The Hong Kong Polytechnic University

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THE IMPACT ON FAMILIES WITH HOSPITALIZED CHILDREN: DEVELOPMENT OF A HOSPITALIZATION IMPACT AND COPING SCALE ON FAMILIES (HICS)

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CERTIFICATE OF ORIGINALITY

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

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ABSTRACT

The aim of this study was to deepen understanding of the dimensions that underlie the concept of hospitalization impact and coping of families with hospitalized children, through in-depth interviews with parents and developing a multidimensional measuring scale for clinical use in the Chinese community.

With increased awareness of the psychological trauma to children caused during hospitalization, practices have now shifted towards family-centered care and parental participation. Pioneer studies in parental involvement in hospitalized childcare have highlighted parental stresses, but with limited knowledge about its related patterns and severity. The coping strategies believed to have a mediating effect on stresses have not been thoroughly evaluated regarding pattern and effectiveness.

The Hospitalization Impact and Coping Scale (HICS) was designed to measure the parental perception of the hospitalization impacts and their perceived effectiveness of coping strategies of the family, which is viewed within the concept of the Double ABCX model. The HICS was developed in two phases: Phase One for item generation through interviewing parents with hospitalized children, literature review, content validity testing and a pilot study; and Phase Two for testing the psychometric properties of the HICS, such as internal consistency, reliability, construct validity and factor structures.

A convenience sample of 218 Chinese parents (52% mothers, 26.6% father, and 20.6% joint participation with consensus) was recruited in China. In the final 51-item scale, the HICS demonstrated excellent internal consistency in both sub-scales (Cronbach's alpha values of the impact sub-scale = 0.94 and coping sub-scale = 0.84). All six domains of the impact sub-scale demonstrated excellent internal reliability (Cronbach's alpha values ranged from 0.77 – 0.86), and the four domains of the coping sub-scale demonstrated satisfactory to good internal reliability with Cronbach's alpha values ranging from 0.62 to 0.71. The construct validity was established through the convergent validity approach.

Using exploratory factor analysis (EFA), six factors were extracted from the impact sub-scale contributing to 63.48% variance. The six factors are psychological, social, physical, health service utilization, family and burden impacts. Four factors were extracted from the coping sub-scale, namely, effort to maintain positive and active parental care; attempts to readjust mental stability; utilizing internal and external resources; and maximizing quality and quantity of childcare. These factors contributed to 58.47% variance of the coping sub-scale. Confirmatory factor analysis (CFA) was used to validate the six-factor impact subscale model (RMSEA = 0.06, CFI = 0.839, and TLI = 0.828) and the four-factor coping subscale model (RMSEA = 0.067, CFI =

0.863, and TLI = 0.833). These CFA fit indices provided confirmatory evidence for the factor structures of both subscales.

Preliminary psychometric properties of HICS show its potential for a valid and reliable assessment of families at risk for nursing attention. However, generalization may only be useful in pediatric settings. The parental perception may not reflect all family members but it should not be de-valued because if one member suffers, it affects the family system as a whole. Further studies in other populations would help the future development of HICS.

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LIST OF ABBREVIATIONS

Abbreviation	**Full name**
BSI	*Brief Symptom Inventory*
CBCL	*Child Behavior Checklist*
CFA	*Confirmatory Factor Analysis*
CFAM	*Calgary Family Assessment Model*
CFI	*Comparative Fit Index*
CHIP	*Coping Health Inventory for Parents*
CICI PQ	*Chronic Impact and Coping Instrument Parent Questionnaire*
CMP	*Cooperative Medical Plan*
EFA	*Exploratory Factor Analysis*
FACE	*Family Adoption and Cohesion Scale*
FAD	*Family Assessment Device*
FES	*Family Environment Scale*
FCC	*Family Centred Care*
FES	*Family Environment Scale*
FFFS	*Feetham Family Functioning Survey*
FILE	*Family Inventory of Life Events and Changes*
FIRM	*Family Inventory of Resources for Management*
FSI	*Family Satisfaction Inventory*
GIP	*Government Insurance Program*
HAMA	*Hamilton's Scale for Anxiety*
HICS	*Hospitalization Impact and Coping Scale*
ICU	*Intensive Care Unit*
IOF	*Impact on Family Scale*
KMO	*Kaiser-Meyer-Olkin Measure of Sampling Adequacy*
LIP	*Labor Insurance Program*
PCSI	*Parental coping strategy inventory*
PICU	*Paediatric Intensive Care Unit*

Abbreviation	**Full name**
PCA	*Principal Components Analyses*
PSS:IH	*Parental Stressor Scale: Infant Hospitalization*
PSS:NICU	*Parental Stressor Scale: Neonatal Intensive Care Unit*
RMSEA	*Root-mean-square Error of Approximation*
SAS	*Self-Rating Anxiety Scales*
SCL-90	*Symptom Checklist -90 症狀自評量表 (SCL-90)*
TCM	*Traditional Chinese Medicine*
TLI	*Tucker-Lewis Index*

CHAPTER 1: INTRODUCTION

Background of the Problem

Traditionally, parents bear the responsibility in caring for sick children in families. With the development of hospital care in recent centuries, the very sick children and those who require special care are now usually admitted to hospitals (Hall, 1987). The early development of the care of children in hospitals was quite traumatic, because sick children were routinely taken away from their families for the sake of 'better' care (Spock, 1946; Spence, 1951; Burgess, 1988; Young, 1992). With the advanced development of child psychology, there were increasing evidences about the psychological trauma caused to children during hospitalization (Bowlby, 1951; Robertson, 1958; Bonn, 1994). As a result, the practices of rooming-in were gradually introduced and later confirmed to be effective in reducing children's distress during and after hospitalization in many studies (Illingworth & Holt, 1955; Brain & MacLay, 1968; McGillicuddy, 1976). While there are a number of recent studies focusing on symptoms and other experiences of hospitalized Chinese children and adolescents (Franck et al., 2004; Kennedy et al. 2004; Kools et al., 2004), there is limited literature exploring Chinese parents' or families' experiences with sick children during hospitalization (Lam et al., 2006).

Currently, the practices for the care of children in hospitals have evolved to the extent that it has been increasingly accepted that parents should participate in their children's hospital care (Young, 1992). However, these practices have now raised increasing concerns for unrecognized parental needs, and the readiness of parental involvement is being questioned (Darbyshire, 1993; Espezel & Canam, 2003). To support evidence based care delivery and quality care, a deeper understanding of parents' feelings and experiences associated with the impacts of hospitalization is fundamental and necessary. Coyne's (1995b) finding in her study about parents' views of participation in their hospitalized child's care further suggested that better understanding should be extended to the families concerned because parents' readiness to care had been encouraged by supportive family network (Conye, 1995b).

Naturally, families play an important role in providing support, love, nurturing and attention for their children. During a time of crisis such as hospitalization, families are the direct resources for all patients and carers concerned (Astedt-Kurki et al, 1997). When a child gets sick and requires hospitalization, parents are usually the primary caregivers staying with the child most of the time (Palmer, 1993; Coyne, 1996). No matter how trivial the problem, it affects daily life and causes anxiety and uncertainty for the family (Martinson, 1982; Martinson et al, 1993; Wang, 2001; Hallstrom et al., 2002; Hopia et al., 2005). Many studies found that families, in particular mothers, were stressful during the hospitalization of their children (Strachan, 1993; Wang, 2001; Liu et al, 2002).

There is also an increasing body of literature based upon fathers as participants that found fathers also share similar stressful responses comparable to those of mothers (Sloper, 2000a; Kazak et al., 2004; Bonner et al., 2007). The impact of a child's hospitalization on siblings has been underrepresented in studies on pediatric care. Non-hospitalized siblings have often been described as emotionally overlooked because of the limited capacity of parents to support and attend to their needs while caring for another sick child (von Essen & Enskar, 2003; Bonner et al., 2007).

Parents are usually subjected to a lot of pressure during a child's hospitalization, for they have to face challenges resulting from the change of environment and family role (Eberly et al. 1985; Lee et al, 2005), feelings of frustration, guilt or sorrow (Darbyshire, 1994; Shields, 2001; Ford & Turner, 2001), while at the same time meeting the needs of other family members, particularly other siblings (Phillips et al., 1985; Wang & Martinson, 1996; von Essen & Enskar, 2003). While parents' contributions for the hospitalized children were frequently reported as distressing (Calley, 1997; Simons et al., 2001), the change of parental role from primary caregiver to a less certain role during hospitalization also creates a great deal of stress to these parents (LaMontaigne et al., 1995). The other issues that receive less attention in the literature are the financial, social and personal costs to the families (Hall, 1987; Callery, 1997). These complex issues may manifest as an individual parental problem affecting the child's recovery or turn into distrust, conflict, anger, complaints or even aggressive behaviors against hospital staff as occasionally reported in China and other part of the world (Dahal, 2008; Armed doctors to ward off angry patients, 2007; Wyman et al., 2007; Kwok et al., 2006; di Martino, 2003; Shooter, 2002; Baker, 1994).

It is well recognized that nurses play important roles in understanding and supporting the family during the stressful time of a child's hospitalization. This is part of the holistic care nurses should offer to enhance recovery of the sick child and to take care of the family's questions or concerns (Baker, 1994; Kain et al., 1996). The impact related to a child's hospitalization described in the literature have mostly been negative, but there were also some encouraging reports from mothers who had gained a sense of mastery and coping during the hospitalization (Meadow, 1964; Wong & Chan, 2004).

With better understanding of parents' experiences related to their children's hospitalization, and their perception of related impacts, it may be possible to empower these parents or families to be more functional and satisfied. For the benefit of the sick children and their families, it will require more effort from nurses taking up the challenge to move beyond merely routine care to explore and understand the impacts of children's hospitalization on parents and families.

Assessment of the family is the beginning and fundamental step for the success of this mission of quality care in understanding and empowering parents and families during hospitalization of a child family member. Development of a useful clinical tool for assessing parental perception is timely and justified because parents are usually the primary carer in hospitals and the families often affect the child's parents' ability to cope. These actions of assessment and related care can also indicate a sincere gesture of caring and concern, which may be much treasured by some families during a time of distress and helplessness (Ford & Turner, 2001).

There is growing empirical evidence that the dimensions of impact on parents and families with hospitalized children are complex. The effect of the hospitalization of children on the families may be manifested by a wide variety of physiological, psychological and social symptoms. Since parents usually are the primary caregivers and the most affected members of the families during a child's hospitalization, this study explored related issues through parental interviews and a literature review. Based on these preliminary empirical findings and guided through the family theories, particularly the Double ABCX model of the family stress theory, this study developed a useful clinical tool. That tool is the Hospitalization Impact and Coping Scale (HICS), for assessing parents' perception of the impact and related coping strategies resulting from the hospitalization of their children.

The Gap in Research and Clinical Practice

As will be further discussed in the literature review, research on family adjustment to a child's chronic illness has drawn much attention. At the same time, there are limited research studies focusing on the impact of a child's hospitalization on related families. Within these limited studies, the focus is primarily on describing family stress and coping experiences, and/or related parental needs (Miles et al., 1993; Noyes, 1998; Miles et al., 2002; Vrijmoet-Wiersma et al., 2008). Many of these studies used in-depth interviews of parents (Swallow & Jacoby, 2001; Yeh et al., 2000). The qualitative findings would be meaningful but the demand of time and effort using this method by front line staff appeared impractical in many clinical settings. The other method of investigation for related hospitalization impacts on families reported in the literature was the use of measurement tools (Docherty et al., 2002; Miles & Davis, 2002; Lee, 2004).

Data collection reported in these studies was usually a bit complicated with the administration of a few instruments or by using a very lengthy questionnaire. Both of these methods could be too exhausting and demanding for parents adapting to the hospitalization crisis (Vrijmoet-Wiersma et al., 2008). Also, nearly all related instruments were developed in a western cultural context. Transferability of these instruments into a different culture – such as China – is questionable. China has a one child policy and is officially atheist. Even for a similar Chinese instrument recently developed in Taiwan, the applicability of many items related to siblings and spiritual beliefs may not be relevant in the Chinese mainland (Yeh, 2001). A review of previous studies, no matter which method was used, frequently has narrowed the focus to the critical care units (Docherty et al., 2002; Noyes, 1998), or on coping or stress issues only (Lee, 2004; Yeh, 2001). The gap in research and clinical practice lies in the lack of a locally developed, generic, simple but comprehensive instrument to help identify families who are in need of special attention, particularly when adverse impacts of a child's hospitalization exist.

Statement of the Problem

The impact of a child's hospitalization on families is evident in the literature. However, the manifestation of the problem is complex. It raises a challenge for nurses working in pediatric units to first of all find some way of identifying families' stress, and then assisting them to cope in order to ensure that the best care can be delivered. Many times, the nurse may be well aware of difficulties that families are encountering, but until there is an instrument that can accurately measure the presence and extent of the severity associated with such impacts of hospitalization, intuition and conjecture will perpetuate the non-scientific approach to intervention. Currently, there is no available instrument in China to measure the impact of hospitalization on Chinese families with hospitalized children and their coping abilities. Because China has a unique political and social system, direct adoption of instruments developed in foreign settings may not be culturally and socially appropriate. To enhance the efficacy of quality care during hospitalization, better understanding of the impact of hospitalization on families and their coping strategies requires the implementation of a locally developed practical measuring tool.

Focus of the Study

This study was designed to explore the impact on Chinese families with hospitalized children. The project began with interviews with parents during their children's hospitalization. The empirical findings, together with the literature review, contributed to the development of an assessment tool measuring the parental perception of the hospitalization impacts on the family.

The Hospitalization Impact and Coping Scale

In response to this endeavor, this project developed a user-friendly assessment tool, Hospitalization Impact and Coping Scale (HICS), through exploring the Chinese families' experiences with children's hospitalization from the parents' perspectives by qualitative interviews, extensive literature search and using pediatric nursing experts' validation, and then testing the new tool for reliability and validity. To make the assessment more meaningful, this assessment tool also attempted to differentiate respondents' characteristics for suggested interventions.

Purpose of the Study

The initial purpose of this study is to help nurses to gain better understanding of the impact on and coping of families with hospitalized children through the development and validation of an ethnically specific instrument entitled “Hospitalization Impact and Coping Scale” (HICS).

The second purpose of this study is to examine the relationships and differences among selected demographic variables regarding the perceived impact on families.

Specific objectives of the study:

- To explore the parental perception of the impact of their child’s hospitalization on the family through qualitative analysis.
- To explore the parental perception of the effectiveness of their coping strategies used during hospitalization through qualitative analysis.
- To identify concurrent difficulties the family encountered during the child’s hospitalization from the qualitative data.
- To describe common biopsychosocial dimensions of impact (e.g., physical tiredness, anxiety, and decreased social activities) on parents with hospitalized children.
- To develop an instrument entitled “Hospitalization Impact and Coping Scale” (HICS) which integrates the concepts of System Theory, and Family Stress and Coping Theories (the Double ABCX model).
- To validate the instrument within the acute care pediatric hospital setting with parents having a hospitalized child.

- To evaluate the construct validity of the ‘HICS’ through factor and discriminant analysis (hypothesis-testing and convergent approaches).
- To evaluate the reliability (internal consistency using Cronbach’s alpha) of the HICS.

Given adequate psychometric properties of the HICS, additional objectives of this study were:

- To examine the differences of the hospitalization impact scores of the respondents groups (father, mother, and both parents groups).
- To examine the differences of the hospitalization coping scores of the respondents groups (father, mother, and both parents groups).
- To examine the relationship between the hospitalization impact scores and the length of hospital stay of the children.
- To examine the relationship between the hospitalization coping scores and the length of hospital stay of the children.
- To examine the relationship between the hospitalization impact scores and the perceived severity of the children’s condition.
- To examine the relationship between the hospitalization coping scores and the perceived severity of the children’s condition.

Hypotheses

1. There will be statistical differences of the hospitalization impact scores of the respondent groups (father, mother, and both parents groups).
2. There will be statistical differences of the hospitalization coping scores of the respondent groups (father, mother, and both parents groups).
3. The hospitalization impact scores will be associated with the length of hospital stay of the children.
4. The hospitalization coping scores will be associated with the length of hospital stay of the children.
5. The hospitalization impact scores will be associated with the perceived severity of the children's conditions.
6. The hospitalization coping scores will be associated with the perceived severity of the children's conditions.

Significance of the Study

As mentioned earlier, there was no locally developed instrument in China to measure the impact of hospitalization on families with hospitalized children and their coping abilities. This study was designed to explore the dimensions of impact on families with hospitalized children in China for the development of an instrument, the Hospitalization Impact and Coping Scale (HICS). This locally developed tool may assist the front line staff to obtain better insight and understanding to the complex phenomena associated with the hospitalization of a child family member. This can be a useful instrument for planning and evaluating care for families with a hospitalized child, particularly in the Chinese population.

This instrument may provide nurses and nursing students with the skills to assess clients' family impact and coping effectiveness when a child is hospitalized. When there is more than one nurse working with the family, a structured and easily completed tool would be helpful in data collection and continuity in care. Friedman and her colleagues (2003) agreed that more structured checklists, inventories and questionnaires can be especially helpful when a great deal of information needs to be gleaned or recorded. As practitioners are faced with more and more complex social and clinical conditions of patient and families, the application of a multidimensional assessment measure can promote consistency in interpretation of problems and decision making in similar types of cases.

Findings revealed the multidimensional impact on the families during the hospitalization period. HICS may be a useful instrument for planning and evaluating the care for families with a hospitalized child, particularly in the Chinese population. The results may provide a basis for better quality care in hospital settings.

Once norms are established, such a tool can be used to identify adverse effects of hospitalization on families with hospitalized children. Together with the understanding of the effectiveness of families' coping strategies, this can have implications for predicting a special service need useful in case conference discussions, counseling, case management and discharge planning.

This project hopes to contribute in enriching the foundational knowledge on family in the nursing care context, as well as to provide a useful assessment tool, specifically developed for Chinese families with a hospitalized child.

Operational Definitions

Operational definition was described by Garson (2002) as the process of specifying specific indicators for each dimension of a concept. In order to have concrete measures to reflect the dimensions of parentally perceived impacts of their child’s hospitalization on the family, the following operational definitions were adopted to describe the related constructs.

Dimensions

According to Garson (2002), dimensions are the ***set of scales*** applicable to a given conceptual definition. As will be further discussed in Chapter Four, the conceptual definition of “impact of hospitalization on families” in this study has reflected six scalable dimensions: psychological, social, physical, health service needs, family and financial impacts. “Coping methods” has reflected four scalable dimensions: effort to maintain positive and active parental care; attempts to readjust mental stability; utilizing internal and external resources; and maximizing quality and quantity of childcare.

Impact

Impact was defined as the ***perceived effects*** on the family from the parents' perspective. The word 'impact' has been used in the literature to describe the perceived effects of chronic illness on the family (Satterwhite, 1978; Stein & Riessman, 1980; McCormick et al., 1986; Ireys, 1996; Stein & Jessop, 2003).

Hospitalization 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. Zurlinden (1985) recognized hospitalization is a disorganizing experience that may create a crisis, and recommended preventive intervention beginning with assessment is important to minimize the hospitalization impact.

Physical Impact

Physical Impact refers to the perceived physical condition of the parents and/or other family members in response to the experience of having a hospitalized child.

Psychological/Emotional Impact

Psychological/Emotional Impact refers to the perceived psychological or emotional condition of the parents and/or other family members in response to the experience of having a hospitalized child.

Family Function Related Impact

Family Function Related Impact refers to the perceived family function including communication, relationships, activities, role and responsibilities within a family in relation to the experience of having a hospitalized child.

Social Impact

Social Impact refers to the perceived social situation of the parents and/or other family members including social activities and concurrent life crisis in relation to the experience of having a hospitalized child.

Health Services Related Impact

Health Services Related Impact refers to the perceived health service situations the family members encountered during hospitalization of a child.

Coping

Coping refers to the method (strategies used and activities performed) used to protect the family from being harmed by a problematic social experience – adverse hospitalization impact. It is behavior or attitude that importantly mediates the adverse impact that hospitalization has on family members.

According to Pearlin and Schooler (1978), parental coping is a complicated ***psychological and behavioral process***. The protective function of coping behavior can be exercised in three ways: (1) by eliminating or modifying conditions giving rise to problems; (2) by perceptually controlling the meaning of experience in a manner that neutralizes its problematic character; and (3) by keeping the emotional consequences of problems within manageable bounds.

Family

Family in this study means the ***immediate family members who live together*** with the child before hospitalization. This can include parents, siblings, and grandparents (if applicable) who live together with the child. Aunts / uncles who live with the extended family would not be counted as immediate family members. This has to be explained to parents when they consider the impact on their own family.

Parent

Parents, in this study, were considered as the ***child's natural or adoptive parents, stepparents or any other context of parent-child relationship*** (Shields, 2001).

Organization of the Thesis

There are six chapters in this dissertation providing the theoretical and empirical foundation for the assessment of the dimensions of impact on the family when a child is being hospitalized. This first chapter presents brief background information on the hospitalization of children and outlines related impacts on parents and families. After a brief introduction, this chapter pointed out the gaps in research and clinical practice for the need of a locally developed assessment tool to measure the parental perception of the hospitalization impacts on the family. An overview of the problem statement, the study focus with related instrument, the purpose and objectives of the study were then presented. A discussion of the significance of the study followed. The related concepts and operational definitions used by the study were then explained. Lastly, the organization of the thesis was presented.

What follows in the second chapter is a review of relevant literature. The areas to be discussed are: background information of hospitalization and service delivery, including the Chinese experiences in relation to the perception of impacts, the dimensions of impacts on the families associated with a child's hospitalization, the manifestation of impacts on different family members, the factors affecting the perception of impacts on families, the coping strategies of families in response to hospitalization of a child, the methods in assessing the families in the pediatric wards, the family assessment tools with particular references to hospitalization experiences, research challenges and the application of families theories. Explanations will be given on how the proposed assessment tool, Hospitalization Impact and Coping Scale (HICS), can overcome limitations in those reviewed instruments. The chapter is summarized with a conceptual framework to provide direction and guidance for the research study.

Chapter 3 describes the research plan and study methodology in detail. The description of instrument development in this chapter includes the item generation process through phase one – parental interviews and validation – and phase two – testing related psychometric properties. Limitation of the study was highlighted as well. This chapter also presents the results and discussions of the phase one interviews and pilot study which contributed to the development of the first and second version of the instrument, Hospitalization Impact and Coping Scale (HICS).

Chapter 4 presents the results of the phase two study with detailed descriptions of the third version of the developed instrument Hospitalization Impact and Coping Scale (HICS). Findings reported in this chapter include descriptive information about the characteristics of the hospitalized children and their parents, psychometric properties and data related to the hypotheses developed in chapter one.

Chapter 5 discusses the findings of this study. The discussion of results includes major findings with further reference and support from the literature. Implications of the findings are interwoven in the discussions. Finally, chapter 6 draws conclusions from the findings. An overview of the development of the instrument (HICS) is shared with emphasis on its focus and limitation. Recommendations for the best use of the instrument and future plans to extend this study are highlighted at the end of the session.

CHAPTER 2: REVIEW OF THE LITERATURE

To understand issues related to the dimensions and severity of the impact of hospitalization on families and its related research needs, this literature review begins with background information on hospitalization, health services, current trend of care practices, and characteristics of Chinese families. It is important to understand related background information in order to appreciate the pattern, dimension and severity of impact caused to families during hospitalization of a child.

A more in-depth exploration and discussion will focus on the multi-dimensional perspectives of impact on families with a hospitalized child and related coping strategies used by the family; predictors of high family impact; interventions to minimize hospitalization impact; theories and concepts related to parental and family responses of a child’s hospitalization including family stress and coping. To follow are the exploration of the need and methods for assessing families and discussions about the research challenges for the study that lead to the development of the next chapter on research methodology. To conclude, a conceptual framework based on the Double ABCX Model is presented detailing the relationship between variables in assessing the dimension of hospitalization impact and coping.

Background Information of Hospitalization

Historically, parents played a primary role in caring for sick children. This practice never changed until the modern hospital began to appear in Europe in the eighteenth century (Hall, 1987). Through the development, in the second quarter of the 19th century of special children's hospitals, hospitals then became places for treatment of sick children in many countries (Hall, 1987). Hospitalization of children in the early development had been quite traumatic because children were removed from their families until discharge. According to Burgess (1988), there was a belief in the old practice that children 'settled' better without the disturbance of familiar faces. Many health professionals in the 1930s believed that independence from mother was good for the child even at a very young age. They also advised mothers that frequent visiting would hinder their children from gaining emotional independence. Parents had to line up to see the intern on duty on visiting days. For those sick children admitted to the infant isolation wards, their parents had to view them from outside balconies regardless of bad weather (Gee, 1938). At that time, the hospital personnel were considered superior caregivers and parents of the sick children were limited to twice-weekly visits even though staff had great compassion for the plight of poor families (Young, 1992).

Spock (1946) reported in his book for parents entitled, *The Normal Child*, that a physician-in-chief of a hospital for sick children advocated the importance of rigid feeding and sleeping schedules for infants. This physician-in-chief also believed that parents should handle their infant as little as possible. Strict schedules were the result of the scientific feeding movement, which had gained ascendancy in the 1920s (Spock, 1946).

Since the 1930s, a few pioneer studies in psychological trauma caused during hospitalization have raised concerns and increased awareness, which contributed to later changes of practices (McGrew & McGrew, 1985). A professor of pediatrics, Spencer, delivered a speech at a special conference in which he had highlighted the importance of collaboration between doctor and nurse to enhance better outcomes of sick children (Spence, 1951). In the same speech, he also said, "*A nation may achieve physical fitness through technical pediatrics but can lose its soul if at the same time it subordinates the responsibilities of its mothers or diminishes their maternal skills*" (Spence, 1951, p.15). He was one of the pioneers who advocated maternal skill and confidence allowing mothers to become the chief instruments of childcare in the hospital setting. It took a few decades for this idea to evolve and change pediatric practices.

Evolution of Pediatric Care Practices

Beginning in the 1960s, a child-focused approach of care changed the philosophy of pediatric practices and rectified the previous rigid schedules (Iversen et al, 2003). Parents became more involved in the care of hospitalized children. With more recognition of the role that family played in the integration and carryover of care, the focus shifted from child-centered to the current family- centered service delivery (Hopia et al., 2005; Iversen et al, 2003).

Family-Centered Care

Family-centered care (FCC) is a philosophy that acknowledges the central role of the family as the constant in the child's life. The concept includes collaborative relationships, with the goal of finding the best way to meet the needs of the child and family. According to Baker (1994), the goals of family-centered care are to maintain the integrity of the family, empower family members to assume a leadership role, and support the family during stressful times, such as hospitalization of the child. It was suggested that care conferences, especially multi-disciplinary meetings that include the family and key health professionals, could provide an opportunity for joint sharing of ideas and expression of feelings of concerns (Hockenberry et al., 2003). Families were recommended in the literature as partners in care giving and decision making in developing assessment and treatment plans, mobilization of resources and support (Herman, 2007a); or in discharge planning during hospitalization (Griffin & Abraham, 2006).

However, most of the studies related to FCC did not involve implementation or evaluations, leading to uncertain effectiveness of the programs. A majority of the reports focused only on assessing the attitudes towards FCC, the negotiation between staff and families, or expectations of care (Corlett & Twycross, 2006a; Corlett & Twycross, 2006b; Hopia et al., 2004). One of the few evaluation studies on FCC was done by Neal and colleagues (2007). That study found that staff members were more negative regarding the delivery of FCC, and the major concern was about the ward environment – believed to be inadequate in supporting FCC. Other literatures highlight inconsistencies in the degree to which nurses were willing to negotiate with parents or to welcome family participation in decisions regarding childcare (Neal et al., 2007; Corlett & Twycross, 2006b). Nurses usually appeared to have clear ideas about what nursing care parents could be involved with. Therefore, it was noticed that nurses did not actively negotiate with parents in the hospital care context (Corlett & Twycross, 2006; Newton, 2000; Kirk, 1998).

In pediatric nursing practice, the parent-nurse relationship is considered to be a cornerstone of quality care. This long-standing view is manifest in the family-centered care philosophy embraced by most health care organizations on a global scale. However, while family-centered care is promoted philosophically by policy makers and nurse leaders, it is unclear as to how this espoused view is enacted in practice (Espezel & Canam, 2003). Family-centered care has always been difficult to achieve because of the lack of related knowledge on families concerned. In a review of current practices, it appears that the provision of care for families often been mere lip service (Espezel & Canam, 2003; Rose, Mallinson & Walton-Moss, 2004; Newton, 2000).

According to Bruce and Ritchie (1997), family-centered care has no clear consensus regarding meaning, concepts or related practices. The diversity of practices is associated with a hierarchy of concepts ranging from parental involvement, parental participation, and partnership with parents to a parent-led model of care. Despite the variety and hierarchy of concepts that have evolved, family and parental roles in the hospital care of children are being valued in some cases.

In Australia, the realization of a patients' need for the support of relatives brought the relaxation of visiting hours in the 1990s (Lee, 2001). Many Australian hospitals introduced policies to allow close relatives to stay with patients in pediatric wards and labor wards, but nursing care was never expected to be done by relatives (Lee, 2001). In Hong Kong and Singapore, relaxation of visiting hours had been progressively implemented, but became tightened and restricted again after 2003 as a result of the SARS epidemic and the desire to control any possible infection (Tze, 2003; Hospital Authority, 2007). Similar to Australia, nursing care is not expected to be done by relatives in Hong Kong especially within the limited visiting hours. However, due to a sense of obligation to care for the sick in Chinese culture as described by Lee (2001), many relatives would bring extra food and help attend to hygiene needs for patients during visiting hours.

In China, the practice of ‘accompany the sick’ has been common in hospitals where relatives would physically stay together with the patients by the bedside or share a bed with the patient and would provide much of the basic nursing care such as feeding and other daily needs (Lee, 2001). Lee explained this in his recent ethnographic study that found nurses are overloaded and family members are obliged to care for the sick in Chinese culture. ‘Accompany the sick’ is also perpetuated by geographic and economic factors, such as family members from rural areas having no other place to stay while visiting a hospitalized relative. In pediatric settings, parental role and participation in care have been active and obvious but the concept of care of the family during a child’s hospitalization have gained recognition only in this decade (李英, 2008; Liu et al, 2002; 林茂英等, 2001). Although this concept of care for a hospitalized child’s family is still in its early development in China, the effort to acquire a better understanding of parents and families is evidenced. However, the need for a useful assessment tool is apparent to empower nurses for assessing a family’s concerns and special needs during hospitalization of a sick child.

Early Discharge Policies

Another current trend of hospital care is early discharge policies. With early discharge policies, children would not stay in the hospital until they are recovered, or at least until have reached a stable condition. Early discharge policies would not help decrease the adverse hospitalization impact, but more likely to increase anxiety-ridden experiences for the caregivers resulted from inadequate caregiver training and planning (Levine, 2001).

As a result of early discharge polices problems surrounding transitions are more likely to increase with transfers from one care setting to another, or discharge from hospital to home. So, one reason to look to hospitals for family assessment is to prevent problems that may arise during recovery of the children. Another reason is that hospitalization can provide a good opportunity to assess the care-giving situation and to provide parents with referrals and resources to help them in the community, if indicated. This would be especially helpful for cases of child abuse and families of disadvantaged groups (Herman, 2007).

In China, it is also observed that the duration of hospital stays for children is decreasing. In a reported study covering the past 30 years of hospital records in a remote district of northwest China, the average hospital stay in pediatrics has gradually decreased from 19.21 to around 12 days (段

玉清等, 2003). Another study done in a well developed city in southern China – Shenzhen (a special economic region) – which is near the Hong Kong Special Administrative Region, the average hospital stay is about three to seven days for children under seven years old, which is comparable to other developed cities (徐龙饯, 1998; Hospital Authority, 2007-2008). In Hong Kong, the average length of stay was eight days in the public sector hospitals and three days in the private sector (Fitzner et al., 2000).

Although the hospital stay may be generally shorter than decades ago, the impact on the family would not be decreased particularly in China because of the possible pre-admission consultations and transfer of the sick child from the rural area to the urban health care institutions. The family would have been too exhausted to face another crisis of hospitalization in a new environment. The short hospital stay, without full recovery, may also cause increased anxiety particularly for those disadvantaged families with lower socio-economic and education status (Liu et al., 2002). Early assessment of these families' adverse impact related to the hospitalization would help in developing a better plan of care and referral.

Hospital service development in China

Unlike Western countries, hospitals in China were experiencing different developments and this section will discuss this process and its implication to health care delivery in China. The information will provide better understanding of Chinese families' hospitalization experiences within the context of health care system in China.

Hospital services in China were established in the beginning of the twentieth century when Western missionaries came to China, bringing with them the Western concept of medical services. They built churches and hospitals to care for the sick and dying (Davis, 2005; Lee, 2001; Liu, 1991). Most of China's 16,732 hospitals were built after 1949 in accordance with Chinese Communist Party health policies. Hospitals in China aimed to maintain health for all, emphasized preventive care over curative care and sought to unify Chinese medicine and bio-medicine (Jonsson & Lu, 2008; Davis, 2005).

When the economic reform was introduced in 1979, government subsidies for public health care reduced drastically in a few years' time to a mere 10 percent of the facilities' total revenues by the early 1990s (Yip & Hsiao, 2008). Hospitals were encouraged to run in a 'self-financed' mode through charges for high-tech diagnostic services and drug prescriptions (Yip & Hsiao, 2008).

New government policies raised the quality of health care but restricted its accessibility for many Chinese people because of the skyrocketing medical costs. Hospitals are responsible for their own profits and losses, so the large hospitals with more profit-seeking entities are flourishing while the lower-tier health institutions suffer (The World Bank, 1997). This leads to shrinking of rural health services. Increasing child health disparities in Chinese children were also evidenced (Chan et al., 2008).

Medical Insurance in China

Medical Insurance has an implication for residents' health. Initially in China, there were two major insurance programs. Labor Insurance Program (LIP) was an employer-based insurance program, primarily for urban employees and retirees, covering around one-third of the urban residents or ten percent of the total population. Government Insurance Program (GIP) was a government financed program mainly for people working in public sectors but it only covered two percent of the total population. These programs were criticized as low coverage, poor risk pooling and lacking accountability for economic efficiency (Davis, 2005; The World Bank, 1997). Rural residents and uninsured urban residents are increasingly unable to afford the ballooning medical costs.

Since 1996, all community-wide employers and employees have joint premium contributions through the individual Saving Accounts and Social Pooling Account (Davis, 2005; Jonsson & Lu, 2008). However, the rural residents, accounting for over 70 percent of the total population, must either pay out of pocket for health care, or join the 'cooperative medical plan'

(CMP) operated with voluntary contributions – but this covers no more than ten percent of the rural population. This has an implication for the villagers' health and the hospital services to this uninsured people. Heavy financial burden caused by hospitalization is the expected result from the existing health services system.

Hospital Price Regulation in China

Despite the government's effort in regulating hospital prices to provide affordable health care services, the system does not seem to work well. According to a Liu and colleague's (2000) study, empirical evidence revealed hospital problems of violation of price regulations (over charging than the regulated price) as well as over-provision of profitable high-tech services, and over-prescription of drugs. The experience shows that low regulated fees cannot always reduce the economic burden of patients but often leads to distorted service provision. With the current overview of hospital situations in China, financial burden is likely to occur especially for rural people seeking treatment in an urban area.

Recent government health funding and policies in China

In 2008, the Chinese government increased health spending by 25% (about 830 billion) to expand rural services and universal basic health care (Parry, 2008; Yip & Hsiao, 2008). In the 2010 Reform, provisional measures on the transfer and renewal of medical insurance of migrant workers were introduced to try to solve problems of low insurance coverage among underprivileged groups (衛生部網站, 2010). Although the government has taken giant steps forward to address its problems of unaffordable access and medical impoverishment, these problems appear unresolved and still under heated debate in China at the time of this report (衛生部網站, 2010; 南方周末, 2009; Yip & Hsiao, 2008).

Health care system in Hong Kong and mainland China

Hong Kong, a Special Administrative Region of China since 1997, has maintained a 'one country, two systems' policy and continued to adopt health care financing and organize health systems within a capitalistic economy. Mainland China has integrated many features of health care systems associated with market economies, while its overall economy is largely centrally planned. Hong Kong has health statistics comparable to those in leading western nations while Mainland China is associated with health statistics and expenditures similar to those found in most developing countries except for the recent increase in health investment as mentioned above (衛生部網站, 2010; Fitzner et al., 2000). Hong Kong people have been enjoying subsidized health care while a large portion of the population in China cannot afford basic health care and many families are driven into poverty because of large medical expenses (衛生部網站, 2010; Yip & Hsiao, 2008; Fitzner et al., 2000).

However, this discrepancy may be minimized in the near future with increased health funding invested by the Chinese government as mentioned, while the Hong Kong government is planning for medical and health reform with some inevitable policy and financial changes to contain health care costs (Yip & Hsiao, 2008; Fitzner et al., 2000). According to Fitzner and associates (2000), it would not be surprising to see one country and one health care system in Mainland China and Hong Kong in the future.

Chinese Parent–Child Relationship

The background information has provided a macroscopic view of the health care system in China and its possible impact on families when a family member is hospitalized. To explore the traditional Chinese family culture, especially the parent-child relationship, will provide a microscopic view to enrich our understanding of the impact on families when a child is hospitalized.

Traditionally, Chinese fathers have believed that their role was decidedly not to encourage or tolerate emotional indulgence or promote dependency of their children. They assumed the role of stern disciplinarian (Fei, 1939; Ho, 1987). The traditional Chinese concept of the parenting process assumes that men perform a instrumental or competence-directed role, whereas women perform the more expressive or empathetic role. This typology is an accurate representation of how the Chinese peasant views parent-child relationships (Ho, 1987). The understanding of these traditional beliefs and behaviors help clinicians to work better with Chinese families and be more cautious in family assessments. However, clinicians should also take into consideration that Chinese people are becoming more ‘Westernized’ with influences through the TV, movies and internet communications (Chan & McNeal, 2003; Beck et al., 2003). In clinical practices working with Chinese clients, an open-mind with flexibility about possible changes of cultural influences is important. Current literature about the dynamic nature of the Chinese family culture appears inadequate in catching up with the rapid development of China in these two decades. Research in Chinese family situations and responses is needed.

Summary of Background Information

The background information regarding the development of hospitalized care of children and the dynamic Chinese family culture has strengthened our belief that more research studies, reflections and evaluations would enrich the understanding of the services provided and could lead to a clear direction for better care and service delivery. Both family-centered care and early discharge policies support the assumption that an assessment of family stress and coping during hospitalization would benefit the hospitalized child and family concerned. The unique nature of hospital service development in

China has justified an urgent need for more investigation into the impact of hospitalization on families and a locally developed scale for the assessment is strongly indicated. The following section explores and discusses the dimensions of impact on families with hospitalized children.

Hospitalization Impact and the Family

This session begins with a broad discussion within the context of having a sick child – usually with a chronic disease – staying at home with the family, and the general impact of hospitalization on patients and families. Following, the focus is narrowed to explore in detail the impact of hospitalization on families when having a sick child in the hospital.

Families with a Sick Child at Home

Since the early 1960s, attempts have been undertaken to measure the impact of a patient on the family (Tizard & Grad, 1961; Test & Stein, 1977). Within the field of child health care, many studies reported the effects of chronic childhood illness on the family and these were mostly taken from the community (Salk, Hilgarten, & Granich, 1975; Klein, 1976; Kirk, 1998; Burke et al., 1999).

For many studies concerning care of children with chronic illness, parents reported physical exhaustion because of the lack of rest. Stress related to worries about the health problem had also affected the well-being of the family (Hockenberry, Wilson, Winkelstein, & Kline, 2003; Sartain et al., 2000; Burke et al., 1999). Marital problems were another concern that was assessed, although it was less reported (Stein, Bauman, & Jessop, 1994). Other adverse social impacts included financial problems, the reorientation of job and responsibility, and maternal educational attainment in some reported cases (Su et al., 1997; Stein et al., 1994; McCormick et al., 1986).

General Hospitalization Impact on Patients and Families

Having discussed the impact on families with sick children at home, hospitalization of a sick family member would be more challenging or may even become a crisis for many families. Much literature has identified the impact of hospitalization in a broad sense that could range from infringement of privacy, loss of autonomy, change of life-style, and economic burden (Kozier, Erb, Berman, & Burke, 2000; Hockenberry, Wilson, Winkelstein, & Kline, 2003). The adverse impacts caused by hospitalization may also be extended from the patient to the related family concerned because family members are interconnected as a whole.

The Hospitalization Impact on the Person Involved within a Family

Family members typically are affected by hospitalization based on their relationship to the sick child and their role in the family. The following sections will discuss the impact of hospitalization on a sick child and then explore different family members' responses (e.g., related impact on mothers, fathers and siblings).

Impact of Hospitalization on a Sick Child

Children are more vulnerable during hospitalization. Related adverse impacts can affect the child's physical and psychosocial well-being. Most children under five years of age are emotionally disturbed by admission to hospital (Sheldon, 1997). Physical impacts as described by Youngblut and Brooten (1999) include loss of newly acquired developmental skills and aggressive or hyperactive behaviors. Psychological impacts can be expressed as separation anxiety problems presented with protest, despair and detachment, lack of trust and emotional deprivation (Whaley & Wong, 1997; Sheldon, 1997). Social impacts include social isolation and disrupted normal routine, such as playing games and going to school (Noyes, 2000; Sartain et al, 2000).

The hospitalization syndrome of children has been known for 30-60 years with detailed descriptions of children's responses, and has resulted in successful policy changes, such as adoption of a rooming-in system, frequent visiting or other more liberal policies (Thompson, 1986; Zetterstrom, 1984). Zurlinden (1985) developed the Zurlinden Hospital Crisis Model to guide nurses to identify the hazards of hospitalization and balancing factors for mitigating the hazards for children of all ages to minimize the impact of hospitalization for children and their families. Many of these identified problems may magnify the negative impact experienced by the family. However, the assessment involved was purely children-oriented and offered no description of the parental or family impact. The extent and severity of impact on families were not reported.

Impact of Hospitalization on Siblings

Fleitas (2000) interviewed siblings of hospitalized children and identified similar negative impacts described as stress that presented as loneliness, resentment, fear, jealousy, guilt, sadness, embarrassment and confusion. Adopted below is a letter from a boy that reminds nurses about the complexity of the impact of hospitalization on a family as reported by Flietas (2000, p.267):

"Dear Mom,

Tonight Dad was telling me how hard it was when Trudy was in hospital. He doesn't think it was hard for me at all. I missed you. I saw her get all these presents. I saw everyone visiting her and babying her, and there was nothing I could do about it. Sometimes I feel so alone and left out and even unloved. I know I'm overacting, and I know that some people have so much less than me, but it's not my fault I don't have any medical problems. I wish I did!

Love,

Jeffery"

Siblings' responses can be affected by misconceptions or lack of knowledge about the sick child's condition and feelings of loss, parent neglect, isolation, or loneliness (Freeman et al., 2003; Flietas, 2000). Other negative impacts reported in the literature include increased behavior problems; lower social competence scores (Murray, 1999; Wang & Matinson, 1996); conduct problems and mood disturbances (Zelter et al., 1996); headaches, trouble sleeping, and loss of attention, loss of certainty and security (Heffernan & Zanelli, 1997; Barbrain et al., 1995).

In other situations, resilience in terms of 'altruism, independence, and lesson learn' was also shared among siblings indicating the positive aspect of impacts gained through the experience (Flietas, 2000). Similar positive impacts were reported in other studies, such as some siblings becoming more sensitive to the needs of others, more thoughtful, and the development of closer family relationships (Heffernan & Zanelli, 1997; Zelter et al., 1996), as well as gains in maturity, understanding and compassion (Sloper, 2000b; Fleitas, 2000).

The study of sibling effect draws no clear conclusion and remains an under-researched areas that needs to be addressed because siblings are described as the most emotionally overlooked and unhappy of all family members in childhood cancer conditions (von Essen & Enskar, 2003; Murray, 1999). Nurses, when asked in a study about the practical support or assistance that siblings might need, mentioned that they did not know about any important care aspects of assistance (von Essen & Enskar, 2003). Obviously, nurses need to learn more about the impacts on siblings when a child is hospitalized and what kind of help siblings need to cope well during this life crisis.

Impact of Hospitalization on Parents

When a child is hospitalized, parental stress levels are often higher for mothers than fathers (Holditch-Davis & Miles, 2000; Ko, 1998; Noyes, 1998; Shields-Poe & Pinelli, 1997; Miles, 1989; Riddle et al, 1989). Recent studies appear to have more diverse findings. Bonner and associates (2007) have compared 23 mothers and 23 fathers and found no differences between groups on self-report measures of distress, but with a greater proportion of fathers endorsing elevated levels of depression on the Brief Symptom Inventory (BSI). However, including fathers in pediatric psycho-social research is uncommon. There are very limited studies using only small sample sizes available for a more in-depth understanding of the issue. One of these was conducted by Joseph and colleagues (2007) and assessed 22 fathers with the Parental Stressor Scale: Infant Hospitalization (PSS-IH) and found that parental stress was highest in the domains of “Parental Role Alternation” and “Infant Appearance and Behavior.” Due to small sample size and inadequate research, more studies and observations about the parental perception, particularly the paternal perception, of stress level is needed.

A recent study of Chinese-American parents of 30 infants during their ICU hospitalization indicated that the parental stress perceptions were correlated and not significantly different (Lee et al., 2005). In China, female relatives (including 170 mothers and grandmothers) were reported to have higher level of psychological symptoms than male respondents (Liu et al., 2002). Another recent study from Beijing, China reported no correlation between the anxiety of the in-patients and their parents (Wang, 2001). This might have been affected by the small sample size of 33 children and only one parent as respondent. The adoption of measurement tools, such as The Hamilton Anxiety Scale and Self-rating Anxiety Scale, originated from a Western culture without explicit explanation of its validity and reliability has made it more difficult to interpret the results.

Overall, the knowledge about maternal and paternal stress level differences appears inconclusive in the literature indicating a need for further research, but parental stress during hospitalization of a child is strongly evidenced as a global problem in the care of the families of hospitalized children.

