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Acculturation and ICU stress among Chinese/Chinese-American parents

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Acculturation and ICU Stress among Chinese/Chinese-American Parents

by

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DISSERTATION

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Life is what we make it and how we take it. In the moments of discouragement or defeat, or even despair, there are always certain things to cling to. More or less in that sense, I would like to dedicate this dissertation to the memory of my grandfather, Mr. Lee Lai-fa who passed away right before I started my first nursing education in Taiwan.

ABSTRACT

ACCULTURATION AND ICU STRESS

AMONG CHINESE/CHINESE-AMERICAN PARENTS

Shih-Yu Sylvia Lee

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A descriptive study was conducted to explore the relationships among family variables (acculturation, social support), uncertainty regarding the child's illness, stress perception, and stress responses (sleep disturbance, fatigue) of Chinese/Chinese-American parents with a child in the Intensive Care Unit (ICU). Four sets of data were collected: 1) child's medical records, 2) Parental Stress Scale: Infant Hospitalization, General Sleep Disturbance Scale (GSDS), Suinn-Lew Acculturation Scale, Family Support Scale, 3) sleep diary with the Numerical Rating Scale-Fatigue, and 4) wrist actigraphy. Participants were recruited from five intensive care units (ICUs) in the San Francisco Bay Area..

Both mothers (N=30) and fathers (N=25) rated their child's appearance as the most stressful experience, followed by parental role alteration, staff communication and behavior, and ICU environment. Results indicated that parents also experienced stress related to cultural beliefs. The majority of mothers (93.3%) and fathers (60%) experienced sleep problems during their child's hospitalization.

Worry about child's illness and its future impact, belief in Asian values, and perceived lack of support from health care providers accounted for 43% and 56% of variance in the overall stress for mothers and fathers, respectively. Stress from parental role alteration and the health care provider's behavior accounted for 30% of the variance

in total sleep time (TST) for mothers, and stress from the child's appearance and health care provider's behavior accounted for 48% of the variance in TST for fathers. Stress from ICU environment accounted for 22% of the variance in wake after sleep onset (WASO) for mothers. Stress from communication with health care providers accounted for 26% of the variance in GSDS for mothers, and stress related to parental role alteration accounted for 22% of the variance in GSDS for fathers. Stress from communication with health care provider accounted for 19% of the variance in morning fatigue for mothers.

Findings from this study suggested implications for education of both family and ICU staff. The relationships between parental sources of stress, sleep disturbance, fatigue, and parental role competencies need to be further explored for the parents of both acutely and chronically ill children.

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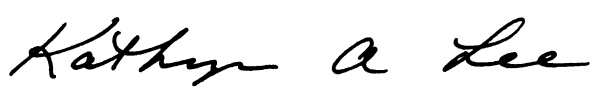

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CHAPTER I

INTRODUCTION

Experiences of stress occur regularly for parents, beginning from the pregnancy to the intense hours of childbirth, and continuing through developmental milestones. In addition to the normal stresses of parenthood, having a sick child can become extremely stressful for parents. Because parents act as protectors of their offspring under all circumstances, they suddenly become vulnerable and feel incompetent, especially when their child is ill and requires any type of medical treatment.

There is strong research evidence that a child's illness event is stressful for parents. The stress may come from several different sources, such as the physical environment of an intensive care unit (Miles, 1989; Miles et al., 1989a; 1989b), parental role alteration whereby the professional health care provider assumes some of the role as "parent"(Carter, Miles, Buford, & Hassanein, 1985; Miles, Wilson, & Dochery, 1999), and the child's appearance or the severity of illness (Shields-Poe & Pinelli, 1997; Wereszczak, Miles, & Holditch-Davis, 1997). Because of different social and cultural backgrounds of each parent, a child's illness might be perceived and reacted to in different ways. For immigrants from another culture, parental stress may also come from language barriers or unfamiliarity with American culture and the health care system. The tears shed by parents in different ethnic cultural groups, although briny and transparent, may have different meanings, if one knows their background.

These five chapters comprising the dissertation provide the theoretical and empirical foundation to comprehend Chinese/Chinese-American's parental stress with a

critically ill infant. This first chapter outlines the significance of the study, the purpose of this study, and the research questions for this study.

The second chapter provides a selective critical review of literature pertinent to this study. The areas to be discussed are: sources of stress for parents during the time their child is in an intensive care unit (ICU), uncertainty, personal/family characteristics and acculturation, social support, coping strategies, and stress responses (i.e. sleep disturbances, fatigue). This is followed by a discussion of the paradigm for Asian-American research methods and concludes with a conceptual framework of parental stress and coping related to Asian-American parents with a critically ill child.

Chapter three describes the study methodology in detail. In this chapter, the research design, the study sites, the sample, the recruitment procedure, methods of protection of human subjects, the instrument used to measure the variables, the procedures utilized to collect data, and the data analyses are described.

Chapter four presents the results of this descriptive correlational study of acculturation and ICU stress among Chinese/Chinese-American parents. Findings reported in this chapter include descriptive information about the characteristics of the infants and their parents, and data related to the four research questions.

Finally, chapter five discusses the findings and presents the conclusions drawn from the findings. The discussion of results includes major findings and discussion of the research questions. Limitations of the study are then discussed, implications for clinical practice are outlined, and recommendations for future research are delineated.

Significance of the Research

The Chinese were the first Asian group to migrate to the United States (U.S.) in the mid-19th century and the majority resided in California to work in mining and railroad construction. The U.S. government implemented several discriminatory steps between the late 19th and early 20th centuries to prevent Asians from coming to the U.S. The Immigration Act of 1965 opened the door to immigrants from all countries and admitted them into the U.S. based on three criteria: occupational immigration, family reunification, and vulnerability to religious persecution in their native country. As a result of the Immigration Act of 1965, the majority of Chinese now residing in the U.S. were born in a place such as Mainland China, Hong Kong, and Taiwan, and most of the Chinese immigrants arriving around 1980 came with their families (Wong, 1995). U.S. Census (2000) currently shows that more than 4% of the total American population is of Asian origin, and Chinese-Americans are the largest group (23.8%) of Asian-Americans. It is predicted that 9.3% of Americans will be of Asian origin by 2050, with this percentage increasing to 13.2% by 2100.

Given the increasing diversity of America's pluralistic cultures, researchers will do well to look seriously anew into how the various ethnic minorities are interacting with the dominant American group. The reason for this concern is that, with international migration, the resulting acculturation threatens the validity of research based on culture-group comparisons (Devins, 1999). Chinese culture has influenced most Asian groups, especially the East Asian groups, such as the Japanese and Koreans. Therefore, comprehending Chinese parent's stress and coping could be an essential foundation to understanding other Asian groups of parents and their perceptions of a sick child.

To date, infant morbidity reports have only been classified based on the causes of disease and not by the child's ethnic group. Asian infant mortality rate in the U.S. was first reported in the year 2000, and it was 4.9 per one thousand live births, which is only 0.2% lower than the nation's average. An important phenomenon on infant mortality from the National Vital Statistics Report (2003) is that babies born to second-generation mothers have a higher mortality rate (6.4 per 1,000) than babies born to first-generation mothers (4.5 per 1,000). As the census reported, there will be a dramatic increase in the Asian population of the U.S., non first-generation Chinese-Americans will increase in number in the near future and, therefore, the infant mortality rate will also be increased for the Asian groups living in the U.S. Although better medical care may lower infant mortality rates, it does not mean that the morbidity rate would equally decrease. The advanced technologies in health care systems allow many children to survive previous congenital defects or fatal illnesses, but it may still result in long-term physical and psychosocial consequences for both children and parents.

The healthcare system in the U.S. functions predominantly within traditional Western values (Aiken & Cantalano, 1994). To date, most research on parental stress and coping has focused on Caucasian experiences and has dealt with identification of ICU stressors and development of measurement tools. A few studies about Asian parents coping with their child's chronic disease were found (Cheng & Tang, 1995; Koizumi, 1992; Martinson, Zhong, & Liang, 1994), but none focused on critically ill children, and no study examined the relationships between acculturation, parental stress, and stress responses. Although human beings have universal characteristics and parenting behavior is similar regardless of culture, Chinese/Chinese-Americans, with their unique

philosophical views of life, need to be studied for their perception of a child's critical illness, interactions with the Western healthcare system, and culturally relevant social support mechanisms.

Purpose of the Study

The purpose of this study was to explore relationships among selected family variables and stress perceptions of Chinese/Chinese-American parents with a child in the ICU. The specific aims for this descriptive correlational study were:

1. To describe Chinese/Chinese-American parents' stress experiences while their child is in the ICU.
2. To assess sleep disturbance and fatigue severity as responses to stress for parents with a critically ill child in ICU.
3. To assess the influence of acculturation, parent's characteristics, gender of ill child, and family support on parental stress, sleep disturbance, and fatigue.

Research Questions

1. What are major stressors for Chinese/Chinese-American parents of children who are in intensive care units?
2. Is parental stress associated with objective and subjective sleep disturbance or perception of fatigue?
3. To what extend is parental stress explained by a parent's level of acculturation, personal/family characteristics (age, financial status, education, gender of the ill child, support resources), and uncertainty (perceived severity of the child's illness, worry about child's illness and its future impact)?
4. To what extend are sleep disturbances and fatigue explained by parental stress?

CHAPTER II

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Following is a selective review of literature pertinent to this study. The literature review is organized into six sections based on stress theory and acculturation as a conceptual framework for this dissertation. Literature selected for review included research related to: (1) sources of stress for parents during an ICU experience, (2) uncertainty, (3) personal/family characteristics and acculturation, (4) social support in the form of personal and social resources, (5) coping strategies, and (6) stress response in the form of sleep disturbance and fatigue. This chapter synthesizes the major strengths and limitations of current research, along with a discussion of the paradigm for Asian American research. Finally, a conceptual framework adapted from stress theory and assimilation/acculturation theory will be presented.

Review of Literature

Sources of Stress for Parents during an ICU Experience

Many researchers have discussed parental stress related to child illness. Miles and colleagues (1989a, 1989b) were the first to use a theoretical framework to assess parental stress in the ICU settings and it was based in part on Lazarus and Folkman's (1984) stress theory. In these studies, parents rated their stress on four different dimensions: child's behavior and emotions, parental role alterations, sight and sounds, and staff communication. Their findings provided a general guideline for healthcare providers to help parents cope and led to the development of the Parental Stressor Scales (Carter & Miles, 1989; Miles, Funk, & Carlson, 1993; Miles & Brunssen, 1998). Miles and colleagues' research has shown that children's behavioral and emotional responses, along

with parent role alterations, are the most significant stressors for mothers in the ICU (Miles et al., 1989a; 1989b; Riddle Hennessey, Eberly, Carter, & Miles, 1989). These findings have also been replicated in other recent studies (Board & Ryan-Wenger, 2003; Holditch-Davis & Miles, 2000; Seideman, Watson, Corff, Odle, Hasse, & Bowerman, 1997).

Most parental stress studies were descriptive designs and conducted in the first week of a child's hospitalization. Affonso and colleagues (1992) identified that maternal stress perceptions may change in frequency of occurrence and intensity throughout a child's hospitalization. They pointed out that in the beginning of an infant's hospitalization, the major stressors were similar to those found by Miles and colleagues. However, toward the end of the infant's hospitalization, the major stressors became financial concerns, emotional issues, maternal concerns, infant's health, and problems in relationships with spouse/partner, family, and friends. No matter which phase of hospitalization, parental role was the major concern for most of the participants. Findings suggest that because of a baby's critical situation, the whole family dynamic may undergo changes and parents may derive several negative experiences from the crisis situation.

The perceptions of stress differ between mothers and fathers, and parental stress scores are often higher in mothers (Riddle et al., 1989). Shields-Poe and Pinelli (1997) found that mothers perceived more stress from sights and sounds ($p = .01$) and from interaction with the baby ($p = .0001$) than fathers. Trait anxiety and perceived morbidity explained 23% of the variance in perceived stress scores for mothers, and perceived morbidity contributed the most ($R^2 = .14$) to explaining the fathers' stress scores.

Uncertainty

Mishel (1981, 1988) highlighted uncertainty as a critical factor affecting both the appraisal of illness events and the overall stress response. According to Mishel uncertainty involves one's perception of the lack of clarity, lack of information, and unpredictability of a particular situation. Incorporated into the Miles and Carter's Parental Stress Theoretical Framework (1983) are specific uncertainties such as whether the critically ill child will live or die, how the child will look and function in the future, and the potential length of illness and hospitalization.

Turner, Tomlinson, and Harbaugh (1990) conducted a grounded-theory study to develop a model of parental uncertainty in pediatric ICU. Four categories of uncertainty (environmental, illness, caregiver, and family system) were derived from the interview data and were reviewed extensively and supported by colleagues. Unfamiliarity with hospital routines and the roles of each staff member generated uncertainty about the environment of care. Illness uncertainty resulted from parents' lack of understanding about their children's condition, treatment, and progress. Inability to judge the competence of caregivers and perceived inadequacy of response to emergencies led to uncertainty about caregiving. Finally, family system uncertainty included boundary uncertainty, parental role performance, inter-role uncertainty, and present/future effects. The findings were consistent with Miles and Carter's (1983) theoretical framework of parental stress.

In a study of 40 mothers, Tomlinson and colleagues (1996) went one step further and examined the relationships among uncertainty, severity of illness, parental perceptions, and family resources during the initial stage of a child's critical illness.

They concluded there was a negative relationship between perception of family cohesion and maternal uncertainty ($r = -.39$, $p < .01$) and a positive association between the severity of a child's illness and maternal uncertainty ($r = .36$, $p < .01$). Hierarchical regression showed that illness severity, family cohesion, and social support accounted for 22% of the variance in maternal uncertainty ($F = 3.12$, $p < .04$). Among these three predictors, family cohesion was the strongest, followed by illness severity.

In Tomlinson and colleagues (1996) study, the child's severity of illness was measured by the Pediatric Risk of Mortality (PRISM) Index (Pollack, Ruttimann, & Geston, 1988). Since the perception of threat is influenced by a particular system of self-values and contemporary evaluative standards (Kaplan, 1996), it is possible that mothers perceive a different degree of severity of illness than the severity level assessed by the PRISM Index. If maternal perception of severity of illness is used, it might result in a different level of severity of illness for each child and the relationships among uncertainty, family cohesion, and social support may be changed.

In a typical Chinese family, filial piety is an important value whereby sons carry on the name of the family and the ancestors (Kim, Atkinson, & Yang, 1999). Because of these beliefs, having a critically ill child, especially a male infant, may trigger a Chinese parent's fears about not having a child to carry on the family line. The degree of a parent's fear varies according to the severity of the child's illness and the parent's level of acculturation, but the perceived threat of having no one to carry on the family name may have a greater impact on Chinese parents than on parents of other cultures.

Personal/Family Characteristics and Acculturation

Personal and family characteristics refer to the many bio-psycho-social

background variables, such as the past experiences with a sick child, impact of concurrent life events, coping skills, and family/social resources. For the immigrant, it should also include their immigration experiences, and extent of acculturation. Chinese can be viewed as an ethnic group with traces of Confucianist thinking and Buddhist teachings (Braun, 1998; Kim, Yang, Atkinson, Wolfe, & Hong, 2001; Spector, 2000). Authoritarianism is preserved through the cultivation of a willingness to concede that seniors are, by virtue of age, somehow superior and therefore should be listened to and obeyed. Therefore, Chinese seldom question authority and they respect and obey the healthcare providers as being the highest level of authority (Giger & Davidhizar, 1990). Asians also have difficulty in expressing strong or negative feelings; under stress they may even, though bilingual, communicate only in their primary language (Lassiter, 1995; Tabora & Flaskerud, 1997). This phenomenon probably occurs because experiences are processed in the symbol system of the language in which they occur (Spector, 2000).

Parenthood is a developmental process. From the beginning, parents strive for a sense of competence in their relationship with the child. Competence arises from a need to cope effectively with the environment and children help their parents feel competent by being readable (giving clear signals), predictable (responding to similar situations in similar manners), and responsive (being able to react to external stimuli) (Bornstein, 2000; Goldberg, 1979). In general, competence is difficult in the early stage of parenting, for the infant's needs are indistinct and its crying most likely will be taken as a reproach for parental incompetence. In addition, if a child becomes ill, the parents' self-perception of incompetence, actual or imagined, will no doubt intensify.

Studies have shown that maternal age is a factor, with younger mothers being more stressed by parental role disruptions (Bell, 1997) and older mothers tending to have higher parental stress scores (Shields-Poe & Pinelli, 1997). Parents of low-birth-weight infants reported more feelings of stress, anxiety, and guilt than parents of full-term babies (Miles, Holditch-Davis, & Shepherd, 1998; Robson, 1997). Adoptive mothers have been reported to experience more stress related to their child's behavior or emotional response to hospitalization than biological mothers (Smit, 2000).

Whether a stressful situation is a threat or a challenge is largely dependent on perception, and the perception of threat is influenced by a particular system of self-values and contemporary evaluative standards (Kaplan, 1996). The value system may come from one's cultural background since culture consists of standards for deciding what is, what can be, how one feels about it, and how to go about doing it (Goodenough, 1966). Some anthropologists conceptualize culture as a set of rules that provides the individual with a means for behaving and interpreting the behavior of others. Harrison and Ritenbaugh (1981) elaborate on the idea that "culture is to behavior" as "language is to speech." Cultural behavior, or how to act appropriately, is socially acquired, not inherited (Hoebel, 1966). Therefore, cultural behavior patterns provide explanations for life events, such as birth, death, rearing of children, health, and illness.

For decades, culture has been identified as a stress moderator (Dohrenwend & Dohrenwend, 1970), influencing external forces (environmental factors), internal forces (locus of control beliefs), and stressor stimuli. Aldwin (2000) states that culture can affect the stress and coping process in four ways. First, culture influences the types of stressors that an individual is likely to experience as threatening. Second, culture affects

the appraisal of the stressfulness of a given event. Third, culture affects the choice of coping strategies that an individual utilizes in any given situation. And last, culture provides institutional structure and mechanisms by which an individual can cope with stress. Family function is a series of complex processes in line with one's cultural context and expectations, and it becomes even more challenging when immigrants want to bridge two cultures. In order to correctly comprehend parental role within a Chinese cultural perspective, it is essential to look at Chinese traditional belief systems – the origin of their culture.

