the study. The decision to participate or not had no impact on their rights and interests, or those of their children who were receiving medical services.

The questionnaire survey took about 15-20 minutes and the interview took about one hour. The parents had opportunities to ask questions and voice any concerns. They were free to withdraw from the study at any time without reason. Withdrawal would not lead to penalty or negative consequences of any kind.

An interview room was arranged. The semi-structured interviews took place at the location of the participant’s choosing. A hot drink was offered to the parent during the interview. There was a small risk that parents could experience certain levels of grief during the interview when they were talking about their terrible experiences. Some psychological support was provided to the parents when it happened. These strategies included listening to their feelings with empathy, using tender, loving care for mood stabilization, and encouraging the parents by holding their hands and informing them that these feelings were normal. In cases where an interviewee felt extremely unease or inconvenience, the interview was stopped. There was no possibility of physical harm. Potential risks to the participants were minimal. There were no biomedical procedures or drugs involved in the study.

It was anticipated that the parents might appreciate the opportunity to discuss their child’s illness and hospital experience with a concerned researcher. After the survey or interview, a self-made blessing angel pendulum ornament was given to the parent to express appreciation for his/her participation. Angel pendulum ornaments may bring some happiness to the children. The respondents were told that the findings from the study would help pediatric oncology nurses to gain a deeper understanding of the impact on families and their coping during a cancer child’s hospitalization. This would eventually benefit the families and child oncology patients during hospitalization.

The data were treated confidentially. No personal identifiable information was used in any reports. The questionnaires were entirely anonymous, meaning that all responses were identified by codes known only to the researchers. Paper materials were locked in a cabinet. Only the research team has access to view these. All the electronic information was locked in the researcher’s personal computer with a password. Quotes in the qualitative part were modified slightly to ensure that no identifying information would be disclosed. The data will be destroyed five years after the study.

CHAPTER 5 RESULTS OF QUANTITATIVE STUDY

This chapter presents the findings of the quantitative study. It begins with the demographic characteristics of the sample, and then presents the level of family impact and family coping. Finally, this chapter ends with the validation of Hospitalization Impact and Coping Scale.

5.1. Demographic characteristics of family and parents

Two hundred and seventy-nine eligible families participated in the survey, from September 2013 to March 2014. Of 279 received questionnaires, 26 were deleted because the percentage of missing data in each questionnaire exceeded 50% and many important questions were not answered, resulting in 253 completed questionnaires. No significant difference in demographic characteristics was detected between the missing 26 families and the other 253 families.

Of these respondents, 191 (75.5%) were mothers and 62 (24.5%) were fathers. Over half of the 253 families (*n*=141, 55.7%) from rural areas. Nearly three fifths considered themselves to be religious (*n*=150, 59.3%) at the time of the survey. The major religious belief was ancestral worship (*n*=108, 42.7%). Buddhism was the second most common religion, with 10.3% (*n*=26) of the respondents being followers. Nearly 96% of parents were married, with an average of two children. More than half (*n*=161, 63.6%) of the families were nuclear families and four were single-parent families. About a quarter (*n*=60, 23.7%) of the families had no monthly household income during their children’s hospitalization.

The average age of the parents was 33±5.9 years. More than half of (*n*=150, 59.3%) mothers were housewives. Nearly three quarters (*n*=181, 71.5%) of the mothers were unemployed, about half (*n*=106, 42.7%) of the fathers were unemployed after their children’s hospitalization. Table 1 summarizes the demographic characteristics of the parents and their families.

Table 1 Profile of families and parents

Family	*N (%)*	**Parents**	*N (%)*
Present residence		**Fathers' education**	
Rural area	141 (55.7)	Elementary school or below	65 (25.7)
Non-rural area	112 (44.3)	Junior middle school	108 (42.7)
Religion		High school/ Secondary vocational school	39 (15.4)
Atheist	103 (40.7)	College/ University	38 (15.0)
Ancestral worshipper	108 (42.7)	Postgraduate or above	3 (1.2)
Buddhist	26 (10.3)	**Mothers' education**	
Christian	12 (4.7)	Elementary school or below	39 (15.4)
Muslim	3 (1.2)	Junior middle school	116 (45.8)
Taoist	1 (0.4)	High school/Secondary vocational school	54 (21.3)
Family structure		College/ University	42 (16.6)
Single-parent family	4 (1.6)	Postgraduate or above	2 (0.8)
Nuclear family	161 (63.6)	**Mother' employment status**	
Extended family	88 (34.8)	Full-time	44 (17.4)
Family monthly income (RMB)		Part-time	5 (2.0)
No income*	60 (23.7)	Self-employed	23 (9.1)
500-1000	28 (11.1)	Unemployed	31 (12.2)
1001-2000	52 (20.6)	Housewives	150 (59.3)
2001-3500	48 (19.0)	**Fathers' employment status (n=249)**	
⩾3501	65 (25.7)	Full-time	99 (39.7)
Number of children in family		Part-time	13 (5.2)
1	138 (54.5)	Self-employed	31 (12.4)
2	84 (33.2)	Unemployed	106 (42.7)
3	21 (8.3)		
⩾4	10 (4.0)		

Note: * No family income temporarily, families live on previous savings.

5.2. Demographic characteristics of hospitalized children

Table 2 presents the demographic characteristics of the hospitalized cancer children. Of the 253 children, 165 (65.2%) were males and 88 (34.8%) were females. The children were aged between 1 and 14, and their mean age was 6.00±3.35 years. More than one third (*n*=91) of the children were too young to go to school, while 83 (32.8%) were in kindergarten and 70 (27.7%) children were in elementary school at the time of the survey.

The majority of the children (*n*=212, 83.80%) had been diagnosed with acute lymphoblastic leukemia (ALL), the remainder (*n*=41, 16.20%) had been diagnosed with acute nonlymphocytic leukemia, lymphadenoma, neuroblastoma, nephroblastoma, or rhabdomyosarcoma. Children with ALL are usually treated according to risk groups classified according to age of onset, white blood cell (WBC) count, response on day 8 (Peripheral Blood) and myelogram on day 15/day 33. There are three risk groups: standard-risk (SR), medium-risk (MR) and high-risk (HR) (Huang *et al.,* 2014).Of the children diagnosed with ALL, at the time of investigation, 89 (42.0%) were SR, while MR and HR accounted for 31.6%, 26.4%, reactively.

The total days of all admissions ranged from 4 to 900. The median was 100 days. About one third (33.2%, *n*=84) of the children had been hospitalized for less than 60 days, followed by 25.7% (*n*=65) hospitalized for 61-120 days. The number of readmissions ranged from 1 to 50. The median number of readmissions was 5. Around two-thirds (65.2%, *n*=165) of the children had been hospitalized more than three times. The figures mentioned above show that most of the children had experienced prolonged and repeated hospitalization for cancer treatment. All of them were undergoing active chemotherapy at the time of the investigation. More than 80% (*n*=221) had received treatment that was very good or good in its effectiveness. This treatment effectiveness was assessed by parents based on their perceptions of their children's conditions and the information they got from doctors. About one tenth (*n*=26, 10.3%) of the children were undergoing relapse treatment at the time of the investigation.

Table 2 Profile of hospitalized children

Demographic characteristics related to children	*N (%)*	**Demographic characteristics related to children**	*N (%)*
Gender		**Number of readmissions(times)**	
Male	165 (65.2)	*Range*: 1-50, *Median*: 5, *M*±*SD*: 6.7±7.0	
Female	88 (34.8)	1-2	88 (34.8)
Age (Years)		3-6	67 (26.5)
1-2	47 (18.6)	7-10	54 (21.3)
3-5	92 (36.4)	11-50	44 (17.4)
6-8	52 (20.6)	**Treatment effectiveness**	
9-14	62 (24.5)	Very good	177 (70.0)
Education		Good	44 (17.4)
No schooling	91 (36.0)	Not good	32 (12.7)
Kindergarten	83 (32.8)	**Treatment stage**	
Elementary school	70 (27.7)	Relapse treatment	26 (10.3)
Junior middle school	9 (3.5)	Primary treatment	227 (89.7)
Diagnosis		**Cancer treatment interrupted**	
ALL*	212 (83.8)	No	228 (90.1)
Others	41 (16.2)	Yes	25 (9.9)
Severity of ALL (*n*=212)		**Reasons form Interruption (*n*=25)**	
Standard risk	89 (42.0)	Worry the side effects	3 (12)
Medium risk	67 (31.6)	Financial issues	15 (60)
High risk	56 (26.4)	Disease reason	7 (28)
Total days of all admissions (days)		**Source of medical cost**	
Range: 4-900, *Median*: 100, *M*±*SD*: 135.3±129.4		Self-funded	47 (18.6)
4-60	84 (33.2)	Commercial insurance	9 (3.6)
61-120	65 (25.7)	New rural cooperative medical scheme (NRCM)	159 (62.8)
121-180	53 (20.9)	Social medical insurance	37 (14.6)
181-900	51 (20.2)	Commercial insurance+ NRCM	1 (0.4)

*: Acute Lymphoblastic Leukemia

5.3. Responses of families on the HICS

The participants reported that they had no difficulty in understanding the questionnaire. More than 80% of parents reported that they could complete the HICS within 15-20 minutes, which evidenced that it was a time-efficient measure.

Parents were asked to indicate the level of impact on them due to their children's hospitalization on a five-point Likert scale represented by 'no, little, some, great, extreme'. For items that were not relevant to the parents' experiences, 'not applicable' (N/A) was used. Those who answered 'great' and 'extreme' were grouped together and classified as 'high impact'. As is shown in Table 3, the impact that were most reported by the parents were item 28, 'have more expenses (84.6%)', item 11, 'worry about disease progress (81.8%) ', and item 27 'lose time from work with reduced income' (79.9%). The items on which the least respondents reported great or extreme impact were item 31 'cannot freely adopt alternative therapies (0%)', item 36 'cannot adapt to the hospital routines (11.8%)', item 33 'cannot adapt to the hospital environment (19.8%)', and item 22 'seldom have a chance to talk about problems we encounter (21.8%)'.

Table 3Responses of families on Hospitalization Impact Subscale (*n*=253)

Factors* and Items	***M***	***SD***	**Percentage of Responses (%)**					
			No (0)	**Little (1)**	**Some (2)**	**Great (3)**	**Extreme (4)**	**(3)+(4)**
Factor 1: Physical impact								
1.feel tired	2.65	1.08	2.0	15.0	25.7	30.8	26.5	57.3
2. health is adversely affected	2.25	1.24	7.5	22.5	30.0	17.4	22.5	39.9
3.cannot sleep well	2.62	1.17	3.6	16.2	25.7	24.1	30.4	54.5
4.lose appetite	2.48	1.10	4.0	14.6	32.8	24.9	25.7	50.8
6.become irritable	2.53	1.46	4.0	15.4	30.0	26.5	21.1	48.6
Factor 2: Psychological impact								
7.cannot concentrate on work	2.94	1.09	4.0	12.3	19.0	25.7	37.5	63.2

13.donot know how to deal with our child's emotions	2.36	1.22	7.5	17.8	29.2	22.1	23.3	45.4
11.worry about disease progress	3.33	0.88	0.4	4.0	13.8	25.7	56.1	81.8
15.consider our child's condition is serious	2.57	1.34	11.5	11.1	19.0	26.1	32.4	58.5
9.feel guilty for inadequate care leading to hospitalization	2.63	1.30	7.9	13.0	23.3	19.4	36.4	55.8
8.feel nervous	3.04	1.05	2.0	5.5	24.5	22.5	45.5	68.0
5.emotions fluctuate according to our child's medical condition	2.97	1.15	3.6	7.1	20.6	24.1	43.5	67.6
16.want to take care of my child but feel inadequate to do so	2.09	1.44	19.8	15.4	25.3	15.0	24.5	39.5
10.feel hurt because my child is suffering in hospital	2.50	1.35	11.5	13.4	20.2	23.3	31.6	54.9
Factor 3: Social impact								
14.cannot rely on others to take care of my child	3.26	0.97	0.8	5.5	16.2	21.3	56.1	77.4
12.are more tolerant of our child's misbehavior	2.71	1.29	8.7	9.5	21.7	22.1	37.9	60.0
19.donot have much time left for other family members	2.67	1.30	8.3	11.5	22.5	20.6	37.2	57.8
17.daily life needs to be changed	3.01	1.18	4.3	7.1	20.2	24.1	44.3	68.4
20.cannot complete the household chores	1.90	1.31	17.4	22.9	28.5	15.0	16.2	31.2
18.have to give up a lot of things	3.00	1.14	2.8	10.3	17.8	22.1	47.0	69.1
24.see family and friends less	2.85	1.19	4.8	7.1	22.2	24.6	40.1	64.7
25.are unable to take a stroll or travel out of the town	2.62	1.46	13.0	13.0	15.0	17.4	41.1	58.5
26.become very busy and have no free time	2.78	1.19	5.1	10.3	22.5	25.3	36.8	62.1
Factor 4: Health service Utilization impact								
31.cannot freely adopt alternative therapies	0.48	0.76	68.4	15.0	16.6	0	0	0
32.have feelings that hospital staff are too busy to be bothered	1.47	1.27	28.9	26.1	23.7	12.3	9.1	21.4
33.cannot adapt to the hospital environment	1.41	1.23	27.3	33.2	19.8	11.1	8.7	19.8

34.do not know details of our child's condition	1.91	1.40	20.9	23.3	16.6	22.1	17.0	39.1
35.worry about malpractice	2.03	1.40	17.0	21.3	28.5	8.3	24.9	33.2
36.cannot adapt to the ward routines	1.02	1.16	43.9	26.9	17.4	6.7	5.1	11.8
Factor 5: Family functioning impact								
21.blame each other for improper care	1.51	1.32	28.9	24.9	24.5	9.5	12.3	21.8
22.seldom have a chance to talk about problems we encounter	1.88	1.29	16.6	25.7	26.1	16.6	15.0	31.6
23.relationship is affected because of the bad mood	1.65	1.48	31.2	20.9	17.4	12.3	18.2	30.5
30.burden can hardly be understood by others	2.88	1.20	4.7	6.7	19.0	19.4	50.2	69.6
Factor 6: Extra burden								
27.losing time from work with reduced income	3.34	1.00	2.0	4.3	13.8	17.8	62.1	79.9
28.have more expenses	3.45	0.87	0.4	4.0	11.1	19.0	65.6	84.6
29.have extra burdens	3.04	1.18	4.7	6.7	19.0	19.4	50.2	69.9

Note: * Factors are structured by Kong (2010).

Parents were also asked to indicate the level of effectiveness of coping strategies on a five-point Likert scale representing ‘no, little, some, great and extreme’. For items that were not relevant to the parents’ experiences, ‘not applicable’ (N/A) was used. Those who answered ‘great’ and ‘extreme’ were grouped together and classified as ‘high effectiveness’. As the findings in Table 4 show, the coping strategies that were most reported as having a great or extreme effect were item 5 ‘keep asking doctors and nurses questions, and monitor the child closely ourselves (74.3%)’, item 3 ‘stay close to my child (73.6%)’, and item 14 ‘cut down working hours to participate more childcare’ (70.8%). The least reported as having great or extreme effect were item 1 ‘try to relax and control emotions (13.9%)’, and item 10 ‘do not expect too much and do not plan for too long (27.3%)’.

Table 4Responses of families on Hospitalization Coping Subscale (*n*=253)

Factors* and items	***M***	***SD***	**Percentage of Responses**					
			No (0)	**Little (1)**	**Some (2)**	**Great (3)**	**Extreme (4)**	**(3)+(4)**
Factor 1: effort to maintain positive and active parental care								
3.stay close to my child	2.92	0.94	2.0	6.3	18.2	44.7	28.9	73.6
4.prepare food for my child	2.77	1.01	3.6	6.7	24.1	40.3	25.3	65.6
5.keep asking doctors and nurses questions, and monitor the child closely ourselves	2.97	0.84	0.8	3.6	21.3	46.2	28.1	74.3
9.encourage family members, including the sick child, to express their inmost feelings	2.27	1.13	8.7	13.8	34.0	28.9	14.6	43.5
13. hope things will get better	2.25	1.06	1.2	7.9	22.1	25.3	42.7	68.0
Factor 2: utilizing internal and external resources								
2.support each other and share responsibilities	2.81	1.20	7.9	5.5	19.0	32.8	34.8	67.6
7.make use of what we see in hospital as learning experiences	2.89	0.98	2.0	6.7	22.5	38.3	30.4	68.7
11.seek and accept help from relatives	2.08	1.18	10.7	21.3	30.8	24.1	13.0	37.1
12.seek and accept help from friends	1.82	1.26	5.1	17.0	39.9	23.3	14.6	37.9
16.try our best to endure and be co-operative	2.84	1.10	3.6	8.3	24.1	28.9	35.2	64.1
Factor 3: maximizing quality and quantity of childcare								
14.cut down working hours to participate more in childcare	2.89	0.90	0.4	7.9	20.9	43.9	26.9	70.8
15.ask relatives and friends about hospitalization experiences	2.11	1.30	16.2	14.2	27.7	25.7	16.2	41.9
Factor 4: attempts to readjust mental stability								
1.try to relax and control emotions	1.68	0.90	9.5	30.4	46.2	10.7	3.2	13.9
6.consider hospitalization can be more of a relief to us	2.55	0.96	2.4	11.5	30.8	39.9	15.4	55.3
8.treat my child as usual	2.36	1.09	5.9	13.0	38.3	24.9	17.8	42.7
10. do not expect too much and do not plan for too long	1.82	1.26	19.4	17.4	36.0	16.6	10.7	27.3

Note: * Factors are structured by Kong (2010).

5.4. Family perceived impact and coping

The test of normality (Shapiro Wilks W test) revealed that the data related to family impact (*p*=0.20) and coping (*p*=0.07) approximated normal distributions.

The total score for family impact was 87.84±22.72 (21-133), and the mean score for family coping was 39.02±9.84 (11-64). Since the numbers of items (*N*) in the factors varies, the mean of each subscale (*M±SD)* divided by *N* was calculated to compare the contributions of factors to the total score. With respect to the impact of a cancer child's hospitalization on families, social impact was the highest, followed by extra burden and psychological impact. In terms of family coping reported by parents, the coping strategy 'effort to maintain positive and active parental care' was rated as the highest, followed by 'maximizing quality and quantity of child care'. Detailed information is displayed in Table 5.

Table 5 The scores of the family impact and coping scale

Factors	**Number of items (*N*)**	***Range***	***M±SD***	***(M±SD)/N***
Impact	**36**	**0~144**	**87.84±22.72**	**2.44±0.63**
Social impact	9	0～36	26.81±7.81	2.98±0.86
Extra burden	3	0～12	8.83±2.49	2.94±0.83
Psychological impact	9	0～36	23.43±7.25	2.60±0.80
Physical impact	5	0～20	12.53±4.42	2.51±0.88
Family functioning impact	4	0～16	7.92±4.16	1.98±1.04
Health service utilization impact	6	0～24	8.32±4.74	1.39±0.79
Coping	**16**	**0～64**	**39.02±9.84**	**2.44±0.62**
Effort to maintain positive and active parental care	5	0～20	13.18±3.70	2.64±0.74
Maximizing quality and quantity of child care	2	0～8	5.00±1.76	2.50±0.88
Utilizing internal and external resources	5	0～20	12.43±4.03	2.49±0.80
Attempts to readjust mental stability	4	0～16	8.40±2.79	2.09±0.69

5.5. Association between demographic characteristics and family impact and coping

A t-test and one-way ANOVA were conducted to explore the association between demographic characteristics and family impact and coping. The family residence, family with a religious background, total days of all admissions, number of readmissions, and severity of illness were tested and found to be statistically significantly associated with family impact. Number of readmissions, family with a religious background, and age of a hospitalized child were found to be statistically significantly associated with family coping. The results are shown in Table 6- Table 11.

5.5.1. Association between demographic characteristics and family impact

As shown in Table 6, a significant difference was detected between families from rural and non-rural areas in two factors, social impact and health service utilization. There were no differences found in the other factors. No significant difference was detected between families with or without religious backgrounds for total impact score, however, families with a religious background appeared to experience more social impact ($p=0.02$).

Regarding the total days of all admissions (Table 7), the longer the hospitalization was, the greater impact the family experiences ($p<0.01$). However, no significant difference was found between families with children hospitalized for 121-180 days and families with children hospitalized for more than 181 days.

With respect to the number of readmissions, the families with children hospitalized frequently were more likely to experience higher impact ($p<0.01$) (Table 8). The impact score increased along with the number of readmissions. Families with children hospitalized more than three times suffered significantly higher impact than those with children hospitalized less than twice ($p<0.05$).

The significant differences in family impact were detected among the families with children with ALL in different levels of severity ($p < 0.01$) (Table 9). Families with children diagnosed with high-risk ALL perceived significantly more impact than other families ($p < 0.01$). Families with children with medium-risk ALL perceived significantly more impact than families with children with standard-risk ALL ($p < 0.01$).

5.5.2. Association between demographic characteristics and family coping

As shown in Table 10, there were significant differences in family coping scores among families with children with different number of readmissions and ages. There was a significant decrease in family coping along with the increased times of re-admission (F=8.75, $p < 0.01$). However, the decrease was insignificant between families having children hospitalized 3-6 times and 7-10 times.

A difference in family coping scores between families with and without religious background was also detected ($p < 0.01$). The families with a religious background perceived more effective coping than families without a religious background ($p < 0.01$) (Table 10).

The older the hospitalized children were, the more the parents perceived the family to be coping ($p < 0.01$). There was no significant difference in coping scores between families having children aged 3-5 and aged 6-8 years (Table 11).

Table 6 The associations of family residence and religion with family impact (*n*=253)

Family impact score	***N (%)***	**M±SD**						
		Total score	Physical impact	Psychological impact	Social impact	Family functioning impact	Health service utilization impact	Extra burden
Family residence								
Rural area	141 (55.7)	86.00±22.26	12.33±4.70	24.36±6.91	23.90±8.19	7.93±4.46	7.56±45.44	9.91±2.40
Non-rural area	112 (44.3)	90.14±22.65	12.76±4.04	24.52±7.52	25.96±7.18	7.91±3.93	9.25±4.94	9.72±2.56
t (*P*)		1.44 (0.15)			2.09 (0.04)		2.86 (<0.01)	
With a religious background								
Yes	103 (40.7)	88.27±22.34	12.85±4.49	22.84±7.11	26.03±7.49	8.34±4.16	9.27±4.53	9.29±2.57
No	150 (59.3)	87.41±23.34	13.27±4.31	22.77±7.47	23.96±8.10	8.54±4.16	8.50±4.86	9.58±2.38
t (P)		-0.37 (0.71)			2.29 (0.02)			

Table 7 The association of total days of all admissions with family impact (n=253)

Family impact score	***N (%)***	***M±SD***						
		Total score	Physical impact	Psychological impact	Social impact	Family Functioning impact	Health service utilization impact	Extra burden
Total days of all admissions (ds)								
①4-60	84 (33.2)	74.55±23.55	9.56±4.56	21.05±7.64	21.38±8.53	7.84±4.63	6.10±3.93	8.61±2.85
②61-120	65 (25.7)	84.53±17.98	12.32±3.83	22.93±6.66	24.76±6.45	8.10±4.45	6.30±3.31	10.09±2.05
③121-180	53 (20.9)	93.56±19.31	13.71±3.95	25.43±6.52	26.37±6.45	8.54±5.00	8.92±3.99	10.56±1.99
④181-900	51 (20.2)	98.72±21.50	14.45±4.27	26.92±6.80	27.84±7.35	9.11±4.99	10.66±4.05	10.73±2.49
F (P)		15.80 ($p<0.01$)	9.97 ($p<0.01$)	6.94 ($p<0.01$)	11.03($p<0.01$)	16.83($p<0.01$)	0.85 (0.47)	12.13 ($p<0.01$)
		③＞①($p<0.01$) ②＞①($p<0.01$) ④＞①($p<0.01$) ③＞②($p=0.02$) ④＞②($p<0.01$)	③＞①($p<0.01$) ②＞①($p=0.02$) ④＞①($p<0.01$) ④＞②($p<0.01$)	③＞①($p<0.01$) ④＞①($p<0.01$) ④＞②($p=0.02$)	③＞①($p<0.01$) ②＞①($p<0.01$) ④＞①($p<0.01$) ④＞②($p=0.03$)	③＞①($p<0.01$) ②＞①($p<0.01$) ④＞①($p<0.01$) ③＞②($p=0.02$) ④＞②($p<0.01$)		③＞①($p<0.01$) ②＞①($p<0.01$) ④＞①($p<0.01$)

Table 8 Differences in impact scores for number of readmissions (n=253)

Family impact score	***N (%)***	***M*±*SD***						
		Total score	Physical impact	Psychological impact	Social impact	Family functioning impact	Health service utilization impact	Extra burden
Number of readmissions								
①1-2	88 (34.8)	79.17±23.29	10.88±4.63	22.56±7.59	22.45±8.34	6.13±3.64	8.45±4.14	8.68±2.83
②3-6	67 (26.5)	90.22±19.76	13.50±3.61	24.41±7.19	25.67±7.18	8.29±4.05	7.83±4.75	10.49±1.94
③7-10	54 (21.3)	92.81±21.44	12.85±4.53	26.48±6.31	26.09±6.72	8.83±4.08	8.31±5.67	10.24±2.12
④11-50	44 (17.4)	95.43±22.55	13.90±4.06	25.70±6.95	26.63±8.01	9.81±4.21	8.77±4.69	10.59±2.16
F (P)		7.57 ($p<0.01$)	7.15 ($p<0.01$)	3.99 ($p<0.01$)	4.39 ($p<0.01$)	10.52 ($p<0.01$)	0.39 (0.76)	10.77 ($p<0.01$)
		②>①($p<0.01$) ③>①($p<0.01$) ④>①($p<0.01$)	②>①($p<0.01$) ③>①($p<0.01$) ④>①($p<0.01$)	②>①($p<0.01$) ④>①($p<0.01$)	②>①(p=0.01) ③>①($p<0.01$) ④>①($p<0.01$)	②>①($p<0.01$) ③>①($p<0.01$) ④>①($p<0.01$) ④>②(p=0.04)		②>①($p<0.01$) ③>①($p<0.01$) ②>①($p<0.01$)

Table 9 Differences in impact scores for severity (n=212)

Family impact score	***N (%)***	***M±SD***						
		Total score	Physical impact	Psychological impact	Social impact	Family functioning impact	Health service utilization impact	Extra burden
Severity of ALL*								
①Standard risk	89 (42.0)	74.96±16.86	10.38±3.81	21.33±6.10	21.13±6.90	6.12±3.48	7.01±4.45	8.97±2.56
②Medium risk	67 (31.6)	91.15±20.51	13.44±4.19	24.47±6.92	26.40±7.14	8.58±3.85	8.10±4.25	10.13±2.36
③High risk	56 (26.4)	106.02±18.60	15.03±4.09	29.89±5.72	29.30±6.40	9.98±4.43	10.85±4.87	10.94±1.75
F(P)		29.61 ($p<0.01$)	16.62 ($p<0.01$)	19.77 ($p<0.01$)	16.29 ($p<0.01$)	12.03 ($p<0.01$)	8.38 ($p<0.01$)	8.29 ($p<0.01$)
		③＞②＞① ($p<0.01$)	③＞②＞① ($p<0.01$)	③＞②＞① ($p<0.01$)	②＞①($p<0.01$) ③＞①($p<0.01$) ③＞②(p=0.027)	②＞①($p<0.01$) ③＞①($p<0.01$) ③＞②(p=0.05)	③＞①($p<0.01$) ③＞②($p<0.01$)	②＞①($p<0.01$) ③＞①($p<0.01$)

Note: *ALL: Acute Lymphocytic Leukemia

Table 10 Differences in coping scores for number of readmissions and religion (n=253)

Family coping score	***N (%)***	***M*±*SD***				
		Total score	effort to maintain positive and active parental care	utilizing internal and external resources	maximizing quality and quantity of childcare	attempts to readjust mental stability
Number of readmissions						
①1-2	88 (34.8)	41.79±8.95	14.10±3.42	13.45±3.50	5.36±1.76	8.87±2.65
②3-6	67 (26.5)	39.85±10.20	13.44±3.49	12.79±4.27	4.95±1.83	8.65±2.84
③7-10	54 (21.3)	38.35±8.31	13.01±3.71	12.11±3.99	4.94±1.59	8.27±2.33
④11-50	44 (17.4)	33.00±10.45	11.15±3.83	10.22±3.95	4.43±1.75	7.18±3.19
F (P)		8.75 (p＜0.01)	6.78 (p＜0.01)	7.01 (p＜0.01)	2.84 (p＜0.01)	4.00 (p＜0.01)
		①＞③(p=0.03) ①＞④(p＜0.01) ②＞④(p＜0.01) ③＞④(p<0.01)	①＞④(p＜0.01) ②＞④(p＜0.01) ③＞④(p=0.01)	①＞③(p=0.04) ①＞④(p＜0.01) ②＞④(p<0.01) ③＞④(p=0.02)	①＞④(p<0.01)	①＞④(p<0.01) ②＞④(p<0.01)
With a religious background						
Yes	150 (59.3)	41.61±9.94	14.02±3.68	13.24±4.15	5.40±1.63	8.94±2.96
No	103 (40.7)	35.24±8.48	11.96±3.38	11.25±3.56	4.42±1.80	7.60±2.30
t (*P*)		5.30 (p＜0.01)	4.52(p＜0.01)	3.95(p＜0.01)	4.45(p＜0.01)	3.84(p＜0.01)

Table 11 Differences in coping scores for age of a hospitalized child (n=253)

Family coping score	**N (%)**	***M*±*SD***				
		Total score	effort to maintain positive and active parental care	utilizing internal and external resources	maximizing quality and quantity of childcare	attempts to readjust mental stability
Age of a hospitalized child (Ys)						
①1-2	47 (18.6)	34.11±10.91	11.48±3.97	10.57±4.00	4.25±2.04	7.78±2.94
②3-5	92 (36.4)	37.77±8.93	12.92±3.45	12.04±3.89	4.79±1.62	8.01±2.63
③6-8	52 (20.6)	40.07±9.52	13.59±3.65	12.75±4.11	5.07±1.50	8.65±2.72
④9-14	62 (24.5)	43.69±8.58	14.51±3.38	14.14±3.53	5.82±1.66	9.20±2.80
$F(P)$		10.213 ($p<0.01$)	6.762 ($p<0.01$)	8.043 ($p<0.01$)	8.366 ($p<0.01$)	3.321 ($p=0.02$)
		②＞①($p<0.01$) ③＞①($p<0.01$) ④＞①($p<0.01$) ④＞②($p<0.01$) ④＞③($p=0.04$)	②＞①($p=0.03$) ③＞①($p<0.01$) ④＞①($p<0.01$) ④＞②($p<0.01$)	②＞①($p=0.04$) ③＞①($p<0.01$) ④＞①($p<0.01$) ④＞②($p<0.01$)	③＞①($p=0.02$) ④＞①($p<0.01$) ④＞②($p<0.01$) ⑤＞③($p=0.020$)	④＞①($p<0.01$) ④＞②($p<0.01$)

5.6.The predictive factors of family impact and family coping

Stepwise multiple linear regression analysis was employed to identify factors predicting family impact and family coping. The dependent variable was the score of family impact and the score of family coping, while the independent variables were current residence, total days of all admissions, number of readmissions, severity of the child's illness, age of a hospitalized child, and with a religious background. Two criteria were set for selecting the appropriate significant factors, the entry of using probability of F=0.05, and the removal of using probability of F=0.1. The independent variables were excluded if p> 0.05.