Impact of Hospitalization of a Sick Child on the Family as a Whole

The above discussions indicated that the impact does not only affect the child but other family members as well. Mothers as caregivers of sick children are often supported by other relatives or family members (Stein et al, 1994). Family members are interconnected, so the study of impact has to emphasize family as a whole. When a child gets hospitalized, research findings have supported that the family as a whole is affected (Stein et al., 1994). Adverse parental responses to a child's hospitalization may directly affect parents' coping and, more importantly, parental anxiety may be conveyed to children and that may result in ineffective therapeutic outcomes (Hatfield et al, 2008; Liu et al., 2002; LaMontagne et al., 1997; Thompson, 1986). International studies conducted in medical settings supported a relationship between maternal anxiety and children's responses during hospitalization (Sides, 1978; Goslin, 1979; Lamontagne et al., 1997). Psychologists such as Hatfield and colleagues (2004; 2008) have recently advocated awareness of the existence of emotional contagion. Other research supports the belief that parental emotion would affect children's distress and adjustment during hospitalization (Sawyer et al., 1998; Kain et al., 1996; Bennett-Branson et al., 1993; Bush, J.P., 1986).

Better understanding and assessment of a family's responses to a child's hospitalization is timely and much needed for the sake of quality care and children's health outcome. Generally, the effort to study parental and family responses is relatively under-developed. Currently, there is no standardized approach by which nurses can identify those families who are at greatest risk of developing adverse outcomes and poor coping when a child member is hospitalized. Literature based on Chinese experiences, especially from a local context, is even more limited. A few studies that were conducted on the

Chinese mainland have used the Self-Rating Anxiety Scales (SAS) and Hamilton's Rating Scale for Anxiety (HAMA), indicating the focus of concern was mainly on the negative view of anxiety on families (張和增等, 1998; Wang, 2001). There is a knowledge gap in positive views of family support and its related impact in the Chinese literature. The reviewed literature demonstrates that the impacts involved constitute a complex issue that has been viewed mainly in a fragmented manner. Current thinking does not recognize the severity and dimensions of impact a child's hospitalization has on the parents or related family. The complexity of interaction within a family is also not well recognized. The next section further explores and focuses on the dimension and severity of impacts concerned.

The Dimensions of Hospitalization Impact on the Family

The dimensions of hospitalization impact on families described in the literature were multidimensional in nature (Shields, 2000; Sheldon, 1997; Kristjansdottir, 1991; Kasper & Nyamthi, 1988; Thompson, 1986). The multi-dimensional aspect of impacts would various according to the age and family role of the sick family member. These may include physical, emotional, psychological, social, family function and financial impacts on families. Extra burden may be experienced if the family encounters other concurrent life crisis.

When adult family members were being hospitalized, the common impacts on families described in the literature include the change in family roles and responsibilities that threaten and alter the family state of equilibrium; financial concerns; and stress and anxiety resulting from a number of reasons such as lack of information and support (Swallow & Jacoby, 2001; Hallgrimsdottir, 2000; Jamerson et al., 1996). Occasionally, these complex issues would lead to family frustration and even more negative responses such as anger and complaints (Wong, 1995; Baker, 1994).

When the hospitalized patient was a child, the dimensions of impact affecting the patient and family were similar but the parents became the key informants in a majority of studies (Vrijmoet-Wiersma et al., 2008; Joseph et al., 2007; Miles & Brunssen, 2003; Board, 2004; Berenbaum & Hatcher, 1992; Miles, 1989). Studies investigating Chinese parents of hospitalized children reflected similar family experiences of the multi-dimensional aspect of impacts (Yam et al., 2004; Wang, 2001; Yiu & Twinn, 2001; 張和增等, 1998; Matinson et al., 1994). Further details of these impacts will be discussed in the following sessions.

Physical and Psychological Impact

Both physical and psychological impacts appear interrelated in the literature and they have to be discussed together. Lansdown (1996) reported that parents who stay in hospital with a child often complain of boredom and fatigue. Lee and associates (2007) have identified sleep disturbances and fatigue was related to parental stress. A major of the mothers (93%) and fathers (60%) experienced sleep problems after the infants were admitted to the ICU. Mothers also experienced much more wakeful time during the night than did fathers. Findings from Lansdown's study provided more objective measures of sleep pattern of parents by using wrist actigraphy recordings. However, there no similar studies confirm these findings, particularly on the prevalence of impaired sleep and fatigue of other parents staying overnight together with their hospitalized children in the general pediatric wards.

Martinson and colleagues (1995) studied the responses of Chinese families to hospitalization, and reported 30% of mothers experienced stress with intense fear, worry and burden. Half (50%) of the mothers experienced negative effects on their own health such as fatigue, and other adverse physical symptoms included loss of appetite, weight loss and sleep difficulties. These symptoms were reported based on parental perception and self-reporting of the problems. Martinson and colleagues (1997) further studied the physio-psychological reactions to parental stress and the most often reported symptoms were loss of appetite, weight loss, and sleeping difficulty. These findings have indicated that Chinese people are especially concerned with the physical health of their bodies. Similar manifestations of physical symptoms in response to distress among Chinese people were also reported in some other studies (Martinson, 1997; Kleinman et al., 1978; Kleinman, 1977).

Parental responses to a child’s hospitalization were generally perceived as stressful in the literature (Vrijmoet-Wiersma et al., 2008; Joseph et al., 2007; Miles et al., 2002; Martinson et al., 1997; Martinson et al., 1995; Berenbaum & Hatcher, 1992; Turner et al., 1990; Frieberg, 1972). No matter how trivial the diagnosis, any in-patient admission and outpatient appointments bring anxiety and uncertainty in the family. The psychological impacts of loss with a child living away from home in the hospital may include responses such as feelings of guilt, regret, pain and sorrow among family members (Board, 2004; Swallow & Jacoby, 2001; Lansdown, 1996). Most of the studies described in the literature review of previous work have concentrated in studying parental responses and determined that hospitalization was generally considered stressful (Thompson, 1986; Kirks, 1998).

The most commonly reported associations to parental stress included a lack of understanding of the child’s situation; uncertainty of the child’s outcome; the sick child’s appearance and behavior; pain and suffering; parental role alteration; staff behavior and communication; and unfamiliarity with the hospital’s environment (Miles & Brunssen, 2003; Shields-Poe & Pinelli, 1997; LaMontaigne et al., 1995; Ko, 1998; Miles, 1989; Eberly et al., 1985). Other common parental responses included anxiety, fear, helplessness, guilt, and loss of control (Swallow & Jacoby, 2001; Tomlinson et al., 1996; Turner et al., 1990).

Emotional upheaval was commonly reported to be associated with parents' experiences (Dudley & Carr, 2004; Carr & Clarke, 1997; Stein & Reissman, 1980). The emotions of parents are generally described in the literature as "up and down." Carr and Clarke (1997) characterized emotional upheaval as anxiety, shock, uncertainty and life-and-death decisions. Dudley and Carr (2004) further illustrated parents' feelings through interviews, which indicated that parents described their emotions as going up and down according to the conditions of the sick child.

Liu and associates (2002) was one of the few studies that explored the psychological health condition of relatives of hospitalized children in China. This study demonstrated that all evaluation indexes using SCL-90 (a multidimensional self-report symptom inventory) for the relatives of hospitalized children were significantly higher than those of the control group were. The psychological symptoms were influenced by a number of factors, such as respondents' gender, occupation, economic status, education level and residence. These symptoms reported in this study included anxiety, depression, confusion, interpersonal relationship, sleep and eating anomalous. With a cut-off point of the total score at 160, female respondents, low social economic status, rural residents, and low education level respondents all contributed to a higher level of psychological symptoms.

Family Role and Function-Related Impact

Parents staying in the hospital with a sick child could easily cause role difficulties and if the parents are not fully involved and informed, parental stress may increase, and satisfaction with care decrease and, what is worst, the child's anxiety increases (Skipper & Leonard, 1968). Some other early studies also supported similar findings that mothers were predominantly feeling bored and uncertain about their roles in hospital (Meadow, 1964; Keane et al., 1986). A more recent study done by Lansdown (1996) also reported that some parents considered that they were being de-skilled as parents for the care of their children in the hospital.

Parents usually described the change of parental role from primary caregiver to an uncertain role, which created significant stress related to separation. Feeling helpless by not being able to protect, help and hold the child were the other common emotional responses reported in other studies (Hallström et al., 2002; Miles, 1999; Asted-Kurki et al., 1997). Parental role alterations were reported as an area of significant stress for parents in many Western countries (Coyne, 1995a; Callery & Smith, 1991; Miles, 1989). A local study done in Hong Kong by Yam and colleagues (2004) did not indicate similar results among Chinese families. According to the authors, the finding was related to Chinese socio-cultural influences. Even when parents had to relinquish their basic caregiver role and entrust the care of their child to strangers (hospital staff), the importance of deferring to authority is deeply entrenched according to the Confucian social structure (Bond & Hwang, 1986).

Kools and colleagues (2004) studied family functioning of 103 hospitalized adolescents (aged 11-18 years) in Chinese families from Hong Kong and five other mainland cities in China. In this study, family functioning was assessed by use of the Family Assessment Device (FAD) with either parent as informants. The only FAD sub-scale that was significantly correlated with adolescent psychosocial functioning (internalizing, externalizing, and total behavior problems as measured on the CBCL/4-18 – Child Behavior Checklist for ages four to eighteen years) was affective involvement. Families from the mainland cities of China exhibited potential problems in this area (mean, 2.36; cutoff score, 2.1). This finding suggested that Chinese mainland families were over-involved emotionally. In contrast, the Hong Kong families exhibited a healthy pattern (mean, 2.07) of affective involvement. As highlighted by the authors, careful interpretation of these findings should also consider the possible cultural differences with the patterns of relating and childhood socialization (Lau, 1996; Wu, 1996), as well as the length of hospital stay between Hong Kong (2.53 days) and the other cities (10.15 days) which might have intensified the need for family involvement and protection.

Kennedy and associates (2004) reported on the other group of 210 hospitalized Chinese children (aged two to 11 years) and their families from the above-mentioned project of Hong Kong and five other cities in the Chinese mainland. This group of children had greater problems when their families demonstrated poorer affective involvement according to the FAD.

All these findings highlighted the need for further research to gain better understanding of family roles and functions in the face of the stress of hospitalization of children and adolescents. The findings also support the need for culturally appropriate assessment with hospitalized children and their families.

Social Impact

The description of social impact was less reported in the literature and discussions were mainly focused on work commitment (Lam et al., 2006; Knafl, 1985). Due to the parental sense of obligation to care for the hospitalized child, the demand for other social activities was seldom reported during the hospitalization period. How a child’s hospitalization affected parents’ jobs was described in a 1982 publication (Knafl et al., 1982). Of the 24 dual-breadwinner families involved, 11 mothers and three fathers took time off work during the child’s hospitalization. Six of the mothers took time off work for the entire length of the hospitalization. Only two mothers stayed with the child 24 hours a day. The length of time that either parent stayed was dictated by the flexibility of work schedule and job security. Family activities were reported to have a high impact on the family when a child is sick or hospitalized (McCormick, Stemmler, Bernbaum, & Farran, 1986). The geographic impact may exist when distance and transport difficulties arise and that would take away family time and energy to overcome these barriers (Yantzi et al, 2001).

Financial Impact

An international perspective of hospitalization impact on individuals focused attention on the fact that financial impact is of great concern to many parents. Because parents' desire to do the best for their children would usually over-ride financial, social and personal considerations, they were particularly vulnerable during their children's hospitalization.

In India, Subramanian (1998) reported that financial problems were highly prevalent among hospitalized patients; with 84% of patients reporting this factor as the greatest problem. When compared with financial problems, all other issues appeared insignificant. In China, the health reforms of the 1990s raised medical costs of individuals and the cost of medicines and medical treatment skyrocketed to an unaffordable level (Yip & Hsiao, 2008; Chan, 2006). Martinson and colleagues' studies, conducted in the 1990s, provided some information on the expressed financial concerns of 40% of the parents that surveyed (Martinson et al., 1995). However, there is limited knowledge of the financial impact on families with hospitalized children reported from studies done in China. In some developed countries, such as

Australia, or cities, such as Hong Kong SAR, the financial burden of certain health problems has been discussed as a negative impact on the hospitals and governments more than on the families concerned (Chong et al., 2008; Nelson et al., 2005).

Callery (1997), in a study conducted in the United Kingdom, reported on the under-studied issue related to parental costs involved in care of their hospitalized children. The financial costs included the direct loss of income or holiday, extra expenses for food and drink, and travel. In Canada, Yantzi and colleagues (2001) investigated the geographical dimension of family impact using distance to the hospitals as a key factor to study the impact with repeated hospitalization. Results showed that distance to hospital did play a financial role that negatively impacted families.

In the United States, Leader and colleagues (2002) asked families directly about time and monetary costs associated with a confirmed RSV chest infection hospitalization of infants. They were critical of the existing debate over the cost-effectiveness of RSV prophylaxis, stating that it was handicapped by the narrow definition of costs to be measured. They suggested that the best way to study and capture the actual economic burden of hospitalized children on the families was to ask a combination of closed and open-ended questions about time, lost productivity, lost income, and itemized expenses incurred by all adult caregivers in the family.

Nonetheless, the expenses and lost income reported by the family would be difficult to verify in many studies. To avoid the possibility of introducing unknown bias based on the researchers' assumptions about costs to families, the researcher agreed with Yantzi and colleagues' (2001) beliefs that the use of self-perception and assessment with some open-ended questions would be a useful method for collecting related data from the family.

Concurrent Life Crisis

Caring for a child in hospital would be stressful, but the situation can become even worse if there are also some other concurrent life crises involved, such as unemployment, marital problems or having another sick family member (Bauman & Adair, 1992; Stein et al., 1994). Bauman and Adair interviewed women who looked after their children with chronic illnesses and reported how they described hardships with jobs and finances, family problems and issues with extended family as well as marital problems. Finally, there were negative effects on the mothers themselves, their mental health and well-being, as well as their physical health. All of this is in addition to the responsibilities of providing care for her child.

The issues of having concurrent life crises during the hospitalization of a child have drawn little or no attention and are inexplicitly mentioned. It was thus strongly supported that this study should include an investigation of concurrent life crises that would reflect a more meaningful picture of difficulties the family is encountering during the period of a child's hospitalization.

Hospital or Health Service-Related Impact

Other sources of stress described by Miles (1989) were related to the ICU environment, such as the child's appearance and behavior, staff communication, sights and sounds of the unit, and parental role alteration. This has drawn more subsequent attention to the hospital environment and services in later studies (Lee et al, 2007; Miles and Brunssen, 2003). Martinson and colleagues (1995) reported parents' concerns with the quality of nursing care. In the same study, about 18% of the mothers expressed that their children disliked the hospital. It is important that future research about parental concerns and experiences can further illuminate information about these problems, since health professionals have the greatest responsibilities to improve the services.

Culturally related struggles may also result due to the parental attitudes towards the available traditional Chinese medicine (TCM) and Western medicine in China (Hesketh & Zhu, 1997). For example, regarding one of the most common childhood diseases in the hospital – respiratory tract infection – parents may have uncertainties about their choice of Western treatment in the hospitals since TCM is also known to be effective and with fewer complications, at least according to the Chinese belief system (Lam, 2001; Liu & Douglas, 1999). This may create an adverse impact during hospitalization if the intervention from Western medicine would not be as effective and efficient as expected. However, this area is also under-researched. There is limited evidence regarding these ideas and, therefore, this study has included an investigation into these issues, based on a desire to explore any possible impact on the family.

With the current environment related to hospital in China, predictors of high family impact could be very different from the other parts of the world. Due to the limited knowledge of the impact on families resulting from a child's hospitalization in China, it is worthwhile to study the hospitalization impact on families.

Predictors of High Hospitalization Impact

It is imperative for nurses to gain better understanding of the families of hospitalized children so they may be equipped with knowledge in identifying families in need or in crisis during hospitalization of a child. The severity of impacts is difficult to compare and seldom objectively measured in the literature. Therefore, the descriptions of familial (mainly parental) concerns or adverse experiences during hospitalization were used to help identify the possible predictors of high impacts in most situations. The following section reviews some descriptions of parental or familial experiences in terms of intensity or prevalence of particular impacts found in the literature.

Uncertainties as a Predictor

In a study conducted in Taiwan, Mu and colleagues (2001) identified factors that impact on a mother's anxiety during a child's cancer treatment in hospital. Uncertainty was a good predictor of family boundary ambiguity, which refers to the form, function, role assignment and rules regarding who was within and who was outside the family system, according to Boss and colleagues' descriptions of families in trouble published in 1988. Mothers would become more stressful and confused when too many uncertainties arose, such as the progress of illness and the expectation of parental involvement in the care. The nurses' and parental roles in the care of the sick child caused confusion and uncertainty leading to high impacts on the families. Other families with a hospitalized child living in the general pediatric units with less serious conditions are less reported on in the literature and this knowledge gap needs to be filled with more research findings for a comprehensive picture of family impact.

Child's Condition as a Predictor

The perceived severity of the child's illness was reported as the most powerful variable associated with both parents' stress scores (Shields-Poe & Pinelli, 1997; Tomlinson et al., 1996). Fathers who reported worrying about their child’s illness and its future impact tended to report higher levels of stress (Lee et al, 2005).

Regarding the source of stress during hospitalization of a child, it was common to find that parents worried about their child’s current and future health status (Docherty, Miles, & Holditch-Davis, 2002; Miles et al., 1999). The child’s severity of illness was again reported as an important factor affecting relatives’ psychological well-being (Liu et al., 2002). Miles (1989) reported more precisely about parental stress that was related to the child’s appearance and behavior within the ICU environment. Parents would be more stressful if the child experienced pain or apnea; looked frightened or sad; was weak, with tubes or needles inserted, or even with intubation (Board & Ryan-Wenger, 2002; Miles, 1999). Lee reported in her study in 2004 that parents rated their child’s appearance in the hospital as the most stressful experience, followed by change of parental role, staff communication and ICU environment (Lee, 2004).

Youngblut and Jay (1991) interviewed parents of ten critically sick children between 20 and 36 hours after admission to the PICU and developed the Parental Concerns Scale. This scale asked parents to quantify their experiences relating to three different periods (upon admission but before the parent was able to visit the child, after the first visit and one subsequent occasion). Individual concern items noted with the highest ratings were: the child’s survival; the possibility of mental or physical impairment; the child’s diagnosis; and the amount of pain experienced by the child. This study reported an important finding that total concern scores decreased over time for both mothers and fathers. This finding filled part of the knowledge gap, as many other studies failed to consider this variable.

Child's Gender as a Predictor

Liu and associates (2002), in a study based in China, identified a number of important factors associated with high psychological impact on families related to the hospitalized child's gender and severity of illness. Boys and the more severely ill children contributed to a higher score ratio by their relatives. This report finding added to the knowledge regarding specific cultural characteristics of Chinese families, and supported Chan and colleagues' report in 2002 that strong gender selection preference of son in the Chinese culture. But, the number of children in the family and the length of stay revealed no significant impact.

Complexity of Predictors

Shandor and colleagues (2002) reported the most important predictors of high family impact with medically fragile infants were related to a number of problems, such as separation with the child, inability to care for the child, inability to share baby, financial resources, and the maternal perception of the child's health. In another study for families with very low birth weight babies, similar high predictors of problems for the family were related to family activities limited by health, age and financial resources (Vrijmoet-Wiersma et al., 2008; McCormick, Stemmler, Bernbaum, & Farran, 1986).

Skipper (1966) and his later study conducted with other colleagues (Skipper et al., 1968) reported that 60% of parents rated their fear or anxiety as ‘intense’ the day before their child’s surgery. Frieberg (1972) found that all 25 respondent parents reported at least some degree of ‘uneasiness, fear or anxiety’ during their children’s hospitalization, even in the absence of a specific frightening event. Some other studies reported no parental gender differences in the stress level experiences during a child’s hospitalization (Yeh, 2000; Lee, 2004). Berenbaum and Hatcher (1992) found that mothers with children in the PICU experienced a greater state of anxiety, depression, confusion and anger than other mothers. Maternal age, family stress, number of prior hospitalizations of the ill child, and the mother’s rating of the severity of her child’s illness were predictive of emotional distress. However, the major limitation of Berenbaum’s study was the small sample size, with only 20 subjects from each group of parents from ICU, general pediatric units, and non-hospitalized sick children. More studies with larger sample sizes would provide stronger evidences for future research and practice.

Better understanding of the common predictors of high hospitalization impact on families will help clinicians to be more alert to families’ needs and concerns. Failure to observe these predictors of high impact and ineffective coping may result in families’ frustration and negative responses, including anger and complaints (Hallgrimsdottir, 2000; Jamerson et al., 1996; Baker, 1994; Wong, 1995).

Maladaptive Behaviors

Some parental problem behaviors were noted, such as manipulation, disturbances in mood, excessive complaints, and interference with the care of other children. These situations created an extremely unpleasant atmosphere on the ward and it suggested that parents' feelings should be explored and shared (Joseph et al., 2007; Lansdown, 1996).

Baker (1994) clearly described the stressors some parents experience when a child is being hospitalized. These include having to learn unfamiliar words, viewing frightening equipment, seeing a child in unrelieved pain, or circumstances that may cause the child to be chronically ill or handicapped. Some parents may lose control of their emotions and use maladaptive coping mechanisms. The point of impact occurs when their values and expectations collide with those of the nurse. In many situations, parents may use threats or manipulative behavior when encountering stress related to their child's hospitalization. With these problem areas in mind, Baker (1994) suggested ways for a nursing staff to respond constructively. The most important action addressed was to recognize what is happening in order to prevent a potential confrontation. Therefore, it is important that nurses can assess the impact of hospitalization of a child on the family that may result in better design of appropriate interventions.

Interventions to Minimize Hospitalization Impact

It is important for nurses to understand that a family is an open system: if one member changes in some way, the others will adapt in some way themselves. Lansdown (1996) suggests that it can be beneficial to simply realize that the child’s family system is affected due to hospitalization.

Knowledge learnt from the history about the need for family support during a hospital stay and about the dangers of separation has influenced institutions and parents to increase the level of parent’s involvement in the hospitalization of their children and adaptation of family-centered care (Levy, 1945; Prugh & Jordan, 1975). Studies showed that the best way to reduce stress and prepare an infant or young child for the hospital experience was to prepare the parents (Maxwell & Siu, 2008; Skipper & Leonard, 1968). Wolfer and Visintainer (1975) indicated that short orientations of parents at particular stress points, rather than a long orientation in the beginning, reduced anxiety and increased cooperative behavior – both of parents and of children. These studies reinforced the researcher’s belief that knowledge about the family, and the assessment of their concerns for the provision of appropriate support is worth the effort and resources, since it improves the quality of care offered.

Other studies suggested unrestricted parental visits and the provision of opportunities for child and family to participate in activities. According to Sheldon (1997), children in the ‘Care by Parent’ group spent less time awake alone, cried less, slept less, and had more social interaction with others in the hospital. Maintaining the hospital as a “homelike” atmosphere and minimizing social isolation by reinforcement education, praise and recognition were all suggested, in addition to offering ward teachers (Whaley & Wong, 1997). Encouraging the children to express their feelings through drawings, photos or medical play can help relieving stress. Building up trust and rapport through consistent care, good communication and information giving can help the child and family to cooperate and become more comfortable with their surroundings (Miles, 2003; Swallow & Jacoby, 2001; Wong et al, 2001; Noyes, 2000; Whaley & Wong, 1997).

Based on a study done by Liu and associates (2002) on the psychological health conditions of relatives of hospitalized children, the researchers recommended that psychological nursing care should include not only the sick children but also their relatives. Including relatives in care would benefit the child’s recovery progress. They recommended individualized care to deal with different therapeutic situations that nurses may encounter in clinical situations. For example, it is important to prevent the spread of negative feelings among relatives and the sick child. Nurses need to cultivate a relaxed atmosphere in the care setting, by means of personal behaviors, such as smiles and good communication, changing the ward's physical environment with attractive pictures, etc. It was further highlighted that having good social support and physical wellness are both important to help relatives cope better. Liu and associates (2002) demonstrated that psychological care interventions for families are part of the important nursing care that helps improve the partnership of care given to the sick child.

The above discussions have highlighted a number of interventions that nurses can help minimizing hospitalization impacts, but how families perceive and cope with these impacts would be other interesting areas to be further explored.

Coping with Hospitalization Impact

While most literature addressed the potentially negative impact of hospitalization experiences of children and their families, some families were able to capitalize on opportunities provided by hospitalization for their own growth (Perrin, 1993). For some other families, the stress resulting from a child's hospitalization can lead to strengthening of family coping behaviors and the emergence of new coping strategies (Kirkby & Whelan, 1996). Interestingly, behaviors or attitudes of these families help mediate the adverse impact of hospitalization. To make the health care support more effective, a better understanding is required regarding the nature of family coping and how it changes according to the family characteristics and experiences. Supporting and enhancing families' coping efforts are a major intention underlying professional support (Nolan et al., 1996; Milne et al., 1993). This section describes the nature of family coping and its relationship to stress in the hospital care-giving experience.

Coping is usually referred to as the way individuals deal with difficult situations. More precisely, Turnbull and Turnbull (1993) defined 'coping' as the things people do (acting and thinking) to increase a sense of well-being in their lives and to avoid being harmed by stressful events. The word 'adaptation' was preferred by Patterson (1993) while some others opt for 'managing' (Burr et al., 1994; Boss, 1988). Boss (1988) suggests that 'coping' should be used when referring to the strategies used or activities performed and the term 'managing' applied to the outcome. The current study follows the same line of reasoning for 'coping' as suggested by Boss. 'Coping' is referred to as the method, including strategies used and activities performed, by which families are protected from being affected adversely by hospitalization impacts.

Family coping skills are important factors to consider during a child's acute illness and hospitalization because families who face this crisis are at risk for psychosocial maladjustment (Melnyk et al., 2004). Families who use effective coping skills tend to adjust well to the child's hospitalization, which result in successful psychological management of the ill child (Lesley, 1997; Wolfer & Visintainer, 1975).

Pearlin and Schooler (1978) further described parental coping as a complicated psychological and behavioral process. According to the authors, the protective function of coping behavior can be exercised in three ways: (1) by eliminating or modifying conditions giving rise to problems; (2) by perceptually controlling the meaning of experience in a manner that neutralizes its problematic character; and (3) by keeping the emotional consequences of problems within manageable bounds.

Effective family coping will enhance the recovery of hospitalized children, and, at the same time, there are many other factors affecting families' ability to cope well during hospitalization of their children. A number of studies found that the most helpful support for parents while their infants were in an ICU came from their spouses and other family members (Lee et al, 2005; Miles, Carlson, & Funk, 1996). It was encouraging to find that physicians and nurses were also reported as one of the most supportive resources to parents. Indeed, parents who had received more support from health care professionals tended to report lower stress levels (Lee et al, 2005). Providing appropriate interventions can help families minimize the adverse impacts and cope better during a child's hospitalization.

Although hospitalization is understandably considered as a stressful time for children and families, it also presents an opportunity for the family to develop positive change. In Taiwan, Mu and colleagues (2001) identified a number of factors that impact a mother's anxiety during a child's cancer treatment, and the mother’s sense of mastery was found to act as a mediator between uncertainty and anxiety. Therefore, it is also important for nursing interventions to focus on maximizing the potential benefits of the experience. Providing appropriate interventions can also help families minimize the adverse impacts and to cope better during a child’s hospitalization.

Hockenberry and her colleagues suggested several strategies that can inspire nurses to make hospitalization an opportunity to permit families to cope (Hockenberry et al. 2003). These include fostering the parent-child relationship; providing educational opportunities to the sick child and family members; promoting self-mastery that the child and family are proud of having survived the experience and feel good about their achievement; and providing socialization opportunities for the child and parents as well.

Positive Impact of Hospitalization as a Coping Sign

The negative impact of hospitalization has been widely studied. It is generally assumed to create negative impacts, particularly emotional responses of children and families resulting from children's hospitalization (Shields, 2001; Ford & Turner, 2001; Darbyshire, 1994). Yet, positive impacts were frequently reported as part of the unexpected results (Dudley & Carr, 2004; Callery, 1996). Although only focused on studying families having children with an intellectual disability, Stainton and Besser (1998) provided a unique example in examining only the positive impacts on their families; a focus that was not commonly found in the literature studying hospitalization impact. Among the nine core themes Stainton and Besser identified in their report in 1998, "family unity and closeness" and "personal growth and strength" could be relevant to positive coping of families with hospitalized children.

Dudley and Carr (2004) identified five themes to describe the experience for parents staying with their hospitalized children. Within these themes, commitment to care and resilience could be considered as positive impacts. Love, advocacy, responsibility, a sense of protection and other positive feelings about staying at the bedside, constituted a commitment to care and positive impact of hospitalization experiences. Resilience was characterized by the parents' ability to care for themselves and have hope, persevere, and keep a positive front for their children. In the literature, it is easier to discover positive impacts for families who had children with chronic illnesses rather than those with acute conditions during short-term hospitalization (Endo et al., 2000; Stainton & Besser, 1998). The recognition of positive impacts described during short-term hospitalization of a sick child was quite remote. This situation thus indicated a need for nurses to place greater emphasis on empowering families throughout the hospitalization process.

Parental Participation as a Coping Strategy

The literature addressing parental participation in care identified it as a complex issue. Lesley (1997) concluded in her literature review that the involvement of parents in the care of their sick child in hospital has a positive therapeutic effect on the child's recovery, but it also associated with a great deal of parental stress concerning the child's illness, hospitalization, treatment and change of role. Coyne (1995a) described related literature of parental participation as fragmented, under-researched and inconclusive regarding its impact on parents.

The extent to which parents were willing and prepared to participate in the care of their hospitalized children needs to be carefully assessed prior to a premature implementation of practice (Coyne, 1995a). According to Grant (1978), parental participation in the care of the hospitalized children was beneficial for the child and the family, and stress and anxiety could be reduced for both parents and child when parents were more involved in the care. However, other studies in parental involvement in hospitalized childcare highlighted parental stress and strain associated with parental participation in care (Rhonda & Ryan-Wenger, 2002; Kirk, 1998; Sheldon, 1997). Nevertheless, the existing literature provides limited knowledge about the pattern and severity of stress caused to the family during hospitalization of a child (Kirk, 1998). The coping strategies believed to have a mediating effect to stress were also not well evaluated, especially regarding its pattern and effectiveness (Swallow & Jacoby, 2001).

In China, the family has long been involved in hospitalized patient care as a social norm. Lee (2001) described Chinese patients as expecting relatives to look after them and families are obligated to care for the sick family members in hospital. Based on a robust search, the term ‘Family Centered Care’ has never been used or discussed in the Chinese literature, but the concept of care extended to the family in the hospital setting has recently be advocated by a few researchers in China (白莉, 2003; Liu et al., 2002; Wang, 2001). With the opening awareness and advocating of family care in Chinese hospitals, more information about the families is needed to achieve quality care. Having evidence of family stress related to the hospitalization experiences, more investigation into the issues – particularly the assessment of hospitalization impact – is warranted before we can promote parental participation as a coping strategy (Wang, 2001; 林茂英等, 2001).

Nurses' Role

To assist families in minimizing adverse hospitalization impact and to cope well during the process, nurses must understand their roles and responsibilities in looking after sick children and their family as a whole. In a study done by Hallgrimsdottir (2000), it was reported that nurses' perception of their responsibility includes taking care of the patients' families. Nurse participants were found to be familiar with families' needs and they felt it was important to meet those needs, if possible. Caterinicchio (1995) confirmed that effective health care systems should be driven by patients' and families' needs. Kleinpell and Powers (1992) argued that nurses cannot provide optimal patient care unless they care for the patient as a part of a family unit.

Kozier, Erb, Berman, and Burke (2000) highlighted the fact that, if nurses want to achieve holistic care, it is important for them not to ignore the care of the family. The current state of the art in family care consists of a predominant focus on family as the context for treating patients' illnesses, and families are contacted to provide information about patients. Recent literature from China also shared increasing recognition of parental stress and advocated related care in hospital settings, yet the actual practice or interventional programs are not evidenced (Zhang et al., 2005; Liu et al., 2002). In general, families' needs related to stress management and quality of life have not been systematically addressed. Rose and colleagues (2004) highlighted two barriers to holistic family care as lack of understanding of ethnic minority and low-income families' needs, and the lack of attention to personal and historical relationships within families.

According to another study (Lansdown, 1996), many parents made little use of the help offered by staff because they believed they had a good supporting network, while other families used hospital staff extensively. For the latter case, there was usually a time of getting to know each other before the support really began. It helps if there is a clear message or action from the staff/hospital that emotional care and concerns for families are part of the package offered by the hospital (Lansdown, 1996). According to Hayes and Knox (1984), if nurses understood parents' own perception of their hospital-related stress, more effective nursing care could be developed. Further research is needed in assessing the hospitalization impact on families for achieving such a mission of effective nursing care.

Under-Researched Areas

Although families play an important role in the recovery of patients, it was also noticed that families have been neglected in nursing research (Hanson & Boyd, 1996). Nursing has awakened recently to the fact that family dynamics and health and illness are related, but such knowledge needs to be further developed (Gilliss & Davis, 1993; Wright & Leahey, 1993; Feetham, 1991; Moriarty, 1990; Murphy, 1986). Caterinicchio (1995) stated that effective health care systems are driven by patients' and families' needs, and Kleinpell and Powers (1992) argued that nurses cannot provide optimal patient care unless they care for the patient as a part of a family unit. In a study completed by Hallgrimsdottir (2000), nurses perceived their responsibilities to include taking care of patients' families. Participants were familiar with families' needs and felt that it was important to meet those needs.

Illness will affect the normal life of a person. Hospitalization will create further impact not only on the individual, but on his/her family as well. Coping Health Inventory for Parent (CHIP) is one of the instruments that was specifically developed for families of children with chronic illness or disability. Various other studies focused on the impact of hospitalized children and reactions of families in relation to chronic illness and life threatening illness (Lee et al., 2005; McCormick, Charney, & Stemmler, 1986). Yet, there is minimal knowledge on the impact of families with hospitalized children, especially in Chinese families (Chen et al., 2003). Without this knowledge, the quality of care is limited and the promotion of parental involvement in family centered care is premature and can be risky; 'risky' in the sense that it may lead to crises that may not be manageable.

Summary: Dimension of Impact

To conquer this under-researched area and better understand the hospitalization impact on families with a hospitalized child in China, certain forms of family assessment is the beginning of the endeavor for quality care. The following section explores the various methods that can help assess a family and to critique its relevancy and practicality in assessing families during the hospitalization of their children.

Methods in Assessing Families in Pediatric Wards

Family assessment has been advocated by nursing scholars in recent decades. The purpose of a family assessment is to identify and determine what help a family may need in managing the care of their child. The range of assessment varies from using an Ecomap to illustrate the family's relationships and interactions with groups and individuals in the immediate environment, to a comprehensive assessment of the family in the context of the larger community by the Friedman Family Assessment Tool (FFAM) (Friedman et al., 2003). However, these may not be specific enough to identify the family's situation or responses during hospitalization of their child.

A common approach during research was to ask parents open-ended questions regarding family problems related to their child's chronic ill health. These questions were able to assess the extent of worry, financial difficulties, fatigue, restriction of social life, and other areas of impact, such as sibling-related effects (Callery, 1997; Stein et al., 1994; Satterwhite, 1978). Some studies completed this process retrospectively (Callery, 1996; Pless & Pinkerton, 1975) while others followed the child and his/her family throughout their hospitalization experience (Strachan, 1993; Darbyshire, 1992).

To develop a plan of care in hospital including all family members, there are many suggested protocols providing many detailed and guiding questions (Adam & Towle, 2009; Ball & Bindler, 2008). For example, the Calgary Family Assessment Model (CFAM) and Friedman Family Assessment Tool (FFAM) are two examples of popular tools that use a lot of structured questions to guide the family interviews (Wright & Leahey, 2005; Friedman et al., 2003). Though detailed and useful in assessing a family’s problems and needs during hospitalization of their child, the feasibility and cost in administrating such assessment is problematic. As highlighted by Thomlison (2007), assessment approaches and the types of tools employed during the meeting, depend very much on where one looks for problems and what one tries to explore.

According to the Encyclopedia of Psychological Assessment (2003), there are two major methods to collect data for family assessment: self-reports of family members and direct observation of families during actual interactions. The key feature of the self-report approach is that the participant is asked for his/her perception of family events. The advantages of a self-report method are convenience, the strong face validity, and modest cost for administration and scoring. Given the possibility of have a large sample size, normative data may be available to which an individual protocol can be related. However, if researchers want to understand the actual family processes, those are only available through observation.

Regarding the unit of assessment, individual assessment represents the most basic level of family characterization (Encyclopedia of Psychological Assessment, 2003; Jacob & Windle, 1999). Families can be assessed as a whole. This is done across all family members to characterize the family in general or as a totality. It is typically done by obtaining self-report measures concerning an individual's perception/descriptions of his/her family. There are other projective methods that address the family as a unit, such as conjoint family drawings and a consensus version of the Thematic Appreciation Test (Jacob & Tennenbaum, 1988). Additionally, there are measures of social support and social network (Anderson, 1982), and instruments in the area on family adaptation and utilization of extra-familial resources associated with specific stressors, such as chronic illness, divorce, or death (Stein & Jessop, 2003; McCubbin et al., 1996; Conoley & Werth, 1995; Buehler, 1990). Other examples of instruments that evaluate community and extended family supports include the Feetham Family Functioning Survey (FFFS) and Family Inventory of Resources for Management (FIRM) (McCubbin, et al., 1996; Feetham, 1991).

Family studies that focus on dyadic descriptions, for example, marital, parent-child, child-sibling relationships, have raised concerns for the low to moderate correlations identified between family members (Jacob & Windle, 1999). Recent studies have provided a clearer and more encouraging view across different family members' reports. For example, Cook and Goldstein (1993) examined the correspondence among three members' reports (mother, father, and child) on the same dyadic relationships, and the investigators were able to determine the degree to which each member's report represented a 'unique perspective' versus a 'common perspective' shared by that of other family members. This demonstrated a significant common experience across family members. Although this data does not permit a conclusion specifically that having a key informant from a family would yield the same result, this has at least minimized the concern of assessing the family as a whole or using an individual's perception/descriptions of his/her family in many studies as discussed in the previous paragraph.

Thomlison (2007) highlighted four important reasons for selecting quantitative measures as part of the family assessment process. First, practitioners can quantify family problems for focusing on the most critical areas of family concerns. Thus, more time and resources for interventions can be located. Secondly, such measurement adds to the quality of information on which practitioners base their clinical decisions. It serves to support and improve clinical judgment. Thirdly, quantitative measurement can provide a common and consistent perspective to problems. Family problems can be reassessed over the course of service. Monitoring and evaluation of change can be undertaken. Reassessing the same factors makes it possible to determine the progress a family has made in reducing problems (or, conversely, the lack of progress). From these data, relevant and timely plans for a family can be made. Lastly, a quantitative instrument can determine the appropriate level of service. Practitioners can identify the key factors that must be addressed through intervention.

However, family measures can be adversely affected by a few important issues, such as misuse of instruments; inadequate practitioner knowledge and skill; poorly constructed instrument; and using an inappropriate instrument in an inappropriate context (Thomlison, 2007). So, the development of a valid and reliable instrument is fundamental and essential for the success of its application. Clinicians also play an important role in the use of assessment tools for collecting information and evaluating family change.

In determining which tools to use, Thomlison (2007) suggested that clinicians consider the following:

- Decide what information is needed.
- Choose a measure that is simple, practical, and meaningful to the family.
- Measure one or two thing well.
- Involve the family in defining the outcomes to measure.

- Review the measure with the family who will be using it.
- Build on what the family is prepared to document. Do not overwhelm the family.
- Collect multiple and repeated measures.

The above criteria can also be useful for researchers who want to development instruments that are practical, user friendly, meaningful and applicable for clinical applications.

Family Assessment Tools

Several instruments can be used to assess the family's overall functioning and support systems including some specific tools developed for families with children with chronic illness or disability. Below are some well-known examples relevant to the assessment of family functions and responses of illness of family members (A summary of other tools are listed in the Appendix 2.1):

The Calgary Family Assessment Model (CFAM) (Wright & Leahey, 2005) is one of those using system, cybernetics, communication and change theories to measure the structural, developmental, and functional assessment of the family. It is a comprehensive assessment model designed to evaluate multiple aspects of family life. However, repeated contacts with family are necessary to obtain comprehensive data. Nurses need to use many interview questions as suggested by the authors. Practicability can be limited because the time and skills required are very demanding.

Feetham Family Functioning Survey (FFFS) (Roberts & Feetham, 1982*)* has 25 closed-ended questions with three different sets of responses for each question. It measures three major areas of family relationships and is known to be somewhat difficult to understand (Bowen, Dickey & Greenberg, 1998). Its strength is the ability to identify conflicting views of family life because both parents complete the tool for comparison purposes. The focus of this instrument limits clinical usefulness in hospitalization situations.

Family Environment Scale (FES) (Fuhr, Moos, & Dishotksky, 1981) has 90 items with true-false responses. Scoring is complex with no theoretical position on the nature of families. It is useful to measure change after interventions, measuring real and ideal situations. It is a research-oriented tool with no clinical model associated with it, thus clinical utility is unclear (Bowden, Dickey, & Greenberg, 1998).

Coping Health Inventory for Parents (CHIP) (McCubbin et al, 1983; McCubbin, McCubbin, Cauble, & Nevin, 1979) has 45 items measuring self-reported parent responses to the management of family life when they have a child who is seriously and/or chronically ill. The CHIP has three subscales developed through factor analysis: (1) Maintaining family integration, cooperation, and an optimistic definition of the situation; (2) Items Maintaining social support, self-esteem and psychological stability; and (3) Understanding the medical situation through communication with other parents and consultation with medical staff. Cronbach's alpha of the three subscales ranged from 0.71 to 0.79. Parents are asked to rate how "helpful" the coping items are to them in managing the home illness condition (McCubbin et al, 1983). It is based on the ABCX model, theories of the individual psychology of coping, social supporting and family stress theories. It can be used pre- and post-test with an intervention program aimed at strengthening coping. The applicability of this tool in the hospitalization context appears doubtful as it would limit the understanding of various impacts and the original problems.

The Impact on Family Scale - revised version (Stein & Jessop, 2003; Stein & Riessman, 1980) is a 27-item tool measuring the perceived reactions of a family member towards the care of a child with chronic illness. This scale was subsequently developed to a single-factor 15 item assessment tool. The internal consistency alphas (Cronbach's Alphas) are high for the overall scores of the IOF in several studies ranged from 0.82 to 0.93 (Stein & Jessop, 2003). It is a relatively short and easy tool that can be self-administered. However, the focus is not based on hospitalization experiences, and important factors such as coping and financial impact were not included. It is only available in English and Spanish and the cross-cultural validity is not yet established.

Parental Stressor Scale: Infant Hospitalization (PSS: IH)

The Parental Stressor Scale: Infant Hospitalization (PSS: IH) is a 22-item instrument measuring the parental perception of stressors related to having an infant admitted to an ICU or general pediatric unit **(**Miles & Brunssen, 2003). The potential stressors for parents of hospitalized infants are related to the appearance and behavior of the sick infant (eight items); the alterations in the parental role (eight items); and the sights and sounds of the physical environment (six items). The scale was adapted from the Parental Stressor Scale: NICU version (PSS: NICU) from a previous study (Miles, Funk, & Carlson, 1993). Responses are scored on a five-point Likert scale ranging from one (not at all stressful) to five (extremely stressful). For items that were not relevant to the parents’ experiences, they can indicate “not applicable” (N/A).

Psychometric analysis of the original 28-item PSS: IH was reported in a study with 81 mothers and 43 fathers of 83 infants with a life-threatening condition (Miles & Brunssen, 2003). Internal consistency reliabilities (Cronbach’s alphas) of the total score were 0.87 for mother and 0.9 for father respondents. Subscale scores ranged from 0.76 to 0.79 for mothers and 0.75 to 0.87 for fathers. The continuous development and steps involved in the process of adapting the PSS: NICU and the several revisions of the scale into the existing 22-item PSS: IH provide promising results of psychometric analyses, and has provided initial support for the reliability and validity of the PSS: IH. Because of inadequate sample size, factor analysis of the PSS: IH was not conducted. The reliability and validity of the final version of 22-item PSS: IH are to be further established with a more diverse and larger sample. Clinical applicability is also limited because it is restricted to parents whose infants are small and are medically fragile and technology-dependent. This scale also did not cover the stressors related to health care professionals’ communications.

Lee (2004) did her PhD study using the PSS: IH, with three added items related to communication with health care providers, as one of her measuring tools to assess parental stress. Both mothers (N = 30) and fathers (N = 25) rated their child’s appearance living in the critical care units as the most stressful experience, followed by parental role alteration, staff communication and behavior, and the ICU environment. Lee and her associates (2005) also reported that Chinese migrant parents also experienced stress related to cultural beliefs. In this study, the mothers and fathers' stress perceptions were correlated and not significantly different. Due to the established reliability, validity and relevancy of the parental stress measurement during hospitalization, the current study has adopted Lee's validated Chinese version of PSS: IH as one of the tools for concurrent validity testing.

Family Assessment Device (FAD)

The Family Assessment Device (FAD) is a well-known family assessment tool proposed as a reliable and valid method for assessment of the transactional and systematic properties of the family system (Stevenson-Hinde & Akister, 1995; Epstein, Baldwin, & Bishop, 1983). It is based on the McMaster Model of Family Functioning that is focused on systems, roles, and communication theories (Epstein, Bishop, & Levine, 1978). An original 53-item self-report questionnaire was developed measuring six dimensions of family functioning. Continued development of this instrument into a 60-item FAD was reported in a later study (Kabacoff et al., 1990). The six subscales of the FAD include: 1) Problem Solving – assesses the family's ability to resolve problems within and outside the family in a way that maintains effective family functioning; 2) Communication – assesses whether communication in the family is clear and direct or indirect and vague; 3) Roles – assesses the extent to which families have established patterns of behavior for handling family tasks; 4) Affective Responsiveness – assesses the ability of family members to respond to a range of situations with appropriate quality and quantity of emotion; 5) Affective Involvement – assesses the degree to which family members are involved and interested in the activities of other family members; and 6) Behavior Control – assesses the ways in which a family expresses and maintains standards of behavior.