Traditional Chinese family values have been, and still are, strongly influenced by Confucianism and Buddhism. Familism, the valuing of family over the individual, is a significant Chinese value. The individual exists for the preservation of the family and experiences an identity in terms of the development of the family and its goals. Chinese families have been characterized by a traditional system of hierarchical roles based on age, birth position, and gender. Other family characteristics observed among Chinese-Americans are a desire for harmony and balance, an ability to suppress emotions, tendencies toward stoicism, passivity, frugality, and fatalism, with behavior patterns often based on a moral code of ethics (Kim, Atkinson, & Yang, 1999; Lee, 1982; Wong, 1985).

Under this traditional cultural influence, there are six typical characteristics of Chinese-American families: (1) stability, indicated by low rates of divorce and illegitimacy; (2) close ties between generations, shown in low rates of adolescent rebellion and delinquency; (3) economic self-sufficiency, demonstrated by avoidance of welfare and by a propensity toward involvement in family business; (4) conservatism expressed as retention of Chinese language and customs in the home; (5) the father is

responsible for economic support and the discipline of family members, and the mother is responsible for care of children and domestic work; and (6) filial piety is an important value in the traditional Chinese family system; sons are a blessing because they carry on the family name for their ancestors (Char, 1981; Glenn & Yap, 1998; Kim, Atkinson, & Yang, 1999; Lee, 1982; Tsai, 1999).

As cultural influences affect Chinese-American families, approaches to the study of any existing phenomena need to be reformulated. It has even been asserted that there is no longer a "traditional Chinese family style," as the family structure has become very complex because of acculturation (Glenn & Yap, 1998). Much of the literature until recently was in the form of book chapters or general overviews that discussed broad features of various Asian immigrant families and the cultural bases for their familial role and patterns (Thomas, 1995). Although few studies have examined Asian parents who are coping with the stress of a child's chronic disease, none of the studies examined the relationships between acculturation and the stress. Shen and Takeuchi (2001) utilized a structural equation model to examine the role of acculturation and its direct and indirect impact on depressive symptom severity in 983 Chinese-Americans as part of the first psychiatric epidemiological study of Chinese-Americans. The participants' daily language use and preference in a variety of situations, patterns of social contact, and participation in cultural activities were used to describe levels of acculturation. They concluded that a higher level of acculturation was associated with a higher level of stress that, in turn, contributed to more depressive symptoms.

It is important to point out that Chinese-Americans tend to deny feelings of depression or express depression somatically (Parker, Gladstone, & Chee, 2001).

Therefore, it is possible that people with higher levels of acculturation can more easily express emotions such as stress and depression. Another important factor that needs to be considered is that acculturation includes not only one's preferred language and interaction with the mainstream society (assimilation), but also self-identification with, and retention of, the beliefs of one's culture of origin (ethnic identity) (Brooker, 1999; Kitano, 1989). In other words, more reliable research findings may be expected from including the ethnic identity to examine level of acculturation since the relationship between assimilation and ethnic identity is not necessarily a linear one. In addition, measures of somatic symptoms caused by stress may become very important for less acculturated Chinese-Americans because they use different resources and coping strategies compared with European-Americans.

Social Support

Social support is defined as the resources provided by another person. For each individual, social support may differ in type and function, and also differ by period of life. Research with European-American populations shows four types of supportive resources: (1) appraisal support involves helping an individual to comprehend the stressful situations and to adopt resources and coping strategies to deal with the event; (2) tangible support involves the provision of material support; (3) information support involves the provision of specific information about a stressful event and informative resources for coping with it; and (4) emotional support reassures an individual that he or she is a valuable person cared for by others (Cohen, 1988; Reis, 1984).

Miles, Carlson, and Funk (1996) examined parents' perceptions of helpful support while their infants were critically ill in an ICU. Parents reported that the major source of

support came from their spouse, nurses, and their own parents. This indicated that appraisal support (from nurses) and emotional support (from one's own spouse and parents) might be the major source of social support parents need while their child is critically ill. Other researchers (Shields-Poe & Pinelli, 1997) also identified the spouse as the most helpful person for a parent during their child hospitalization period, followed by their families, friends, and health professionals. In general, highly socially connected families perceive more support from their social network, and mothers received more network support than did fathers (Tomlinson & Mitchell, 1992)

Brazy, Anderson, Becker, and Becker (2001) identified the process by which parents of premature infants seek information, the types of information they seek, and the resources they use to meet their needs for education and support. On average, the sample of 138 parents spent 10 to 20 hours per week gathering information during the first month of their baby's hospitalization. Parents needed more information than was provided by hospital staff, particularly in the areas of infant health, infant care, and coping. Family was the primary source of support before birth and after discharge, but during the infant's convalescence, nurses were the main source of support for parents. Keller and McDade (1997) found that Asians tend to choose family members as their primary resource for help; only a few turn to books, magazines, or videos as a resource, and none opted for parenting classes or parent support groups.

Some researchers have discussed the meaning of seeking support from different cultural perspectives. Liang and Bogat (1994) found that social support buffered the effects of stress with internal locus of control on adjustment for Caucasian but not for Chinese participants. For Caucasians, seeking support might be seen as adaptive, but the

Chinese might favor self-discipline, as their culture values emotional restraint, and therefore seeking help might be stressful for them. While Western cultures favor internal control, Eastern cultures emphasize external control through cooperation with authoritarian structures and acceptance of fate (Bjorck, Lee, & Cohen, 1997; Bjorck, Cuthbertson, Thurman, & Lee, 2001; Weisz, Rothbaum, & Blackburn, 1984).

Social support has been identified as a significant buffer and an important resource for families in stressful situations. Social support may not only enable people to cope more successfully with stressful events, but also may influence stress-related behaviors that can proactively function to eliminate stressful situations before they occur or prevent a stressful event from intruding into other aspects of life. For immigrants, a new social system, different family dynamics, and lack of available family bonds may lead to greater difficulty obtaining the social support needed to reduce stress. Level of acculturation might play an important role in the whole process of coping by seeking help or by using emotional restraint.

Coping Strategies

Coping strategies are the strategies reported by individuals who attempt to reduce the intensity of stress to a tolerable level. Problem-focused coping serves the function of managing or altering the person-environment relationship that is the source of stress. Emotion-focused coping regulates stressful inner feelings. In general, problem-focused coping is used when the situation is viewed as changeable, and the other form of coping may be used when it is perceived that little can be done to change the situation (Lazarus & Folkman, 1984; Lazarus, 1999). People rely on both forms of coping when managing

the demands of stressful encounters; the two forms may often occur concurrently, and neither one should be interpreted as being more preferable than the other.

Elfert, Anderson, and Lai (1991) utilized a phenomenological method to explore the experiences and help-seeking behaviors of 16 Chinese immigrant families and 15 Euro-Canadian families caring for children with chronic health problems. For most of the Euro-Canadian families, only the mothers were interviewed, but both parents were present for nearly all of the interviews with Chinese families (14 of 16), and seven of the interviews with Chinese families included other family members (usually grandparents) as well. The fact that almost all of the fathers in the Chinese families were present for the interviews demonstrates the family-oriented Chinese trait of fathers acting with recognized authority within the family. The Euro-Canadian families described their children in positive ways and focused on strengths, minimizing the negative effects of the illness experience. In contrast, the Chinese families tended to see the effects of their child's illness as damaging and global, affecting many aspects of their present and future lives.

Koizumi (1992) examined 28 Japanese mothers and their responses to the diagnosis of their child's diabetes. The mothers in the group of "easy coping" reported obtaining additional information, gaining confidence to manage family life and the child's disease, and unburdening self. Those in the "difficult coping" group said they frequently expressed their grief and stress. Martinson, Zhong, and Liang (1994) explored Chinese parental reactions to the conditions of their terminally ill child with cancer and suggested that there was a cultural attitude of not wanting to talk about sad things or to share bad news with others in the family or the community. Noting that perseverance and

self-control are among the acquired virtues valued by Asians, these researchers explained that the silence of Chinese parents in their study was a manifestation of "moral excellence."

The social and cultural environment can influence both the appraisal of stress and the use of coping strategies. Chinese psychologists have argued that Chinese coping strategies are not reflected in most of the coping scales developed in Western societies. In an early study, Hwang (1977) classified four major coping styles for adults in Taiwan. These strategies include relying on self, seeking help from social resources, appealing to supernatural power, and adopting a "do-nothing" philosophy. Latter, similar coping strategies were found in Cheng and Tang's studies (1993, 1995) on Chinese parents of children with Down's syndrome. Based on Lazarus and Folkman (1984), for these Chinese populations, appealing to supernatural power may be classified as an emotional-focused strategy. On the other hand, relying on self and seeking help from social resources may be seen as problem-focused strategies.

Scherer and colleagues (2000) used the Ways of Coping Questionnaire (Folkman & Lazarus, 1988) to investigate coping strategies in Mainland China health care providers (N= 396). The researchers found that, like the U.S. normative sample, the Chinese participants also used problem-focused and objective coping strategies more than they used emotion-focused and subjective coping strategies such as avoidance and denial. But Chinese participants in this study were more likely applying passive "wait-and-see" approaches rather than direct confrontational approaches. The researchers also pointed out that this difference might be influenced by Chinese belief in "fate" originating from traditional Chinese philosophies (Confucianism, Buddhism, and Daoism).

Stress Response – Sleep Disturbance and Daytime Fatigue

Stress and strain were first conceived as a basis of ill health in the 19th century (Lazarus & Folkmann, 1984). Now, there is ample evidence that psychosocial factors can affect an individual's susceptibility to illness, whether it is the common cold, immune system disorders, or sleep disorders (Calabrese, Kling & Gold, 1987; Hall et al., 2000; Schleifer, Kellers, Bond, Cohen, & Stein, 1989; Herbert & Cohen, 1993; White & Porth, 2000). On the other hand, stressors elicit a response from a person's entire body, including psychological and physiological components experienced as fatigue or depressive psychomotor retardation symptoms in an attempt to normalize its previous state of homeostasis.

There are three primary generic axes involved in the stress response: the neurological axis, the endocrine axis, and the immune axis. In general, when the sympathetic portion of the autonomic nervous system is activated, a "fight-or-flight" reaction is manifested as accelerated heartbeat, increased respiration, and redistribution of blood from peripheral areas of the body into the head and trunk. Each stressor activates the sequence just described, thereby enabling the body to fight or take flight. The neurological response occurs quickly and lasts only a short time but can result in hyperarousal. A state of hyperarousal decreases likelihood of sleep onset and can result in initiation insomnia. The endocrine response is initiated more slowly and lasts longer but can alter circadian rhythms for adrenal function and cortisol levels incompatible with sleep. On the other hand, stress leads to decrease natural killer cell activities, lymphocyte proliferation, and peripheral blood mononuclear cells production of interleukin-2 and interferon-r (Glass et al., 1993; Kiecolt-Glaser et al., 1998; Schleifer et al., 1983).

Interleukin-6 (IL-6) was found to increase in the chronic stress elderly (Lutgendorf et al., 1999), and IL-6 was associated with excessive daytime sleepiness. It is hypothesized that initiating a stress response many times over a long period has a wear-and-tear effect on the body, often perceived as fatigue or weariness, eventually lowering resistance to disease (White & Porth, 2000).

The three axes of the stress response are inextricably linked to sleep disturbance and perception of daytime fatigue. Insomnia often begins in response to a stressful life event such as a death or trauma, and it is one of the first warning signs of excessive daily stress. In an earlier retrospective study comparing 31 chronic insomniacs with 31 good sleepers, the insomniacs had more stressful life events during the year prior to their insomnia. In addition, the insomniacs had lower self-concept, less satisfaction with their lives, and more health problems (Healey, Kales, Monroe, Bixler, Chamberlin, & Soldatos, 1981). Empirical support for stress as a significant correlate of hyperarousal includes attenuated delta power and heightened alpha power, as noted throughout non-REM sleep in insomniac subjects (Hall et al., 2000). A study of stressed rats demonstrated decreased active waking and deep sleep, and disrupted REM sleep, including increased duration of and transitions into REM sleep and reduced latency to the onset of the first REM period (Cheeta, Ruigt, Proosdij, & Willner, 1997).

Studies have shown that sleep disturbance is one of the most common complaints for family caregivers of medically ill members (Bramwell, MacKenzie, Laschinger, Cameron 1995; Chentsova-Dutton, Shuchter, Hutchin, Strause, Burns, & Zisook, 2000; Roca Roger et al., 2000; Wilcox & King, 1999). In a cross-sectional correlational study, Carter and Chang (2000) found that most of the caregivers (95%) expressed severe sleep

problems. Among these 51 caregivers, more than half were experiencing depressive symptoms at a level that would suggest risk for clinical depression. As in many studies, the extent to which their depressive symptoms overlap with fatigue was not addressed. There were strong correlations between caregiver depression and their overall sleep quality ($r= 0.70$, $p < 0.001$), habitual sleep efficiency ($r= 0.54$, $p< 0.001$), and daytime dysfunction ($r= 0.59$, $p < 0.001$).

Carter (2002) went further to describe the relationship between sleep problems and depression symptoms among 47 primary caregivers of patients with advanced stage cancer. There were two themes identified from open-ended interviews: sleep problems and depression symptoms. The family caregiver also described the relationship between sleep problems and depression as beginning with chronic sleep loss, which leads them to feel irritable toward the care recipients. The irritability leads to feeling of anger and then guilt in caregivers, and finally the guilt leads to depressive symptoms.

In Carter's study (2002), male caregivers reported an overall sleep quality that was slightly better than female caregivers, although there was no significant difference. The gender difference in sleep problems was also identified from an earlier study where Smith, Ellgring, and Oertel, (1997) examined 153 subjects consisting of Parkinson's disease patients, their spouses, and healthy controls. Sleep disturbances were significantly higher in women than in men in all three groups from this study.

To date, there is no study focused on sleep problems or daytime fatigue in parents with a sick child. As a clinical practitioner who has worked in the neonatal and pediatric intensive care units for the past two decades, the most common complaints heard from either the patient or the family members are related to sleep disturbances. Parents usually

described difficulty falling asleep as a result of hyperarousal and thoughts racing and surrounding their minds with the image of their sick child in the hospital. They also describe feelings of fatigue or weariness during the day.

Summary of Relevant Research

The critical illness of a child can be a devastating experience for parents. All research has indicated that parents with critically ill children are likewise in one vulnerable group, and are likely to run the risk of becoming overwhelmed with social and psychological stressors. In addition, the experiences of immigrant families coming to the U.S. brings about physical, psychosocial, and cultural changes among family members as they adjust to the new mainstream society (Roer-Strier, 1997). Research has shown that immigrants have less educational attainment than non-immigrants (Chiswick & Sullivan, 1995). Consequences of inability to speak English and low educational attainment lead immigrants to live in households with incomes below the poverty level (U.S. Census, 2003). Therefore Chinese-American parents with a critically ill child can easily be seen as a vulnerable group for many reasons.

Although a great deal has been learned about parental stress related to a critically ill child, most of the research has been conducted with Caucasian mothers and middle-class families. Paternal stress perceptions, low-income families, and ethnic minority populations are limited in the research literature. Many issues remain to be clarified, and a number of methodological problems have made certain findings about parental stress perception unable to be generalized to all parents exposed to this type of stress. These problems include the lack of instruments with adequate psychometrics for examining the relationship among the variables of parental stressors; too little attention to the

determination of reliability and validity of measures in different populations; and more importantly, the absence of culturally diverse perspectives.

A major future direction for parental stress research is the cultural perspective approach for minority ethnic populations, low-income families, paternal perceptions, and health outcomes for those families. The interaction among different sources of stress needs to be examined. The relationships among stressors, stress response, and coping strategies also need to be described. Cross-cultural theory and research is needed in the understanding of parental stress and coping among Asian families related to their critically ill child. Strong, efficient and culturally sensitive care delivery systems are critically necessary to provide the highest quality of care for ethnic minority populations. There may also be specific issues that should be discerned and corrected, so that Asian-American families can easily and willingly make use of health care services and receive other forms of appropriate support to maintain their physical and emotional health and well-being.

Historically, health care in the U.S. has largely depended on a common language and the shared beliefs that contribute to a process of mutual understanding between providers and clients. These shared beliefs derive from a Eurocentric construction of values. This ethnocentric approach is based on one's own particular cultural viewpoint and the belief that it is the best approach. In reality, it is now socially appropriate and politically necessary to assert that cultural sensitivity is necessary because multicultural clients are found in any service delivery setting. Consequently, openness to new cultural understanding is also a necessity. To provide the most culturally sensitive services to ethnic minorities, it is also very important to understand that Asian-Americans are not a

homogeneous group called "Asian" and that there are differences among Asians (Kim et al., 2001; Root, 1998; Sue& Sue, 1999). Health professionals must recognize the existence of cultural relativism in regard to modern scientific medicine. Only through culturally relevant care can we meet the individualized needs for each client.

The Paradigm for Asian-American Research Methods

A scientific paradigm, as Kuhn (1962) stated, defines the boundaries of what questions can be asked and what methods can be used to answer these questions. Thus, a paradigm presents a model that can be applied by various persons conducting research at a specific point in time. The domain paradigm in research has been the Western model (Devins, 1999). Mainstream study methods may serve as the foundation for cross-cultural study; however, without adaptation, they fail to fit the unique needs of a cross-cultural study. Therefore, the inference of the research findings can be either invalid or too broad and not generalizable (Miyamoto et al., 2001; van de Vijver, 2001). As cultural influences affect Chinese-American families, we need to begin reformulating our approaches to the study of these existing phenomena. In this section, research paradigms for the study of Asian-American family health will be discussed.

Study Design

Appropriate research methods form the heart of scientific inquiry. Without appropriate methods with which to investigate hypotheses, research data cannot be summarized in a comprehensible form. A cross-cultural theory is needed to link research questions and study design, and then proper research methods must be used to provide empirical support for the results. Tanaka and colleagues (1998) have suggested a paradigm adopting process-oriented models to explain both the antecedents of Asian-

American self-identity and subsequent behavioral consequences. In other words, ethnic identity and assimilation are the two most important variables to be examined in any study of Asian health.

When conducting cross-cultural studies, researchers should clearly define the concepts and operationalize acculturation. A recent study compared the association between acculturation of Asian-American women and their survival after diagnosis of breast cancer (Pineda, White, Krisstal, & Taylor, 2001). These investigators used the participant's place of birth as the indicator of acculturation and concluded that there was no relationship to cancer survival. However, acculturation, as discussed in this chapter, is not just the place of birth, but rather a complicated process resulting from the interaction between the ethnic minority culture and the host group's culture. Although the study utilized a large sample size (N= 6,759 Asian-American women) and appropriate statistical methods, the results should be interpreted in light of their definition and measure of acculturation, and their conclusion of no relationship between acculturation and survival may not be valid.