Tables 12 and 13 present the stepwise multiple linear regression analysis results. The significant predictors of family impact were the severity of a child's illness and total days of all admissions, which accounted for 21% of the observed variance. The significant predictors of family coping were number of readmissions, with a religious background, and age of a hospitalized child. The full model accounted for 23% of the observed variance of family coping. The regression model for family impact and family coping were statistically significant (p<0.05).

Table 12 Stepwise multiple linear regression for variables predicting impact (*n*=212)

Variables	*Cum.R^2*	*Adjusted R^2*	*β*	*t (p)*	*F (p)*
Total days of all admissions	0.16	0.15	0.35	6.14(<0.01)	46.18(<0.01)
Severity of a child's illness	0.22	0.21	0.25	4.47(<0.001)	34.82(<0.01)

Table 13 Stepwise multiple linear regression for variables predicting coping (*n*=253)

Variables	*Cum.R^2*	*Adjusted R^2*	*β*	*t (p)*	*F (p)*
Age of a hospitalized child	0.11	0.11	0.25	3.85(<0.01)	30.58(<0.01)
Number of readmissions	0.19	0.19	-0.28	-7.68(<0.01)	29.42(<0.01)
With a religious background	0.24	0.23	0.23	4.12(<0.01)	29.23(<0.01)

5.7. Validation of Hospitalization Impact and Coping Scale (HICS)

After the detailed description of family impact and family coping according to the score of original HICS, this section aims to evaluate the psychometric properties of HICS.

First, confirmatory factor analysis (CFA) was performed using Mplus 5.1to evaluate the fitness of original four-factor model of the HCS and six-model of the HIS to the present data. Second, item-to-total correlations (ITCs) were calculated before exploratory factor analysis (EFA). Items with item-to-total correlations <0.30 were removed before conducting an EFA (Dixon, 2004; Pett *et al.,* 2003).

Then, the EFA was conducted to determine the optimal factor structure of the HCS and HIS for this sample (Sass & Schmitt, 2010). Since the item data were ordinal, the EFA was conducted using Mplus software version 5.1 with polychoric correlations, geomin rotation, and weighted least squares mean and variance-adjusted estimation (WLSMV) (Muthén & Muthén, 2007). For EFA and CFA, Mplus reports the Root-Mean-Square Error of Approximation (RMSEA), the Comparative Fit Index (CFI), the Tucker-Lewis index (TLI), and the Standardized Root Mean square Residual (SRMR) (Muthén & Muthén, 2007). These goodness-of-fit indicators were used to assess the fit of a hypothesized model to sample data. The criteria for good fit are RMSEA$\leqslant$0.06, CFI$\geqslant$0.95, TLI$\geqslant$0.95, and SRMR $\leqslant$ 0.05 (Hu & Bentler, 1999).

Next, the Cronbach's α coefficient was assessed to examine the internal consistency reliability of the revised HCS and HIS. Internal consistencies were considered satisfactory if the Cronbach's α values were at least 0.70 (Calefato *et al.*, 2008).

Finally, Pearson correlation analysis between the revised HCS and CHIP, HIS and FIM was carried out to demonstrate the concurrent validity of the revised subscales.

5.7.1. Construct validity

Initial confirmatory factor analysis

Confirmatory factor analysis (CFA) was performed to assess the model fitness (Pett *et al.*, 2003). An initial confirmatory factor analysis (CFA) was specified with 6 factors and 36 HIS items as indicators. The fit for the original six-factor model was poor: χ^2=464.54, *df*=98, *p*<0.001; *CFI*=0.73, *TLI*=0.67, *RMSEA*=0.12, *SRMR*=0.09. The initial confirmatory factor analysis (CFA) was specified with 4 factors and 16 HCS items as indicators. The fit for the original four-factor model was poor: χ^2=1489.58, *df*=579, *p*<0.01; *CFI*=0.77, *TLI*=0.75, *RMSEA*=0.08, *SRMR*=0.07. The poor fit of the original model indicated that another optimal structure might represent the data better.

Item- to- total correlations (ITCs)

ITCs of the HIS and HCS were calculated and evaluated as an indicator of construct validity using the minimum acceptable correlation criterion of 0.30 (DeVon *et al.*, 2007; Ferketich, 1991; Kim *et al.*, 2014; Pett *et al.*, 2003). The item was not associated adequately with other items to contribute meaningfully to measurement if its *ITCs*<0.30 (Ferketich, 1991). Kim and colleagues (2014) stated that each item in a scale should be an adequate measure of the construct of interest. Therefore, items with *ITCs*<0.3 should have been removed before conducting the exploratory factor analysis (Dixon, 2004; Pett *et al.*, 2003). The results (*r*=0.31-0.67) indicated that all items were retained for exploratory factor analysis.

Exploratory Factor Analysis (EFA)

EFA was conducted to determine the optimal factor structure of the HIS and HCS items for this sample.

1) Exploratory Factor Analysis for Hospitalization Impact Scale (HIS)

The EFA showed that the HIS items were loaded under seven factors with the load ranging from 0.43 to 0.91 (Table 14). Two items (item 14 “We cannot rely on others to take care of our child”; item 31 “cannot freely adopt alternative therapies) were removed since their factor loadings were less than 0.30 (Nunnally & Bernstein, 1994). EFA of the retained 34-item HIS showed items loaded on seven factors with the load ranging from 0.45 to 0.92 (Table 15). EFA in Mplus 5.1 also provided fit statistics indicating how well each of 1- to 7-factor solutions fit the data as shown in Table 16. The seven-factor model was found to meet all the criteria for good model fit, *RMSEA=0.049, CFI=0.992, TLI=0.986 and SRMR=0.031*, indicating that a seven-factor model of the HIS provided the best fit for the data. Since the nature of the items in the sixth and seventh factors both pertained to the impact on family functioning, the decision was made to combine them into one factor, namely, family functioning impact. Finally, the revised 34-item HIS included six factors, psychological impact, physical impact, extra burden, health service utilization impact, social impact, and family functioning impact.

There were several differences between the original and revised HIS; first, the number of items, with the original version having 36 and the revised version 34 because of the removal of items 14 and 31. Second, item 6 and item 30 were included in the physical impact and family functioning impact factor in the original HIS, however, item 6 loaded on psychological impact, while item 30 loaded on extra burden factor in the revised HIS. Finally, four items (item 12, 19, 17, 20) were included in family functioning impact in the revised HIS while they were included in the social impact factor in the original version of the HIS (Table 15).

Table 14 Factors derived from Exploratory Factor Analysis for the Hospitalization Impact Scale

Hospitalization Impact Scale		**Factor loadings**						
		Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7
7	cannot concentrate at work	**0.51**	-0.10	-0.05	-0.07	-0.02	-0.05	0.01
13	do not know how to deal with our child's emotions	**0.43**	0.04	0.02	0.09	0.19	-0.04	0.22
11	worry about disease progress	**0.49**	0.08	0.06	0.05	-0.05	0.08	-0.09
15	consider our child's condition is serious	**0.53**	0.07	0.07	0.11	0.22	0.09	-0.03
9	feel guilty for inadequate care leading to hospitalization	**0.68**	-0.01	0.11	-0.01	0.08	0.04	0.02
8	feel nervous	**0.61**	0.07	0.07	0.05	-0.12	0.06	0.01
5	emotions fluctuate according to our child's medical condition	**0.73**	0.07	-0.01	-0.04	-0.23	0.03	0.03
16	want to care for my child but feel inadequate to do so	**0.71**	-0.03	-0.12	0.05	-0.01	-0.07	0.12
6	become irritable	**0.63**	-0.02	0.06	0.05	-0.02	-0.01	0.18
10	feel hurt because my child is suffering in hospital	**0.46**	0.06	-0.17	-0.05	-0.33	0.11	0.04
2	health is adversely affected	0.12	**0.46**	0.10	0.14	-0.03	-0.19	0.07
3	cannot sleep well	0.22	**0.72**	-0.01	-0.06	0.06	0.02	-0.11
1	feel tired	0.13	**0.80**	0.04	-0.02	0.01	0.02	-0.03
4	lost appetite	-0.04	**0.74**	-0.08	-0.01	-0.05	-0.01	0.03
27	losing time from work with reduced income	0.03	-0.03	**0.71**	-0.11	-0.04	0.02	0.22

28	have more expenses	0.02	0.07	**0.80**	-0.03	-0.15	-0.07	0.01
29	have extra burdens	0.09	0.03	**0.67**	0.29	-0.05	0.04	0.02
30	burden can hardly be understood by others	-0.16	0.01	**0.61**	0.06	0.04	0.02	0.40
32	have feelings that hospital staff are too busy to be bothered	0.09	-0.07	0.13	**0.60**	0.04	0.08	0.01
33	cannot adapt to the hospital environment	-0.01	-0.12	0.01	**0.79**	-0.030	0.002	-0.01
34	do not know details of our child’s condition	0.04	0.10	-0.06	**0.60**	0.03	0.13	0.01
35	worry about malpractice	0.22	-0.02	0.04	**0.54**	-0.05	-0.06	-0.09
36	cannot adapt to the hospital routines	-0.06	0.03	-0.12	**0.80**	-0.05	-0.05	0.05
18	have to give up a lot of things	0.19	0.01	0.13	0.04	**0.51**	0.02	-0.03
24	see family and friends less	0.01	0.18	0.04	0.05	**0.64**	0.01	0.06
25	unable to take a stroll or travel out of the town	-0.02	-0.04	0.03	0.12	**0.72**	0.04	0.01
26	too busy and have no free time	0.01	0.18	0.05	0.18	**-0.48**	0.13	0.03
12	are more tolerant of our child’s misbehavior	-0.02	-0.01	-0.01	0.11	-0.02	**0.91**	0.01
19	do not have much time left for other family members	0.09	-0.03	0.06	0.03	-0.01	**0.86**	0.01
17	daily life needs to be changed	0.13	0.16	0.11	-0.04	-0.22	**0.45**	-0.02
20	cannot complete the household chores	0.01	0.11	-0.13	0.07	-0.09	**0.47**	0.10
22	seldom have a chance to talk about problems we encounter	0.17	-0.01	-0.04	-0.002	0.22	-0.04	**0.69**
21	blame each other for improper care	0.01	0.11	0.01	0.10	-0.01	0.25	**0.57**
23	relationship is affected because of the bad mood	0.01	-0.01	0.11	-0.07	0.01	0.14	**0.82**

Table 15 Results of Exploratory Factor Analysis for the revised Hospitalization Impact Scale (34 items)

	Hospitalization Impact Scale#	**Factor loading**						
		Factor 1 Psychological impact	Factor 2 Physical impact	Factor 3Extra burden	Factor 4 Health service utilization impact	Factor 5 Social impact	Factor 6 Family functioning impact	Factor 7
7	cannot concentrate at work	**0.51**	-0.10	-0.05	-0.07	-0.02	-0.05	0.01
13	do not know how to deal with our child's emotions	**0.45**	0.05	0.02	0.09	0.20	-0.04	0.24
11	worry about disease progress	**0.51**	0.08	0.06	0.05	-0.06	0.08	-0.10
15	consider our child's condition is serious	**0.48**	0.07	0.07	0.11	0.22	0.09	-0.04
9	feel guilty for inadequate care leading to hospitalization	**0.68**	-0.01	0.11	-0.01	0.08	0.04	0.02
8	feel nervous	**0.58**	0.08	0.07	0.05	-0.11	0.06	0.03
5	emotions fluctuate according to our child's medical condition	**0.73**	0.05	-0.01	-0.04	-0.23	0.03	0.02
16	want to care for my child but feel inadequate to do so	**0.72**	-0.05	-0.12	0.05	-0.01	-0.07	0.13
6	become irritable	**0.62**	-0.03	0.06	0.05	-0.02	-0.01	0.20
10	feel hurt because my child is suffering in hospital	**0.47**	0.03	-0.17	-0.05	-0.33	0.11	0.04
2	health is adversely affected	0.13	**0.47**	0.10	0.14	-0.03	-0.19	0.07
3	cannot sleep well	0.23	**0.68**	-0.01	-0.06	0.06	0.02	-0.12
1	feel tired	0.12	**0.81**	0.04	-0.02	0.01	0.02	-0.04

4	lost appetite	-0.02	**0.76**	-0.08	-0.02	-0.05	-0.01	0.04
27	losing time from work with reduced income	0.04	-0.03	**0.72**	-0.11	-0.04	0.02	0.24
28	have more expenses	0.05	0.07	**0.80**	-0.03	-0.15	-0.07	0.02
29	have extra burdens	0.02	0.03	**0.65**	0.29	-0.05	0.06	0.01
30	burden can hardly be understood by others	-0.09	0.01	**0.62**	0.06	0.04	0.02	0.41
32	have feelings that hospital staff are too busy to be bothered	0.16	-0.07	0.13	**0.62**	0.04	0.08	0.02
33	cannot adapt to the hospital environment	-0.02	-0.11	0.01	**0.81**	-0.03	0.01	-0.02
34	do not know details of our child’s condition	0.07	0.11	-0.06	**0.61**	0.03	0.13	0.02
35	worry about malpractice	0.26	-0.02	0.04	**0.54**	-0.05	-0.06	-0.08
36	cannot adapt to the hospital routines	-0.09	0.03	-0.12	**0.81**	-0.05	-0.05	0.05
18	have to give up a lot of things	0.19	0.01	0.13	0.05	**0.52**	0.02	-0.03
24	see family and friends less	0.01	0.18	0.04	0.09	**0.66**	0.01	0.06
25	unable to take a stroll or travel out of the town	-0.02	-0.04	0.03	0.11	**0.71**	0.04	0.01
26	too busy and have no free time	0.01	0.17	0.08	0.19	**0.49**	0.13	0.06
12	are more tolerant of our child’s misbehavior	-0.02	-0.01	-0.01	0.11	-0.02	**0.92**	0.01
19	do not have much time left for other family members	0.09	-0.03	0.06	0.03	-0.01	**0.87**	0.03
17	daily life needs to be changed	0.17	0.17	0.11	-0.04	-0.22	**0.47**	-0.03
20	cannot complete the household chores	0.01	0.16	-0.13	0.07	-0.09	**0.46**	0.11

22	seldom have a chance to talk about problems we encounter	0.17	-0.01	-0.04	-0.01	0.22	-0.04	**0.72**
21	blame each other for improper care	0.01	0.11	0.01	0.10	-0.01	0.25	**0.60**
23	relationship is affected because of the bad mood	0.01	-0.01	0.11	-0.07	0.01	0.14	**0.84**
Cronbach's α=0.92		0.84	0.80	0.78	0.77	0.81	0.82*	0.80*
							0.81**	

* The Cronbach’s α value of sixth and seventh factors before combination. ** The Cronbach’s α value after combination.

Deleted items (item 14 ‘We cannot reply on others to take care of our child’; item 31 ‘Cannot freely adopt alternative therapies’) with factor loadings ranging from 0.07-0.26.

Table 16 Fit Indices for Exploratory Factor Models of the revised Hospitalization Impact Scale

Measure	***χ2***	***df***	***CFI***	***TLI***	***RMSEA***	***SRMR***
1 Factor	4709.099	594	0.898	0.885	0.144	0.095
2 Factors	3477.615	559	0.932	0.919	0.121	0.073
3 Factors	2459.167	525	0.951	0.937	0.106	0.063
4 Factors	1903.468	492	0.966	0.953	0.092	0.053
5 Factors	1439.378	460	0.979	0.969	0.075	0.043
6 Factors	1039.958	429	0.987	0.980	0.060	0.036
7 Factors*	598.668	370	0.992	0.986	0.049	0.031

*The seven-factor model was found to meet all the criteria for good model fit.

2) Exploratory Factor Analysis for Hospitalization Coping Scale (HCS)

Regarding the HCS, the EFA showed that the items were loaded under three factors with the load ranging from 0.47 to 0.89 (Table 17). Item 10 (‘Do not expect too much and do not plan for too long’) was removed since its factor loading was less than 0.30. EFA of the 15 retained items showed all items loaded on three factors with the factor loading ranging from 0.49 to 0.98, as shown in Table 18. Fit statistics of 1- to 3-factor solutions fit the data, as shown in Table 19. The three-factor model was found to meet all the criteria for good model fit, *RMSEA=0.06, CFI=0.98, TLI=0.96 and SRMR=0.04*, indicating that a three-factor model of the HIS provided the best fit for the data. The researcher renamed the factors of the revised HCS based on the item contents. Finally, the revised 15-item HCS included three factors, namely maintaining mental stability, mutual support for childcare and seeking support from external systems. Table 18 presents all factor loadings for the 15 items of the revised HCS.

There were two differences between the original and revised HCS. The first was the number of items. The original version included 16 items while the revised version contained 15 because of the removal of item 10. Second, the structure of the revised HCS was different from the original version. The original version contained four factors, while the revised HCS had three. The names of the factors were different.

Table 17 Factors derived from Exploratory Factor Analysis for the Hospitalization Coping Scale

Hospitalization Coping Scale		**Factor loading**		
		Factor I	Factor II	Factor III
1	try to relax and control emotions	**0.47**	-0.13	-0.13
6	consider hospitalization can be more of a relief to us	**0.53**	-0.02	-0.06
8	treat my child as usual	**0.59**	-0.24	0.06
9	encourage family members, including the sick child, to express their inner most feelings	**0.70**	-0.04	-0.04
13	hope things will get better	**0.89**	0.04	-0.01
2	support each other and share responsibilities	-0.04	**0.50**	-0.19
3	stay close to my child	0.06	**0.75**	-0.01
4	prepare food for my child	0.15	**0.64**	0.07
5	keep asking doctors and nurses questions, and monitor the child closely ourselves	0.13	**0.61**	0.03
7	make use of what we see in hospital as learning experiences	-0.02	**0.79**	-0.02
14	cut down working hours to participate more in childcare	0.14	**0.71**	0.01
16	try our best to endure and be co-operative	0.02	**0.61**	-0.24
11	seek and accept help from relatives	-0.07	0.11	**0.79**
12	seek and accept help from friends	0.12	0.01	**0.87**
15	ask relatives and friends about hospitalization experiences	0.21	0.05	**0.52**

Table 18 Factors derived from Exploratory Factor Analysis for the revised Hospitalization Coping Scale (15 items)

Hospitalization Coping Scale[#]		**Factor loading**		
		Factor I: Maintaining mental stability	Factor II: Mutual support for childcare	Factor III: Seeking support from external systems
1	try to relax and control emotions	**0.49**	-0.15	-0.14
6	consider hospitalization can be more of a relief to us	**0.51**	-0.02	-0.06
8	treat my child as usual	**0.59**	-0.23	0.06
9	encourage family members, including the sick child, to express their inner most feelings	**0.72**	-0.05	-0.04
13	hope things will get better	**0.98**	0.05	-0.01
2	support each other and share responsibilities	-0.04	**0.53**	-0.21
3	stay close to my child	0.07	**0.77**	-0.02
4	prepare food for my child	0.16	**0.67**	0.08
5	keep asking doctors and nurses questions, and monitor the child closely ourselves	0.13	**0.65**	0.04
7	make use of what we see in hospital as learning experiences	-0.04	**0.79**	-0.03
14	cut down working hours to participate more in childcare	0.14	**0.72**	0.01
16	try our best to endure and be co-operative	0.02	**0.62**	-0.28
11	seek and accept help from relatives	-0.07	0.11	**0.78**
12	seek and accept help from friends	0.11	0.01	**0.89**
15	ask relatives and friends about hospitalization experiences	0.23	0.07	**0.53**
Cronbach's α=0.87		0.78	0.83	0.79

Deleted items (item 10 ‘Do not expect too much and do not plan for too long’) with factor loadings ranging from 0.14-0.17.

Table 19 Fit Indices for Exploratory Factor Models of the revised Hospitalization Coping Scale

Measure	***χ2***	***df***	***CFI***	***TLI***	***RMSEA***	***SRMR***
1 Factor	1609.161	104	0.817	0.789	0.106	0.092
2 Factors	542.313	89	0.944	0.924	0.067	0.061
3 Factors*	202.384	75	0.977	0.963	0.059	0.045

*The three-factor model was found to meet all the criteria for good model fit.

5.7.2. Coefficient of internal consistency of HICS

The internal consistency reliability coefficients for the two subscales were 0.92 and 0.87 respectively. The Cronbach's alpha values of factors ranged from 0.77 to 0.86. Detailed information about the Cronbach's alpha coefficients for each factor are provided in Tables 15 and 18.

5.7.3. Concurrent validity of HICS

Tables 20 and 21 contain the correlation coefficients between the HICS and the FIM, CHIP. The impact subscale of the HICS was significantly correlated with the FIM (r=0.64; $p<0.01$).The coping subscale of the HICS was correlated with CHIP (r=0.48;$p<0.01$). The absolute values of the correlation coefficients among the factors ranged from 0.21 to 0.57. Coefficient values less than 0.3 indicated a weak relationship and factors included in different instruments measure different foci (Godwin *et al.*, 2013).

Table 20 Correlations between revised Hospitalization impact scale and Family Impact Module (*r**)

Correlations	Total impact	Psychological impact	Physical impact	Extra burden	Social impact	Health Service utilization impact	Family functioning impact
FIM	-0.64	-0.54	-0.48	-0.48	-0.48	-0.33	-0.57
Parental QOL	-0.64	-0.55	-0.48	-0.52	-0.49	-0.31	-0.54
Family functioning	-0.46	-0.36	-0.35	-0.33	-0.33	-0.29	-0.49
Physical	-0.55	-0.43	-0.46	-0.43	-0.44	-0.26	-0.43
Psychological	-0.57	-0.51	-0.43	-0.46	-0.36	-0.29	-0.44
Social	-0.46	-0.34	-0.29	-0.38	-0.43	-0.21	-0.35
Cognitive	-0.50	-0.43	-0.41	-0.36	-0.37	-0.22	-0.44
Communication	-0.48	-0.41	-0.30	-0.41	-0.36	-0.25	-0.45
Worry	-0.45	-0.42	-0.30	-0.38	-0.28	-0.27	-0.35
Family activity	-0.49	-0.37	-0.34	-0.33	-0.42	-0.29	-0.46
Family relationship	-0.36	-0.27	-0.30	-0.28	-0.21	-0.24	-0.42

*Note: All correlations are significant at 0.01.

Table 21 Correlations between revised Hospitalization Coping Scale and Coping Health Inventory for Parents (*r**)

Correlations	**Total score of CHIP#**	**CHIP1a**	**CHIP2b**	**CHIP3c**
Total score of HCS	0.48	0.48	0.41	0.43
Maintaining mental stability	0.42	0.43	0.39	0.36
Mutual support for childcare	0.38	0.41	0.31	0.35
Seeking support from external systems	0.32	0.32	0.27	0.31

*Note: All correlations are significant at 0.01.

[a] Maintaining family integration, cooperation, and an optimistic definition of the situation

[b] Maintaining social support, self-esteem, and psychological stability

[c] Understanding the medical situation through communication with other parents and medical staff

5.8. Summary

This chapter has described the results from the quantitative survey with 253 parents from different families with children hospitalized for cancer treatment. The results revealed that a family was affected moderately by a cancer child's hospitalization, with social functioning mostly being affected. The longer the duration of a child's hospitalization and the worse a child's condition was, the higher the family impact score was. Effort to maintain positive and active parental care was the most effective coping strategy perceived by families for handling these negative impacts. The older the hospitalized child was, the more likely that the family could cope well. The number of readmissions adversely affected the effectiveness of family coping. Religious background was another factor identified as protecting the family from ineffective coping.

Psychometric properties of the Hospitalization Impact and Coping Scale (HICS) were also examined. The revised HICS demonstrated sound reliability, construct validity and concurrent validity among the families with children hospitalized for cancer treatment.

Qualitative results will be presented in the next chapter.

CHAPTER 6 RESULTS OF QUALITATIVE STUDY

This chapter presents the findings of the qualitative study. It begins with the profiles of the families participated into the interviews, and then presents the themes and categories generated from the qualitative study.

6.1. Profile of the study population

In total, 19 parents (5 fathers and 14 mothers) from 19 families participated in the qualitative study. Of the 19 families, 8 were considered to be coping well, with coping scores more than 45, while 11 were regarded as experiencing serious ineffective coping, with scores less than 30. Sixteen children were diagnosed with ALL, and the rest were diagnosed with malignant lymphoma or neuroblastoma. All the children were still in active chemotherapy at the time of the interviews. The total days of all admissions ranged from 21 to 800, while the number of readmissions ranged from 1 to 50. The children were all aged less than 13 years old. Table 22 presents the profile of the study population.

Most of the parents involved in the qualitative study were willing to share their hospitalization experiences with the researcher. During the interviews, parents seemed relieved and, although some mothers cried while narrating their experiences. They said that describing their experiences gave them comfort because it was an opportunity to vent and they felt they were helping others as well.