Additionally, 12 items in FAD make up a General Functioning scale that is used as a global assessment of overall health/pathology of the family (Chen et al., 2003; Epstein et al., 1983; Epstein et al., 1978). The FAD uses a four-pointed Likert-type scale, ranging from strongly agrees to strongly disagrees, to assess a family member's perception of the family. Some negative statements require reverse scoring before item responses are totaled and averaged to obtain a scale score. A higher average score indicates poor family functioning (Sawin & Harrigan, 1995; Kabakoff et al., 1990).

Initial and subsequent psychometric study reports consistently support internal stability of all scales with the exception of the Roles scale. The coefficient alphas were the highest for the General Functioning Scale (0.83 – 0.92) and lowest for the Roles scale (0.57-0.72) (Kabakoff et al., 1990; Miller et al., 1985; Epstein et al., 1983). Thus, the Roles scale should be used cautiously, particular with nonclinical samples (Sawin & Harrigan, 1995).

The FAD is available in English, French, Hungarian, Dutch, Portuguese, Spanish, Afrikaans, Russian, Hebrew, Haitian, and Italian. Cross-cultural studies using the FAD suggested that cultural values could affect a family's functioning (Keitner et al., 1990). However, the factor structure of the FAD was not reported in this study. A more recent study adapted the FAD to the Chinese population with families of hospitalized children and compared these with a sample of families with healthy children in Hong Kong and mainland China (Chen et al., 2003). The study indicated the Chinese FAD had a different eight-factor structure explaining 30.34 % of the variance in family functioning. The Cronbach's alphas in families with hospitalized children ranged from 0.29 to 0.74, with the General Functioning subscale yielding the highest alpha score. The authors provided explanations suggesting the possibility of cultural variations and some item inappropriateness when measuring Chinese family functioning. Chen's (2003) study finding supported the effort of this current study to develop a culturally specific tool for measurement of hospitalization impact on the family (HICS) based on local empirical findings. The adoption of the General Functioning Scale of the FAD for the concurrent validity test can be justified because of its locally established validity and its unique nature of measuring family functions.

It was recommended that the General Functioning Scale (12 items) of the FAD can be used independently as an overall measure of family function (Sawin & Harrigan, 1995; Epstein et al., 1978). Several other studies also confirmed that the General Functioning Scale of the FAD provided an adequate measure for the entire FAD. In Ridenour and associates' study (1999), the General Functioning Scale was the only factor that had an Eigen value greater than one and it accounted for 63% of the FAD's inter-subscale co-variation. Chen and her colleagues (2003) also agreed that the General Functioning Scale appeared more promising among the seven dimensions with the highest internal consistency of 0.74. While the debate is ongoing regarding the structure of the FAD, the presence of a strong general factor in the FAD is encouraging (Gregory et al., 2007; Chen et al., 2003; Ridenour et al., 2000; Miller et. al., 2000; Ridenour et al., 1999). It gives a sense of validity for the use of the General Functioning Scale of the FAD as a concurrent validation tool.

Summary of Assessment Tools Used to Measure Family

There are many good family assessment instruments found in the literature (Wright & Leahey, 2005; Miles & Brunssen, 2003; Stein & Jessop, 2003; Grotevant & Carlson, 1989; Jocob & Tennenbaum, 1988; Epstein et al., 1983; Filsinger, 1983; McCubbin et al., 1983; Roberts & Feetham, 1982; Moos & Moos, 1976, 1984), but none is designed specifically for a systemic assessment of Chinese families with a hospitalized child in the general pediatric unit. Such an instrument will greatly help nurses make the transition from a patient to a family perspective. To that end, this study will contribute in filling this knowledge gap, to foster family care in empowering nurses to assess the client’s family.

The use of Qualitative and Quantitative Measures

The method of study for the development of an assessment tool determines the usefulness and success of the instrument. Qualitative research excels at generating information that is very detailed and tends to both shape and limit the analysis, and to move on to formulate some tentative theories and hypotheses that can be explicitly tested. The other reason for using qualitative research in this study is to become more experienced with the phenomenon of families having children being hospitalized. The data are more ‘raw’ and are seldom pre-categorized. Qualitative methods enable detailed descriptions of the phenomena of interest in the original language of the research participants (Jenks, 2007). Too much detail makes it hard to determine what the generalizable themes may be for policy-making or decision-making. Mixing qualitative research with quantitative method is one of the best solutions (Yoshikawa et al., 2008; Tashakkori & Teddlie, 1998). This study is interested in how parents view the impact on families when their children are being hospitalized, so a combined qualitative and quantitative method of study appeared most appropriate.

Use of Existing Literature and Interviews

Spector (1992) advised researchers to use the existing literature as a starting point for construct definition. With a well-defined construct, it is easy to develop themes and to derive hypotheses for validation purposes. This inductive approach is highly recommended for scale development (Streubert, 2007; Spector 1992). Qualitative semi-structured interviews leading to item generation of an instrument is also an important step to avoid the direct adoption of the Western concept into the study of a Chinese subject, which may not be culturally appropriate (Yang, 1996, 2001; Yang, 1982).

Dreher and Hayes (1993) used similar methods of triangulation at the design level to study the effects of a marijuana use during pregnancy, but the tool they had expected to use was developed in another country and, thus, was culturally inappropriate to the study groups. Instead, the researchers used interview and observation to revise the tool for cultural appropriateness. The qualitative method helped the researchers refine the language and relevancy of the instruments and, modified in a related manner, the tool was administrated. The researchers were then able to elicit valid and reliable responses. This mixed study method becomes a current trend and has received continuous positive feedback and support from researchers (Yoshikawa et al., 2008; Goldsmith, Bankhead, & Austoker, 2007).

Research Challenges

There is a requirement in nursing to establish a knowledge base about the needs of families with hospitalized children. The shortage of available data may be due to the lack of the concept of hospitalization impact as well as the difficulties encountered in doing research with family members. With the busy ward environment, packed routine schedules and care concerns, detailed interviews or communications with families may be so difficult that it may not encourage researchers to work in pediatric situations.

Access and follow-up studies may be difficult with some groups, including families that live far away from the city, such as farmers or villagers coming for treatment of their children from remote regions. Establishing a trusting relationship might be difficult with those participants who are skeptical about the results of the research and who worry that the researcher's information might lead to trouble with the authorities (Saunders & Valente, 1992).

Future Research

In the area of hospitalization impact, there are many opportunities for research. It would be helpful for nurses to develop tools to measure and assess hospitalization impact. In terms of quality care, it would be helpful to determine which factors in the family or in the environment are most problematic in affecting the care (Stein & Riessman, 1980). Answering some of these questions may help nurses to prevent family grievances or reduce problems by allowing them to intervene earlier to alter personal or other factors. Qualitative studies would illuminate the experience of hospitalization impact on families from the parents' perspective. Listening to the voices of those who have 'been there' may give answers to some of the above questions.

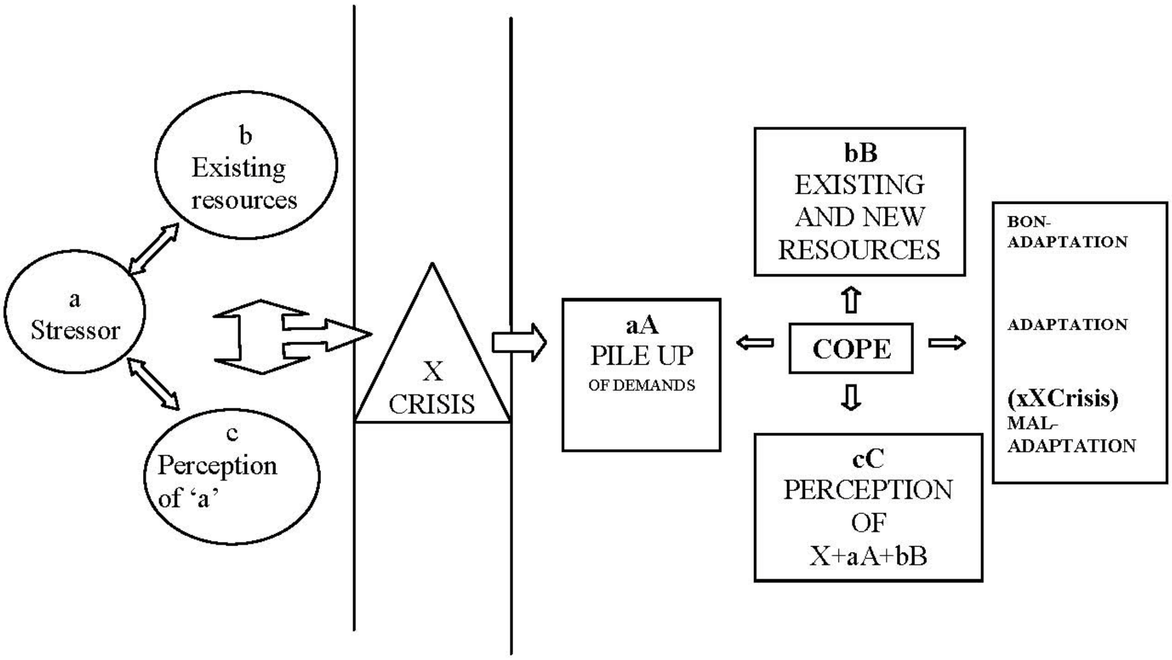
Major Theories Related to Family

A family theory can be used to describe families and explain how the family unit responds to events. Each family theory makes certain assumptions about the family and has its own strengths and limitations. The family stress theory is discussed in this section to explain its relevance to the study of children and their families.

Family Stress Theory

Family stress theory explains how families react to stressful events and suggests factors that promote adaptation to these events. Merging systems and developmental approaches, researchers interested in stress and coping have developed frameworks that explain how families and individuals cope with and adapt to various crisis events (Bowden, Dickey, & Greenberg, 1998). Hill (1949) was the first to conceptualize a model that describes processes a family undergoes when a stressor situation occurs. The ABCX model described the pre-crisis variables that accounted for family differences in adaptation to a crisis (Mederer & Hill, 1983, p.45). In this model (Figure 2.1), the letters ABCX represent the stressor event (A), the family's crisis-meeting resources (B), the family's definition or interpretation of the crisis event (C), and the family crises itself (X). Thus, the ABCX model allows the professional to consider both the presence and impact of these variables on family adaptation.

Figure 2.1 The Double ABCX Model



Adapted from McCubbin and Patterson (1983b, p.12)

The Double ABCX model, developed by McCubbin and Patterson (1981), was an extension of Hill’s classic family stress theory and ABCX family crisis model (Figure 2.1). McCubbin and Patterson (1981) extended Hill’s model to address the issue that no event occurs in isolation and introduced the concept of ‘pile-up’ of stressors. The McCubbin Double ABCX model has attempted to examine the relationship between family functioning variables over time. Previous studies with families of children with special needs or disabilities that made use of this model include Redington et al., (1995), Reddon, McDonald, and Kysela (1992); Gallagher and Bristol (1989) and Bristol (1987). In each of these studies, the dimensions of the model were found to be helpful in explaining some of the ways in which families coped with stressors and demands. They each reported mediating effects of family supports and parental appraisals when considering the effects of demands and stressors on family adaptation.

More recently, McCubbin and McCubbin (1991) and McCubbin et al., (2001) proposed the Resiliency Model of Family Stress, Adjustment, and Adaptation. They directed researchers’ attention more towards critical elements of adjustment and adaptation during illness or stressful times (McCubbin, Thompson, & McCubbin,, 1996). However, their model does not provide much direction for exploring the nature of stress. So it may not be suitable for researchers and clinicians who are interested in exploring the factors causing the impacts (stressors) which can be detrimental and lead to a crisis. Not knowing the full picture of stressors a family may experience during their child’s hospitalization may also prevent health care practitioners from playing their parts in preventing some stressors related to health services. As emphasized in the resiliency model, the stressful event is not necessarily negative to the family (McCubbin et al., 1996). This would justify and further support the need for better understanding of the nature of stressors and coping strategies as advocated in this study.

Development of Conceptual Framework to Guide the Present Study

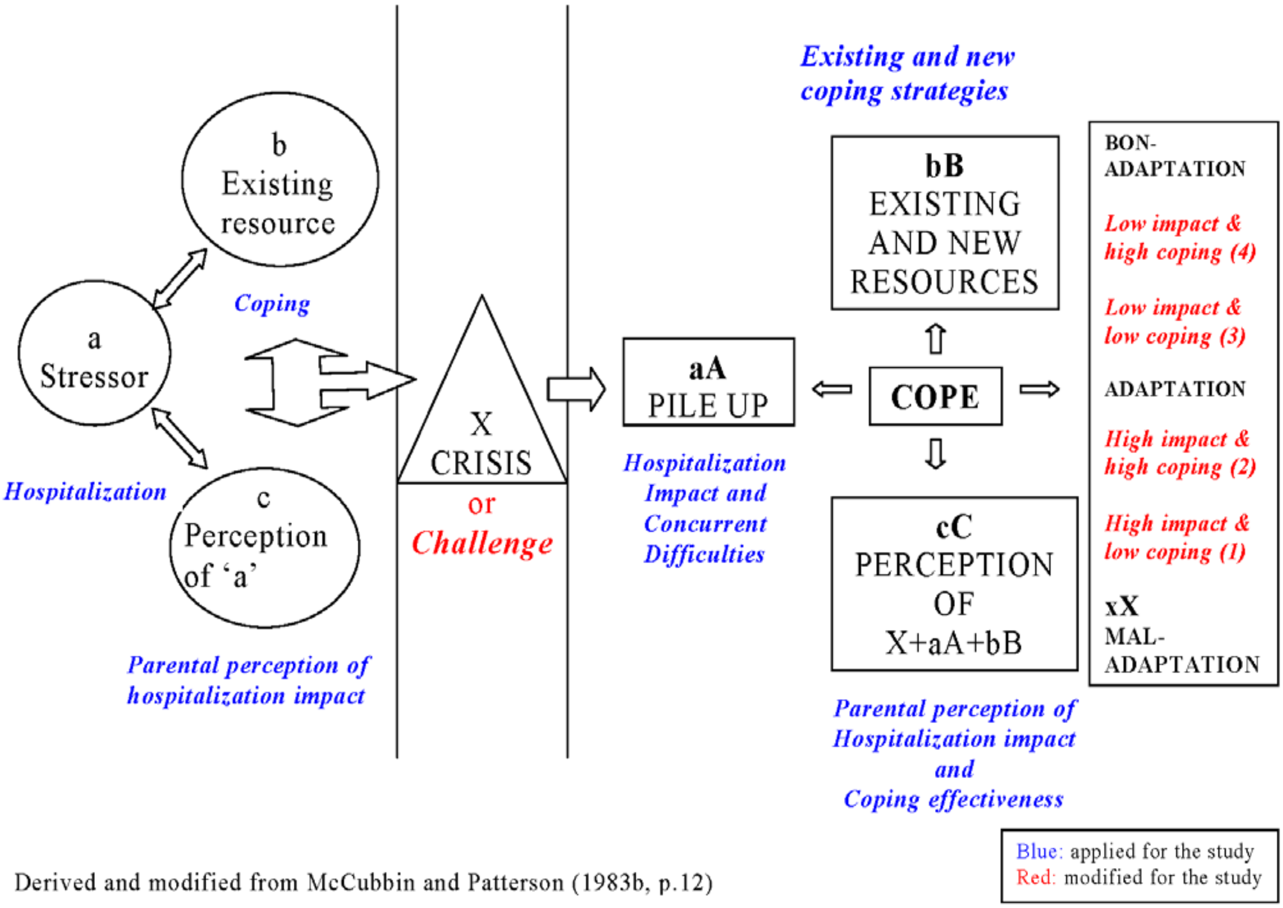
Burns and Grove (2005) highlighted conceptual frameworks in research studies as offering a framework for generating knowledge and new ideas; assisting in discovering knowledge gaps in the specific field of study; and offering a systematic approach to identifying questions for study, selecting variables, interpreting findings, and validating nursing interventions.

Given the complexity of family assessment within the context of hospitalization impact, there is a need for a multi-dimensional framework that will facilitate the assessment of families along several dimensions at the same time. Based on the literature, a conceptual framework was developed to provide guidance for this study (Figure 2.2). The conceptual framework for this study was derived using constructs from the Double ABCX model of family stress to explore parental perception of the degree of impact of their pile-up stressors and the effectiveness of available resources used (McCubbin & Thompson, 1991).

In the context of hospitalization impact, every negative response of the family resulting from a child's hospitalization experience is considered a risk factor that may cause a (family) crisis. Early intervention to prevent such a crisis from occurring is an important role of health care practitioners. In some families, it may not be a crisis if the existing resources can provide adequate support during this transitional period. The ABCX model ***proposes***

to provide an option of 'crisis' or 'challenge' for X. According to McCubbin and his associates (1981; 1996), stressors are cumulative and can overwhelm the family's ability to cope, thus placing the family system at risk for breakdown or its members at risk for physical and emotional health problems. As described by McCubbin and his associates in 1996, the outcome of the adaptation process is either bonadaptation (successful adaptation) or maladaptation (unsuccessful adaptation). This study would suggest differentiating the outcome of family characteristics into four groups for management/therapeutic purposes.

Figure 2.2 Conceptual Framework



Derived and modified from McCubbin and Patterson (1983b, p.12)

The purposes of the proposed conceptual framework (Figure 2.2) are to provide direction and guidance for the research study and help generate new ways of thinking about hospitalization and its impact on families by developing a new assessment measure based on the relationships between hospitalization impact and supportive coping strategies. The choice was eclectic and was based on both theoretical and empirical considerations such as the proposed changes as discussed above.

The concepts of impact and coping system to reflect the multi-dimensional nature of the construct are to be assessed in this study. It explains how families and individuals cope with and adapt to various crisis events such as hospitalization of a child family member. The concepts applied for this study are described in Figure 2.2 and are elaborated as follows:

- Crisis or Challenge (X) – a child being hospitalized.
- Pile-up of stressors (aA) – adverse hospitalization impacts experienced by the family and additional difficulties (including concurrent problems e.g., unemployment) the family encountered during hospitalization of the child.
- Existing and new resources (bB) – existing resources and coping strategies the family used to mediate the adverse effect of hospitalization.

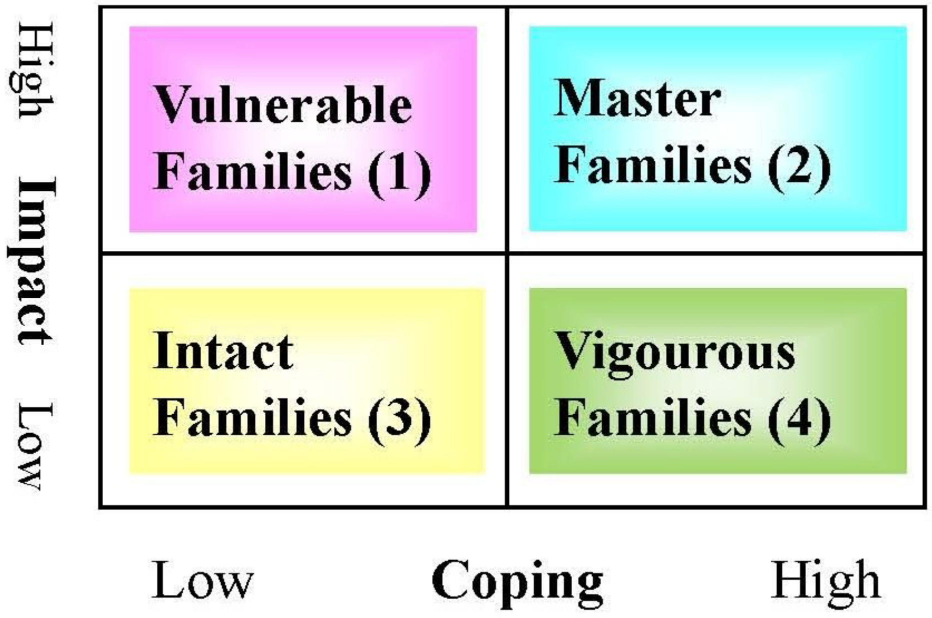
- Perception (cC) of (X+aA+bB) – parental perception of the effects / impacts of hospitalization on the family (X), evaluation of pile up stressors with concurrent difficulties (aA) and the effectiveness of existing and new resources - coping strategies (bB).

- Family adaptation – family outcomes based on the parental evaluation of hospitalization impact on the family and coping strategies involved.

To address the possibility of various outcomes to provide a direction of therapeutic management, the researcher modified the model to accommodate four different family outcomes (Figure 2.3). Assigning two levels (high and low) to each dimension of impact and coping scale enables identification and description of four types of family systems.

Based on this method, the study proposed some hypothesized outcomes.

Figure 2.3 Family typology of adaptation outcome



1. Vulnerable Families – families with high adverse hospitalization impact and low coping scores would be at greatest risk of developing crisis.

2. Master Family – families with high negative hospitalization impact and high coping scores are likely to cope well despite having high adverse impact.

3. Intact Families – families with low hospitalization impact and low coping scores may do well while their children are in the hospital.

4. Vigourous Families – families with low hospitalization impact and high coping scores are likely to manage well during their children's hospitalization.

Implicit in the model is that the pile-up of family stressors negatively affects family adaptation. For families with hospitalized children, children's illness-related demands, hospitalization-related stress and strain, previous strains, and concurrent stressors contribute to the pile-up of demands that may impact family adaptation and children's well-being. The model depicts family adaptation not only as an outcome of family efforts to achieve balance in family functioning but also as a mediating variable between the pile-up of family stressors and patient psychological well-being and coping.

The purposes of this conceptual framework are to provide direction and guidance for the research study and help differentiate the focus of nursing from other professions. The information provided by the qualitative interviews and assessment instrument, Hospitalization Impact and Coping Scale (HICS), will provide information according to this proposed theoretical framework. Details of the research plan and method will be discussed in the next chapter.

Summary

With the knowledge of background information, we understand that China's health care system development is unique and the direct adoption of theories and experiences from other parts of the world (especially the West) may not be appropriate. The information detailed in the literature justified the urgent need for a locally developed instrument to measure the impact on families with a hospitalized child in China. This literature review provides a clear direction that the use of a combined method of qualitative and quantitative strategy in the development of an instrument is most appropriate in avoiding omission of important experiences, and at the same time, to prevent researcher bias regarding the issues. Using a quantitative scale with a few open-ended questions would best fit the purpose of practicability and efficiency for the clinical settings.

The literature review has attempted to consolidate the available material reflecting the hospitalization impact on families. An examination of the literature revealed that this is an area that requires further investigation since some issues are under-studied. Although a stressful family in the hospital is at higher risk for adverse responses, they are also in a better position to reveal the problems and direct nurses for better care. Nurses need to be able to assess the families' strength and weakness in the care of the hospitalized children.

Interventions to support resources, whether at the personal, familial or environment level, may help to decrease complaints and enhance quality care. Awareness of the sources of problems that families are encountering may assist nurses to provide more holistic and comprehensive care to their clients.

Research is required to enable more effective assessment of families in the hospital pediatric context that leads to this expanding initiative for the development of a culturally specific instrument for clinical use. A conceptual framework was developed based on the Double ABCX Model to guide the development of the proposed instrument. To facilitate discussions and provide more insight in the underlying theoretical model, the review of literature has also documented various assessment methods and argued for the selection of assessment measures used in this studies.

CHAPTER 3: METHODOLOGY

As described in the literature review, the concepts of hospitalization impact and coping system are multifaceted and need to be further operationalized for translating into a research tool. Together with the consideration of possible cultural differences, it seemed wise to combine a qualitative study with a quantitative procedure (Tashakkori & Teddlie, 1998).With the guidance of the literature and a proposed conceptual framework described in Chapter Two, this chapter describes the research plan that is outlined in Figure 3.1. The instrument, Hospitalization Impact and Coping Scale (HICS) was designed to measure the parental perception of the hospitalization impact on the family, which is viewed within the concept of the stress and coping model. It was developed in two phases: Phase One for item generation, through interviewing parents with hospitalized children and content validity testing by clinical experts; and Phase Two for testing other psychometric properties, such as internal consistency reliability and construct validity.

Method

Scale development is an itemization process closely related to the development of theory and data (Reise, Waller, & Comrey, 2000). To avoid the direct adoption of the Western model into the study of Chinese subjects, qualitative interviews provide a very good foundation for a culturally congruent item pool (Yang, 2001). On the basis of a theoretical model, items of the HICS were developed and assigned to the respective factors. The structure of the factors was examined, improved, then pilot-tested and modified for further improvement. This process underwent a series of cross-validated analysis before the final version of the scale was ready for clinical use. The following sections describe the procedures used in different pilot studies as well as the main studies.

A diagrammatic description of the steps in the development of this measuring scale was formulated based on the steps suggested by Stommel and Wills in 2004 (Figure 3.1).

Figure 3.1 Research Plan

Phase One Study

Conceptual and theoretical exploration of the dimensions of the construct of hospitalization impact on parents with a hospitalized child. (Chapter 2)

⇓

A review of existing literature on related constructs (Chapter 2)

⇓

Selection and definition of target population

⇓

Initial exploratory discussions through interviewing parents with hospitalized children (first pilot study)

⇓

Development of an item pool designed to be indicators of each conceptual dimension of the construct (first version of HICS)

⇓

Validation testing of items by experts in the fields and parents based on the first version of HICS

⇓

Item reduction to develop the second pre-test version of HICS

Administration of the questionnaire (second pre-test version of HICS) to parents in the second pilot study for pilot testing of psychometric properties, item analysis, and further item reduction

⇓

Third revised version of HICS

Phase Two Study

⇓

Administration of the questionnaire (third revised version)

to a larger sample of parents

⇓

To be followed by exploratory factor analysis,

selection of final subscale items after reliability analysis of each subscale;

and validation of construct through exploring its relationship to other constructs (convergent and discriminant validity).

⇓

Confirmatory Factor Analysis (CFA) to validate the factor structure derived from Exploratory Factor Analysis (EFA) of the HICS

Phase One Study

A combined qualitative and quantitative procedure was used to operationalize the proposed multiple-factor model as suggested in the literature review (Tashakkori & Teddlie, 1998). This method not only helped to develop an item pool and optimized item phrasing, but it also stimulated hypothesis development and took differing aspects of impact into account.

Qualitative Interviews

As discussed in the literature review, a mixed method using qualitative interviews is a highly recommended approach to avoid direct adoption of the western concept into the study. The process would also help fine-tune the language and relevance of the developing instrument. This method is becoming more popular and highly recommended by researchers (Yang, 2001; Dreher & Hayes, 1993; Goldsmith, Bankhead, & Austoker, 2007; Yoshikawa et al., 2008).

Interview and Guiding Questions

Literature concerning the impact of illnesses or hospitalization on families was critically reviewed. The purpose of this critical review was to ensure complete coverage of the content domain by identifying related concepts to be described, conceptualized and measured. This review process has allowed the researcher to generate a list of guiding and probing questions, which served as part of the item construction process.

The first pilot study encompassed semi-structured qualitative interviews with open-ended questions. This qualitative study aimed to explore the parents’ perspectives on how families with a hospitalized child experienced the impact of hospitalization as a whole within the domains of stress-related factors and coping behaviors.

Open questions were used and meant to explore the interviewees’ perceived impact on families when their children were hospitalized (Appendix 3.1). They were originated from part of a tool used in a Collaborative Project with UCSF entitled, “Psychosocial functioning of hospitalized Chinese children and their families”. Examples of the questions are: (1) How is your child’s illness and hospitalization affecting you and your family? (Probe for effects on work, finances, family activities.); (2) What are some of the things that have happened in the hospital that have been distressing/upsetting/stressful to you and your family?; (3) How have you and your family responded to these things? (Use specific examples from the previous question.). These open-ended questions allowed participants to respond to questions in their own words. They allowed for a richer and fuller perspective on the topic of interest, that is, the dimensions of impact on families with a hospitalized child. The purpose of using semi-structured questions was to ensure comparability of responses and to facilitate analysis.

Two interviewers were trained and practised until their interviewing skills were consistent and skillful. The researcher used a tape recorder for later transcription. Part of the qualitative data leading to the first phase of this study was collected in the year 2000 and 2001 for a Collaborative Project, entitled “Psychosocial functioning of hospitalized Chinese children and their families,” between the University of California, San Francisco and The Hong Kong Polytechnic University. To ensure truth-value, the researcher continued to collect data in the year 2007-8 in the same Guangzhou hospital before the pilot study of the second stage until data analysis reached saturation and no new information could be obtained through subsequent interviews.

Participants

Purposive sampling was used to select parents whose children were hospitalized in four different hospitals with pediatric units (two from Hong Kong and two from Guangzhou, China). Selection criteria for parents included those having children being hospitalized for at least 24 hours and being able to communicate in Putonghua or Cantonese.

Procedures

The interview setting was in the general pediatric wards. The interviewer first established rapport by greeting the parents and giving their child a little souvenir (a sheet of cartoon stickers or an activity booklet with stickers for older children). This made the parents feel respected and helped to promote the rapport relationship. The interviewer then introduced herself and explained her role and the purpose of the interview. All ethical procedures were followed, including the explanation of voluntary participation, and the confidentiality of information was assured. Following the interview guide (appendix 3.1), the interviewer asked questions in simple and lay terms, addressing only one point at a time to avoid misunderstanding and confusion. Parents were allowed plenty of time to respond. All parents chose to stay close to their children during the interviews. Occasionally, some interviews were interrupted shortly for attention to the child's immediate need. Overall, all interviews were conducted very smoothly within a period of 30 to 45 minutes with children attracted to play with the stickers and parents willing to talk about their concerns.

Data Analysis

The interview narratives constituted the data source. Analyses guided by Boyatzis (1998) involved inductive generation of themes/sub-themes and connection of these themes to generate a conceptual support of a measuring scale – Hospitalization Impact and Coping Scale (HICS). The interview transcripts were first read to identify significant statements about how parents perceived the impact of their children's hospitalization on the family and their related responses. Next, the statements were grouped into meaningful units. The verbatim examples from the interviews were extracted accordingly. Common categories from the transcripts were collated into themes. The coding procedure and descriptions of themes were cross-validated by at least one other researcher with postgraduate qualitative research experience. Since the purpose of this qualitative study was to identify the dimension of impacts experienced by the families during hospitalization of their children, a holistic concept that can provide a more comprehensive view of concerns was used to help explain and make sense of data. Since the holistic concept was not precisely defined and the meaning was unclear in the literature, the World Health Organization’s definition of ‘holistic’ was used (Strandberg et al., 2007; WHO, 1994). In this WHO charter for General Practice/Family Medicine in Europe, 'holistic' means the physical, psychological, and social perspective of individuals, families, and communities (WHO, 1994). Discussions and consensus were reached before the final comments were made. Lastly, a coding file was completed, which summarized a description of common themes relating to how parents perceived the impacts of hospitalization on families and their responses or coping strategies used to mediate related adverse effects (Appendix 3.2). With the inductive nature of qualitative analysis, the description comprise more dimensions of impact than the holistic concept defined by WHO.

Results (Phase One Qualitative Study)

Semi-structured, open-ended in-depth interviews were conducted with 36 Chinese parents (either parent from each family with children from two months to 12 years old). Every session lasted from 30 to 45 minutes. Ages of the children were between two to 12 years, with an average age of eight years (SD = 4). Of the 36 parents, only four fathers were available for the interviews. The age for mothers ranged from 26 to 46 years old, with an average age of 35 years (SD = 5.2). All parents interviewed were married. Other demographic characteristics are presented in Table 3.1.

Table 3.1 Demographic profile of parents and their hospitalized children (n=36)

Characteristics	*GuangZhou* *n*	*Hong Kong* *n*	*Total*	
Child's age (year)				
2-5	4	8	12	Mean=8 SD=4 Range=3-13
6-11	3	8	11	
12-14	5	8	13	
Child's gender				
Male	7	14	21	
Female	5	10	15	
Length of stay (days)				
1-3	6	16	22	Mean=10 SD=20 Range=2-60
4-9	4	4	8	
10 above	2	4	6	
Illness type				
Acute	9	17	26	
Chronic	3	7	10	
Family Informants				
Mother	9	23	32	
Father	3	1	4	
Family Informants' age				
Mother's age	Mean=35 SD=5.2 Range=26-46			
Father's age	Mean=38 SD=6.2 Range=26-50			

This study identified six themes indicating different dimensions of impact: physical, psychological, family function, social, coping and health service related. Four sub-themes were derived from the ‘family function’ domain; three sub-themes were derived from the ‘social’ theme and six sub-themes from the ‘coping’ theme. The issues were classified as being multidimensional in nature according to the themes and sub-themes being identified, and they are listed as follows:

1) Physical impact
2) Psychological/emotional impact
3) Family function related impact
    a) Family activities and relationship
    b) Parental role and care
    c) Family role and responsibility – educational activities
    d) Sibling(s) effect
4) Social impact
    a) Social activities
    b) Financial concerns
    c) Extra burden
5) Health services related impact

6) Coping

   a) Emotion

   b) Family function

   c) Parental role

   d) Sibling(s)

   e) Social

   f) Health services related

These themes reflected the adverse impacts of hospitalization and showed some coping characteristics. Details of the theme, sub-themes and quotations were presented in Appendix 3.2.

(1) Physical impact – Physical well-being of parents was adversely affected during the child's hospitalization period. Physiological complaints such as fatigue, illness, problems with sleep and appetite were included. Some typical responses were noted in the following excerpts;

Travelling to the hospital is exhausting. I come and go three times a day….

We both (parents) get sick as well because of exhaustion. It's really tiring…. (QC5)

I am exhausted because of staying in the hospital for too long. I haven't seen the sun for many days… (UB7, UBEXT2)

(2) Psychological/emotional impact – Psychological and emotional well-being of parents were mostly reported as problems during the child's hospitalization based on parental descriptions of stress, feelings and emotional responses. The most commonly reported issues on this theme in the interviews consisted of complaints about anxiety, intermittent emotional distress and worries heightened by symptom-related factors such as unpredictability of health outcome. For example, some mothers stated:

I feel nervous. I always think of some misfortune that can happen to my child in the hospital.... (UC11)

Our emotions fluctuate according to our child's medical condition. If we are told about his improvement, we'll be much relieved. I remember we felt very depressed the days when my child was very sick last week. Now, we are much better because he is now improved. (QA14)

...... My partner becomes agitated and angers easily during this period of the child's hospitalization…. (QA15, UB3, GB8)

We cannot concentrate at work while our child is still in the hospital (UA5, GB, GC8, GB8). He (husband) doesn't want to go to work and prefers to stay with our child in hospital. He calls many times a day to ask about the boy. He rushes to the hospital after work every evening. (UA5)

I'm filled with pain and sorrow when my child has pain for an unknown reason, nausea and vomiting… (QC5)

I feel guilty for not having done my best to care for my child, which resulted in this hospitalization… (UB3)

. …. Of course, I am very worried…extremely worried. I don't know what is happening to my child. There is no known cause of his problem…..I suspect that may be related to brain condition, or due to a heart problem. I requested to have examinations on…….whatever investigations that can help finding out the cause of his disease…. (UG4)

I'm very anxious and worry a lot about my boy's condition. I cry a lot particularly when he requires isolation. (GC6)

I worry a lot……I feel upset seeing that other kids can go home but my child cannot… I also worry about the medical cost. (GB1)

I feel sad. I don't want to tell others about my daughter's disease………. I need to bear the burden myself…… She's my child. It's my own burden anyway. (GA6)

I miss my other 8-year-old daughter, who is staying in our village. I haven't see her for nearly a month and it'll take a few hours to go home……(weeping) I cry at times when I think about her. (GA1)

(3) Family function related impact – family functions include activities, relationships, communications, roles and responsibilities within a family.

(3a) Family activities and relationship - family activities and relationship were adversely affected during the period of hospitalization. Family activities were affected mostly because of frequent visiting and change of daily routine related to hospitalization of a child. Family relationships were affected due to a more complex consequence of changed family activities, reduced contact time, and dysfunctional family communications. This dynamic can be observed in the following excerpts.

Our daily activities (work, eating, and sleeping) are all being affected.... (QA11,QA13,UB7,GA1,Gc7,GB2,GA5,GA6,GA10,GB1,GB2,GB8,GC2,GC6, GC7,GC11)

Frequent visiting and preparing food for my hospitalized child have affected my other family life activities… (UB3)

We feel worried but do not want to talk about it with my family. (UB3)

…..I better rely on myself for it would not help to discuss with my husband. I only would get angry after that. (QA11)

We blame each other for the child's condition (hospitalization). Grandma (mother-in-law) has complained of our carelessness in childcare…… (UB7, GB2)

(3b) Parental role and care – practices related to childcare, child discipline and nurturing behaviors are affected. Parents became more tolerant of their children's behavior and family rules became loose in the hospital. Some parents tried their best to care but many felt they were helpless and incapable. Some other parents became more protective and tried to justify their children's abnormal behaviors.

Family rules become loose while my child is in the hospital. We normally restrict him to watch TV or listening to CD. It’s so boring in the hospital, so I let him do all these here. (QC18, GA1)

I cook for him every meal in the hospital. Home cooking is always better. It doesn’t matter if I’m busy or not.((QC5, UC6, GA10, GB8).... I come 3 times a day rushing for every meal..... (QC5)

…..It is hard to rely on others to take care of my child… (GA5)

I (mother) cannot cook at home and my other kid(s) eat(s) junk food and whatever is available. (QC16)

…..I would love to help with attending to my child in the hospital but I feel inadequate to do so. (GA10)

We are more tolerant of our child’s behavior because s/he is in the hospital. We think he is affected by the illness, and maybe the medicine plays a role in making him uncomfortable and not behaving normally. (GC6)

(3c) Family role and responsibility in relation to educational activities **–** **e**ducational activities of the hospitalized children or the sibling(s) were adversely affected and found to be associated with the disrupted family roles and responsibilities. Parents from Hong Kong and Guangzhou reported similar concerns about the study of the hospitalized children and their siblings. Some typical examples were observed in the following excerpts:

I am busy taking his homework from school every day. It would not be good for her to get behind in school. (UB7)

My elder daughter has problems keeping up in school because of frequent visiting to the hospital. We were asked to discuss her study problems at school with the teacher and principal. (QA14)

This child's hospitalization affects the studies of my other boy. My elder son will sit for the high school public examination. I cannot support and care about him during these days. I just hope he can cope well. …. I feel sorry for him. But he is a big boy, he should learn to cope. (UB3)

(3d**)** Sibling(s) effect – mostly related to psychological responses such as siblings 'miss' each other or jealous about the way parents treat the hospitalized child. Some siblings' school studies were adversely affected.

These descriptions of sibling experiences and their responses to the hospitalization of a child family member indicated that there were special needs for these children family members.

We need special arrangements for the other sibling during the hospitalization period of this sick child. (QB17)

My other girl is 8 years old. She is very bright.... I have not seen her for a month. She is now staying with grandma in the village (4 hours by bus). I miss her very much…..(with tears). She called us a few times and said that she misses us very much but I cannot go back home because my younger boy is still sick in the hospital. She started to get jealous. (GA1)

My younger daughter is jealous about the way we treat her hospitalized sister, as too much allowance is being given. (QC18)

(4) Social impact - revealed the complicated dimension of impacts that were associated with reduced social activities, financial concerns and extra burden, particularly on concurrent difficulties that the family was experiencing.

(4a) Social activities - many families were reported to have reduced social activities and less desire to enjoy life during the period of a child’s hospitalization.

We see family and friends less because of hospitalization of my child. (QA11, QA14, UA16)

We have little desire to take a stroll because of my child's hospitalization. (QA14)

I need to take a leave to look after my child in the hospital. (QA9, QA16)

Staying in the hospital is like living in a prison particularly during isolation. (GA6)

(4b) Financial concerns – Issues related to reduced income, increased expanses and financial concerns were reported by parents. Heavy financial cost was particularly a major problem reported by parents from Guangzhou.

I need to quit my job and that affects family income. (QA11)

We have more expenses during the hospitalization (mobile phone and traveling expenses, etc. (QC5)

I need to borrow money from relatives in order to cover the cost of medical expenses. (GA1, GA6, GB1)

The medical cost is expensive. I worry about the financial burden. (GA1, GA6, GA10, GB1, GB8, GC7, GC8, GC11)

I cannot do my business sales anymore while staying in the hospital with my daughter….it's a great loss….the medical cost is too expensive. I'm about to use up all my savings and need to borrow money from relatives. (GA6)

(4c) Extra burden – Issues related to extra pressure and concurrent problems such as unemployment; be deep in debt; marital problem; or a close relative was sick at the same time described the extra burden that some families were experiencing. These reported extra burdens can be illustrated in the following interview excerpts:

We have added pressure because my spouse is unemployed…... (QC9)

Grandma (mother-in-law) is not happy. She must have blamed us for my child's injury. She would not compliant because she knows that my husband is already beleaguered with…. My husband's uncle was just admitted to the other hospital, so he is very busy running around different hospitals to visit his uncle and comes here for our son. My mother-in-law is also very distressed but she doesn't say a word. (UB3)

No, we don't talk to each other. He doesn't (husband) care. How can we talk? Just let it be…..talking to him is a waste of time, I don't bother to say a word……I don't want to get angry….how could I say?….. it's difficult to say...…it's a personality problem, hai…(heaved a sigh)….I have tried to discuss the problem with his dad (husband) but it's no use. I had to work out everything myself. (QA11)

I borrowed ¥10,000 (10 times his monthly salary) from my relatives to continue treatment in the hospital. I left our village for 2 months and cannot do farming since admission. (GA1)

I cannot continue my business as a storekeeper for nearly two months. There is a great loss of income (~¥2,000 per month). We've spent over ¥40,000 for medical expenses. We're now living on limited savings and loans. (GA6)

(5) Health service related impact – described issues related to the communication with health care workers, experiences of using health services, or expectations of services provided. There were common impressions that staff members were too busy to help and a lack of information about the child's health condition was reported. The communications between staff and parents appeared inadequate and did not meet the expectation of parents. These can be illustrated by some typical responses:

You cannot expect too much because nurses are really busy. I can understand that…it's always like that…when a child was discharged during the day, then a few more would be coming at night …..(UB3, UBEXT1, QB17)

I feel that I am bothering the health professionals when in need of care. (QA9)

We are concerned about the progress of my child's medical condition but we are not being well informed…. (QC5, UC4)

I worry that some negative hospitalization experiences as mentioned by the media and friends may happen. (UB3)

……The doctor's expression and answer made me feel upset. (UC4)

….The ward routine and lighting at night has affected my sleep. (UC10)

…..Other crying babies affect our life in the hospital. (GA5)

(6) Coping – many coping strategies were used by parents and some positive impacts were identified.

(6a) Emotion - self-control of emotion was described by some parents. Some typical responses as reported are:

I try to control my emotions (UBEXT2)

I try to take it easy and to relax. (UC10, QB2)

I stay focused on handling challenges related to her illness and ignore all other matters. (GA6)

I can only wait and maintain hope to get well soon. (GB1)

(6b) Family function - positive changes were noticed in the readjustment of family roles and activities. Family communication and relationships were also improved due to the hospitalization of a child in some families. Some examples found in the interview excerpts are:

We support each other as a family during this period of hospital stay. (UA16, GC6, GC7)

My hospitalized child expressed more of his/her inner world to the parents because of the increased opportunities in the hospital environment. (UC6)

The other family members (including extended family) all take turns visiting the hospitalized child, or looking after the other children at home. (UB10, UC10, QC18, GA1, GA5,)

We have mobilized everyone to take part. (UA12, UB10, QC18, GA1,GA5,) *Family relationship is strengthened through the hospitalization experience. (UB10, UC6, GC6)*

(6c) Parental role - active parental role and participation was noticed for the care of the hospitalized child. Some of these activities were described by parents as follows:

We (parents) both need to take leave from work to look after my child in the hospital and the other sibling(s) who stay at home. (QA9)

We explain to and encourage our child to face all challenges in the hospital. (QB17, QA13)

We stay with him all the time. (QC18, QA11, QB17)

I prepare food for my child. Home cooking is always better …….. (GA10, GB8, UC6, UB10)

(6d) Sibling(s) - some siblings were able to readjust positively during the period of hospitalization of their brothers or sisters. These responses were reported by parents as follows:

The other sibling(s) become(s) more mature and independent. (UB3)

The other (s) is / are much better behaved, extraordinarily well regimented during this period. (UC4)

(6e) Social - parents' coping strategies included readjustment of personal and family activities; and to seek and receive external help. These can be seen in the following interview excerpts:

We do not plan for a holiday or to take a stroll during this period. (QA16, GB2)

We are cutting down the hours we work to care for my child in the hospital. (GA1, GA5, GA6,QA9, QA16)

Other relatives help to look after the hospitalized child or the other child at home, or to support daily chore. (UB10)

We ask for help from our neighbors and friends during my child's hospitalization. They help looking after my other child at home. (UC4, QB17, GC2)

(6f) Health services related - the descriptions of hospitalization experience in relation to health service utilization included mixed feelings of helplessness, distrust, struggles, to acceptance and coping behaviors. For example, some parents stated:

We try to find out the cause of the disease because doctors could not explain the situation. (QC16)

They are too busy….We cannot expect too much. We understand that…
(QA9, QB2, UB3)

We ask other people about their hospitalization experiences. We cannot trust the public services…. We keep asking about his condition and look after him closely. (QC5, GA5)

We do not expect too much and accept the hospital environment, including the noises. (QA13, QC18)

We try to tolerate as much as possible while we are in the hospital. (QA13)

I cooperate with the ward routine and staff. (UB3)

I would not rely solely on the public medical service but to seek more advice from friends. (QC5)

Characteristics of family impact and coping from the two cities

Parents from Hong Kong and Guangzhou experienced a similar range of negative emotions and psychological impacts such as anxiety, fear, worry, nervousness, sadness, grief, blame, guilt, pain and sorrow during their children's hospitalization. These negative feelings were usually accompanied with uncertainty about the disease and treatment. Worries and anxiety usually fluctuated according the severity and progress of the child's disease and condition.

Physical symptoms of poor appetite and sleep were commonly reported by parents of both cities. Physical tiredness was more typically complained of by parents from Hong Kong due to travelling for frequent visits within a day and there was usually no special resting place in the hospital unit, while those families in Guangzhou usually stayed 24 hours in the hospital, resting in the same bed with their children.