It should be noted that in any single investigation, sampling pragmatics would minimize generalizability of study findings. Multiple-area and different-generation research approaches will then best serve the purpose. Rather than relying on convenience samples, researchers need to understand the characteristics of their own samples in a more complete manner. Kellam (1990) suggested a two-stage sampling method, whereby the researcher, after obtaining an initial population-based sample, draws a sub sample of individuals who have either strongly or weakly identified themselves as Chinese-Americans and then compares differences between these two groups. This method can

provide a greater insight into how self-identity as a Chinese-American serves as a guide for behavior. Furthermore, incorporation of qualitative research methods may help to amplify the relationships among variables beyond the extent conceivably determined through quantitative methodologies.

Measurement Issues

There are three measurement issues of concern when conducting studies of ethnic minority groups. These issues include the cultural appropriateness of the assessment instruments, use of standardized instruments, and the measurement equivalence of translations of these instruments (Tanaka, Ebreo, Linn, & Morera, 1998). The main issue regarding cultural appropriateness of the assessment instrument is the distinction between constructs that are universal (etic) and those that are specific to a particular culture (emic) (Marin & Marin, 1991). Triandis and Marin (1983) advocated that measurement instruments should include both emic and etic items to provide a clearer picture of the cultural groups being studied. Therefore, an acculturation scale to examine Chinese-American's ethnic identity and level of assimilation can enhance the researcher's comprehension of a participant's belief in their original culture and their level of adaptation toward the dominant society (Ponterotto, Baluch, & Carielli, 1998).

The second issue concerns the use of instruments designed for Euro-American populations. Bias can occur when such instruments are administered to minority groups, because researchers may find that such instruments measure constructs in these groups that differ from those measured in the normed sample. For example, Alkon and colleagues (2001) found that Chinese-American parents tend to define affection as doing something for a child, but the other ethnic groups tend to define it as holding and

hugging. This phenomenon may be related to the fact that Chinese people express their emotions through actions rather than verbalizations (Lee, 1989). Therefore, because of the different construct, the psychometric properties of the instrument might differ by ethnic group, and the reliability and validity of a measure may be unstable.

A third measurement issue concerns the use of translated instruments. Translation is often necessary when research participants are unable to read or understand English. In addition, participants may favor the Chinese language over English. The major goal of translation is to develop a version of the standardized instrument that is culturally equivalent to the original one (Marin & Marin, 1991). Furthermore, using a competent bicultural translator is very important, and any literary translations should be compared not only with the original, but also with previous translations of the same work to ensure the translation's linguistic and cultural appropriateness (Brislin, 1970; Kraszewski, 1998).

Participant Recruitment and Retention

Another challenge for researchers who conduct studies of ethnic minority groups is participant recruitment and retention. First of all, language can be a major barrier for a Chinese-American when participating in a research study. Therefore, adopting a translated instrument for the participants and using a same-ethnicity data collector may enhance their participation and completion of research. Other reasons that a member of an ethnic minority group may hesitate to participate in research include not understanding the value of research, not trusting the researcher, or having concerns such as fear of exposure of their legal status (Demi & Warren, 1995; Marin & Marin, 1991).

In general, participant retention is a greater problem than recruitment. A few strategies to help the researcher's success include showing respect to the participant,

providing help, and establishing an ongoing relationship between research staff and each participant (Demi & Warren, 1995; Marin & Marin, 1991).

Data Interpretation

Marin and Marin (1991) indicated that Hispanics tend to exhibit extreme response styles in answering scaled items. Chinese people may have a tendency to respond in a more neutral manner compared to other ethnic groups. A researcher's stereotypes or lack of cultural sensitivity or knowledge will cause a misinterpretation of responses. For example, healthcare providers may easily misunderstand Chinese mothers who practice the traditional postpartum month-long confinement ritual and assume that these mothers are suffering from depression that renders them unable to resume their normal daily activities.

In summary, understanding a particular ethnic minority group's cultural background is the foundation for validity in data collection, analysis, and interpretation. Before data analysis, it is necessary to establish the equivalence of measurements to prevent bias. Equivalence is associated with the measurement level at which scores obtained in different cultural groups can be compared. On the other hand, bias distorts data interpretation and slants the findings away from truth. A multidisciplinary research group may also be beneficial in analyzing data objectively and ensuring culturally and linguistically appropriate research.

The Theoretical Model of Stress and Coping

Stress and Coping Theory

Lazarus and Folkman (1984) have provided the most widely accepted framework for conceptualizing strategies for coping with stressful events. To develop their model,

they focused their attention on three critical concepts: stress, appraisal, and coping. Stress arises when some type of discrepancy exists between one's perceived environmental demand and his or her perceived ability to cope with that demand. Each demand can be of one or more types: social, cultural, psychological, or physiological.

The act of coping is a constantly changing cognitive and behavioral effort to manage specific demands that are seen as taxing or exceeding available resources. People rely on two forms of coping, problem-focused and emotion-focused, when confronted with a stressful situation (Lazarus & Folkman, 1984). Recently, Lazarus (1999) reemphasized the interdependent relationships among emotion, stress, and coping. The model has been revised to integrate stress, coping, and emotion within a system approach. The outcomes of stress and coping have been modified to include the various emotions and their effects on well-being.

Parental Stress Framework

To begin to understand parental stress when a child is admitted to an ICU, Miles and Carter (1983) developed a framework based on stress theory (Figure 2.1). They identified three sources of stress for parents: personal and family background factors, situational conditions, and environmental stimuli. Personal and family background factors are the past and present factors that a parent brings to an ICU experience. Situational factors are related to the child's illness and include perceived severity, type of admission (planned or unplanned), adequacy of parental preparation for the experience, and uncertainty about the outcome. Environmental stimuli are potential stressors arising from the physical and psychosocial aspects of the ICU environment. Recently, this model was modified and became the Preterm Parental Distress Model (Holditch-Davis &

Miles, 2000) to further explain the phenomenon of parental stress caused by the premature birth of an infant (Figure 2.2).

Figure 2.1 Conceptual Model for Parental Stress in the Intensive Care Unit (Miles & Carter, 1983)

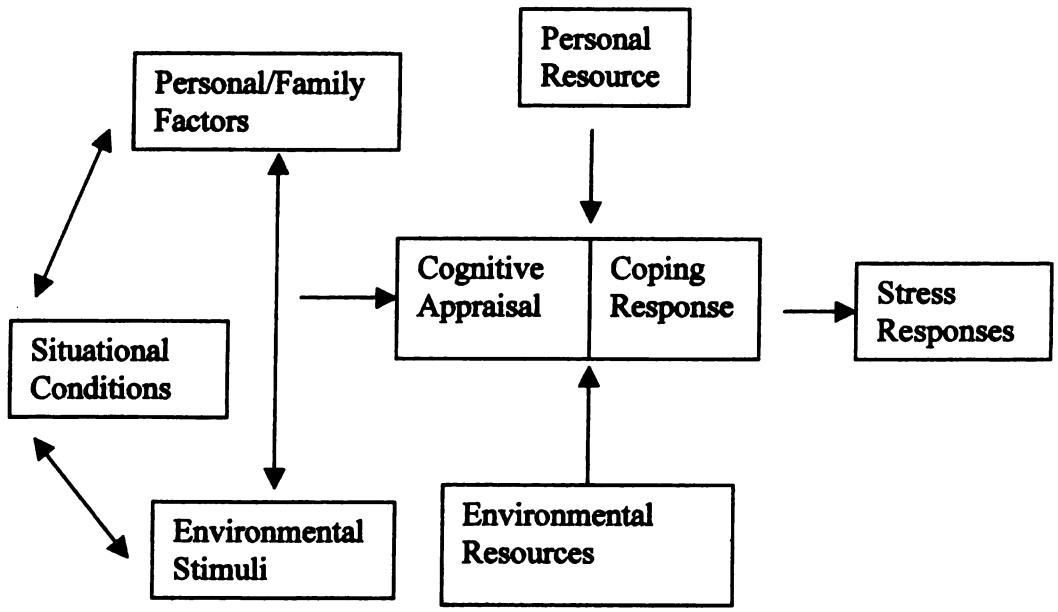
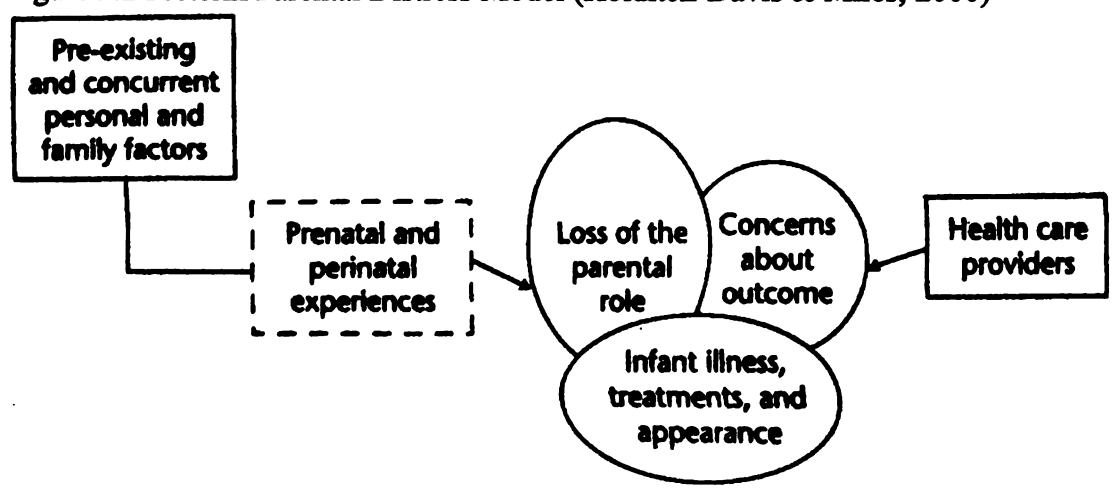


Figure 2.2 Preterm Parental Distress Model (Holditch-Davis & Miles, 2000)



The Parental Stress Framework has been widely used in clinical research. However, when it is applied to immigrant families, the parent's cultural background is not adequately addressed as a variable, and only attended to among personal/family factors as an antecedent. Attention to the concept of acculturation within this model

would address the need to assess the strength of a parent's cultural identity, thereby possibly leading to some insight into what conflicts parents may experience in the Western healthcare system.

Assimilation/Acculturation

In the U.S., two paradigms have been found in studies of ethnic relations. Assimilation models were the dominant paradigm up to the 1960s (Min, 1999). In those traditional assimilation models, it was assumed that all immigrants eventually would achieve acculturation, social integration, and socioeconomic mobility. However, the paradigm has changed since the 1970s to emphasize both ethnic identity and assimilation.

Kitano (1989) developed an Assimilation Model that is specifically for the Asian-American population. He stressed the importance of two variables, assimilation and ethnic identity. Assimilation encompasses integration into the school, the workplace, and social groupings, as well as identification with the majority population. In contrast, ethnic identity focuses on the retention of ethnic ways. Kitano's typologies are useful and helpful to explain Chinese-American's acculturation process because he separates assimilation from ethnic identity and emphasizes these important variables.

Kitano (1989) described four groups of assimilation/ethnic identity: (1) high assimilation, low ethnic identity: The person in this group identifies more with Americans than with people of his/her ethnic origin. For example, the third-generation Asians or Asians who desire to become Americans, and the Asians who are isolated from their ethnic communities fall into this group; (2) high assimilation, high ethnic identity: The person in this group is bicultural, and is similar to the previous person except that he/she retains a strong ethnic identity; (3) low assimilation, low ethnic identity: Only a

small number of Asian-Americans fit into this category. They have acquired little of the American culture and are also uncomfortable with their own ethnic identity; (4) low assimilation, high ethnic identity: Newly arrived immigrants, as well as those Asian-Americans who have spent much of their lives in a strong ethnic community, fall into this group. Such people are more comfortable in their own ethnic group with their own language and cultural practices.

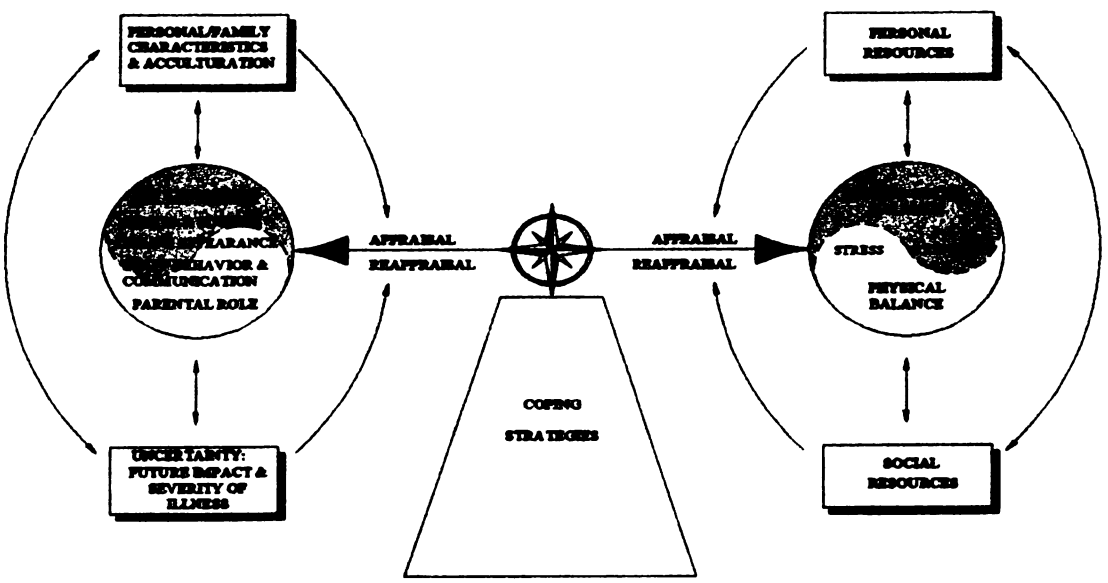
Asian-American Parental Stress-Coping Conceptual Framework

The conceptual model (Figure 2.3) described in this section combines aspects of the three models previously discussed. The Stress and Coping Model helps clinicians understand perceptions of stress and the coping process in general situations. The Parental Stress Framework emphasizes the specific stressors parents face in relation to their child's ICU setting. Miles and Carter, and Lazarus and Folkman, agree that the stress response is the result of complicated interactions between a number of biopsychosocial variables and the individual's perception of the stressor. Kitano's assimilation model introduces cultural relevance and the importance of assessing the uniqueness of an individual in order to further understand a person's perception of stress, stress response, and coping strategies from a cultural perspective.

This newly proposed model would suggest that if a child's illness remains a "stressor" in the family, both physical and psychosocial imbalance would continue. To reestablish balance or to reach an adaptive state, a parent will undergo a process of appraisal and reappraisal, then repeat the process if necessary. More importantly, these processes are accompanied by coping strategies involving personal and social resources that impact parental stress responses. For any cultural background, there are common

categories of stressors that parents face with a critically ill child: the ICU experience itself, their personal and family characteristics, the severity of their child's illness, and the perceived future impact of that illness on the child and family. In addition to these four categories of stressors, Asian-Americans also have the added stressor of their level of acculturation into the dominant U.S. culture. Coping strategies act as a balancing scale between stressors such as an ICU experience (on the left side of Figure 2.3) and stress responses (on the right side of Figure 2.3). If the stressors outweigh a parent's personal resources, then the stress-response side will rise and cause a biopsychosocial imbalance and risk for adverse health effects.

Figure 2.3 Conceptual Stress-Coping Model for Asian-American Parents with a Critically ill child



Conceptual Definition of Terms

Stressor is the stimulus that initiates the stress process. The stressor related to a critically ill child may come from the parent's personal/family characteristics and acculturation level, and ICU experiences, and uncertainty about the severity of the child's illness and future impact.

Personal/Family Characteristics refers to bio-psycho-social background, past experiences with a sick child, impact of concurrent life events, family functioning style, coping skills, family resources, family's migration experience, and level of acculturation.

Acculturation is the cultural assimilation, adoption of cultural patterns of the host group, and ethnic identity.

ICU Experience refers to the parents' experiences in the ICU, such as ICU sights and sounds, child's appearance, staff behavior and communication, and alterations in parental role functions (Miles & Carter 1983).

Uncertainty refers to the perception of child's morbidity and worry about child's illness and its future impact (Miles & Carter, 1983).

Coping Strategies are defined as the strategies reported by individuals who attempt to reduce the intensity of stress to a tolerable level by utilizing problem-oriented coping methods or affective-oriented coping methods to maintain well-being (Lazarus & Folkman, 1984).

Appraisal refers to the cognitive process of categorizing an encounter, and its various facets, with respect to its significance for well-being. Primary appraisal is the individual evaluation of a stressful situation. Secondary appraisal, often occurring simultaneously with the primary appraisal, is the judgment of what may happen or may be done, and involves consideration of resources and options for coping (Lazarus & Folkman, 1984).

Reappraisal refers to a change in appraisal on the basis of new information from the environment, which may resist or nourish pressures from the person, and/or information from the person's own reaction (Lazarus & Folkman, 1984).

Stress Response refers to the individual's physical and psychosocial responses to stress, such as sleep disturbances and fatigue. Sleep disturbance refers to either sleep deprivation resulting from an inadequate total amount of sleep, or sleep disruption resulting from fragmented sleep during the night (Lee, 2003). Fatigue refers to the results of excessive energy consumption and a subjective state of weariness related to stress and/or sleep disturbance (Lee, Hicks, & Nino-Murcia, 1991).

Personal Resource refers to the individual's own coping skills and the support from family members.

Social Resource refers to the supports from outside the family, such as the health care system and community.

Research Questions

A descriptive correlational study was designed to answer the following four research questions:

1. What are major stressors for Chinese/Chinese-American parents of children who are in intensive care units?
2. Is parental stress associated with objective and subjective sleep disturbance or perception of fatigue?
3. To what degree is parental stress explained by a parent's level of acculturation, personal/family characteristics (age, financial status, education, gender of the ill child, support resources), and uncertainty (perceived severity of the child's illness, worry about child's illness and its future impact)?
4. To what degree are sleep disturbance and fatigue explained by parental stress perception?

CHAPTER III

METHODOLOGY

The purpose of this study was to describe the Chinese/Chinese-American parent's stress experiences with a critically ill infant in the intensive care unit (ICU), including factors associated with parent's perception of stress and stress responses. Figure 2.3 presented in Chapter 2 depicts the Conceptual Model for Asian-American Parents with a Critically Ill Child and provides the theoretical framework for this prospective descriptive, correlational study. The purpose of this chapter is to describe the study methodology in detail. The research design, setting, recruitment procedure, instruments and data analysis to answer each of the four research questions will be described.