Table 22 Profile of the interviewees

No	Subjects	Interviewees	Number of children	Coping/impact	Family structure	Family monthly income (RMB)	With a religion	Diagnosis	Total days of all admissions (ds)	Number of readmissions (TS)	Age of child (Y)
1	S16	Mother	2	60/79	Nuclear	5000	Yes	ALL	100	4	11
2	S17	Father	3	55/70	Nuclear	2000	Yes	ALL	21	1	12
3	S11	Mother	1	54/94	Nuclear	0	Yes	ALL	360	9	7
4	S19	Mother	2	53/82	Joint	2000	Yes	ALL	180	11	9
5	S9	Father	1	47/124	Joint	3000	No	ALL	35	2	2
6	S10	Mother	3	48/113	Nuclear	0	Yes	ALL	350	12	9
7	S18	Father	4	50/79	Joint	3000	No	Malignant rhabdomyoma	150	13	4
8	S8	Mother	1	49/129	Nuclear	4000	No	ALL	22	1	3
9	S1	Mother	4	27/100	Joint	0	No	ALL	150	2	7

10	S3	Mother	1	22/94	Nuclear	3000	No	ALL	100	6	4
11	S14	Father	1	27/80	Nuclear	0	No	ALL	120	10	4
12	S15	Mother	1	23/79	Nuclear	3000	Yes	ALL	127	1	10
13	S4	Mother	2	21/100	Joint	3000	Yes	ALL	800	50	13
14	S7	Father	3	23/110	Joint	650	No	ALL	260	8	10
15	S2	Mother	2	24/104	Joint	0	Yes	Neuroblastoma	35	2	3
16	S5	Mother	1	22/114	Nuclear	0	No	ALL	61	3	4
17	S12	Mother	1	21/68	Nuclear	0	No	ALL	108	6	3
18	S6	Mother	1	26/108	Joint	0	No	ALL	163	4	4
19	S13	Mother	4	29/80	Joint	0	No	Malignant lymphoma	350	15	12

6.2. Qualitative findings

The qualitative section captures an in-depth understanding of a family’s situation during a cancer child’s hospitalization. Four themes were identified at the end of the data analysis: (1) family impact; (2) family coping; (3) family adaptation; and (4) unmet family needs. More details were included in Appendix 1. In the following sections, a detailed introduction is given to the above-mentioned themes, one–by-one. All quotes cited throughout this document were taken directly from the raw data. The original quotes were in Chinese, and those that needed to be included in this thesis were translated into English. Two other bilingual (English and Chinese) experienced researchers with PhD qualifications confirmed that the meanings of the English transcripts were consistent with the original Chinese texts.

6.2.1. Theme 1: Family impact

Hospitalization of children with cancer affected not only the children but also their families. Family members faced a lot of challenges and difficulties, which have been referred to in this study as ‘impact’. In this study, five identified categories pertaining to the impact of a cancer child’s hospitalization on a family are: (1) impact on family functioning, (2) heavy financial burdens, (3) impact on parental well-being, (4) impact on hospitalized children’s well-being; and (5) impact on healthy siblings’ psychosocial well-being.

(1) Category 1: Impact on family functioning

According to Miller and colleagues (1994), family functioning is demonstrated by 6 dimensions: problem solving, communication, roles, affective responsiveness and affective involvement, and behavior control. In this study, impacts on family functioning were demonstrated by: (1) change of family focus, (2) change of roles and responsibilities, and (3) altered family relations.

Change of family focus

After children’s hospitalization for cancer treatment, all families reset their focuses with more energy, time and attention being placed on hospitalized children. In some cases, healthy siblings were being neglected for a prolonged time. Families also have abandoned their original day-to-day routines as they regarded hospitalized children as the only center of family life. They believed that the hospitalized children should be given first priority and constantly had in mind.

> *“We have no choice. My son is in hospital for cancer treatment. Both of them (the sick child and his sibling) are my children and deserve good care….[sigh]…My hospitalized son is sick. I should mainly focus on taking care of him.” S19P8L10*

> *"We ignore everything around us. We pour all the attention and energy onto my hospitalized child…… Nothing else matters as much as my child does. Our main concern is our child." S3P5L4*

> *"I always had a happy family. Every day, my husband came home from his work. I picked up my son from his school, and then I cooked the dinner. After the dinner, we went out for a walk together. Now, we seldom go out, even though my son has been discharged and returned home. We cannot go to places crowded with lots of people. I feel…..[sigh]…"S11P12L31*

Change of roles and responsibilities

When a child was hospitalized for cancer treatment, family members were bearing too many readjusted demands, including to accompany sick children receiving treatment, to prepare food, to take care of healthy children at home and to complete housework, etc. Members were compelled to reorganize their roles and responsibilities to handle the pile-up demands, including undertaking new or more responsibilities and disruption of original roles. Changing roles and responsibilities demonstrated how families struggled to adapt.

A mother indicated that her husband had begun to take a new responsibility to prepare food for the sick child in hospital. Another mother mentioned that her 6-year-old son at home took the responsibility to send his young siblings to school.

> *"His (the child's) father has never cooked before, and now I tell him to put his entire attention to cooking because our son has become a fussy eater……. I always ask my husband to seek my child's advice on food preference before cooking. My husband did not even know how to cook before my child's hospitalization….. huh……" S11P12L10*

> *"We have other three healthy children at home. The eldest one is 6 years old. He walks to school every day by himself…….The other two younger children follow him……" S1P4L35*

Another mother expressed that she faced the disruption of her parental role as a tutor for her healthy son at home in the following text:

> *"Well, I never go to work, and I just stayed at home to look after our children and help them with their studies. I used to keep an eye on my son's (her healthy son at home) study……I would ask him to correct it immediately once he made a mistake. So my son's academic performance was not bad at all….[sigh]…but now, it is really poor……." S4P4L34*

A family expressed how they had reoriented their roles and responsibilities during a child's hospitalization. Everyone in the family knew his/her own roles and fulfilled them.

> *"Everything at home has settled down. My family members are reoriented. The old and the youth stay at home. His grandmother takes the responsibility to care for my daughter at home. I stay in the hospital to care for my hospitalized son, while my husband works hard to make money."S19P7L1*

Altered family relations

It describes family relationship issues that occurred due to the stress and dynamics resulting from a child's hospitalization. Some parents in this study reported that the family tie was strengthened after their cancer children's hospitalization. Whereas, others indicated that their family members were not as close because of reduced family time spent together.

> *"I feel we are closer than ever. There was not so much telephone contact before, but now there are lots of calls every day……"S9P3L7*

> *"He (healthy sibling) is not willing to talk a lot with me nowadays. I feel we are not as close as we were. Before his sister's hospitalization, both children were very willing to share their school news with me…….We have been here (hospital) for two-and-a-half years, and only have gone back home three times for short home stays. Each time was about one week or 10 days……We came here in April*

> *and have not returned home for 6 months. We have very little time to get together as a family." S4P4L4*

(2) Category 2: Heavy financial burdens

This category refers to the economic effects of a cancer child's hospitalization on his/her family. Nearly all parents in this study reported that their families were suffering great financial hardships during their cancer children's hospitalization. More than half (10/19) of families indicated that they had to borrow money to cover the costs, which resulted in massive debt. Some also reported an increase in borrowing. Four identified major reasons of family financial burdens were high medical costs, other expenses, change of employment status, and issues related to inadequate health insurance or national financial support.

Medical costs

High medical costs, including treatment costs, regular examinations and childcare, accounted for a great percentage of family expenses. Associated with unpredictable disease outcome, adverse treatment reactions and complications, family payment capacity was likely to be exhausted. The following description presents the medical costs families had to bear:

> *"The first course of chemotherapy cost more than 90,000 RMB…… It will cost more if my child gets an infection. Last month, we spent about 100,000RMB within half a month because my child got a pulmonary fungus infection. We pay all the medical costs ourselves. Medical expenses are relatively high. Besides, blood routine examinations every other day also cost a lot……My family income is less than 1500RMB since my husband just do some casual jobs. The situation is really difficult for us" S1P2L3*

Other expenses

Other expenses, mainly resulting from traveling, lodging, and buying food, were found to be crucial contributing factors of family financial burdens.

A mother reported that they came from the rural area and had to travel a great distance to big cities for treatment. Frequent and long-distance travelling between the hospital and home costs a lot.

> *"We are from a village. Our home is very far away from the hospital. Frequent traveling between home and hospital cost us a lot. We return home immediately once the short treatment course is finished because we have another two children at home who need to be cared for……My husband and sick daughter have to come to the hospital several times before hospitalization to book an unoccupied bed. Two round trips cost 300 RMB. If there is a vacancy, they will take it immediately; otherwise, they need to return home. We travel back and forth many times, which costs a lot of money." S10P1L21*

Due to inconvenient transportation and children's susceptibility to infection, parents chose to rent rooms near the hospital instead of going home during a child's hospitalization.

> *"My hometown is far away from the hospital. We rent a room nearby the hospital. It costs about 7000-8000RMB for half a year……" S14P3L5*

Parents need to purchase food for themselves and their hospitalized children. They complained that the food was expensive and not appealing. Parents usually buy several special foods to satisfy the hospitalized children's taste, it could be costly.

> *"We spend 50-60 RMB to buy food every day; even breakfast will cost a few dollars. Sometimes, the food is not to her taste, so I will buy more food with different tastes, and then the child can choose and eat more. The food is very expensive here, while a meal costs very little at home." S10P3L23*

Decreased family income

Decreased family income due to change of employment status was another factor could aggravate family financial burdens. Parents expressed that their family incomes had decreased since they had to reduce their work times or quit their jobs to participate more in long-term childcare during their children's hospitalization. The following illustration indicated the loss of family income caused by a change of employment status:

> *"The most serious is the financial burdens. Both of us cannot go to work and we need to stay here to care for the hospitalized child. We have no family income now……The length of my child's hospitalization is extremely long and both of us cannot go to work to earn money." S10P3L13*

Issues related to inadequate health insurance or national financial support

Health insurance could alleviate family financial burdens to some extent. Often families from rural areas faced difficulties in buying health insurance for their children, and they have to pay for all drugs and medical supplies by themselves. Families with a health insurance also complained about the small coverage of medical costs. The Chinese government has provided financial support for families with children with cancer, several parents complained about the long time waiting for the results of their applications.

> *"We came from a small village. We did not buy health insurance for my child because our financial situation was not good at the time. We intended to buy it two years later when our financial situation got better. However, he was sick and we did not have enough time to buy health insurance for him." S6P1L34*

> *"We have to spend a year to apply the government funding. The procedures are complex. It takes quite a long time. The treatment may be finished when we get the application result…… We may not need the money at that time." S18P3L37*

(3) Category 3: Impact on parental well-being

Well-being is a comprehensive indicator to evaluate how a parent functions every day. During children's hospitalization for cancer treatment, the increased responsibilities led to many negative impact on parents' well-being, such as sleep disorders and other somatic symptoms, anxiety, fear, guilt and adverse impact on social functioning.

Physical functioning

A vast majority of parents indicated that they were suffering various physical health problems resulting from their caregiver roles during their children's hospitalization. The most prevalent problems were deteriorating physical fitness, sleep disturbance and fatigue, change in appetite and weight loss.

Deteriorating physical fitness

Parents sometimes suffered from deteriorating physical fitness (e.g. menstrual problems, flu-related symptoms, pain, dizziness, unstable blood pressure) when they were devoting themselves to care for their hospitalized children. They explained that their deteriorated physical fitness was related to the demands of childcare and the hospital environment.

> *"My health becomes poor after my child's hospitalization. I get sick frequently…..As you know, there are lots of things I have to do every day for my child. I cannot leave her even just for a minute. Even if I get sick, I still have to take care of my child." S5P2L23*

> *"Sometimes I cannot adapt to the temperature-controlled hospital environment. The inside of the hospital is hot, while the outside is cold. We (parents and children) are susceptible to cold in here. Sometimes I feel pain in my legs or back (relating to the air-conditioning environment)." S9P1L30*

Sleep disturbance and fatigue

The normal sleep pattern of family members was interrupted during a child's hospitalization for cancer treatment. The parents reported that they were experiencing troubles in falling asleep, interrupted sleep, and not feeling refreshed in the morning.

It was found that two key causes leading to sleep disturbance were round-the-clock childcare and worries about their hospitalized children. They also reported that the disruption caused by noise and lights in hospital made it difficult for them to get a good night's sleep in hospital. Although they were given the opportunity to sleep, they slept vigilantly, attuned to respond to their children. One mother expressed that her sleeping behavior had reversed completely and she had become used to the sleep-waking habit.

> *"I cannot fall asleep. Even if I can sleep, I feel uncomfortable when I wake up. It looks like that I have been beaten by somebody. Therefore, I do not like to sleep because I feel uncomfortable from head to toe when I wake up. I guess it is because I have to stay up long time for childcare......I am too scared to sleep when my child is undergoing chemotherapy... [Sigh] ....." S1P3L6*

> *"If you ask me what I want most, I will tell you what I most want to do is to have a good sleep. ……I cannot sleep when the child is on a drip. I have to keep an eye on my child every minute. ……When I am going to sleep, my child would call "Mom, I want to go to the bathroom." I am extremely lack of sleep. In general, parents in here almost stay up 24 hours for childcare." S10P2L37.*

> *"I cannot sleep well, but I become used to it. Even though I have time to sleep, I just sleep for an hour and wake up immediately to check whether my child is OK or not.……. I always fear bad things would happen to my child." S10P2L37*

Parents also mentioned about the feeling of tiredness, which was induced by the demands of the caregiving experience and sleep disturbance.

> *"I take care of my hospitalized child all by myself, I feel tired." S19P1L4*

> *"My body is too weak, can't sleep well and that is why I feel so tired." S13P2L4*

Change in appetite and loss of weight

About 80% (15/19) of the parents were experiencing a change in appetite. The parents mentioned that their appetites fluctuated along with their emotional responses to their children's conditions.

> *"At the beginning of my child's hospitalization, I could not eat anything since I was so worried about my child. My weight dropped. Now my appetite is a little bit better, but I still cannot eat well because of my bad moods." S12P4L21*

> *"Sometimes when my child gets an infection and has a fever, we don't want to eat at all. When my child gets better, our moods would improve and we can eat more. When my child doesn't want to eat, we don't want to eat, either." S11P6L8*

Weight loss, a problem reported by nearly half of the parents (8/19), was closely associated with poor appetite. It was difficult for parents to maintain a healthy eating habit while they were devoting all of their attention to their children. A mother reported that they (mother and her spouse) often ate leftovers for the purpose of saving money and avoiding waste.

> *"My weight dropped by 10 kg during the past 6 months staying in hospital…… Both of us (parents) have poor appetites. We don't care what we parents eat, but my sick child's nutrition is extremely important. We parents often eat the leftovers, so we can save some money and avoid wastage." S19P5L34*

Psychological functioning

Parents were struggling with various psychological reactions to their children's hospitalization, such as feelings of sadness and hurt, worries, fear, uncertainty, feelings of inadequacy, mood fluctuations and feelings of guilt.

Feelings of sadness and hurt

About half (9/19) of the parents expressed their feelings of sadness and hurt because of witnessing a child's suffering and traumatic experiences. It was very painful for parents to see the children in pain or distress.

> *"We would feel hurt seeing a child is suffering, no matter who the child is. For instance, the day when we arrived at the hospital, I saw a child who was undergoing a lumbar puncture and was crying loudly, and then I couldn't eat well for 2 days….. I knew it must be very painful. The sight of the poor child crying tugged at my heartstrings. My heart was almost broken and tears rolled down my face. ……It was so pathetic." S 3P7L18*

Worries/ fear

Having a child hospitalized for cancer treatment also elicited worries or fear in parents. The identified contributing factors were: (a) the possibility of dying or relapse of disease; (b) the long-term effects of disease and treatment; (c) the possibility of getting infections; and (e) unbearable financial burdens.

One mother recounted her fear and worry about losing her child:

> *"The result of the first examination indicated that my child had a high residual (an indicator of poor prognosis), I was so worried…I was so worried about losing him…… [Crying]……because my child had been diagnosed with high-risk Acute Lymphoblastic Leukemia, besides, with a high residual…… [Sigh]……" S3P1L7*

The other mother expressed that she was afraid of the possibility of a relapse, particular when she heard about readmission of other children because of a relapse of cancer.

> *"I fear of a relapse, even when the chemotherapy is successfully completed. I always think of these things day and night. I am so worried and afraid when seeing other children coming back (to the hospital) because of relapses." S1P3L11*

Another mother also expressed her worries about the long-term effects of disease and treatment on her child's future.

> *"My child's physical functioning is not as good as he was. The disease and treatment are great traumas. There must be some late side effects that will happen to my child in the future……I am not sure whether my child may be able to return to school and whether he can get married or have a baby. Even if he can go back to school, I still worry that he may have difficulties catching up with other children" S15P3L19*

Another worry one mother mentioned was that her hospitalized child might get infected due to the child's susceptibility to infection.

> *"I worry that my child may get an infection……If so, the chemotherapy would be discontinued because of this." S15P1L11*

The families who could afford the medical costs at the time of the interview indicated that they also worried that they would encounter unbearable financial burdens like other families in the future.

> *"We can afford the cost at the beginning. However, I am not sure in the later stage. For instance, if the cancer relapse …[Sigh]… I worry that we may also be in financial trouble one day." S15P1L18*

Uncertainty

Many parents reported that they were faced with the uncertainty of what lay ahead for their children and families. They had to live with uncertainty about their children's poor prognosis, including the unsatisfying outcomes, the possibility of death, and the manifestation of long-term ill effects.

> *"Everyone knows cancer is a 'bottomless pit'. When my child can be cured, whether my child can be cured, whether my child will survive or die…. We have no ideas! My child's condition may change suddenly. Sometimes, the treatment effect is very good; however, it can change all of sudden. We have to be more watchful. No one can guarantee good treatment results." S10P5L23*

Mood fluctuation

Mood fluctuation was a fairly common symptom among parents of children hospitalized for cancer treatment. Nearly all parents reported that they were experiencing mood fluctuations along with their children's conditions.

> *"At the beginning of my child's hospitalization, a bad mood was wedged in my heart. I thought my child was too ill to survive the cancer. After a short period of chemotherapy, I saw my child's condition improved, and my mood got better too……" S16P3L9*

Feelings of inadequacy

Parents were filled with feelings of inadequacy when facing the harsh reality that they failed to protect their hospitalized children from painful and invasive procedures.

> *"Actually, I can do nothing. My child suffers from painful examinations every day. I want to help him, but I am afraid I am not in a position to do so. I cannot find a way ……"S7P3L7*

Feelings of guilt

Parents often had feelings of guilt when they looked back at what may had 'caused' the hospitalization or disease, such as inappropriate childcare or medicine given previously.

> *"Sometimes I think it is my fault for having delayed my child's diagnosis. I am so sorry for this. I regret not having taken good care of my child……[Crying] ……I always blame myself for having given my child too many medicines….. I still can't figure out the reason and don't understand the cause of his disease." S2P2L36*

Social functioning

During children's hospitalization, parents experienced a disruption of social roles and activities. Some of them had to give up their own careers and social activities to accompany their children in the hospital for cancer treatment.

Change of employment status

Children's hospitalization for cancer treatment sometimes required parents to reduce their working hours, or to leave their jobs for the sake of their hospitalized children.

> *"Both of us are now unemployed. Before my child's hospitalization, I worked in a factory, while my husband did casual jobs. After my child's hospitalization, I had no time to work. I had asked for a long leave from my boss but I resigned later…….Now both of us are out of jobs because my child is sick and hospitalized." S1P2L8*

Disruption of normal social activity and relationship

Most of the parents reported being isolated and ‘trapped’ in hospital during their children’s hospitalization. They have difficulties to participate in their usual social activities. This detached them from their friends.

> *“Before my child’s hospitalization, I used to contact my friends frequently. We met every month and connected with each other through the internet. I haven’t used the QQ chat application since my child’s hospitalization. My friends always send me messages to ask about my child’s condition, but I never tell them. I have many friends in Shenzhen. We met several times a year previously. However, we haven’t met each other at all this year and calls have also become less.” S6P4L29*

(4) Category 4: Impact on hospitalized children’s well-being

This category refers to the impact the sick children experienced during their hospitalization, including the impact on children’s physical, psychological, social and cognitive functioning. Hospitalization for cancer treatment is a painful experience for children. They need to tolerate invasive procedures and side effects caused by their treatment; to readjust interruptions to their social routines; to put up with suspension of leisure activities, disrupted self-image; to adapt to the separation from family members and the unfamiliar hospital environment. All these hospitalization experiences would create impact on the children’s daily well-being.

Physical functioning

This refers to the issues related to cancer children’s hospitalization leading to physical incapability, adverse treatment-related symptoms, and sleep disturbance.

Physical incapability

Due to the hospitalized children’s conditions, some of them were bed ridden. The restricted physical activities naturally have an adverse impact on children' physical functioning and capability. One mother described how the physical restriction could affect her son’s ability to walk after staying in bed for a month:

> *"He (the hospitalized child) had to stay in bed. One month later, we moved into a general ward. Surprisingly, he did not know how to walk because of having stayed in bed for such a long time. He had to 'relearn' how to walk like a little baby." S3P8L1*

Adverse treatment-related symptoms

Cancer treatment can result in many side effects, including a decreased in immunity leading to infection, weight fluctuations, hair loss, anorexia, nausea and vomiting. The texts below describe some symptoms the children suffer:

> *"…… My child got fungal and bacterial infections, so the chemotherapy was discontinued. Many bad things are happening to my child….." S2P2L8*
>
> *"My child experienced hair loss…….His weight increased by10kg." S3P5L37*
>
> *"The appetite turns to be fine once the chemotherapy is stopped. It becomes poor during chemotherapy, he just can't eat anything. He vomits frequently." S15P5L10*

Sleep disturbance

The hospitalized children had difficulties in falling asleep due to poor hospital environment, such as the bright lights, alarms, the noise created by ringing and crying.

> *"We can't sleep well because of the strong lightings and noisy alarms in the hospital. It is the most upsetting. We need to stay for a long time. Even though we parents can stand the noisy environment, the children are unable to bear it. …… Several children in this room often cry all night long. My daughter just can't fall asleep." S13P4L23*

Psychological functioning

The traumatic experiences of hospitalization placed children at risk of a range of psychological responses, including guilt, sadness/unhappiness, fear and worries, missing home and close people.

Sadness / unhappiness

The major reasons for children's sadness or unhappiness during hospitalization were the disruption of family activities and separation from significant others.

One mother reported that her son had expressed his unhappiness resulting from the disruption of pervious family activities:

> *"He (hospitalized child) said, 'Mom, I am sick. I can't enjoy whatever I like or go to a big restaurant to enjoy the food as before.' We always went out together as a family for breakfast and lunch. We used to go to a vacation village and had barbecues with friends. But now, my son said, 'Mom, I can't go there anymore'."....[Sigh].... S11P5L15*

Another factor contributing to the hospitalized children's sadness was separation from significant others (classmates and families).

> *"He misses his classmates very much. Last time, one of his classmates called him and he cried sadly. He asked me whether he could visit his school when we go back home." S11P5L22*

> *"My child says that he misses his father every day. What he thinks about is going back home. He cried sadly several times and asked me to take him home. He called his father to come to the hospital to take him home." S6P3L40*

Fear of death and medical examinations

Parents reported that the hospitalized children were afraid to die and to receive frequent medical examinations. The following texts indicate some of the hospitalized children's fears:

> *"She knows little about her disease. She learned from movies that people with leukemia die. She even asked me whether she would die or not……I know she is afraid of death." S1P6L26*

> *"He is afraid of lumbar punctures. His worst fear is going into that small room for lumbar punctures." S8P7L11*

Feelings of guilt

A feeling of guilt often came up soon after the hospitalized children realized that their diseases and hospitalization were causing great difficulties to the families. One mother described her daughter's guilt feelings after knowing her family's financial difficulties:

> *"My daughter once told her older brother 'Our parents spend all the money to cure me. There is no money for your tuition and marriage.' She thought her disease cost all our money…… she even told me that she wanted to stop the treatment." S16P2L25*

<u>Social functioning</u>

Social functioning refers to the disruption of children's normal childhood roles and social activities during their hospitalization. Parents reported that their children experienced social isolation and disrupted social development during hospitalization.

Social isolation

Most parents reported that their children were being isolated in the hospital to avoid getting infections. Usually, the children were isolated in single rooms for extended periods. They couldn't receive visitors or to visit others, and parents were the only persons they could reach. Mothers expressed how the long-term hospitalization isolation affected the children's social skills.

> *"My child has been isolated in a single room to protect him from getting infections. We never go outside of the room, so we are not familiar with people around here." S3P7L35*

> *"Last year, my child couldn't speak after he had been isolated in the ward for several months. I had to accompany him all the time." S13P2L13*

Diminished social skills

Hospitalization also affected sick children's social skills in some cases. Some parents expressed that the hospital environment was not facilitating and that their children encountered difficulties in making friends with others of similar age. Some others reported that their children reduced contact with classmates and friends intentionally because of long-term separation and negative self-image. One mother even reported that her child showed a sign of withdrawal behavior.

Additionally, the children had difficulties in making friends in hospital because they had no access to other children of similar age. One mother described her daughter's difficulty in making friends:

> *"My child is 13 years old. The other children living in the same ward are much younger than her. It is a little difficult for her to play with the younger children, so she feels the hospital life is very boring." S16P5L1*

The hospitalized children found it was difficult to communicate with classmates and friends because of long-term separation from them. One mother mentioned that her daughter thought her and her classmates were living in two different worlds.

> *"At the beginning of her hospitalization, she called her friends every day. Recently, she hasn't want to contact her classmates anymore…….She started to experience difficulties in communicating with her friends because of long-term separation……..She thought it was difficult to find a topic. She felt that they were living in two different worlds." S4P5L8*

While these children were going through the phases of chemotherapy, physical appearance changes happened to them, such as hair loss or having IV canulas, diminished their self-esteem. They perceived themselves as being different. They feared being teased or rejected by their peers. Many parents considered their children were more likely to view themselves as having lower levels of social acceptance from peers.

> *"She is particularly concerned about other peoples' views of her. Kids at home are healthy and do not wear masks or have any IV canulas. She will need to wear a mask when going out. She purposely hides her arm with the canula behind her body because she doesn't want others to see it." S10P3 L37*

Hospitalized children tend to show a sign of withdrawal behavior; for instance, one mother mentioned that her daughter wanted to be close to her all the time and became more dependent on her.

> *"The longer she stays here (hospital), the younger my child behaves. I have to embrace her when she is sleeping……. She used to sleep alone at home. I must be together with her all the time. Otherwise, she will cry." S10P5L11*

Cognitive functioning

Cognitive functioning refers to the impairments in cancer children's cognition during hospitalization. Some parents found that their children were absent-minded, slow-witted and clumsy.

> *"The child seems absent-minded. All the children here appear dull because of long-term treatment." 18P1L13*

> *"I feel my child is slow, and is not as smart as he was." S11P11L13*

(5) Category 5: Impact on healthy siblings' psychosocial well-being

During the cancer child's hospitalization, some healthy siblings at home had also presented with adverse psychosocial impacts, as reported by their parents in this study. However, there were also positive changes in some siblings who became more thoughtful and mature.

Sadness because of separation

> *"My daughter knows her younger brother is sick. She always cries at home because of missing her brother." S2P2L18*

> *"I make a call to my home every evening. Otherwise, my little daughter will cry all the time and not go to sleep. She will keep asking, 'Why does Mom not call me?" I told my daughter that I would be back in a few days and she would be better for several days. My daughter misses me very much." S19P4L27*

Jealousy of the disproportionate amount of care being focused on the hospitalized child

> *"I am afraid they (healthy siblings) said we (parents) do not love them. They claimed that mother and father were prejudicial, and parents valued their sister more. I told them, 'All of you are our babies. Mother and father do not have time to care for you all because your sister is seriously sick'." S13P5L12*

> *"Sometimes, I just prepare some food for his sister. He complained that he had nothing to eat while his sister had lots of food. I know he just mentioned it without any purpose. However, what he said is his real thoughts and feelings inside. He is jealous. I can see it. He just does not speak out." S4P4L29*

Attention seeking behavior

> *"My healthy son came to the hospital last summer holiday. He acted like a spoiled child and seemed squeamish. He asked me to do many things for him, such as helping him to take a bath." S4P4L22*

Deteriorated academic performances because of less parental attention

> *"The teacher sent me a message to tell me that my son did not complete his homework. However, I have no mood to talk with his teacher. No one corrects his mistakes in time. My son is a little lazy and spends more time playing." S4P2L3*

> *"They are smart. Their academic performance was excellent. I was absent from home last year. Their academic performance became extremely poor." S13P1L34*

Becoming more thoughtful and mature

> *"He (the healthy son at home) knows his sister is sick and hospitalized. He has become mature. His mother told me that one day she asked him what he wanted to eat. He said drumsticks. Her mother promised to buy him a drumstick later.....However, he said, 'Forget it; I do not want to eat it, save the money for*

> *my sister. 'My heart was broken when I heard this…… He is only six year old. He is so thoughtful." S17P3L28*

> *"He (the sick child's brother) is living with his uncle now. At the beginning, he was separated from us suddenly. He felt confused and was not used to the life without us (parents) because he had never left us before. Now, he has become used to the new life gradually. He is very amenable now…… I think he has accepted the reality already." 18P2L18.*

6.2.2. Theme 2: Family coping

Family coping refers to the strategies and methods employed by a family member or the family as a whole to overcome the adverse hospitalization impact during a cancer child's hospital stay, and their effectiveness. The researcher identified four types of coping strategies in this study: (1) building up family strength, (2) maintaining self-consoling thoughts and behaviors, (3) seeking external support, and (4) covering up the bad.

(1) Category 1: Building up family strength

This describes families' efforts to help family members bond together. It shows how a family mobilizes its internal resources to cope with a child's hospitalization. It is demonstrated by family cohesiveness and mutual support.