Parenting style in both cities was found to be very similar. Parents were very much concerned about food (particularly keen to prepare homemade food) and problems in catching up with homework and school. A few parents were found more tolerant of the hospitalized child's behavior. Except for a few families that reported having problems in communication and blaming each other for the illness and hospitalization, most families in both cities reported having very good family support. If the family had more than one child, the other child at home usually got jealous. But there were also positive impacts; for example, some elder children at home became more mature and independent.

Nearly all families interviewed in mainland China have very good family support from extended families or close relatives. Support that the families received included the care of another child who stayed at home, chores, farm work and loans of money when needed.

Indeed, one mother treasured the experience of her child's hospitalization as a precious opportunity to recognize and appreciate her relationship with some close relatives. She began the conversation with worries about her daughter's disease but ended up in a grateful attitude, "*It's difficult...… With so many hospitalizations and clinic visit experiences, I've gotten so distressed with the results that all had turned into bad news….. I cry a lot……you know, I believe I could not survive without the support from my relatives. They are so understanding and encouraging*."

Parents in both cities also reported difficulties concentrating at work and many of them sacrificed work hours and reduced their earnings to visit their sick child in the hospital. However, financial difficulty was typically a concern of parents in Guangzhou because of the skyrocketing medical costs, as previously discussed in the literature review. Most parents spent about two to four times their monthly salary for a few days' hospitalization. Those whose children had been hospitalized for more than two months would spend 10 to 20 times their monthly salary. Many of them survived by using up their family savings and needed to borrow money from relatives.

A mother said "*We are farmers and we do not earn much money. The medical expenses are far beyond what we can afford. There is not much we can do but to borrow money from our relatives……it's now close to RMB¥10,000. We earn only around one thousand something RMB per month. The burden is heavy……*"

Another father of a three-year-old daughter suffering with leukemia has spent over RMB¥40,000 for the two and half months' hospitalization. He stayed with his daughter most of the time in hospital and found maintaining his retail business very difficult with reduced involvement at work. His business, relying on helpers, started to decline and at the same time he had to cope with the hospital bills that were far beyond what he could earn every month. He was close to using up all his savings and beginning to get loans. He refused to talk about the issues with health care workers because he reckoned that they were there just to look after children.

He said, "There is *nothing else the nurses can help with. They are only here to care for my child. It would not be their business to be concerned about anything else. Anyway, this is our own problem. I have to face it myself. I need to bear the burden myself……"* Then, he shifted the focus and said, "*Now, I need to face the problem (illness) and ignore any other matters. The most important thing is my girl's health. I need to face it because I brought her to this world. I have the responsibility to do so."*

This father was obviously in great trouble struggling with financial and psychological burdens while helping his daughter to fight against the distressing disease. Unlike the subsidized health care system in Hong Kong, nearly all families in Guangzhou complained of financial difficulties with a hospitalized child. This problem of skyrocketing medical costs is unlikely to be settled in the near future due to the complexity of health care issues in

China. Hospitalized children and their families are going to suffer with heavy financial burdens and the inaccessibility of good medical service in rural areas. Due to the uniqueness of health services and the heavy burdens families experienced in mainland China, the second stage of the study is justified to be conducted only in Guangzhou, China, to assess the greater impacts and ensure homogeneity of data.

In summary, parents from Hong Kong and Guangzhou reported a similar range of negative emotions and physical symptoms, except for more complaints of physical tiredness from Hong Kong parents. Parenting style in both cities was similar with much concern about preparing food and catching up with school activities. The major difference found was the heavy financial burden experienced by the Guangzhou families. Many of them went into debt to survive through the hospitalization period.

Although the experience of hospitalization was generally negative, some parents considered that hospitalization did provide growth and development for the whole family and the sick child. Coping strategies in this study population included seeking external support from extended family members or friends and maintaining hope for improvement of the child’s health. Good family support was commonly recognized in both cities but with particular appreciation of financial support from extended family among the Guangzhou families.

The above qualitative findings provided directions for assessment and evidence for developing a clinical user-friendly assessment tool to identify the impact on and coping of families during hospitalization of a child. Due to the uniqueness of health service and family experiences in China as reported, the second stage of the study is justified to be conducted only in mainland China to ensure homogeneity of data.

The themes and domains that emerged from the interview data were used to build on the related concepts and constructs (Appendix 3.2). These constructs have provided the basis for the development of scale items, which were tested for validity, reliability and utility in Phase Two of this study.

Item Selection – first version of HICS

With a critical review of existing literature on hospitalization impacts on families and related assessment tools, a first draft of the item pool was developed (Appendix 3.3). The choice of wording and format used to construct questions considered respondent's literacy skills and educational level. People at primary six levels should be able to read and understand the questions. The statements were carefully crosschecked to avoid using negative statements that were difficult to understand. Effort was made, according to DeVellis' recommendations, to write all statements in a clearly understandable way that was unambiguous to the respondents (DeVellis, 2003).

The interview data discussed in the last section were also used to further develop this first draft of items into a final 156-statement item pool (Appendix 3.3). The developed item pool was validated by an expert panel of five raters for item reduction.

Validation Test and Item Reduction (face and content validity)

The item pool for each hypothesized dimension was created as described earlier. Since the initial set of information was generated from the perspective of parents and verified by the published literature that specialized in the field, this approach ensured the content validity of the tool at the beginning of the research. Effort was made to write items in both positive and negative directions in order to minimize the possibility of set responses. All coping-related items needed to be reversely coded before computing for the total item score.

This developed item pool was validated by a five-member expert panel selected for expertise in the areas of clinical practice, life experience as a parent with a hospitalized child, and research methodology. With regard to expert judgments, the minimum number of content experts should be two (Thorn & Deitz, 1989). Criteria used by the judges for retention or elimination of items included clarity of expression, face validity, appropriateness for the construct being measured, and potential for differentiating the target population. Each expert was given a checklist of updated items to make comments (such as ‘redundant’ or ‘unclear’) and indicate her suggestion/decision (to remove, modify, or keep) for each item. The first expert validation reduced the items into 83. It was in this stage that items were categorized into two sub-scales – impact and coping. These two sub-scales were found conceptually diverse and the response scales required slight modifications to adjust for the question stem.

Items which were consistently judged to be poorly written, ambiguous, redundant, or inappropriate to the construct were eliminated. This process of item review was carried out twice to insure a quality set of items that could be tested empirically. It was also important that sufficient items were retained in each dimension to allow for the identification of reliable and valid scales of measurement (DeVellis, 2003; Kline, 2005).

A resulting 56 items were retained after the second round of item reduction. These items were used for the first draft of Hospitalization Impact and Coping Scale (HICS) after two cycles of item reduction. Another six items concerning sibling effects were retained in a separate section of the questionnaire. These items would not be added into the analysis of the total HICS instrument. It was expected that a large number of families might not have more than one child, so these items would be irrelevant to many of the respondents. This decision is supported in the literature. Stein and Riessman

(1980) included items to measure sibling effect in their original test version, but these items were deleted in the latest version because of missing data on 50% of the respondents in the US samples who either did not have other children or had only first born infants, making the sibling items inapplicable (Stein & Jessop, 2003). With the one child policy in China, an even higher percent of missing data for the sibling items would be expected. The decision to split out these sibling items was well justified.

The Second Pre-Test Questionnaire Version of the Hospitalization Impact and Coping Scale (HICS)

The second pre-test version of the Hospitalization Impact and Coping Scale (HICS) instrument was developed as a tool for clinical and health service research to examine variability in the parental perceived impact of hospitalization on families with a hospitalized child. Impact was conceptualized as the effect of a child's hospitalization on the family system. Six dimensions were proposed as relevant through qualitative interviews: physical; emotional; family function; social; health services related; and coping.

A four-part questionnaire was developed on the basis of the 56 items item pool and an extra six items to measure sibling effects. The first part of the questionnaire included some fill-in-the-blank and multiple-choice items to collect demographic information. The second part consisted of 39 items using a six-point response format to obtain an ordinal measure of frequency

(0 = no impact; 1 = little impact; 2 = some impact; 3 = great impact; 4 = extreme impact; X = not applicable) for the parental perceived hospitalization impact on family. The third part consisted of 17 items using a similar six-point response format to obtain information on the effectiveness of coping (0 = no effect; 1 = effect; 2 = some effect; 3 = great effect; 4 = extreme effect; X = not applicable). The last section consisted of six items measuring sibling effect with the same response format as mentioned. The total scores were obtained by summing all the ratings of each item of each scale in the impact and coping sub-scales.

The use of response scale ranged from 0 to 4 with ‘0’ indicating ‘not helpful’, or ‘not at all’ are commonly found in many stress and coping scales such as CHIP – Coping Health Inventory for Parents (McCubbin et al., 2001) and Horowitz’s Impact of Event Scale (Sundin & Horowitz, 2002). In this study, it was anticipated there may be some ‘no impact’ or ‘no effect’ responses, and so adding the option was a wise move and a decision supported by Kline’s discussions on designing continuous responses for a summated-rating scale (Kline, 2005).

This pre-test version of HICS was again sent to five experts for validation of face and content validity. These experts included two academic professionals with PhD qualifications and specializing in pediatric care; one senior nursing manager with PhD qualification and rich experiences in pediatric care; one Departmental Head Nursing Manager of pediatric units in

Guangzhou; and one housewife mother from Guangzhou with personal experiences of having her child being hospitalized. The content validity index (CVI) was 0.92.

Pilot Study using the Second Pre-Test Version of HICS

The second version of the pre-test instrument (HICS) was given to a convenience sample of 67 parents in a pediatric unit in a Guangzhou hospital to evaluate item clarity and response variance and to estimate reliability. Parents' comments revealed a lack of clarity in the wording of a few items. Examination of frequency distributions indicated that the full ranges of responses were being used for most items. Data were analyzed for internal consistency and the Cronbach's co-efficient alpha (Cronbach, 1951) was 0.93, indicating high internal consistency. The instrument as a whole appeared to have sufficient reliability and warrant further development.

The participants consisted of 52 (77.6%) mothers (mean age 30.6 years) and 13 (19.4%) fathers (mean age 33.1 years). The hospitalized children consisted of 22 (32.8%) girls and 45 (67.2%) boys. Overall mean age of children was 2.3 years and their average length of stay at the time of interviews was four days (SD=3.05, range from one to 20 days). Less than 10% of children's diagnoses were classified as chronic conditions, based on to Breskin's definition of chronic illness (2008). There were only 30% (n = 20) of children with one other siblings and 3% (n = 2) of them have two siblings. Most of the families (80.6%, n = 54) were living as a nuclear family. About one-third of the families (19.4%, n = 13) are living with grandparents. Many respondent families (23.9%, n = 16) are new migrants to the city settled in within a period of five years.

In addition, preliminary internal consistency reliability coefficients (Cronbach's alpha) of the two sub-scales (named impact and coping) were computed to examine the extent to which the items were homogeneous. The impact sub-scale has 39 items with Cronbach's Alpha 0.94. The coping sub-scale has 17 items with Cronbach's Alpha 0.81. With coping items being reversely recoded, the Cronbach's Alpha of the overall 56-item scale is 0.93.

Further Item Reduction

An examination of descriptive statistics for the individual items on the HICS was conducted to examine the extent to which items were meaningful to respondents. The researcher examined the frequency of responses rated 'not applicable' (N/A), the means and standard deviations, the range, skewness, and the correlations among items. Among the 56 items, some were found to have high percentages of 'not applicable' responses. The item 'concerned that hospitalization would affect the child's progress of study at school' had over 50% of parents reported as not applicable because most of children (70%, n = 47) were under the age of three. In view of this, this item was deleted from the scale. Another item, 'hospitalization adversely affected marital relationship' had also got a high percentage (53%, n = 36) of 'not applicable or no effect' responses. The context of this item, if deleted, could be captured by another item measuring the impact on family relationship. So, this item was also deleted from the scale. The last item of the impact sub-scale asked about 'concurrent difficulties and the related impact', and this also yielded a high percentage (57%, n = 38) of not applicable, no impact or missing responses.

This result reflected the reality that concurrent difficulties have no direct relationship with hospitalization but it existed only as a coincident effect. It was also decided that such effect should not be measured as an impact resulting from hospitalization. However, it was found very meaningful to be aware of such situations, if they exist. With parents' reported concurrent difficulties, it is worth nurses' effort to pay special attention to determine if these situations would cause an increased stress to the families. The final decision was to keep this item as an opened-ended question, without including it in the scale structure.

Within the coping subscale, an item 'Ask for blessings from God' has obtained about 60% responses in the 'not applicable/no impact/missing data' categories. Given that China has gone through a period of atheism and is still having limited freedom of religious belief at this time (Potter, 2003; Chan, 2005), these responses from parents in this study are understandable. Another item 'We discussed coping strategies and everyone in our family knows his/her own responsibilities' appeared redundant to respondents with another item, 'we support each other and share responsibilities'.

As a result, the above-mentioned five items were deleted from the scale – HICS. The item concerning ‘concurrent difficulties,’ though deleted from the scale, was retained as an open-ended item, not counted into the analyses. A few items with wordings that appeared to be less commonly used by respondents were rewritten. These included ‘alternative therapy,’ ‘reflection’ and ‘negative experiences.’

Pilot Testing and Validation of HICS

Empirical validation of the HICS followed the approach advocated by Nunnally (1978), and guided by Field (2005) and Pallant (2007). Item analysis was conducted on the pool of 36 items of the impact sub-scale to identify which contributed most to the homogeneity or internal consistency of the scale, followed by factor analysis to investigate the factor composition (dimensions) of the refined scale. Lastly, the reliability measures to estimate the internal consistency of the scale were done in its final version. Same procedures applied to the remaining 15-item coping sub-scale as well.

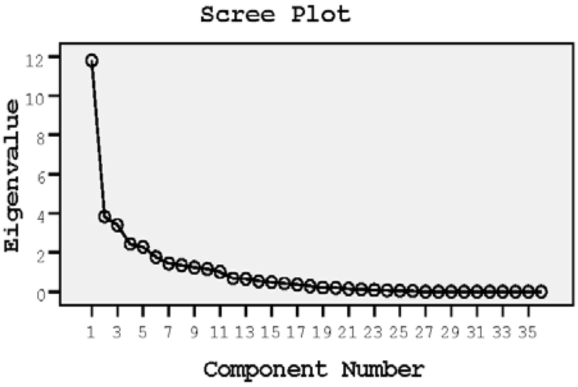
To verify that the data was suitable for factor analysis, the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) value should be 0.6 or above (Kaiser, 1970, 1974) and the Barlett’s Test of Sphericity value should be significant at 0.5 or smaller (Bartell, 1954). In the pilot study KMO value was 0.7 and Barlett’s Test of Sphericity was significant ($p = 0.000$), therefore applying factor analysis was appropriate.

Principal components analyses (PCA) with Varimax rotation (Kaiser 1958) were performed as an exploratory statistical procedure to examine the structure of the HICS. Principal components analysis (PCA) is concerned with establishing which linear components exist within the data and how a particular variable might contribute to that component. It is conceptually less complex and bears numerous similarities to discriminant analysis and MANOVA (Field, 2005). Missing values replaced with mean was used to form the correlation matrix for analysis. This procedure lowered the standard deviation of variables and so could lead to significant results that would otherwise be non-significant. This avoided a massive loss of data from the 'not applicable' items. Due to the expected inter-relationships between factors, an obliquely rotated solution such as Varimax rotation was preferred and therefore used for this study (Field, 2005).

With the Hospitalization Impact sub-scale, there were ten components with recorded eigenvalues above one, which explain a total of 74.45% of the variance. According to Cattell (1966), with the use of Scree plot provided by SPSS, a change in the shape of the plot was found between the sixth and seventh components (Figure 3.2). Components one to six explained 61% variance, which was much more of the variance than the remaining components. Component one contributed 12.34%, component two contributed to 8.75%, and component three contributed to 8.0%. The rotated solution of the component matrix, as described by Thurstone (1947), revealed the presence of a simple structure of six factors in the impact sub-scale (Appendix 3.4)

Figure 3.2 Pilot study: Scree Plot of component number

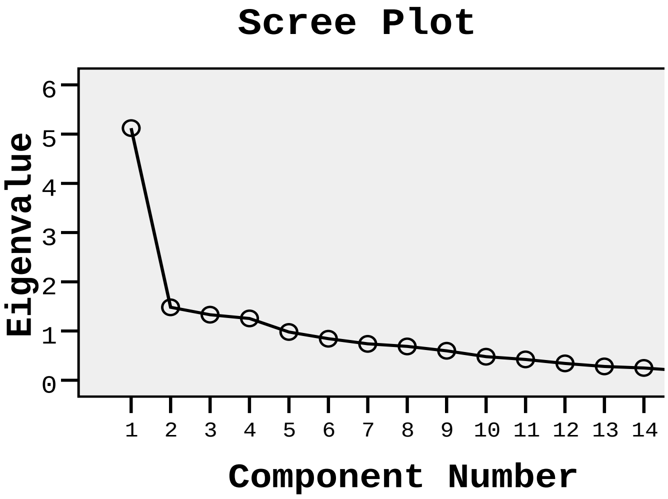
Hospitalization Impact Subscale



With the Hospitalization Coping sub-scale, there were four components with recorded eigenvalues above one, which explains a total of 61.26% of the variance. According to Cattell (1966), with the use of Scree plot provided by SPSS, a change in the shape of the plot was found between the fourth and fifth components (Figure 3.3). Component one contributed 18.50%, component two contributed to 17.56%, component three contributed to 14.92%, and component four contributed to 10.28%. The rotated solution of the component matrix as described by Thurstone (1947) revealed the presence of a simple structure of four factors in the impact sub-scale (Appendix 3.5).

Figure 3.3 Pilot study: Scree Plot of component number

Hospitalization Coping Subscale



Summary of Phase One Study

This study began with a review of existing literature on the background and related constructs related to the dimensions of impact on parents with a hospitalized child. Parents with a hospitalized child were interviewed in the pediatric ward settings in both Hong Kong and Guangzhou, China. Initial exploratory discussions through interviewing parents identified six major themes. Based on the findings, development of an item pool with 156 items designed to be indicators of each conceptual dimension of the construct was undertaken. Validation testing of items by five experts in the fields including a parent from Guangzhou was carried out twice for the first and second pre-test versions. The first expert validation reduced the items into 83. It was in this stage that items were categorized into two subscales, impact and coping. Item reduction was further achieved resulting to a 56-item HICS (39 items for the impact sub-scale and 17 for the coping sub-scale) pre-test version.

Administration of this questionnaire (second pre-test version of HICS) to parents in a pilot study was done in Guangzhou with 67 parents. Pilot testing of psychometric properties, item analysis, and further item reduction were carried out resulting to a 51-item HICS (36 items for the impact subscale and 15 for the coping sub-scale). Data were analyzed for internal consistency and the Cronbach's coefficient alpha was 0.93, indicating high internal consistency. The instrument as a whole appeared to have sufficient reliability and warrant further development. Given that the KMO value was 0.7 and the Barlett's Test of Sphericity was significant ($p = 0.000$), both indicating that factor analysis was appropriate and thus was carried out. Principal components analysis (PCA) with Varimax rotation was performed and that revealed the presence of a simple structure of six factors in the impact subscale and four factors in the coping subscale.

Phase Two Study

Phase Two of this study involved cross-sectional quantitative data collection by using the third version of the constructed questionnaire, Hospitalization Impact and Coping Scale (HICS), on families with a hospitalized child (Appendix 3.6 and 3.7). The validation of the instrument (HICS) used a survey design for testing the psychometric properties and to examine relationships and differences in the impact among families on variables such as the child's age, nature of the illness, and length of hospital stay.

Sampling Method

According to Crocker and Algina (1986), there is no absolute rule for the minimum number of examinees to use in an item analysis study. As a general rule, most item parameters can be estimated with relative stability for samples of 200 subjects, and so this was recommended as the minimum number desired (Crocker and Algina, 1986, p. 322). Another long-standing rule-of-thumb recommendation is to have five to ten times as many subjects as items (Nunnally, 1978; Kass & Tinsley, 1979). A recent review of related literatures also suggested that a minimum of 100 was recommended by Kline (1994), and a minimum requirement of five cases per item was recommended (Watson & Thompson, 2006). According to this, since HICS has 36 items in the impact sub-score, 180 subjects probably would be the minimum sample size for this study.

Since all patients from the pediatric units can be judged to be representative of the total population of pediatric clients, this study selected a few pediatric units and invited the parents of all their clients who had been admitted for at least 24 hours to participate in the study. This sampling method was justified and reduced the cost of preparing samples and fieldwork (Miller, 1991).

Data Collection Procedure

All families were invited to participate in the study 24 hours after their child's admission to the pediatric units. The researcher explained the project to parents and provided clear direction about the HICS instrument. Parents were asked to respond to the items in terms of severity of impact experienced around the time of reporting. It was suggested that the family come to a consensus as a unit measurement. However, parents were also encouraged to reflect their views of the impacts on the family even if other member might not agree. The instrument can be self-administered or conducted as an interview for respondents with a low educational level or for those who need help when holding babies.

Ethical Considerations

The primary caregivers (parents) for the hospitalized child were invited to participate in the study. The data collection process took place 24 hours after admission in order to avoid unsettled situations. The researcher explained to the parents about the procedures as well as the potential risks to the child or caregiver, although potential risks to the participants were minimal. There were no biomedical procedures or drugs involved in the study. The questionnaire only took 15-20 minutes to complete and the parents could stop the interview at any point or refuse to answer any question. If the parents were too tired, data collection was re-scheduled or discontinued.

It was stressed that participation in the study was voluntary and refusal to participate or withdrawal from the study would not have a negative influence on the care that the child received at the hospital concerned. The caregiver was given an information sheet that contained a written summary of the information presented above. If the caregiver agreed to participate in the study, she/he would be required to give verbal and written consent.

There was no identifying information on any study records nor would participant names be used in any reports on the study findings. Only the research team would have access to the study records. Collected data were kept in a locked cabinet and tapes from the interviews were transcribed and then destroyed.

Parents might appreciate the opportunity to discuss their child's illness and hospital experience with a concerned member of the research team. Findings from the study would contribute to the limited knowledge base on the impact of hospitalization on Chinese families. Findings may have implications for improving clinical practice with this population.

Limitations

The respondents in this study were limited to those parents with a hospitalized child, and the generalization may only be useful in pediatric settings. For the purpose of this instrument, it was better to have the family come to a consensus as a unit measurement. However, family unit data are difficult and often expensive to gather because one must gather data from more than one person (Vaughan-Cole, 1998). If only one parent acts as a proxy for the entire family she/he should be advised that the family should come to a consensus. The decision may not reflect the family as a whole. It should not be assumed that data from one member are the same as or equal to the data from the whole family. But at the same time, the data should not be de-valued because if any one member of a family suffers, it affects the family system as a whole. This research studied families with a member in hospital and it focused on addressing health care issues that are important to practicing nurses rather than researching couple's adjustment in family life. The specific aim is to empower nurses to assess, plan, deliver and evaluate nursing care to patient and families through better understanding. Vaughon-Cole (1998) suggested that the prudent approach is to accept the presence of the dilemma and seek more discussion of it in the literature.

Psychometric Evaluation of the Questionnaire

The HICS was examined for the three psychometric properties – acceptability, reliability and validity. These properties were tested with reference to standardized procedures and instrument review criteria developed by the Scientific Advisory Committee of the Medical Outcome Trust (Lohr et al., 1996; Moussaoui et al., 2004).

Acceptability

The acceptability of the questionnaire was analyzed based on the amount of missing data. It is recommended that they should not exceed 5%. Floor and ceiling effects (percentage of respondents with the lowest and highest scores) can be used to detect variances in the extremes. These are recommended not to exceed 20% (Holmes & Shea, 1997; Moussaoui et al., 2004).

Reliability

Reliability is the degree to which the instrument is free from random error. Internal consistency is one indicator for reliability of the instrument (Burns, 2005). Internal consistency reliability was selected rather than a test/re-test method to minimize respondent burden. Previous studies of similar multi-item scales have indicated that internal consistency estimates approximate test/re-test estimates (Yeh, 2001; Stein & Riessman, 1980; Ware & Karmos, 1976).

Empirical criteria were employed to refine the impact scale. Items were deleted that did not produce variability. Cronbach's alpha is a measure of how well each individual item in a scale correlates with the sum of the remaining items. It measures consistency among individual items in a scale. Inter-item correlations were examined to eliminate highly redundant items. After these procedures, those items defining each hypothesized dimension were logically summed and item total score correlations were computed. Items which did not reach the 0.01 level of significance would be dropped. Whatever items remained in the list was included in the final revised version.

Validity

Face and content validity

Based on the qualitative data and literature review, an item pool for each hypothesized dimension was created as described earlier. Effort was made to write items in both positive and negative directions in order to minimize the possibility of set responses. This developed item pool was validated by an expert panel selected for its expertise in the areas of clinical practice, life experience as a parent with a hospitalized child, and research methodology. Criteria used by the judges for retention or elimination of items included clarity of expression, face validity, appropriateness for the construct being measured, and potential for differentiating the target population. Items which were consistently judged to be poorly written, ambiguous, redundant, or inappropriate to the construct were eliminated. This process of item review was done twice to insure a quality set of items that could be tested empirically. It was also important that sufficient items were retained in each dimension to allow for the identification of reliable and valid scales of measures. Those that appeared to be misunderstood by respondents were re-written or deleted.

As highlighted by Kline (2005), most analysis requires at least two, and more appropriately five to ten, items to perform analyses that suggest the construct is a reasonable one. The author has been very careful in making a rational consideration of both statistical needs and administrative concerns. Special precaution was taken to avoid respondent burden by keeping the length of the scale reasonable for parents to complete within 15-20 minutes. Otherwise, those who were willing to participate might have been fatigued by the end and thus would provide “garbage” answers as described by Kline in her writings (Kline, 2005).

Given that impact and coping are theoretically distinct constructs, they should be retained as separate scales. Two response sets were developed on a six-point intensity Likert scale: (1) perceived degree of hospitalization impact on the family (impact subscale) ranging from “0 – 4” (no, little, some, great to extreme impact), or “X” representing not applicable. (2) The second part (coping sub-scale) with perceived degree of effectiveness of coping strategies ranging from no effect, little, some, great to an extreme effect, or "X" representing not applicable (in the case of never tried or never thought of). The point of reference for all items was based on "this hospitalization experience."

Construct Validity

Construct validity is based on the extent to which a test measures a theoretical construct or trait. The factor analytical approach was adopted as a procedure to give the researcher information about the extent to which a set of items measures the same underlying construct or dimension of a construct (LoBiondo-Wood & Haber, 2002). This approach involved the least inconvenience to the subjects concerned when compared with the other methods, and it was therefore the most suitable strategy to be used in clinical situations. The following discussions, concerning convergent and discriminant validity as well as factor analysis, all help to establish construct validity.

Convergent Validity

This study used correlation testing for convergent validity to explore the relationship of HICS and the Parental Stressor Scale: Infant hospitalization (PSS: IH) and the general functioning scale (12 items) of the Family Assessment Device (FAD). These scales were previously justified in Chapter Two, establishing them as appropriate for use in this study. The Pearson product-moment correlation coefficient (*r*) is a common measure of the correlation between two variables *X* and *Y*. Pearson's correlation reflects the degree of linear relationship between two variables. It ranges from +1 to -1. A correlation of +1 means that there is a perfect positive linear relationship between variables. A correlation of -1 means that there is a perfect negative linear relationship between variables. A correlation of 0 means there is no linear relationship between the two variables. Correlations are rarely if ever 0, 1, or -1 (Burns, 2005; Polit, Beck, & Hungler, 2001). Cohen (1988) has suggested the following interpretations for correlations in psychological research, in the table below.

Table 3.2 Interpreting Correlations

Correlation	Negative	Positive
Small	−0.3 to −0.1	0.1 to 0.3
Medium	−0.5 to −0.3	0.3 to 0.5
Large	−1.0 to −0.5	0.5 to 1.0

Discriminant Validity

Campbell and Fiske (1959) introduced the concept of discriminant validity and stressed the importance of using both discriminant and convergent validation techniques when assessing new tests. Discriminant validity analysis refers to testing statistically whether two constructs differ. A successful evaluation of discriminant validity shows that a test of a concept is not highly correlated with other tests designed to measure theoretically different concepts. The impact and coping sub-scales developed in this study are theoretically distinct constructs. To establish discriminant validity, this study used correlation testing to show that measures of the impact and coping sub-scales were not related.

Factor Analysis

Factor analysis is a technique for identifying groups or clusters of variables. Field (2005) described a few reasons for its usage: (1) to understand the structure of a set of variables; (2) to construct a questionnaire to measure an underlying variable; and (3) to reduce a data set to a more manageable size while retaining as much of the original information as possible.

Factor analysis assesses the degree to which the individual items on a scale truly cluster together around one or more dimensions. Items designed to measure the same dimension should load on the same factor; those designed to measure differing dimensions should load on different factors (Anastasi, 1988; Nunnally & Bernstein, 1993). This analysis will also indicate whether the items in the instrument reflect a single construct or several constructs. Once a factor structure has been found, it is important to decide which variables make up which factors. Many researchers take a loading of an absolute value of more than 0.3 to be important, whereas Field (2005) considered that the significance of a factor loading should depend on the sample size. According to Stevens (2002), a sample size of 50 with a loading of 0.722 can be considered significant; for 100 the loading should be greater than 0.512; for 200 it should be greater than 0.364; for 300 it should be greater than 0.298; for 600 it should be greater than 0.21; and for 1000 it should be greater than 0.162. These values are based on an alpha level of

0.01 (two-tailed). With a sample size of 218, this study will use a loading value of 0.36 to consider the significance of a factor loading.

Previous discussions in the section about pilot testing and validation of HICS has covered factor analysis related important concepts of Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) value, Barlett's Test of Sphericity value, Principle components analyses (PCA) with Varimax rotation, eigenvalues and the Scree plot test. The same principal and experiences gained in the pilot study was applied again in the main study.

Confirmatory Factor Analysis (CFA) was used to cross-validate the factor structure derived from Exploratory Factor Analysis (EFA) of the HICS (Carver et al., 1989). The root-mean-square error of approximation (RMSEA) and Comparative fit index (CFI) and Tucker-Lewis Index (TLI) were selected to evaluate the six-factor impact model and the four-factor coping model, because these indices are well known to be the most sensitive to model mis-specification (Hu & Bentler, 1998). For RMSEA, values ≤ 0.06 indicate a good fit (Floyd & Widaman, 1995). For CFI and TLI, values ≥ 0.9 indicate a very good fit (Bentler & Bonett, 1980).

The Scatter Plot of Impact and Coping Scores

To address the possibility of various outcomes of family responses, this study proposed four hypothesized outcomes to categorize families in a family typology of adaptation. This can be achieved by assigning two levels (high and low) to the impact dimension with the total impact Z scores and the coping dimension with the total coping Z scores on a scatter plot. A scatter plot can show the pattern of distribution of the data based on the impact and coping sub-scores. A scatter plot is a graph that plots each subject's score on one variable against their score on another (Field, 2005). The data is displayed as a collection of points, each having the value of the coping score determining the position on the horizontal axis and the value of the other variable (impact score) determining the position on the vertical axis. One of the most powerful aspects of a scatter plot, however, is its ability to show non-linear relationships between variables. The scatter plot of all the people in the study enabled the researcher to obtain a visual comparison of the two variables in the data set, and helped to determine what kind of relationship there might be between the two variables.

Other data Analysis

Data analysis of quantitative data from the Phase Two study was undertaken using SPSS (Version 12). As mentioned above, this study used Exploratory Factor Analysis (EFA) to examine the factor structure and other psychometric properties of the newly developed instrument, Hospitalization Impact and Coping Scale (HICS). Given that impact and coping are theoretically distinct constructs, they were retained as separate scales.

Correlation tests, particularly the Pearson product-moment correlation coefficient (*r*), were used to study the relationship of HICS with other well established scales for convergent and discriminant validity tests. Inter-item correlations and the Cronbach's coefficient alpha were used to determine the internal consistency and reliability of the scale.

Given adequate psychometric properties of the HICS, additional objectives of this study were analyzed with the following statistical procedures:

1. Using ANOVA to compare the differences of hospitalization impact scores of the respondent groups (father, mother, and both parent group).
2. Using ANOVA to compare the differences of coping scores of the respondent groups (father, mother, and both parent group).
3. Correlation tests, particularly the Pearson product-moment correlation coefficient (*r*), to study the relationship of the total impact sub-scores with the length of hospital stay of the children.
4. Correlation tests, particularly the Pearson product-moment correlation coefficient (*r*), to study the relationship of the total coping sub-scores with the length of hospital stay of the children.
5. Correlation tests, particularly the Pearson product-moment correlation coefficient (*r*), to study the relationship of the total impact sub-scores with the perceived severity of the child's condition.

6. Correlation tests, particularly the Pearson product-moment correlation coefficient (*r*), to study the relationship of the total coping sub-scores with the perceived severity of the child's condition.

Further details about data analysis and related results are provided in the next chapter.

CHAPTER 4: RESULTS

Phase Two Study

With results and discussions of the interviews and pilot study presented in the last chapter and the appendix section, this chapter will only focus on the results of the Phase Two study.

In the second phase of the study, a convenience sample of 218 Chinese parents with hospitalized children was recruited in Guangzhou, China, to test the psychometric properties of the instrument, the Hospitalization Impact and Coping Scale (HICS).

The Third Version of the Instrument - Hospitalization Impact and Coping Scale

The third version of the instrument Hospitalization Impact and Coping Scale (HICS) consists of four major parts. Part one consists of demographic characteristics of the hospitalized child and his/her family. Part two consists of a 36-item scale that measures the severity of impact on the family during hospitalization of a child. Parents were asked to rate the degree of impact of this hospitalization on their families according to a scale that ranged from no impact as 0, little impact as 1, some impact as 2, great impact as 3, extreme impact as 4, and not applicable as "X". The choices of "X" scores are recoded as 0 in the analysis. At the end of this part, parents were asked if they had been experiencing extra burdens because of some concurrent adverse life experiences such as unemployment, work stress, marital problems, or having some other relatives to look after at that moment. Although parents were expected to rate the severity of such impact, this item is not included in the analysis of the impact scale for two reasons. First, these are concurrent difficulties which are not direct impacts resulting from hospitalization of the child. Secondly, it is not expected that such situation(s) would be relevant to all respondents. The last item of this session is an open-ended question asking parents to describe or list any other possible impacts they were experiencing during hospitalization of their children.

Part three of the HICS is a 15-item scale measuring the coping strategies experienced by the families. Parents were asked to rate the effectiveness of each strategy according to a scale ranging from no effect as 0, little effect as 1, some effect as 2, great effect as 3, extreme effect as 4, and not applicable (never tried) as “X”. Again, choices of “X” scores are recoded as 0 in the analysis. At the end of this part, parents were asked to list other strategies they found effective in helping their children to cope with or overcome the adverse effect of hospitalization. Another open-ended question asked parents to list or describe strategies that they found useful in coping with the adverse hospitalization impact on their families.

The final part consisted of 6 items measuring sibling effects. These impacts are only relevant and important to families with more than one child. Since it was not expected to be relevant to a large number of one-child families in China, these items were not included in the analysis of the scale. A similar situation related to missing data from single-child families was also reported in a study done in the USA (Stein et al., 2003). At the end of this questionnaire, parents were asked to express any other comments related to their children's hospitalization experiences on their families.

Family Information and Demographic Characteristics

A total of 281 Chinese families from the pediatric units of a Guangdong Provincial maternal and children hospital were invited to participate in the study. Either parent (52% mothers, 26.6% father, and 20.6% parental joint participation with discussions and consensus) from each family participated in the study. Seventeen families refused to participate, mainly due to inconvenience or lack of interests in the study. Fourteen families did not return the questionnaires before discharge or home leave. Majority of the families were able to complete the questionnaires within 20-30 minutes (including the instruments for validity testing (Family Assessment Device (FAD), and Parental Stressor Scale: Infant hospitalization (PSS: IH) and returned them the same day. Some parents required assistance to complete the questionnaire due to low educational level or inconvenience when holding the child.

A total of 250 questionnaires were returned in which 13 were excluded because of incomplete information particularly in the demographic section. Another 17 questionnaires were excluded because of loss of variability in most items. This study only included parents as informants and therefore two other questionnaires completed by an aunt and a grandmother caretaker were also excluded from this study. As a result, a total of 218 questionnaires were included in the data analysis.

Descriptive Statistics

Descriptive statistics (numbers and percentages) were used to illustrate the distribution of responses for the entire questionnaire, including demographic data. Mean scores and standard deviations (SDs) for each item were calculated to determine the degree of impact and the effectiveness of coping strategies (Table 4.1).

Table 4.1 presents the demographic characteristics of the hospitalized children. Among the 218 families, there were more boys (61.9%, n = 135) than girls (37.6%, n = 82) and most of them were infants 12 months old or younger (55.0%, n = 120 less than six months old, and 13.3%, n = 29 for seven to 12 months old). Only about 5.9% (n = 13) of children were over five years old. The most common health problem that the children suffered from was respiratory tract infections (74.8%, n = 163). The average length of stay of children on the day of study was 4.71 days (SD = 3.56), with a range from one to 30 days. In this study, all respondent families had their children stay in the hospital for at least 24 hours in order to build up the desired effect of hospitalization impact and coping experiences. A majority of them had their hospitalization experiences for one to six days, with 39% of children (n = 85) staying in the hospital for one to three days, and 41.3% (n = 90) staying for four to six days. Only a few children (1.4%, n = 3) stayed in the hospital for more than 15 days. Most of the children were the only child in the family (65.6%, n = 143). Despite the one-child policy in the country, there were still 30.7% (n = 67) of children having a sibling and 3.7% (n = 8) with two or three siblings.

Table 4.1 Summary of Demographic Variables

Characteristics of the Hospitalized Children (N= 218*)

Demographic Variables	N*	%	Mean (SD)	Range
Age of the hospitalized child	218	100	15.15 (23.75) months	Birth – 12 years old
Birth to 6 months	120	55.0		
7 to 12 months	29	13.3		
12 – 36 months	42	19.3		
3 – 5 years old	14	6.4		
6 - 10 years old	11	5		
10 - 12 years old	2	0.9		
Sex of the hospitalized child				
Boy	135	61.9		
Girl	82	37.6		
Twins	1	0.5		
Diagnosis				
Respiratory infections	163	74.8		
Neonatal jaundice	11	5		
Blood disorder	3	1.4		
Surgical conditions	16	7.3		
Heart disease	2	0.9		
Others	20	9.2		
Length of hospital stay (days)			4.71 (3.56)	1 - 30 days
1- 3 days	85	39		
4 - 6 days	90	41.3		
7- 9 day	24	11		
10-15 days	12	5.5		
16-30 days	3	1.4		
Number of sibling				
No sibling (one child family)	143	65.6		
One sibling	67	30.7		
Two siblings	5	2.3		
Three siblings	3	1.4		

* Ns - vary because of missing values on some variables.

Other demographic details of the children’s families were shown in Table 4.2. All participants in this study were parents of the hospitalized children. There were more mother respondents (53.2%, n = 116) than fathers (26.6%, n = 58). Some parents jointly participated in this study following discussion of the issues (20.6%, n = 44 families). Mothers’ age ranged from 18 to 41 years old (mean = 28.9, SD = 4.78). Over half of the mothers (62.0%, n = 135) were under 30 years old. Fathers’ age ranged from 19 to 49 years old. Their average age was 31(SD = 5.47), with the mean at 26 to 30 years (31.7%, n = 69). Many mothers were housewives (31.2%, n = 68), and the others were quite evenly distributed as workers (13.3%, n = 29), farmers (12.8%, n = 28), and businesswomen (11%, n = 24). Fathers were involved more in the business sector (21.6%, n = 27), then as workers (18.8%, n = 41), farmers (14.2%, n = 31) and drivers (12.4%, n = 27). In this study, more mothers (32.1%, n = 70) and fathers (29.8%, n = 65) received lower secondary education than in the other levels of study. Most of the reported monthly family income was in the range of ¥1001-2000 (28%, n = 61), followed by the category of ¥2001-4000. A considerable number of families (17.9%, n = 39) reported to have at least ¥6000 income per month.

A majority of families lived as a nuclear family (68.8%, n = 150) with only parents and their children. About 26.1% (n = 57) of families lived with grandparents and only a few (5.1%, n = 11) lived with other relatives or some other persons. Most of the families (71.6%, n = 156) lived in Guangzhou city where the hospital was situated. Still, there were quite a number of families that lived out of town in the remote villages (12.4%, n = 27) or in other cities or little towns (9.2%, n = 20) within or outside the province of Guangdong. The ethnic background of the families indicated that half of them (45.9%, n = 100) were new to their county or local communities. The reported period of stay in the area of residence also revealed a recent migration trend within the past ten years. Only about 27% (n = 59) of families resided in their local community for more than ten years. Many of the other families (30.3%, n = 66) lived in their current areas for less than five years.

Table 4.2 Summary of Demographic Variables

Characteristics of parents and families of hospitalized children

(N= 218*)

Demographic Variables	N*	%	Mean (SD)	Range
Mother participants	116	53.2		
Father participants	58	26.6		
Parents (joint participation with discussions)	44	20.6		
Mothers’ age	209	95.9	28.9 (4.78)	18-41
18-25	54	24.8		
26-30	81	37.2		
31-35	49	22.5		
36-40	24	11.0		
41-45	1	0.5		
Fathers’ age	203	93.1	31.4 (5.47)	19-49
18-25	27	12.4		
26-30	69	31.7		
31-35	57	26.1		
36-40	42	19.3		
41-45	4	1.8		
46-50	4	1.8		
Mothers’ Occupation	197	90.4		
Housewife	68	31.2		
Business	24	11		
Worker	29	13.3		
Officer, government servant	7	3.2		
Farmer	28	12.8		
Professional	13	6		
Unemployment	17	7.8		
Others				
Fathers’ Occupation	192	88.1		
Driver	27	12.4		
Business	47	21.6		
Worker	41	18.8		
Officer, government servant	12	5.5		
Farmer	31	14.2		
Professional	15	6.9		
Unemployment	6	2.8		
Others	13	6.0		

Table 4.2 Summary of Demographic Variables……. (continue)

Demographic Variables	N*	%	Mean (SD)	Range
Mothers' education	169	77.5		
Primary	15	6.9		
Lower secondary	70	32.1		
Higher secondary	43	19.7		
Tertiary	41	18.8		
Fathers' education	171	78.4		
Primary	10	4.6		
Lower secondary	65	29.8		
Higher secondary	49	22.5		
Tertiary	47	21.6		
Monthly Family income (¥)	202	92.7		
No income	1	0.5		
Below1000	28	12.8		
1001-2000	61	28.0		
2001-4000	50	22.9		
4001-6000	23	10.6		
Above 6000	39	17.9		
Household structure				
Parents and child (children)	150	68.8		
Live with grandparent(s)	57	26.1		
Live with other relatives	6	2.8		
Live with other members	5	2.3		
Ethnic				
Cantonese	118	54.1		
Others Provinces	100	45.9		
Where do the family live?	203	93.1		
Guangzhou	156	71.6		
Villages	27	12.4		
Other cities / towns	20	9.2		
Period of residence in the living area	164	75.2		
Life long residence / more than 10 years	59	27.1		
Migrated more than 5 years	39	17.9		
Migrated less than 5 years	66	30.3		

* Ns - vary because of missing values on some variables.

Thirty-six items are used to compute overall scores on the hospitalization impact (HI) scale, such that higher HI scale scores represent an adverse impact (Appendix 3.6 & 3.7). The other 15 items (item 37 to 51) are worded so that higher item scores indicate effective coping, consequently, they needed to be reverse-scaled before all the 51 items are summed to create an overall HIS scale score.

In the mean scores of the impact scale, higher scores implied more adverse impact and lower scores implied less adverse impact. In the coping sub-scale, higher scores indicated more effective coping as perceived and vice versa.

Table 4.3 shows the overall mean score and the percentage of impact distribution of the 36 impact items. When great to extreme impacts were put together to measure the severity of an impact on the families, the most frequently reported impacts were item ten, ‘feeling hurt when my child being suffered in the hospital’ (75.7%), item 11 ‘worry of disease progress’ (68.3%), item 28 ‘more expanses’ (67.3%), item five ‘become emotional’ (62.2 %), item one ‘tired’ (54.6%), and ‘problems with sleep’, which was item three (52.3%). The least reported frequency for extreme impact were ‘seldom have chance to discuss problems we encountered’ (3.2%) and ‘relationship is affected because of the bad mood’ (4.6%).

When ‘not applicable’ and ‘no impact’ items were put together to explore the less significant issues or impact, ‘cannot freely adopt alternative therapies’ appeared causing least significant impact to families as ‘not applicable’ scored 20.2% and 26.6% reported to cause no impact. The reports of no impact were high in a few other items: ‘relationship is affected because of the bad mood’ (33.9%), ‘seldom have chance to talk about problems we encountered’ (25.7%), ‘blame each other for improper care’ (25.7%) and cannot adapt to the ward routines (25.2%).