Research Design

A descriptive correlational study was conducted to identify sources of parental stress for Chinese/Chinese-American parents with a critically ill child in ICU and examine relationships between parental stress and level of acculturation, personal/family characteristics, and uncertainty. The influence of stress on parents' sleep disturbance and fatigue was also examined. There are four sets of data to be collected. The first was the Child's Data Form and Parent's Demographic Data. The second set included four instruments (Parental Stressor Scale: Infant Hopsitalization, General Sleep Disturbance Scale, Suinn-Lew Asian Self-Identity Acculturation Scale, Family Support Scale) and a structured interview form completed during a face-to-face interview. The third set was a short sleep log, used to collect the parent's subjective fatigue in the evening and morning, and their subjective sleep disturbances for two days and nights. The last set was the wrist acigraphy data, a noninvasive wrist motion sensor (Mini Motionlogger Actigraphy,

AAM-32 Ambulatory Monitoring Inc., Ardsley, NY) was used to monitor activity continuously for 48 hours to provide an estimate of objective sleep.

Research Questions

1. What are major stressors for Chinese/Chinese-American parents of children who are in intensive care units?
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3. To what degree is parental stress explained by a parent's level of acculturation, personal/family characteristics (age, financial status, education, gender of the ill child, support resources), and uncertainty (perceived severity of the child's illness, worry about child's illness and its future impact)?
4. To what degree are sleep disturbance and fatigue explained by parental stress perception?

Setting

Study participants were recruited from five tertiary ICUs in three San Francisco teaching hospitals (A, B, and C). Site A has 50-bed NICU, 8-bed Cardiac ICU, and 14-bed Pediatric ICU. Site B has 18-bed NICU and Site C has 8-bed NICU. Primary care nursing was the organizing structure for delivery of nursing services in each ICU. In all settings, policy allowed parents to visit their child at any time except for the shift changing periods and parents were encouraged to participate in care-taking activities as they felt comfortable, or as the child's condition allowed.

Sample

Convenience sampling was used in this study. Over a 10-month period, 33 parents who met criteria for participation in the study were approached and three couples declined to participate, and the overall refusal rate was 9.1%. Two of the refusing families expressed interest in participating until the researcher approached with the informed consent. The other family decided not to participate due to their baby's unstable condition. A convenience sample of 30 Chinese families (30 mothers and 25 fathers) of 31 infants (29 singleton and one set of twins) in five ICUs was screened and enrolled from a population of all parents whose child had been admitted to an ICU. Parents did not need to speak or read English to participate in this study. The inclusion criteria were: 1) father and mother who were 18 years of age or older, self-identified as Chinese or Chinese-American and had a child in the ICU, 2) child's age 12 months or less, 3) child in the ICU between 3-10 days and deemed medically stable, 4) child had no indication of abuse, and 5) father and mother did not have an allergy to metal.

Human Subject Approval

Approvals for the study were obtained from the Committee on Human Research (CHR) at UCSF (Approval Number H5464-21640), the Institutional Review Board (IRB) from SFGH and the IRB from CPMC (Approval Number 23.030) (Appendix A).

Instrumentation

The study utilized a Parent's Demographic Data Form, Child's Data Form, the 22-item Parental Stressor Scale: Infant Hospitalization, 21-item General Sleep Disturbance Scale, 26-item Suinn-Lew Asian Self-Identity Acculturation Scale-modified, and 20-item Family Support Scale. It took about 60 to 90 minutes to complete the questionnaires with

the researcher interviewing each participant. In addition, a structured interview form was utilized to obtain qualitative data from parents regarding their stress responses and their coping. Parents also kept a 48-hour sleep diary to record their subjective sleep-wake patterns. The diary included the modified Numerical Rating Scale for Fatigue to assess for morning and evening fatigue severity.

All questionnaires (see Appendix B) as well as Consent Forms (Appendix C) were translated into Chinese. There are no standardized procedures that exist for adapting measures validated for other cultures. In adapting the instruments for this study, translation theory (Chau, 1983; Kraszewski, 1998) and the recommended procedures for cross-cultural research (Brislin, 1970; Brislin, Lonner, & Thorndike, 1973) were used to first translate the instruments into Chinese and then back-translate using the three criteria developed by Flaherty and colleagues (1988) to test the semantic, content, and technical equivalence of the original and translated versions (see Appendix D).

Two Chinese-American freelance translators first translated all of the English version questionnaires separately and then cross-examined and revised it became the Chinese version #1. A panel of 6 Chinese committees (6^{th} and 7^{th} grade Chinese language arts teachers) evaluated the Chinese version #1 for content equivalence and the reading level of 5th to 6th grade. The final product from the committee's review was became the Chinese version #2. To ensure the semantic equivalence of the Chinese translation, the back translation of Chinese version #2 into English was utilized. In this step, one professional translator and one Chinese-American who were not familiar with the original questionnaires but with bicultural background were used. They

independently translated the Chinese version back to English version, then cross examined each person's product and finalized it became the English version # 2.

After the back translation was finished, a panel of 4 experts (one Chinese-American neonatologist, one master prepared Chinese-American neonatal nurse, one free lance translator, and one retired Chinese-American social worker) was used to examine the original English version and the back translation English version for the semantic equivalence. They rated each item on a 3-point scale recommended by Flaherty and colleagues (1988), with 3 equaling "exactly the same meaning in both version," 2 equaling "almost the same meaning in both versions," and 1 equaling "different meaning in each version." Any items rates as "2" or lower by all examiners were reevaluated and revise by a bilingual person. A pretest was done with two Chinese parents who had a child hospitalized in the ICU followed by minor modifications. In addition, panel of 4 bilingual Chinese immigrant committees were used to examine the meaning errors among the modification questionnaires, the back translation English version and the Chinese version. The final products became English version #3 and Chinese version # 3.

Demographic Data Form

This demographic form, developed by the researcher, was used for the collection of parent's personal and family background data. Data included the participant's age, marital status, educational level, birth place, immigration history, financial status, health status, sleep problem before and after child's admission, help-seeking, past ICU experience, and special ritual for child caring. In addition, three questions were designed to obtain parental perception about their child's severity of illness and their worry regarding the illness and future impact on their child. Data from these questions were

utilized for both descriptions of the sample and as independent variables in the data analysis.

Child Data Form and Clinical Risk Measures

This form was designed to obtain information about the child's medical condition. It included: date of birth, child's age, child's diagnosis, lab tests, medications, and ventilator requirements. Data on this form were used to calculate the Clinical Risk Index for Babies Score (CRIB, see Appendix B) (The International Neonatal Network, 1993) or the Pediatric Risk of Mortality Score (PRISM, see Appendix B) (Pollack, Ruttimann, & Getson, 1988) to obtain a more objective assessment for the severity of the child's illness. The CRIB was used for the newborn and the PRISM was used for the rest of babies in this study.

The CRIB score was based on birth weight, gestational age, maximum and minimum fraction of inspired oxygen and maximum base excess during the first 12 hours of life, and presence of congenital malformations. This score system was validated by comparing its scores with a cohort of 812 premature infants of birth-weight equal or less than 1500gm as a predictor of hospital mortality with that of birth weight in a separate cohort of 488 similar infants ($p = .03$). Theoretical scores can range from 0 to 23. The baby who scores 5 or less on the CRIB has a 5% hospital mortality risk while the baby who scores more than 16 on the CRIB has a 90% hospital mortality risk.

The PRISM (Appendix B) score was based on routine data describing clinical risk and disease severity within 24-hour of admission and then weighted to reflect the probability of subsequent death. The predicting mortality was used to test the validity of

the PRISM (χ^2 (5)= .80, P > .95). This index includes 14 routinely measured, 23 variables ranges, and theoretical scores can range from 0 to 76.

Parental Stressor Scale: Infant Hospitalization (PSS:IH)

The PSS:IH was developed to measure parental perception of stressors arising from the physical and psychosocial environment in an ICU and general pediatric unit (Miles & Brunssen, 1998). This scale was adapted from the Parental Stressor Scale: NICU version (Miles, Funk, Carlson, 1993) and includes 22 items to assess perceived stress related to the sights and sounds of the environment (6 items), infant's behavior and appearance (8 items), and parental role alterations (8 items). This scale can be used for parents who have had a child in the NICU, Pediatric Intensive Care Unit (PICU), or general pediatric unit. Responses are scored on a five-point Likert-type scale ranging from 1 (not at all stressful) to 5 (extremely stressful). Because of the diversity of diagnoses, treatments, and ages of the infants, parents have the option of marking "N/A" for not applicable items.

Validity and Reliability

Psychometric analysis was done with 81 mothers and 43 fathers of 83 pre-term or full-term infants who hospitalized in a tertiary care unit for a life-threatening condition. Pediatric nurses were used as consultants and a pilot study with parents of medically fragile infants was conducted to verify content validity. Construct validity was supported by significant correlations between the PSS:IH and maternal distress outcomes. Internal consistency reliabilities (Cronbach alphas) for mothers were: total score .87, parental role alteration .76, infant appearance and behavior .79, and sights and sounds .78. Internal consistency reliabilities for fathers were: total score .90, parental role alteration .82,

infant appearance and behavior .87, and sights and sounds .65. Correlation coefficients among the three subscale scores for mothers ranged from .52 to .84; for fathers, the correlation coefficients ranged from .41 to .89 (Miles & Brunssen, 1998).

In this scale, none of the questions assess parents' stress perception related to their interaction with the health care providers. Therefore, three questions were added to the PSS: IH to obtain Chinese parent's stress levels related to communication with the health care providers, stress derived from the behavior of health care providers, and general stress levels of the ICU experience. Two respondent-initiated questions were also added to obtain parent's other stressful life experiences, and the parents were asked to compare those experiences with this specific hospitalization experience.

Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA)

To date, the only objective measure of acculturation for Asian-Americans that has been empirically validated is the SL-ASIA (Suinn, Rickard-Figueroa, Lew, & Vigil, 1987). The SL-ASIA was adapted from the Acculturation Scale for Mexican-Americans developed by Cuellar, Harris, and Jasso (1980). This instrument contains 21 items covering six topics, including behavior (5 questions), language (4 questions), identity (4 questions), friendship choice (4 questions), generation/geographic background (3 questions), and attitudes (1 question). The respondent rates the items on a 5-point scale, with 1 representing low acculturation/high Asian identification and 5 representing high acculturation/high Western identification. A person would be called "bicultural" if the mean score was 3. This 21-item scale has been adapted and used in various studies of college students as well as community based Japanese-Americans (Iwamasa, Pai, Hilliard, & Lin, 1998).

Validity and Reliability

The scale was developed using 284 college students from Colorado State University and 59 students from the University of California, Los Angeles. Concurrent validity has been established by the correlations between average acculturation scores and generational status, length of residence, and years of schooling in the United States (Suinn, Richard-Figueroa, Lew, & Vilig, 1987; Suinn, Ahuna, & Khoo, 1992). Construct validity has been examined by factor analysis, and five factors have been identified: 1) reading, writing, cultural preference, 2) amount of interaction with members of the same ethnic group, 3) affinity for ethnic identity and pride, 4) generational identity, and 5) food preference. These five factors accounted for 69.7% of total item covariance on the SL-ASIA (Suinn, Ahuna, & Khoo, 1992). Consistent and high internal consistency reliability coefficients (Cronbach alphas) of .88, .89, and .91 were reported in three studies (Suinn, Richard-Figueroa, Lew, & Vilig, 1987; Atkinson & Gim, 1989; and Suinn, Ahuna, & Khoo, 1992). For the Japanese-American community based study, the reliability was lower, with a Cronbach alpha coefficient of 0.71.

Suinn (personal communication June 14, 1999) added 5 new questions to the original 21-item scale to further classify research participants in multi-dimensional and orthogonal ways. The five new items are related to cultural values, behavioral competencies, and self-identity. The 26-item SL-ASIA scale has been modified and translated into Chinese and then psychometrically tested (Lee & Rankin, 2004). Both English and Chinese versions used 195 Chinese-Americans with a mean age of 39 years. The majority (80%) had attended school in the U.S. The internal consistency reliability for the scale was .83 for the English version and .86 for the Chinese version. For this

study, the 26item SL-ASIA was adopted, and the five additional questions (item 22 to item 26) were examined separately from the 21-item SL-ASIA as suggested by Dr. Suinn (personal contact).

Family Support Scale (FSS)

The FSS was designed by Dunst, Trivette and Jenkins (1988) to assess the helpful sources of support for participant's child caretaking. The scale includes 18 items each rated on a five-point scale, and two respondent-initiated items. The resources include the participant's direct and indirect family members, social group, health care provider and other professional helpers. The five-point Likert-type scale ranges from 1 (not at all helpful) to 5 (extremely helpful). The participants also have an option of "not available" ("N/A") on any item. A total score is calculated by adding the scores for the 18 items. Higher scores indicate the respondent's higher sense of support.

Validity and Reliability

Psychometric analyses involved 139 parents of preschoolers who were retarded, handicapped or developmentally at-risk children. Factor analysis was used to evaluate the construct validity. Six factors were found in this scale: informal kinship, social organizations, formal kinship, immediate family, socialized professional services, and generic professional services. Alpha coefficient for the 18-item scale was .77, split-half reliability was .75, and test-retest reliability one month apart was .91 (Dunst, Trivette, & Jenkins, 1988).

General Sleep Disturbance Scale (GSDS)

The GSDS includes 21 items related to frequency, in the past month, of difficulty getting to sleep (1 item), waking up during sleep (1 item), waking up too early from sleep

(1 item), quality of sleep (3 items), quantity of sleep (2 items), fatigue and alertness at work (7 items), and use of substances to help induce sleep (6 items). This is a self-rated 10-point scale from 0 (never) to 9 (all the time), in which the items are summed from 0 to 189. Higher score indicates more severely disturbed sleep. Psychometric analysis was done on a sample of 760 female registered nurses who were working at least 4 days/week and 32 hours/week in seven hospitals on the west coast of the U.S. (Lee, 1992). The GSDS was revised for longitudinal studies to become a 0-7 weekly rating scale, from 0 (no days this week) to 7 (every day past week) for intervention studies in childbearing women.

Validity and Reliability

The modified Stanford Sleep Questionnaire–Assessment of Wakefulness (SQAW) was used to evaluate the construct validity of the GSDS. Different mean scores for shift-workers support its validity and sensitivity. The Cronbach alpha coefficient for the overall scale was 0.88 and for the subscale use of sleep aids, sleep quality, and sleepiness were 0.62, 0.79, and 0.82 respectively (Lee, 1992).

Numerical Rating Scale for Fatigue (NRS-F)

The NRS-F is an 18-item numerical rating scale modified from the original10 cm visual analogue format (Visual Analogue Scale-Fatigue, VAS-F) that includes a 13-item fatigue subscale and a 5-item energy subscale. The 18 items are self-rated from 0 (not fatigued) to 10 (extremely fatigued). Psychometric tests were done on a sample of 75 healthy male and female subjects who ranged in age from 18 to 55 years and another sample of 57 male and female patients who had sleep disorders (Lee, Hicks, & Nino-Murcia, 1991). Some of the terminology for the 18 items was difficult to differentiate

after translation into Chinese. Thus, the translation panel decided to modify the original 18-item scale into a 9-item scale, which includes a 7-item fatigue subscale (tired/fatigue, sleepy, exhausted, effort to moving body, concentrating, carrying on a conversation, desire to lie down) and a 2-item energy subscale (energetic, efficient) to measure parent's fatigue severity as one of the outcomes of parental stress with a child in the ICU.

Validity and Reliability

The Stanford Sleepiness Scale and the Profile of Mood States were used to evaluate the concurrent validity of the VAS-F ($r > .03$, $p < .01$). The Cronbach alpha coefficient, for the 13-item fatigue scale and 5-item energy scale ranged from .91 to .96 for the healthy subjects and the patient groups (Lee, Hicks, & Nino-Murcia, 1991). It was modified to a numerical rating scale for ease of use in subsequent studies with childbearing populations as well as chronically ill populations such as cancer and HIV/AIDS without any change in psychometric measures.

Activity Monitoring

Wrist actigraphy (Mini Motionlogger Actigraphy, AAM-32 Ambulatory Monitoring In., Ardsley, NY) was used to measure continuous movements, which can then be used to estimate whether one is awake or asleep using an auto-scoring software program (Action3) algorithm to minimize scoring bias. This recorder uses a battery-operated wristwatch-size microprocessor that senses motion with a piezoelectric beam and detects movement and acceleration in all three axes. One-minute intervals were used in this study to calculate the total sleep time and wake after sleep onset. Various researchers have used polysomonographic measures of sleep to validate ($r = .93$ to .99) wrist actigraphy as a measure of total sleep time and wake during the night (Ancoli-

Israel, Clopton, Klauber, Fell, & Mason, 1997; Brown, Smolensky, D'Alsonzo, & Redman, 1990; Jean-Louis, von Gizycki, & Zizi, 1996; Walsh, Schweitzer, Anch, Muehlbach, Jenkins, & Dickins, 1991).

Structured Interview Form

This form was designed by the researcher to expand knowledge about the participant's ICU experiences. Six questions were included in this form:

1. Is there anything else that was stressful for you during the time that your child has been in the intensive care unit?
2. Have there been any communication issues between the health care providers and yourself that affect your understanding about your child's condition and treatment plan?
3. During this period of time, how do you feel physically, in your body?
4. During this period of time, what do you feel emotionally?
5. What helps you most to cope with this period of time?
6. What kind of assistance would you like to have to help you cope during this period of time?

Study Procedures

The researcher contacted the ICU charge nurse or the attending physician to see if there were any potential subjects hospitalized in the ICU. Staff nurses at each site who made first contact with those meeting selection criteria initiated recruitment. If parents were interesting in hearing more about this study, the researcher approached them at bedside and explained the study to them. The opportunity was given for the parents to discuss the project privately and a later contact was made to answer questions and enroll

the subject. Either parent or both parents could participate. Finally, an appointment was established for the consent procedures and data collection interview with those willing to participate.

During the first interview, the study was described again and each mother and father was given an opportunity to ask questions or clarify the procedures. The consent form was reviewed with each individual interested in taking part, and each participating father and mother signed a consent form. At all sites, protection of subjects' anonymity and privacy was assured, as was the freedom to withdraw at any time, or to decline to participate in the study without repercussions. Risks and benefits of participating were also included in the written informed consent.

Thirty families participated in this study (30 mothers and 25 fathers), and all of them completed the Family Support Scale (FSS), General Sleep Disturbance Scale (GSDS), Suinn-Lew Self-Identity Acculturation Scale (SL-ASIA), Parental Stressor Scale: Infant Hospitalization (PSS:IH), and Numerical Rating Scale for Fatigue (NRS-F). All of the instruments were completed during a face-to-face interview with the exception of the NRS-F scale completed both mornings (immediately after awakening) and evenings (right before bedtime) in each parent's 48-hour diary.