<u>Maintaining family cohesiveness</u>

Family cohesiveness represents family members' perceptions of the accessibility and availability of emotional bonding. Everyone belonging to a family with high cohesion moved together fluidly in a complementary pattern during a child's hospitalization for cancer treatment.

Several parents interviewed indicated the importance of family cohesiveness, which was considered as the most effective and strongest resource within a family. Strong family cohesiveness reassured the parents to focus on the hospitalized cancer child with full hearts. Parents considered family members as the most important source of support during this challenging period.

> *"What makes me feel most comfortable and relieved is my family. We understand each other, work together and are all of one mind. Family members bond together. My husband said we should work together as a family and be of one mind. Otherwise, we cannot overcome the stressful situation." S6P2L39*

Maintaining mutual support

Parents in the present study reported that their family members were supportive of one another. In general, both parents were accompanying the hospitalized children receiving cancer treatment, since treatment-related symptoms were too demanding for them, who worked together to stabilize the children's conditions.

> *"The whole family mobilized to handle the current situation. We share responsibilities together. Because we need to prepare food for the child by ourselves, one parent goes to prepare food and the other one will stay at the child's bedside. Both of us stayed in hospital for more than one month during the first treatment course, since the child was experiencing serious emesis and two of us could share the childcare responsibilities." S15P2L2*

> *"We family members understand each other. To be honest, life is not easy for anyone in my family. It is extremely tiring for my mother-in-law to care for my little daughter and older grandmother at home. I do also feel tired caring for my hospitalized son in hospital and cannot sleep well at night. Therefore, we all appreciate each other." S19P4L1*

(2) Category 2 : Maintaining self-consoling thoughts and behaviors

This coping strategy describes parents' efforts to maintain mental stability by maintaining self-consoling thoughts and behaviors. Maintaining self-consoling thoughts and behaviors were demonstrated by being optimistic and focusing on childcare.

Being optimistic

Optimism refers to families disposed to taking a favorable view of events or conditions and to expecting the most favorable or positive outcomes. Some parents chose to be optimistic about whatever life events they encountered. One mother tried to strengthen her optimistic view by using other successful treatment experiences. A father said that he was able to keep optimistic when compared with families having children with incurable diseases. He considered that they were much luckier.

> *"What I wish is that my husband's leg will recover soon and I can take good care of my son. That is all. Being alive is better than anything is. Sometimes I am quite optimistic. It is useless to worry every day." S5P4L28*

> *"The most fortunate thing is that my child still has a chance to be cured…… We are much luckier than others. There is a silver lining that my child can be cured. Every family has its own problems, no exception." S17P4L23*

> *"When I see the treatment is effective for other children, I am not so worried. Some children who are younger than my child can be cured; my child also can be cured." S5P5L16*

Focusing on childcare

Focusing on the hospitalized child's daily care was indeed a self-consoling behavior that helped parents to cope, to avoid guilt feelings and to increase a sense of fulfillment. This is a positive vicious circle for self-consoling behavior (child care) leading to self consoling thoughts (reduced guilt and increased fulfillment) that can keep up the spirit for physical and psychological wellbeing - a fuel for further childcare behaviors.

> *"I will make every effort to take care of my child; otherwise, I will blame myself if some adverse things happen to him. I cannot help him psychologically. What I can do is to devote myself to childcare." S6P2L15*

> *"Although I don't have the appetite to eat, I have to eat more for my child. There is no one can help me to take care of my child if I get sick. I must be strong and eat more for the sake of my child." S2P1L21*

(3) Category 3: Seeking external support

During the children's hospitalization, families also actively sought external professional and social support to cope with the challenges. Professional support was usually provided by medical professionals (e.g. doctors and nurses), while social support was from other family networks (e.g. relatives, friends, other parents and community agencies). External support had alleviated families' psychological and financial burdens to some extent.

Professional support

Parents expressed that they had sought support from medical professionals to cope with their children's hospitalization, including information (related to cancer, treatment, childcare, resources) and emotional support.

> *"When I came here for the first day, the nurse told me that the child should eat less fatty food and fully cooked vegetables and not to eat too much fruit during chemotherapy……Nurses also provided guidance for childcare at home before discharge……. Sometimes, I feel confused about many things. I would understand more after talking with doctors or nurses. That really can relieve a lot of my burden……I usually ask XX, who is an associate nurse leader. She is in charge of half of the ward. I like to talk with her when I am in a bad mood and she always says something that can comfort me. Then I feel relaxed." S19P7L20*

> *"There is a child whose situation is similar to my daughter's. Several days ago, a nurse told me, 'There is a boy diagnosed with M3 (a type of Acute Lymphoblastic Leukemia) and his treatment course has almost been completed. You can talk to his parents and gain some experiences from them.' The nurse was so kind……I appreciate what the nurse has done for my family." S17P2L38*

Social support

Parents also indicated that they had sought and received support from relatives, friends, other families in the hospital and social communities (e.g. schools, government and charity agencies).

Relatives and friends

Relatives and friends could be instrumental in helping with childcare, financial assistance, and emotional support for families during children's hospitalization.

> *"I like to talk with my sister and friends. This allows me to feel relaxed. My sister helps me a lot. I do not have to worry about preparing food, renting a unit and so on. My sister manages all of these things for us." S8P4L28*

> *"My friends call me frequently. I told them my child was receiving chemotherapy. They showed concerns for my child and me. They asked me to give them my bank account number. They provided financial support to my family." S6P4L42*

Other families in the hospital

Parents sought information and emotional support from other families who were experiencing similar situations in the hospital. The shared information was considered as useful and reliable because of their similar and real experiences. The sharing and emotional support was usually mutual and easily accessible in the ward. Families' confidence and abilities to manage day-to-day challenges were enhanced ultimately because of the sharing. Parents valued this kind of support because of its comforting and relaxing nature. It was also helpful in protecting parents from social isolation.

> *"We parents usually talk about how to care for our hospitalized children because we know they are very vulnerable. We also share experiences on how to prevent infection and what we to do when children get infected. We always share some childcare tips. Some families have stayed here for a long time and they have rich experiences. I feel confident when chatting with these parents……We*

> *also like to talk with families having children who have completed the treatment when they come back for reexamination." S5P5L11*

> *"Sometimes, my friends are not available when we want to talk with them. While they are free, I am busy with childcare. But here, we parents can talk with each other anytime, so what I need to do is just walking to the next door." S15P7L9*

> *"To be honest, what we parents can do is to comfort each other. Everyone here is very sad. We have to face all difficulties. We are already stucked in the hospital, we should not isolate ourselves……There are many difficulties ahead of us, it is important for us to find some time to take a break and relax. I would like to talk with other parents. This can allow us to relax for a while." S18P3L14*

Community agencies

One mother reported that her family had received financial support from several community agencies:

> *"We get financial support from the local government. The school donated about 20,000RMB. The media donated 3, 0000 RMB. We also applied for 30,000 RMB from the 'Sunlight' Foundation." S6P3L9*

(4) Category 4: Covering up the bad

Parents tend to hold back unpleasant information (e.g. poor prognosis, incurable conditions) with family members, friends and relatives.

<u>Shielding the sick children from bad news</u>

Most parents in this study had never disclosed the diagnosis of cancer and related information to their children. One mother explained that her reason for filtering information was that her hospitalized child was incapable of understanding and accepting the information.

> *"He knows a little about his disease. He is too young to understand. I never explain it to him." S15P3L7*

Protecting other family members from bad news

Parents were not willing to disclose bad news to family members, with the aim of minimizing the psychological burden on them.

> *"I would only share good news with my wife. She has already borne with heavy psychological burdens. I know more about the cancer and my child's condition, I can handle it better. She knows little about this, so I only tell her what is good while concealing the bad." S17P4L3*

Avoiding talking to friends

Parents reported that they were not willing to share their negative feelings and news with non-family members (friends or relatives). Two factors attributed to this avoidance. First, parents did not want to bother their friends and relatives, who would worry about the child as well if they knew the truth. Second, they worried that their friends might see the family differently when others knew the truth. What a family dislikes most was being labeled as pathetic.

> *"I do not want to bother them (friends and relatives). I am the kind of person who reports only good news. People are happy when sharing some good news, but if it is the bad news, I do not want to tell…." S6P4L26*

> *"Sometimes, when I contact my friends, they are more nervous than me because they think my son is diagnosed with an incurable disease and we must be 'pathetic'. When some of my friends came to the hospital, they began to cry when they saw me. That is why I do not like to contact them." S8P5L23*

6.2.3. Theme 3: Family adaptation

Family outcomes can vary from bon-adaptation to mal-adaptation. By reviewing the categories pertaining to the family impact and family coping above, some characteristics pertaining to bon-adaptation and mal-adaptation were identified.

(1) Bon-adaptation

Bon-adaptation is on the positive side of the family adaptation continuum. A bon-adapted family system can be characterized by close and supportive family relationships, being positive about the financial burdens, being thankful for the assistance received, having adequate available family resources, and being confident about the family's future. Bon-adapted families further gave the message that the availability of internal family resources was the most important. They always relied on their family members and attached a great deal of value to them. This further justified the important of family strength. The families showing bon-adaptation generally reported satisfying lives, an optimistic view of life, and the feeling of being calm in their lives and environments. They typically conveyed a sense of peace and satisfaction even in the face of such a stressful event. The following text provides an example of a bon-adapted family system:

> *Family description: The family is from a rural area. The child was 9 years old and diagnosed with high-risk ALL. The treatment effectiveness was very good. The total days of all admissions were about 180. The child had been hospitalized for 11 times. The mother was caring for the child alone, while the father was working to make money to pay the medical cost. The little daughter was taken care of by the grandmother at home.*
>
> *The mother said: "Now, everything at home seems back to normal. We have adapted it since it has been such a long time. No difficulty is unconquerable. Our family members support and understand each other. Family is the most important support. The effectiveness of cancer treatment on my child is very good. My mood is getting better when I see my son's condition is stable and he is recovering from the cancer gradually. We definitely can get through this stressful event. We trust the doctors and nurses. The medical treatment is advanced and the effectiveness of the chemotherapy is very good. Now I feel relaxed. I hope that medical science can make more achievements in future. As we know, the M3 (a type of leukemia) is curable now, and that would have been impossible ten years ago. Medical science is developing all the time. Although we have to bear high financial burdens during this crisis period, the government provides financial support during our child's hospitalization. Our government is*

> *so generous. We can get reimbursement through the New Rural Cooperative Medical Scheme. It is unrealistic to ask the government to pay all the medical costs for every family. There are numerous children diagnosed with cancer, not just one or two. Our country will bear such a heavy financial burden. Sometimes, I tell my husband that our country and our government are supportive. We have the New Rural Cooperative Medical Scheme and we just borrow some money from relatives or friends. Then we can get through this finally. Families here are similar. We are not the only one with a child with cancer." S19P8L11*

(2) Mal-adaptation

Families were considered to be close to the mal-adaptation side of the continuum if there were a large discrepancy between the demands of the numerous accumulated impacts and family's ability to cope with them. A mal-adapted family system appeared to bear more burdens and adopt ineffective coping strategies. They tended to be disappointed about the child's treatment and facing severe uncertainty about the future, neglected other family members, abandoned some important roles or responsibilities, lacked supportive networks, extremely passive about their current situations, and covered up their feelings. The following text presents a typical mal-adapted family:

> *Family description: The child was 7 years old and diagnosed with high-risk ALL. The treatment effectiveness was not good. There were three siblings at home. The children's grandmother was the only one they could rely on. The length of all admissions was 150 days. The child was hospitalized for the second time.*
>
> *The mother said: "I am not sure whether my child can survive or not. No one knows. My child has been diagnosed with high-risk ALL and at high risk of residual disease. I am filled with uncertainty and extremely worried every day. The child's daily treatment and hospitalization cost a lot. I want to jump off a building with my child. It is difficult for us to move on. We are in despair. Our other three children at home also need to be cared for. Their grandmother now is bearing the responsibility to take care of them. However, their grandmother is*

> *too old to take them to school. They dropped out of school and were being ignored for a long time. We do not have a source of family income. We are farmers and totally depend on the Lao-tian (老天, Heavenly God). Our farmlands have been abandoned because we have no time to do farm work. The elderly at home are in poor health and are incapable of doing the farm work….. [Sigh]….. When I think about these things, I feel hopeless and we do not know what will happen tomorrow. I cannot tell these worries to others, since everyone has their own family. I also do not have a friend I can talk with. Other people cannot understand our suffering. The friends and relatives can only help us for a while but not lifelong. They are not rich and they have their own families. Things are getting really hard for us……" S1P6L7*

6.2.4. Theme 4: Unmet family needs

Most of the parents praised the medical professionals positively. They reported that the medical professionals paid special attention to every aspect of the hospitalized children's needs and endeavored to stabilize the children's unstable conditions. However, we cannot ignore the negative views for the sake of service improvement. These negative views were identified as 'unmet family needs'.

Unmet family needs refer to services that parents perceived as unconducive to bon-adaptation. These unmet needs included warm and supportive attitudes, competent care, health information, comfortable environment and catering support.

(1) Category 1: Unmet need for warm and supportive attitudes

This refers to parents' desire to be treated warmly, fairly and in a friendly way during their children's hospitalization for cancer treatment. These include work attitudes and interpersonal communications.

<u>Unmet need for good working attitudes</u>

During a cancer child's hospitalization, there were some situations where family members felt disappointed or offended when staff did not show respect to their needs or special requests.

A mother expressed her disappointment about the inactive support and guidance received during her child's hospitalization.

> *"Nurses will only answer my questions when I ask them. They never initiate help because they seem so busy, and sometimes they may not be in charge of my child anyway. As you know, they have to comply with their routine tasks." S7P5L5*

One parent reported an incident in which they felt upset when a doctor ignored her desire to protect her daughter from receiving negative information:

> *"Sometimes the doctor asks me to sign the 'Critical Condition Notice". I always ask them to give the notice to me instead of putting it on the bedside table. However, the doctor has put this notice on the bedside table several times. If my daughter reads it, it will affect her mood. " S4P3L19*

Unmet need for sympathetic communication

Medical professionals sometimes displayed unsympathetic attitudes when communicating with parents. Many parents felt that they were treated unfairly and unfriendly. These kinds of situations sometimes became a sore point. A considerable energy was expended on handling these negative emotions. Several parents complained about nurses' unsympathetic attitudes to them:

> *"One nurse said: 'Why do you wash your hands here?' She scolded me loudly. I wanted to cry at that moment. The expression in her eyes, coldness in her voice and attitude, I really felt…… She looked down on us because we came from a rural area, we are not as rich as other families and our clothes are not as good as well. That is why she looked down on us." S8P3L35*

> *"Some (doctors and nurses) are indifferent and cool. However, we have no choice. My child's life is already in their hands. I have to be tolerant." S14P2L18*

(2) Category 2: Unmet need for competent care

Some parents complained about the incompetent care delivery they observed during their children's hospitalization, which has threatened the trust and respect they should have for professional practice:

> *"Some nurses take a long time to complete a task and they are awkward. Some other skilled nurses are responsible and finish tasks quickly. New nurses often make mistakes. Sometimes, they leave several needles in the bed……Anyway, sometimes; I do not feel safe to leave my child to them." S7P5L17*

(3) Category 3: Unmet need for adequate information

Another important category was an unmet need for adequate and honest information, including knowledge about the disease and prognosis, and information about childcare. Appropriate information giving could reduce parents' feelings of uncertainty and protect them from feelings of being out of control over the current situation. Parents expressed their pressing demands for information regarding what is going on and how to care for their children. The following statement illustrates the information parents expected to obtain:

> *"We should be informed about some information at the beginning of the child's hospitalization. The information includes why the child's behavior is like this, what kind of side effects may emerge during the treatment, why the child becomes irritable and some symptoms recur, and so on……" S11P6L17*

Parents reported they often felt insecure and helpless at the beginning of their cancer children's hospitalization because of the unfamiliar environment, which often brought about lots of difficulties in managing daily life in hospital, such as buying food or taking buses. They expressed a need to get information related to hospital surroundings. The following comment illustrates this point:

> *"We knew nothing at the beginning of our child's hospitalization. They should provide adequate information, such as the detailed treatment-related*

> *information, caring and nutrition. The nurses should introduce where to take a bus, buy food, where a restaurant was and where to dry clothes." S11P9L27*

Families expected healthcare professionals to explain honestly according to their experiences about the children's conditions. Some parents would like to know about their children's diseases and the treatment details, while some doctors just mentioned some superficial information. Parents also complained that doctors delayed answering their questions about their hospitalized children's conditions:

> *"The doctor is not willing to tell us too much information about my child. They just mention something superficial. I asked the doctor some questions about the therapeutic regimen several days ago. He said he would explain it to me when he was available. Until now, I have not got any explanation." S14P2L11*

(4) Category 4: Unmet need for a comfortable environment

This refers to the unmet need to have a better environment with good hygiene, adequate facilities and a comfortable ward. Parents expressed that they were often placed in noisy wards without comfortable lighting or neatness. They indicated that they and their children were exposed to noisy sounds, unpleasant light and poor hospital hygiene. Such uncomfortable hospital environments were often linked to burnout. Stress with the disturbances negatively affects their concentration and increases their tiredness. The following comments illustrate this point:

> *"The ward environment is not good. We parents just keep our own areas clean. There are many bacteria in the air-conditioning. The wall is dirty (point to the wall). The ventilation is very poor here." S11P7L38*

> *"The light is the worst. The alarm is ringing all the time. It must be better if some lamps can be turned off. We have to live in the gallery because there are no unoccupied beds in the ward. We are so exhausted because we cannot sleep well at night after a whole day's busy life. …… We are so tired here. This is really an urgent problem need to be settled." S13P4L12*

Since most parents take their children to the big cities to seek the best cancer treatments, the hospitals for pediatric oncology treatment are limited and the available hospital beds cannot meet the needs of all children. Parents expressed that their children were forced to live in crowded wards without adequate beds. Many parents complained that they needed to wait outside for several days due to insufficient beds. It was dangerous for children with cancer living outside of hospital because of their susceptibility to infection. Sometimes, children needed to stay in a corridor. Additionally, hospitalized children may get cross-infections because of crowed wards. Parents expected that their children could be in single rooms, especially those who were seriously ill. The following statement illustrates this point:

> *"Sometimes, beds in the hospital are not available. Then we have to wait outside the hospital for several days. Last time we waited for half a month. There was no remission after treatment in the outpatient clinic, and then the child had to be hospitalized in the ward." S16P5L1*

Some parents voiced an unmet need for supportive hospital rules. They complained that there were so many restrictive rules in the hospital, which enhanced their feelings of stress. They wished that hospital administrators and healthcare providers could be especially committed to providing a supportive environment for families during cancer children's hospitalization. The following texts describe parents' comments on hospital rules:

> *"We are not allowed to hang the towel here (bedside). Nurses ask me to hang it inside, where it is dark. It is difficult to dry the towel. We also are not allowed to hang the towel on the window. There are so many requirements here." S14P3L2*

> *"The nurse leader has so many requests. We can change the sheet only once a week. What shall we do if the child wets the bed? It is too unreasonable. We just have two kettles of water per day. The child drinks more water during intensive chemotherapy. We have no idea where to get it once we run out of water. We have born many stressors already, and we have to tolerate these requirements in the hospital." S12P3L24*

Many parents expressed their unmet needs for necessary facilities. Several parents voiced their dissatisfaction with the hospital facilities. Factors such as inadequate cooking facilities, and no place for parents to stay overnight at the hospital while their children were being treated were noted as frustrations by parents. The following statement describes parents' dissatisfaction with hospital facilities:

> *"There is no facility here, even a microwave oven. I have told the nurse leader and it has not been solved until now. To be honest, a micro oven is necessary because the child eats frequently. He is not allowed to eat cool food." S15P4L13*

(5) Category 5: Unmet need for catering support

Meals are an integral part of hospital treatment and the consumption of a balanced and delicious diet is crucial to recovery. Parents in the study complained about the quality and variety of hospital food. Parents and their children were not satisfied with hospital food because it was too bland, offered few choices and extremely expensive. Most parents preferred to cook themselves rather than buy the hospital food. The following statement illustrates parents' opinions about the hospital food:

> *"We are not used to the hospital food. The child hardly eats it because of the porridge with too much water, limited variety and too many green vegetables. Anyhow, the hospital food does not satisfy my child's appetite." S1P1L24*

6.3. Summary

This chapter has described the results from 19 face-to-face interviews with parents from 19 different families with children hospitalized for cancer treatment. A qualitative method was used to collect the data in order to deepen an understanding of family impact and coping in its entirety. The results revealed that a cancer child's hospitalization affected his/her family adversely. These effects included the disruptions to family functioning and heavy financial burdens. Family members, including the parents, hospitalized children, and healthy siblings experienced decreased well-being. Fortunately, families tended to adopt various coping strategies to adapt to the stressful situation and keep all the tasks manageable. These coping strategies included building up family strength, maintaining self-consoling thoughts and behaviors, seeking external support, and covering up the bad. The characteristics of bon-adapted and mal-adapted families were identified through reviewing family impact and family coping. To give more insights about what is required to achieve bon-adaptation; parents voiced their unmet family needs related to health care service, including supportive medical staff and hospital environment.

The next chapter will discuss the findings in relation to the reviewed literature. The implications of these findings for clinical practice will be suggested.

CHAPTER 7 DISCUSSION

This chapter discusses the quantitative and qualitative results described in Chapters 5 and 6. The results of the quantitative and qualitative sections are integrated to shed light on the implications for clinical practice. Finally, the applicability of the HICS is discussed.

7.1. General findings

This study aims to understand family adaptation by investigating the impact on families and their coping strategies during their cancer children's hospitalization. The quantitative survey revealed that a family was affected moderately by a cancer child's hospitalization, with the social functioning mostly being affected. The longer the duration of a child's hospitalization and the worse a child's condition was, the higher the family impact score was. Effort to maintain positive and active parental care was the most effective coping strategy perceived by families for handling these negative impacts. The older the hospitalized child was, the more coping effectiveness a family perceives. The number of readmissions adversely affected the effectiveness of family coping. Religious background was another factor identified as protecting the family from ineffective coping.

To understand family impact and coping during their cancer children's hospitalization in further detail, parents were then invited to participate in qualitative interviews. Four themes emerged from 19 sets of parents' interviews: family impact, family coping, family adaptation and unmet family needs.

This study used a mixed method to triangulate and complement the findings. For instance, 'covering up the bad' as a culture-specific coping strategy was not covered in the questionnaire when it was originally designed in the general pediatric context. The 'unmet family needs', which can be considered as sources of impact (item 33, item 35-36 concerning professional attitudes, information giving and hospital environment), became more visible and lively when triangulated with the qualitative data. On the other hand, inadequate catering support and staff competence were qualitative data that complemented the quantitative results. These findings were able to enrich the knowledge for future development of the assessment tool when applying it in oncology settings.

The findings from this study supported the Double ABC-X Model. Family adaptation is associated with family coping, family resources, and family perceived impact. Whether a family was inclined to bon-adaptation or mal-adaptation is largely determined by family coping. The relationships among these themes have been reflected by the characteristics of bon-adapted and mal-adapted families. In the following sections, the researcher will discuss the main components of the findings.

7.2. Family impact and its predictive factors

7.2.1. Family Impact

Families were affected moderately by cancer children's hospitalization. They experienced the disruption of family and individual functioning. Compared with families of children hospitalized for reasons other than cancer (Kong, 2010), the families of children hospitalized for cancer treatment appeared to experience more serious impact. This could be explained by the nature of cancer. Children with cancer often experience 2-3 years of repeated and prolonged hospitalization, whereas repeated hospitalization was uncommon for children with non-cancer disease and the length of hospitalization was shorter ranging from two days to two months. The qualitative report provided more in-depth information about family impact, including the disruption of family functioning, heavy financial burdens, and decreased well-being of family members. These qualitative findings further triangulated and enriched the information obtained related to family impact in the quantitative section.

Regarding to the decreased well-being of family members, the qualitative interviews recognized decreases in well-being of the hospitalized children and their healthy siblings, which were not described clearly in this quantitative survey. These are crucial to families, and the impact of hospitalization on them cannot be neglected. This information helps to deepen the understanding of the family situation. It also reminds the researchers that the original questionnaire design has an extension of six items related to the impact of hospitalization on healthy siblings should be attached in future studies.

7.2.1.1. Impact on family functioning

The quantitative survey revealed that family functioning was affected moderately by a child's hospitalization for cancer treatment (7.92±4.16, Range: 0-16). Findings from the qualitative interviews provided more detailed information related to the disruption of family functioning. Having a hospitalized child receiving cancer treatment led to family daily life having to revolve around the hospitalized child. Families' worlds were 'turned upside down' (翻天覆地) during this challenging period. This is similar to the findings of a previous study, in which family members of children with cancer described their lives as 'a broken-life world', which was filled with fear, uncertainty, chaos and loneliness (Bjork *et al.*, 2005). Another study revealed that a cancer child's repeated and prolonged hospitalization caused severe disruption in family life, and that families suffered a situation of disequilibrium (Arabiat *et al.*,2013). Family members in this study experienced change of family focus, change of roles and responsibilities, and altered family relationships. All these studies indicated a fact that a child's hospitalization dramatically disrupted 'normal' family life.

The findings of the present study indicated that families' focus shifted from the entire family to the hospitalized children. A family's time, energy and attention often centered solely on the hospitalized child, a fact that has also been discovered by previous studies (Jones & Neil-Urban, 2003; Kars *et al.*, 2008; Quin, 2005). Change of family focus often lead to the rearrangement of families' roles and responsibilities, so that no family task would be left unmanageable during the hospitalization. Parents were often faced with role conflict; they could not simultaneously be with the hospitalized child at the hospital and with other family members at home, even the healthy children they had left at home. Similar findings were also found in an earlier study conducted with families who had members admitted to an intensive care unit, in which families experienced reallocation of responsibilities and roles (Van Horn, 2000). In another longitudinal study, healthy siblings expressed that they were experiencing a loss of family way of life, in which all things were changed, including routine family activities (e.g. mealtime, regular gathering),family roles and responsibilities, and family events, such as birthdays and holidays (Woodgate, 2006b). As their priorities became to tend to their hospitalized cancer children, families were compelled to establish a new balance through realignment of roles and responsibilities. This reallocation, which put family members’ needs on hold, was maybe the only way families could continue to function.

Our results also showed that family relationships were affected adversely because of the reduction of family time spent together. Spending time together is an important part of family life. This can take place during mealtime, playtime, entertainment activities, or family vacations. It was very difficult for families to find time together because of long-term separation resulting from a cancer child’s repeated and prolonged hospitalization. Members were living as a split family: usually one parent at hospital with the ill child, others at home managing household and sibling care. Family members felt detached, disjointed and isolated. These findings were similar to those revealed in another study, in which fragmentation of families was identified as a major theme (Johnson *et al.,* 1995). In another study, the mothers commented that their marital relationships were often strained because of long-term separation (Clarke, 2006). Fortunately, some families in this study considered their children’s hospitalization enhanced the growth of the family unit and family members bonded closer than ever. Similarly, a study conducted on healthy siblings of hospitalized children found increased closeness and a strengthening of bonds among family members (Prchal & Landolt, 2012). An earlier study exploring family experience after a child’s admission to a pediatric intensive care unit indicated that 85% of family members reported a great bond within the family (Alves *et al*., 2013). Thus, a child’s hospitalization for cancer treatment can either unite family members or cause detachment.

Family functioning is an important factor that can affect a variety of aspects of an individual’s quality of life and family life (Openshaw, 2011). A well-equipped family, which functions in a healthy manner, is capable of managing a variety of normal or unexpected changes that occur throughout a lifetime. Family functioning plays a crucial role in predicting the development of post-traumatic stress and traumatic reactions across a range of stressful situations (Alderfer *et al.* 2009; Meiser-Stedman *et al.,* 2006; Proctor *et al.,* 2007). However, in clinical practice, it seems that family functioning has not been given adequate attention. This may be attributed to time constraints or inadequate interactions with family members. Nurses should be aware of the potential changes to family functioning through interpersonal interactions with family members during their cancer children's hospitalization. Nursing assessment and intervention should not only focus on stabilizing the hospitalized child's condition but on the improvement of family functioning, because family functioning is central to the quality of life in children under treatment for cancer and it may promote positive outcomes for them (Barakat *et al.,* 2010). Family interviews, family counseling and family therapist can be included in the treatment process to help families to maintain healthy family functioning.