Table 4.3 Descriptive statistics of the Hospitalization Impact subscale

While my child is hospitalized, we / our		Mean score	SD	N	Percentage of responses					
					No	little	Some	Great	Ex-treme	NA
1.	feel tired.	2.58	1.07	213	3.7	11.9	27.5	33.5	21.1	1.4
2.	health is adversely affected.	1.71	1.28	214	22	22.9	25.2	17.9	10.1	1.4
3.	cannot sleep well.	2.46	1.27	213	8.3	15.6	21.6	27.1	25.2	2.3
4.	lost appetite.	2.10	1.28	207	12.8	16.5	31.5	17	17	2.8
5.	emotions fluctuate according to our child's medical condition.	2.86	1.15	210	4.1	9.6	17.4	29.4	35.8	0.9
6.	become irritable.	1.99	1.25	207	12.8	22.9	24.8	21.1	13.3	3.7
7.	cannot concentrate at work.	2.43	1.18	208	5.5	16.5	26.1	26.1	21.1	2.8
8.	feel nervous.	2.58	1.21	206	5.0	14.7	22.5	24.8	27.5	2.3
9.	feel guilty for inadequate care leading to hospitalization.	2.36	1.35	207	11.5	13.8	25.2	17.9	26.6	4.1
10.	feel hurt because my child is suffering in hospital.	3.12	1.08	217	3.2	6.4	14.2	27.5	48.2	0
11.	worry about disease progress (causes, treatment, sequela).	2.96	1.14	213	4.6	6.4	18.3	27.5	40.8	1.4
12.	are more tolerant of our child's misbehavior.	1.95	1.32	194	16.5	17	22.9	19.7	12.8	7.3
13.	do not know how to deal with our child's emotions.	1.99	1.14	196	7.8	23.9	30.7	16.5	11.0	8.3
14.	cannot rely on others to take care of my child.	2.29	1.30	199	9.6	17.0	23.4	20.2	21.1	8.3
15.	consider our child's condition is serious.	2.19	1.28	196	8.7	22.0	21.1	19.7	18.3	8.3
16.	want to care for my child but feel inadequate to do so.	2.21	1.37	191	11.5	18.8	18.8	17.0	21.6	10.1
17.	daily life (work, activities and recreation) need to be changed.	2.40	1.31	203	6.4	22.5	18.8	18.3	27.1	5.0
18.	have to give up a lot of things.	2.48	1.28	206	6.9	15.6	27.1	15.6	29.4	4.1
19.	do not have much time left for other family members.	2.00	1.40	198	15.6	22.9	17.4	15.6	19.3	7.3
20.	cannot complete the household chores.	1.88	1.41	200	20.6	19.3	19.3	16.1	16.5	7.3
21.	blame each other for improper care.	1.31	1.19	186	25.7	27.5	18.3	7.8	6.0	13.8
22.	seldom have a chance to talk about problems we encounter.	1.32	1.15	180	25.7	21.1	22.9	9.6	3.2	15.1
23.	relationship is affected because of the bad mood.	1.20	1.21	198	33.9	25.2	16.1	11.0	4.6	8.7
24.	see family and friends less.	1.69	1.31	207	22.0	23.4	22.5	16.5	10.6	5.0

Table 4.3 Descriptive statistics of the Hospitalization Impact subscale (Continue)

While my child is hospitalized, we / our		Mean score	SD	N	Percentage of responses					
					No	little	Some	Great	Ex-treme	NA
25.	are unable to take a stroll or travel out of the town.	2.11	1.43	187	15.1	16.5	19.3	13.8	21.1	11.9
26.	become very busy and have no free time.	2.42	1.20	209	3.7	22.5	23.4	22.5	23.9	4.1
27.	lose time from work with reduced income.	2.20	1.47	206	17.4	16.1	16.5	18.8	25.7	5.0
28.	have more expenses (e.g., travel and medical expenses).	2.99	1.16	210	2.3	11.9	15.1	22.5	44.5	2.3
29.	have extra burdens (daily care, food preparation, teaching).	2.32	1.33	207	10.1	18.8	20.6	21.6	23.9	4.6
30.	burden can hardly be understood by others.	2.05	1.34	192	14.2	18.3	19.7	20.6	15.1	11.0
31.	cannot freely adopt alternative therapies (e.g., Chinese medicine).	1.46	1.35	169	26.6	14.7	18.3	10.1	7.8	20.2
32.	have feelings that hospital staff are too busy to be bothered.	1.72	1.24	199	17.9	22.5	28.4	12.4	10.1	7.3
33.	cannot adapt to the hospital environment (e.g., noises, lighting, or hygiene, etc).	2.06	1.38	202	16.1	17.0	24.8	14.7	20.2	6.0
34.	do not know details of our child's condition.	1.97	1.28	204	14.2	21.1	25.7	18.3	14.2	6.0
35.	worry about malpractice.	1.77	1.36	204	21.6	22.0	18.8	18.8	12.8	5.0
36.	cannot adapt to the ward routines (e.g. visiting, meal time, night observations).	1.44	1.22	196	25.2	22.9	25.2	9.6	6.9	6.4
	Overall mean	2.13	1.27							

Table 4.4 shows the overall mean score and the percentage of reported effectiveness of the 15 coping items. The most frequently reported ‘great’ to ‘extreme’ effective strategies were ‘stay close to the child’ (74.7%), ‘hope things will get better’ (64.7%), ‘keep asking doctors and nurses, and to monitor the child closely by ourselves’ (63.3%), ‘support each other and share responsibilities’ (57.8), ‘consider hospitalization can be more relieved to us’ (52.8%), and ‘prepare food for our child’ (51%).

Items that were more frequently reported to have ‘no effect’ included ‘treat our child as was usual with her/him’ (15.6%), ‘try to relax and control emotion’ (12.4%) and ‘seek and accept help from relatives and friends’ (11.5%). Items that were reported as ‘not applicable’ were ‘do not expect too much and plan for too long’ (27.1%), ‘seek and accept help from relatives and friends’ (22.9%), and 21.6% for both items ‘encourage family members including the sick child to express their inmost feelings’ and ‘ask relatives and friends about hospitalization experiences.’

Table 4.4 Descriptive Statistics of the Hospitalization Coping Subscale

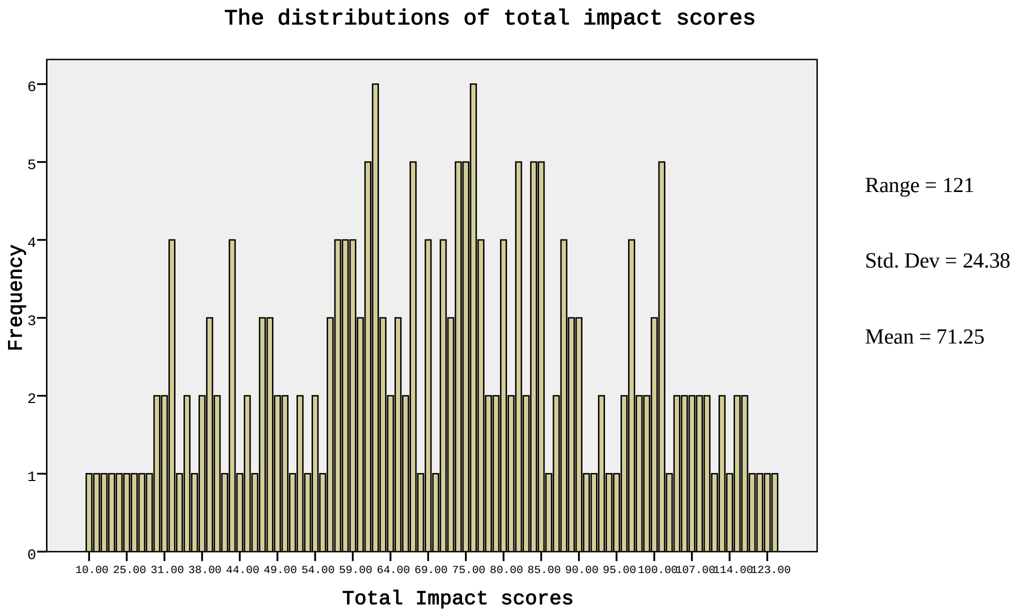
In order to cope with the impact of hospitalization, I (we):		Mean score	SD	N	Percentage of responses					
					No	Little	Some	Great	Ex-treme	NA
1.	try to relax and control emotion.	1.55	0.98	192	12.4	30.7	32.6	9.2	3.2	11.0
2.	support each other and share responsibilities.	2.69	0.96	211	1.4	9.2	28.4	36.7	21.1	2.8
3.	stay close to our child.	3.01	1.06	207	4.6	4.6	11.0	39.4	35.3	4.6
4.	prepare food for our child.	2.62	1.03	190	5.0	8.3	22.9	29.4	21.6	12.4
5.	keep asking doctors and nurses questions, and monitor the child closely ourselves.	2.8	1.10	208	5.5	4.6	22.0	34.9	28.4	4.6
6.	consider hospitalization can be more of a relief to us.	2.51	1.27	205	8.3	13.8	19.3	27.1	25.7	5.0
7.	make use of what we see in the hospital as learning experiences.	2.19	1.14	175	6.9	12.8	30.3	18.3	11.9	17.4
8.	treat our child as usual.	1.95	1.26	189	15.6	15.1	22.9	23.9	9.2	10.6
9.	encourage family members, including the sick child, to express their inmost feelings.	2.37	1.22	167	6.4	12.8	18.3	23.9	15.1	21.6
10.	do not expect too much and do not plan for too long.	1.71	1.06	149	9.6	18.8	24.8	11.9	3.2	27.1
11.	seek and accept help from relatives and friends.	1.96	1.30	161	11.5	17.4	19.7	13.3	11.9	22.9
12.	hope things will get better.	2.82	1.22	206	6.0	10.1	13.8	30.3	34.4	4.6
13.	cut down working hours to participate more childcare.	2.50	1.22	194	7.3	10.6	23.9	24.8	22.5	9.2
14.	ask relatives and friends about hospitalization experiences.	2.27	1.11	168	3.7	17.0	22.5	22.5	11.5	21.6
15.	try our best to endure and be co-operative.	2.51	1.06	194	2.3	14.7	24.3	30.7	17.0	8.7
	Overall mean score	2.36	1.13							

Norms

Category sub-dimensions were obtained by summing scores of all items within a category. Summing all category scores within a sub-scale provided a total score for the hospitalization impact sub-scale and coping sub-scale respectively. To obtain an overall total score of the Hospitalization Impact Scale, the 15 coping items needed to be reversely scaled before summing up the other 36 impact sub-scores.

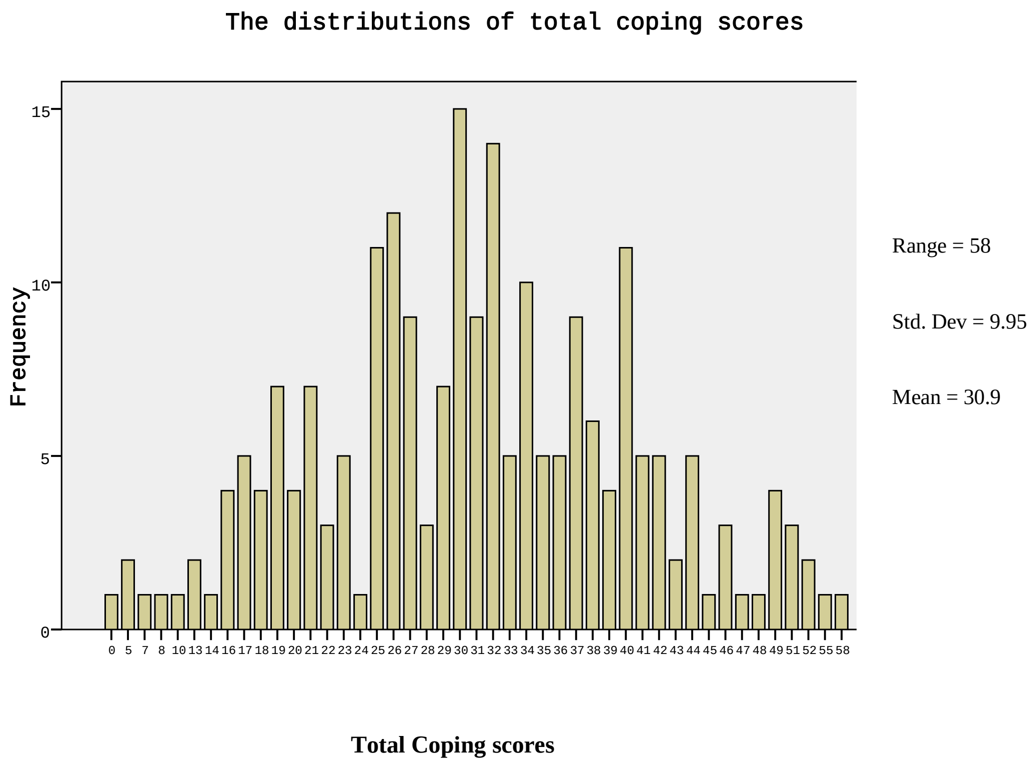
The distributions of total scores on the impact and coping sub-scales are shown in Figure 4.1 and 4.2 respectively. In both cases, the shape is very close to normal. The mean score was 71.25 (SD = 24.38) for impact index and 30.9 (SD = 9.95) for coping sub-scale. Ranges were 10 to 131 for impact and 0 to 58 for coping.

Figure 4.1 The Distributions of Total Impact Scores



Family Impact Scale scores ranged from 10 to 131, indicating that the measure was sensitive to variations in family impact. Floor effects were absent with only 5% of subjects having a total score less than 30 and there were no ceiling effects, that is, subjects with maximum scores.

Figure 4.2 The Distributions of Total Coping Scores

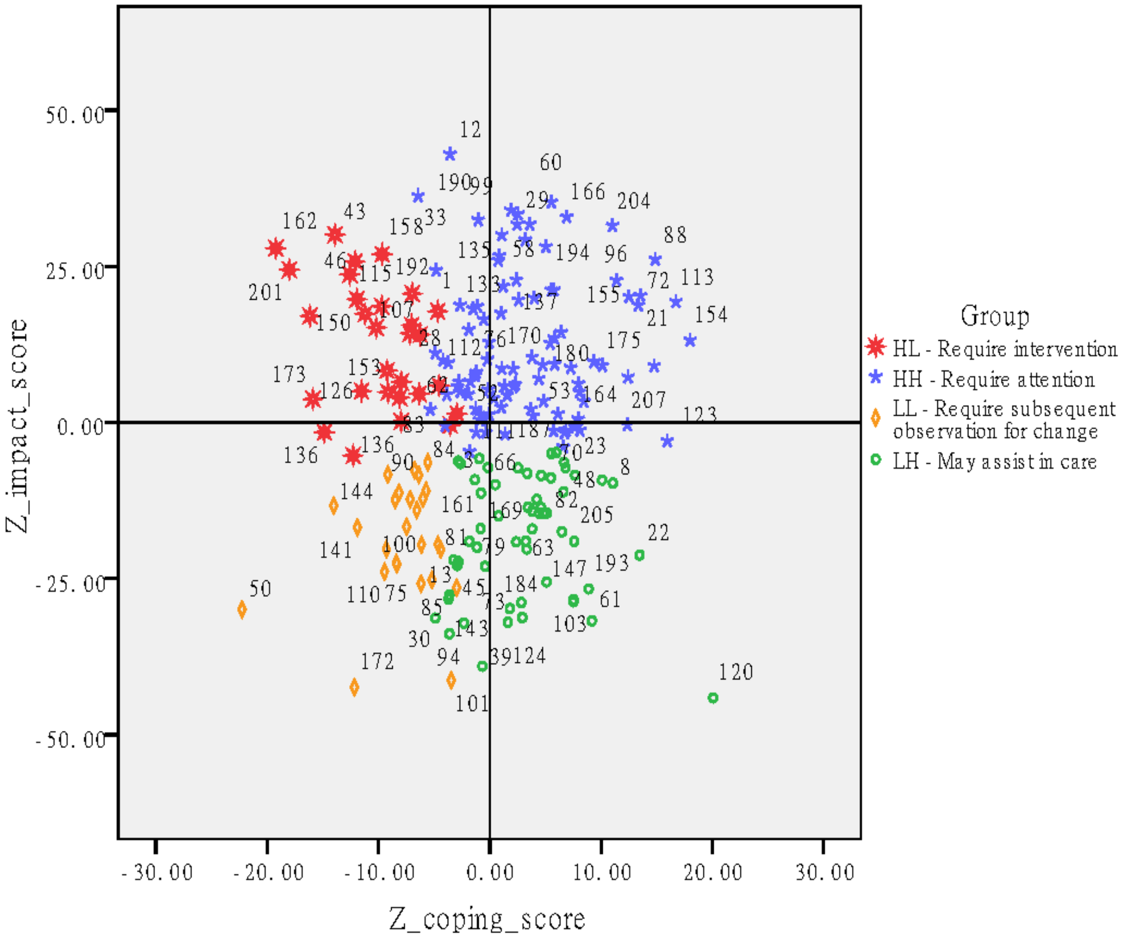


The coping sub-scale scores ranged from 0 to 58, indicating that the measure was sensitive to variations of individual family differences. Floor effects were minimal with only 0.5% of subjects having a score of zero and there were no ceiling effects, that is, subjects with maximum scores.

Preliminary Analysis of the Pattern of the Impact and Coping Scores

In order to observe the pattern of impact and coping scores to address the possibility of various outcomes of family responses, a scatter plot was used in this study to look at the pattern of the data for the impact and coping sub-scores. When applying standardized scores for the total impact and coping scales to Z scores, the findings showed that there were four major groups which coincided nicely with the distribution pattern of the groups using the total scores ranging from “high impact and low coping”, “high impact and high coping”, “Low impact and low coping” to “low impact and low coping”. For management purposes, this graph will provide a direction to identify the distribution of at risk families (groups) for recommended interventions (Figure 4.3).

Figure 4.3 Scatter Plot of Impact and Coping Scores with Recommended Intervention

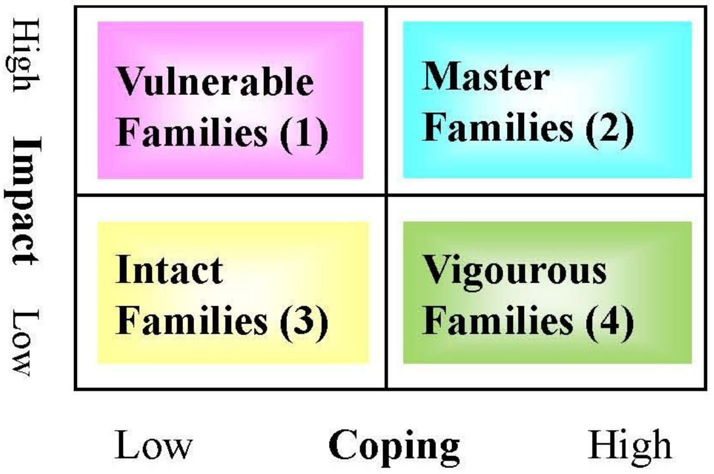


The above model of family types is achieved by assigning two levels (high and low) to the impact dimension with the total impact Z scores and to the coping dimension with the total coping Z scores. The high and low cut off points for each dimension were set at two.

The impact dimension was defined as the parental perception of the degree of impact on the family during the child's hospitalization. The families scoring high on this dimension may be described as families being most adversely affected by the impact of hospitalization. The coping dimension is defined as the parental perception of effectiveness of their own coping strategies that tried to mediate the adverse effect of hospitalization. The families scoring high on this dimension may be described as families being most effective with their coping strategies that helped mediate the adverse impact of hospitalization.

Figure 4.4 describes the distribution pattern of the proposed typology of families and further discussions will be presented in the next chapter.

FIGURE 4.4 Typology of Families



Factor Analysis

Based on previous discussions about factor analysis and related experiences gained in the pilot study, the main study also used factor analysis to discover the factor structure of HICS and to explain the relationship between variables that were measured. By reducing a data set from a group of interrelated variables into a smaller set of factors, factor analysis helped explained the maximum amount of common variance in a correlation matrix. Principal component analysis was used to establish which linear components exist within the data and how a particular variable might contribute to that component.

The main study examined methods using eigenvalues and then confirming with a scree plot analysis. Only those factors with relatively large eigenvalues were retained. This study followed Kaiser's recommendation with eigenvalues greater than one for the analysis (Kaiser, 1960). Typically, there were six factors with quite high eigenvalues, and all other factors with low eigenvalues. The scree plot advocated by Cattell (1966) was used to plot a graph of each eigenvalue (*Y*-axis) against the factor with which it was associated (*X*-axis). The resulting characteristic shaped with a sharp descent in the curve followed by a tailing off, as presented in Figure 4.5. According to Cattell (1966), the cut-off point for selecting factors was set at the point of inflexion of this curve, which was the sixth factor (Figure 4.5). Steven (1992) further confirmed that, with a sample of more than 200 participants as in the case of this main study, the scree plot provides a fairly reliable criterion for factor selection.

Factor analysis of the items on the Hospitalization Impact sub-scale using Principal Components Analyses (PCA) with Varimax rotation (Kaiser 1958) was performed as an exploratory statistical procedure to examine the underlining dimensions of impact and coping strategies for both sub-scales. Missing values replaced with mean was used to form the correlation matrix for analysis.

Factor Structure of the Hospitalization Impact Sub-Scale

Principal components analysis followed by varimax rotation yielded six factors accounting for 63.5% of the variance (Table 4.5). Examination of the component number scree plot also suggested extraction of six factors (Figure 4.5). KMO measures of sampling adequacy = 0·78; Bartlett's test of sphericity ($p < 0{\cdot}001$).

Figure 4.5 Scree Plot of Component Number for the Impact Sub-Scale

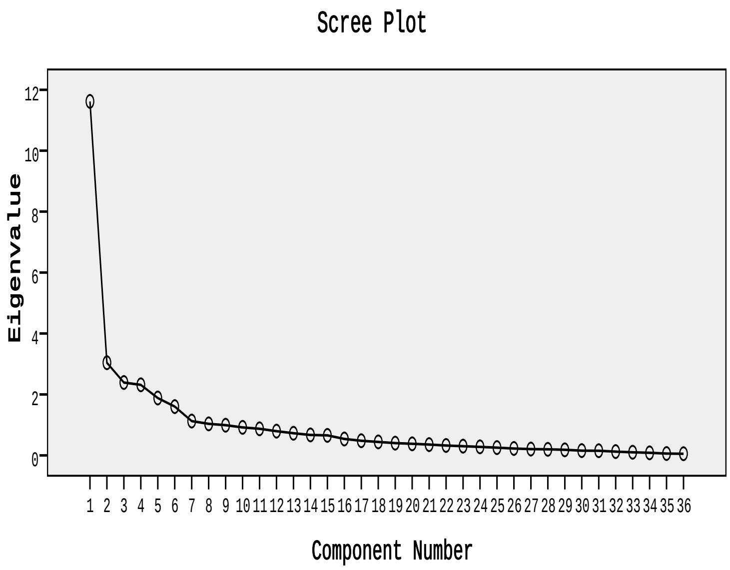


Table 4.5 The Impact Sub-Scale has Six Dimensions Developed Through Factor Analysis:

	Factors	**% of variance**	**Cumulative %**
1.	Psychological impact	13.997	13.997
2.	Social impact	13.371	27.368
3.	Physical impact	10.743	38.111
4.	Health Service needs impact	9.311	47.422
5.	Family impact	9.202	56.623
6.	Burden impact	6.860	63.483

Factor one, accounting for 14% of the variance, had nine items with factor loadings > 0.5 (0.5 – 0.76) (Table 4.5 & Table 4.7). Table 4.6 presents the impact sub score of the rotated matrix. This factor seems to reflect parental psychological and emotional responses towards hospitalization of the sick child and associated with the child's health condition. This corresponds closely to the factor structure done in the exploratory factor analysis of the pilot study. Factor two, accounting for 13.4% of the variance, was comprised of another eight items with factor loadings ranging from 0.37 to 0.80. Factor two is a collection of responses reflecting a dimension of socially related issues concerning roles and activities that may also affect families. Factor three, accounting for 10.8% of the variance, had five items and factor loadings ranged from 0.5 to 0.77. Factor three seems to reflect physical impact family experienced from hospitalization of the child. Factor four, accounting for 9.3% of the variance, had six items and factor loadings ranged from 0.44 to 0.76. Factors four seems to reflect a dimension related to the families' experiences of utilization of health services. Factor five, accounting for 9.2% of the variance, had four items with factor loadings ranging from 0.59 to 0.80. The items are reflecting the family function in terms of communications and relationship within the family system. Factor six, accounting for 6.9% of the variance, had three items with factor loadings ranging from 0.55 to 0.71. This last factor seems to reflect the family burden and financial impact during hospitalization of the child.

Five dimensions were proposed as relevant through qualitative interviews. ‘Burden’ was originally classified as a sub-dimension under the ‘social dimension’ and was later captured as a distinct factor through the factor analysis in both pilot and main study. Phase two study has confirmed the structure of the six factors from the pilot study in the impact sub-scale: physiological, social, physical, health service needs, family and burden impacts. Items were united and summed up to compute factor scores (Floyd & Widaman, 1995) and Cronbach’s alpha coefficients of these factor scores ranged from 0.77 to 0.86 (Table 4.7). Factor intercorrelations were low, with most < 0.3 (see Table 4.8).

Table 4.6 Impact Subscale Rotated Component Matrix(a)

	Component					
	1	2	3	4	5	6
Psychological impact associated with child’s conditions						
feels hurt because my child is suffering in hospital	**.755**					
worry about disease progress	**.723**					
feel nervous	**.697**					
want to care but feel inadequate	**.642**				.433	
emotion fluctuate according to child’s condition	**.586**		.381			
cannot concentrate at work	**.575**		.316			.312
consider our child's condition is serious	**.560**				.460	
daily life need to be changed	**.511**	.494				
feels guilty for inadequate care leading to hospitalization	**.502**			.420		
do not know how to deal with our child's emotions	**.498**		-.330			
Social impact related to role and activities						
unable to take a stroll or travel		**.796**				
become very busy and no free time		**.757**				
see family and friends less		**.742**				
cannot complete the household chores.		**.715**	.338			
not much time left for other family members	.306	**.658**	.347			
have to give up a lot of things	.450	**.557**				
cannot rely on others to care for the child	.381	**.433**				
more tolerant of our child's misbehavior		**.366**	.339	.302		
Physical impact						
lost appetite			**.770**			
health is adversely affected			**.766**			
feel tired		.313	**.751**			

Table 4.6 Impact Subscale Rotated Component Matrix(a) Continued

cannot sleep well			**.706**			.305
irritable	.316	.386	**.490**			
Health care impact related to hospitalization experiences						
do not know details of our child’s condition				**.761**		
worry about malpractice				**.755**		
cannot adapt to the hospital environment				**.698**		
cannot freely adopt alternative therapies (e.g., Chinese medicine, traditional treatment).				**.640**	.440	
have feelings that hospital staff are too busy to be bothered.		.411		**.626**		
cannot adapt to the ward routines				**.443**		.376
Family Impact related to family functions						
seldom have a chance to talk about problems					**.796**	
blame each other for improper care					**.761**	
relationship is affected because of the bad mood.					**.715**	
burden can hardly be understood by others.					**.589**	.464
Financial Impact						
have more expanses (medical, traveling)						**.712**
lose time from work with reduced income						**.655**
have extra burdens in daily care	.398	.378				**.545**

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a Rotation converged in 7 iterations.

Table 4.7 Factor loading, validity and reliability test on the impact subscale (*n* = 218)

Items		Factor loading	Item – total correlation	Cronbach's Alpha
Psychological impact				
10	feel hurt because my child is suffering in hospital.	0.76	0.477	0.863
11	worry about disease progress (causes, treatment, sequela).	0.72	0.448	
8	feel nervous.	0.70	0.495	
16	want to care for my child but feel inadequate to do so.	0.64	0.563	
5	emotions fluctuate according to our child’s medical condition.	0.59	0.587	
7	cannot concentrate at work.	0.58	0.594	
15	consider our child's condition is serious.	0.56	0.562	
9	feel guilty for inadequate care leading to hospitalization.	0.50	0.550	
13	do not know how to deal with our child’s emotions.	0.50	0.337	
Social impact				
25	unable to take a stroll or travel out of the town.	0.80	0.510	0.853
26	too busy and have no free time.	0.76	0.663	
24	see family and friends less.	0.74	0.599	
20	cannot complete the household chores.	0.72	0.605	
19	do not have much time left for other family members.	0.66	0.633	
18	have to give up a lot of things.	0.56	0.652	
17	daily life need to be changed	0.49	0.625	
14	cannot rely on others to take care of my child.	0.43	0.423	
12	are more tolerant of our child’s misbehavior.	0.37	0.399	
Physical impact				
4	lost appetite.	0.77	0.575	0.845
2	health is adversely affected.	0.77	0.553	
1	feel tired.	0.75	0.599	
3	cannot sleep well	0.70	0.560	
6	become irritable	0.49	0.666	
Health services utilization impact				
34	do not know details of our child’s condition.	0.76	0.366	0.781
35	worry about malpractice.	0.76	0.310	

Table 4.7 Factor loading, validity and reliability test on the impact subscale (*continued*)

Items		**Factor loading**	**Item – total correlation**	**Cronbach's Alpha**
33	cannot adapt to the hospital environment	0.70	0.335	
31	cannot freely adopt alternative therapies (e.g., Chinese medicine).	0.64	0.570	
32	have feelings that hospital staff are too busy to be bothered.	0.63	0.505	
36	cannot adapt the hospital routines	0.44	0.326	
Family impact				
22	seldom have a chance to talk about problems we encounter	0.80	0.444	0.783
21	blame each other for improper care	0.76	0.522	
23	relationship is affected because of the bad mood.	0.72	0.446	
30	burden can hardly be understood by others.	0.59	0.560	
Extra burden				
28	have more expenses (e.g., travel and medical expenses).	0.71	0.559	0.772
27	lose time from work with reduced income	0.66	0.523	
29	have extra burdens (daily care, food preparation, teaching).	0.55	0.728	
			Overall	0.937

All presented factor scores are considered to be important according to Steve (1992, p382) with his recommendation of greater than 0.364 for a sample size of 200.

Table 4.8 Impact Subscale: Factors Inter-Correlations

Impact factor	**1**	**2**	**3**	**4**	**5**	**6**
Psychological	1.000					
Social	.136	1.000				
physical	.200	.165	1.000			
Health service needs	-.213	-.136	-.114	1.000		
Family	-.315	-.275	-.202	.315	1.000	
Burden	-.071	-.148	-.148	.132	.120	1.000
P < 0.001						

Factor Structure of the Hospitalization Coping Subscale

Principal components analysis followed by varimax rotation yielded four factors accounting for 58.5% of the variance. Examination of the factor scree plot also suggested extraction of four factors (Figure 4.6). KMO measures of sampling adequacy = 0·78; Bartlett's test of sphericity (*p* < 0·001).

Figure 4.6 Scree Plot of Component Number for the Coping SubScale

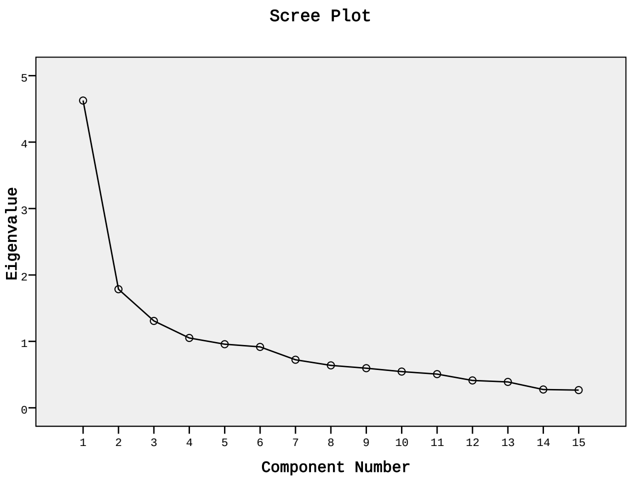


Table 4.9 Four Dimensions of the Coping Subscale were Developed Through Factor Analysis:

	Factors	% of variance	Cumulative %
1.	Effort to maintain positive and active parental care	19.49	19.49
2.	Attempts to readjust mental stability	15.59	35.05
3.	Utilize internal and external resources	13.40	48.45
4.	Maximize quality and quantity of child care	10.02	58.47

Table 4.10 presents the rotated matrix of the coping subscale. Factor one, accounting for 19.49% of the variance (Table 4.9), had five items, and factor loadings ranged from 0.58 to 0.76. (Table 4.11). This factor seems to reflect parental effort in maintaining positive and active parental care of the sick child. Factor two, accounting for 15.59% of the variance, was comprised of another four items and factor loadings ranged from 0.49 to 0.83. Factor two is a collection of attempts designed to readjust mental stability. Factor three, accounting for 13.40% of the variance, had four items with factor loadings ranging from 0.5 to 0.77. Factor three seems to reflect parents' attempt to mobilize internal and external resources for coping. This included asking and accepting help from others and mobilizing internal and external

resources through mutual support and attitudinal changes. Factor four, accounting for 10.02% of the variance, had two items, and factor loadings ranged from 0.75 to 0.78. Factor four seems to reflect strategies to maximize quality and quantity of childcare by collecting information of hospitalization and reducing work for more childcare.

Table 4.10 Coping Scale Rotated Component Matrix(a)

	Component			
	1	2	3	4
Effort to maintain positive and active parental care				
Prepare food for my child	**.756**	.214	.047	.164
Stay close to my child	**.713**	.152	-.173	.159
Encourage talk	**.666**	.078	.187	.209
Keep asking health care workers & observe my child	**.632**	.391	.062	.129
Maintain hope for improvement	**.579**	.045	.238	.087
Attempts to readjust mental stability				
Do not plan for too long	-.020	**.828**	-.024	-.025
Reckon hospital is safer for my child	.289	**.669**	.257	-.017
Try to relax	.211	**.581**	.081	.133
Treat my child as normal	.310	**.490**	.121	.131
Mobilizing internal and external resources				
Ask & accept help	-.055	.500	**.490**	.272
To endure and cooperate	.048	.047	**.765**	.261
Use hospitalization experiences as learning opportunities	.078	.358	**.746**	-.189
Mutual support	.526	-.024	**.634**	-.065
Maximize quality and quantity of child care				
Reduce work for more childcare	.166	.113	.106	**.780**
Ask friends about hospital	.346	.061	-.008	**.746**

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a Rotation converged in 7 iterations.

As if the Impact sub-scale, items of the Coping sub-scale were united and summed to compute factor scores (Floyd & Widaman, 1995). Cronbach’s alpha coefficients of theses Coping factor scores ranged from 0.62 to 0.71 (Table 4.11). Factor inter-correlations were low, with majority < 0.3 (see Table 4.12).

Table 4.11 Factor loading, validity and reliability test on the Coping subscale (*n* = 218)

Items		Factor loading	Item – total correlation	Cronbach's Alpha
Effort to maintain positive and active parental care				
40	Prepare food for my child	0.756	0.588	0.714
39	Stay close to our child.	0.713	0.433	
45	Encourage to express their inmost feelings	0.666	0.530	
41	Keep asking doctors and nurses questions, and monitor the child closely ourselves.	0.632	0.607	
48	Hope things will get better	0.579	0.439	
Attempts to readjust mental stability				
46	Do not plan for too long	0.828	0.331	0.628
42	Consider hospitalization can be more of a relief to us.	0.669	0.563	
37	Try to relax and control emotion.	0.581	0.444	
44	Treat our child as usual.	0.490	0.467	
Attempts to mobilize internal and external resources				
47	Ask & accept help	0.490	0.432	0.650
51	try our best to endure and be co-operative.	0.765	0.371	
43	make use of what we see in the hospital as learning experiences.	0.746	0.402	
38	support each other and share responsibilities.	0.634	0.482	
Attempts to maximize quality and quantity of child care				
49	cut down working hours to participate more childcare.	0.780	0.375	0.620
50	ask relatives and friends about hospitalization experiences.	0.746	0.406	
			Overall	0.835

All presented factor scores are considered to be important according to Steve (1992, p382) with his recommendation of greater than 0.364 for a sample size of 200.

Table 4.12 Coping Factors: Inter-Correlations

Coping factor	1	2	3	**4**
Effort to maintain positive and active parental care	1.000			
Attempts to readjust mental stability	.185	1.000		
Utilize internal and external resources	-.263	-.216	1.000	
Maximize quality and quantity of child care	.299	.093	-.184	1.000
$P < 0.001$				

Internal Consistency and Reliability

Cronbach’s alpha was used to test the internal consistency of each sub-set of the questionnaire and to examine the reliability of the instrument (Cronbach, 1951). It has been recommended that Cronbach’s co-efficient alpha should be at least 0.6 for a self-reported instrument to be reliable (Nunnally & Bernstein, 1994; Cronbach, 1951). This demand was fulfilled in both findings of impact and coping sub-scales. In both cases, it had excellent internal consistency and reliability with a Cronbach’s alpha of 0.94 for the impact sub-scale and 0.84 for the coping sub-scale (Table 4.7 & 4.11). When the coping sub-scale items were recoded, the overall internal consistency and reliability of the Hospitalization Impact and Coping Scale was 0.91.

All items appeared to be worthy of retention: there was no increase in alpha from deleting any item reviewed from the item-total statistics. All items correlated with the total scale to a good degree (Impact subscale with lowest r = 0.31, majority at around 0.5 to 0.7; Coping subscale with lowest r = 0.331, majority at around 0.45 to 0.6).

Correlations between HICS subscales indicated a moderate to good correlation ranging from 0.772 to 0.863 for the Impact sub-scale and 0.620 to 0.714 for the Coping sub-scale (Table 4.7 & 4.11 present the correlations among sub-scales.).

HICS Validity

The previously discussed factor analytical approach has informed us about the construct validity of the HICS. Other construct validity tests, using convergent and discriminant validity approaches, were also used and reported in this section.

Convergent validity assessment was based on expected significant correlations between the Impact subscale of HICS and the Parental Stressor Scale: Infant hospitalization (PSS: IH). According to Cohen (1988), the result of this test obtained at 0.521 (p = 0.000) is considered to achieve significantly high correlations. The Cronbach's alphas of the previous published Parental Stressor Scale: Infant hospitalization (PSS: IH) used in Chinese hospitalized children' parents was 0.91 & 0.92 respectively for mothers and fathers (Lee et al., 2005; Appendix 12).

Convergent validity assessment based on correlation between the Coping sub-scale (a higher score indicates better family coping) and Family Assessment Device (FAD) General Functioning sub-scale (Appendix 10) with its higher score indicating unhealthy family functioning. The result was -0.301 (p = 0.000) at a borderline moderate level of correlation according to Cohen (1988). The Cronbach's alphas of the previously published FAD (general functioning subscale) used in Chinese hospitalized children's family was 0.74 and for non-clinical Chinese family was 0.45 (Chen et al. 2003).

Discriminant validity assessment was performed using correlation tests between the Impact and Coping sub-scales. These two subscales are theoretically distinct constructs and the correlation assessment shows that these two sub-scales do not correlate, but did not reach the level of significance (r = 0.03, p = 0.62).

Confirmatory Factor Analysis (CFA)

Confirmatory factor analysis (CFA) was used to cross-validate the six-factor impact model and four-factor coping model derived from Exploratory Factor Analysis (EFA) of the HICS. For both impact and coping CFA models, all standardized regression weights (regression paths) and correlations were found to be significant ($p < 0.001$).

Several CFA fit indices (RMSEA = 0.06, CFI = 0.839, and TLI = 0.828) indicated moderately good fit for a model that represents the impact subscale has six moderately correlated factors. These indices provide confirmatory evidence for the factor structure. Figure 4.7 provides the loadings and path coefficients for the impact sub-scale model.

The characteristics of the impact model are (a) Impact sub-scale had six underlying factors (physiological, social, physical, health service needs, family and burden impacts); (b) six factors were inter-correlated; (c) each variable had only one factor loading; and (d) errors of measurement of each observed variable (e1 – e36) were independent of each other and of the factors.

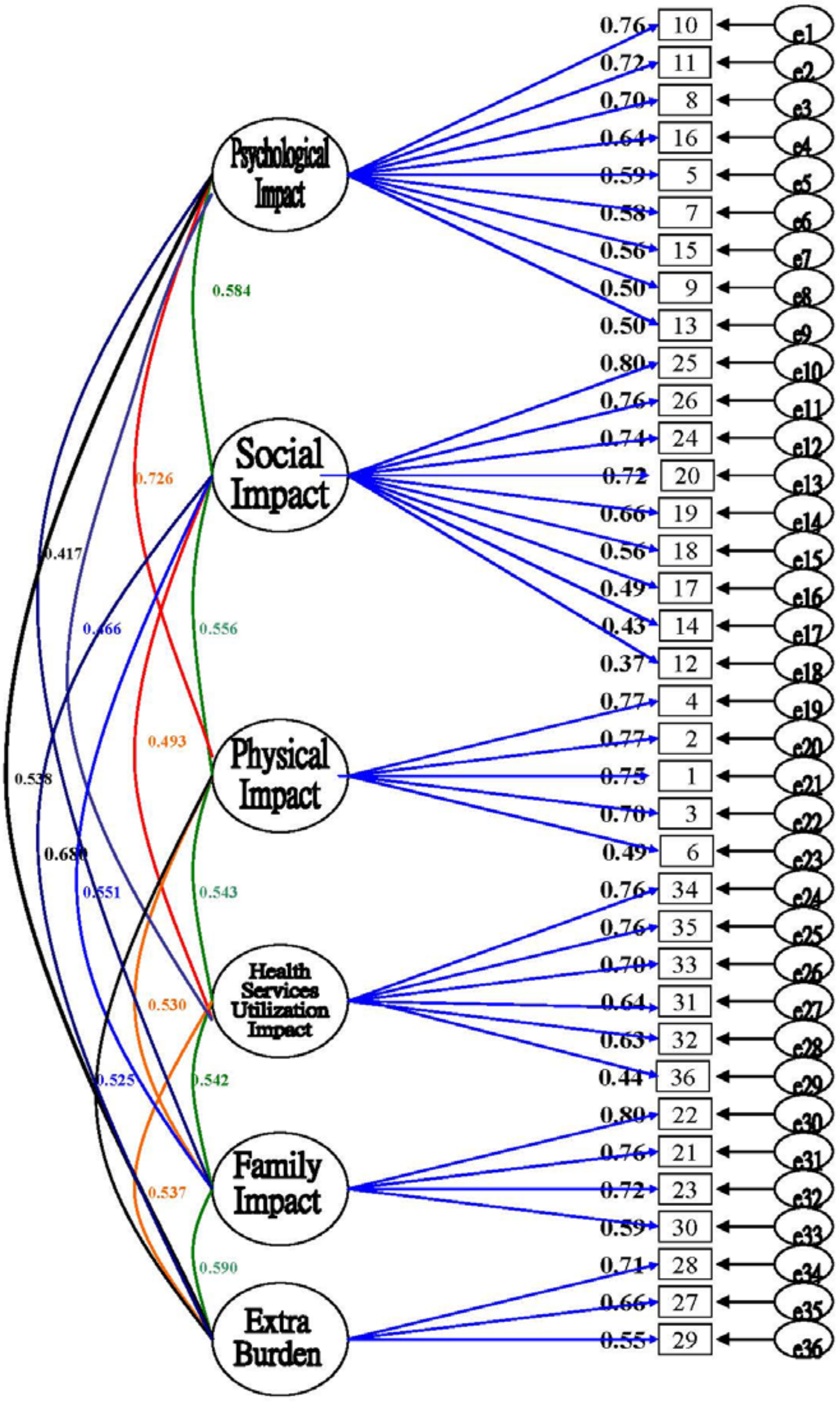


Figure 4.7 **Impact subscale model**

The above figure shows confirmatory factor analysis results for the six-factor model of hospitalisation impact. Standardized regression weights are shown on the straight arrows, and factor inter-correlations are shown on the curved arrows. Numbers in rectangles indicate original numbers of Hospitalisation Impact and Coping Scale (HICS) items, and e1 – e36 in the circles on right represent error terms. See Appendix 3.6 & Table 4.7 for the original items and impact factor scores.

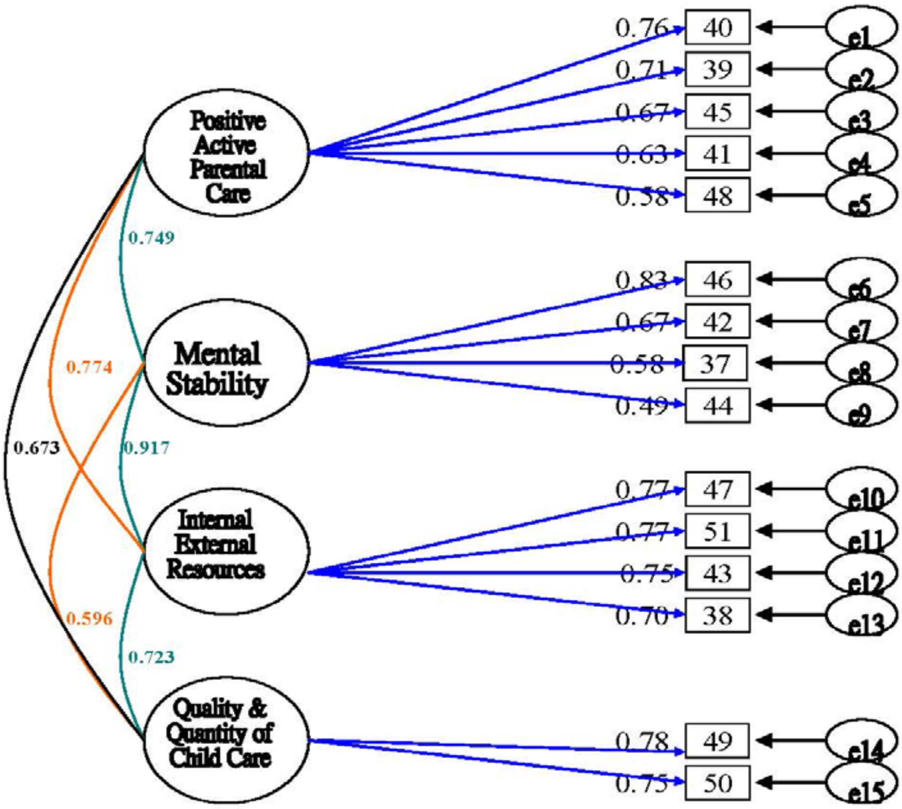


Figure 4.8 **Coping subscale model**

The above figure shows confirmatory factor analysis results for the four-factor model of the Coping subscale. Standardized regression weights are shown on the straight arrows, and factor inter-correlations are shown on the curved arrows. Numbers in rectangles indicate original numbers of Hospitalisation Impact and Coping Scale (HICS) items, and e1 – e15 in the circles on right represent error terms. See Appendix 3.6 & Table 4.8 for the original items and impact factor scores.

Similarly, confirmatory factor analysis was used to cross-validate the four-factor coping sub-scale. All results are significant with $p < 0.0001$. Several CFA fit indices (RMSEA = 0.067, CFI = 0.863, and TLI = 0.833) also indicated good fit for the model. This model possibly could be improved, but it was already supported that the coping sub-scale has four moderately correlated dimensions. Figure 4.8 provides the loadings and path coefficients for the impact sub-scale model.