After obtaining informed consent, the researcher used the questionnaires to interview father and mother separately. The demographic data were obtained first, followed by the Family Support Scale, General Sleep Disturbance Scale, Suinn-Lew Asian Self-Identity Acculturation Scale-modified, and Parental Stressor Scale: Infant Hospitalization. The six structured interview questions (SIQ) were coordinated and applied into each related questionnaire interview. SIQ #1 and #2 were conjoined with the

PSS: IH interview; SIQ #3 and #4 were bracketed into the Demographic data interview; and SIQ #5 and #6 were coalesced with the FSS interview. After the parents answered each question, the researcher verbally summarized the parent's answers to confirm responses. The researcher reviewed infant's medical records after the interview.

After the initial interview, parents were asked to re-confirm no allergy to metal and a written instruction was gave to parents before they put on a wrist actigraph for 48 hours to monitor their activities to obtain objective sleep data. In addition, parents also kept a sleep diary to record their subjective sleep data regarding their sleep-wake patterns and fatigue level. The sleep diary and all the questionnaires were bound together as a booklet. While the parents kept this booklet to record their sleep diary, they were asked to review the records of questionnaires and structured interview data, and correct any data not truly reflecting their ICU experiences. None of the data were changed by subjects, which indicated parents agreed with each document that the researcher made during the interview. In general, the interview to complete the questionnaires took about 60 to 90 minutes. In cases requiring a longer interview time period, data collection was interrupted and completed when the actigraph and sleep diary were returned to the researcher. Data from 30 mothers and 25 fathers were collected and reported separately.

Methods of Data Analysis

Data were analyzed using the Statistical Package for the Social Science (SPSS) Version 11.0. Responses were coded and entered twice to ensure accuracy of the data. The automatic sleep-scoring program (Action3 Software Program, Ambulatory Monitoring Inc., Arbsley, NY) was used to calculate total sleep time (TST), and percentage of wake after sleep onset (WASO) during the night. All of the data were also

verified for accuracy by reviewing questionable data in the questionnaires. The linkage between variables, empirical indicators and measures are detailed in Table 3.1.

Table 3.1: Linkages Between Variables, Empirical Indicators and Measures

Variables	Empirical Indicators	Measurement
ICU Stressors: * Parental role alteration * Child's appearance * ICU environment * Health care provider's behavior * Health care provider's communication * Others	1. Parental Stressor Scale: Infant Hospitalization (PSS:IH) – * Parental role alteration * Child's appearance * ICU environment 2. The added questions in the PSS:IH – * Health care provider's behavior * Health care provider's communication * General stress levels 3. Structured Interview Form (Question # 1 and #2)	1.Mean of PSS:IH and three subscales 2. Score of the three added questions 3.Mean of PSSALL: Mean of parental role alteration, child's appearance, ICU environment, health care provider's behavior and health care provider's communication 3. Content analysis.
Predictors of stress * Acculturation: assimilation and ethnic identity * Parents' characteristics and social support * Uncertainty: perception of child's morbidity and worry about child's illness and its future impact	26-item SL-ASIA Parent Demographic Data Form Family Support Scale (FSS) Child Data Form and clinical risk measure (CRIB, PRISM) Demographic Data Form: Parent's perceived of child's severi of illness Parent's worrisome with child's illness and its future impact	Mean score of 21-item SL-ASIA and scores of the 5 added questions Education, age etc. Mean score of FSS CRIB score for newborn PRISM for the infants who age more than one month old Parent's rating from 1 (not sick) to 5 (extremely critical) Parent's rating from 1 (not worry at all) to 5 (extremely worry)
Stress Responses: * Sleep disturbance * Daytime fatigue	1. General Sleep Disturbance Scale (GSDS) 2. Wrist Actigraphy 3. Sleep Diary 1. Numerical Rating Scale for Fatigue (NRS-F)	1. Total score of GSDS and each subscale 2. Total sleep time (TST) and wake after sleep onset (WASO) 3. Total sleep time needed by parents to fell refresh Sleep-wake patterns 1. Mean of two evenings fatigue and mean of two mornings fatigue

Descriptive Information

Statistics were computed for all demographic characteristics of the child from the child's medical record and family characteristics. Internal consistency reliability measures for all instruments were calculated using Cronbach alpha coefficients. Mean scores and standard deviations were obtained for each scale.

Analysis Plans for the Four Research Questions

Chi-square and ANOVAs were used first to determine if there were any significant differences on demographic variables for parents and children between the five units of three research facilities. Independent t-tests were used to determine if there were any mean differences in parental stress measures by gender of the hospitalized child.

Research Question 1: What are major stressors for Chinese/Chinese-American parents of children who are in intensive care units?

This question was analyzed by calculating the mean scores on the PSS:IH and each subscale of the PSS: IH, which included the parental role, child's appearance and ICU environment. Three 5-point Likert-type questions were also included to address parental stress from the behavior of health care providers, stress from the communication with the health care providers, and general stress from the ICU setting. A new overall stress score (PSSALL) was created by calculated the mean scores of each subscale of PSS:IH, stress derived from health care provider's behavior and health care provider's communication. In addition, the qualitative data from structured interviews (question one and two) were also coded and analyzed using content analysis.

Research Question 2: Is parental stress associated with objective and subjective sleep disturbance or perception of fatigue?

This research question was analyzed by creating a correlation matrix using Pearson product moment correlations. Scores on ICU stressors (PSS: IH mean score; subscale of PSS:IH – parental role, child's appearance, ICU environment; the scores of added questions in PSS:IH – health care provider's behavior [PSSe1], communication with health care provider [PSSe2], and the overall stress level from ICU [PSSALL]) were placed in a correlation matrix with objective sleep data from actigraphy (TST, WASO), the parent's subjective sleep report (GSDS), and evening and morning fatigue scores (mean NRS-F scores of two evenings and two mornings).

For the objective sleep data, there was a correlation and without significant difference between the first night and second night for both total sleep time ($r = .70$ for mothers; $r = .55$ for fathers) and for wake after sleep onset ($r = .57$ for mothers; $r = .46$ for fathers). The average of two nights was used for analysis of sleep patterns since there was no first-night effect for habituating to the equipment.

Research Question 3: To what degree is parental stress explained by a parent's level of acculturation, personal/family characteristics (age, financial status, education, gender of the ill child, support resources), and uncertainty (perceived severity of the child's illness, worry about child's illness and its future impact)?

Research question 3 was analyzed by hierarchical regression analyses to determine whether any independent variables (acculturation, personal/family characteristics and social support, and uncertainty) predicted parental stress scores. Child's gender was entered first to statistically control for the effects from the traditional Chinese cultures values related to the male gender. Pearson correlations were used as initial tests of relationships among the independent variables with the dependent variables

(PSS:IH, PSSALL). Independent variables with a Pearson correlation coefficient greater than 0.25 were included in the hierarchical regression models as step two. Guidelines to determine which variables should be included in the model were based on the Conceptual Stress Model for Asian-Americans Parents with a Critically Ill Child (See Chapter 2, Figure 2.3).

Research Question 4: To what degree is sleep disturbance or fatigue explained by parental stress perception?

This final research question was analyzed by two hierarchical regression models to determine which parental stress variables (PSS:IH, subscale of PSS:IH, PSSALL) predicted parental sleep disturbance (GSDS, TST, WASO) and parental fatigue severity (morning and evening NRS-F). Those parental stress variables with a Pearson correlation coefficient greater than 0.25, as determined by the correlation matrix in the research question 2, were entered as step 2 after controlling for variables in step 1 from research question #3.

CHAPTER IV

RESULTS

The results of this cross-sectional descriptive correlational study of Chinese/Chinese-American parents with a child in the intensive care unit are presented in this chapter. Findings reported here include descriptive information concerning the parents, infants, reliability of instruments, and data addressing each of the four research questions.

Sample Characteristics

Of the 30 families in this study, 11 (36.7%) were recruited from site A, six (20%) from site B, and 13 (43.3%) from site C. Among the 11 families from site A, seven babies were hospitalized in the neonatal ICU, three were in the pediatric ICU, and only one was in the cardiac ICU. Site B and site C only house NICU. Chi-Square tests and ANOVAs confirmed there were no significant differences on demographic variables between the parents (education, financial status, age, marital status) and infants (age, gender, severity of morbidity) by hospital setting.

Participants (Table 4.1) were predominantly first-generation Chinese-American (83.3% mothers, 84% fathers), married couples (90%), and had earned at least a college degree (63.3% mothers, 68% fathers). Mothers ranged in age from 18 to 43 ($M = 31.5 \pm 4.8$ years) and fathers ranged in age from 24 to 42 ($M = 33.4 \pm 4.6$ years). On average, mothers had lived in the U.S. for about 12 years, and fathers averaged about 16 years. The two-parent family was the most frequent family structure (60%), and remaining families were either living with the grandparents or other relatives. A majority of the parents reported no specific religion (63.3 % mothers, 52 % fathers), and the others

reported their religion as Buddhism, Christianity, or ancestor worship. Almost half of the fathers (48%) reported an annual family income of greater than $60,000, while 36% reported less than $40, 000 and 12% refused to answer the income information. On average, mothers stated that the total sleep time (TST) perceived as needed to restore their energy level was 477 minutes; for fathers it was 457 minutes.

Table 4.1 Characteristics of the Parents by Gender

	Mothers (N=30)	%	Fathers (n=25)	%
Age	18 to 43 (M= 31.53 ± 4.84)		24 to 42 (M= 33.40 ± 4.62)	
Generation	1st generation (N=25) 2nd generation (N= 5)	83.3 16.7	1st generation (N= 21) 2nd generation (N= 4)	84.0 16.0
Years lived US	.3 to 36 years (M=12.2 ± 11.7)		.3 to 38 years (M=16.2 ± 11.7)	
Marital Status	Married (N=27) Divorced (N=1) Living together (N=2)	90.0 3.3 6.7	Married (N=23) Living together (N=2)	92.0 8.0
Family structure	Two-parent (N=19) Parents and grand parents (N=6) Parents and relatives (N=3) Parents, grandparents, and relatives (N=2)	63.3 20.0 10.0 6.7	Two-parent (N=15) Parents and grand parents (N=6) Parents and relatives (N=3) Parents, grandparents, and relatives (N=1)	60.0 24.0 12.0 4.0
Religion	None (N=19) Buddhism (N=6) Christianity (N=5)	63.3 20.0 16.7	None (N=15) Buddhism (N=2) Christianity (N=7) Ancestor worship (N=1)	60.0 8.0 28.0 4.0
Education	Middle school (N=3) High School (N= 8) College (N= 13) Graduate school (N= 6)	10.0 26.7 43.3 20.0	Middle school (N=2) High School (N= 6) College (N= 13) Graduate school (N= 4)	8.0 24.0 52.0 16.0
Income	Refused to answer (N= 4) Less than $ 20,000 (N= 6) $20,000-40,000 (N= 7) $40,000-60,000 (N= 1) $60,000-80,000 (N=1) $80,000-100,000 (N=5) More than $100,000 (N= 6)	13.3 20.0 23.3 3.3 3.3 16.7 20.0	Refused to answer (N= 3) Less than $ 20,000 (N= 4) $20,000-40,000 (N= 5) $40,000-60,000 (N= 1) $60,000-80,000 (N=1) $80,000-100,000 (N=3) More than $100,000 (N= 8)	12.0 16.0 20.0 4.0 4.0 12.0 32.0
TST needed by parents	477 ± 46.84 minutes		457.2 ± 56.31minutes	

Though the babies were not participants in this study, their situational information was pertinent since they were the focus and context within which the parents were reacting and forming perceptions. Therefore, data from 31 babies (14 boys, 17 girls) are presented in Table 4.2. One of the 30 families in this study had twins with one boy and

one girl. The majority of babies were premature (N= 16, 51.6%), and the rest were diagnosed with respiratory distress, sepsis, congenital defect, or other problem. The 31 infants ranged in age from 3 days to one year old; 18 infants were less than one week old, and 6 were between 8 days to one month old.

The Clinical Risk Index for Babies Score (CRIB) or Pediatric Risk of Mortality Score (PRISM) classified most of the babies as low risk (90.3%). Parents were asked to rate their child's illness condition at admission and at the time of interview, rating from 1 (not sick at all) to 5 (extremely critical); for the twins, parents were only asked to rate the sick one. The majority of parents rated their child's severity of illness as moderately sick (50% mothers, 44% fathers). Ratings of child's severity of illness at admission by mothers were significantly higher than the severity based on CRIB or PRISM ($t\ [29]= 11.27$, $p< 0.001$), and the same result was found in fathers ($t\ [24]= 9.77$, $p< 0.001$). In addition, the perceptions of child's morbidity were highly correlated and not significantly different between mothers and fathers at admission as well as at interview.

The ill child's morbidity levels, as measured by CRIB or PRISM, indicated no significant difference in the severity of illness between boys and girls. Parents, however, rated a higher severity of illness for baby boys than for baby girls, and a statistically significant difference was found in mothers. Mothers distinguished the boy's morbidity as being more severe than girls ($t\ [28]= 2.38$, $p< .03$) at the time of interview. For first generation parents (25 mothers and 21 fathers), fathers of baby boys perceived a significantly higher severity of illness for their child at admission than fathers of baby girls ($p< .05$).

Table 4.2: Demographic Characteristics of the Babies

Characteristic	Subject number (total 31 babies)	%
Age	3 days to 7 days (N= 18)	58.0
	8 days to one month (N= 6)	19.4
	More than one month (N = 7)	22.6
Gender	Boy (N=14)	45.2
	Girl (N=17) one set of twins	54.8
Diagnosis	Premature baby without congenital defect (N= 11)	35.5
	Premature baby with congenital defect (N= 5)	16.1
	Term baby, R/O sepsis (N= 5)	16.1
	Term baby with congenital defect (N= 3)	9.7
	Seizure (N=1)	3.2
	Respiratory distress (N= 5)	16.1
	Head injury (N=1)	3.2
Severity of Illness rated by CRIB or PRISM	Low risk (N= 28)	90.3
	Mildly ill (N=3)	9.7
Child's severity of illness at admission rated by the mothers	Not sick at all (N= 2)	6.7
	Mildly sick (N= 3)	10.0
	Moderately sick (N= 15)	50.0
	Severely sick (N= 6)	20.0
	Extremely critical (N= 4)	13.3
Child's severity of illness at admission rated by the Fathers	Not sick at all (N= 1)	4.0
	Mildly sick (N= 5)	20.0
	Moderately sick (N= 11)	44.0
	Severely sick (N= 4)	16.0
	Extremely critical (N= 4)	16.0

Description of Research Instruments

The reliability (Table 4.3) of each instrument, as well as the mean scores or total scores and standard deviations (SD), are reported in this section.

Family Support Scale (FSS)

The FSS (Dunst, Trivette, & Jenkins, 1988) was computed by summing the parent's helpfulness rating for each of the help resources available to them. Answer choices and related scores ranged from 1 (not at all helpful) to 5 (extremely helpful). Parents had an option of "not available" on any item if the resource did not exist. The original scale included 18 items and two respondent-initiated items. Since the first 10 families in this study all reported nurses as one of the very helpful resources, the support from nurses was added as "item 19" in the interviews for every parent to rate.

The possible range of scores is 0 to 95 for the 19-item FSS, with higher scores indicating a greater degree of resources for parents. Cronbach alpha coefficients for the 18-item FSS were .68 for both mothers and fathers, and .69 for the19-item FSS for both mothers and fathers. The actual range of scores obtained from the 19-item scale was 12 to 48 (M= 28.1, SD= 9.95) for mothers, and 12 to 47 (M= 30.52, SD= 11.02) for fathers. Mothers rated their spouse/partner and nurses as the most helpful support resources, followed by the support from the child's physician. Fathers also reported the same three most helpful resources; they viewed nurses as the most helpful one, followed by their spouse or partner, and then the child's physician.

General Sleep Disturbance Scale (GSDS)

The 21-item GSDS (Lee, 1992) was used to measure parent's subjective sleep disturbances, and it was computed by summing the frequency, in the past 7 days, of difficulty falling asleep, awakening during sleep, waking up too early from sleep, quality of sleep, quantity of sleep, sleepiness and interference with daytime function, and use of substances to induce sleep. The possible range of scores is 0 to 147, with higher scores indicating a greater amount of sleep disturbances. The actual range of scores obtained was 16 to 81 (M= 51.20, SD= 18.43) for mothers and 0 to 80 (M= 36.88, SD= 21.06) for fathers. The mean score for the 3-item sleep quality subscale was 4.56 (SD= 2.0) for mothers and 4.05 (SD= 2.52) for fathers; indicating parents reported poor sleep quality for more than 4 times in a week.

The Cronbach alpha coefficient for the 21-item GSDS was .78 for mothers and .86 for fathers. The 3-item subscale that assesses participant's quality of sleep also had a very high reliability with Cronbach alpha coefficient .86 and .91 for mothers and fathers.

Suinn-Lew Asian Self-Identity Acculturation (SL-ASIA)

The SL-ASIA (Suinn, Rickard-Figueroa, Lew, & Vigil, 1987) was utilized to determine the parent's level of acculturation. A score was obtained by summing all the answers for the first 21 items and then dividing by 21 for a mean score that can range from 1 (low acculturation/Asian oriented) to 5 (high acculturation/Westernized). The five additional questions (item 22 to item 26) were examined separately from the 21-item SL-ASIA as suggested by Dr. Suinn (personal contact).

Cronbach alpha coefficients for the 21-item SL-ASIA were .94 for both mothers and fathers. This 21-item acculturation scale was validated with item #26 "Describe how you view yourself?" as it is a separate self-rating scale. The mean score of 21-item SL-ASIA and item #26 were highly correlated ($r = .75$, $p < .001$). For the 21-item scale, the actual range of scores obtained from the current study was 1.05 to 3.65 ($M = 2.08$, $SD = .82$) for mothers and 1.24 to 3.52 ($M = 2.17$, $SD = .73$) for fathers. The mean score for the first generation ($N = 46$) was 1.89 ($SD = .62$) and for the second generation ($N = 9$) was 3.30 ($SD = .25$). Findings from item 22 to item 25 indicated the participants strongly believed in Asian values and fit in very well with the Asian ethnicity group. On the other hand, they moderately believed in American values and fit in moderately well with other non-Asian Americans.