7.2.1.2. Financial burden

The quantitative survey revealed that 84.6% of families chose 'great or extreme impact' in response to the item 'have more expenses (traffic and medical cost)'. This high rating was supported by the follow-up qualitative interview, in which all families reported that it was extremely difficult to meet the expenditure caused by their children's hospitalization. More than half of the families were compelled to borrow money to cover the increased expenses. An earlier Chinese study found that financial consideration was a major obstacle for a family to overcome in cancer treatment (Martinson, 1993). This situation has not changed much in a more recent study even in the general pediatric units (Kong, 2010). Financial burden was also discovered in an Australian study, in which the financial burden was the highest impact perceived by parents in the first year of a cancer child's treatment, in which 74% of parents experiencing a great or moderate degree of economic hardship (Heath *et al.,* 2006). Another New Zealand study revealed that 37% of families reported that they needed to borrow money because of the adverse financial impact resulted from the hospitalized children’s cancer treatment (Dockerty & Skegg, 2003).

This probably reflected the reality that the economic impact of their cancer children’s hospitalization and long-term inpatient treatment became a considerable strain for many families despite the socio-economic development of the country. The present study also shed light on the factors contributing to heavy family financial burdens during children’s hospitalization for cancer treatment. These included high medical costs, other expenses, decreased family income and issues related to inadequate health insurance or national financial support.

Medical and other expenses

The medical costs due to cancer treatments far outweighed the other expenses. Medical charges covered the diagnostic procedures, treatments, frequent examinations and inpatient costs. Medical costs were associated closely with a child’s health status. In general, poorer health equals higher medical costs. Once the children were diagnosed with cancer and admitted to the hospital for treatment, families began to worry about their ability to pay the medical costs.

Apart from high medical costs, the other expenses, including travelling, accommodation, food and other miscellaneous items, were also large expense categories. This is consistent with a previous study (Cohn *et al.*, 2003), in which the most frequently reported costs were travel, accommodation and communication. Another study in Canada indicated that the costs associated with travel and accommodations were substantial for many families (Miedema *et al.*, 2008). Dockerty and associates (2003) also found that the transport, food, telephone, gifts and accommodation were typical types of expenditure. They further revealed that the extra amount spent represented approximately 13% of after-tax family income. Since the best treatment for childhood cancer are only available in the capital or big cities in Mainland China, families living in remote areas often travel hundreds of kilometers to big cities to seek the best treatment for their children. Families were more vulnerable to extra expenses if they needed to use expensive inter-city transportation. Similar situation was found in New Zealand, where some children were required to travel large distances from their homes to pediatric oncology centers to receive treatment (Dockerty *et al.,* 2003). Agazio and associates (2003) also revealed that the families residing more than 200 miles from the medical centre appeared to be more stressful than for those from the local areas. Distance from hospital was evidenced to be a better predicting factor of economic hardship (Heath *et al*., 2006).

The accommodation expenses accounted for a portion of the total expenditure. Most families reported that they chose to relocate in the city adjacent to the hospital temporarily for overnight stays during children's hospitalization. Families also needed to find suitable conditions for temporary housing when their children were discharged temporarily from hospital. During this period, usually for weeks or months in between stages of treatment, the children did not need to stay in hospital but required follow-up visits. This study has shown that families from rural areas were at a higher risk of financial disadvantage because of extra travelling and accommodation expenses. These factors related to non-medical costs should be fully recognized in care for families with hospitalized cancer children. Similar situations with the demand for hospital with nearby accommodation appear to be a genuine need for families with hospitalized cancer children; however, the support in different places can be very different. In Hong Kong and Singapore, Ronald McDonald House Charities can help to address the accommodation problems by providing a 'home away from home' accommodation for families, so that they can stay close to their hospitalized children and accommodation expenses can be reduced to some extent. All families at the 'House' can enjoy a well-equipped kitchen, library, dining room, living room, study room, outdoor and indoor play area, laundry and an isolation suite (Ronald McDonald House Charities Hong Kong, 2016; Ronald McDonald House Charities Singapore, 2016). In the UK, Great Ormond Street Hospital (GOSH) aims to relieve some pressure by providing accommodation to children and their families (Great Ormond Street Hospital for Children, 2016). It is reasonable to expect that the hospitals or local government in Mainland China could provide such temporary accommodation service for hospitalized children and their families to alleviate their burdens.

Decreased family income

Decreased family income caused by change of employment is another huge burden. Most families experienced ‘great or extreme impact’ because of losing time from work with reduced income. Parents have to reduce their working hours, take time off from work, or even give up paid work altogether for the purpose of caring for their hospitalized cancer children. Similar results were reported by Longo (2006), who indicated that parents’ loss of employment worsened the family financial burdens. Another study conducted on families having children with acute lymphoblastic leukemia revealed that a majority of parents reported their family income had decreased because of their unemployment since the start of the child’s treatment (Mostert, 2008). All in all, the reduced income was associated with unemployment, change of employment, or reduced working hours for shifting their attention on hospitalized children.

Issues related to medical insurance or inadequate national financial support

Medical insurance provided certain assistance for some families but not all; some had not been able to buy medical insurance for their children because of economic hardship. People from the rural areas could not transfer their insurance from their hometowns, and that applied to over half of the families in this study. Even with medical insurance coverage, reimbursement was only for a small portion of the total costs. Imported medicines, loss of family income, and non-medical expenses were not covered.

Chinese local governments also provide some funds to help families with children with cancer. However, families had to wait a long time for payment because the application process was complex. Families bore extra unnecessary burdens resulting from the delays between their applications and the receipt of benefits.

There have been some differences in health policies reported in different countries. For example, a USA study reported that non-medical costs were not reimbursed (Lansky *et al.,* 1979), which was similar to the situation in Mainland China. However, Australian families with children with cancer will qualify for government assistance once the diagnosis confirmed. This assistance includes a nominal weekly caregiver’s allowance, prescribed medication subsidies, and reimbursement of some travel and accommodation costs (Cohn *et al.*, 2003). The Canadian Cancer Society also assists cancer patients and their families with transportation funding (Lightfoot *et al.*, 2005). In New Zealand, government agencies provided both parents with financial support (e.g. transportation, accommodation, meals) at the very beginning of the treatment, but at other times provision is only for one parent (Dockerty *et al.,*2003). The family financial burdens may differ in different societies due to the extent of support and reimbursement of costs. In the present study with Chinese families, both parents usually had to abandon their paid work and travel long distances to hospital with their children. Financial difficulties related to non-reimbursed expenses could be extremely stressful. It will be helpful for the families if Chinese government could extend the scope of health insurance reimbursement categories and increase the reimbursement portion. Related government agencies could also alleviate family burdens by simplifying the funding application procedures and shortening the waiting time for application and payment.

Although financial issues emerged as a significant concern for families during children’s hospitalization, none of the parents ever expressed that they would choose to withdraw care for their children because of financial strains. Many parents struggled with financial difficulties through working harder or borrowing more from their friends and relatives. China needs to evaluate and recognize the existing supportive financial programs for families with children hospitalized for cancer treatment, or to encourage more community support at different levels (e.g. charity agencies, media, schools) to solicit financial support for the families. When the burden of financial struggles is relieved, families may be more focused on the care for their hospitalized children with the hope of better treatment outcomes.

The medial social worker, as an important social resource and family advocate, has not been introduced in Mainland China. Social workers have been identified as the first point of call for families in need. Their advocacy for financial support for the families is much needed, as illustrated by Goodenogh and associates (2005). Social workers have functioned as an indispensable resource in Australia, especially in pediatric oncology departments, where most applications for financial assistance from government or charitable agencies depended very much on the advocacy provided by a social worker (Goodenough *et al.*, 2005). Medical social workers in many places (e.g. Hong Kong, UK, America) take the responsibility of providing specialized professional family advocacy and counseling in addition to performing many other welfare-related tasks. Mainland China should mobilize medical social workers to provide financial assistance to these families with hospitalized children with cancer, and they will benefit a lot.

7.2.1.3. Impact on parental well-being

Many parents agreed that accompanying their children receiving cancer treatment was a traumatic experience. Consistent with the findings of previous studies (Pai *et al.*, 2007; Jastrowski & Khan, 2011), parental well-being was affected adversely during this challenging period. They were suffering from a variety of social, emotional and physical problems during their children's hospitalization for cancer treatment.

Physical functioning related to parents

The quantitative study revealed that parents' physical functioning was affected by a cancer child's hospitalization moderately (12.52±4.42, Range: 0-20). More than half of the parents were experiencing physical problems pertaining to tiredness, sleep disturbance and poor appetites. Their overall health was adversely affected. These findings were supported by the qualitative interviews, in which the main physical problems reported by parents were sleep disturbance, fatigue, changes in appetite or weight loss and deteriorating physical fitness. This was consistent with the findings from an earlier qualitative study with mothers of children with cancer, showing mothers were experiencing physical problems such as insomnia, loss of appetite, fatigue, backache and headache when they were trying to cope with many challenges (Elcigil & Conk, 2010). Similar findings were also discovered in a study conducted with Chinese-American parents having an infant under care in an intensive care unit, in which 93% of mothers and 60% of fathers experienced sleep disturbances and fatigue (Lee & Lee, 2007). When compared with parents whose children are healthy, parents of children with cancer experience significantly poorer sleep quality, more upper respiratory infections and gastrointestinal discomforts (Pollock *et al.,* 2013). The qualitative interview in this study may be able to explain the reason for such differences. Most of the parents with children hospitalized for cancer treatment tended to ignore their own self-care and dedicated themselves to the hospitalized child completely. This was also the major factor contributing to the parents' physical-related problems as reflected in above-mentioned studies.

Of the physical symptoms, sleep disturbance was most frequently reported by parents. They experienced poor sleep quantity and quality with frequent night-time awakenings. This is in line with the findings from an earlier study, in which mothers of children with acute lymphoblastic leukemia described their poor sleep throughout the treatment period (Neu *et al.,* 2014). Zupanec and associates (2010) found that 48% of parents had reported sleep disturbance as a common and distressing problem during their children's hospitalization. A comparison study indicated that parents sleeping in the wards with children with cancer reported significantly poorer sleep outcomes than those sleeping at home with healthy children (McLoone *et al.,* 2013). Another quantitative study also revealed that more than half of the parents of children with cancer experienced poor sleep quality, which was significantly higher than those with healthy children (Pollock *et al.,* 2013). Sleep problem may be a universal phenomenon among parents with children hospitalized for cancer treatment.

The present study further revealed that parents' sleep was interrupted mainly by the demands of childcare, intense worries about the children's conditions and environmental factors (e.g. noise, light).The findings were confirmed by an earlier study (Meltzer & Montgomery-Downs, 2011), indicating that the potential causes of sleep disturbance in parents of children with serious illnesses included night-time caregiving, heightened vigilance and monitoring of the child's illness, worry, and altered sleep arrangements. Similar causes have been found in another study, in which mothers of children with acute lymphoblastic leukemia reported greater insomnia compared to controls, this being correlated with anxiety, depressive symptoms, and stress (Matthews *et al.,* 2014).

As reflected in the present study, the long-term sleep disruption adversely affected a wide range of factors including fatigue and pain. These factors further contributed to the worsening of parental well-being. Some studies have revealed that cumulative long-term effects of sleep loss were associated negatively with several serious medical issues, including increased risk of hypertension, diabetes, obesity, heart attack, stroke, impaired daily functioning and decreased quality of life (Lee & Lee, 2007; Meltzer & Montgomery-Downs, 2011; Pollock *et al.,* 2013). Sleep quality is also the strongest predictor of parental quality of life (Klassen *et al.*, 2008). As sleep disturbance can influence parental health status adversely in numerous ways, sleep habits and sleep-wake assessment of parents is warranted throughout children's hospitalization. Targeted interventions for sleep problems may alleviate the effects of hospitalization on parents and improve their well-being. At least, hospital environments with darkness, silence, and comfortable room temperature should be designed to minimize disturbance and promote parents' sleep quality.

Psychological functioning related to the parents

The quantitative study revealed that psychological functioning was affected seriously (24.43±7.25, Range: 0-36). In-depth feelings of sadness, worry, fear, uncertainty, feelings of inadequacy, guilty, and mood fluctuation were identified in qualitative interviews. These results corroborated previous studies (Ogle, 2006; Qi, 2008), in which parents with children hospitalized for cancer treatment were experiencing serious negative emotions, some parents even experienced symptomatological repercussions such as crying, screaming, sudden hypertensive crises, insomnia, and loss of motivation to live (Coa & Pettengill, 2011).

Factors identified in the present study as contributing to parents' negative emotions included witnessing a child's invasive procedures, instability of a child's condition, relapse and unknown future. The quantitative survey revealed that more than half of the parents responded with 'great' or 'extreme' impact to the item 'feel hurt because my child is suffering in hospital'. Witnessing a child's invasive procedure is an unpleasant experience for parents. It was trying and heartrending for them to hear their loved children begging for help to escape from painful procedures. Supporting a hospitalized child was described by parents as an experiential sensing of ‘heart aching’ (心痛) when they saw the child’s pain and suffering. A Chinese saying illustrates the parents’ embodiment of a child’s suffering: ‘Beat on the child’s body, pain in the mother’s heart (打在儿身，痛在娘心)’. Another study conducted in a pediatric intensive care unit revealed that the greatest source of parental stress was the unpleasant procedures conducted on their children (Ames *et al.,* 2011). A parent is more likely to be afflicted with intense hurt caused by a child’s pain. A suggested solution is that healthcare providers can ask family members if they want to wait outside until the required invasive operations are completed. Information support should incorporate preparing parents for the behavioral and emotional responses of their children to painful procedures. Medical professionals should inform the parents that these painful procedures are a necessary part of the medical care.

Moreover, the instability of a hospitalized child’s conditions can keep parents in a state of mental tension and unease, which is demonstrated by worry, fear, mood fluctuation and uncertainty. This was in line with the quantitative results, in which nearly 70% of the parents responded that the item ‘emotions fluctuate according to our child’s medical condition’ had a great or extreme impact. Worry about disease progression was the most common manifestation, majority of the parents considering their degree of nervousness was affected greatly or extremely by their children’s disease progression. Rothstein (1980) revealed that parents of children with very unstable clinical conditions presented with higher-level anxiety. On the other hand, the stability of children’s clinical status was a protecting factor in the parents’ healthy adjustment to pediatric intensive care and parental quality of life (Klassen *et al., 2008).* When children progress positively, that is present stability or improvement in their clinical conditions; parents may start to express positive feelings, such as joy, relief and pleasure. Overall, positive clinical responses of their hospitalized children can be perceived as helpful for parents to maintain psychological health.

Feelings of inadequacy were common in parents when they realized that the current situation was beyond their control. They grieved about the loss of their ability to protect their children from getting cancer and saving their lives or assisting them combat the disease. This was confirmed by the quantitative survey, in which around 40% of parents reported of having ‘great’ or ‘extreme’ impact when they wanted to take care of their children but felt inadequate to do so. Similar results were revealed in another qualitative study, in which parents expressed their feelings of inadequacy regarding the care process (Elcigil & Conk, 2010). This feeling of inadequacy has contributed to the high adverse hospitalization impact, which may increase the risk of family mal-adaptation. Early identification of parents at risk for feelings of inadequacy and the provision of support are crucial for family adjustment. The opportunities for sharing would allow parents to feel that they were not alone, which helped to overcome the feelings of inadequacy (Hallström & Elander, 2007).

Parents reported that they often experience feelings of guilt in response to difficulties caused by their cancer children’s hospitalization. They felt great or extreme guilt that some inadequacies in their care may have led to their children’s illnesses and hospitalization. A previous study pointed out that parents’ casting about for causes and meanings for the disease was highly related to their sense of guilt, as they were usually responsible for the welfare of their children (Matteo & Pierluigi, 2008). During the process of questioning about the causes of cancer, some parents ended up with wrong and non-scientific hypotheses, making them feel responsible for it, followed by feelings of guilt. It appears to be important to clarify with parents about the causes of disease, to avoid any unnecessary psychological burden.

Clinical nurses should ensure that parents do not let these negative feelings distract them from the tasks they must face when their children hospitalized for cancer treatment. It is necessary to provide families with an empathetic environment, in which they can express their negative emotions. If negative emotions are not managed effectively, this further hinders family adaptation to the stressful situation. Pediatric oncology nurses should engage families in discussions about their negative emotions, since family care is an important component of a nursing service.

Social functioning related to parents

The quantitative survey revealed that parents' social functioning was mostly affected by children's hospitalization for cancer treatment, with a change in family daily life, social activities and recreation. The results were supported by the qualitative study, in which parents felt they were isolated from their normal social activities to dedicate themselves to care for the hospitalized children.

The disruption of social functioning was illustrated by the change of employment status and disruption of normal social activities and relationships. Parents considered that their presence with their children was important, and accepted the social isolation resulting from their children's prolonged hospitalization. The findings were supported by a study, indicating that parents felt that the sick children were given first priority and constantly foremost in their minds, and that they had little time for themselves, together or alone (Nedović *et al.*, 2013). The quantitative study revealed that about 30% of working mothers and 43.5% of working fathers resigned from their jobs after their children's hospitalization. Another United Kingdom study also observed that 34.7% of working mothers and another 1.7% of fathers gave up paid employment after their children's diagnoses (Eiser & Upton, 2007). In a Canadian study, 86% of mothers reported that their working hours changed during their children's treatment while, among the fathers, the proportion was 61% (Miedema *et al.*, 2008). As noted, the Chinese fathers were more likely to stop their working than mothers; as mentioned, this was different from the situations in other countries. This is also inconsistent with Chinese culture, in which the father usually takes the responsibility to raise the whole family, while the mother often is considered as the one who takes responsibility for taking care of the family members. One possible explanation for the higher unemployment among the Chinese fathers in this study was that one of the hospitals required both parents to be present during children's chemotherapy; hence the fathers had to give up their paid employment.

Most of the parents reported being isolated in hospital during their children's hospitalization. They were no longer able to maintain normal social lives, which detached them from their friends and even family members. Griffiths (2009) also highlighted that there was a potential risk that family might lose the outside resources because of extended isolation. Parents might perceive even more serious isolation and loneliness. Clinical nurses should maintain sharp vigilance for the signs of such possible negative cyclic.

7.2.1.4. Impact on the hospitalized children’s well-being

Hospitalization creates inevitable changes in children’s lives, such as being forced to stay in bed, and experiencing regular contact with unfamiliar people, painful procedures, and changes in daily diet, and separation from their significant ones. These stressors ultimately affect the well-being of hospitalized children with cancer. This was consistent with previous investigations documenting physical and social difficulties (e.g. peer bullying or teasing) (Miller *et al.*, 2011; Nedović *et al.*, 2013), and distressing emotional reactions (e.g. anxiety, sadness) for children with cancer (Berrios-Rivera *et al*., 2008; Freeman *et al.*, 2003).

Physical functioning related to hospitalized children

The findings from this study indicated that children hospitalized for cancer treatment were experiencing physical functioning impact including physical incapability, adverse treatment-related symptoms and sleep disturbance.

The poor health status prevented the hospitalized children’s participation in physical activities, such as sporting and recreational activities. Some of them were bedridden for an extended period, and their physical abilities were impaired. This result was supported by Griffiths (2009), who stated that the hospitalized children experienced physical restrictions and suffering, which gave them a sense of desperation. Besides the disease itself, another possible reason for children’s physical restriction is the Chinese culture. The philosophical concepts of Confucianism emphasize balance and harmony of the body. Under the influence of this philosophy, it is believed that physical activities will aggravate the existing diseases and violate the rule of harmony (Li, 2009). In this cultural context, many parents might advise their children not to engage in any energy-consuming physical activities. The researchers call for future studies focusing on recreational activities and appropriate play therapy for children who are forced to stay in bed, as a way to protect them from physical dysfunction.

Other difficult experiences were adverse treatment-related symptoms caused by long-term intensive chemotherapy, such as infections, hair loss, nausea, appetite and weight fluctuations, which were consistent with extensive reports in the previous studies (Berrios-Rivera *et al.*, 2008; Baggott *et al.*, 2010; McCaffrey, 2006; Nedović *et al*., 2013). The chemotherapy causes severe side effects, causing as much fear, pain and suffering as the disease itself (Gunawan *et al.*, 2013). These symptoms were closely associated with cancer treatment but not long-term hospitalization. Yet, these symptoms cannot be ignored as they cause great physical burdens to the children and made their hospitalization experiences more stressful. Clinical nurses are encouraged to find effective ways for children to alleviate these treatment-related symptoms during their hospital stay.

In this study, sleep disturbance associated with the noisy hospital environment was another important physical problem the hospitalized children experienced. A previous cross-sectional survey revealed that the majority of the children receiving acute lymphoblastic leukemia treatment reported that sleep disturbance was a common and distressing problem (Zupanec *et al.*, 2010). Another study revealed that about one-third of children with cancer were experiencing sleep difficulties during their hospitalization (Miller *et al.*, 2011). The authors of this study identified that the causes of children's sleep disturbance were poor ventilation, bright lights and the noise created by talking, crying and telephones ringing,. This was in line with the present study, showing that a noisy hospital environment was the only reason identified by parents as contributing to hospitalized children's sleep disturbance. Given that the complaints about hospital environments causing sleep disturbance to both parents and their children were so loud and clear, nurses should have an obligation to rectify this situation and to provide an environment conducive to better sleep quality.

Psychological functioning related to hospitalized children

Hospitalization was an unpleasant experience for the children as it was comprised of regular invasive examinations, chemotherapy, painful needles, separation from their families and significant ones, and being in an unfamiliar environment. The parents described that their sick children were confronted with a range of psychological difficulties including sadness, fear/worry, and feelings of guilt during this stressful period. These findings were consistent with an earlier study with Hong Kong Chinese children with cancer, in which the children reported high states of anxiety scores on admission for cancer treatment and nearly all hospitalized children with cancer expressed different degrees of sadness and worry (Li *et al.*, 2010). Another study also revealed that the hospitalized children experienced a range of fears and concerns about issues including separation from parents and family, the unfamiliar environment, and painful medical procedures and treatments (Coyne, 2006). Concerning the feelings of guilt, similar findings were found in an Argentine study (Vindrola-Padros, 2012), in which some children talked about wanting to stop treatment in order to stop disrupting their families' lives.

As noted, the hospitalized children were in need of psychological support to cope with the unpleasant experience. Psychosocial interventions, including the provision of a safe atmosphere for children to express their sadness, worry, fear and guilt in supportive groups or with play therapists may be helpful in assisting children to adjust and work through their emotional issues productively. Play therapy as a well-established and popular mode of child treatment should be involved in clinical settings to help the hospitalized children resolve their psychological difficulties. Effective play therapy techniques could include 'the feeling word game', 'balloons of anger', or 'the mad game' (Hall *et al.*, 2002). Pediatric oncology nurses are encouraged to spend time actively with children, to explain their treatment, to develop trusting relationships with them, and to listen to their feelings. Sufficient preparation, age-appropriate explanations and relaxation techniques applied prior to invasive procedures are necessary.

Social functioning related to hospitalized children

Long-term hospitalization and health condition issues had serious negative effects on children’s social functioning. They experienced social isolation and diminished social skills.

Due to repeated and prolonged hospitalization, the children experienced long-term absences from school and a reduction of contact with their schoolmates or friends. Social isolation surrounded them during the stressful period. This was in line with previous studies, in which children reported that they were unable to attend school or extracurricular activities, which contributed to their isolation (Moody *et al.*, 2006; Woodgate, 2000). Other studies also revealed that the loss of their peer groups and the changes in the quality of friendship due to long-term separation contributed to the hospitalized children’s social isolation (Coyne, 2006; Griffiths *et al.,* 2011).

Furthermore, some hospitalized children could notice their changed appearances and differences from the ‘norm’, which led to negative self-image. Children were afraid of being rejected or teased, so they intentionally created social isolation, which further disrupted their social skills. Similar results were found with adolescents, who changed their personalities and entered into a new and scary world when they realized the changes in their images (Lombardo, 2011). It was not easy for these children to go back into their social groups. Some children tended to cope with social isolation by forming friendships with other children on the same ward. Yet, older children would have more problems to find patients of similar ages in hospital.

Social connection is an important component of quality of life during hospitalization, yet this has not been given enough attention in Mainland China. Fostering continuous contact between the hospitalized children and their friends, family and school should be one of the strategies to address hospitalized children’s social problems. Videoconferencing may be a good way to achieve this. A previous study showed that the use of videoconferencing was associated with a greater reduction in stress in children during hospitalization (Yang *et al.,* 2014). Pediatric nurses could collaborate with psychologists, medical social workers or play therapists to develop social skills training programs for these socially isolated hospitalized children to prevent adverse outcomes (Patel *et al.,* 2009). Strategies that aim to foster normal childhood social experiences may help to lessen the negative impact of long-term hospitalization. For instance, the hospital surroundings can be decorated like a playground to facilitate children to play together and make friends.

Cognitive functioning related to hospitalized children

The results from this study have also indicated that hospitalized children receiving cancer treatment experienced cognitive problems, such as becoming absent-minded, slow and clumsy. One possible cause was the toxicity of the cancer treatment. Cognitive deficits have been observed consistently in a proportion of children who were undertaking chemotherapy and/or cranial irradiation; these cognitive deficits may be long-lasting and can be disabling (Kahalley *et al.*, 2013; Kunin-Batson *et al.*, 2014; Packer & Mehta, 2002; Walsh *et al.*, 2015). Another possible reason was related to the lack of environmental and active stimulation, which are associated closely with human cognitive development (Farah *et al.*, 2008).

Appropriate measurements should be used to identify the impairment of children's cognitive functioning and its severity during treatment. Attention Process Training (APT) as one of the effective cognitive training programs (Penkman, 2004; Solberg & Mateer, 1987) can be implemented in these hospitalized children with cognitive impairment. Clinical nurses could collaborate with psychologists, neurologist and play-therapists to implement individualized cognitive-improving interventions. More attention should be given to the increase of positive environmental stimulations and create a more child-friendly environment, including a variety of toys, books, televisions, pictures, conversations and other dynamic stimulations.

7.2.1.5. Impact on healthy siblings' psychosocial well-being

Healthy siblings' psychosocial well-being was affected negatively, as reported by the parents in this study. This is consistent with the majority of previous studies (Alderfer *et al.*, 2010; Houtzager *et al.*, 2004; Houtzager *et al.*, 2005; Long *et al.*, 2013; Prchal & Landolt, 2012; Woodgate, 2006a). However, parents also expressed that the healthy siblings had some gains during this challenging period.

This study found that healthy siblings may have been ‘at risk’ psychologically. The disproportionate amount of care given to the sick child, and the long-term separation from their parents, can result in sadness, resentment and jealousy in healthy siblings. Previous studies have also revealed that the siblings of ill children experienced significantly worse psychological functioning (Barrera *et al.,* 2005; Bayliss, 2007; Nolbris *et al.,* 2007). Feelings of loss, abandonment, and jealousy have also been reported in some studies (Bjork *et al.,* 2005; McGrath *et al.,* 2005; Woodgate, 2006b).

One special psychological response in healthy siblings was the feeling of jealousy. Healthy children at home felt abandoned because they perceived that they were not getting their fair share of attention. They resented all of the attention devoted to the ill children and some even showed attention-seeking behaviors to handle this psychological reaction. The present findings were consistent with reports by Prchal and Landolt (2012), who found that living with a sick brother or sister often resulted in sibling jealousy. Poignant comments from healthy siblings left parents feeling torn between their responsibilities to the hospitalized child and those left at home. Another study indicated that mothers faced the dilemma of balancing their emotional obligations in helping their cancer children with the risk of raising the siblings’ feelings of exclusion or neglect (Young *et al.*, 2002b). Although the healthy siblings could understand why the attention was distributed unequally, their jealousy was difficult to suppress. It is recommended that parents make sure to tell the healthy children who will be helping to take care of them in parents' absence, including where they will stay and who will take them to school. Trying to spend time alone with the healthy siblings, like special trips to get ice cream or shopping trips, will help to curb these feelings of jealousy as well.

Parents reported that further difficulties related to healthy siblings’ deteriorated academic performances because of less parental attention. Previous studies also indicated a decline in the academic performances of healthy siblings of children with cancer; and they demonstrated lower scientific merit when compared with the norms (Lähteenmäki *et al.,* 2002; Labay & Walco, 2004; Prchal & Landolt, 2012). Packman and associated (2005) further explained that healthy siblings experienced more difficulties than the norm in academic performances, including memory and learning.

It would be helpful for the healthy siblings if the parents could explain to the teachers what is going on within the family, so that teachers can help to support the children and watch for warning signs of stress to prevent deterioration of academic performances. Teachers, other significant guardians and healthy siblings’ own perspectives might provide a more comprehensive understanding about healthy children’s school performances in future study.

Encouragingly, it was found that the stressful experiences could promote psychological growth in siblings, who often became more mature, thoughtful and caring. In agreement with the present study, previous studies have revealed that majority of healthy siblings of critically ill children reported positive changes, including increased sensitivity, enhanced empathy and personal maturation, increased maturity and supportiveness (Lehna, 2010; Sloper, 2000). This may reflect an expectation to become more self-sufficient as parental attention shifts to the care of a child with cancer. These findings demonstrated that some healthy siblings appeared to benefit psychologically from the stressful experience and they became resilient to the experience.