The characteristics of the coping model are: (a) coping sub-scale had four underlying factors (Effort to maintain positive and active parental care; Attempts to readjust mental stability; Utilize internal and external resources; Maximize quality and quantity of child care); (b) four factors were inter-correlated; (c) each variable had only one factor loading; and (d) errors of measurement of each observed variable (e1 – e15) were independent of each other and of the factors; (f) the coping four-factor model has more ‘low’ standardized estimates than the impact model, in particular are the two items concerning ‘encourage family members to express inmost feelings’ at 0.406 and ‘do not plan for too long’ at 0.345.

Further Analyses for Additional Objectives

Given adequate psychometric properties of the HICS, additional objectives of this study were analyzed with the following statistical procedures:

To analyze the data and determine if there are significant differences in the hospitalization impact scores of paternal, maternal, and both parents groups on the HICS assessment. Table 4.13 displays the results of an ANOVA testing whether the difference between these three groups in total impact is significant or not. If the test was significant, post-hoc Tukey tests would be run to determine which specific variables were significantly different. However, as indicated by the Table 4.13, there is not a significant difference between the three groups, as the p-value is .086, greater than .05, the significance level for the study.

Table 4.13: ANOVA Test for Difference in Total Impact across Respondent Groups

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2913.233	2	1456.616	2.483	.086
Within Groups	126113.891	215	586.576		
Total	129027.124	217			

Similarly, Table 4.14 displays the results of an ANOVA testing whether the difference between these same three groups in total coping score is significant or not. If the test were significant, post-hoc Tukey tests would be run to determine which specific variables were significantly different. However, as indicated by the table, there is once again no significant difference between the three groups, as the p-value is .491, which is well greater than .05. Hence, the second hypothesis, like the first, was not supported.

Table 4.14: ANOVA Test for Difference in Total Coping Across Respondent Groups

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	141.794	2	70.897	.714	.491
Within Groups	21353.183	215	99.317		
Total	21494.977	217			

Table 4.15 was used to assess the third hypothesis to determine whether there is a relationship between the length of hospital stay and total hospitalization impact score, using a Pearson's product-moment correlation coefficient (*r*) to measure this relationship. However, the *r* score of .027 and its corresponding p-value of .689 indicated there was no significant linear relationship between these two variables.

Table 4.15: Correlation between Days in the Hospital and Total Impact

		Days in the hospital	Total Impact
Days in the hospital	Pearson Correlation	1	.027
	Sig. (2-tailed)		.689
	N	214	214
Total_Impact	Pearson Correlation	.027	1
	Sig. (2-tailed)	.689	
	N	214	218

Table 4.16 was used to assess the fourth hypothesis to determine whether there is a relationship between the length of hospital stay and the total coping score, using a Pearson's product-moment correlation coefficient (*r*) to measure this relationship. However, the *r* score of -.130 and its corresponding p-value of .057 indicate there is no significant linear relationship between these two variables.

Table 4.16: Correlation between Days in the Hospital and Total Coping

		Days in the hospital	Total Coping
Days in the hospital	Pearson Correlation	1	-.130
	Sig. (2-tailed)		.057
	N	214	214
Total Coping	Pearson Correlation	-.130	1
	Sig. (2-tailed)	.057	
	N	214	218

Table 4.17 assessed the fifth hypothesis to determine whether there is a relationship between the perceived severity of the child’s condition and total hospitalization impact scores. A Pearson’s product-moment correlation coefficient (*r*) was used again to measure this relationship. Unlike the previous two correlations, the *r* score of .671 is very significant, with a corresponding p-value of well below .001.

Table 4.17: Correlation between Perceived Severity of child condition and Total Impact

		Perceived severity	Total Impact
Perceived severity	Pearson Correlation	1	0.47**
	Sig. (2-tailed)		.00
	N	196	196
Total_Impact	Pearson Correlation	0.47**	1
	Sig. (2-tailed)	.00	
	N	196	218

**. Correlation is significant at the 0.01 level (2-tailed).

Finally, Table 4.18 assessed the sixth hypothesis to determine whether there is a relationship between the perceived severity of the child's condition and total hospitalization coping scores. A Pearson's product-moment correlation coefficient (*r*) was used again to measure this relationship. However, the *r* score of -0.054 and its corresponding p-value of .455 indicate there is no significant linear relationship between these two variables.

Table 4.18: Correlation between Perceived Severity of child condition and Total Coping

		Perceived severity	Total Coping
Perceived severity	Pearson Correlation	1	-0.054
	Sig. (2-tailed)		.455
	N	196	196
Total_Coping	Pearson Correlation	0.054	1
	Sig. (2-tailed)	.455	
	N	196	218

Summary

There was no difference in total impact or total coping scores between the paternal, maternal, and both parents groups. Similarly, there was not a significant correlation between the length of a child's hospital stay and hospitalization impact or coping subscale scores. However, perceived severity of the child had a very strong correlation with total impact scores.

But perceived severity of the child was not significantly correlated with total coping scores. Chapter 5 will further discuss issues related to the results and draw conclusions from the data and address topics for future research.

CHAPTER 5: DISCUSSIONS AND IMPLICATIONS

This section discusses the development of the instrument, Hospitalization Impact and Coping Scale (HICS), related findings and implications. Included are: an overview of background information; psychometric properties; issues regarding the item reduction; potential development of HICS; characteristics of Chinese respondents in research; multidimensional impact and management implications; discussions based on findings regarding specific impact and coping characteristics; family typology and its potential development. Lastly, personal reflection and vision are shared.

Background

Currently, there is no standardized approach by which nurses can identify those families who are at greatest risk of developing adverse impact and ineffective coping as a result of their children being hospitalized. This situation will indirectly affect the recovery of the sick child and family satisfaction of health services. The availability of a simple clinical assessment tool to measure the hospitalization impact on families may be of great help in assessing and identifying families requiring special support. This would contribute to effective involvement and support of families in the caring process, and be particularly useful in the promotion of family centered care (Kristensson-Hallstrom, 1999; Coyne, 1995a; Coyne, 1995b).

Currently, there are few culture-specific assessment tools available for the Chinese population, and there is no specific assessment for hospitalization impact on families with hospitalized children in general pediatric units. Accordingly, it is of great importance to develop a tool that can help clinicians to better understand families who are in need of special attention during the critical period of their children’s hospitalization. Understanding of the various hospitalization impacts on families will allow clinicians and nurses to identify areas where hospital services need improvement or where collaboration with other practitioners must be further developed. The present study was designed to facilitate assessment through the development of a useful and valid tool, the Hospitalization Impact and Coping Scale (HICS). This scale was developed by using evidence from a variety of sources to inform the process, including interviews with parents, a literature review and expert opinions. This approach supports the active involvement of parents in the assessment of hospitalization impact and evaluation of the family coping as an advocate in pediatric practices (Newton, 2000; Coyne, 1995a; Coyne, 1995b; Kristensson-Hallstrom, 1999).

Data and the results of this study indicated that the Hospitalization Impact and Coping Scale (HICS) is an easily administered, reliable and valid measure of a family member’s perception of the effect of a child’s hospitalization that can be used across all pediatric units in the hospital. The HICS fills a gap in the measurement of the overall psychosocial impact including physical, emotional, social, family function, financial and health services related to the consequences of childhood hospitalization on families. This can be useful in clinical and health services research, with improvement of quality care at large.

Psychometric Properties of HICS

To measure the internal consistency of a measurement tool, it is generally recommended that the Cronbach's alpha should be above 0.7, but not much higher than 0.9, for a set of items to be considered a scale. However, some use 0.75 or 0.80, whilst others are as lenient as 0.60 (Nunnally, 1978; 1994). The HICS has met this requirement, although it is slightly higher in the impact subscale alpha at 0.94 and coping subscale at 0.81.

The significant correlation between the Parental Stressor Scale: Infant hospitalization (PSS:IH) and the Impact subscale of HICS has provided evidence to support convergent validity of the HICS Impact subscale. Similarly, the Coping subscale of HICS also significantly correlated with the Family Assessment Device (FAD) General Functioning subscale. Both convergent validity test findings have supported the construct validity of HICS as a valid measuring tool for assessing family stress and coping situations during a child's hospitalization.

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) value and the Barlett's Test of Sphericity value both verified that the samples were suitable for factor analysis in the pilot, as well as in main study. In the main study, exploratory factor analysis (EFA) of the impact subscale yielded a six-factor model that explained 63.5% of the variance in the main study, with the participation of 218 families. Reliability for the factors was good to very good. Low to moderate factor inter-correlations provided preliminary evidence that the factors represented distinct dimensions of the impact subscales in this sample of parents. With similar analysis and findings, the coping subscale yielded a four-factor model that explained 58.5% of the variance.

Confirmatory factor analysis (CFA) was used to validate the EFA derived factor structures of the impact and coping subscales. Results indicated a moderately to good fit in both cases, offering confirmatory evidence for the factor structure. The fact that CFI and TLI fit indices did not achieve values > 0.9 may be due to the fact that perceptions and evaluation of experiences are shaped by contextual issues, and parents having their newborn staying in the neonatal intensive care unit may have differed in experience and stress because they could only visit and 'look at' their babies twice a week. Future studies with a much larger sample would be suggested to differentiate the sample groups for more in-depth analysis. An excellent fit of model may be achievable with a larger sample size and homogenous sample group.

The coping four-factor model had a few more ‘low’ standardized estimates than the impact model. In particular, are the two items concerning ‘encourage family member including the sick child to express inmost feelings; and ‘do not plan for too long’. Again, these items appear more relevant to families with older children or chronically ill children. Given that the sample consisted of a majority of hospitalized children at very young age and few chronically ill children – which is congruent to the current utilization of pediatric services (Hospital Authority 2007-08; 段玉清等, 2003; 徐龍餞, 1998) – further item reduction of HICS may be possible with more supporting evidence in future studies. However, the main study did not find additional strong supporting evidence for further item reduction in its final version.

Potential Development of the HICS

According to the psychometric properties of this newly developed instrument, it is a promising and useful tool in measuring families' differences in impact and coping. With the distributions of mean scores and total scores of the two impact and coping subscales, this instrument – HICS – is found sensitive to variations in family impact as well as to coping characteristics. The overall internal consistency reliability of both subscales and the overall scale were very good.

Preliminary findings support the opinion that HICS can be a useful tool for assessing how families respond to hospitalization of their children. HICS may also become a valuable screening device for directing therapeutic interventions for high risk families resulting from high hospitalization impact and ineffective coping. It is a breakthrough that fills the knowledge and practice gap of assessing families in pediatric care. For instance, families whose impact sub-score reflects extreme adverse impact, yet their ability to cope appears extremely weak in the coping sub-score, may need immediate attention and help in dealing with problems that have arisen. This may include an interview with the family to discuss their problems. During that interview, nurses can help identify appropriate interventions, such as counseling or referral to medical social workers, introducing community resources, or help strengthen clients' own supportive network, if appropriate. Families with a high impact score, but appear to endure well despite that score, ought to be informed of nurses' availability and concerns to them in times of needs. These families should be encouraged to express their needs over time when long-term hospitalization is expected.

For families with low hospitalization impact and low coping, it is important to observe the increase of impact on these families over time. If families with low hospitalization impact and high coping are identified, they may be invited to help supporting other families with hospitalized children who are in stress or in other need of support, if appropriate. This may include the participation in patient support groups, parent support groups or cheer team members for children in the ward. The ability to recognize clients' and families' adverse hospitalization impact and to show support for them, is a major challenge to nurses. This important role helps make quality care visible and deliverable to those families and children who are in need.

With the information of its sub-dimensions highlighted in the Hospitalization impact subscale, referral can be made to other multidisciplinary team members, such as medical social workers or psychologists. Early identification of adverse hospitalization impact would make appropriate interventions timely and avoid conflict or collisions that may arise. It would benefit the child, the family and the health service at large because HICS would provide useful information for program evaluation to measure change when pre- and post-tests are conducted. When more data is collected, information to measure unit differences can be achieved. When using the HICS even more extensively, a national HICS data bank may help in identifying and evaluating the price regulation policy.

Issues and Concerns Related to the Additional Objectives of this Study

When maternal, parental and both parents groups were tested for differences between the three groups in total impact and total coping score, there was no significant difference found. These results helped to justify the use of sampling methods, which allowed mothers, fathers or both parents as informants to report their perceptions of family experiences in this study.

There was not a significant correlation between the length of a child's hospital stay and hospital impact or hospital coping scores. This demonstrated that families should be well looked after throughout the hospitalizing period. No matter how long is the hospital stay, there may be different challenges every day during hospitalization. However, perceived severity of the child's illness has a very strong correlation with total impact scores. This information provides nurses and health workers a clear direction of care for families who have very sick children. The assessment using HICS would provide better ideas of the dimension of impact that need special attention.

Cultural-Specific Concerns

These items were developed based on qualitative data from semi-structured interviews, and therefore, can enhance the significance of the meanings of items for the parents. A few items originated from the literatures were deleted when they were found unfamiliar to most respondents. One example was an item related to “Ask for blessings from God”. China has been an atheistic country for a long period of time, under the governance of the Communist Party (Potter, 2003). It appeared in the pilot testing of the instrument that a majority of respondents had never thought of such coping strategy or they did not believe in God or God’s power at all. Additionally, the possibility of denial could not be excluded. The item was thus removed from the list in the third version.

Another interesting observation found in the factor analysis leads to discussions about cultural interpretation of ‘emotions’. The item – “irritable” – was found related to a few dimensions (psychological – 0.316; social – 0.386 and with a relatively higher factor loading of 0.49 at the physical dimension) consistently in both pilot and current study. Attempting to explore such questions and review those writings on Chinese emotions, particularly on the concept of ‘irritable’, was not easy. Russell and Yik (1996) agreed that writings on Chinese emotions and related evidence available to researchers are discouragingly minute.

We can interpret and discuss these phenomena from many different perspectives. Firstly, Klineberg (1938) discovered from the Chinese literature that Chinese believe emotion to be harmful and socially undesirable. In extreme situations, emotions can cause illness, according to practitioners of traditional Chinese medicine (Wu, 1982). To report on a spouse’s less socially desirable emotional behavior, one might interpret and associate it with physiological conditions. On the other hand, Potter (1988) argued that Chinese emotions are best ignored just like minor aches and pains since they are less relevant in China. With the high response rate of this item, ‘irritable’, the researcher considered Potter’s argument might not be supported by the findings. Based on Kineberg’s findings, it would be interesting to study Chinese beliefs and interpretations of some emotional key words. We need more evidence to support how Chinese think about some emotional terms. There are a few translations of the term, ‘irritable’ including ‘mem’ 忟； ‘feenu’ 憤怒； 脾氣 (spleen, breath); 生氣 (get breath); 急躁(restless, rash, hot-tempered). It appears that both English and Chinese share some physiological nature of the word. As a result, it is hard to interpret if the difference is cultural or linguistic. It becomes even more difficult to interpret if it is ‘somatization’ of emotion or ‘psychologizing’ the emotion (Bond, 1982, p.172).

Fortunately, how respondents view the nature of the problem does not affect the validity of this instrument because the measure concerns only whether this behavior exists and, if so, how much it has affected the family.

Respondents' beliefs about its dimension in physiology or psychology would not affect their evaluation of the phenomenon. However, the researcher needs to explore further and try to explain the interpretation since it may affect future application and interpretation of results in an international cross-cultural application or modification of this item.

Characteristics of Chinese Respondents

Some Chinese scholars have highlighted a need for caution in studying Chinese people with the Western model of questionnaire (Yang, 1982; Yang, 1996, 2001). Others have pointed out the importance of cross-cultural accommodation of questionnaire language (Bone & Yang, 1982). This study has used some qualitative interviews with Chinese parents for the fundamental development of item pools to avoid the direct adoption of the Western model into the study of Chinese subjects. The newly evolving ‘holistic’ concept used to help explain qualitative data appears to be globally acceptable in the interpretation of human characteristics, total patient needs and care (Strandberg, et al., 2007; WHO, 2004). In an era of globalization, it is more appropriate to use this new internationally recognized holistic concept to help frame / explain the data, just as we use kilogram instead of the Chinese weight standards of Catty, teal or Sheng. However, special attention needs to be given to interpretation of a few emotional terms such as ‘irritable’ among Chinese respondents, as mentioned above.

Yang (1996) highlighted four major challenges when using questionnaires among a Chinese population. Though not fully explained or substantiated with evidence in many areas, Yang (1996) has first mentioned that Chinese participants would be less favorable when compared with the Western world in the following areas:

1. Put forth best effort in completing the questionnaire;

2. Find meanings in the questionnaire items;
3. Be willing to reveal their true feelings;
4. High correlation of the reported feelings and associated behavior.

The nature of the HICS has no socially desirable effect and the researcher has no direct or indirect relationship with the participants, so the concern of willingness to disclose personal feeling could not be well justified in this current study. Therefore, the concerns of Yang (1996) have no explicit grounds to imply that Chinese participants would have more problems in research activities. Indeed, the correlation of reported feelings and associated behavior would be a cross-cultural generalised issue. Being well discussed, some studies have reported a satisfactory level of consistency for the above-mentioned issues of concern (Ajzen & Fishbein, 1980). By administering the tool in a culturally appropriate manner, the researchers would be able to elicit valid and reliable responses (Jenks, 2007).

Being Chinese, the researcher agrees with most of Yang's comments, but considers the above-mentioned challenges manageable with better skills and planning of the study, from the development of the instrument to data collection procedures. This study carefully acknowledged each challenge to ensure that the study overcame related problems. The following may explain such endeavors and experiences gained through the process of data collection:

Participants were well respected for their voluntarily contribution to ensure enthusiastic and genuine participation. The researcher noticed that it was easier to establish rapport when a small souvenir was given to their child at the beginning of greetings, whether they wanted to participate in the study or not. With the established rapport, parents were more willing to participate and talk about the study and their feelings and became more enthusiastic in answering the questionnaire. The difference in parents’ willingness to participate was observed when compared with the pilot study where the souvenir was given after completion of the questionnaire as a reward for participation. According to Chinese culture, courtesy and respect always gains the best reward (Gao & Ting-Toomey, 1998). Participants were willing to do their best and reveal their true feelings when good rapport was established.

Some mothers preferred to wait for their husbands to discuss answers for the HICS, which can be explained in two ways. First, it may be related to submissiveness of some Chinese women. A few of these women admitted that they were less educated and reckoned that their husband could do better in answering the questionnaire. Some other women wanted to discuss the answers with their husbands, since they considered this a family issue. A few mothers needed to ask their husbands regarding particular items, such as the total family monthly income. Nevertheless, all these responses indicated that respondents were very serious and enthusiastic in giving accurate answers to the questions.

Demographic Characteristics - Gender Imbalance

The imbalanced gender ratio – with more males than females – is a pattern seen in many Asian countries, and to the greatest extent in China. China has the highest gender ratio imbalance, with 106 males: 100 females (National Bureau of Statistics of China, 2005). The extreme gender imbalance found in this study cannot be explained but the possibility of better care of male children, as explained in Chan and her colleagues' report, cannot be excluded as a factor (Chan et al, 2002). This phenomenon of gender imbalance is also consistent with many other hospital statistical reports in China (段玉清, 2003; 徐龍饒, 1998). Specifically, the gender ratio of children in this study was extremely close to a recent study done in the same city with a report of 61.1% boys and 38.9% girls (Liu, 1999).

Multidimensional Impacts and Management Implications

This study found that the greatest impact on the families were 'feeling hurt when the child suffered in hospital', 'worries of disease progress', 'more expenses', 'become emotional', 'tired', and 'problems with sleep'. The two most significant impacts highlighted the psychological trauma and burden that existed among the majority of parents. This understanding will enhance health care professionals' sensitivity to parents' psychological needs. The next four impacts captured a more holistic perspective of financial, emotional and physical concerns. The demand for quality services will go beyond the individual professional's sensitivity, understanding, or communication skills, but to a higher level of multi-disciplinary, institutional, or even national involvement.

At a multi-disciplinary level, referral or consultation can be made when problems are identified. Medical social workers or psychologists would be good partners for quality services. However, even with the awareness of parental stresses and needs, this concept of referral or expert consultation within a multi-disciplinary team approach for the care of families does not exist in the current health care system in China (Liu et al., 2002; Wang, 2001). As discussed in the literature review, the health care system in China has developed and evolved quickly in recent decades. Thus, the researcher hopes this study will encourage new initiatives in the development of a more holistic multi-disciplinary team in the near future.

At an institutional level, improvement of facilities and policies would help prevent parents from experiencing physical exhaustion. Many hospitals in developed countries have facilities and comprehensive supportive services, such as common room for parents' relaxation and rooms for afternoon naps and rest (U. S. News & World Report, 2008; Arkansas Children's Hospital, 2008). A recent publication by Huo and her colleagues (Huo et al, 2004) in Beijing was very unique, including reports on nurses' initiatives in establishing home-like wards to observe the psychological reaction of children in hospital. They found that children in the intervention group had a lower frequency of adverse psychological responses when compared with the control group and the difference reached a level of statistical significance (Huo et al, 2004).

This report set a good example for childcare professionals to reconsider practices for quality services. Unfortunately, the initiative to improve the pediatric ward facilities and policy based on parental or familial needs is yet under-developed in the country. The researcher hopes that this study contributes to the existing knowledge and provides better understanding of the dimension of impacts on parents or individual family members related to a child's hospitalization. Furthermore, a systemic use of the developed assessment tool (HICS), would facilitate collection of more data and evidence to justify practice changes at an institutional level.

At the national level, governments need a policy to protect people's right to affordable medical services (WHO, 2008). As discussed in the literature review, China is now facing a great challenge to meet the health needs of her huge population, through hospital price regulation (Liu et al., 2000) and medical insurance schemes (The World Bank, 1997). Given the current Chinese economy and population, the uninsured status of the rural population continues to be a disadvantage resulting in uneven resource distribution (Jonsson & Lu, 2008; Davis, 2005). Heavy financial burdens caused by hospitalization are expected within the existing health services system. The result of this study supported this argument, with financial cost as the second highest reported impact on the family. The HICS, with a subscale measuring social and financial impact, may also be able to serve as an indicator for reviewing effectiveness of social policy based on parental perception of impact on the family related to a child's hospitalization.

Specific Impact and Coping Characteristics

According to other descriptive findings of the study, the following sections focus on related discussions and implications on specific impacts and coping variables, namely:

Psychological burden related to guilty feelings and blaming;
Family function - communications during hospitalization;
Family function - care for the hospitalized child;
Family function - housework during hospitalization;
Health services related impact during hospitalization;
Coping effectiveness and related implications; and
Less effective coping strategies and their implications.

Psychological Burden Related to Guilty Feelings and Blaming

With the extremely high reported experiences of 'feeling hurt' among parents, it is important to try and prevent this from happening. These feelings would have an adverse impact on the children and may even affect their recovery and psychological adjustment (Immelt, 2006; Wallander & Varni, 1998). Another interesting finding was parents having personal feelings of guilt (feeling what they were able to do for their children was inappropriate and inadequate) verses blaming the hospital for inadequate childcare. Indeed, the problem of personal guilt feelings related to childcare was of much greater severity of impact than the blaming and faultfinding on others, as indicated in the results. This has an implication for nurses to obtain a better understanding of parents' psychological burdens related to hospitalization of their children. According to the literature, appropriate actions can be taken to relieve family stress and anxiety, ranging from passive listening to active reassurance and counseling (曾朝辉等, 2006；Liu et al., 2002). Providing opportunities for more childcare participation and empowerment through parent-education was also recommended (Lam et al., 2006; Corlett & Twycross, 2006b).

Family Function - Communications During Hospitalization

From the result of this study, the least reported frequencies of extreme impact on the family were 'less chance to discuss difficulties together' (3.2%), 'bad mood has affected family relationship' (4.6%) and 'blame each other for inadequate care' (6%). These indicated that family functions were still quite intact during hospitalization. In fact, the report of irrelevancy (not applicable) of these three items with 15.1%, 8.7%, and 13.8% respectively was also relatively higher than other items. Even parents considered as relevant to their situations, 25.7%, 33.9% and 25.7% of them reported no impact of these items on their families.

However, these results may not be conclusive due to several reasons. First, communication today is more convenient, especially through mobile phones. The popularity of mobile phone service is increasing in the city. Being hospitalized should not deprive individuals of the opportunity to communicate among family members as reported from previous literature (Yantzi et al., 2001) unless it is due to poverty or a hospital policy that restricts mobile phone use in certain units, such as the intensive care units. Secondly, given that the average length of hospital stay is considered to be short – at around five days – the stress level might not be intensified to a level that would affect family relationships. Indeed, this critical initial stage of crisis might help increase the cohesiveness of family members (Newton, 2000). Thirdly, there may also be cultural implications for these phenomena. In general, Chinese people do not value open discussions as much as Westerners (Yang, 2001). When there is no expectation of the need for discussions, regardless of opportunity, it would not create an impact as such. Fourthly, Chinese people typically deal with crisis in a different way (Davis 2005; Chen & Ma, 2002). Instead of outspoken communications, internalization may more commonly occur (Chen et al, 2003). In future studies, further exploration of mobile phone usage and related communication needs would be beneficial. Further exploration would also be good regarding populations with chronic illnesses. Cultural studies on Chinese families regarding family functions, communications and crisis coping would also be beneficial to deepen our understanding of possible cultural differences.

Family Function - Care for the Hospitalized Child

The relatively high report of irrelevancy of one item in the HICS, “We want to care for our sick child but feel inadequate to do so”, as indicated by 10.1% ‘not applicable’ and 11.5% ‘no impact’, was observed. This could be explained by nearly all parents staying with their children in the hospital, except for those in the intensive care units. However, over 38% of parents reported this item as having great to extreme impact, so it might also indicate that a sense of helplessness existed in the care of a sick child in the hospital. Nurses should pay an important role in educating, facilitating and empowering parents to be more confident in their parental role (Lam et al., 2006; Corlett & Twycross, 2006b). It was evidenced from the literature as well as from this study, that continuation of the parental role during hospitalization of children was an effective coping strategy for parents.

Hospitalization of an older child may impose an added burden to a young couple who have a toddler to look after at home. Hospitalization impact on an adolescent and his/her family may be different from those with a hospitalized infant. Qualitative data from this study revealed these characteristics of families, however, to include the ‘sibling effect’ determined by a scale used to assess families in the hospital settings. Unfortunately, a large number of missing data was problematic with the one-child families. This experience had also been reported in a study by Stein et al. (1980). The HICS tried to overcome this problem by putting the sibling items at the end of the questionnaire for those families with more than one child. Also, the inclusion of an open-ended item asking about concurrent difficulties might help to uncover some of these problems regarding the ‘sibling effect’.

Family Function - Housework During Hospitalization

The results of this study showed a high percentage (about 40%) of ‘no impact’ or ‘little impact’ for the item, “We cannot finish housework such as cooking and cleaning”. That may reflect a high supportive network to those who lived in the village with extended families. Or, this issue may not be a concern because of the relatively short stay in hospital and housework may not be a priority to mothers. However, having chronic health conditions that resulted in a long hospital stay might have resulted in a different pattern of results in other studies focusing on chronic illnesses (Grootenhuis & Last, 1995; Satterwhite, 1978). In situations like families in Hong Kong, where a domestic helper is quite common, this item may become irrelevant (Lo et al., 2003).

Health Services Related Impact During Hospitalization

Within the impact sub-scale of the HICS, it is helpful to understand what issues may be least important to parents with hospitalized children. When ‘not applicable’ and ‘no impact’ items were combined to explore the less significant issues or impact, ‘inconvenience to use alternate therapy’ was prominent – scoring 20.2% and 26.6% respectively. This result indicated that parents had great confidence and reliance on the medical treatment in the hospital. Using alternative therapy was not an option for them. This was also reflected in qualitative reports from the open-ended questions. Some parents commented that they felt satisfied with their choice of hospital.

Some local studies in Hong Kong and China indicated that the local communities' care-seeking orientation still favors Western medicine over traditional Chinese therapy and some traditional Chinese medicine is under-utilized (Leung et al., 2005; Hesketh & Wei, 1997). There may also be other explanations for the parents' devotion to the existing treatment. Given the short period of hospital stay, the hope and trust in medical treatment in the hospital should be best maintained. Otherwise, hospitalization would not be their choice. Having mostly small infants in this study, alternative therapy may not be much of a choice for parents. Further research should explore in more detail parents with older children and children having chronic illnesses or severe conditions, such as cancers.

To echo with the above-mentioned trust of health services provided in the hospital, another item asking about parents' worries of malpractice scored high in the categories of 'no impact' and 'little impact' at the level of 21.6% and 22% respectively. Similar patterns of overall skew towards 'no to somewhat an impact' existed among other health services related items. This may be due to a number of factors. First, the health services provided might be extremely good so that little impact was set forth making the related items not relevant at all. However, the low percentages of related ‘not applicable’ items did not support that as the case, nor did qualitative information from the open-ended questions.

Some parents expressed their need for more information about their children’s disease progress, whilst others complained of ward environments related to hygiene, noises, and facilities. That implies that the problems did exist, but these were not be bad enough to cause greater impacts during the time of report. The researcher also considers the possibility that some characteristics of Chinese culture previously discussed (Chen, 2001; Holroyd et al., 1998; Chae, 1987) about social sensitivity to maintain harmony between person and environment and avoid conflict may be involved in these results.

Another possibility is that respondents were generally experiencing mixed characteristics of greater acceptance, tolerance, allowance, understanding or respect. These characteristics may have resulted from natural responses or cultural influences. For example, having found that health care workers were very busy, the natural response might be to adopt an attitude of allowance and avoidance of frequent contact and demand. However, parents still need the support of nurses for timely intervention, such as during intravenous therapies. This situation would increase parents’ internal struggle because the underlying health services and information needs would not diminish accordingly. Greater impact would be created when more adverse experiences accumulated. The inclusion of short hospital stays in this study sample might have partly contributed to the skewing of the results towards lower impact. This explanation has not taken into consideration other possibilities of adaptation and unknown saturation effects that may occur when long hospital stay occurs. Therefore, more research into the issues discussed is necessary.

For some other parents' worries of malpractice, a significant number of them (31.6%) expressed great concerns and impact. Levine (2001) pointed out that hospital staffing patterns with less-trained staff and publicity about hospital incident of errors in medication and surgery made family members concerned about patient safety. The hospital where the study was conducted was under pressure of having high admission, and the staff was seen to be very busy, at least as determined by parents' descriptions in the open-ended questions. However, it was observed that a majority of parents in this study trusted the health services provided. This can be supported by many open-ended comments whereby a number of parents expressed that they had carefully chosen the hospital and were not disappointed by the services they received in the hospital. When compared with other countries, such as the United States, the issue of malpractice related worries appeared to be minimal (Selbst, Friedman, & Singh, 2005; Institute of Medicine, 1999).

In the case of hospital environmental cause of impact, there is greater evidence of a need for improvement as indicated by the relatively higher percentages of ‘great’ to ‘extreme’ impacts (about 35%) and supported with some open-ended comments. With this information, it appeared that a majority of the parents (65%) were having greater tolerance, allowance and acceptance of the ward environment. In terms of effectiveness, change of physical environment might be more manageable and visible. Thus, it is advisable to put a high priority on improvement of the environment to allow better quality health services.

With regard to the responses to an item asking about the impact on the family when the child’s condition was not fully explained, the reports of ‘great’ to ‘extreme’ impacts were also relatively high (28.5%). This is another area of health service that needs to be, can be and should be improved. It is a shared responsibility of doctors and nurses. For nursing management, having team nursing and name nurse system may be a solution for better understanding of the patient and family resulting in higher quality care (Newton, 2000).

Regarding the effect of ward routines, this item appeared to have the least impact on families. This resulted from a flexible schedule and policies or high tolerance of parents, making it worth commendation for the services provided and cooperation of patient and relatives.

Coping Effectiveness and Related Implications

Among the 15 coping items of the Coping sub-scale of HICS, the most effective and popular strategies were 'stay close to the child', 'maintain hope', and 'keep asking health care workers and observe the child closely'. This reflected that positive and active involvement of childcare in the hospital does play an important role for families coping with a hospitalization crisis as reported in previous literature (Reddon et al, 1992). Besides frequent visiting and overnight stays with the children, meeting parents' information needs was also an important nursing intervention to help families combat negative impacts. Other strategies parents found useful were to have 'mutual support and shared responsibility' at familial level, 'consider more relieved with hospitalization', and 'prepare food for the hospitalized child' can be described as mobilizing external and internal resources at personal and familial level.

In addition to discussing and showing concern for and support of the family when communicating with parents, nurses should also find ways to strengthen parents' trust and belief in hospital health care services. Information through leaflets, careful introduction of hospital routines and health care procedures, and demonstration of professional knowledge, skills and behaviors are all important characteristics described in the literature (Freda, 1998). Comforting parents before, during and after some procedures appeared to be very important according to the results of this study. For instance, parents indicated the number one adverse impact was feeling hurt because the child suffered in the hospital. Last, but most import according to the literature and results from this study, is to make sure that parents are kept well informed regarding their children’s progress (Hall, 1987).

Also, the hospital and nurses should develop policies and facilitates to meet other needs that parents valued as important, such as preparing food for their children. Having access to a small pantry or a common room with simple cooking facilities such as microwave oven, stove or electric cooker might be helpful to parents. Some hospitals in China even allow parents to use a common pantry for cooking in the hospital. Regardless of whether the service is free of charge or on a rental basis, it would enhance the hospital service, encourage parents’ participation of childcare, decrease fatigue of travelling, increase family satisfaction, and, most importantly, benefit the child’s recovery.

Less Effective Coping Strategies and their Implications

Seeking help and resources beyond the family level appeared irrelevant in many cases as indicated in questionnaire item 11 and 14 (i.e. ‘seeking and accepting help from friends and relatives’, and ‘asking friends and relatives about hospitalization experiences’). This might be due to the fact that most of the families lived as nuclear families and could be described as new migrants to their region as indicated in the demographic data. These conditions weakened their support networks beyond the family level.

Some items were found ‘not applicable’ or with ‘no effect’ because a majority of children were infants and there were only few cancer conditions in the study sample as reported in previous literatures and qualitative interviews. ‘Treat the child as usual’ and ‘encourage the child to talk’ were reported in literatures and pilot interviews as commonly found among parents with children having chronic illnesses and of older age group when behavior problems or emotional responses were expected (McCubbin et al., 1983a; Stein & Riessman, 1980). Similarly, ‘do not expect too much and plan for too long’ was a situation more commonly reported by parents with children with chronic illnesses or cancer (Stein & Riessman, 1980), general pediatric children and so other families are unlikely to have these experiences. The results presented in this study appeared reasonable and congruent with the sample characteristics. More research using other demographic characteristics would certainly help to illuminate more evidence of the validity of this newly developed instrument.

It is important to realize that ‘tried to relax’ was not effective for most of the parents. To relax is something beyond parents’ ability to control and might be difficult in their situation. Besides strengthening parents’ helpful coping strategies as previously discussed, there is a strong implication for nurses to explore further alternative strategies to help parents to feel more relaxed. Introducing light relaxing background music and storytelling as suggested in some literature might be a strategy that could be further explored and studied in the future (de Vries, 2008; Kemper et al., 2008).

Relationship of the Conceptual Framework and Findings.

The conceptual framework of this study provides insight about the relationships between perceived hospitalization impact and coping strategies in affecting family outcomes. Its value is in guiding the focus of the study and the development of HICS. The HICS total impact and total coping scores of each family have informed the researcher as to how this family perceived the hospitalization experience in terms of related impact and coping. Qualitative data collected from one open-ended item of HICS on concurrent difficulties has provided extra useful information about the family's unique experiences (shown as 'Pile Up – aA' in the conceptual framework). The pattern of concurrent difficulties commonly reported among all participants ranged from work related stress or unemployment (11%); having financial difficulties (1.5%); having another sick relative to look after (6%); and other problems that all indicated the genuine existence of concurrent difficulties as described in the conceptual framework. As hypothesized from the conceptual framework, families were confirmed to have coping strategies such as seeking help from relatives (external resources) as evidenced by 62.3% of families responding in item 11 about seeking and accepting help from relatives. The scatter plot of total impact and coping Z scores has also identified a typology with four types of family outcomes as proposed in the conceptual framework.

Family Typology and its Potential Development

The family typology reported in this study was a preliminary attempt to classify and explain family characteristics on empirical and hypothetical basis with the use of the scatter plot. With this attempt, we have uncovered some patterns that would help to fill the knowledge gap about how families can be described in terms of their hospitalization impact and coping effectiveness. Below are the four types of family characteristics that can be identified from the data analysis.

1. Vulnerable Families – families with high adverse hospitalization impact and low coping scores are at greatest risk of experiencing crisis. Immediate attention and concern would help identify the families' needs to prevent crisis.

2. Master Family – families with high negative hospitalization impact and high coping scores cope well despite having high adverse impact. They demonstrate high coping ability to master the negative impacts. They may require relatively less attention. However, attention is needed to check if coping would be exhausted during hospitalization.

3. Intact Families – families with low hospitalization impact and low coping scores may also be well while their children are in the hospital. They may belong to those children with planned admission for investigations or minor surgeries. Hospitalization does not create any impact in their daily life. However, some repeated measures would be suggested to observe changes of

impact that may arise over time. For example, more than ten days hospitalization might warrant another assessment, according to the preliminary finding of this study.

4. Vigorous Families – families with low hospitalization impact and high coping scores are managing well during their children's hospitalization. These families can be empowered to serve in the support groups or make other contributions. They are the best candidates for implementing successful family-centered care.

The above proposed family typology and its related management suggestions would provide useful information and direction for clinical decisions. However, this study with its focus on developing and testing an instrument can only uncover some patterns about how families can be described in terms of their hospitalization impact and coping. Further research is needed to validate the hypothesized situations and related management strategies.

Limitations

Principal component analysis is a technique that assumes that the sample used is the population, and so results cannot be extrapolated beyond that particular sample (Field, 2005). With the use of the principal component analysis as a method in this study, it is important to note that conclusions are restricted to the sample collected and generalization of the results can be achieved only if analyses using different samples reveal the same structure. This will become a future challenge to the researcher and for those interested in exploring further with this tool.

The existing data set, with 218 subjects, did not facilitate splitting of the data set for EFA and CFA cross validation and, as such, findings should be interpreted with caution. However, true cross validation can still be claimed with the different data sets used in the pilot and main study. Factor structures appeared stable throughout these procedures at different point of time and with two different set of data.

Respondent parents were asked to rate their perceived level of impact of a child's hospitalization on families and it may be argued whether a single person can truly reflect the family situation (Friedman et al., 2003). While acknowledging the use of key informants as respondents is a limitation of this study and caution must be maintained regarding interpretation, the researcher argues for the logic of using key informants for community research. If it is well justified that the key informant is trustworthy, the information gathered should not be under-valued. The researcher has carefully considered this, but still chose to use parents as key informants to study the impact on families due to several reasons. Firstly, parents are usually the primary carers of children and they usually stay with or visit their children in hospitals. It is therefore reasonable and practical to ask parents about their family responses toward hospitalization of their children.

Secondly, parents also bear many burdens and play different roles in a family. The burdens parents are experiencing may not be fully understood by others. In most situations, parents also know the family better than any other family members.

Again, it is more appropriate to ask parents about the hospitalization impact. If the assessment is to be meaningful and feasible, having parents as respondents would be the best option. Many well known and successful assessment tools also utilized parents as key informants for the family, such as the Chronic Impact and Coping Instrument – CICI: PQ (Hymovich, 1983); Coping Health Inventory for Parents – CHIP (McCubbin et al., 1983); and the Impact on Family Scale (Stein & Jessop, 2003).

Reflection and Vision

The results reported in this study are of preliminary findings that, whilst very encouraging and promising, are still very coarse and need further refinement, such as viewing crisis as "challenge or crisis", and "the typology of families". In particular, the researcher would highlight the following issues for additional research: (1) To make the results more reliable, we would need to have a larger and more controlled sample. (2) The use of cut off point can be better determined after a norm is set, following repeated studies. (3) To further explore the issues of "challenge" during hospitalization and illnesses, and to investigate how health care workers can empower these 'quality' of families into ‘quality of care’. (4) To further explore the “typology of families” in health care settings for the development of ‘facilitating model of care’.

Lastly, the researcher, through the process of this study, has learned from history that health care workers have taken away the functional role of care from families, but little has been done to observe and prevent the adverse impacts that this action might have caused to all members of the families concerned. The result of this study has informed us that adverse hospitalization impacts do exist and could be very diverse; the intensity could be very high in some families as well. The coping sub-scale has informed us that families are doing their best to struggle along whilst their children are staying in the hospital. Better knowledge of the hospitalization impact needs to be sought to help understand the families and their coping effect, which will also inform us when and where health care workers can intervene during the process of hospitalization. This study has demonstrated that the HICS appeared clinically acceptable, reliable, valid and promising. Future research especially, across the country, may strengthen the establishment of a norm. The development of this instrument – HICS – is the beginning of an endeavor for better care of families. Joint effort by the health care team and family is important for the success of this mission. Hopefully, HICS can be further developed into a useful tool taking part in and supporting current national health care reform in assessing needs and evaluating program effectiveness.

CHAPTER SIX: CONCLUSIONS AND RECOMMENDATIONS

The aim of this project was to develop a simple, practical and culturally appropriate assessment instrument, the Hospitalization Impact and Coping Scale (HICS), for assessing parents' perception of impact on their families resulting from hospitalization of their children and to evaluate the effectiveness of their coping strategies. Although further psychometric data for the HICS is needed to strengthen its future development, preliminary findings suggest that the tool would be useful in measuring perceived family impact and coping resulting from hospitalization. The assessment process and outcome can enable parents to identify their own hospitalization impacts and coping. It should also provide valuable information for clinicians and families to support better services. Although the measures focus on impacts that are mostly negative in nature, clinicians can use details from the coping subscale to highlight family strengths.

It is important to remember that using family measures is not an end in itself but an important way in which clinicians and the family can gain mutual understanding about the focus of care, and a way to facilitate further communications when indicated. The success or failure of measurement depends greatly on how clinicians present the assessment to the family.

Overview of the Development of HICS

The Hospitalization Impact and Coping Scale (HICS) instrument was developed as a tool for clinical and health service research to examine variability in the parentally perceived impact of hospitalization on families with a hospitalized child. Impact was conceptualized as the effect of a child's hospitalization on the family system. The development of this instrument was based on the qualitative data partially contributed to a large project, "Psychosocial functioning of hospitalized Chinese children and their families"; extensive literature reviews; the stress and coping theory; and previous work of three other instruments as listed below:

(1) The Impact on family scale (IOF) on parental perceived effects of chronic illness by Stein and Riessman (1980), Stein and Jessop (2003);

(2) The Coping Health Inventory for Parents (CHIP) on parental response to management of family life when they have a child who is seriously and /or chronically ill, by McCubbin et al. (1983); and

(3) The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU) on parental stress when their children were hospitalized in pediatric intensive care units by Miles and Cater (2003),

In Phase one of this study, an item pool for each hypothesized dimension was created using qualitative data from 36 parent interviews, reviews of the literature and clinical experience of the researcher and an expert panel. The item pool was reviewed by the expert panel and items were reduced twice for pre-testing in a pilot study. In the first item reduction process, items were categorized into two sub-scales (impact and coping) which were hypothesized as two different constructs. Psychometric properties of data provided information for fine-tuning the instrument and a factor analysis of the first 67 cases revealed six dimensions in the impact subscale and four dimensions in the coping subscale.

Phase Two study, with 218 subjects, confirmed the structure of the six factors in the impact subscale: physiological, social, physical, health service needs, family and burden impacts; and a four-factor structure in the coping subscale: (1) effort to maintain positive and active parental care; (2) attempts to readjust mental stability; (3) utilize internal and external resources; (4) maximize quality and quantity of child care.

The final instrument (HICS) consists of three major parts and an optional session for measuring sibling effects. It begins with the demographic information. The second part consists of 36 items measuring the multidimensional facets of parental perception of hospitalization impacts on families. The third part has 15 items evaluating the perceived coping effectiveness. The fourth part is an optional session measuring sibling effect, if applicable. A Likert scale was used for part two, with a six points scale ranging from 0 = no impact; 1 = little impact; 2 = some impact; 3 = great impact; 4 = extreme impact; X = not applicable. Another similar Likert scale was used for part three with a six points scale ranging from 0 = no effect; 1 = little effect; 2 = some effect; 3 = great impact; 4 = extreme impact; X = not applicable. The total score was obtained by adding the ratings of each item.

Nurses assessing families should decide which subcategories are particularly relevant after this preliminary assessment so that these can be explored in more depth during family interviews or discharge planning. Not all the subcategories assessment areas may need to be assessed – the depth and breadth of assessment is dependent on family’s goals, problems and resources, as well as the nurse’s role in working with the family. It may be repeated to determine a pattern of changes of the impact over time.

Applicability of the Instrument (HICS)

Finally, the applicability of this instrument (HICS) as part of the family assessment process should be made clear to clinicians or practitioners. Practitioners can use this instrument in quantifying hospitalization impacts for focusing on the most critical areas of family concerns. When the severity of problems and other factors facing family members is determined, interventions can be allocated with more time and resources focused on the identified family concerns that are most challenging. At the same time, the coping subscale can also inform clinicians about the family's strengths.

HICS is designed to support and improve clinical judgment in a way that it guides practitioners in developing care (case) plans that address the most pressing concerns of the family. This measurement adds to the quality of information that practitioners use to base their clinical decisions.

Using HICS, hospitalization impacts can be reassessed over the course of service. Practitioners can administer the instrument at the beginning (pre-test) and at the end (post-test) of a program or intervention, such as increased parental participation in family centered care practices to monitor changes due to intervention and evaluate the effectiveness of a program. Monitoring and evaluation of change can be undertaken. Reassessing the same factors makes it possible to determine the progress a family has made in reducing problems or adverse impacts to enhanced coping behaviors. From these data, relevant and timely plans for a family can be made.

Lastly, this quantitative instrument can determine the appropriate level of service. Practitioners can identify the key factors that must be addressed through intervention.

Although this instrument is simple, practical, unobtrusive, culturally appropriate, and of importance to family and practitioner, the author would like to advise users of this instrument to note the following principles:

1. Be familiar with the instrument through practicing before administering to parents.

2. Briefly introduce and review the entire HICS with the parents before self-administration of it.

3. Explain that the objectives of measurement are to obtain information that will assist clinicians and the family to evaluate the impact of hospitalization and to plan for better care for the child and family concerned.