Parental Stress Scale: Infant Hospitalization (PSS:IH)

PSS:IH (Miles & Brunssen, 1998) was adopted to examine parent's stress levels related to their child's ICU hospitalization. Scores were calculated by averaging stress levels for the items on the total scale and on three subscales – parental role (8 items), child's appearance (8 items), and environment (6 items). Stress scores can range from 1

(not at all stressful) to 5 (extremely stressful). Parents had the option of choosing "not applicable" if a certain situation did not appear, and it was scored as "0" for final calculations. Three questions were added to the PSS:IH to examine the Asian parent's stress levels derived from health care provider's behavior (PSSe1), communication with health care providers (PSSe2), and the general stress level from the ICU experiences (PSSe3).

Cronbach alpha coefficients for the complete scale were .91 for mothers and .92 for fathers. Alpha coefficients were also computed for the three subscales: parental role subscale was .83 for mothers and .90 for fathers, child's appearance subscale was .87 for mothers and .82 for fathers, environment subscale was .88 for mothers and .84 for fathers. This 22-item PSS:IH scale was validated with the PSSe3 "How stressful, in general, has the experience of having your child in the ICU been for you?" as it is a separate stress self-perception rating scale. A correlation was found between means of the 22-item PSS:IH and item PSSe3 ($r = .67$, $p < .001$). The actual range of the PSS:IH obtained in this study was 1.0 to 4.9 ($M = 2.79$, $SD = .93$) for mothers and 1.05 to 4.86 ($M = 3.19$, $SD = .89$) for fathers. Details for each subscale and the three additional questions are reported in the results for research question 1.

Numerical Rating Scale for Fatigue (NRS-F)

The modified 9-item (7-item fatigue, 2-item energy) Numerical Rating Scale for Fatigue (NRS-F) was used to measure parent's fluctuating daily fatigue severity (Lee, Hicks, & Nino-Murcia, 1991). Parents completed this scale four times over a two-day period (before they went to bed on each night, and immediately after awakening each morning). A mean score ranging from 1 (not fatigued at all) to 10 (extremely fatigued)

was obtained by averaging fatigue levels for the 7-item fatigue scale. The Cronbach alpha coefficients, for the two evenings and two mornings, ranged from .89 to .97 for mothers, and from .87 to .97 for fathers.

The first and second evening fatigue levels as well as the first and second morning fatigue levels were significantly correlated for both mothers and fathers; there were no significant differences between the first and second day using paired t-tests. Therefore, the mean value for both evenings and both mornings were used for further data analysis. For mothers, the evening fatigue severity mean score was 6.90 (SEM= 0.29) and the morning fatigue score was 5.33 (SEM= 0.35), while for fathers the evening fatigue score was 5.27 (SEM= 0.39) and the morning fatigue score was 3.26 (SEM= 0.29).

Table 4.3 Reliability of Instrument by Gender

Instruments	Cronbach's Alpha Mothers (N=30)	Cronbach's Alpha Fathers (N=25)
Family Support Scale	.69 (19 items)	69 (19 items)
General Sleep Disturbance	.78 (21 items)	.86 (21 items)
SLASIA- Acculturation Scale	.94 (21 items)	.94 (21 items)
Parental Stressor Scale: Infant Hospitalizati	.91 (22 items)	.92 (22 items)
NRS-Fatigue Scale	.89 to .97 (7 items)	.87 to .97 (7 items)

Results for Research Question One

Research question one: What are major stressors for Chinese/Chinese-American parents of children who are in intensive care units? To answer this question, the mean scores on the PSS:IH and each of its three subscales were calculated. Scores on the three added questions obtaining parent's perceived stress levels related to communication with the health care providers, the behavior of health care providers, and general stress levels of the ICU experience were also computed (Table 4.4).

The PSS:IH mean scores were normally distributed and for mother was 2.80 (SD= .92) and for father was 2.87 (SD= .94), which indicated both parents had moderate

stressful experiences from their child's ICU hospitalization. Parents found the child's appearance to be the most distressful, and this was followed by parental role function alteration and staff communication. Parents rated seeing their child in pain as the most distressing experience (M= 4.52 for mothers, M= 3.73 for fathers) for them in the child's appearance subscale. For the parental role subscale, mothers identified that not being able to comfort or help her child (M=4.4) and fathers rated not being able to protect his child from pain and painful procedure (M= 4.12) as the most distressful experience for them. The health care provider's behavior, and the ICU environment were the least stressful. Parents in the three research sites rated a similar order and the ANOVAs indicated that the mean scores (PSS:IH, subscale of PSS:IH, PSSALL, PSSe1, PSSe2, and PSSe3) were not significantly different among the three sites.

The health care providers' behaviors (PSSe1) and communication (PSSe2) may contribute to the parental stress level because the general stress levels (PSSe3) of the ICU experience (M= 3.6, SD= 1.04 for mothers; M= 3.36, SD= 1.11 for fathers) were significantly higher than the mean score of PSS:IH (paired t [29]= 6.12, $p < .001$ for mothers, paired t [24]= 2.68, p= .01 for fathers). Therefore, by combining the three scores of the PSS:IH subscale (parental role alteration, child's behavior, ICU environment), PSSe1 and PSSe2, a new mean score was created to represent parent's overall stress (PSSALL) due to their child's ICU hospitalization. The mean score of PSSALL was 2.56 (SD= .86) for mothers and 2.53 (SD= .89) for fathers. Although mothers and fathers scored each stressor differently, paired T-tests indicated that the couple's stress perceptions were correlated and not significantly different.

In a traditional Chinese family culture, sons are typically considered a blessing because they carry on the family name (Kim, Atkinson, & Yang, 1999; Char, 1981; Tsai, 1999). Further examinations were done to determine the relationships between the child's gender and parent's perception of stress levels. Independent t-tests determined that there were no significant differences in the various sources of ICU stress for mothers and fathers by gender of the hospitalized child. On the other hand, parents of baby boys perceived higher stress levels than parents of baby girls in almost every stressor except health care provider's behavior (for both mothers and fathers) and ICU environment (only for mothers) (Table 4.5). Independent t-tests confirmed no significant differences by stressor or overall stress level between parents of baby boys and parents of baby girls in this small sample of 30 mothers and 25 fathers.

Table 4.4 Means and Standard Deviations for Parental Stress Scale: Infant Hospitalization (PSS:IH)

	Mothers (N=30) M (SD)	Fathers (N=25) M (SD)
Mean score of PSS:IH	2.80 (.92)	2.87 (.94)
PSS subscale: parental role	3.13 (.96)	3.11 (1.06)
PSS subscale: child's Appearance	3.26 (1.30)	3.45 (1.03)
PSS subscale: environment	1.73 (1.13)	1.76 (1.09)
Health care providers' behavior (PSSe1)	1.90 (1.13)	1.88 (1.13)
Health care providers' communication (PSSe2)	2.77 (1.43)	2.44 (1.47)
The general stress level in the ICU (PSSe3)	3.60 (1.04)	3.36 (1.11)
Overall Stress (PSSALL)	2.56 (.86)	2.53 (.89)

Table 4.5 Parent's Stress Perceptions by Ill Child's Gender

Parents	Mothers (N=30)		Fathers (N=25)	
Child's gender	Boy (N=14)	Girl (N=16)	Boy (N=11)	Girl (N=14)
Mean score of PSS:IH	2.91 ± .75	2.71 ± 1.07	3.09 ± .92	2.68 ± .96
PSS subscale: parental role	3.21 ± .90	3.06 ± 1.04	3.24 ± 1.09	3.01 ± 1.07
PSS subscale: Child's appearance	3.55± 1.21	3.01 ± 1.36	3.76 ± .95	3.20 ± 1.06
PSS subscale: environment	1.63 ± .95	1.83 ± 1.27	2.00 ± 1.05	1.58 ± 1.11
Health care providers' behavior (PSSe1)	1.57 ± .94	2.19 ± 1.22	1.73 ± .91	2.00 ± 1.30
Health care providers' communication (PSSe2)	3.07 ± 1.33	2.50 ± 1.51	2.64 ± 1.50	2.29 ± 1.49
The general stress level in the ICU (PSSe	3.79 ± 1.05	3.44 ± 1.03	3.36 ± 1.21	3.36 ± 1.08
Overall stress (PSSALL)	2.61 ± .70	2.51 ± 1.01	2.67 ± .83	2.41 ± .95

Other parental stress phenomena identified from the structured interviews included the following eight areas:

1. Incompetence: almost all of the parents expressed desire to become more involve with the care of their baby. However, they did not have the confidence to take care of them. Four fathers expressed they couldn't protect their wife and children. One mother said, "sometimes I felt I am very useless because I cried in the unit, I never see anyone cry in here, I felt I am useless, couldn't do anything for my baby." Another mother said, "I don't know how to take care of babies, so I am very scared to be alone with my baby."
2. Self-blaming: four mothers and two fathers felt it was their fault that the baby was born with problems. Mothers blamed themselves for not following the traditional Chinese prenatal care (abstinence from cold food). One father said: "I believe I am the person who should take whole responsibility. I need to work in laboratory and sometime exposed to several bad chemical matter, so I think it is because of me so my baby has congenital defect." The father had never talked to anyone about his feelings on the matter until this interview; his baby was almost three months old at the time he was interviewed.
3. Blame from other: one mother had tremendous problems with her mother-in-law after her premature labor. The paternal grandmother said this was purely due to the mother's incompetence to carry a full-term baby.
4. Worry due to the possibility of upsetting their own parents: three families did not tell their parents about the baby's problem because they were worried the grandparents would be upset if they found out. One father told his parents, "...your grandson needs

to stay in the hospital for a period because he was c-sectioned, and this is a typical practice in the U.S.; I don't like them (their parents) to worry because it is most un-filial piety to let my parents worry." Actually, his son had meconium aspiration and developed respiratory distress syndrome.

5. Lack of resources: three families felt overwhelmed due to lack of resources, especially in the area of family support and social resources. One mother said, "I am the only one here, my family is all back in China; I wish I could have some helper from my family." Another mother said, "...although my mother is here and is helping me out with some things, but she can't drive, so there are many limitations; I wish I could have some other family members here like back in my homeland." The other mother said, "I wish I could have handouts written in Chinese to help me take care of my son's asthma problem."
6. Communication issues: For the new immigrants, the stress derived from communication with health care providers was mostly related to language barriers. Others experienced stress from unknown medical terminology and from not being thoroughly informed about their child's condition or treatment plan.
7. Stress related to cultural issues: three families strongly expressed stress derived from the differences in the medical management approach between here and their homeland. One father said, "It was because of the different cultural backgrounds that we [the father and the medical team] have different thinking, so what I wanted to know and what they could offer me had a distance." One grandmother said "My daughter had cesarean section, they [health care providers] should not keep the air conditioning on and let my daughter be exposed to cold air, especially after they

opened the uterus, the cold air was flowing directly into my daughter's body. You know it is very important not to let the postpartum woman be exposed to cold air. I cried when I found out that my daughter was treated this way in the labor room." This grandmother came from Hong Kong to help her daughter for the postpartum month-long confinement. This grandmother was asked what we should do to lessen her worries, she responded, "at least, they [health care providers] should offer a warm blanket to cover my daughter, especially her shoulders."

8. Other issues: two families expressed their frustration related to frequently changing bed space or hospital units, and the difficult access to doctors.

Results for Research Question 2

The second research question was: Is parental stress associated with objective and subjective sleep disturbance or perception of fatigue? The question was analyzed by utilizing Pearson product moment correlation matrix. Scores on perceived parental stress scales (PSS:IH mean scores, parental role, child's appearance, ICU environment, PSSe1, PSSe2, PSSALL), perceived child's severity of illness, and worry about child's illness and its future impact were correlated with objective sleep disturbances, perceived sleep disturbances, and perceived fatigue severity. The correlations between sleep disturbances (subjective and objective) and fatigue severity (AM and PM) are also included. All of the variables used in the correlation coefficient matrix were normally distributed except mother's WASO and father's TST.

Responses to Parental Stress: Subjective Sleep Disturbance and Fatigue

The subjective sleep disturbance data included the self-report general sleep disturbance scale (GSDS) and the severity of evening and morning fatigue levels.

Mothers reported higher GSDS scores than fathers (M= 48.84, SD= 18.56 for mothers; M= 36.88, SD= 21.06 for fathers). Paired t-tests indicated that mothers had significant sleep disturbances (paired t [24]= 2.14, p< .05), more difficulty falling asleep (paired t [24]= 3.82, p= .001), and higher frequency of awakening during sleep (paired t [24]= 5.79, p< .001) than their male partners. Mothers also experienced a significantly higher severity of fatigue both in the evening (paired t [22]= 2.90, p< .01) and the morning (paired t [23]= 5.55, p< .001) than fathers.

Correlations between subjective sleep data and fatigue and parental stressors

For mothers, GSDS was correlated with overall ICU stress levels (r= .39, p= .03), and communication with health care provider (r= .51, p< .01). For fathers, GSDS was correlated with PSS:IH mean scores (r= .45, p= .02) and overall stress levels (r= .40, p< .05). For parent's severity of fatigue, a significant correlation was found only between mother's morning fatigue and the stress derived from her communication with health care provider (r= .43, p= .02) (Table 4.6).

Table 4.6 Correlations Between GSDS, Fatigue (PM and AM) and Parental Stress

	Mothers (N= 30)			Fathers (N= 25)		
	GSDS	PM	AM	GSDS	PM	AM
PSS:IH mean	.23	-.21	.08	.45*	.34	. 17
Child's appearance	.20	-.24	-.03	.41*	.37	.17
Parental role	.22	.01	.27	.46*	.25	.24
ICU environment	.16	-.27	-.01	.31	.29	.02
Communication with health care provider	.51**	.09	.43*	.16	-.18	.22
Health care provider's behavior	.27	-.05	.29	.25	-.11	05
Overall stress (PSSALL)	.39*	-.12	.27	.40*	.12	.19

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

Responses to Parental Stress: Objective Sleep Disturbance (TST/WASO)

Objective sleep disturbance was measured by wrist actigraphy monitoring to assess participant's total sleep time (TST) and percentage of wake time after sleep onset

(WASO). Among the 30 families (30 mothers, 25 fathers), two families (two mothers and one father) were interviewed on the day before their child's discharge, and did not have actigraph data. Three fathers' data were invalid because of mal-functioning monitors, and another two fathers did not wear the actigraphy monitor. Therefore, only 28 mothers and 19 fathers had actigraphy data available for the final analysis, among these parents 26 mothers and 17 fathers had two days of actigraphy data.

Both nights of TST and WASO were significantly correlated for both mothers and fathers; there were no significant differences between nights using paired t-tests (Table 4.7). Thus, mean value for two nights and standard error of the mean (SEM) were used for further data analysis (Table 4.8). The average TST for mothers was 366.9 minutes (SEM= 15.3) and 395.4 minutes (SEM= 16.5) for fathers; this was significantly less than the total sleep time indicated by mothers (paired t [27]= 8.07, $p < .001$) and fathers (paired t [18]= 4.48, $p < .001$) to be required to restore their energy. Although, on average, fathers slept half an hour more than mothers during the night, there was no significant difference in the TST between mother and father pairs (paired t [18]= 1.27, p= .22). A significant difference was found in WASO between mother and father pairs (paired t [18]= 2.84, p= .011).

Table 4.7 Paired t-test and Correlations for 1st Night and 2nd Night of Sleep and Fatigue

	1st night	2nd night	Correlations	Significant Differences
Mothers	N= 28	N= 26		
TST (minutes)	363.5 ± 93.5	364.6 ± 81.4	.70	T (25)= - .54, p= .60
WASO (%)	17.9 ± 16.9	16.0 ± 14.0	.57	T (25)= .88, p= .39
Fathers	N= 19	N= 17		
TST (minutes)	407.1 ± 87.9	392.3 ± 63.6	.55	T (16)= 1.51, p= .15
WASO (%)	8.5 ± 6.6	5.1± 5.7	.46	T (16)= 1.68, p= .11

Table 4.8 Means and Standard Error of the Means (SEM) of Parents' Total Sleep Time (TST) and Wake After Sleep Onset (WASO)

Parameters	Mothers N=28	Fathers N= 19
Average TST (minutes)	366.9 (15.3 SEM)	395.5 (16.5 SEM)
Average WASO (%)	16.7 (2.6 SEM)	7.3 (1.3 SEM)

Correlations between TST/WASO and parental stress

Because the TST and WASO were not normally distributed, the Spearman rank-order correlation coefficient (r_s) was used for analyses. A significant correlation between objective sleep data and parental stress was found only for mothers. Contrary to expectations, mothers who had higher levels of worry about their child's illness and its future impact actually had more TST (r_s = .38, p= .046), and less WASO (r_s = - .47, p= .012). The same relationship was found between mother's sleep and her rating of the child's severity of illness at the time of child's admission (TST: r_s= .49, p= .008; WASO: r_s= - .48, p= .01). This phenomenon was interesting and it would be important to consider which comes first; if additional sleeping relieves stress or if sleeping in the hospital affects mother's TST and WASO, since some mothers were still hospitalized and some of fathers were staying in the hospital with their wives or child during the data collection period.

Scatter plots (See Appendix D) indicated that five mothers had low TST (< 300 minutes) and also less worry about their child's illness and its future impact. These five mothers with cesarean section (subject # 1, 8,11,17,22) were hospitalized while data were collected. The same relationships were also found in two fathers (subject # 44, 45). Thus, another set of data, which only included parents who were not hospitalized (22 mothers and 17 fathers), is presented in the following section.

Correlations between TST/WASO and stress for non-hospitalized parents

After excluding mothers who were hospitalized and parents staying in the hospital with their child during the interview period, 22 mothers and 17 fathers had objective sleep data available. The Pearson's correlations were therefore used for analyses because

the TST and WASO were normally distributed. Significant correlations between TST/WASO and parental stress were found in both mothers and fathers (Table 4.9). There was a significant negative correlation between stress derived from parental role and TST ($r = -.51$, $p = .02$) for mothers, indicating that mothers with more stress derived from the parental role had less total sleep time. On the other hand, WASO was correlated with mother's stress derived from the ICU environment ($r = .47$, $p = .03$), indicating that mothers with higher stress levels had a higher percentage of awakenings during night.

For fathers, there was a significant negative correlation between TST and the PSS:IH mean scores ($r = -.62$, $p < .01$), parental role ($r = -.49$, $p < .05$), child's appearance ($r = -.59$, $p = .01$), ICU environment ($r = -.52$, $p = .03$), overall stress ($r = -.63$, $p < .01$) and worry about child's illness and its future impact ($r = -.61$, $p = .01$).