Providing opportunities for healthy siblings to express their hidden feelings such as sadness and jealousy will benefit their healthy psychosocial development and ease parents’ guilt feelings. A previous study revealed that age-appropriate, open, and truthful conversation with healthy siblings could minimize their acting-out behaviors and feelings of jealousy, rejection, anger, and fear (Murray, 2002). Participating in a sibling support group with children with similar experiences can be a unique opportunity for older healthy siblings to share their innermost feelings candidly (Murray, 2002). An online sibling support group is feasible and convenient for children who live far away from each other. Pediatric nurses can remind the parents about the possible adverse consequences on healthy siblings caused by the sick children’s hospitalization, and encourage parents to mobilize external resources (e.g. neighbors, extended families, and teachers) to observe and support healthy siblings during this difficult time.

7.2.2. Predictors of family impact

The two identified predictors of family impact were total days of all admissions and severity of a child's illness.

Total days of all admissions

The longer a child spent in hospital, the more impact the family perceived. However, in Kong's study, no significant correlation was detected between the duration of a child's hospital stay and hospitalization impact score (Kong, 2010). This disagreement may due to variations between the samples. The sample recruited in Kong's study was made up of families having non-cancer children hospitalized in general pediatric departments. The length of most children's hospitalization in general pediatric departments ranged from two days to two months, while that of children hospitalized for cancer treatment ranged from 21 to 900 days. Therefore, it appears that families with children hospitalized for cancer treatment need more special attention than families with children hospitalized in general pediatric department.

As mentioned above, the qualitative results of this study have revealed that a cancer child's hospitalization brings great challenges to the family. At the beginning of hospitalization, the families mobilized internal and external resources to cope with the stressful situation. With an extended period of a child's hospitalization, family resources were often exhausted. A longitudinal study found that the amount of the support a family received decreased over the first year after the child's diagnosis (Hoekstra-Weebers *et al.,* 2001). Similarly, McGrath (2001) reported that the social support parents received decreased as time passed. Families' capabilities to satisfy the demands of the entire family and the individuals decreased with the extension of their children's hospitalization. The imbalances between families' capabilities and demands imposed heavier burdens on them. Therefore, a family is more likely to perceive more impact as a child's hospitalization continues.

Severity of a child's illness

The severity of a child's illness was another factor identified as one of the best predictors of family impact. This study found that the more severe a child's diagnosis was, the more impact a family would perceive (Mean Differences: HR-SR 31.05;

MR-SR 16.18; HR-MR 14.86). This was supported by Kong (2010), who revealed that the severity of a child's illness had a very strong correlation with total impact scores. Other studies have discovered that the severity of a child's illness could affect his/her relatives' psychological well-being and adjustment (Barlow & Ellard, 2006; Mast *et al*., 2009).

Hospitalized children with different health conditions also pose different demands upon families. The families of children with high-risk ALL were found to be more stressed than others. Their workloads and responsibilities tended to increase (e.g. monitoring the child's condition during chemotherapy, more frequent medications, more dependent on parental care), which cause more disruption to the family. Nurses should aware that the severity of a hospitalized child's illness plays a very significant role causing adverse impact to the family that justify for special attention.

7.3. Family coping and its predictive factors

7.3.1. Family coping (Cc)

The findings from the quantitative survey revealed that the families perceived moderate coping effectiveness during their children's hospitalization (M±SD: 39.02±9.84, Range: 0-64). In comparison with a previous study using the same scale to measure the coping effectiveness of families with non-cancer children hospitalized in general pediatric departments (Kong, 2010), families in this study perceived significantly higher coping effectiveness. This difference could be explained by the extensive usage of coping strategies by the cancer group, while 2.8-27.1% of families chose 'not applicable' on related coping items in Kong's study (2010). The cancer group would use all possible coping strategies because of the severity of the illness and they learnt to cope better through the process of the longer and repeated hospitalization. The findings from the qualitative section also highlighted that families used a range of coping strategies that generated four patterns to be discussed below.

7.3.1.1. Building up family strength

Building up family strength demonstrated how a family worked as a whole to cope with a child's hospitalization for cancer treatment. The quantitative study revealed that more than two thirds of the parents gave a rating of great or extreme effect for the item 'support each other and share responsibilities'. The qualitative study further revealed that family members tried to pull together emotionally and practically to support one another for the challenges caused by their cancer children's hospitalization.

Finding from this study revealed that family cohesion and mutual support were two factors contributing to family strength. High levels of family cohesion and mutual support allow parents to feel relieved and increase family resilience. This is in line with previous studies, showing that family cohesion and mutual support were protective and recovery factors that can promote healthy family coping when they are exposed to significant stressors or adversities (Hawley & DeHann, 1996; Hawley, 2000). Altiere & Von Kluge (2009) indicated that a family with high cohesion could better adapt better to the stress of caring for a child with an illness. Another study revealed that the perception of a supportive and caring family environment was associated closely with better quality of life and reduced anxious and depressive symptoms of family members (Moreira *et al.*, 2013). This demonstrated that the increased emotional and physical bonding among family members can assist a family to realize its strengths and become stronger as a unit. This was consistent with the Chinese culture (Chinese Culture, 2015), which emphasizes family interdependence and cohesion. Chinese people hold the family bonds as sacred and honor them accordingly. Family bonds are stronger than any kind of social bonds not based on kinship (Chinese Culture, 2015). Thus, it was natural for families to mobilize their internal resources first to cope with their cancer children's hospitalization.

Given the importance of family strength, family-centered interventions aiming to facilitate family members to be supportive of each other seem to be particularly useful in Chinese contexts in helping families to cope better with the demands of cancer children's hospitalization. Nurses should pay more attention to families with low degrees of family cohesiveness and provide assistance to enable their unresolved conflicts resolved within family. Emphasize the importance of family strength and encourage family members to work together for the best of the entire family. Continuous observation during the interactions with families will help nurses to respond in time to the deterioration of family strength.

7.3.1.2. Maintaining self-consoling thoughts and behaviors

Maintaining self-consoling thoughts and behaviors, as a process of distraction, was another coping approach adopted by parents for managing the impact caused by children's hospitalization. It prevented parents from concentrating on the negative outcomes and distracted their minds from the stressful situations. The manifestations of this coping approach included being optimistic and focusing on childcare.

Being optimistic

Some parents in the present study chose to be optimistic to cope with whatever life events they encountered. They tried to strengthen their optimistic view by using other successful treatment experiences or making downward comparisons to elevate self-regard (Gibbons, 1986; Wills, 1981; Wood *et al.*, 1985). Being optimistic could be one of the most helpful coping strategies as reported by parents of children with leukemia (Patistea, 2005). Another study stated that parents obtained a positive focus when they held the thought that other families were experiencing a more difficult time (Bjork, 2005). Miedema and associates (2010) further discovered that parents tended to choose other families who were not lucky for comparison so that they could see themselves advantageously. It allowed parents to perceive that a cancer child's hospitalization was manageable. This would be very helpful for those families who felt that they were facing a situation that was perceived as uncontrollable, and something with which they must deal, and move on.

Focusing on childcare

Parents were determined to be strong and devote themselves to childcare to guarantee their hospitalized children received the best care. It was considered to be one of helpful coping behaviors, which helped parents to cope or avoid guilt feelings and to increase a sense of fulfillment. This was consistent with the results reflected in the quantitative survey, that majority of the parents reported great or extreme effects on the items related to childcare. A similar result was found by another study, indicating parents considered ensuring childcare was carried out as one of their effective coping strategies (Ray & Ritchie, 1993). Another study conducted by Kong (2010) also found that similar childcare-related behaviors were great or extreme effective coping strategies during their children's hospitalization. Knowing how much parents treasure childcare as important, clinical nurses could promote family adaptation by empowering parents in their caring roles and facilitating them to fulfill their caregiver roles successfully.

7.3.1.3. Seeking external support

Similar to previous studies (Hodgkinson & Lester, 2002; Norberg *et al.*, 2006), seeking external support was another significant coping approach employed by families with children hospitalized for cancer treatment. The external resources as reported by parents were comprised of professional support from healthcare providers and social support from other parents, relatives, friends, and community agencies. Related nurses' roles should be explored and discussed further.

Professional support

The findings from the quantitative survey revealed that the majority of parents indicated 'great' or 'extreme' effects for the item 'keep asking doctors and nurses questions……'.This was supported by following qualitative interview, indicating that healthcare professionals were significant external sources of informational and emotional support for families during children's hospitalization for cancer treatment.

Parents expressed that they felt relieved when they received adequate information about their hospitalized children. This was consistent with previous studies, showing that available information helps families to face the crises of their children's serious situations, and help them to gain a sense of control and overcome their insecurities (Arabiat & Altamimi, 2013; Hopia *et al*., 2005; Monterosso *et al*., 2007). According to the results, providing up-to-date health information to families is an effective way for healthcare professionals to promote family adaptation.

Emotional support from nurses in this study was found to enhance psychological adjustment of the parents during their children's hospitalization for cancer treatment. Previous studies (Grahn & Danielson, 1996; Northouse, 1988) also indicated that emotional support is helpful in the adjustment of relatives of patients with cancer. In the present study, some parents had established rapport with nurses, and then they wanted to share their inner feelings and concerns with particular nurses, whose comfort could relieve their psychological burdens to some extent. It implied that parents tended to place greater significance on the provision of nurses' emotional support. Nurses should therefore have the sensitivity to recognize families' needs for emotional support and take an initiative to listen to their inner feelings. Referring to a counselor, psychologist or psychiatrist is needed when parents experience serious emotional difficulties.

Social support

Findings from this study revealed that families with hospitalized children with cancer need support from other families with similar experiences, relatives, friends, and communities to assist them to make lives easier. Parents considered parent-to-parent support as the most helpful, reliable and relaxing. They expressed their desires to seek out other families with similar experiences. Exchange of useful and practical information has been reported as an important element of parent-to-parent support (Sullivan-Bolyai & Lee, 2011).Another study further revealed that shared experience fostered a sense of belonging and support, enhanced families' confidence to cope, and reduced their sense of isolation and loneliness (Law *et al.*, 2001).

The present and previous studies suggested that perceived similarity of experiences and mutuality of support were the bases of an equitable parent-to-parent connection. Common experiences may enable families to fully understand each other and accept thoughts and behaviors without judgment. Self-help groups, as the most common parent-to-parent connection, have becoming increasingly popular in North America and the UK (Law *et al.*, 2001). Parent-to-parent connection offers a unique form of support that may complement nursing services to some extent. However, there was only one informal self-help group in one of the four hospitals recruited in this study. Clinical nurses should recognize families' desires and needs to obtain support from other families with similar experiences, and help connecting them together for mutual support. This could be the first step for the establishment of a self-help group.

7.3.1.4. Covering up the bad

'Covering up the bad' was another coping strategy identified in the present study. Parents of hospitalized children with cancer were inclined to refuse to discuss their negative emotions and news with the hospitalized child, other family members, or their friends.

Shielding children from bad news

Almost none of the children in the present study had been informed about their diseases or conditions because their parents had never disclosed related information to them. In China, parents do not tell their children about their diagnoses and prognoses in order to protect them from 'bad news'. This is often seen in other Asian countries, such as Japan (Parsons *et al.*, 2007; Watanabe *et al.*, 2014). However, disclosure is common in the US (Parsons *et al.*, 2007). An earlier study of Caucasian-Americans revealed that close to 100% of both parents and physicians felt it was important to inform the children of their diagnoses, courses of treatment, and prognoses (Martinson *et al.*, 1999).

Usually, pediatric oncologists leave it to parents to make a decision regarding what, when and how their children will be told. However, some parents were against disclosing the diagnoses to their children. One reason identified in present study was that the parents felt that their children would be incapable of comprehending details about the disease and the information they were given. This is in line with a study conducted in Japan, in which Japanese parents' disclosure of disease depended on their children's ages and levels of development (Watanabe *et al.,* 2014). Therefore, the decisions made by parents regarding disclosure of related information to the disease seemed to be influenced by their perceptions of their children's maturity.

In China, the treatment environment may not facilitate parents' non-disclosure requests because the hospital departments are often identified as 'oncology' or 'hematology'. Some children may infer the diagnosis from certain subtle information such as the name of the department. Thus, for some children, even though they are not informed or given any opportunity to ask questions about their illnesses or treatment, this may not necessarily protect them from fear or worry. On the contrary, this may result in a misunderstanding that the illness is a dangerous secret that should not even be spoken about. A previous study found that the psychological adjustment of children and their families could be improved by disclosing the diagnosis in the early stages of the treatment (Slavin *et al.,* 1982).

It is a complex issue to discuss a life-threatening illness with a child. One suggested approach is to involve the child in the parent-doctor communications. This allows the doctor to deliver the news to the child in the parents' presence. Yet, the personal preferences need to be respected. Permanent changes of practice or advice without careful consideration of the clients' readiness may lead to strong resistance or negative emotional responses. More studies to investigate the effects and implications of covering up the bad as a coping strategy are needed to inform clinician about the directions to follow and to advise parents accordingly.

Protecting other family members from negative emotions and news

The parents in this study often refused to share their negative emotions and bad news with other family members to minimize the effect of a cancer child's hospitalization on families. Whether to share the negative emotions and bad news with their family members is a difficult decision. This depends on how parents evaluate their family members' ability to deal with the unpleasant news.

When parents underestimated other family members' ability to manage it, they tended to sacrifice themselves to suffer the psychological burden alone to protect their family members by concealing the unpleasant. As Rarick (2007) reported, the spirit of self-sacrifice is prevalent in traditional Chinese families. It is common for individuals to sacrifice themselves for the welfare of the family. The resilience of Chinese people through stressful events is largely due to their culture that values self-sacrifice for the collective good.

Avoiding talking with friends

Some parents in this study were reluctant to ventilate much information to their friends to protect others from worries. This might be determined by the Chinese culture, in which people tend to ‘share happiness but not worries (报喜不报忧)’.

Another reason was that parents were afraid of being labeled as pathetic or appearing to be weak. Parents worried that having a child hospitalized for cancer treatment might be perceived by their friends as pathetic and need help. They did not want to ‘lose face’ in front of others. It was closely related to the Chinese ‘Face-culture (面子文化)’. ‘Face (面子)’ is regarded as a ‘self-image’ experienced by an individual because of others’ evaluations of a specific situation (Hwang, 2006). People may have experienced the feelings of gaining or losing face because of positive or negative social evaluation (Hwang, 2006; Hwang & Han, 2010). Parents’ feelings of ‘losing face’ may result in some assistance being ineffective and/or unsatisfying during their children’s hospitalization. It implied that not all helpers actually deliver helpful help, and some even add to parents’ psychological burden. This reminds clinical nurses that the influences of Chinese culture on family coping should be taken into consideration during the development and implementation of family-centered interventions.

7.3.2. Predictors of family coping

The identified predictors of family coping were number of readmissions, family with a religious background and age of the hospitalized child. The results regarding the factors predicting family coping may guide efforts to identify and focus our interventions better for families who may be at risk of developing problems in family adjustment during a child’s hospitalization for cancer treatment.

Number of readmissions

The more readmissions a child had, the less the families perceived coping effectiveness. Repeated hospitalizations were often associated with children’s unstable conditions, which brought about more adverse impact on the family. The other possible explanation was the resource exhaustion, a drain of previously mobilized internal and external resources during the early stage of the disease. Previous studies have revealed that the amount of the support a family received decreased over the first year after the child’s diagnosis, they were experiencing decreased social support as time passed (Hoekstra-Weebers *et al.*, 2001; McGrath, 2001). Families’ coping strategies could not alleviate increased family impact over the period of repeated hospitalization. Nurses should pay more attention to those families whose children are hospitalized very frequently.

Family with a religious background

Families with religious backgrounds perceived more coping effectiveness. They may believe they could get through the adversity because it was a part of their normal lives, so they were more likely to perceive positive outlooks. Previous studies have indicated that religious beliefs can promote an optimistic and hopeful worldview, empower people to cope with their circumstances, reduce the need for personal control, and help to reduce isolation and loneliness (Koenig, 2009). Families with religious backgrounds may have access to religious resources, which played an important role in times of crisis. Accessible religious support network was associated closely with decreased stress and caregiving burdens (Panganiban-Corales & Medina, 2011). Thus, it suggested that clinical nurses could identify families with religious backgrounds and have the potential to serve as supporters to assist other vulnerable families through getting religious resources.

Age of a hospitalized child

The older the hospitalized child is, the more coping effectiveness the family perceives. One possible explanation was that older children may be more mature and thoughtful, which could motivate the entire family to make efforts to cope with the misfortune. This was supported by the qualitative study, showing that some older children took actions (e. g. making jokes, saying something very touching) to help their parents handle their psychological burdens. It seems that older children and their families worked together to overcome the adversities. This suggested that families with younger hospitalized children needed more attention. Yet, no previous study has investigated the relationship between the age of a hospitalized child and his/her family's coping effectiveness. More evidence is needed to validate the findings from this present study.

According to the Double ABC-X Model, coping effectiveness perceived by families plays a key role in determining whether a family is close to bon-adaptation or mal-adaptation. In this study, families with children hospitalized frequently, with very young children, and without religious backgrounds were found to be the most likely to perceive low-level coping effectiveness i.e. mal-adaptation. These families should be given special attention.

7.4.Family adaptation

Coping determines adaptation in the Double ABC-X Model (Kong, 2010; McCubbin & Patternson, 1983). Effective coping leads to bon-adaptation. The higher the coping sub-score in the quantitative data, the more likely the family is to achieve bon-adaptation. The lower the coping sub-score in the quantitative data, the more likely the family is to achieve mal-adaptation. In the qualitative interviews, families revealed the characteristics of bon-adaptation and mal-adaptation.

Identification of bon-adapted and mal-adapted families is the fundamental step of intervention. The characteristics of bon-adaptation and mal-adaptation provided a reference for nurses to identify families who were in desperate need of immediate support and those who could serve as supportive resources to help others.

Mal-adapted families might already have been in despair, reached the threshold of crisis, or been particularly vulnerable to further challenges. Timely interventions to help mal-adapted families are much needed to prevent situations from getting worse. Effective intervention strategies can include problem-solving skills training (Sahler *et al.,* 2005), web-based family-level educational and support program (Svavarsdottir & Sigurdardottir, 2006), and forming parent self-help groups (Ainbinder *et al.,* 1998). These interventions were found to be effective in improving families' abilities to cope with children's chronic illnesses and reducing their negative psychological outcomes (Ainbinder *et al.,* 1998; Sahler *et al.,* 2005; Svavarsdottir & Sigurdardottir, 2006).

Bon-adapted families had achieved positive outcomes, but continuous observation of these families is important. This will alert the clinical nurses to identify potential problems that may lead to a shift from bon-adaptation to mal-adaptation. Timely responses to these families and enhancement of protecting factors (e.g. family support) will prevent them from becoming mal-adaptive.

Nurses can mobilize the bon-adapted families to help others who are experiencing mal-adaptation. This mutual-support group cannot only facilitate mal-adapted families to achieve positive outcomes, but can also allow bon-adapted families to gain more confidence from the supporting process.

7.5.Unmet family needs

Some parents voiced their unmet family needs related to health care during their cancer children's hospitalization. The unmet family needs fit in well with the Double ABC-X Model. According to the Model, unmet family needs (e.g. lack of health information) belongs to the concurrent difficulties under the pileup demands (aA), which can influence coping and affect the outcome of adaptation.

7.5.1. Unmet need for warm and supportive attitudes

Some parents complained that their need for warm and supportive staff attitudes were unmet. They felt they were not treated with respect, kindness or thoughtfulness during their cancer children's hospitalization. Even stronger feelings had been reported by the parents with children hospitalized in a pediatric intensive care unit, where parents perceived hostility from the medical team because they were excluded and slighted by them (Coa & Pettengill, 2010). Family vulnerability was intensified by the disaffection between the health care team and the families. Another previous study also revealed that family health was associated with the actions of medical staff, whose inappropriate attitudes or behaviors may have added additional stressors to families' psychological burdens (Tomlinson & Hall, 2003).

These findings suggested that families were sensitive to hospital staff's attitudes. In some situations, families may consider interactions with health care professionals as the source of help as well as stress. It is important to address families' needs with warm and supportive attitudes to avoid possible psychological burdens.

7.5.2. Unmet need for competent care

Another unmet family need was for competent care to attend to their hospitalized children. Incompetent care not only led to very painful experiences for the hospitalized cancer children and their families, but also shattered the trust families should have for professional practice. Competent care has always been one of the most important indicators of quality of care (Cygan *et al.*, 2002; Hallström *et al.*, 2002b). Providing competent care is fundamental and essential to establish confidence and trust in health professionals, and to avoid building up pile-up demands.

7.5.3. Unmet need for adequate information

Parents frequently expressed that their demands for adequate information remained unmet. This was consistent with the results from a previous study (Yiu & Twinn, 2001), indicating that families' needs for information were not always heeded. Lack of information may lead to the deprivation of an important family coping resource as well as create extra stress for the family. Previous studies also supported our findings that access to information was one of the most important coping means for parents during their children's hospitalization (Hopia *et al*., 2005; Miles, 2003; Miles & Brunssen, 2003). Parents viewed adequate information as an important basis from which they could face the crisis of their children's serious illnesses and gain a sense of control, and overcome their insecurity (Arabiat & Altamimi, 2013; Hopia *et al*., 2005; Monterosso *et al*., 2007). Therefore, ensuring that adequate information is delivered in an understandable, non-jargonistic language during a cancer child's hospitalization is one of the vital components of health service delivery in pediatric oncology settings.

7.5.4. Unmet need for a comfortable environment

Some parents expressed their unmet need for a comfortable hospital environment. Hospital physical environment was considered as one important element of service quality in pediatric departments, which should be calm, clean, and comfortable, and be able to provide enough space and privacy (Schaffer *et al.*, 2000). Parents in this study complained about the noisy wards, poor hygiene, lack of facilities and equipment, as well as the restrictive hospital rules. This demonstrated the discrepancy between parents' needs and the reality of their actual experiences in hospitals. These findings implied the need for managerial interventions to provide and maintain a quiet, clean, well-equipped environment with supportive policies (e.g. dim lightings at night) during their children's hospitalization.

7.5.5. Unmet need for catering support

Another important unmet need was catering support. No other culture is as food-conscious as that of the Chinese, who regard food as of fundamental importance (min yi shi wei tian 民以食为天) (Shek, 2005). Another belief among Chinese is that food can have therapeutic effects. The traditional Chinese believe that optimal health is obtained by maintaining a balance in a body between the yin (cold) and yang (hot) through a balanced diet (Liang *et al*., 2004). All food stuff is assumed to possess qualities that correspond to the yin and yang elements, with some having 'han 寒' (cold) properties paralleling yin, while others are considered having 're 热' (hot) nature, paralleling yang (Shek, 2005). A person having a cold body condition should therefore ingest food of a hot nature in order to restore the balance between yin and yang (Shek, 2005). Similarly, a person having a hot body condition such as a fever needs to consume cold foods to bring about the desired balance. Taking in the wrong kind of food will only worsen the situation when the body is already out of balance (Shek, 2005). This explains why patents were so eager to prepare the food for their children themselves. The parents in this study complained that the hospital food was lacking in choice, expensive and unappealing. This may result in parents' dissatisfaction with hospital catering services. Previous studies have revealed that the presentation, taste of food service and food quality were major predictors of client satisfaction in hospital settings (Hwang *et al.,* 2003; O'Hara *et al.,* 1997; Williams *et al.,* 1998). In this study, the hospitalized children's decreased appetite might have been worsened by the poor quality of the hospital food. Hospital managers should implement some practical measures to improve the hospital food to meet the special needs of hospitalized children.

Hospital staff should acknowledge that a catering service is an important part of clinical treatment and care of patients (Theurer, 2011). A catering committee including dietitians, catering managers, chefs, nurses, and support staff should be established as the first step towards catering service improvement. The committee could arrange meetings with children and parents regularly to learn about their perspectives on food-catering service quality (e.g. the meals taste nice, the menu has enough variety for families to choose, the meals have excellent flavors, the crockery and cutlery looks good, etc.). Detailed information can help catering managers to develop effective measures to improve hospital catering services. These measures may include providing themed plates for children to stimulate their appetites, developing a specially constructed menu together with children and their families (with pictures, portion sizes and price), and improving the flavor to meet different preferences. The implementation of these measures has been found to be helpful in improving families' satisfaction with catering service and children's appetites (Houlston *et al.,* 2009).

7.6. Application of HICS

As discussed above, cancer children's prolonged and repeated hospitalizations are an immensely stressful experience for children and their families. A comprehensive assessment of family impact and coping as a fundamental step of nursing intervention should be based not only on nurses' observations and interactions with families, but also on families' perspectives. A timesaving and validated screening tool to reflect self-evaluated family responses is needed for identifying families at risk for nursing attention in pediatric settings.

The Hospitalization Impact and Coping Scale (HICS) is a promising instrument measuring both impact and coping of families with hospitalized children using two subscales (Kong, 2010). It has the potential to be a valid and reliable assessment of families at risk and needing nursing attention in pediatric settings. The psychometric properties of HICS were examined to justify its application in this population.

7.6.1. Hospitalization Impact Subscale (HIS)

The revised 34-item HIS focuses primarily on six different aspects of impact, namely physical, psychological, social, family functioning, health service utilization, and extra burden. The findings from the exploratory factor analysis suggested the removal of item 14 and item 31.

Item 14 stated that parents 'cannot rely on others to take care of their children'. One possible reason for omitting this item was that the parents in this study had very little experience of leaving their children to others because of their children's vulnerability. Parents also mentioned this point in the qualitative interviews. The medical staff usually informed the parents that their children required their continuous care round the clock during active chemotherapy. Given the children's susceptibility to infection, parents may have felt secure only when caring for their children themselves, since they knew their children's conditions in detail. Nearly all of the parents had sacrificed their personal lives and stayed in the hospital all the time. They did not rely on others to take care of their hospitalized children. Although more than 70% of the parents selected ‘extreme impact’ as the response to this item, this item demonstrated very low correlation with other items (<0.15). Further study may be needed to add more items related to how parents respond when their children are taken care of by others. It is suggested that Item 14 is retained in the scale for further examination (Lyu *et al.,* 2015).

Another item for removal was Item 31. About 70% of the families selected ‘no impact’ when asked about seeking alternative therapies. One possible explanation is that all pediatric oncology departments were well recognized for providing expert specialized care. Seeking alternative therapies was not the parents’ concern. This result was observed also in the qualitative interviews; parents reported that they had never sought other treatment methods to cure their children. The parents further explained that they feared something bad might happen to their children if they chose other alternative treatments. They trusted the medical staff and tended to surrender their control to the doctors who had developed the therapeutic regimes for their children. This was a unique characteristic of oncology practice (Lyu *et al.,* 2015).

It do make sense that Item 6 (become irritable) and Item 30 (burden can hardly be understood by others) loaded on the psychological impact and extra burden impact factor respectively in the revised HIS, considering the nature of the item content. The other four items (12, 19, 17, 20) included in the social impact dimension in the original version were concerned with parenting style, family time spent together, daily family life and carrying out of family responsibility, respectively. These are crucial components of family functioning (Minuchin & Fishman; 2009). It would be more understandable to include these four items in the family functioning impact factor instead of the social impact factor. As indicated by Zhang and colleagues (2007), professional knowledge, as a more important aspect, must be taken into consideration in making factor retention decisions. This further justified the combination of the sixth and seventh factors.

The final 34-item HIS, with item deductions, focuses primarily on six different aspects of impact, namely, physical, psychological, social, family functioning, health service utilization, and extra burden. Assessment of the internal consistency of each factor with Cronbach's $\alpha \geqslant 0.7$ demonstrated that the revised HIS is a reliable measuring tool (Calefato *et al.,* 2008). The items in each domain of the revised HIS could be considered homogeneous and to measure the same traits. The significant and moderate correlations between the HIS and FIM indicated that a moderate overlap exists between these two instruments. However, the HIS measures a more specific construct on the impact of a child's hospitalization compared with the FIM. The results indicated that families with high impact assessment on the HIS had lower scores on the FIM. These significant correlations support the concurrent validity of the HIS.

7.6.2. Hospitalization Coping Subscale (HCS)

The results of the exploratory factor analysis indicated that three factors underlie the HCS. Three renamed factors were maintaining mental stability, mutual support for cancer treatment, and seeking support from external systems. The revised 3-factor structure of the HCS differed from the original version of 4 factors (Kong, 2010). This difference could be explained by the variances in sample and testing contexts. In this study, the sample consisted of families with children hospitalized for cancer treatment in pediatric oncology units, whereas the sample in which the HCS was developed was composed of families with children hospitalized for non-cancer treatment in general pediatric units. Streiner and Kottner (2014) have indicated that a measurement might be valid in assessing a certain group in a specific situation, although not valid in another group or testing circumstance. Reliability and validity of instruments are incremental as they are constantly being tested with different populations and in different circumstances; their psychometric properties must be established for these (Streiner & Kottner, 2014). This explains and justifies the revised 3-factor structure when applying the HCS for family coping assessment in the cancer group (Lyu *et al.,* 2016).