4. Reassure the parents that there is no right or wrong answer. Always stress family consensus, accuracy and honesty. In case of difficulties in getting consensus, their personal perception on the issues concerned is also highly valued.

5. Convey the message that the institution as a whole values the family’s responses.

6. Be sensitive to individual needs – for example, the reading and language ability for self-administration. Be aware of special family patterns such as single parent family, new migrant, or family with concurrent crisis such as recent death of a family member or unemployment.

7. Review the results with the family and explain the significance of and/or how you will use the results. This shows respect for the family and facilitates better communication between the practitioner and the family.

8. Use the individual items or details provided by this measurement tool to discuss the adverse impacts or strengths as well as areas for further improvement of the care.

9. Consider using this assessment as a form of clinical intervention and make use of the chance to build up rapport, through discussion and better understanding of the client and his/her family situations.

10. Do not just use the total score because it is only a guideline for quick reference. Remember, individual items or the emerging dimensions of impact would provide more information for discussions with the family.

With this experience of instrument development, the researcher encourages future researchers to (a) select a theory or model as a guide to the research; (b) complete a systematic instrument development process; and (c) report psychometric properties of instruments for data collection.

Future Plans

In addition, future plans to extend this study include (a) administering the survey to more parents with hospitalized children in different specialty pediatric units of the hospital; (b) continuing to assess the reliability and validity of the existing scale; (c) further item reduction, if indicated; (d) extending the survey to many more cities or countries with Chinese pediatric families; (e) developing a parallel instrument based on the HICS structure to be completed by adolescent patients and their parents or other caregivers; (f) developing a modified version and administering the survey to care givers in other specialty units of the hospital; (g) determining perceived differences in the experiences of the hospitalization impact among clinicians, patients (if applicable) and their caregivers; and (h) developing an interactive computerized program for data entry, analysis and full reporting of related scores and family typology, including recommendations, if appropriate.

Replication of this study with a randomly selected sample, a larger sample size, and expanded illness types, such as chronic illnesses, is recommended. In addition, other possible influencing factors, such as children's temperaments should be further explored. For multidisciplinary clinical researchers, such as nurse practitioners, medical social workers or clinical psychologists, a joint research program would benefit further development of intervention strategies according to the family typology based on HICS.

To fully utilize the function of HICS, nurses are encourage to collaborate with other health professionals to: (a) develop quality care for assessment and timely interventions of parents experiencing negative impact of a child's hospitalization; (b) create informational resources for quality care among diverse groups of pediatric patients and family members; and (c) design interactive, continuing nursing education to enhance family communication and assessment skills.

Finally, it is hoped that better understanding of the impacts on families with hospitalized children can be achieved with the use of HICS. Health care providers would find the HICS useful in clinical settings. Joint efforts in future development are most welcome for further improvement and development of the HICS. Hopefully, HICS, in the near future, can be further developed and better utilized for the benefit of families with a hospitalized child, and to contribute at a local level of pediatric development and at a national level taking part in current national health care reform exercise. A long-term goal of the HICS development is to contribute at a global level for the benefit of children and families at large.

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APPENDIX 2.1 FAMILY ASSESSMENT TOOLS

Tools (Author / Year)	**Supporting theories / models**	**Concepts Involved**	**Administration and scoring**	**Strength**	**Weakness**
Parental Stressor Scale: Infant Hospitalization PSS:IH (Miles & Brunssen, 2003)	Nursing model: environmental stressors	♦ Parental stress ♦ Stressors ♦ Appearance and behavior of the sick infant ♦ Parental role ♦ Physical environment	♦ 22 items ♦ Likert scale ♦ Easy to administer	♦ Assesses stress in parents ♦ The focus is clear about 3 major aspects of stress to be measured	♦ Clinical applicability is limited to parents of critically ill infants with technology dependent ♦ The scope of stressors to be measured is limited

Tools (Author / Year)	**Supporting theories / models**	**Concepts Involved**	**Administration and scoring**	**Strength**	**Weakness**
FAD McMaster Family Assessment Device (Epstein, Baldwin, & Bishop, 1983)	McMaster model of Family Functioning	♦ Problem solving ♦ Communication ♦ Roles ♦ Affective responsiveness ♦ Behavior control ♦ Affective involvement ♦ General functioning	♦ 60 items ♦ Likert scale ♦ Easy to administer	♦ Measures areas nurses could change through care plans	♦ Requires family members to speak for family ♦ Not clear if useful with clients of different social and cultural backgrounds, or in different life stages.

Tools (Author / Year)	**Supporting theories / models**	**Concepts Involved**	**Administration and scoring**	**Strength**	**Weakness**
The Impact on Family Scale (IOF) - revised version (Stein & Jessop, 2003; Stein & Riessman, 1980)	Coping and adaptation	♦ Financial Burden, ♦ Familial/Social Impact, ♦ Mastery ♦ Personal Strain	♦ 27-item ♦ Quick to administer particularly with the 15-item version	♦ measuring the perceived reactions of a family member towards the care of a child with chronic illness ♦ was subsequently developed to a single factor 15-item assessment tool. ♦ Easy to follow	♦ the focus is based on home care experience of families with chronically children
Family APGAR Family Adoptability, Growth , Affection, and Resolve Test (Smilkstein, 1978)	Family structure, function, and social support.	♦ Adoptability ♦ Partnership ♦ Growth ♦ Affection ♦ Resolve	♦ 5 items ♦ Quick to administer	♦ Measures relevant factors ♦ Can be completed by adults and children age 10 years and older	♦ Not to be used to evaluate a family problem in depth ♦ Has screening function

Tools (Author / Year)	**Supporting theories / models**	**Concepts Involved**	**Administration and scoring**	**Strength**	**Weakness**
FES Family Environment Scale (Fuhr, Moos & Dishotsky, 1981, Moos & Moos, 1976, 1984)	Interactionist perspective	♦ Relationship ♦ Personal growth ♦ System maintenance	♦ 90 items---true/false ♦ Scoring is complex ♦ Standardized scores; two categories	♦ Short from available ♦ Useful to measure ♦ Change after ♦ Interventions ♦ Measures real and ideal	♦ A research-oriented tool that does not have a clinical model associated with it, thus clinical utility is unclear.
PCSI Parental coping strategy inventory (Yeh, 2001)	Grounded theory	♦ Coping strategies ♦ Adaptation process	♦ 48 items ♦ 5-pointed Likert-scale	♦ Culturally specific to Chinese	♦ New and awaiting for more psychometric reports

Tools (Author / Year)	**Supporting theories / models**	**Concepts Involved**	**Administration and scoring**	**Strength**	**Weakness**
FFFS Feetham Family Functioning Survey (Robert & Feetham, 1982)	Ecological Systems Approach	♦ Three major areas of family relationships: ♦ Between family and broader social units such as school and work ♦ Between family and sub-systems within the family ♦ Between family and individuals within the family	♦ Somewhat complicated scoring	♦ Differences between what is and what should be are measured ♦ Identifies factors nurses could focus on ♦ Evidence of class-bias	♦ Somewhat difficult to understand ♦ Developed with families with handicapped children
FILE Family Inventory of Life Events and Changes (McCubbin, Patterson, & Wilson, 1981)	Double ABCX model	♦ Pile up of stressors or life events	♦ 85 items ♦ Can be hand scored ♦ Evaluates life changes on 9 different subscales	♦ Assesses stress in a family presently and over past year ♦ Examines the multiple stressors a family is experiencing	♦ May be difficult for family members to remember events within the past year

Tools (Author / Year)	Supporting theories / models	Concepts Involved	Administration and scoring	Strength	Weakness
CFAM Calgary Family Assessment Model (Wright & Leahey, 1994)	System theory Cybernetics theory Communication theory Change theory	♦ Structural developmental and functional assessment of the family	♦ As assessment and family intervention model does not have a paper and pencil measure for families to complete ♦ Interview questions are suggested by Wright & Leahey (1994)	♦ Comprehensive assessment model in evaluate multiple aspects of family life ♦ Data collected can be used directly to guide and support nursing interventions	♦ Repeated contacts with family are necessary and optimal to obtain comprehensive assessment data.
Family Satisfaction (Olson & Wilson, 1982)	Complex model	♦ Family satisfaction ♦ Cohesion ♦ Flexibility	♦ 14 items Likert scale ♦ Easily administered ♦ Simple scoring procedures ♦ Norms obtained	♦ Direct measures family satisfaction ♦ Takes into account normative backgrounds and cultural background	♦ None identified

Tools (Author / Year)	Supporting theories / models	Concepts Involved	Administration and scoring	Strength	Weakness
CHIP Coping Health Inventory for Parents (McCubbin, McCubbin, Cauble, & Nevin, 1979)	ABCX model Social support theory Family stress theory Theories of individual psychology of coping	♦ Coping behaviors ♦ Coping patterns ♦ Coping strategies	♦ 45 self-support coping behaviors ♦ Hand scored	♦ Each parent can complete the tool to get complete picture of family's overall coping strategies ♦ Can be used as pre- and post-test with intervention program aimed at strengthening coping	♦ Not designed to evaluate child members of the family
CICI: PQ Chronicity Impact and Coping Instrument Parent Questionnaire (Hymovich, 1983)	Crisis theory Coping theory	♦ Impact of child's chronic illness ♦ Perception s of stressors ♦ Coping strategies	♦ 48 items ♦ Scoring unknown	♦ Identified areas relevant for nursing intervention ♦ Can be used to measure outcome of intervention strategies	♦ Only for family with chronically ill child

Tools (Author / Year)	**Supporting theories / models**	**Concepts Involved**	**Administration and scoring**	**Strength**	**Weakness**
FACE III/ FACE IV Family Adoption and Cohesion Scale (Olson, 1994, Olson, Portners & Lavee, 1985; Olson et al., 1982)	Complex model	♦ Cohesion ♦ Adoptability, flexibility ♦ Communication ♦ Social desirability	♦ 30 items in four point scale ♦ Likert- scale ♦ Easy to administer	♦ Measure relevant for nursing ♦ Measures real and ideal perceptions of the family	♦ Family members may be unwilling to accesses themselves ♦ Assumes family have children

Sources: Partially adapted from Friedman, Bowden and Jones (2003); & Bowden, Dickey & Greenberg (1998)

APPENDIX 3.1 INTERVIEW GUIDE

訪問指引

1. Please describe your understanding of the reason for your child’s hospitalization.

   據你了解，孩子入院的原因是什麼？

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

   孩子的疾病和住院對你和你的家庭有什麼影響？試從工作、經濟狀況或家庭活動舉例說明之。

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

   孩子住院如何影響你的家庭關係？試從夫妻、子女、兄弟姊妹、親戚或朋友關係舉例說明之。

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

有什麼發生在醫院內的事情，令你和你的家人感到憂慮、不快和壓力？

5. How have you and your family responded to these things? (Use specific examples from Q4)

你和你的家人如何應付這些事情？(請以第四條的例子具體回答)

6. How do the nurses respond to your or your family' s distress?

護士如何應付你和你的家人的憂慮？

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

當你和你的家人感到憂慮時，護士做些什麼是能夠幫助你們呢？

8. What do the nurses do that is not helpful to you and your family when you are distressed?

當你和你的家人感到憂慮時，護士做些什麼是不能夠幫助你們呢？

9. What would you like the nurses to do when you and your family are distressed?

當你和你的家人感到憂慮時，你希望護士會做些什麼呢？

10. What would make the hospital experience easier for your child and your family?

怎樣能令你的孩子和家人更易於面對住院的經歷？

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

對於孩子住院的經歷，你還有什麼想告訴我？

APPENDIX 3.2 CODING FOR THEMATIC ANALYSIS

Code Name	Description	Examples (Qualitative data)	Items pool
1. Physical impact	Physical well being of parents was adversely affected during the child's hospitalization period. Physiological complaints such as fatigue, illness, problems with sleep and appetite were included.	♦ Travelling to the hospital is exhausting. I come and go three times a day….(QC5)	1
		♦ We both (parents) get sick as well because of exhaustion. It's really tiring…..(QA15, UBEXT2)	2,3,5,
		♦ I cannot sleep well while my child is in the hospital. (QA11,UBEXT1,UC4, GA10)	7-9
		♦ I am exhausted because of staying in the hospital for too long. I haven't seen the sun for many days. (UB7, UBEXT2)	4,11

Code Name	Description	Examples (Qualitative data)	Items pool
		♦ I eat with a sense of unease while my child is hospitalized.(QA13, GA10) ♦ I'm very tired (GA5)	10 6
2. Psychological or emotional impact	Psychological well being was adversely affected. Descriptions such as stress, feelings and emotional responses were included. This theme was most commonly reported as a problem: complaints are related to anxiety, intermittent emotional distress and worries heightened by symptom-related factors such as unpredictability of	♦ Our emotions fluctuate according to our child's medical condition. If we are told about his improvement, we'll be much relieved. I remember we felt very depressed the days when my child was very sick last week. Now, we are much better because he is now improved. (QA14) ♦ It drives me crazy…I'm too exhausted and worried. (UB7) ♦ I am more irritable because of exhaustion. (QA11)	15 16,17 12,16,14,31

Code Name	Description	Examples (Qualitative data)	Items pool
Psychological or emotional impact (continue)	health outcome.	♦ My partner becomes agitated and angers easily during this period of the child's hospitalization. (QA15, UB3) ♦ I'm worried and nervous. (UA5,QA15,QA13,UB10, GA1, GB1, GB2, GC8) ♦ I cannot concentrate at work while our child is still in the hospital. He doesn't want to go to work and prefers to stay with our child in hospital. He calls many times a day to ask about the boy. He rushes to the hospital after work every evening. (UA5) ♦ Daddy (my partner) misses his child and cannot concentrate at work. This affects his mood….he becomes irritable and angers easily…. (GB1)	14,18 21 16,17 19

Code Name	**Description**	**Examples (Qualitative data)**	**Items pool**
Psychological or emotional impact (continue)		♦ I feel guilty for not having done my best to care for my child, which resulted in this hospitalization. (UB3, GB1, GC8, GB8) ♦ Uncertainty about the disease is my biggest worry. (QC16, UC4) ♦ I feel nervous. I always think of some misfortune that can happen to my child in the hospital. (UC11) ♦ We worry that there might be long-term sequelae. (UBEXT1, QB18, UB3) ♦ I cannot concentrate at work while my child is still in the hospital. We always think of her while we are working. (UB3)	15,29, 30 21 24,23,34,35 17,20 23,16

Code Name	Description	Examples (Qualitative data)	Items pool
Psychological or emotional impact (continue)		♦ I’m filled with pain and sorrow when my child has pain for an unknown reason, nausea and vomiting. (QC5)	19,33
		♦ Grandparents worry a lot but it’s inconvenient for them to come for a visit. (UA12,UB3)	25
		♦ I feel distress because of some unhappy things that happened during hospitalization. …. Of course, I am very worried…extremely worried. I don’t know what is happening to my child. There is no known cause of his problem…..I suspect that may be related to brain condition, or due to a heart problem. I requested to have examinations on..…whatever investigations that can help finding out the cause of his disease, am I right?....But the doctor said it couldn’t be any faster. If time was my concern, I could consult the private sector….I was not able to answer but with tears.	32 16,24,25

Code Name	Description	Examples (Qualitative data)	Items pool
Psychological or emotional impact (continue)		(UC4)	
		♦ I'm very anxious and worry a lot about my boy's condition. I cry a lot particularly when he requires isolation. (GC6)	34 28
		♦ I worry and feel uncertain about his disease and the planned operation ……….. (GC11)	17,24
		♦ I feel sad. I don't want to tell others about her disease (Leukemia)…….. I need to bear the burden myself…… It's my burden anyway…… (GA6)	18,62
		♦ I worry a lot about my boy's illness…..I feel upset seeing that the other kids can go home but my boy cannot……. (a sigh) …. I also worry about the medical cost. (GB1)	27,16,24,77

Code Name		Description	Examples (Qualitative data)	Items pool
3. Family function related impact (3a,b,c,d,) Family functions include communications, relationships, activities, roles and responsibilities within a family.	**3a. Family activities and relationship**	Family activities and relationships were adversely affected during the period of hospitalization. Family activities were affected mostly because of frequent visiting and change of daily routine related to hospitalization of a child. Family relationships were affected due to a more complex consequence of changed family activities, reduced contact time, and dysfunctional family communications.	♦ Our daily activities (work, eating, and sleeping) are all being affected. (QA11, QA13, UB7, GA1,GC7, GB2, GA5,GA6,GA10,GB1,GB2,GB8,GC2,GC6,GC7,GC11) ♦ Frequent visiting and preparing food for my hospitalized child have affected my other family life activities. (UB3) ♦ All family members come to visit as if we are all being hospitalized. (GA5, UB3) ♦ As our family activities have all been affected, I cannot take my other child to and from school. (UBEXT1) ♦ We feel worried but do not want to talk about it with my family. (UB3) ♦ I better rely on myself for it would not help to discuss with my husband. I only would get angry after that. (QA11) ♦ We blame each other for the child’s condition (hospitalization). Grandma (mother-in-law) has complained of our carelessness in childcare. (UB7,GB2) ♦ I know she (my in-law) would say something this time. She just pretends to keep silent. (UB7) ♦ Relationship is affected because of the bad mood resulting from the child’s hospitalization experience. (UB7,UB3)	47 56 57 58,60 62 63 69 65 69 65 69,49,63

Code Name		Description	Examples (Qualitative data)	Items pool
	3b. Parental role and care	Practices related to childcare, child discipline and nurturing behaviors are affected. Parents became more tolerant of their children's behavior and family rules became loose in the hospital. Some parents tried their best to care but many felt they were helpless and incapable. Some other parents became more protective and tried to justify their children's abnormal behaviors.	♦ Family rules become loose while my child is in the hospital. We normally restrict him to watch TV or listening to CD. It's so boring in the hospital, so I let him do all these here. (QC18, GA1)	37
			♦ I (mother) cannot cook at home and my other kid(s) eat(s) junk food and whatever is available. (QC16)	55
			♦ I cook for him every meal in the hospital. Home cooking is always better. It doesn't matter if I'm busy or not. I come 3 times a day rushing for every meal. (QC5, UC6, GA10, GB8)	113
			♦ It is hard to rely on others to take care of my child. (GA5)	40
			♦ I would love to help with attending to my child in the hospital but I feel inadequate to do so. (GA10)	45
			♦ We don't know what to do about my child's condition.(UC4)	42
			♦ We are more tolerant of our child's behavior because s/he is in the hospital. We think he is affected by the illness, and maybe the medicine plays a role in making him uncomfortable and not behaving normally. (GC6)	36
			♦ We explain and encourage our child to face all challenges in the hospital. (QA13)	114

Code Name		Description	Examples (Qualitative data)	Items pool
	3c. Family role and responsibility – educational activities	Educational activities of the hospitalized children or the sibling(s) were adversely affected and found to be associated with the disrupted family roles and responsibilities. This was reported by more parents from Hong Kong than the Guangzhou families.	♦ I am busy taking his homework from school every day. It would not be good for her to get behind in school. (UB7)	44
			♦ My child cannot go to school and do the homework (GB1,GC6,GC7)	44, 107
			♦ As our family activities have all been affected, I cannot take my other child to and from school. (UBEXT1)	103
			♦ My elder daughter has problems keeping up in school because of frequent visiting to the hospital. We were asked to discuss her study problems at school with the teacher and principal. (QA14)	106,107
			♦ My other 8 years' old daughter has to move to live with grandma. Nobody supervise her homework. I seldom see her recently. (QA11)	106,107
			♦ This child's hospitalization affects the studies of my other boy. My elder son will sit for the high school public examination. I cannot support and care about him during these days. I just hope he can cope well. …. I feel sorry for him. But he is a big boy, he should learn to cope. (UB3)	104,105, 106
			♦ I miss my other 8-yr-old daughter and cry at times when I think about her (GA1)	50

Code Name		Description	Examples (Qualitative data)	Items pool
	3d. Sibling(s) effect	The descriptions of sibling experiences and their responses to the hospitalization of their siblings have indicated that there are special needs for these children family members.	♦ My hospitalized child misses his/her sibling(s). (UBEXT1)	100
			♦ We need special arrangements for the other sibling during the hospitalization period of this sick child. (QB17)	103
			♦ My other girl is 8 years old. She is very bright.... I have not seen her for a month. She is now staying with grandma in the village (4 hours by bus). I miss her very much…..(with tears). She called us a few times and said that she misses us very much but I cannot go back home because my younger boy is still sick in the hospital. She started to get jealous. (GA1)	101,102, 108,141, 156
			♦ My younger daughter is jealous about the way we treat her hospitalized sister, as too much allowance is being given. (QC18)	109

Code Name		Description	Examples (Qualitative data)	Items pool
4 Social impact (4 a,b,c) It revealed the complicated dimension of impacts that were associated with reduced social activities, financial concerns and extra burden particularly on	**4a. Social activities**	Many families were reported to have reduced social activities and less desire to enjoy life during the period of a child’s hospitalization.	◆ We see family and friends less because of hospitalization of my child. (QA11,QA14,UA16) ◆ Staying in the hospital is like living in a prison particularly during isolation (GA6) ◆ We have little desire to take a stroll because of my child's hospitalization. (QA14) ◆ I need to take a leave to look after my child in the hospital. (QA9, QA16) ◆ I need to quit my job to look after my hospitalized child. (QC5) ◆ I am very busy while my child is in the hospital. (UB7,QA9)	70 70 71 73 74 75

Code Name	Description	Examples (Qualitative data)	Items pool
4b. Financial concerns	Issues related to reduced income, increased expanses and financial concerns were reported by parents. Heavy financial cost was particularly a major problem reported by parents from Guangzhou.	♦ I need to quit my job and that affects family income. (QA11)	80
		♦ We have more expenses during the hospitalization (mobile phone and traveling expenses, etc.). (QC5)	81
		♦ I have no money….If I had money, I'd sought help from the private sector. (UC4)	82
		♦ I need to borrow money from relatives in order to cover the cost of medical expenses. (GA1,GA6, GB1)	77,78
		♦ The medical cost is expansive. I worry about the financial burden. (GA1,GA6,GA10,GB1,GB8,GC7,GC8,GC11)	77,78
		♦ I cannot do my business sales anymore while staying in the hospital with my daughter….it's a great loss….the medical cost is too expensive. I'm about to use up all my savings and need to borrow money from relatives. (GA6)	79,80
		♦ I stop working for 2 months ….and we spend over ¥40,000 (20 times of monthly salary) for medical expanses…..(GA6)	77,78,79,80

Code Name		Description	Examples (Qualitative data)	Items pool
	4c. Extra burden	Issues related to extra pressure and concurrent problems such as unemployment; in debt; marital problem; or a close relative was sick at the same time described the extra burden that some families were experiencing.	♦ We have an extra burden in daily care (to prepare food, entertainment…) for my child in the hospital. (QC5, UB3)	83
			♦ I borrowed ¥10,000 (10 times his monthly salary) from my relatives to continue treatment in the hospital. I left our village for 2 months and cannot do farming since admission. (GA1)	77,79,80
			♦ I cannot continue my business as a storekeeper for nearly two months. There is a great loss of income (~¥2,000 per month). We’ve spent over ¥40,000 for medical expenses. We’re now living on limited savings and loans. (GA6)	77,79,80
			♦ We have added pressure because my spouse is unemployed. (QC9);	85
			♦ Grandma (mother-in-law) is not happy. She must have blamed us for my child’s injury. She would not compliant because she knows that my husband is already beleaguered with…. My husband’s uncle was just admitted to the other hospital, so he is very busy running around different hospitals to visit his uncle and comes here for our son. My mother-in-law is also very distressed but she doesn’t say a word. (UB3)	86
			♦ No, we don’t talk to each other. He doesn’t (husband) care. How can we talk? Just let it be…..talking to him is a waste of time, I don’t bother to say a word……I don’t want to get angry….how could I say?….. it’s difficult to say..…it’s a personality problem, hai…(heaved a sigh)….I have tried to discuss the problem with his dad (husband) but it’s no use. I had to work out everything myself. (QA11)	84,86

Code Name	Description	Examples (Qualitative data)	Items pool
5. Health services related impact	Issues were related to the communication with health care workers, experiences of using health services, or expectations of services provided.	♦ You cannot expect too much because nurses are really busy. I can understand that…it's always like that…when a child was discharged during the day, and then a few more would be coming at night …..(UB3, UBEXT1, QB17, GA6) ♦ I feel that I am bothering the health professionals when in need of care. (QA9) ♦ We are concerned about the progress of my child's medical condition but we are not being well informed. (QC5, UC4) ♦ I feel anxious about the information and opinions being given. (UC4) ♦ I worry that some negative hospitalization experiences as mentioned by the media and friends may happen. (UB3) ♦ The doctor's expression and answer made me feel upset. (UC4)	89 90 92 93 94

Code Name		Description	Examples (Qualitative data)	Items pool
			♦ The ward routine and lighting at night has affected my sleep. (UC10) ♦ Other crying babies affect our life in the hospital. (GA6)	97 95
6. Coping	6a. Emotion	Self-control of emotion was described by some parents.	♦ I try to control my emotions (UBEXT2) ♦ I try to take it easy and to relax. (UC10, QB2) ♦ I would appear happy in front of my sick child (GA1)	110 111 110

Code Name		Description	Examples (Qualitative data)	Items pool
	6b. Family function	Positive changes were noticed in the readjustment of family roles and activities. Family communication and relationship were also improved due to the hospitalization of a child in some families.	♦ We support each other as a family during this period of hospital stay. (UA16,GC6,GC7)	135
			♦ My partner takes over the role of doing housework. (QC9)	137
			♦ My hospitalized child expressed more of his/her inner world to the parents because of the increased opportunities in the hospital environment. (UC6)	134,127
			♦ The other family members (including extended family) all take turns visiting the hospitalized child, or looking after the other children at home. (UB10, UC10, QC18, GA1, GA5,)	130,141
			♦ We have mobilized everyone to take part. (UA12, UB10, QC18, GA1,GA5,)	131,140, 156
			♦ Family relationship is strengthened through the hospitalization experience. (UB10, UC6, GC6)	127,133, 134,135
			♦ We do not expect too much and do not plan for too long. (GA6)	136
			♦ My partner and I discuss my child's problems together. (QA11,QA16)	128

Code Name		Description	Examples (Qualitative data)	Items pool
	6c. Parental role	Active parental role and participation was noticed for the care of the hospitalized child.	♦ We (parents) both need to take leave from work to look after my child in the hospital and the other sibling(s) who stay at home. (QA9)	112
			♦ We explain to and encourage our child to face all challenges in the hospital. (QB17,QA13)	114
			♦ We use drawing to divert my child’s attention from the impact of hospitalization. (QA13)	115
			♦ We stay with him all the time. (QC18,QA11,QB17)	119
			♦ I prepare food for him. Home cooking is always better for my child. (GA10, GB8,UC6,UB10)	113

Code Name		Description	Examples (Qualitative data)	Items pool
	6d. Family - sibling(s)	Some siblings were able to readjust themselves positively during the period of hospitalization of their brothers or sisters.	♦ The other sibling(s) become(s) more mature and independent. (UB3)	153
			♦ The other sibling(s) is / are much better behaved, extraordinarily well regimented during this period. (UC4)	154,155

Code Name		Description	Examples (Qualitative data)	Items pool
	6e. Social	Parents’ coping strategies include readjustment of personal and family activities, and to seek and receive external help.	♦ We do not plan for a holiday or to take a stroll during this period. (QA16, GB2)	136,139
			♦ We are cutting down the hours we work to care for my child in the hospital. (GA1, GA5, GA6,QA9,QA16)	144,142
			♦ I quit my job to look after my hospitalized child in the hospital. (QC5)	143
			♦ Other relatives help to look after the hospitalized child or the other child at home, or to support daily chore. (UB10)	140,141, 156
			♦ We ask for help from our neighbours and friends during my child’s hospitalization. They help looking after my other child at home. (UC4, QB17, GC2)	138,140

	6f. Health services related	The descriptions of hospitalization experience in relation to health service utilization included mixed feelings of helplessness, distrust, struggles, to acceptance and coping behaviors.	♦ We try to find out the cause of the disease because doctors could not explain the situation. (QC16) ♦ They are too busy….We cannot expect too much. We understand that… (QA9,QB2,UB3), ♦ We ask other people about their hospitalization experiences. We cannot trust the public services…. We keep asking about his condition and look after him closely. (QC5,GA5) ♦ We do not expect too much and accept the hospital environment, including the noises. (QA13, QC18) ♦ We try to tolerate as much as possible while we are in the hospital. (QA13) ♦ I cooperate with the ward routine and staff. (UB3) ♦ I would not rely solely on the public medical service but to seek more advice from friends. (QC5)	145 147 149 148 151 152 150

APPENDIX 3.3 INITIAL ITEM POOL

Physical

1. Travelling to the hospital is exhausting.

   往反醫院的路途是辛苦的。

2. I feel tired because of my child's hospitalization.

   因小兒住院，我感到勞累。

3. My own health is adversely affected because of my child's hospitalization.

   我的健康狀況因小兒住院而變得更差了。

4. I cannot sleep well while my child is hospitalized.

   小兒住院期間，我難以安睡。

5. Both parents get sick as well.

   父母也同時病了。

6. I eat with a sense of unease while my child is hospitalized.

   小兒住院期間，我吃也不安樂。

7. I am about to get sick with exhaustion.

   我因疲勞過度而快要病了。

8. I am very tired caring for my child in hospital.

   我因在醫院照顧小兒，非常疲勞。

9. I am fatigued resulting from frequent visiting.

   我因頻繁探病而力盡筋疲。

10. I am exhausted resulting from staying in hospital for too long.

    我因在醫院停留太長時間而精疲力竭。

11. My partner cannot sleep well while my child is hospitalized.

    我的配偶在小兒住院期間難以安睡。

12. It looks like I'm mentally broken down but I think this is just due to sleep deprivation.

    我看似是精神崩潰，但相信只因為睡眠不足。

Psychological / emotional

13. Our emotions fluctuate according to our child's medical condition.

我們的情緒跟孩子的病況起伏。

14. I become irritated resulting from exhaustion.

我因太疲累而變得易於被激怒生氣。

15. My partner becomes irritable and angers easily during this period of the child's hospitalization.

當孩子在醫院期間，我的配偶變得十分激動不安，易於發怒。

16. I worry a lot.

我十分憂慮。

17. I feel nervous.

我內心緊張、擔心和膽怯。

18. I am in a bad mood.

我心情不好。

19. I cannot concentrate at work while my child is still in the hospital.

孩子還在住院，我做事未能專心。

20. I am apprehensive about misfortune that may happen in the hospital.

我擔心會有不幸的事可能在醫院內發生。

21. I feel guilty for not having done my best to care for my child, which resulted in this hospitalization.

我內疚照顧不周以致孩子需要住醫院治療。

22. Not knowing what is happening about my child's condition makes the whole family worry a lot.

當未了解孩子的病況，整個家庭都感到十分焦慮。

23. We worry that there might be long term sequelae.

我們擔心將來的後遺症。

24. Uncertainty about the disease is my biggest worry.

我最擔憂的是疾病之不明朗因素。

25. I'm filled with pain and sorrow when my child has pain for an

unknown reason, nausea and vomiting.
孩子因不明因素而感到痛楚、噁心、嘔吐，我感到十分痛苦和憂傷。

26. I feel guilty for the accident leading to my child’s hospitalization.
我為那意外以引致孩子需要住院感到內疚。

27. I feel miserable for my child being in hospital for so long.
要住院那麼久，我心痛小兒受苦了。

28. I feel distress because of some unhappy things that happened during hospitalization.
在院期間發生了一些不愉快的事情，我感到悲痛起來。

29. My partner misses our child much during his hospitalization.
我的配偶很掛念留院的孩子。

30. My partner worries our hospitalized child so much that it adversely affects his work.
我的配偶因太擔憂留院的孩子而影響他的工作。

31. I found it hard to explain my emotion while my child is still in the hospital.
當孩子還住院時，我不懂怎樣形容自己的情緒。

32. Grandparents worry a lot but it’s inconvenient for them to come for a visit.
祖父母都很擔憂，但他們又不便探訪。

33. I cannot concentrate at work because of the worries about my child being hospitalized.
因太擔憂住院孩子，我在工作上不能集中精神。

34. I am concerned about the progress of my child’s medical condition.
我擔憂小兒的病情進度。

35. I am worried about the progress and the chance of relapse of the disease.
我擔憂孩子的病情進度和復發機會。

Parental role and care

36. We are more tolerant of our child because s/he is in the hospital.
因他/她住院，我們會多一點容忍小孩。

37. Family rules become loose during my child’s hospitalization.
在住院期間，我們的家規也會被降低。

38. Sometimes we wonder how to deal with my child while s/he is in the hospital.
孩子住院期間，有時也不知如何處理他/她。

39. I think about not having more children because of this hospitalization.
因他/她的住院，我會考慮不想再生小孩。

40. It is hard to rely on others to take care of my child.
要依賴別人來照顧自己的小孩是十分困難的。

41. We consider my child's condition is serious.
我們覺得小兒的病情是嚴重的。

42. We don't know what to do about my child's condition.
對於孩子的情況，我們也不知怎麼辦。

43. My partner has to come to visit our hospitalized child after work.
我的配偶下班後一定要來院探病。

44. I am busy taking his homework from school every day.
每天我都忙於到他/她的學校取功課。

45. I would love to help with attending to my child in the hospital but I feel inadequate to do so.
在院我也想協助照顧孩子，但感無能為力。

46. I am concerned that my child’s studies will be affected by this hospitalization.
我擔心小兒的學習進度會被住院影響。

Family function

47. Our daily activities (bathing, eating, and sleeping) are affected.
我們的日常生活 (洗澡，吃及睡覺)也受影響。

48. Our family gives up things because of my child's hospitalization
為了孩子住院，我們都要放棄很多事情。

49. My child's hospitalization creates tension on our martial relationship.
孩子的住院使我們的婚姻關係緊張。

50. We don't have much time left over for other family members after caring for my hospitalized child.
照顧住院孩子後，便沒有太多時間留给其他家人。

51. I live from day to day and don't plan for the future due to my child's hospitalization.
因孩子住院，我只活在當下，不作他朝之想。

52. Visiting my child in the hospital has affected our family's daily life.
到醫院探病已對我們的日常家庭生活造成影響。

53. We are not enthusiastic to talk about our burden to others.
我們不喜歡向外人講及我們的負擔。

54. I'm distressed because I cannot do the housework.
我因未能承擔家務而苦惱。

55. Mother cannot cook at home and the other kid(s) eats junk food and whatever is available.
母親未能在家煮食，其他子女只好隨便亂吃了。

56. Frequent visiting and preparing food for my hospitalized child have affected my other family life activities.
為了住院孩子的頻繁探病及煮食，我的其他家庭生活已受影響。

57. All family members come to visit as if we are all being hospitalized.
全家都忙於探病，就像大家都是住院一般。

58. Our family life is affected.
我的生活已受影響。

59. We could only communicate through mobile calls and it is inconvenient.
我們只能依賴電話聯絡，十分不便。

60. As our family activities have all been affected, I cannot take my other child to and from school.

我們的家庭生活已全受影響，我未能帶另外一個孩子往反學校。

61. Grandparents and other siblings also worry about the hospitalized child.

祖父母及其他兄弟姊妹也為住院孩子憂心。

62. We feel worried but do not want to talk about it.

大家都感擔心但都不想說出來。

63. I better rely on myself for it would not help to discuss with my spouse.

跟配偶討論是沒幫助的，我依靠自己還好。

64. The other child at home is being temporarily looked after by grandma.

祖母暫時在家照顧另一位孩子。

65. We blame each other for the child’s condition / hospitalization.

為小兒的留院，我們互相責備大家。

66. We seldom have a chance to talk about problems we encountered during hospitalization of our child.

住院期間，家人很少機會談論大家面對的難處。

67. Because of hospitalization, we have to cancel some family activities.

因孩子住院，我們要取消一些家庭活動。

68. All family members are involved in dealing with this hospitalization experience, thus our daily lives are being affected.

全家總動員應付今次住院，日常生活難免受影響。

69. Relationship is affected because of the bad mood resulting from the child’s hospitalization experience.

因孩子住院所引致的壞心情影響了大家的關係。

Social

70. We see family and friends less because of hospitalization of my child.

因孩子住院，少見了家人及朋友。

71. We have little desire to take a stroll because of my child's hospitalization.

因孩子住院，我們都不渴望外出閒逛。

72. Because of the hospitalization we are not able to travel out of the city.

因孩子住院，我們未能外出旅遊。

73. I need to take a leave to look after my child in the hospital.

因孩子住院，我要請假照顧他/她。

74. I need to quit my job to look after my hospitalized child.

因孩子住院，我要辭職照顧他/她。

75. I am very busy while my child is in the hospital.

小兒在院期間，我十分忙碌。

76. It is difficult to arrange for my time during this period.

住院期間，很難安排時間。

Social - financial

77. The illness and hospitalization is causing financial problems to the family.

因孩子患病住院導致家庭經濟出現困難。

78. Extra income is needed in order to cover medical expenses.

為要支付醫藥費，家庭需要額外收入。

79. Time is lost and income is reduced from work because of hospital appointments and visits.

因探病及醫療預约失去了工作時間，減少收入

80. I need to quit my job and that affects family income

我因要辭職而影響了家庭收入。

81. We have more expenses during the hospitalization (mobile phone and traveling expenses, etc.).

住院期間，我們需花費更多（電話及交通费等）。

82. I feel miserable that I have no spare money for my child to consult other doctors.

因沒有餘錢給孩子看多些其他醫師，我感到悽慘。

Social - extra burden

83. We have an extra burden in daily care (to prepare food, entertainment) for the hospitalized child.

為了住院的孩子，我們背起了額外的擔子 (預備食物、娛樂等)。

84. Nobody understands the burden I have borne.

無人了解我所背負的擔子。

85. We have added pressure because my spouse is unemployed.

因配偶現正失業，我們有更大的壓力。

86. We have other problem(s) at the moment (e.g., unemployment; marital problem; a close relative is sick).

我們現正面對其他困難(例如:失業；婚姻問題；另一親人也患病)。

87. Besides hospitalization, our family is facing other challenge(s) at the same time. (e.g., a new job / school, job related demand…)

我們現正面對其他挑戰 (例如:新職位；新學校；工作有關要求..)。

88. This hospitalization has aggravated our other family problems.

這次住院凝聚了我們其他的家庭問題。

Health services related

89. We have feelings that hospital staff are too busy to help.

我們感到醫院職員忙不過來。

90. I feel that I am bothering the health professionals when in need of care.

當需要幫助時，我感覺是打擾了醫護人員。

91. I am not familiar with the hospital environment.

我對醫院環境並不熟悉。

92. We are concerned of the progress of my child’s medical condition but

we are not being well informed.

我擔心小兒病況進展，但情況未被詳細解釋。

93. I feel anxious about the information and opinions being given.

對所提供的資料及意見，我感到憂心。

94. I worry that some negative hospitalization experiences as mentioned by the media and friends may happen.

我擔心會發生一些媒體及朋友所提及醫院的負面經驗。

95. The ward routine and the lighting at night affect sleep.

病房常規及晚上的燈光影響睡眠。

96. I am desperate for the doctor to come for a review.

我極想醫生到來(再)檢查。

97. The doctor’s expression and answer made me feel sad.

醫生的表達使我很悲傷。

98. We feel upset because of some unhappy things that happened during hospitalization.

在院期間發生了一些不愉快的事情，我感到心煩意亂。

99. I am not happy with some of the health professional’s skills.

我不滿某些醫護專業技巧。

Sibling(s)

100. My hospitalized child misses his/her sibling(s).

住院的孩子很掛念在家的兄弟姊妹。

101. The other sibling(s) misses this hospitalized child.

在家的兄弟姊妹很掛念住院的孩子。

102. The other sibling(s) is / are jealous of the time we spend on this hospitalized child.

在家的兄弟姊妹對父母為住院孩子所花的時間感到妒忌。

103. We need special arrangements for the other sibling during the hospitalization period of this sick child.

因孩子住院，我們需要為其他在家的子女作出特別安排。

104. The other child(ren) is (are) being adversely affected during this

period of hospitalization.

因孩子住院，對在家的子女也有不利的影響。

105. I have no time to look after the other child at home.

我沒有時間看顧其他在家的孩子。

106. This child’s hospitalization affects the studies of the other sibling(s).

這孩子住院，影響了其他兄弟姊妹的學業。

107. The other sibling(s) has/have problems catching up in school because of this hospitalization.

因孩子住院，在家的兄弟姊妹未能跟上學校的學習進度。

108. The other child complains that I don’t spend time with him/her.

其他在家的孩子抱怨我不花時間陪伴他/她。

109. The other sibling(s) is /are jealous about the way we treat the hospitalized child as too much allowance is being given.

其他的兄弟姊妹妒忌父母對住院孩子太包容。

Coping strategies

Psychological / emotional

110. I try to control my emotions.

我嘗試抑制情緒

111. I try to take it easy and to relax.

我嘗試放鬆心情。

Parental role

112. We (parents) both need to take leave from work to look after my child in the hospital and the other sibling(s) who stay at home.

我兩都要請假以照顧住院及在家的孩子。

113. I prepare food and bring it to the hospital for my child.

我會預備食物並帶到醫院给小兒享用。

114. We explain to and encourage our child to face all challenges in the hospital.

我會解釋及鼓勵小兒面對所有醫院內的挑戰。

115. We use drawing to divert my child’s attention from the impact of hospitalization.

我用畫畫來幫助孩子轉移住院對他/她的影響。

116. We told him stories about hospitals and doctors to help him/her cope with it better.

為使孩子應付得更好，我會說一些關於醫院和醫生的故事。

117. We make use of what we see in the hospital as a teaching tool to help him grow.

我會利用醫院所見事物作為教材，令他/她成長。

118. We observe my child very closely and take care of him ourselves.

我們緊密的觀察孩子，親自照顧他/她。

119. We stay with him all the time.

我們全時間留守他/她身邊。

120. I talk to the child and try to explain everything around him.

我和孩子談話並向他/她解釋所有事物。

121. I try my best to help during his/ her stay in the hospital.

住院期間，我會盡力幫孩子。

122. I keep asking the doctors and nurses questions, and I monitor the child more closely myself.

我不斷地追問醫護人員，並親自監察小孩。

123. I’m not worried and I feel relieved when my child stays in the hospital.

我不憂慮，小孩留院我會更安心。

124. I am delighted with learning how to manage this hospitalization of my child.

學會處理孩子留院的問題，我也感到欣慰。-

125. We try to treat my child as if s/he were a normal child.

我會把孩子像正常地對待。

126. I would try my best to reassure and explain to my child about his/her concerns, even when it is an unknown medical condition.

就算醫學找不出病因，我也會嘗試安慰及解釋小兒所擔心的問題。

Family function

127. Because of what we have shared, we are a closer family.

因為我們的分享，便成了更親密的一家

128. My partner and I discuss my child's problems together.

配偶與我一起商量孩子的問題。

129. My family is clear about what each member should do to cope with this hospitalization.

家人都清楚各自要做的事以應付住醫院的挑戰。

130. The other family members (including extended family) all take turn to visit the hospitalized child.

其他家人(包括祖父母)輪流到醫院探病。

131. We have mobilized everyone to take part.

我們已動員所有家人合作。

132. I discuss with my spouse on issues related to hospitalization of my child.

我與配偶商討孩子住院事宜。

133. During the hospitalization of my child, the family relationship is closer despite we have fewer occasions to meet face to face.

盡管見面少了，家人關係更親密。

134. My hospitalized child expressed more of his/her inner world to the parents because of the increased opportunities in the hospital environment.

因在醫院多了接觸機會，我兒表達了更多的心底話。

135. We support each other as a family during this period of hospital stay.

住院期間，家人都互相支持。

136. We do not expect too much and do not plan for too long.

我們不期望太多，也不作太長遠計劃。

137. My partner takes over the role for housework.

配偶取代了做家務的角色。

Social

138. We ask for help from our neighbors during my child's hospitalization.

住院期間，我們向鄰居求助。

139. We do not intend to take a stroll during this period.

這期間，我們不計劃閒逛。

140. My relatives and friends have been understanding and helpful.

親友都很理解並作出幫忙。

141. Other relatives help to look after the hospitalized child.

其他親戚都幫助照顧住院孩子。

142. I have taken leave from work to look after my child in the hospital.

我已申請假期來照顧住院孩子。

143. I quit my job to look after my hospitalized child.

我放棄工作以照顧住院孩子。

144. We are cutting down the hours we work to care for my child.

我們減少工時以照顧住院孩子。

Health services

145. We try to be involved in many aspects of care and decisions for my child in this hospital.

我們嘗試參與多方面的照顧及決策。

146. We follow health care professional's advice without reservation.

我們毫不猶疑地跟從醫護人員的意見。

147. We try our best to be more understanding to staff members.

我們對醫護人員盡量通情達理。

148. We do not expect too much and accept the hospital environment, including the noises.

我們不會期望太多，只管接受醫院環境，包括噪音。

149. We ask other people about their hospitalization experiences.

我們會向多一些朋友詢問有關住院的經驗。

150. I would not rely solely on the public medical service but to seek more advice from friends.

我不會只靠公共醫療服務，我會向朋友多方尋求意見。

151. We try to tolerate as much as possible while we are in the hospital.

當我們在醫院時，大家都盡量容忍。

152. I cooperate with the ward routine and staff.

我對病房常規及職員都抱合作態度。

Sibling

153. The other sibling(s) become(s) more mature and independent.

其他子女變得更成熟獨立。

154. The other sibling(s) at home has / have to learn to adjust during this period of hospitalization

這留院期間，在家的子女要學習適應。

155. The other sibling(s) is / are much better behaved, extraordinarily well regimented during this period.

在家的子女都表現更佳，格外地受管教。

156. We cannot look after the other sibling(s) and he/she has to live with other relatives temporarily.

我們未能照顧其他在家的孩子，他/她要跟其他親人同住。

APPENDIX 3.4 PILOT STUDY – ROTATED COMPONENT MATRIX(a) OF THE HOSPITALIZATION IMPACT SUBSCALE

	Component					
	1	2	3	4	5	6
don't know how to deal with child's emotion	.787					.307
feels guilty of inadequate care given to child	.782					
emotional	.694		.487			
worries of misfortune happen in hospital	.668		.523			
do not want to disturb busy staff	.579	.300			.429	
consider the child's condition as serious	.568			.350		
tolerate the child's behavior more	.554	.328				.382
cannot rely on others to care for the child	.553				.383	
no time left for other family members		.842				
less chance to take a stroll		.759				
less chance for social contact		.723				.439
too busy to arrange schedule		.719				
daily life has changed		.700				
feel tired		.673				
cannot finish housework		.641		.301	.315	
health getting worse		.498				.361
cannot concentrate at work			.805			
agitated			.752			
cannot eat well		.363	.655			
feels sorry for the child being suffer in hospital	.504		.646	-.321		
cannot sleep well			.627		.517	.328
concerns of disease progress	.581		.624			
need to give up things			.489		.310	
blame each other for inadequate care				.813		

less chance to talk about problems				.804		
bad mood affects relationship				.700		.526
HC workers did not explain the child' condition	.479			.630		
want to care but don't know how	.422		.538	.581		
extra burden in daily care					.786	
earning less resulting from reduced work	.339				.734	
more expanses (medical, traveling)			.399		.619	
nobody understands our burden			.398	.394	.564	
ward routines affect daily life		.352				.694
not convenient to use TCM or alternative therapy						.673
cannot adapt ward environment	.343				.448	.565
worries of malpractice., negative experiences	.455			.442		.547

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a Rotation converged in 17 iterations.