Table 4.9 Correlations Between Total Sleep Time (TST)/Wake After Sleep Onset (WASO) and Parental Stress for Non-hospitalized Parents

	Mothers (N=22)		Fathers (N=17)	
	TST	WASO	TST	WASO
PSS:IH mean score	-.34	.41	-.62**	.32
Parental role	-.51*	.34	-.49*	.25
Child's appearance	-.06	.22	-.59*	.37
ICU environment	-.31	.47*	-.52*	.18
Communication with health care provider	-.02	-.07	-.28	.41
Health care provider's behavior	-.41	.11	-.46	.16
Overall stress (PSSALL)	-.34	.27	-.63**	.41

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

Results for Research Question 3

Research question 3: To what degree is parental stress explained by a parent's level of acculturation, personal/family characteristics (age, financial status, education, gender of ill child, support resources), and uncertainty (perceived of child's severity of illness, worry about child's illness and its future impact)? This question was analyzed by multiple regression analysis to determine the extent to which variables with a Pearson correlation > .25 account for the variance in parental stress scores. Guidelines to

determine which variables should be added into the model were based on the Conceptual Model for Asian-Americans Parents with a Critically Ill Child (see Chapter 2, Figure 2.3). Nonparametric data were converted to dummy codes and two separate hierarchical regression models were used to test factors contributing to PSS:IH mean scores and overall stress in ICU (PSALL).

Before the regression models are presented, the correlation results between parental stress (PSS:IH, PSSALL), and acculturation (SL-ASIA), family support (FSS), and uncertainty are summarized in Table 4.10. Parents who scored higher in SL-ASIA were found to have less overall stress (r= -.46 for mothers, r= - .40 for fathers). Parents who were more worry about child's illness and its future impact had a higher PSS:IH (r= .65, p< .001 for fathers) and PSSALL scores (r= .38, p< .04 for mothers; r= .62, p= .001 for fathers). A negative correlation between FSS and parent's overall stress was found for both mothers and fathers (r= - .32) although this was not statistically significant in this small sample.

Table 4.10 Correlations Between Parental Stress (PSS:IH, PSSALL), Acculturation, Family Support, and Uncertainty,

	Mothers (N=30)		Fathers (N=25)	
	PSS:IH	PSSALL	PSS:IH	PSSALL
SL-ASIA	-.26	-.46*	-.18	-.40*
FSS-19 (19-item)	-.11	-.32	-.20	-.32
Uncertainty				
Worry about child's illness and its future impact	.35	.38*	.65**	.62**
Child's current severity of illness rated by parents	.30	.23	.33	.30

*p < .05, **p < .01, ***p< .001

Both mothers and fathers reported that their spouse/partner and their child's physician and nurses were the most supportive resources during their child's hospitalization. The relationships between parental stress and these three resources were examined further and summarized in Table 4.11. The parents who perceived more

support from nurses (RN) were found to have less stress derived from the child's appearance (r= -.48 for mothers), ICU environment (r= - .42 for fathers), health care provider's behavior (r= - .45 for mothers, r= - .67 for fathers), communication with health care providers (r= - .63 for mothers, r= - .51 for fathers), and overall stress (r= - .54 for mothers, r= - .56 for fathers). Although mothers rated their spouse/partner as equally helpful to them as nurses, support from spouse/partner was only correlated with stress derived from health care provider's behavior (r= -. 38). Support from the child's physician was also significantly correlated with the father's stress related the ill child's appearance (r= -.46), ICU environment (r= - .41), and overall stress (r= - .41). For mothers, support from the child's physician was only significantly correlated with stress evolved from communication with health care providers (r= - .47).

Table 4.11 Correlations Among the Most Helpful Resource and Parental Stress

	Mothers (N= 30)			Fathers (N=25)		
	Spouse	MD	RN	Spouse	MD	RN
PSS mean	-.11	-.18	-.33	.06	-.45*	-.33
Parental role	-.33	-.09	-.01	.11	-.33	-.22
Child's appearance	-.00	-.27	-.48**	-.02	-.46*	-.28
ICU environment	.05	-.04	-.28	.08	-.41*	-.42*
Health care provider's behavior	-.38*	-.35	-.45*	.04	-.38	-.67***
Communication with health care provider	-.34	-.47**	-.63***	-.34	-.08	-.51**
Overall stress (PSSALL)	-.27	-.36	-.54**	-.06	-.41*	-.56**

*p < .05, **p < .01, ***p< .001

Parental Stressor Scale: Infant Hospitalization (PSS:IH)

The PSS:IH mean score was the first dependent variable used to represent the outcome of parental stress in ICU. The mean score of PSS:IH was normally distributed in this study sample. Two hierarchical multiple regression procedures were applied to assess how much variance in PSS:IH mean score, for mothers and then for fathers, was explained for each set of independent variables – uncertainty, acculturation, and personal/family characteristics. The maximum number of independent variables to enter

the model was limited to three. This criterion follows the regression model's guideline that number of predictors should be equal or less than one tenth of the total sample size (Marascuilo & Levin, 1983). The child's gender was entered first to statistically control for the effects, and it was not significant and accounted for only 1.2 % of the variance in PSS:IH scores for mothers ($F [1, 29] = .33$, $p = .57$), and it explained 4.7 % of the variance in PSS:IH scores for fathers ($F [1, 24] = 1.13$, $p = .30$).

Uncertainty (perceived child's severity of illness at admission and at present, worry about child's illness and its future impact) was the first set of independent variables entered into the model at step one. Worry about child's illness and its future impact explained 13% of the variance in PSS:IH scores for mothers ($F [1, 29] = 3.99$, $p = .056$), and it explained 42% of the variance in PSS:IH scores for fathers ($F [1, 24] = 16.65$, $p < .001$).

Acculturation variables (SL-ASIA score, belief in Asian values, belief in American values, fit in with other Asian groups, fit with non-Asian groups, self-description of acculturation) were included in the second step analysis. These five acculturation variables were individually entered into the model to identify which variable was contributing most to PSS:IH. Belief in Asian values was found to significantly contribute to variance in PSS:IH scores for mothers ($R^2 = .25$, $F [2, 29] = 4.44$, $p = .022$) and fathers ($R^2 = .48$, $F [2, 24] = 9.96$, $p = .001$).

Personal/family characteristics (age, education, financial status, FSS score, support from direct family members [total score of support from parents, spouse's parents, and spouse/partner], support from health care providers [total score of support from nurses and physicians]) were included in the last step of the regression analysis.

Worry about child's illness and its future impact, belief in Asian values, and lack of support from health care providers explained 26% of the variance in PSS:IH score for mothers (F [3, 29]= 3.0, p< .05), and 55% of the variance in PSS:IH score for fathers (F [3, 24]= 8.67, p= .001) (Table 4.12).

Table 4.12 Multiple Regression Analysis for Parental Stressor Scale: Infant Hospitalization (PSS:IH)

	R	R^2	Adjusted R^2	R^2 Change	B	Beta	Sig.
Model for mothers							
a	.35	.13	.09	.13	.28	.38	.056
b	.50	.25	.19	.12	-.61	-.34	.022
c	.51	.26	.17	.01	-.05	-.11	.049
Model for fathers							
a	.65	.42	.40	.42	.41	.51	.000
b	.69	.48	.43	.06	-.36	-.29	.001
c	.74	.55	.49	.08	-.13	-.31	.001

a Predictors: (Constant), worry about child's illness and future impact
b Predictors: (Constant), worry about child's illness and future impact, belief in Asian values
c Predictors: (Constant), worry about child's illness and future impact, belief in Asian values, support from health care providers

Overall Parental Stress in ICU (PSSALL)

The PSSALL was the second dependent variable used; the same three sets of independent variables from the previous regression model were again entered in hierarchical fashion. This dependent variable is a mean score computed from five ICU stressor scores, which include parental role, child's appearance, ICU environment, health care provider's behavior, and communication with health care providers. The same statistical strategy as utilized in the previous regression model was adapted. Gender of the infant was not significant, and accounted for only 0.3 % of the variance in PSSALL scores for mothers (F [1,29]= 0.08, p= .78), and it explained 2.2 % of the variance in PSSALL scores for fathers (F [1,24]= .51, p= .48). The same three independent variables used in the previous model were identified; and results were even more statistically significant for both mothers (F [3,29]= 6.54, p= .002) and fathers (F [3,24]= 8.90, p=

.001). Worry about child's illness and its future impact, belief in Asian values, and support from health care providers explained 43% and 56% of variance in the PSSALL for mothers and fathers respectively (Table 4.13).

Table 4.13 Multiple Regression Analysis for Overall Parental Stress (PSSALL) in ICU

	R	R^2	Adjusted R^2	R^2 Change	B	Beta	Sig.
Model for mothers							
a	.38	.15	.11	.15	.23	.33	.038
b	.58	.33	.28	.19	-.65	-.38	.004
c	.66	.43	.36	.10	-.15	-.34	.002
Model for fathers							
a	.62	.39	.36	.39	.34	.45	.001
b	.66	.43	.38	.05	-.34	-.29	.002
c	.75	.56	.50	.13	-.16	-.40	.001

a Predictors: (Constant), worry about child's illness and future impact
b Predictors: (Constant), worry about child's illness and future impact, belief in Asian values
c Predictors: (Constant), worry about child's illness and future impact, belief in Asian values, support from health care providers

Results of Research Question 4

Research question 4: To what degree are the sleep disturbance and fatigue severity explained by parental stress? This question was also analyzed by multiple regression analysis in the same manner as the previous question. Four separate regression models were created for the group of mothers and group of fathers to explore factors contributing to sleep disturbance (TST, WASO, GSDS) and fatigue severity. Correlation matrices in research question 2 were utilized, as a guideline to decide which independent variables should be added into the model. To have a normal distributed TST and WASO for the regression analyses, the mothers who were hospitalized and fathers who were staying in the hospital during the data collection period were excluded.

Sleep Disturbance

Total sleep time (TST)

TST was the first dependent variable used as an outcome from parental stress. The child's gender was entered first to statistically control for the effects, and it was not

significant and only accounted for only 0.1% of the variance in TST for mothers (F [1, 21]= .02, p= .88). Unlike mothers' TST, the infant's gender accounted 15.4% of the variance in fathers' TST although it was still not statistically significant (F [1, 16]= 2.73, p= .12).

The correlations between TST and PSSALL subscales were completely different between mothers and fathers (see Table 4.9); the regression analysis was separately applied for mothers and fathers. For mothers, the parental role stress score (r= - .51) was first entered, in hierarchical fashion, into the model as an independent variable. A significant equation was found (F [1,21]= 6.87, p= .016), and the parental role stress score accounted 26% of the variance in TST for mothers. Stress related to health care provider's behavior was included in the second step and contributed to TST (F [2, 21]= 4.14, p= .032). The other three subscale scores (child's appearance, ICU environment, communication with health care providers) were also individually entered in the second step and did not significantly account for any further variance in the TST for mothers. The stress derived from parental role function alteration and the health care provider's behavior accounted 30.3% of the variance in TST for mothers (Table 4.14).

For fathers, the stress related to child's appearance (r= - .59) was the first independent variable entered into the TST model at step one and a significant equation was found (F [1, 16]= 7.88, p= .013). Stress related to child's appearance accounted 34% of the variance in TST for fathers. In the second step of this regression model, only the stress score derived from health care provider's behavior significantly contributed to the variance in fathers' TST (F [2, 16]= 6.55, p= .01). In total, stress from the child's

appearance and health care provider's behavior explained 48% of the variance in TST for fathers (Table 4.14).

Table 4.14 Multiple Regression Analysis for Total Sleep Time (TST)

	R	R^2	Adjusted R^2	R^2 Change	B	Beta	Sig.
Model for mothers							
a	.51	.26	.22	.26	-27.57	-.41	.016
b	.55	.30	.23	.05	-11.65	-.24	.032
Model for fathers							
c	.59	.34	.30	.34	-30.83	-.53	.013
d	.70	.48	.41	.14	-15.43	-.38	.010

a Predictors: (Constant), parental role
b Predictors: (Constant), parental role, health care provider's behavior
c Predictors: (Constant), child's appearance
d. Predictors: (Constant), child's appearance, health care provider's behavior

Wake after sleep onset (WASO)

Wake after sleep onset (WASO) was the second objective sleep disturbance variable used as an outcome of parental stress, and the same predictors measuring TST were entered into the model. A significant equation was only found for mothers (B= 3.65, F [1, 21]= 5.63, p= .028). Stress derived from ICU environment explained 22% of variance in WASO for mothers.

General Sleep Disturbance Scale (GSDS)

GSDS was the third dependent variable used as the response of parental stress. The GSDS score was normally distributed in this sample, and every parent who participated was included in the regression model analyses for mothers and for fathers. The same independent variables used for TST as the outcome were used for this model and a significant equation was created for both mothers (B= 6.51, F [1,29]= 9.60, p= .004) and fathers (B= 9.22, F [1, 24]= 6.32, p= .019). Stress derived from communication with health care providers accounted 26% of variance in GSDS for

mothers, and stress related to parental role function alteration accounted 22% of variance in GSDS for fathers.

Fatigue Severity

Morning and evening fatigue severity were the last dependent variable used as another outcome of parental stress. The same predictor as GSDS model was used and a significant equation was found only for mothers and their morning fatigue severity (B= .57, F [1, 28]= 6.13, p= .02). Stress derived from communication with health care provider explained 18.5% of the variance in morning fatigue for mothers.

CHAPTER V

DISCUSSION

Having a child in the intensive care unit is an unquestionably stressful situation for parents. For an immigrant the stress levels may be even more deleterious because of the different culture backgrounds, language barriers, and the unfamiliarity with the health care systems. Culture is defined as the integrated system of learned behavior patterns that are characteristic of a population living as a distinct entity (Hoebel, 1966). Culture has been widely recognized as a fundamental role in defining and sensing health and illness, and in searching for help (Leininger, 1996). Culture is also found to influence how a parent perceives and responds to their child's illness, how to interact with health care providers, and how to utilize existing resources (Bracht, Kandankery, Nodwell, & Stade, 2002). Acculturation is the process by which a minority culture changes as a result of being influenced by the dominant culture, with the adoption of behavioral patterns and ethnic identity of the host group (Kitano, 1989). For immigrants, they usually adapt to most of the customs that exist in their new country and may eventually adopt them as part of their customs, most importantly, they do this by choice and necessity. With continuing immigration into the U.S., American society is becoming an increasingly multiethnic one; health care providers explicitly need a culturally and linguistically appropriate approach to serve the client.

The purpose of this study was to identify sources of parental stress for Chinese/Chinese-American parents with a critically ill child in ICU. In addition, the relationships between parental stress and personal/family characteristics (acculturation, support resources, characteristics of the ill child), uncertainty regarding to the child's

illness (severity of child's illness, worry about child's illness and its future impact), and stress responses (sleep disturbance, fatigue) were explored. In this chapter, the findings from this descriptive correlational study are discussed and the conclusions drawn from the finding are presented. The discussion of results includes a summary of major findings, discussion of the research questions, and additional findings. Limitations of the study are discussed, implications for clinical practices are outlined, and recommendations for further research are delineated.

Principal Findings

Parental Stress

To date, the study of parental stress associated with a critically ill and hospitalized child has been focused in two main areas, identifying the ICU stressor and comparing the difference between father's and mother's stress perceptions. The ICU stressor includes the sick child's appearance, parental role alteration, ICU environment, and staff communication. In general, mothers perceived a higher level of stress than fathers and the parents rated the various stressors in a different order.

The results from this study support the ICU stressors that have been identified in previous qualitative and descriptive studies (Affonso et al, 1992; Holditch-Davis & Miles, 2000; Miles et al, 1989a; 1989b; Riddle et al., 1989; Seideman et al., 1997; Shields-Poe & Pinelli, 1997). Findings from this study indicate that Chinese/Chinese-American mothers and fathers perceived similar stress levels from the various stressors while their child is hospitalized in the ICU. Both mothers and fathers rated the stress related to their child's appearance as the most stressful experience for them, and this was following by the parent's role function alteration, staff communication, health care

provider's non-verbal behaviors, and lastly the physical environment in the ICU. Although in this small sample there were no statistically significant differences in stress perceptions between baby boy's and baby girl's parents, parents of baby boys perceived higher stress levels than parent's of baby girls parents in almost every type of stressor with the exceptions of health care provider's behavior (for both mothers and fathers) and ICU environment (only for mothers). In addition, data retrieved from the structured interview indicate that parents in this study also experienced stress related to parental role incompetence, guilty feelings, family conflicts related to the sick child, and stress related to cultural belief issues.

In Riddle and colleague's (1989) study, mothers perceived a significantly higher stress level than fathers. In addition, mothers and fathers rated the strains associated with a stressor in different orders. For mothers, the three highest stress sources were child's behavior and emotion, parental role alteration, and staff communication; whereas the fathers' higher stressors were staff communication, child's behavior and emotions, and parental role alteration. Later, in Shields-Poe and Pinelli's study (1997), the general stress levels perceived by mothers and fathers were similar, although mothers perceived more stress from the ICU environment and from parental role alteration than fathers. Riddle and colleague's (1989) and Shields-Poe and Pinelli's (1997) studies were a decade apart, and they found that mothers and fathers perceived different levels of stress. In addition to the masculine behavioral expectations of keeping a "stiff upper lip" in U.S. society, it is also possible that in the 1980's men were not encouraged to be involved in childcare and this resulted in fathers who perceived lower stress levels than mothers.

Since parental familiarity with the ICU physical and personal environment is necessary to enhance communication with staff (Affleck, Tennen, & Rowe, 1991), fathers with less involvement in childcare would be more likely to rate the staff communication as the most distressful experience for them in the ICU (Riddle et al., 1989). In Shields-Poe and Pinelli's study (1997), the mothers perceived more stress from the ICU environment and parental role alteration than fathers; however, in this current study parents rated the stressor in the same order and the degree of stress was similar between mothers and fathers. This may have been due to two main reasons; first is the month-long confinement of Chinese women after delivery, and second is the family-oriented Chinese traits with the father commanding recognized authority. As a result, the Chinese father may be more inclined to take care of matters in the ICU than the Caucasian father.

Parental Stress Responses: Sleep Disturbances and Fatigue

Sleep disturbances are a common occurrence for parents who have a child hospitalized in the ICU, yet no study has been done to explore the relationship between parental stress and sleep problems. Stress is the most common cause of transient or short-term insomnia (Roehrs, Zorick, & Roth, 2000). Insomnia plays an important key role in health status (Kripke, Simmons, Garfinkel, & Hammond, 1979; Spiegel, Ledproult, & Van Cauter, 1999), and sleep deprivation negatively affects performance with decreased reaction times, less vigilance, and increase in perceptual and cognitive distortions (Krueger, 1989; Pilcher & Huffcutt, 1996).