The findings from the EFA suggested the removal of item 10 ('do not expect too much and do not plan for too long'). However, it was found in the present study that more than half of the parents reported that this kind of coping strategy was effective. This item appeared to be passive and negative in nature and therefore different from the other items. This item contains some aspects related to the Chinese culture; many

Chinese people believe the Taoist school of thought, which emphasizes the importance of acceptance and contentment. A core concept of the Taoist philosophy is wu-wei (无为), which means nonintervention or doing nothing but following whatever is given in life. The Taoist school of thought advocates that there is no need to feel worried or upset about a negative encounter or to take drastic actions to eliminate it, because nature will take its rebalancing course on its own (Cheng *et al.,* 2010).The meaning of item 10 was consistent with Chinese culture to some extent. It is suggested that this item be retained in the questionnaire with a few more similar items added to enrich this area in future studies (e.g. relying on luck, focusing on the present) (Lyu *et al.,* 2016).

Assessment of the internal consistency of each factor withCronbach'sα ⩾ 0.7 demonstrated that the revised impact subscale is a reliable measure (Calefato *et al.,* 2008). The Cronbach's α of the3 factors ranged from 0.78 to 0.83. The items in each domain of the revised HCS can be considered homogeneous and measure the same trait. In addition, the significant positive correlations between the revised HCS and CHIP support the concurrent validity of the revised HCS and indicate a moderate overlap between these 2 instruments. Families with high coping scores on the HCS had high scores on the CHIP scale, even though the revised HCS measures a more specific area relevant to coping with hospitalization

7.6.3. Relevance of HICS in clinical practice

This study provided initial evidence for the psychometric properties of the revised HICS with families having children hospitalized for cancer treatment in Mainland China, although further enrichment is needed. The revised HICS is suggested as a valid and reliable tool for assessing family impact and coping during cancer children’s hospitalization. It is hoped that it will help clinical nurses to identify the families who are at greatest risk of experiencing adverse impact and ineffective coping during their children’s hospitalization, so that realistic strategies can be implemented to promote families’ achievement of bon-adaptation. The HICS can also identify families who are able to cope well and be a potential support resource for other families in similar situations. Further research should narrow the focus on the establishment of cutoff points for bon-adaptation and mal-adaptation families, as well as the instrument's application in different populations (Lyu *et al.,* 2015; Lyu *et al.,* 2016).

Like many other quantitative tools, the HICS is incapable of providing in-depth specific information about families' concerns. More detailed information about families still depends on the interactions and communications between nurses and families. Further nursing interventions should be based on comprehensive and accurate information about family situation.

7.7. Summary

This chapter has provided a discussion of the findings generated from the current study. In-depth information pertaining to the impact families encountered and how they handled the challenges during their cancer children's hospitalization can provide pediatric oncology nurses with valuable references for developing targeted interventions to promote positive family adaptation. The characteristics related to bon-adaptation and mal-adaptation could help clinical nurses to identify those families who need special attention, or others who can serve as supportive resources. The findings have revealed parents' perceptions of underlying unmet family needs for health services when they are accompanying their children receiving cancer treatment in hospital. This provided insights into improving family care in pediatric oncology units. The healthcare professionals can take actions to satisfy these unmet family needs, and to enable bon-adaptation.

These findings, generated in a Chinese context, also suggest that the diversity of specific cultures and policies should be taken into consideration during the process of developing family centered nursing interventions. The HICS, as an assessment tool for families with hospitalized children, is a promising, timesaving, convenient and validated instrument, with sound psychometric properties. It offers clinical nurses another way to understand family situations efficiently.

CHAPTER 8 CONCLUSION AND RECOMMENDATIONS

This conclusion chapter begins with a summary of the major findings and contributions, followed by a discussion of the study's limitations. The subsequent section turns to a discussion of the implications and recommendations for practice. Finally, the direction for future research is discussed. This chapter ends with a conclusion.

8.1. Summary of findings and contributions

In-depth information related to family impact and family coping during a cancer child's hospitalization has been acquired from the present study. A cancer child's hospitalization is a challenge for the whole family since it causes intense suffering to the entire family. The quantitative survey indicated moderate adverse effects on families. They experienced disruption of family functioning, heavy financial burden and decreased well-being of family members. Families tended to adopt multiple strategies to cope with these impacts. These strategies included building up family strength, maintaining self-consoling thoughts and behaviors, seeking external support, and covering up the bad.

Some characteristics of bon-adapted and mal-adapted families have also emerged from this study. As well, families verbalized their unmet needs, including unmet needs for warm and supportive staff attitudes, competent care, adequate information, comfortable environment and catering support.

The findings from the present study have contributed to the theoretical development of family care in the Chinese context. This can also help nurses to gain a deeper understanding of families' situations, and to provide needed information for intervention development. Nurses can also be informed that families are not only the caregivers of the hospitalized child with cancer but also the clients of nursing service. The experience of a cancer child's hospitalization not only creates negative results for families, but may also strengthen them through seeking ways to recover from the challenge. The unmet family needs voiced by families will eventually provide the direction for nursing service improvement. It allows nurses to devise strategies that can help families to have their unmet needs heeded and satisfied to minimize their vulnerability.

This is the first study to explore family impact and family coping during a child’s repeated and prolonged hospitalization for cancer treatment in Mainland China. Even though some results are similar to the findings of studies conducted in Western populations, this study has generated some knowledge that is very special for Mainland China. For example, the coping strategies related to ‘covering up the bad’, which was an important illustration of Chinese culture. Additionally, unmet family needs may reflect the current reality that the healthcare system in Mainland China is transforming from disease-focused to human focused and the healthcare reform is still underway. This could direct policymakers’ and hospital mangers’ energies on the development and implement of appropriate interventions that in accordance with unmet family needs. This study also tested and revised a promising instrument (HICS) in a cancer group. This will facilitate its application on other populations. The findings may contribute to redirecting supportive actions of pediatric oncology nurses and inspire them to seek to understand families’ situations in-depth during this challenging period.

8.2. Limitations of the study

As discussed earlier, the present study, to some extent, has made some contributions to the field of family care and provided invaluable insights into families’ experiences during cancer children’s hospitalization. However, there were several limitations.

First, due to convenience sampling, 80%of the families had children with leukemia, which may limit the generalizability of the findings. However, this has also reflected the fact that the most common childhood cancer is leukemia. A random sampling is preferred to enhance the generalizability of the findings.

Second, this study has only included parents as the respondents. Parents’ perceptions might not totally reflect all family members' perspectives, and this might limit the richness of the findings. However, their opinions cannot be undervalued and are crucial for an initial assessment of families in clinical settings. In addition, most of the participants in the present study were mothers, which is indicative of the fact that, usually, mothers serve as the primary caregivers, remaining close to their children's bedsides in hospital. Very few fathers participated in the study as a proxy informant, but their perspectives are certainly worthy of further exploration. Further studies could analyze whether the spouse perspectives are independent from one another when both parents participate.

Last, the study examined family impact and coping during cancer children's hospitalization. These experiences were associated with the disease and hospitalization. Even the participants themselves were having certain difficulties in differentiating the effects of the hospitalization from those of the cancer, particularly for the psychological impact. Further investigations recruiting families with cancer children staying at home and those being hospitalized could better differentiate families' experiences pertaining to hospitalization from those related to the disease.

8.3. Implications for clinical practice

The intention of the study was to draw health care providers' attention to families with children hospitalized for cancer treatment by investigating the family impact and coping during such a challenging period. The findings provide a direction for healthcare providers to develop effective and targeted intervention programs to support these families to overcome the stressful events and achieve bon-adaptation.

8.3.1. Alleviating family impact

Improve family functioning

To improve family functioning, family interview or counseling can be included in the treatment process to assess family interactions and find ways to solve their potential problems. Therapeutic alliances between families and nurses can be enhanced by nurse-family meetings or case conference among professionals, which offer nurses opportunities to keep an eye on the change of family functioning. For families who are at risk of disrupted family functioning, like intense family relations, small doses of intervention can be helpful for family relationship recovery. More in-depth family counseling may be necessary, and a referral to a community volunteer agent, a medical social worker, a counselor, or a family therapist may be beneficial if a family is experiencing a serious disruption of family functioning (e.g. divorce or family breakup). Help with mending the nest is an important way nurses can offer support for a family to nurture a hospitalized sick child.

Improve well-being of family members

Being able to identify families in distress and implement timely supportive strategies is important in assisting parents to cope well during their children's hospitalization. Necessary psychosocial and information support from healthcare providers would reduce the traumatic experiences of parents during this challenging period. Appropriate social activities organized in hospitals, such as parent self-help group, could alleviate parents' feelings of social isolation. Nurses could also collaborate with other professionals, such as social workers, counselors, psychologists, or psychiatrists to protect parents from emotional collapse.

To prevent impacts of adverse hospitalization that may affect normal childhood development, supportive interventions can include helping children to speak out about their fears and concerns. It is essential that children's perspectives are incorporated into the design of the ward environment to make it more child-friendly as previously discussed. Play therapy strategies should be incorporated in the daily care for hospitalized children to make their hospitalization experience more lively and fun. Effective play therapy techniques include 'feeling word game', 'balloons of anger', and 'the mad game'.

Healthy siblings should be developed to be another focus of nursing intervention when developing family care plans. Pediatric nurses can remind the parents about the possible adverse consequences to healthy siblings caused by the sick children's hospitalization, and encourage parents to mobilize the external resources (e.g.

neighbors, extended families, and teachers) to observe and support the healthy siblings during this difficult time.

Overall, families should be heard and supported with more individualized and family-centered services to alleviate the adverse impacts of hospitalization on the children and their families.

Reduce financial burden

Families were struggling with heavy financial burdens during their children's hospitalization, indicating their needs for more supportive programs. At present, there are no simple and effective strategies to deal with the financial burdens encountered by these families. It is expected that some forthcoming healthcare legislation will begin to focus on how to assist families to meet the huge medical costs resulting from catastrophic illness and hospitalization. Other than the disease-related costs, obviously, non-medical costs (e.g. traffic costs, accommodation fees) also demand similar attention. Provision of temporary accommodation services in or near the hospital may help to address families' accommodation problems. It would be helpful if the Chinese Government could provide financial support to help families to cope with a loss of family income as implemented successfully in Australia and Canada.

Healthcare policymakers and providers need to restructure and simplify the claims application procedures. Charitable agencies, as an integral part of the social community, could be encouraged to assist families by introducing or being in-kind sponsors for those families in need. Medial social workers, with particular attention to patients and families who are vulnerable, can be introduced in the Chinese medical system to identify families' financial problems and refer to supportive resources.

8.3.2. Strengthening family coping

Families always adopt multiple strategies to cope with the impact caused by children's hospitalization for cancer treatment. It is crucial for clinical nurses to identify the potential problems that may hamper a family from coping effectively and to assist them to find solutions. For example, nurses might identify families with low degrees of family cohesiveness resulting from unsolved conflicts during their adaptation to hospitalization. Helping families to realize their potential problems and recognize the importance of family strength is fundamental to enhance family coping. Other important strategies also include strengthening linkages to their natural pre-existing support, mobilizing families to explore new resources, and referring struggling families to others who are experiencing similar situations.

8.3.3. Identifying and supporting bon-adapted and mal-adapted families

The information related to characteristics of bon-adapted families and mal-adapted families provides a reference for nurses to identify families who are in desperate need of immediate support and those who could serve as supportive resources to help others. Interventions allow clinical nurses to help these mal-adapted families included problem-solving skills training, web-based family-level educational and support programs and forming parent self-help groups. Continuous observation of bon-adapted families will alert the clinical nurses to identify potential problems that may lead to a shift from bon-adaptation to mal-adaptation. Timely responses to these families and enhancement of protecting factors (e.g. family support) will prevent them from becoming mal-adaptive.

8.3.4. Enabling unmet family needs

The unmet family needs in relation to the healthcare service (e.g. supportive staff and hospital environment) have given rise to the need for change of care from disease-focused to human-focused, from individualized care to family-centered care. The findings may motivate nurses to reflect on their practices and to expand their roles for caring the families with hospitalized children. They also provide the directions for quality improvement in nursing care.

To address these unmet family needs requires collaboration between pediatric oncology nursing practitioners, nursing managers, other administrators in the hospital and policy makers. The involvement of administrators and policy makers is important in developing, changing, and implementing measures, including building comfortable environments, providing necessary facilities in pantries and improving catering services.

It is also important that family members be assured that their loved children are receiving the competent care during their hospital stay. Healthcare professionals also need to be aware that inappropriate attitudes may have the potential to worsen a family’s stressful situation. Creating a good rapport and empathy may decrease the intense relationships that may occur between parents and healthcare professionals. More important is to ensure that family members receive adequate, honest, and up-to-date information regarding their loved children in understandable terms.

8.3.5. Further utilization of HICS

It is hoped that HICS as an assessment tool will help clinical nurses to identify the families who are at greatest risk of experiencing adverse impact and ineffective coping during their children’s hospitalization, so that realistic strategies can be implemented to promote families’ achievement of bon-adaptation. The HICS has potential to identify bon-adapted families who can be a potential support resource for other families in need or at risk.

8.4. Suggestions for future research

Findings derived from the present study have opened up a range of potential areas that could be addressed in future studies.

8.4.1. Comparisons among family members

The present study focused on parents’ perspectives of family impact and coping. Further research within the Chinese community should examine other family members’ opinions. Are there any discrepancies between mothers and fathers;

between the parents and the children; or between the hospitalized child and the healthy siblings?

8.4.2. Improvements to sample

To gain a more complete and thorough understanding of family's experiences during cancer children's hospitalization, future studies should involve larger samples and much wider groups of respondents from different backgrounds.

8.4.3. Further implication and validation of HICS

With respect to the HICS, as a promising instrument, further research should attempt to include it as a part of the Hospitalization Information System as an efficient way of identifying families who are in crisis or at high risk of a crisis. To some extent, it could alleviate the time constraints perceived by health professionals, who could have more time to support families psychologically and physically. Although the HICS has shown sound psychometric properties for families having children hospitalized for treatment in general or oncology pediatric units, its applicability in other populations needs to be examined.

8.4.4. To identify which religion is most helpful for families

This study found that families with religious background perceived higher coping effectiveness. It is worthy for further study to identify which religion is most helpful for families.

8.5. Overall conclusion

This study has revealed the impact on families and their coping strategies during their cancer children's hospitalization, the characteristics of bon-adaptation and mal-adaptation, as well as their unmet family needs. The findings, which emerged from a survey and follow-up interviews with nineteen parents, have contributed to a more comprehensive understanding of families experiences during their cancer children's hospitalization. Family functioning, financial status and family members' well-being were affected. To achieve bon-adaptation, families had actively adopted multiple coping strategies, including building up family strength, maintaining self-consoling thoughts and behaviors, seeking external support and covering up the bad.

Successful family adaptation depends largely on the effectiveness of coping strategies. Pediatric oncology nurses, as the most important support resources, could help to relieve families’ burdens by helping them to find more effective coping strategies or resources. The identified characteristics provide a reference for nurses to identify families who need immediate support and those who can serve as supportive resources to help others. The findings about unmet family needs related to health care services have already shed light on areas for healthcare service improvement. Findings from the present study clearly highlight a pressing demand to improve services for families in pediatric oncology departments, since healthcare providers may have ignored families’ stressful situations while focusing only on stabilizing cancer children’s conditions.

The exploratory findings from this study also address the need for further studies in developing supportive interventions to facilitate family bon-adaptation. The assessment, acknowledgment, and understanding of family situations are fundamental for the development of appropriate family interventions.

It is believed that families will continue to face the challenges caused by their children’s hospitalization for cancer treatment. The findings from this study have shed light on some effective coping strategies to help families to overcome the challenges. This study also suggests that success in fostering family bon-adaptation requires a strengthening of family attributes, and synergistic efforts by the healthcare providers, hospitals, the government and other community agencies.

Appendix 1. Results from the qualitative interviews

Code	Sub-category	Category	Theme
Disruption of family routine Ignore other family members	• Change of family focus	➢ Impact on family functioning It describes the impact of a cancer children's hospitalization on the way of a family functions.	**Family Impact** Hospitalization impact refers to the perceived effects of a child's hospitalization on the family from the parents' perspective, measured at least 24 hours after admission to the pediatric unit.
Take new responsibilities and roles Loss of original roles Take more responsibility	• Change of roles and responsibilities		
Become detachment More closer	• Altered family relations		
Regular examination Treatment cost Travelling Accommodation	• Medical cost and other expenses	➢ Heavy financial burden This refers to the economic effects of a cancer child's hospitalization on his/her family.	
Reduced working time Ask for leave Resign	• Decreased family income		
Low reimbursement rate Long time waiting for application result Delay between application and payment	• Issues related to inadequate health insurance or national financial support		
Deteriorating physical fitness Sleep disturbance and fatigue Change in appetite and weight loss	• Physical functioning	➢ Impact on parental well-being This refers to the impact caused by a cancer child's hospitalization on a parent's functions every day.	
Feelings of sadness and hurt Worries and fear Uncertainty Feelings of inadequacy Mood fluctuations	• Psychological functioning		

Feelings of guilt			
Change of employment status Disruption of normal social activity and relationship	• Social functioning		
Physical incapability Adverse treatment-related symptoms Sleep disturbance	• Physical functioning	➢ Impact on hospitalized children's well-being This refers to the impact the sick children experienced during their hospitalization, including the impact on children's physical, psychological, social and cognitive functioning.	
Guilt Sadness/unhappiness Fear and worries Missing home and close people	• Psychological functioning		
Social isolation Diminished social skills	• Social functioning		
Absent-minded Slow-witted and clumsy	• Cognitive functioning		
Becoming more thoughtful and mature Sadness because of separation Jealously of the disproportionate amount of care being focused on the hospitalized child Deteriorated academic performances because of less parental attention Attention seeking behavior		➢ Impact on healthy sibling's psychosocial well-being This refers to the effects of a cancer child's hospitalization on healthy siblings' social and psychological functioning.	
Maintaining family cohesiveness Maintaining mutual support		➢ Building up family strength This describes families' efforts to help family members bond together and shows how a family mobilizes its internal resources to	**Family Coping** Family coping refers to the strategies and methods employed by a family member

		cope with a child’s hospitalization.	or the family as a whole to overcome the adverse hospitalization impact during a cancer child’s hospital stay.
Being optimistic Focusing on childcare		➢ Maintaining self-consoling thoughts and behaviors This refers to parents’ efforts to maintain mental stability.	
Professional support Social support		➢ Seeking external support This describes families’ efforts to actively seek external professional and social support to cope with the challenges.	
Shielding the sick children from bad news Protecting other family members from bad news Avoiding talking to friends		➢ Covering up the bad This refers to parents’ behavior to tend to hold back unpleasant information (e.g. poor prognosis, incurable conditions) with family members, friends and relatives.	
Close and supportive family relationship Being confident about the family’s future Adequate family resources Being positive Being thankful for the assistance received		➢ Bon-adaptation This is the positive end of the continuum and is characterized both by maintenance or strengthening of family integrity and by family members' sense of well-being.	**Family adaptation** This refers to an outcome as a result of changes in the family system over time. It is a continuum from bon-adaptation to mal-adaptation.
Bear more burdens Be in despair Face severe uncertainty/worry about		➢ Mal-adaptation It is the negative end of the continuum and is characterized by deterioration of family	

the future Lose confidence Disrupted family functioning Lack of supportive networks Feel hopeless Sense of helplessness		integrity, of family members' sense of well-being.	
Unmet need for good working attitudes Unmet need for sympathetic communication		➢ Unmet need for warm and supportive attitudes This refers to parents' desire to be treated warmly, fairly and friendly during their children's hospitalization for cancer treatment.	**Unmet family needs** Unmet family needs were part of pile-up demands. It refers to services that parents perceived as unconducive to bon-adaptation.
Nurses' incompetency		➢ Unmet need for competent care This refers to parents' need for their hospitalized children to get the best care and that health-care providers would be competent enough.	
Information related to disease and treatment information related to the childcare Information about the hospital surroundings		➢ Unmet need for adequate information This refers to unmet need for adequate and honest information, including knowledge about the disease and prognosis, and information about childcare.	
Good hygiene Adequate facilities Supportive hospital rules		➢ Unmet need for a comfortable environment	

A comfortable ward		This refers to the unmet need to have a better environment with good hygiene, adequate facilities and a comfortable ward.	
Quality of hospital food Variety of hospital food		➢ Unmet need for catering support This refers to the unmet need for improvement in food quality and variety.	

Appendix 2 Questionnaire (English)

For Staff/ Researcher only

Hospitalization

Impact and Coping Scale

To Be Completed by Parents

Please fill in this form

to reflect your view of the impact on your family

even if other people might not agree.

Feel free to add additional comments at the end of this questionnaire

Demographic sheet

Family information Please circle or ☑ where appropriate	**Child information** Please circle or ☑ where appropriate
Admission number (AD): __________________ **Native place:** _______________________ **Family residence:** ☐Rural area ☐Non-rural area **Who completed the questionnaire?** Father / Mother **Father : _______ years old** **Profession:**☐Full-time_____________ ☐Part-time_____________ ☐Unemployed **Education:** ☐Elementary school or below ☐Junior middle school ☐High or Secondary Vocational School ☐College or University ☐Postgraduate or above **Mother : _______years old** **Profession:**☐Full-time_______________ ☐Part-time_________________ ☐Unemployed **Education:** ☐Elementary school or below ☐Junior middle school ☐High or Secondary Vocational School ☐College or University ☐Postgraduate or above **Marital Status:** ☐ Unmarried ☐Married ☐Divorced ☐ Widowed ☐Other(please state): _______________ **Who lives with the child? (**may☑more than one answer**)** ☐Father ☐Mother☐Grandmother☐Grandfather☐Child's other siblings (age):___years old; ___years old; ___years old☐Other (please state) : __________ **Family monthly income(RMB)** ---______ **Religion:** atheist/ancestor worship/ Catholic/ Christian / Buddhist / Taoism, or ______	**Gender**： Male / Female **Age of Child __** Years **__**Month **Diagnosis and severity_____________** **Treatment stage:** ☐Primary treatment☐Relapse treatment **Education** ☐No schooling ☐ Kindergarten ☐ Elementary school ☐ Junior middle school **Treatment effectiveness:** ☐Very good ☐Good ☐Not good **Cancer treatment interrupted (Not follow the doctor's advice）:** ☐Yes ☐No **If "Yes", the reason(s) is (are):** ☐Worry the side effects ☐Financial issues ☐Disease ☐Other___________ **Source of medical cost**（may ☑more than one answer**):** ☐Self-funded ☐Commercial insurance ☐Rural cooperative medical systems ☐ Social medical insurance **Total days of all admissions** _____days **Number of re-admission** ______times

The following statements describe the impact of a child’s hospitalization on families. According to your family’s experiences of the impact during this period of hospitalization, evaluate the level of impact accordingly:

Please circle **0**, if the item has **no** impact;

Please circle **1**, if the item has **little** impact;

Please circle **2**, if the item has **some** impact;

Please circle **3**, if the item has **great** impact;

Please circle **4**, if the item has **extreme** impact;

Please circle **X**, if the item is not applicable (NA).

(Please □○□or □✓□in the appropriate response)

While my child is hospitalized, we / our	**No Impact**	**Little Impact**	**Some Impact**	**Great Impact**	**Extreme Impact**	**NA**
1.feel tired	0	1	2	3	4	X
2. health is adversely affected	0	1	2	3	4	X
3.cannot sleep well	0	1	2	3	4	X
4.lose appetite	0	1	2	3	4	X
5.emotions fluctuate according to our child’s medical condition	0	1	2	3	4	X
6.become irritable	0	1	2	3	4	X
7.cannot concentrate on work	0	1	2	3	4	X
8.feel nervous	0	1	2	3	4	X
9.feel guilty for inadequate care leading to hospitalization	0	1	2	3	4	X
10.feel hurt because my child is suffering in hospital	0	1	2	3	4	X
11.worry about disease progress	0	1	2	3	4	X
12.are more tolerant of our child’s misbehavior	0	1	2	3	4	X
13.donot know how to deal with our child’s emotions	0	1	2	3	4	X

14.cannot rely on others to take care of my child	0	1	2	3	4	X
15.consider our child’s condition is serious	0	1	2	3	4	X
16.want to take care of my child but feel inadequate to do so	0	1	2	3	4	X
17.daily life needs to be changed	0	1	2	3	4	X
18.have to give up a lot of things	0	1	2	3	4	X
19.donot have much time left for other family members	0	1	2	3	4	X
20.cannot complete the household chores	0	1	2	3	4	X
21.blame each other for improper care	0	1	2	3	4	X
22.seldom have a chance to talk about problems we encounter	0	1	2	3	4	X
23.relationship is affected because of the bad mood	0	1	2	3	4	X
24.see family and friends less	0	1	2	3	4	X
25.are unable to take a stroll or travel out of the town	0	1	2	3	4	X
26.become very busy and have no free time	0	1	2	3	4	X
27.losing time from work with reduced income	0	1	2	3	4	X
28.have more expenses	0	1	2	3	4	X
29.have extra burdens	0	1	2	3	4	X
30.burden can hardly be understood by others	0	1	2	3	4	X
31.cannot freely adopt alternative therapies	0	1	2	3	4	X
32.have feelings that hospital staff are too busy to be bothered	0	1	2	3	4	X
33.cannot adapt to the hospital environment	0	1	2	3	4	X
34.do not know details of our child’s condition	0	1	2	3	4	X
35.worry about malpractice	0	1	2	3	4	X
36.cannot adapt to the ward routines	0	1	2	3	4	X
We have greater stress with concurrent difficulties (e.g., unemployment； stress from work； marital problem； other relative is also sick) Please circle and elaborate ------------ Please describe other impact ____						

The statements below are actions that you and your family may have found helpful in coping with the impact of hospitalization. Please indicate which is true for you and your family.

Please circle **0**, if the attempt has **no** effect;

Please circle **1**, if the attempt has **little** effect;

Please circle **2**, if the attempt has **some** effect;

Please circle **3**, if the attempt has **great** effect;

Please circle **4**, if the attempt has **extreme** effect;

Please circle **X**, for no attempt (not applicable or NA).