APPENDIX 3.5 PILOT STUDY – ROTATED COMPONENT MATRIX(a) OF THE HOSPITALIZATION COPING SUBSCALE

	Component			
	1	2	3	4
try to relax	.742			
hope	.665		.510	
prepare food for my child	.654			
mutual support	.594			
use reflection to comfort ourselves	.468	.458		.304
encourage talk		.806		
treat my child as normal	.423	.753		
reckon hospital is safer for my child		.660		
keep asking HC workers & observe my child	.408	.531		
Less work for childcare			.844	
ask friends about hospital		.399	.602	
cooperative	.530	.321	.559	
stay close to the child, close observation	.350		.547	
ask & accept help				.803
No long term plan				.767

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

a Rotation converged in 10 iterations.

APPENDIX 3.6 HOSPITALIZATION IMPACT AND COPING SCALE (ENGLISH)

For Staff /Researcher Only

Unit: ___________________

I.D.No.: ______________

Date: _________________

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.

To be completed by parents ☐
To be completed by researcher ☐

DEMOGRAPHIC SHEET

Child Information

(Please circle where appropriate)

Name of Child： ___________

Gender： Male / Female

Age of Child： _____Years_____Months

Ethnicity： Guangdong / Other Province (______________)

Diagnosis /Reason for hospitalization：

Respiratory infections/ NNJ / Blood abnormalities / Haemophilia / Heart disease/ Leukemia / Cancer

____

Surgical procedures (if applicable):

____

(Name of Operation)

Length of hospital stay: _____________ (days since admission)

Admission record:

No. of previous hospitalizations ______

The last hospital admission date:

(if applicable):
______year______month

Family Information

(Please circle or ☑ where appropriate)

Who completed the questionnaire? Father / Mother

Father : _______ years old

Profession: Driver / businessman/worker/ civil servant / farmer/ professional /unemployed/ or________

Education: primary / lower secondary / higher secondary / tertiary or above

Mother : _______years old

Profession: housewife / businesswoman/ worker / civil servant / farmer/ professional /unemployed/ or________

Education: primary / lower secondary / higher secondary / tertiary or above

Who lives with the child? (may ☑ more than one answer)

☐ father
☐ mother
☐ child's other siblings **(age) :**
______years old;____ years old;______ years old
☐ grandmother
☐ grandfather
☐ other (please state) : ____________________

Family total income

☐ below 1,000
☐ 1,001 – 2,000
☐ 2,001 – 4,000
☐ 4,001 – 6,000
☐ above 6,001

Religion ： atheist / ancestor worship / Catholic / Christian / Buddhist / Taoism, or ______

Present residential city: Guangzhou/ Village / County ________

Duration of stay_______________(Year)

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.	lost 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 at 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 (causes, treatment, sequela).	0	1	2	3	4	X
12.	are more tolerant of our child’s misbehavior.	0	1	2	3	4	X
13.	do not 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 care for my child but feel inadequate to do so.	0	1	2	3	4	X
17.	daily life (work, activities and recreation) need 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.	do not 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

(Please ○ or ✓ in the appropriate response)

While my child is hospitalized, we / our		**No impact**	**Little impact**	**Some impact**	**Great impact**	**Extreme impact**	**NA**
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.	lose time from work with reduced income.	**0**	**1**	**2**	**3**	**4**	**X**
28.	have more expenses (e.g., travel and medical expenses).	**0**	**1**	**2**	**3**	**4**	**X**
29.	have extra burdens (daily care, food preparation, teaching).	**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 (e.g., Chinese medicine).	**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 (e.g., noises, lighting, or hygiene, etc).	**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 (e.g. visiting, meal time, night observations).	**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 ________________________________		**0**	**1**	**2**	**3**	**4**	**X**
Please describe other impacts ____							

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**	**No attempt**
37.	try to relax and control emotion.	**0**	**1**	**2**	**3**	**4**	**X**
38.	support each other and share responsibilities.	**0**	**1**	**2**	**3**	**4**	**X**
39.	stay close to our child.	**0**	**1**	**2**	**3**	**4**	**X**
40.	prepare food for our child.	**0**	**1**	**2**	**3**	**4**	**X**
41.	keep asking doctors and nurses questions, and monitor the child closely ourselves.	**0**	**1**	**2**	**3**	**4**	**X**
42.	consider hospitalization can be more of a relief to us.	**0**	**1**	**2**	**3**	**4**	**X**
43.	make use of what we see in the hospital as learning experiences.	**0**	**1**	**2**	**3**	**4**	**X**
44.	treat our child as usual.	**0**	**1**	**2**	**3**	**4**	**X**
45.	encourage family members, including the sick child, to express their inmost feelings.	**0**	**1**	**2**	**3**	**4**	**X**
46.	do not expect too much and do not plan for too long.	**0**	**1**	**2**	**3**	**4**	**X**
47.	seek and accept help from relatives and friends.	**0**	**1**	**2**	**3**	**4**	**X**
48.	hope things will get better.	**0**	**1**	**2**	**3**	**4**	**X**
49.	cut down working hours to participate more childcare.	**0**	**1**	**2**	**3**	**4**	**X**
50.	ask relatives and friends about hospitalization experiences.	**0**	**1**	**2**	**3**	**4**	**X**
51.	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: ______________________________________							

If your family has only one child, you can ignore the following questions (You may write your other opinions in the space at the bottom of this page)

(Please ○ or ✓ in the appropriate response)

If your family has other children, please answer the following questions according to the level of impacts.		**No impact**	**Little impact**	**Some impact**	**Great impact**	**Extreme impact**	**NA**
1.	The siblings miss each other.	⓪	①	②	③	④	⊗
2.	Hospitalization affects other sibling(s)' studies.	⓪	①	②	③	④	⊗
3.	Other sibling(s) jealous of the way we treat the sick child with more tolerance.	⓪	①	②	③	④	⊗
If your family has other children, please answer the following questions according to the effectiveness of strategies.		**No effect**	**Little effect**	**Some effect**	**Great effect**	**Excellent effect**	**No attempt**
4.	Ask other siblings to learn to adjust	⓪	①	②	③	④	⊗
5.	Request other sibling take responsibilities and be mature	⓪	①	②	③	④	⊗
6.	Arrange other relatives to take care of the other sibling(s)	⓪	①	②	③	④	⊗

If necessary, you may record your other opinions based on this hospitalization experience.

End of the questionnaire

Thank You

APPENDIX 3.7 HOSPITALIZATION IMPACT AND COPING SCALE (CHINESE)

病房 / 床号：
编号:
日期:

研究 / 职员专用

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。

由父母填写 □
由研究员填写 □

人口统计资料

子女资料

（在适用处，**可打圈。**）

子女姓名：____________

子女性别： 男 / 女

子女年龄： _____岁______月

籍贯： 广东 / 外省（________）

病症 / 入院原因：

呼吸道感染 / 黄胆 / 血小板异常 / 血友病 / 心脏病/ 白血病 / 癌病

____

外科治疗(如适用)：

____

（手术名称）

住院期：入院至现在为第 ____ **天**

住院记录：

曾入院次数 __________

前次入院年份/日期：

（如适用）： 20___年____月

家庭资料

（在适用处，**可打圈或☑。** ）

此问卷之填报人**与病童关系** ： 父 / 母

父亲 ： ________ 岁

职业： 司机 / 商人/ 工人/ 干部 / 农民/ 专业 / 失业/ 或_________

学历： 小学 / 初中 / 高中 / 大专或以上

母亲 ： ________岁

职业： 主妇 / 商人/ 工人/ 干部 / 农民/ 专业 / 失业/ 或_________

学历： 小学 / 初中 / 高中 / 大专或以上

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）：______________________

家庭每月总收入

□ 1000 以下
□ 1,001 - 2,000
□ 2,001 - 4,000
□ 4,001 - 6,000
□ 6,001 以上

宗教：无信仰 / 拜祖先 / 天主教 / 基督教 / 佛教 / 道教 或 _______

现居住城市： 广州 / 农村 / 县市_________

居住年期___________

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

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**
21	互相怪责照顾不力	**0**	**1**	**2**	**3**	**4**	**X**
22	很少机会谈论大家要面对的困难	**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(交通及医药费等)	**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，外人难以了解	**0**	**1**	**2**	**3**	**4**	**X**
31	不能随意采用其他治疗方法（例如中成药、药油等）	**0**	**1**	**2**	**3**	**4**	**X**
32	感到医护人员忙不过来，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	未能详细了解病况	**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、探病规限、晚间巡查等)	**0**	**1**	**2**	**3**	**4**	**X**
压力更大，因现正面对其他困难(例如:失业；工作压力；婚姻问题；另一亲人也患病)，**请圈及说明：** ________		**0**	**1**	**2**	**3**	**4**	**X**

试描述**其他**的影响 ______________________________

以下是一些***方法以应付住院的影响***，就这次住院经验，请根据您的家庭情况，评定那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✓)

为**<u>应付住院</u>**的影响，我(们):		**无效**	**少成效**	**一般成效**	**很有效**	**极有效**	**未有试行**
37	尝试抑制情绪，放松心情	**0**	**1**	**2**	**3**	**4**	**X**
38	一家人互相支持，合力分担责任	**0**	**1**	**2**	**3**	**4**	**X**
39	尽量留守子女身边	**0**	**1**	**2**	**3**	**4**	**X**
40	预备食物给子女享用	**0**	**1**	**2**	**3**	**4**	**X**
41	不断询问医护人员，并亲自监察照顾子女	**0**	**1**	**2**	**3**	**4**	**X**
42	把子女留院，视为更安心	**0**	**1**	**2**	**3**	**4**	**X**
43	从住院经历中学习	**0**	**1**	**2**	**3**	**4**	**X**
44	以平常态度看待小儿	**0**	**1**	**2**	**3**	**4**	**X**
45	鼓励家人及病童更多表达心底话	**0**	**1**	**2**	**3**	**4**	**X**
46	不期望太多，也不作太长远计划	**0**	**1**	**2**	**3**	**4**	**X**
47	向亲友求助，接受帮忙	**0**	**1**	**2**	**3**	**4**	**X**
48	希望明天会更好	**0**	**1**	**2**	**3**	**4**	**X**
49	减少工时以便参与更多照顾	**0**	**1**	**2**	**3**	**4**	**X**
50	向亲友詢问有关住院的经验	**0**	**1**	**2**	**3**	**4**	**X**
51	尽量容忍，抱合作态度	**0**	**1**	**2**	**3**	**4**	**X**
找到了方法帮助子女克服住院的影响（看电视、玩具等） 请说明：____							
用<u>其他</u>方法克服住院对家庭的影响，请说明： ____							

如家庭只有一位子女，以下无需回答。(如有需要，可在空白处记下您的其他意见。)

（请 在适当处画○ 或 ✓）

如果**家中还有其他子女**，请跟据***受影响程度***回答以下问题。		没有影响	少许影响	有些影响	很有影响	极有影响	不适用
1.	子女们都互相挂念	⓪	①	②	③	④	⊗
2.	住院影响了其他子女的学业	⓪	①	②	③	④	⊗
3.	其他子女妒忌父母对住院子女太包容、太偏倚	⓪	①	②	③	④	⊗
如果**家中还有其他子女**，请跟据**成效**回答以下问题。		试行但无效	少成效	有些成效	很有效	极有效	未有试行
4.	要求其他子女学习适应	⓪	①	②	③	④	⊗
5.	要求其他子女学习成长、分担责任	⓪	①	②	③	④	⊗
6.	安排其他子女给其他亲友照顾	⓪	①	②	③	④	⊗

如有需要，可就这次住院经验，在此处记下您的其他意见。

本卷完，谢谢！

APPENDIX 4 ETHICAL APPROVAL LETTER - 1

THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學

MEMO

To : Prof. Susan Kools
From : Dr. Samantha Pang
Ref : ______ **In :** ______ **Your Ref :** ______ **in :** ______
Tel No. : X6409 **Fax No. :** ______
E-mail : ______ **Date :** 8 May, 2001

Ethical Review of Research Project
Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following research project:

Project title : Psychosocial Functioning of Hospitalized Chinese Children and Their Families

Principal Investigator : Prof. Susan Kools

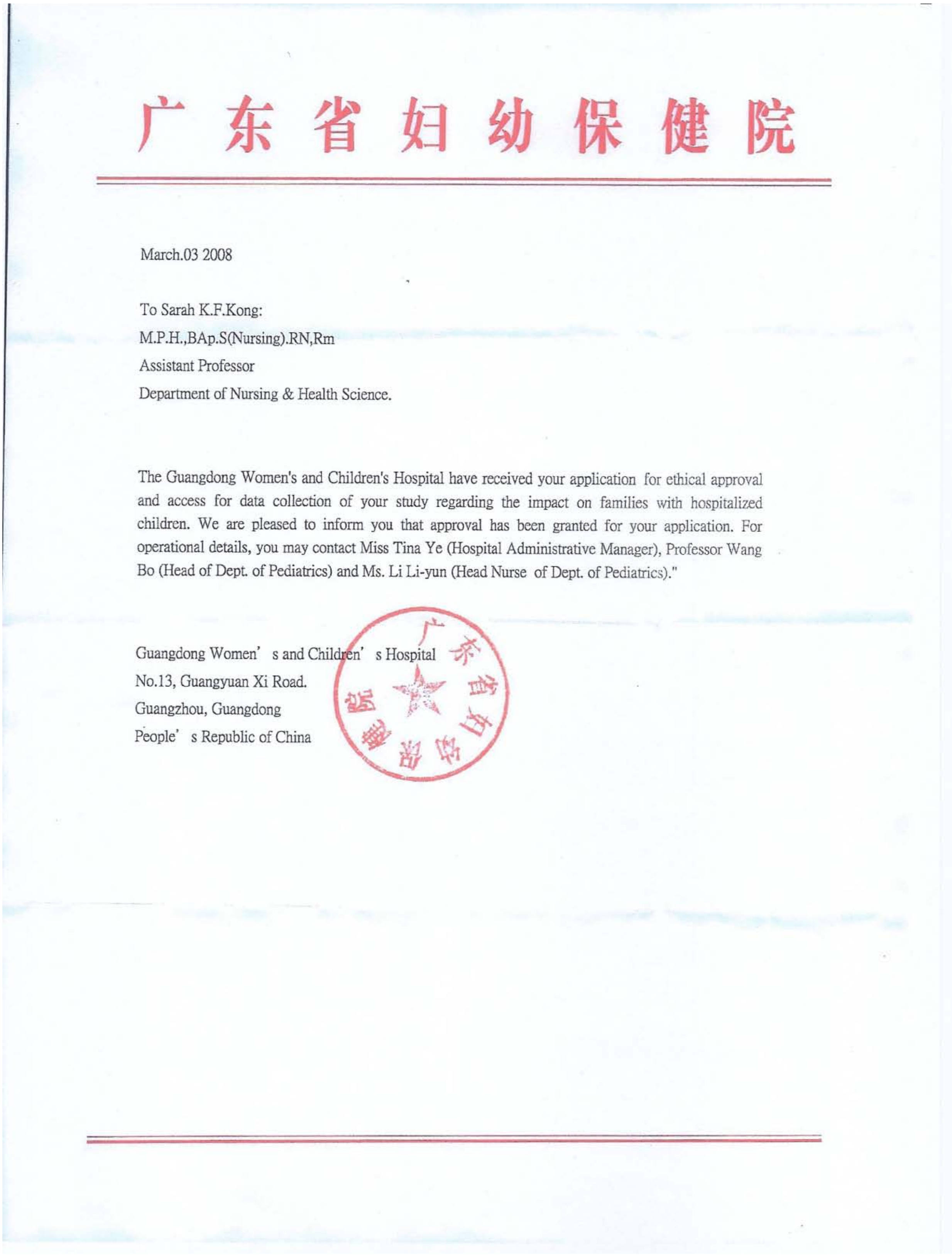
Principal Collaborators : Prof. Ida Martinson, Prof. Thomas Wong

Collaborators : Ms. Sarah K.F. Kong, Ms. Gloria Luk, Ms. Grace Cheng, Ms. Sunshine Chan
Ms. Betty Fung

Please note that you are responsible for informing the Departmental Research Committee as soon as possible within 14 days of any subsequent changes in the research proposal or procedures which may affect the validity of the ethical approval. You will receive separate notification should you be required to obtain fresh approval.

Dr. Samantha Pang
For and on behalf of
Department Research Committee
Department of Nursing and Health Sciences

APPENDIX 5 ETHICAL APPROVAL LETTER - 2



广东省妇幼保健院

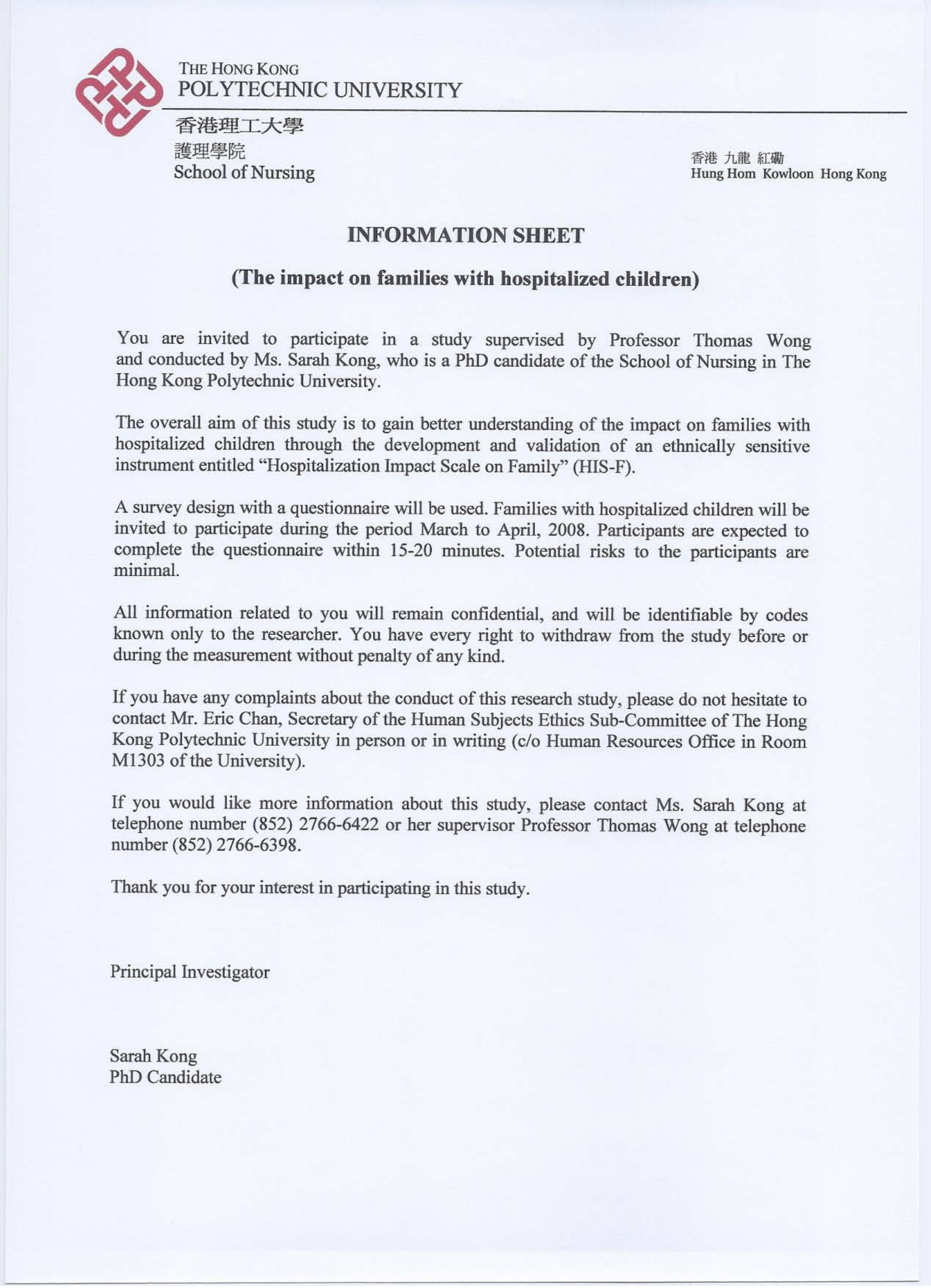
March.03 2008

To Sarah K.F.Kong:
M.P.H.,BAp.S(Nursing).RN,Rm
Assistant Professor
Department of Nursing & Health Science.

The Guangdong Women's and Children's Hospital have received your application for ethical approval and access for data collection of your study regarding the impact on families with hospitalized children. We are pleased to inform you that approval has been granted for your application. For operational details, you may contact Miss Tina Ye (Hospital Administrative Manager), Professor Wang Bo (Head of Dept. of Pediatrics) and Ms. Li Li-yun (Head Nurse of Dept. of Pediatrics)."

Guangdong Women’s and Children’s Hospital
No.13, Guangyuan Xi Road.
Guangzhou, Guangdong
People’s Republic of China

APPENDIX 6 INFORMATION SHEET_ ENGLISH



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學
護理學院
School of Nursing

香港 九龍 紅磡
Hung Hom Kowloon Hong Kong

INFORMATION SHEET

(The impact on families with hospitalized children)

You are invited to participate in a study supervised by Professor Thomas Wong and conducted by Ms. Sarah Kong, who is a PhD candidate of the School of Nursing in The Hong Kong Polytechnic University.

The overall aim of this study is to gain better understanding of the impact on families with hospitalized children through the development and validation of an ethnically sensitive instrument entitled "Hospitalization Impact Scale on Family" (HIS-F).

A survey design with a questionnaire will be used. Families with hospitalized children will be invited to participate during the period March to April, 2008. Participants are expected to complete the questionnaire within 15-20 minutes. Potential risks to the participants are minimal.

All information related to you will remain confidential, and will be identifiable by codes known only to the researcher. You have every right to withdraw from the study before or during the measurement without penalty of any kind.

If you have any complaints about the conduct of this research study, please do not hesitate to contact Mr. Eric Chan, Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Human Resources Office in Room M1303 of the University).

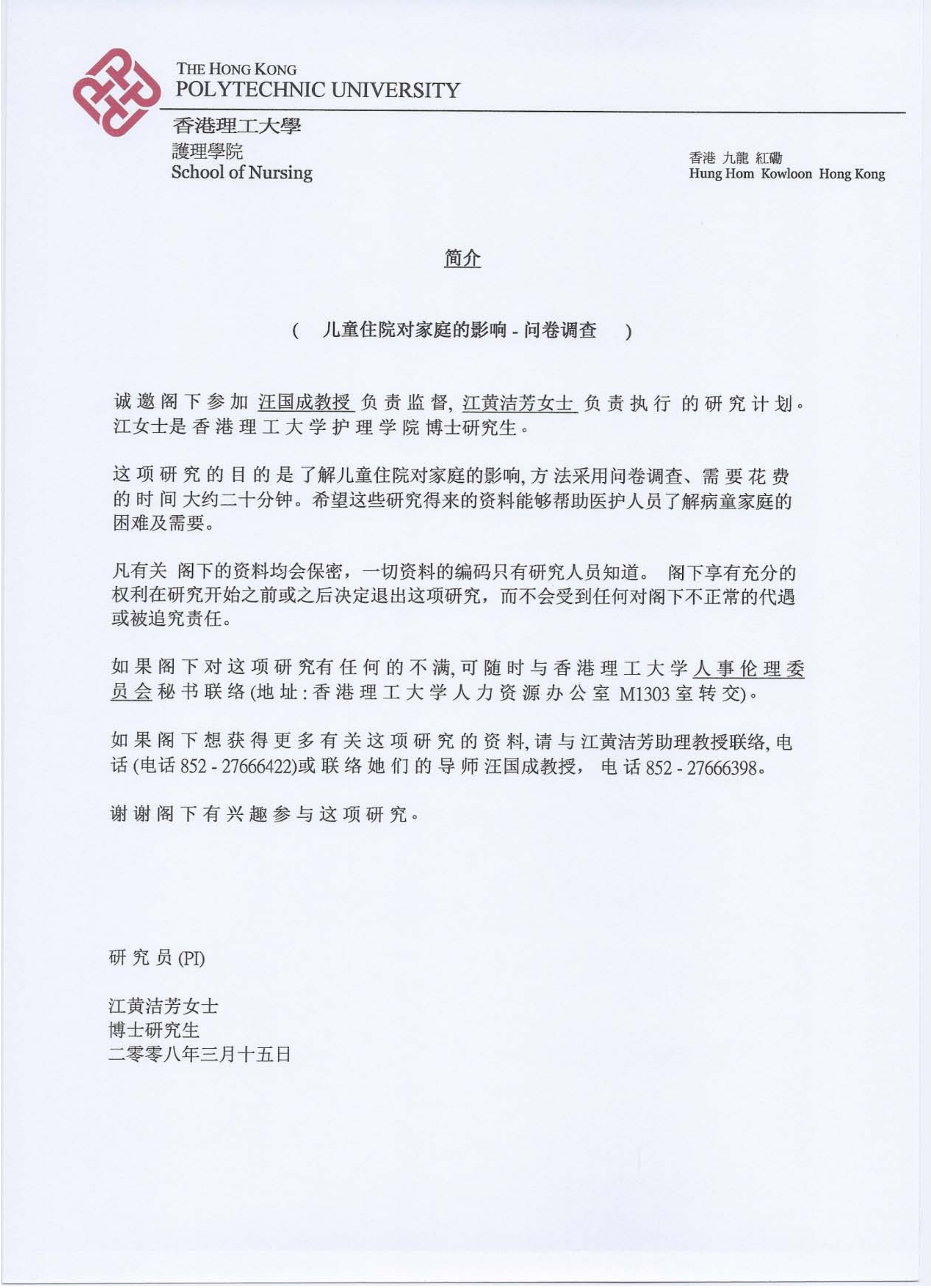
If you would like more information about this study, please contact Ms. Sarah Kong at telephone number (852) 2766-6422 or her supervisor Professor Thomas Wong at telephone number (852) 2766-6398.

Thank you for your interest in participating in this study.

Principal Investigator

Sarah Kong
PhD Candidate

APPENDIX 7   INFORMATION SHEET_ CHINESE



THE HONG KONG
POLYTECHNIC UNIVERSITY
香港理工大學
護理學院
School of Nursing

香港 九龍 紅磡
Hung Hom Kowloon Hong Kong

简介

（ 儿童住院对家庭的影响 - 问卷调查 ）

诚邀阁下参加汪国成教授负责监督，江黄洁芳女士负责执行的研究计划。江女士是香港理工大学护理学院博士研究生。

这项研究的目的是了解儿童住院对家庭的影响，方法采用问卷调查、需要花费的时间大约二十分钟。希望这些研究得来的资料能够帮助医护人员了解病童家庭的困难及需要。

凡有关阁下的资料均会保密，一切资料的编码只有研究人员知道。阁下享有充分的权利在研究开始之前或之后决定退出这项研究，而不会受到任何对阁下不正常的代遇或被追究责任。

如果阁下对这项研究有任何的不满，可随时与香港理工大学人事伦理委员会秘书联络（地址：香港理工大学人力资源办公室 M1303 室转交）。

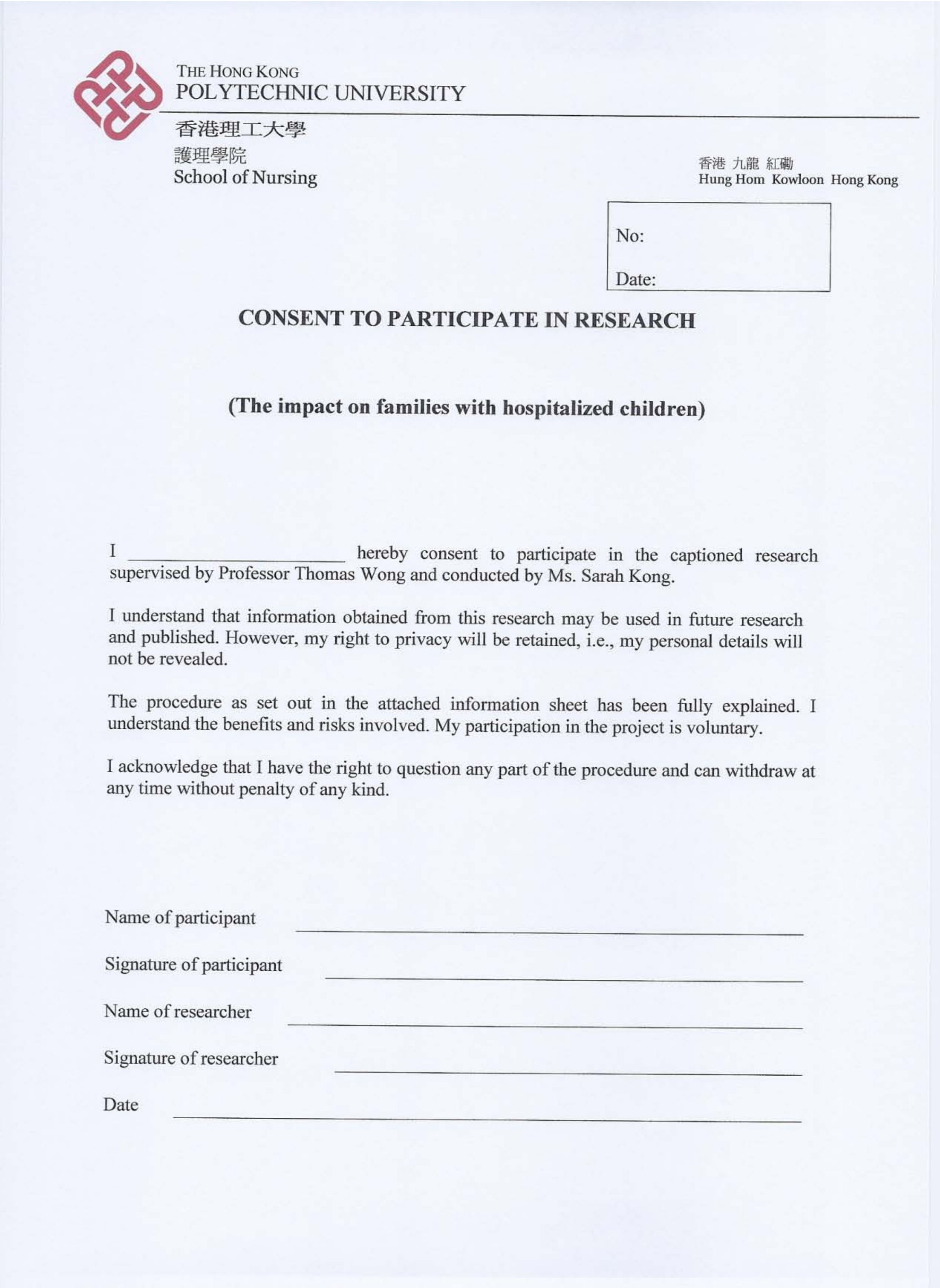
如果阁下想获得更多有关这项研究的资料，请与江黄洁芳助理教授联络，电话（电话 852 - 27666422）或联络她们的导师汪国成教授，电话 852 - 27666398。

谢谢阁下有兴趣参与这项研究。

研究员 (PI)

江黄洁芳女士
博士研究生
二零零八年三月十五日

APPENDIX 8 CONSENT FORM – ENGLISH



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School of Nursing

香港 九龍 紅磡
Hung Hom Kowloon Hong Kong

No:

Date:

CONSENT TO PARTICIPATE IN RESEARCH

(The impact on families with hospitalized children)

I ______________________ hereby consent to participate in the captioned research supervised by Professor Thomas Wong and conducted by Ms. Sarah Kong.

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 benefits 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 ______________________

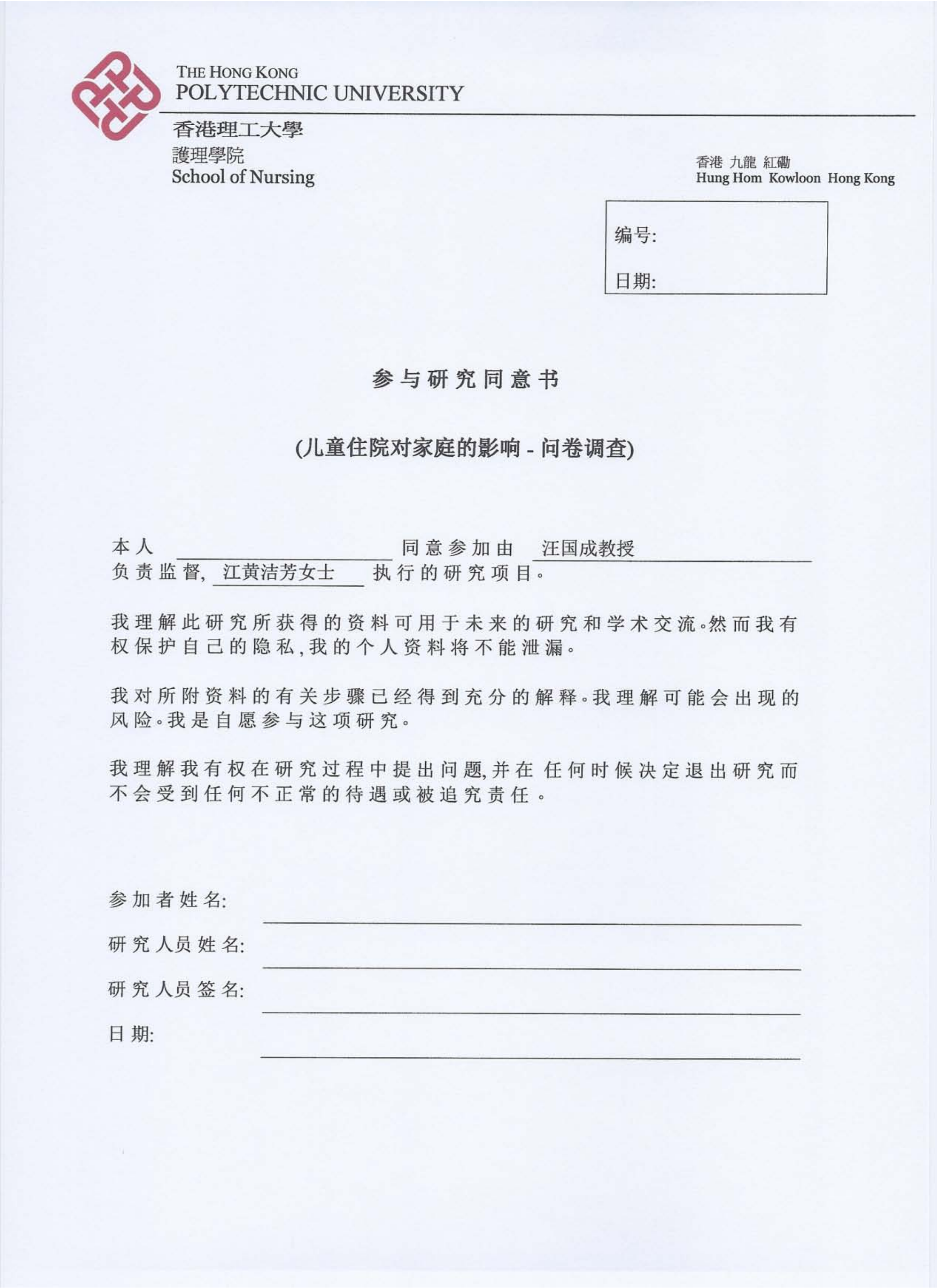
Signature of participant ______________________

Name of researcher ______________________

Signature of researcher ______________________

Date ______________________

APPENDIX 9 CONSENT FORM – CHINESE



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護理學院
School of Nursing

香港 九龍 紅磡
Hung Hom Kowloon Hong Kong

编号:

日期:

参与研究同意书

(儿童住院对家庭的影响 - 问卷调查)

本人 ______________________ 同意参加由 汪国成教授 负责监督, 江黄洁芳女士 执行的研究项目。

我理解此研究所获得的资料可用于未来的研究和学术交流。然而我有权保护自己的隐私,我的个人资料将不能泄漏。

我对所附资料的有关步骤已经得到充分的解释。我理解可能会出现的风险。我是自愿参与这项研究。

我理解我有权在研究过程中提出问题,并在任何时候决定退出研究而不会受到任何不正常的待遇或被追究责任。

参加者姓名: ______________________

研究人员姓名: ______________________

研究人员签名: ______________________

日期: ______________________

APPENDIX 10 FAMILY ASSESSMENT DEVICE: GENERAL FUNCTIONING SUBSCALE_ENGLISH

Staff use
ID#

By：mother/ father/ caregiver

The following two assessment tools were translated from overseas and they have been used in many Chinese studies. You are cordially invited to continue the survey and fill in the information carefully for our better understanding of your feelings and difficulties.
To show our appreciation, please take one little gift after completion. Thank you.

(Please circle or tick accordingly)

This assessment contains a number of statements about families. Read each statement carefully, and decide how well it describes your own family.		**Strongly agree**	**Agree**	**Disagree**	**Strongly disagree**
1.	Planning family activities is difficult because we misunderstand each other.	**1**	**2**	**3**	**4**
2.	In times of crisis we can turn to each other for support.	**1**	**2**	**3**	**4**
3.	We cannot talk to each other about the sadness we feel.	**1**	**2**	**3**	**4**
4.	Individuals are accepted for what they are.	**1**	**2**	**3**	**4**
5.	We avoid discussing our fears and concerns.	**1**	**2**	**3**	**4**
6.	We can express feelings to each other.	**1**	**2**	**3**	**4**
7.	There are lots of bad feelings in the family.	**1**	**2**	**3**	**4**
8.	We feel accepted for what we are.	**1**	**2**	**3**	**4**
9.	Making decisions is a problem for our family.	**1**	**2**	**3**	**4**
10.	We are able to make decisions about how to solve problems.	**1**	**2**	**3**	**4**
11.	We don't get along well together.	**1**	**2**	**3**	**4**
12.	We confide in each other.	**1**	**2**	**3**	**4**

APPENDIX 11 FAMILY ASSESSMENT DEVICE: GENERAL FUNCTIONING SUBSCALE_CHINESE

职员专用 ID#
填写人：母亲/父亲/监护人

各位家长，以下两页是从外国翻译，并曾多次用于各地华人的问卷调查。现诚邀 阁下继续参与，认真填写有关资料，以便我们更准确地了解您们的感受或难处。

为表我们的感谢，请完成后领取一份小纪念品，谢谢！

（请 在适当处画○ 或 ✓）

以下是叙述有关于家庭的句子，请你谨慎的阅读并迅速及真实地圈出最能描绘您家庭实际情况的号码： 在我的家中：		极同意	同意	不同意	极不同意
1	计划家庭活动是异常困难，因为各人常彼此误解	1	2	3	4
2	当有危机时，我们可以互相扶持	1	2	3	4
3	我们不能互相倾诉所感到的忧伤	1	2	3	4
4	无论家人是怎样的人,大家都会接纳他/她	1	2	3	4
5	我们避免谈论各人所恐惧和担心的事	1	2	3	4
6	我们可以彼此表达感受	1	2	3	4
7	我们对家人会有许多不愉快的感受	1	2	3	4
8	我们感觉到无论自己是怎样也会被家人接纳的	1	2	3	4
9	对我们一家人来说, 做决定是很困难的事	1	2	3	4
10	我们有能力决定怎样解决问题	1	2	3	4
11	我们的相处并不融洽	1	2	3	4
12	我们彼此信任	1	2	3	4

APPENDIX 12 PARENTAL STRESSOR SCALE – INFANT HOSPITALIZATION_ENGLISH

We would like to know how stress you have experienced because of your child's illness and hospitalization. By stressful we mean experiences that cause you to feel anxious, upset, or tense.

Below is a list that may describe aspects of your experiences when your child is in the hospital. Read each item and circle the number that shows how stressful the experience is for you. **As the parent of a child who is hospitalized, how stressful are the following experiences?**		**Not stressful**	**A little stressful**	**Moderately stressful**	**Very stressful**	**Extremely stressful**	**Not applicable**
1.	Be separated from your child	**1**	**2**	**3**	**4**	**5**	**X**
2.	Not being able to regularly care for your child (e.g., feed, diaper, hold)	**1**	**2**	**3**	**4**	**5**	**X**
3.	Not having a chance to be alone with your child	**1**	**2**	**3**	**4**	**5**	**X**
4.	Not being able to share your child with family and friends	**1**	**2**	**3**	**4**	**5**	**X**
5.	Not being able to protect your child from pain and painful procedures	**1**	**2**	**3**	**4**	**5**	**X**
6.	Not being able to comfort or help your child	**1**	**2**	**3**	**4**	**5**	**X**
7.	The nurses and other staff seeming closer to the child than you are	**1**	**2**	**3**	**4**	**5**	**X**
8.	Not being able to hold your child	**1**	**2**	**3**	**4**	**5**	**X**
We are also interested in how stressed you are by the way your child looks to you? How stressful is it?							
9.	Seeing your child with tubes or IV lines on him/her	**1**	**2**	**3**	**4**	**5**	**X**
10.	Seeing your child in pain	**1**	**2**	**3**	**4**	**5**	**X**
11.	Having your child look afraid, be upset or cry a lot	**1**	**2**	**3**	**4**	**5**	**X**
12.	Seeing your child look sad	**1**	**2**	**3**	**4**	**5**	**X**
13.	See a needle or tube put in your child	**1**	**2**	**3**	**4**	**5**	**X**
14.	Seeing your child have problems	**1**	**2**	**3**	**4**	**5**	**X**
15.	Seeing your child surrounded by machinery and having medical treatments	**1**	**2**	**3**	**4**	**5**	**X**
16.	When your child can't respond to you	**1**	**2**	**3**	**4**	**5**	**X**
When you visit your child in the hospital, how stressful are the following things you might see or hear?							
17.	Monitors and equipment in the room	**1**	**2**	**3**	**4**	**5**	**X**
18.	The sudden sound of monitor alarms	**1**	**2**	**3**	**4**	**5**	**X**
19.	The other sick children in the room	**1**	**2**	**3**	**4**	**5**	**X**
20.	The large number of nurses, doctors, and other staff who work with your child	**1**	**2**	**3**	**4**	**5**	**X**
21.	When other children in the hospital have a crisis	**1**	**2**	**3**	**4**	**5**	**X**
22.	The needs of other parents in the hospital	**1**	**2**	**3**	**4**	**5**	**X**

Last, please check for any missing part，especially for the first page。Thank you very much and get-well soon，Peace be with your family!

APPENDIX 13 PARENTAL STRESSOR SCALE – INFANT HOSPITALIZATION_CHINESE

我们想知道因为你孩子的生病和住院带给你或家人多少的压力经验。我们指的<u>压力</u>是那些导致你(们)<u>感到焦虑、懊恼、或紧张的经验</u>。

(请 在适当处画○ 或 ✓)

下列是一些描述当你小孩在医院时你或家人会有的经验。阅读每一项然后圈选代表你(们)压力经验的号码。 如果该项不适用于你的情况，请圈选 “X” 。 **身为住院小孩的父母，下列经验带给你(们)多少的压力？**		**没有压力**	**一点压力**	**中度压力**	**很有压力**	**极度压力**	**不适用**
1.	与你的孩子分开	1	2	3	4	5	X
2.	无法规律的照顾你的孩子(例如：喂食、换尿布、抱)	1	2	3	4	5	X
3.	没有机会与你的孩子单独在一起	1	2	3	4	5	X
4.	无法与你的家人和朋友分享你的孩子	1	2	3	4	5	X
5.	无法保护你的孩子免除疼痛和痛苦的程序	1	2	3	4	5	X
6.	无法安慰或帮助你的孩子	1	2	3	4	5	X
7.	护士和其他的工作人员似乎比你还亲近你的孩子	1	2	3	4	5	X
8.	无法抱你的孩子	1	2	3	4	5	X
你孩子的样子给你(们)带来的压力有多少？							
9.	看见你孩子身上的管子或静脉点滴管	1	2	3	4	5	X
10.	看见你的孩子有疼痛	1	2	3	4	5	X
11.	你的孩子看起来害怕、懊恼或哭的很多	1	2	3	4	5	X
12.	看见你孩子悲伤的样子	1	2	3	4	5	X
13.	看见针头或管子插进你孩子的身上	1	2	3	4	5	X
14.	看见你的孩子有呼吸问题	1	2	3	4	5	X
15.	看见你的孩子被机器环绕和接受医疗	1	2	3	4	5	X
16.	当你的孩子无法对你有所反应	1	2	3	4	5	X
当你(们)探视在医院中的孩子时，以下事项对你(们)所造成的压力程度有多少？							
17.	房间里的监测器和设备	1	2	3	4	5	X
18.	监测器突然的警报响声	1	2	3	4	5	X
19.	房间里的其他病童	1	2	3	4	5	X
20.	大量的护士、医生、和其他照顾你孩子的工作人员	1	2	3	4	5	X
21.	当医院中其他孩子有危机	1	2	3	4	5	X
22.	医院中其他父母亲的需求	1	2	3	4	5	X

最后，请查看是否有遗漏，特别是第一页。非常多谢大家，祝早日安康，阖府平安！