(Please □○□or □✓□in the appropriate response)

In order to cope with the impact of hospitalization, I (we):	**No Effect**	**Little Effect**	**Some Effect**	**Great Effect**	**Extreme Effect**	**Not Attempt**
1. try to relax and control emotions	0	1	2	3	4	X
2. support each other and share responsibilities	0	1	2	3	4	X
3. stay close to my child	0	1	2	3	4	X
4. prepare food for my child	0	1	2	3	4	X
5. keep asking doctors and nurses questions, and monitor the child closely ourselves	0	1	2	3	4	X
6. consider hospitalization can be more of a relief to us	0	1	2	3	4	X
7. make use of what we see in hospital as learning experiences	0	1	2	3	4	X
8. treat my child as usual	0	1	2	3	4	X
9. encourage family members, including the sick child, to express their inmost feelings	0	1	2	3	4	X
10. do not expect too much and do not plan for too long	0	1	2	3	4	X
11. seek and accept help from relatives	0	1	2	3	4	X

12. seek and accept help from friends	0	1	2	3	4	X
13. hope things will get better	0	1	2	3	4	X
14. cut down working hours to participate more in childcare	0	1	2	3	4	X
15. ask relatives and friends about hospitalization experiences	0	1	2	3	4	X
16. try our best to endure and be co-operative	0	1	2	3	4	X
We find other useful method(s) for the child to cope with hospitalization (watching TV, toys etc.) Please state:_________________________________ Use other method(s) to overcome the impact of hospitalization on the family , please state:____________________________________						

Family Impact Module (FIM) for concurrent validity testing

	The following statements describe the level of impact accordingly of a child’s health problem on families. 0=never a problem; 1=almost never a problem; 2=sometimes a problem; 3=often a problem; 4=almost always a problem; **(Please □○□or □✓□in the appropriate response)**	Never a problem	Almost never a problem	Sometimes a problem	Often a problem	Almost always a problem
1	Feel tired during the day	0	1	2	3	4
2	Feel tired when I wake up in the morning	0	1	2	3	4
3	Feel tired to do things	0	1	2	3	4
4	Get headaches	0	1	2	3	4
5	Feel physical weak	0	1	2	3	4
6	Feel sick to my stomach	0	1	2	3	4
7	Feel anxious	0	1	2	3	4
8	Feel sad	0	1	2	3	4
9	Feel angry	0	1	2	3	4
10	Feel frustrated	0	1	2	3	4
11	Feel helpless or hopeless	0	1	2	3	4
12	Feel isolated from others	0	1	2	3	4
13	Trouble getting support from others	0	1	2	3	4
14	Had to find time for social activities	0	1	2	3	4
15	Lack of energy for social activities	0	1	2	3	4
16	Hard to keep my attention on things	0	1	2	3	4
17	Hard to remember what people tell me	0	1	2	3	4
18	Hard to remember what I just heard	0	1	2	3	4

19	Hard to think quickly	0	1	2	3	4
20	Trouble remembering what I was just thinking	0	1	2	3	4
21	Others do not understand my family's situation	0	1	2	3	4
22	Hard to talk about my child's health with others	0	1	2	3	4
23	Hard to tell doctors and nurses how I feel	0	1	2	3	4
24	Worry about my child's medical treatment is working	0	1	2	3	4
25	Worry about the side effects of my child's medical treatments	0	1	2	3	4
26	Worry about how others will react to my child's condition	0	1	2	3	4
27	Worry about my child's illness affects other family members	0	1	2	3	4
28	Worry about my child's future	0	1	2	3	4
29	Families activities taking more time and effort	0	1	2	3	4
30	Difficulty finding time to finish household tasks	0	1	2	3	4
31	Fatigue made it difficult to finish the household chores					
32	Lack of communication between family members	0	1	2	3	4
33	Conflicts between family members	0	1	2	3	4
34	Difficulty making decisions together as a family	0	1	2	3	4
35	Difficulty in solving family problems together	0	1	2	3	4
36	Stress or tension between family members	0	1	2	3	4

Coping Health Inventory for Parents (CHIP) for concurrent validity testing

	For each coping behavior you used, please record how helpful it was. 0 = not helpful; 1 = minimally helpful; 2 = moderately helpful; 3 = extremely helpful Please circle X, if the item is not applicable (NA). **(Please○☐ or ✓ in the appropriate response)**	Not Helpful	Minimally Helpful	Moderately Helpful	Extremely Helpful	NA
1	Believing that my child (ren) will get better	0	1	2	3	X
2	Investing myself in my children	0	1	2	3	X
3	Doing things with my children.	0	1	2	3	X
4	Believing that things will always work out	0	1	2	3	X
5	Telling myself that I have many things I should be thankful for	0	1	2	3	X
6	Building a closer relationship with my spouse	0	1	2	3	X
7	Talking over personal feelings and concerns with spouse	0	1	2	3	X
8	Doing things with family relatives	0	1	2	3	X
9	Believing in God	0	1	2	3	X
10	Taking good care of all the medical equipment at home	0	1	2	3	X
11	Believing that my child is getting the best medical care possible	0	1	2	3	X
12	Trying to maintain family stability	0	1	2	3	X
13	Doing things together as a family (Involving all members of the family)	0	1	2	3	X
14	Trusting my spouse (or former spouse) to help support me and my child (ren)	0	1	2	3	X
15	Showing that I am strong	0	1	2	3	X
16	Getting other members of the family to help with chores and tasks at home.	0	1	2	3	X

17	Having my child with the medical condition seen at the clinic/hospital on a regular basis	0	1	2	3	X
18	Believing that the medical center/hospital has my family's best interest in mind	0	1	2	3	X
19	Encouraging child (ren) with medical condition to be more independent	0	1	2	3	X
20	Involvement in social activities (parties, etc.) with friends	0	1	2	3	X
21	Being able to get away from the home care tasks and responsibilities for some relief	0	1	2	3	X
22	Getting away by myself	0	1	2	3	X
23	Eating	0	1	2	3	X
24	Sleeping	0	1	2	3	X
25	Allowing myself to get angry	0	1	2	3	X
26	Purchasing gifts for myself and/or other family members	0	1	2	3	X
27	Concentrating on hobbies (art, music, jogging, etc.)	0	1	2	3	X
28	Working, outside employment	0	1	2	3	X
29	Becoming more self-reliant and independent	0	1	2	3	X
30	Keeping myself in shape and well-groomed	0	1	2	3	X
31	Talking to someone (not professional counselor/doctor) about how I feel	0	1	2	3	X
32	Engaging in relationships and friendships which help me to feel important and appreciated	0	1	2	3	X
33	Entertaining friends in our home	0	1	2	3	X
34	Investing time and energy in my job	0	1	2	3	X
35	Going out with my spouse on a regular basis	0	1	2	3	X
36	Building close relationships with people	0	1	2	3	X
37	Developing myself as a person	0	1	2	3	X
38	Talking with other parents in the same type of situation and learning about their experiences	0	1	2	3	X

39	Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	0	1	2	3	X
40	Reading about how other persons in my situation handle things	0	1	2	3	X
41	Reading more about the medical problem which concerns me	0	1	2	3	X
42	Explaining our family situation to friends and neighbors so they will understand	0	1	2	3	X
43	Being sure prescribed medical treatments for child (ren) are carried out at home on a daily basis	0	1	2	3	X
44	Talking with other individuals/parents in my same situation	0	1	2	3	X
45	Talking with the doctor about my concerns about my child (ren) with the medical condition	0	1	2	3	X

Appendix 3 Questionnaire (Chinese)

研究专用

住院的影响及应付方法

调查问卷

请父母填写

纵然其他家人未必认同您的观点，请根据您的看法填写此问卷。

如有需要，可在问卷最后的空白处记下其他意见。

人口统计资料

家庭资料 (在适用处，**可打圈或☑)**	子女及疾病相关资料 (在适用处，**可打圈或☑。)**
住院号： ______________________ **家庭所住地：** □农村□城镇 **您与病童关系：**父 / 母 **父亲 :** _______ **岁** **职业:** □全职____________________ □兼职____________________ □无业 **学历：**小学/初中/高中或中专/大专或本科/硕士及以上 **母亲 :** _______岁 **职业:** □全职____________________ □兼职____________________ □无业 **学历:**小学/初中/高中或中专/大专或本科/硕士及以上 **婚姻状况** □未婚□已婚□离异□丧偶 □其他(请注明): ____________________ **谁与子女同住？(可☑多于一个)** □父亲□母亲□子女的兄弟姊妹(年龄):___岁;___岁;___岁□祖母□祖父□其他（请注明) : ____________________ **家庭月收入（元）** -- **宗教：**无信仰/拜祖先/天主教/基督教/佛教/道教或 ______	**住院子女性别：男/女** **住院子女年龄：_____ 岁______月** **疾病诊断及严重程度____________________** **治疗阶段：**□初发治疗□复发治疗 **患病孩子的就读情况：** □未达上学年龄□幼儿园□小学□初中 **您认为目前孩子的治疗效果：** □非常好□比较好□不太好 **孩子有无中断治疗（未按照医生的要求治疗）：**□有□无 **如果选择“有”，中断原因为：** □担心药物的副作用 □经济原因 □疾病本身原因 □其他___________ **医疗费用主要来源（可多选)**： □自费□商业保险 □农村合作医疗□社会医疗保险 **到目前为止累计住院天数____________**天 **到目前为止累计住院次数___________**次

以下是有关***子女住院对家庭影响***的描述，就这次住院经验，请根据您的家庭受影响情况，评定下列每项描述的受影响程度：

没有影响，请圈 0；少许影响，请圈 1；有些影响，请圈 2；

很有影响，请圈 3；极有影响，请圈 4；不适用，请圈 X。**(请在适当处画○或✓)**

	子女住院期间我(们):	没有影响	少许影响	有些影响	很有影响	极有影响	不适用
1	疲乏劳累	0	1	2	3	4	X
2	健康变差	0	1	2	3	4	X
3	难以安睡	0	1	2	3	4	X
4	胃口欠佳	0	1	2	3	4	X
5	忐忑不安，情绪跟子女病况起伏	0	1	2	3	4	X
6	心情欠佳，易怒生气	0	1	2	3	4	X
7	不能专心做事	0	1	2	3	4	X
8	内心紧张、担心和胆怯	0	1	2	3	4	X
9	内疚照顾不周以致需要住院	0	1	2	3	4	X
10	心痛子女受苦	0	1	2	3	4	X
11	担忧病情进展（病因、治疗、预后等）	0	1	2	3	4	X
12	会多一点容忍患病子女的行为	0	1	2	3	4	X
13	不知如何处理患病子女的情绪	0	1	2	3	4	X
14	很难信赖别人来照顾自己的患病子女	0	1	2	3	4	X
15	觉得子女的病情严重	0	1	2	3	4	X
16	想协助照顾患病子女，但感无能为力	0	1	2	3	4	X
17	日常生活也需要改变（工作、家庭活动、娱乐等）	0	1	2	3	4	X
18	要被迫放弃很多事情	0	1	2	3	4	X
19	没有时间留给其他家人	0	1	2	3	4	X
20	未能完成煮饭、清洁等家务	0	1	2	3	4	X
21	互相责怪照顾不力	0	1	2	3	4	X

22	很少机会讨论大家面对的困难	0	1	2	3	4	X
23	因坏心情影响了家庭关系	0	1	2	3	4	X
24	减少了家人及朋友的交往	0	1	2	3	4	X
25	不能外出闲逛或旅游	0	1	2	3	4	X
26	生活变得十分忙碌，分身不暇	0	1	2	3	4	X
27	失去了工作时间，减少收入	0	1	2	3	4	X
28	需要更多花费（交通及医疗费等)	0	1	2	3	4	X
29	我们背起了额外的担子（日常照顾、预备食物、教导等）	0	1	2	3	4	X
30	所背负的担子，外人难以理解	0	1	2	3	4	X
31	不能随意采用其他的治疗方法（例如中成药、药油等）	0	1	2	3	4	X
32	感到医务人员忙不过来，不便打扰他/她们	0	1	2	3	4	X
33	对病房环境不适应（例如人声、仪器响声、灯光、卫生等）	0	1	2	3	4	X
34	未能详细了解情况(孩子的病情、预后、治疗等)	0	1	2	3	4	X
35	担心会发生医疗事故	0	1	2	3	4	X
36	对病房常规不适应（例如定时饭餐、探视规限、晚间巡查等)	0	1	2	3	4	X

压力更大，因为现正面对其他困难（例如：失业；工作压力大；婚姻问题；另一亲人也患病请说明

____

以下是一些**方法以应付以上住院的影响，**就这次住院经验，请根据您的情况，评定哪一项对于您或家人是准确的：

已试行但无效，请圈 0；已试行少成效，请圈 1；已试行一般成效，请圈 2；

已试行很有效，请圈 3；已试行极有效，请圈 4；未有试行，请圈 X。**(请在适当处画○或✓)**

		无效	少有效	一般成效	很有成效	极有成效	未有试行
1	尝试控制情绪，放松心情	0	1	2	3	4	X
2	一家人相互支持，合力分担责任	0	1	2	3	4	X

3	尽量留守子女身边	0	1	2	3	4	X
4	预备食物给子女享用	0	1	2	3	4	X
5	不断询问医护人员,并亲自监察照顾子女	0	1	2	3	4	X
6	把子女留院，视为更安心	0	1	2	3	4	X
7	从住院经历中学习	0	1	2	3	4	X
8	以平常态度看待子女	0	1	2	3	4	X
9	鼓励家人及患病子女更多表达心里话	0	1	2	3	4	X
10	不期望太多，也不做太长远计划	0	1	2	3	4	X
11	向亲戚求助，接受帮忙	0	1	2	3	4	X
12	向朋友求助，接受帮忙	0	1	2	3	4	X
13	希望明天会更好	0	1	2	3	4	X
14	减少工时以便参与更多照顾	0	1	2	3	4	X
15	向亲友询问有关住院的经验	0	1	2	3	4	X
16	尽量容忍，抱合作态度	0	1	2	3	4	X
找到了帮助子女克服住院的影响的其他方法（如看电视、玩具等） 请说明：________________________________							
用其他方法克服住院对家庭的影响，请说明：______________________							

家庭影响量表（FIM）

在过去一个月内，由于您孩子的健康，给您及您的家庭带来了多大程度的问题…

没有出现，请圈 0；很少出现，请圈 1；有时出现，请圈 2；

经常出现，请圈 3；总是出现，请圈 4。**(请在适当处画○或✓)**

		没有出现	很少出现	有时出现	经常出现	总是出现
1	我整天感到疲惫	0	1	2	3	4
2	早晨醒来时我感到疲倦	0	1	2	3	4
3	我感到太疲惫以至于无法做自己喜欢做的事情	0	1	2	3	4
4	我感到头痛	0	1	2	3	4
5	我感到身体虚弱	0	1	2	3	4
6	我感到恶心呕吐	0	1	2	3	4
7	我感到焦虑	0	1	2	3	4
8	我感到悲伤	0	1	2	3	4
9	我感到气愤	0	1	2	3	4
10	我感到沮丧	0	1	2	3	4
11	我感到无助或无望	0	1	2	3	4
12	我感到孤立于他人	0	1	2	3	4
13	我从他人处获得帮助有困难	0	1	2	3	4
14	难以抽出时间参加社交活动	0	1	2	3	4
15	我没有足够的精力参加社交活动	0	1	2	3	4
16	我难以集中注意力做事情	0	1	2	3	4
17	我难以记住别人告诉我的事情	0	1	2	3	4
18	我难以记住我刚听到的话	0	1	2	3	4
19	我难以思维敏捷	0	1	2	3	4
20	我难以记住我刚才在想什么	0	1	2	3	4
21	我感到他人不理解我家庭的状况	0	1	2	3	4

22	我难以和他人谈论我孩子的健康	0	1	2	3	4
23	我难以告诉医生和护士我的感受	0	1	2	3	4
24	我担心孩子的治疗是否有效	0	1	2	3	4
25	我担心我孩子治疗的副作用	0	1	2	3	4
26	我担心别人如何看待我孩子的状况	0	1	2	3	4
27	我担心我孩子的疾病影响家庭的其他成员	0	1	2	3	4
28	我担心孩子的未来	0	1	2	3	4
29	家庭活动要花更多时间和精力	0	1	2	3	4
30	难以抽出时间完成家务	0	1	2	3	4
31	感到太疲惫而不能完成家务	0	1	2	3	4
32	家庭成员之间缺乏交流	0	1	2	3	4
33	家庭成员之间存在矛盾	0	1	2	3	4
34	家庭成员难以一起做决定	0	1	2	3	4
35	家庭成员难以一起解决家庭问题	0	1	2	3	4
36	家庭成员之间的关系存在压力或紧张	0	1	2	3	4

父母应对量表（CHIP）

y 当**您的孩子患病后，您是否采取了以下所列的应对方法来保持正常家庭生活?**

请告诉我们该方法对于保持正常家庭生活是“非常有用(3 分)、有些有用(2 分)、少许有用(1 分)、无效(0 分)、未有试行(X)”。（**请在相应空格内划“√”）。**

		无效	少许有用	有些有用	非常有用	未有试行
1	相信我孩子的病情会好转	0	1	2	3	X
2	投入更多精力照顾我的孩子	0	1	2	3	X
3	和孩子一起做事情	0	1	2	3	X
4	相信问题总是可以解决的	0	1	2	3	X
5	对自己说“对很多事情应心怀感激”	0	1	2	3	X
6	为了孩子，和我的爱人建立更亲密的关系	0	1	2	3	X

7	和爱人谈论自己的感受和担忧	0	1	2	3	X
8	和家里人一起做事情	0	1	2	3	X
9	相信老天爷（佛/上帝/神灵）会保佑我	0	1	2	3	X
10	保护好家中的医疗用品	0	1	2	3	X
11	相信我的孩子能得到最好的治疗	0	1	2	3	X
12	努力保持家庭的稳定	0	1	2	3	X
13	家庭成员作为一个整体一起努力	0	1	2	3	X
14	相信我的爱人(或前夫／妻)会支持我和我的孩子	0	1	2	3	X
15	显示出我是坚强的	0	1	2	3	X
16	请家庭其他成员帮助做些日常家庭杂务	0	1	2	3	X
17	定期带孩子到医院检查	0	1	2	3	X
18	相信医院能够以病人的利益至上	0	1	2	3	X
19	鼓励患病的孩子更加独立	0	1	2	3	X
20	和朋友一起参加社会活动(聚会）等	0	1	2	3	X
21	能够暂时放下照顾家庭的责任和工作，去放松一下	0	1	2	3	X
22	给自己独处的时间（独自一个人呆一会儿）	0	1	2	3	X
23	为了更好地照顾孩子，保持正常饮食，并适当增加食量	0	1	2	3	X
24	为了更好地照顾孩子，保持正常睡眠并尽可能多睡觉	0	1	2	3	X
25	允许自己生气	0	1	2	3	X
26	为我自己和（或）其他家庭成员购买礼物	0	1	2	3	X
27	专心于自己的爱好（艺术、音乐、慢跑等）	0	1	2	3	X
28	在本职工作以外还做第二份工作	0	1	2	3	X
29	变得更加自信和独立	0	1	2	3	X
30	保持良好的体形，梳洗整洁	0	1	2	3	X
31	告诉某人(非职业的咨询者／医生）我的感受	0	1	2	3	X
32	和其他(她)人建立某种关系和友谊，它们使我感到受人尊重和欣赏	0	1	2	3	X
33	请亲戚朋友到家中做客	0	1	2	3	X

34	在工作中投入时间和精力	0	1	2	3	X
35	与往常一样，和爱人、孩子一起外出游玩	0	1	2	3	X
36	和周围人建立良好的关系	0	1	2	3	X
37	注重自我发展	0	1	2	3	X
38	和与我的孩子患有相同疾病的父母交流，学习他们的经验	0	1	2	3	X
39	去医院就诊时，和医务人员交谈	0	1	2	3	X
40	看书上介绍的其他与我有相同处境的人是怎么做的	0	1	2	3	X
41	了解更多困扰我的医学问题	0	1	2	3	X
42	把我的家庭情况告诉朋友和邻居，得到他们的理解和帮助	0	1	2	3	X
43	确保为孩子制定的治疗方案在家中顺利实施	0	1	2	3	X
44	和与我的处境相同的个人/父母交谈	0	1	2	3	X
45	和医生谈谈我对孩子病情的担忧	0	1	2	3	X

再次感谢您的帮助与支持！

Appendix 4 Information Sheet (English)

INFORMATION SHEET (for survey)

A study investigating the impact and coping of families during cancer children's hospitalization

Researcher: Lyu Qiyuan Tel: (852)5535 E-mail:
1290 @

You are invited to participate in a study conducted by Lyu Qiyuan, who is a PhD candidate of School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the Human Subjects Ethics Sub-committee (HSESC) of The Hong Kong Polytechnic University (HSESC Reference Number: HSEARS20130604003) and Sun Yat-Sen University (2013ZSLYEC-014).

The aim of this study is to investigate impact and coping of families with hospitalized cancer children. The study will involve completing a questionnaire, which will take you about half an hour. It is hoped that information about your hospital experience will help other families who go through similar experiences and help nurses to develop better care to families with cancer children. After the survey, I will invite you to participate into a follow-up interview to learn the situation of your family in details, if needed. I will inform you one day before the interview.

All information will remain confidential, and will be identifiable by codes only known to the researcher.

You have every right to withdrawn from the study before or during the research without penalty of any kind.

If you would like to get more information about this study, please contact Ms. Lyu Qiyuan on tel. no. 852-5535 and email address: 1290 @.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Dr Virginia Cheng, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in writing stating clearly the responsible person and department of this study.

Thank you for your interest in participating in this study.

Principal Investigator: Dr. Sarah Kong

Co-investigator: Prof. Frances Wong, Prof. Li-ming You

Lyu Qiyuan

INFORMATION SHEET (for interview)

A study investigating the impact and coping of families during cancer children's hospitalization

Researcher: Lyu Qiyuan Tel: (852)5535 E-mail:
1290 @

You are invited to participate in a study conducted by Lyu Qiyuan, who is a PhD candidate of School of Nursing in The Hong Kong Polytechnic University. The project has been approved by the Human Subjects Ethics Sub-committee (HSESC) of The Hong Kong Polytechnic University (HSESC Reference Number: HSEARS20130604003) and Sun Yat-Sen University (2013ZSLYEC-014).

The aim of this study is to investigate impact and coping of families with hospitalized cancer children. The study will involve face-to-face interviews, which will take you about an hour. The interview will be recorded and transcribed into text. After the data analysis, the results will be sent to you to confirm my understanding about your information is accurate. The findings will be published without any personal identifiable information. It is hoped that information about your hospital experience will help other families who go through similar experiences and help nurses to develop better care to families with hospitalized cancer children.

You have every right to withdrawn from the study before or during the research without penalty of any kind.

All information will remain confidential, and will be identifiable by codes only known to the researcher.

If you would like to get more information about this study, please contact Ms.
Lyu Qiyuan on tel. no. 852-5535 and email address: 1290 @.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Dr Virginia Cheng, Secretary of the Human Subjects Ethics Sub-

Committee of The Hong Kong Polytechnic University in writing stating clearly the responsible person and department of this study.

Thank you for your interest in participating in this study.

Principal Investigator: Dr. Sarah Kong

Co-investigator: Prof. Frances Wong, Prof. You Li-ming

Lyu Qiyuan

Appendix 5 Information Sheet (Chinese)

研究知情书（问卷调查用）

恶性肿瘤患儿住院对家庭的影响及家庭应对的研究

研究者：吕启圆电话: (852)5535　　E-mail: 1290　@

我们诚邀您加入我们的研究，此项研究是由香港理工大学护理学院的博士研究生吕启圆组织开展。本研究已经得到香港理工大学伦理委员会（编号：HSEARS20130604003）及中山大学伦理委员的批准 (编号：2013ZSLYEC-014)。

本研究旨在探讨恶性肿瘤患儿住院对家庭的影响及家庭的应对。在研究过程中，需要您填写一份问卷，以帮助研究者全面了解您的家庭目前的状况。完成问卷需花费您大约半小时时间。本研究结果有利于护理人员制定完善的护理方案以帮助和您有相似经历的家庭，同时也可能通过您的榜样作用，激励其他家庭更好的面对患儿的疾病与住院。调查结束后，为了深入了解您的家庭目前的状况，可能会邀请您参加一次访谈，如果需要您的参与，会提前告知您。

您可以自主决定是否参加此研究，也可以在任何时候退出研究，不会对您及您的家人带来任何负面影响。

填写问卷不会给您及您的家庭造成任何影响，对于您的个人信息我们会严格保密。

如果你想了解更多有关本研究的信息，可与吕启圆联系（852-5535　或 1290　@　）。如果您对本研究有任何的建议或意见，可联系香港理工大学伦理委员会秘书 Dr Virginia Chen。

感谢您的参与。

课题负责人：江黄洁芳博士

合作研究者：黄金月教授尤黎明教授

吕启圆（博士研究生）

研究知情书（访谈用）

恶性肿瘤患儿住院对家庭的影响及家庭应对的研究

研究者：吕启圆电话: (852) 5535 E-mail: 1290 @

我们诚邀您加入我们的研究，此项研究是由香港理工大学护理学院的博士研究生吕启圆开展。本研究已经得到香港理工大学伦理委员会（编号：HSEARS20130604003）及中山大学伦理委员的批准 (编号：2013ZSLYEC-014)。

本研究旨在全面深入了解恶性肿瘤患儿住院对家庭的影响及家庭的应对。在研究过程中，需要与您进行一次面对面的访谈，访谈时间约 1 小时，访谈将被录音，且录音稿将由研究者转化成文字稿，以便研究者访谈后分析。分析完成后，我们会将结果反馈给您，以确认我们的理解无误；其后我们会将研究结果发表，但会隐去可以识别身份的个人信息。本研究结果有利于护理人员制定完善的护理方案以帮助和您有相似经历的家庭，同时也可能通过您的榜样作用，激励其他家庭更好的面对患儿的疾病与住院。

访谈可能会给您带来心理上的不适，但是分享您的压力也可能使您感到轻松，如果访谈过程你感到不适或是不便，访谈可以随时终止，不会对您及您的家人带来任何负面影响。您可以自主决定是否参加此研究，也可以在任何时候退出研究。

对于您的个人信息我们会严格保密。

如果你想了解更多有关本研究的信息，可与吕启圆联系（ 852-5535 或 1290 @ 。如果您对本研究有任何的建议或意见，可联系香港理工大学伦理委员会秘书 Dr Virginia Chen。

感谢您的参与。

课题负责人：江黄洁芳博士

合作研究者：黄金月教授尤黎明教授

吕启圆（博士研究生）

Appendix 6 Consent Form (English)

CONSENT TO PARTICIPATE IN RESEARCH

A study investigating the impact and coping of families during cancer children's hospitalization

I ________________________ hereby consent to participate in the captioned research conducted by ___________________.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e. my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. I understand the benefit and risks involved. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant__________________________

Signature of Participant______________________________________

Name of Researcher______________________________________

Signature of Researcher ______________________________________

Date____

Appendix 7 Consent Form (Chinese)

参与研究同意书

恶性肿瘤患儿住院对家庭的影响及家庭应对的研究

本人___________________同意参与由__________________开展的上述研究。

本人知悉此研究所得的资料可能被用作日后的研究及发表，但本人的私隐权利将得以保留，即本人的个人资料不会被公开。

研究人员已向本人清楚解释列在所附数据卡上的研究程序，本人明了当中涉及的利益及风险；本人自愿参与研究项目。

本人知悉本人有权就程序的任何部分提出疑问，并有权随时退出而不受任何惩处。

参与者姓名 ______________________________________

参与者签署 ______________________________________

研究人员姓名 _____________________________________

研究人员签署 _____________________________________

日期 ____

Appendix 8 Ethical Approval-1

THE HONG KONG POLYTECHNIC UNIVERSITY
香港理工大學

To	Wong Kit Fong (School of Nursing)		
From	KWONG Wai Yung, Chair, Departmental Research Committee		
Email	hsenid@inet.polyu.edu.hk	Date	02-Jul-2013

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 17-Sep-2012 to 31-Jul-2014:

Project Title:	A study investigating the impact and coping of families with hospitalized children with cancer
Department:	School of Nursing
Principal Investigator:	Wong Kit Fong

Please note that you will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Departmental Research Committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

You will receive separate email notification should you be required to obtain fresh approval.

KWONG Wai Yung

Chair

Departmental Research Committee

Page 1 of 1

Appendix 9 Ethical Approval-2

中山大学护理学院、附属六院伦理委员会

项目伦理审批表

伦研批第（ 2013ZSLYEC-014 ）号

<table>
<tr><td>项目名称</td><td colspan="6">恶性肿瘤患儿住院对家庭的影响及家庭应对的研究</td></tr>
<tr><td>项目类别</td><td colspan="6">基础____ 临床 __✓__ 药物______其它 ________</td></tr>
<tr><td>项目来源</td><td colspan="2">中山大学护理学院博士课题</td><td colspan="2">经 费</td><td colspan="2">博士生课题经费；</td></tr>
<tr><td>申办单位</td><td colspan="2">中山大学护理学院</td><td colspan="2">单位负责人</td><td colspan="2">谢文主任护师</td></tr>
<tr><td>导师</td><td>护理学博士研究生指导委员会</td><td>主要指导</td><td colspan="2">黄金月教授</td><td>博士生</td><td>吕启圆</td></tr>
<tr><td colspan="7">伦理审查意见</td></tr>
<tr><td colspan="4">Δ 同意</td><td colspan="3">✓</td></tr>
<tr><td colspan="4">Δ 修改后同意</td><td colspan="3"></td></tr>
<tr><td colspan="4">Δ 不同意（项目终止或暂停）</td><td colspan="3"></td></tr>
<tr><td colspan="7">审批意见
同意立项。
伦理委员会
主任委员（签名）__________
2013 年 6 月 8 日</td></tr>
</table>

Appendix 10 Ethical Approval-3

Ethics Committee of School of Nursing, Sun Yat-sen University
Ethics Approval for Research Project

Ethics Approval Number: **2013ZSLYEC-014**

Title of Research Project	A study investigating the impact and coping of families with hospitalized children with cancer				
Project Category	Basic____ Clinical ✓ Drug____Others ____				
Project Sources	Doctoral candidate project of School of Nursing, Sun Yat-sen University	**Funds**	Doctoral Candidate Project Fund from Sun Yat-sen University		
Department/ School	School of Nursing	**Head of the Department / School**	Chief Superintendent Nurse. Wen Xie		
Supervisor	Supervisory Committee for Doctoral Candidate of Nursing	**Chief supervisor**	Prof. Frances Kam Yuet Wong	**Doctoral candidate**	Lv Qiyuan
Ethic Evaluation					
Δ **Approved**	✓				
Δ **Approved after Revision**					
Δ **Disapproved（terminate or suspend the project）**					

Ethic Evaluation Result

Approved

Director of Ethics Committee's Signature ____________ **Date**: Jun 8th, 2013

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