In the current study, 93.3% of the mothers and 60% of the fathers reported experiencing sleep problems after their child's hospitalization. In addition, parental

stress was correlated with both objective sleep disturbances, as measured by total sleep time (TST) and wake after sleep onset (WASO) actigraphy, and subjective sleep disruption, as measured with the General Sleep Disturbance Scale (GSDS). The data collected from wrist actigraphy demonstrated that mothers and fathers had a significantly lower TST than they reportedly required to restoring their energy.

Mothers who perceived a high stress level from the parental role alteration experienced a significantly lower total sleep time. For fathers, in addition to the parental role, the lower sleep time was also correlated with the child's appearance, the ICU environment, and worry about the child's illness and its future impact. On the other hand, the subjective data collected from the GSDS and Fatigue Scale indicated that mothers who experienced higher levels of stress from staff communication experienced a significantly higher sleep disturbance and morning fatigue severity. For fathers, stress related to the child's appearance and parental role alteration were found to cause a significantly high level of sleep disruption.

In this study, the mothers' TST was about 30 minutes less than fathers and the WASO was significantly higher than that of fathers although most mothers were in the postpartum phase and needed extra rest to recover from labor and delivery. Many other researchers have also found that women experience significant sleep changes during pregnancy and the postpartum period. Actigraphic and polysomnographic studies have shown an increase in WASO as pregnancy progresses as well as during the postpartum periods (Brunner, Munch, Biedemann, Huch, Huch, & Borbely, 1994; Shinkoda, Matsumoto, & Park, 1999). Sleep disturbances are observed during the first postpartum

month (Lee, McEnany, & Zaffke, 2000; Gay, Lee, & Lee, 2004) and WASO was highest during the second week of postpartum (Shinkoda, Matsumoto, & Park, 1999).

Gay and associates (2004) demonstrated that the new parent with a healthy baby experienced more sleep disturbance and fatigue during the first month of postpartum than their last trimester of pregnancy. The average TST during the first month (mean time after birth= 19.6 $\pm$ 4.3 days) of postpartum was 381.1 (SD= 76.8) minutes for mothers and 403.2 (SD= 64.5) minutes for fathers. On the other hand, for the self-report data collected from the GSDS, those new parents reported a total score of 55.5 (SD= 15.4) for mothers and 42.8 (SD= 14.1) for fathers. In the current study, the Chinese/Chinese-American parents had less TST (M= 366.9 for mothers, M= 395.5 for fathers) but less self-reported sleep disturbances (51.2 $\pm$ 18.4 for mothers, 36.9 $\pm$ 21.1 for fathers) than the new parent sample. However, in the Gay, Lee, and Lee (2004) study, parents had healthy newborns and were at home; it is likely that the parent's sleep was deprived because they needed to take care of their newborn during the night. For this current Chinese/Chinese-American sample, the baby was hospitalized in the ICU and the parent's total sleep time was even less than those parents faced with the demanding needs of a healthy newborn. Lower general sleep disturbance scores in this sample of Chinese parents compared to new parents with healthy infants may be due to two reasons. First, Chinese parents had a child in the acute phase of hospitalization between 3 to 10 days. Second, Chinese parents may have difficulty expressing their strong or negative feelings because of the different culture background (Lassiter, 1995).

Predictors of Parental Stress

The multiple regression analyses indicated that worry about the child's illness and its future impact, belief in Asian values (family, marriage, education), and perceived support from the health care providers explained 43% and 56% of the variance in the overall parental stress (PSSALL) for mothers and fathers respectively. In Shields-Poe and Pinelli's study (1997), trait anxiety and perceived morbidity explained most of the parental stress in their sample of 206 Canadians. In other words, uncertainty was found to contribute an important component in parental stress from both studies, and the uncertainty is related to the child's severity of illness and the future impact. In another study, Chinese immigrant parents were described as often seeing their child's illness as damaging and affecting many aspects of their present and future lives (Elfert, Anderson, & Lai, 1991).

In this current study, belief in Asian values played an important role in intensifying parental stress for the Chinese/Chinese-American parents. Although a boy child is traditionally considered a blessing in Chinese families, the gender of the infant accounted for only 0.3 % of the variance in PSSALL scores for mothers, and it explained 2.2 % of the variance in PSSALL scores for fathers. Aldwin (2000) states that culture can affect the stress and coping process by influencing the types of stressors that an individual is likely to perceive as threatening. Some anthropologists conceptualize culture as a set of rules that provides the individual with a means for behaving and interpreting the behavior of others (Harrison & Ritenbaugh, 1981). Acculturation includes two important components, assimilation and ethnic identity. Ethnic identity is the retention of attitudes pertaining to the culture of origin (Kitano, 1989). Such an

identity implies a sense of belonging, which is founded in the degree of attachment to an individual's homeland, its cultural heritage, belief system, language, customs, and manners (Brooker, 1999). Therefore, the findings from this study indicate that in the relationship between acculturation and parental stress, the ethnic identity component may influence the Chinese parents more than the assimilation component.

It was very pleasing to find that support from the health care providers diminished parental stress levels, and the nursing support showed the strongest correlational relationship with lower overall stress for both mothers and fathers. Social support has been identified as a significant buffer and an important resource for families in stressful situations. Social support may not only enable people to cope more successfully with stressful events but also provide feedback about the appropriateness of the appraisal process and emotional regulation (Thoits, 1986). In studies of parental stress associated with a sick child, support from the nurse has been recognized as one of the main sources of support for parents during the child's hospitalization period (Brazy, Anderson, Becker, & Becker, 2001; Miles, Carlson, & Funk, 1996).

Predictors of Sleep Disturbances/Daytime Fatigue

Sleep disturbance and fatigue severity were measured in this study as two possible responses to parental stress. The regression analyses indicated that stress derived from the child's appearance, and the health care provider's behavior explained 48% of the variance in TST for fathers. Stress derived from parental role alteration and the health care provider's behaviors explained 30% of the variance in mothers' TST. On the other hand, stress derived from the ICU environment explained most of the variance in WASO for mothers.

Research has repeatedly shown that the child's appearance and behavior, along with parent role alterations, are the most significant stressors perceived by mothers in the ICU (Holditch-Davis & Miles, 2000; Miles et al., 1989a; 1989b; Riddle et al., 1989; Seideman et al., 1997). Typically, children in the ICU are exposed in an open ward, and appear weak and pale, almost naked, with many tubes, dressings, and monitors. Parents often found these situations distressing, especially due to their inability to comfort their own child. In addition, the necessary professional care activities and the multiple equipment and medical devices created a situation where parents felt displaced from both the care of their child and physical proximity to their child.

Parenthood is a development process; from the beginning parents strive for a sense of competence in their relationship with the child. From the structured interview, parents in this study strongly expressed their feelings of incompetence due to a lack of confidence in taking care of their child. Studies suggest that reduction or removal of parental involvement with child care-taking is not only harmful to the child, but also has long-term effects on family health (Turner, Tomlinson & Harbaugh, 1990; Tomlinson, Kirschbaum, Harbaugh, & Anderson, 1996; Youngblut & Lauzon, 1995; Jamsa & Jamsa, 1998). In addition, the infant's health status during the first year was found to be associated with the mother's mental health status (Weiss & Chen, 2002).

Stress derived from staff communication explained most of the mother's self-reported sleep disturbances (GSDS) and morning fatigue severity, while the stress derived from parental role alteration explained most of the father's sleep disruptions. Data from the structured interviews with each parent indicated that the stress related to staff communication, aside from the language barriers, included a lack of knowledge

concerning both their child's situation and the child's treatment plan. Researchers have shown that information offers parents a better sense of control and reduces stress (Bass, 1991; Brazy et al., 2001; Kirschbaum, 1990; Shellabarger & Thompson, 1993). In addition to the necessary information, a culturally and linguistically appropriate level of communication needs to be utilized for new immigrants in the situation of having a hospitalized child.

Additional Findings

Perceived Severity of Child's Illness

Perception of threat is influenced by a particular system of self-values and contemporary evaluative standards and it is a function of the actual experiences, past experiences, and characteristic coping patterns (Kaplan, 1996). In this study, the child's morbidity was measured by objective data (CRIB or PRISM) and by subjective data (parent's perception). A full range of perceived severity of the child's illness was reported twice during data collection (once retrospectively to reflect on severity at admission and once prospectively to reflect on current severity) on a continuum from a rating of 1 (not sick at all) to 5 (extremely critical). Half (50%) of mothers and 44% of fathers retrospectively rated their child's severity of illness at the time the child was admitted into ICU as moderately sick, while 43.3% of mothers and 32% of fathers retrospectively rated their child's severity of illness as severely sick or extremely sick. At the time of data collection, 33.3% of mothers and 24% of father perceived their child's current severity of illness as moderately sick, and 13.4% of mothers and 12% of fathers still rated their child as severely sick or extremely sick. The CRIB or PRISM classified most (90.3%) of the baby's severity of illness at admission as low risk, and there was no

significant difference between boys and girls. Ratings of the child's severity of illness at admission by mothers were significantly higher than the severity based on CRIB or PRISM, and the same result was found in fathers. In general, fathers and mothers rated baby boy at a higher severity of illness than baby girls, but statistical significance was only found for mothers' ratings. Mothers distinguished a boy's morbidity level as being more severe than a girl at the time of interview. For the first generation parents (25 mothers and 21 fathers), fathers of baby boys perceived a significantly higher severity of illness for their child at admission than fathers of baby girls ($p < .05$). This finding indicates that gender affects parents' perception of their child's severity of illness, especially for the first generation Chinese immigrants.

For mothers, perception of the child's current severity of illness was positively correlated with parental stress score, parental role alteration, general sleep disturbance score, and stress derived from the child's appearance. Fathers' current severity of illness rating of their child was also correlated with their parental stress score, child's appearance, parental role alteration, and general sleep disturbance score. The finding suggests that the parent's perception of the severity of child's illness tended to influence their stress levels as well as one of the stress responses (sleep disturbance), and the subjective parental perception is more valuable in predict parental stress than an objective morbidity severity score (such as CRIP or PRISM score).

Translation Issues

Chinese parents in this study suffered the unnecessary burden resulting from language barriers and inappropriate translations by the non-professional interpreters. The three research sites selected for this study all had interpreters in-house during daytime

office hours. This kind of resource indeed benefits those Chinese parents who have language barriers in communicating with English-speaking health care providers. In addition to the challenges due to a limited number of interpreters (for example, two Chinese interpreters serve a 600-bed hospital and clinics), another issue is that the interpreters are not available 24 hours a day. Thus, sometimes the staff members volunteered to be interpreters, although they were not native-born Chinese and did not complete an interpreter-training program, and misunderstandings could result.

Several examples of translation issues between the parents and the health care providers were found in this study. For instance, one of the mothers in this study was confused about her son's jaundice and a potential heart problem because an unofficial interpreter translated bilirubin as cholesterol. In Mandarin, bilirubin sounds as "tan-hung-su" and cholesterol sounds as "tan-ku-chun." One mother said,

> "Two doctors came to my room, one speaks Chinese but with some accent, they told me not to worry, it is a common problem for newborns because the liver function was not fully developed yet. I know that cholesterol is related to heart problem, and I asked the doctor several times to make sure my son did in fact have high cholesterol and what would cause that. She just kept telling me it was a common condition and asking me not to worry, how is that possible for me not to worry? My son is only a few days old and he has problems both in his liver and heart..... I couldn't sleep at all that night. Although I would like to ask more questions, I really don't know how to ask."

This occurred during her first postpartum night, when the physician came into her room after midnight and explained that her son needed to be transferred to ICU for further treatment. The mother had no opportunity to clarify her concern until she was interviewed in this current study.

It is very common to see the health care provider use a convenient interpreter (for example, colleagues or family members) to translate for those clients who have language barriers. Using this kind of non-medically or non-culturally trained interpreter can jeopardize the accuracy of information because it is impossible for the health care providers or the clients to find out if those messages have been translated with cultural and linguistical appropriateness.

Postpartum Special Rituals

Chinese believe that a yin-yang imbalance within the human body results in dysfunction or disease (Kleinman & Lin, 1981; Spector, 2000). The month-long postpartum confinement is one of the yin-yang approaches to healing, and is based on the Chinese health practice of holistic balance and harmony of energy fields. According to this approach, postpartum women should drink and eat warm foods, stay heavily clothed, and avoid contact with cold water. Most (N= 23) mothers in this study were in the postpartum period and 17 (74%) were practicing the Chinese traditional postpartum ritual, which includes special diets, avoiding cold water, resting as much as possible, and remaining emotionally balanced. There were various kinds of special diets, but the common theme was eating "warm" foods (for example, ginger rice, ginger chicken, red bean rice, and pork legs and eggs soaked with vinegar for months and then used as one of the main dishes) during the postpartum period. Fresh chicken is preferred for the postpartum diet, and several fathers made a trip to Chinatown to get fresh chicken daily for their wives. Many mothers did not take the meals from the hospital because several of them were "cold" foods (such as salads and bananas). Some mothers were hesitating

to take showers, especially during the first week, and one of the mother said she did not take a shower for a whole month with her first child.

Four mothers blamed themselves for not following the traditional Chinese prenatal care, which they believe caused their baby's premature delivery. However, they did not discuss this with the health care providers because they thought no one could understand their concerns. It is part of human nature, to try to find an explanation for each situation, and it is very common to hear mothers express their feelings of guilt with a sick child (Afflect, Tennen, & Rowe, 1991; Leuthner, Bolger, Formmelt, & Nelson, 2003). Yet the true challenge for Chinese mothers in this study was that they could not share their feelings with others due to their perceptions of cultural gaps.

Help-Seeking and Social Support

In this study, only 40% of mothers and 36% of fathers sought support or help from others while their child was in the ICU. Among those parents who searched for extra help, direct family members and friends were the major resource for mothers (92%), while fathers used family members and health care providers equally (44%) as their major resources. Parents tried to gain knowledge about their child's problem from health care providers and through experiences of family members. For those parents who did not seek help, two mothers and one father said there were no resources for them, two mothers stated that they did not like other people to know about the child's problem, and the rest of them felt they did not need extra help for their current situation. This finding supports previous studies, suggesting that Asian immigrants tend to choose family members as help sources (Keller & McDade, 1997), and Chinese tended to not share bad news with others in the family and community (Martinson, Zhong, & Liang, 1994).

Tomlinson and Mitchell (1992) found that mothers received more network support than fathers did while their child was in the ICU. A later study found that parents received a moderate level of support during the hospitalization, and fathers reported higher support scores than mothers during first week of their child's ICU hospitalization. However, Miles and colleagues reported that it became the reverse situation in the second week, and mothers reported received more support than fathers. In the first week mothers rated the child's father as the highest source of support and nurses as the second most helpful resource, while the fathers rated their spouse/partner and nurses as the most helpful resources in this primarily Caucasian sample (Miles, Carlson, & Funk, 1996). The Chinese parents in the current study reported receiving only a low level of support, and mothers and fathers perceived similar support. The mothers rated their spouse/partner and nurses as the most helpful resources, and fathers rated nurses as the highest source of support with their spouse/partner being the second. In contrast to parents in Miles' study (1996), participants in this study received low levels of support; this is likely related to Chinese parents who barely used support beyond family members, friends, and health care providers. In addition, several parents in the current study did not even realize the availability of social resources. This phenomenon again supports Keller and McDade's (1997) findings, and indicates that a new social system and lack of proper family resources result in greater difficulty in accessing social support and reducing stress.

Objective and Subjective Sleep Measurements

In this study, correlations were found between parents' objective sleep data (TST, WASO), subjective sleep data (GSDS), and perceived fatigue severity. Mothers with less total sleep time (TST) had higher self-reported general sleep disturbances, and more

severe morning fatigue. Mothers who reported higher levels of sleep disturbance also had more severe morning fatigue and evening fatigue. For fathers, less total sleep time was correlated with more severe morning fatigue, and a higher level of general sleep disturbance. Fathers with higher sleep disturbance scores had more severe morning fatigue, and evening fatigue.

From the correlations between objective and subjective sleep data, it can be said that General Sleep Disturbance Scale (GSDS) is a valid measure to evaluate parent's quality and quantity of sleep. Since wearing a wrist actigraph may become a burden to participants, and equipment failure is common, and an actigraph is not generally available in most clinical settings, it was reassuring that the GSDS provides a valid and reliable way to assess sleep disturbance in this population of parents.

Implications for Clinical Practice

The stress and burden of having an infant in intensive care is one kind of pain for parents, and the symptoms experienced as a result of this type of stress, which include physical (for example, sleep disturbances and fatigue) and emotional suffering, are similar to the pain caused by any disease. The difference is that parental stress does not have any existing medicine to sooth it, and parents either do not complain or lack the opportunity to express their pain while they are suffering, so it is a "silent pain." As a result of this phenomenon, parents with a sick child become one of the most neglected types of caregivers and are at risk for health problems. As a health care provider, the fundamental nursing intervention message to convey is the importance of assessing the parent's "pain" and considering what interventions may be culturally sensitive and appropriate.

The findings from this study suggest that support from the health care providers may reduce mothers' and fathers' stress levels while their child is hospitalized in the ICU. The other two independent variables related to parental stress (beliefs in Asian values and worry about child's illness and future impact) cannot be directly affected by the health care provider's interventions. However, staff should be sensitive to the immigrant parent's ethnic identity, and offer culturally appropriate care for them by paying attention to the parents' belief systems and helping them to discuss and find ways to cope and reduce stress. Acculturation indeed played an important role in the Chinese/Chinese-American parents perceived parental stress while their child was hospitalized in the ICU. Another important finding from this study indicated that stress decreased total sleep time for both mothers and fathers, and increased mother's fatigue severity. An important area for future research would be to evaluate the extent to which this reduced sleep and daytime fatigue results in daytime dysfunction, particularly at a time when a higher level of functioning is important to the parenting role.

Results from this study have many implications for clinical practice. Implications for clinical practice can be classified into three categories: family education, health care provider's education, and cultural interpreter's utilization.

Family Education

The reason behind emphasis on family education rather than parents' education is because grandparents often share the stress and burdens along with the parents. Family, as a unit, is an important concept in nursing interventions to assist each family in caring for their sick child and coping with a crisis situation. How to define the family is based on each individual's different cultural background. For Chinese, especially first

generation, grandparents need to be included since Chinese families have been characterized by a traditional system of hierarchical roles based on age and gender. In this study, more than 25% of the parents were living with their parents, and most of the other families also had grandparents actively involved in the child's care. Some grandparents even came from overseas to help out during the postpartum period and visit their new grandchild. Three grandmothers in this study insisted upon speaking with the researcher regarding their concern about the medical management of their grandchild, based on their different experiences between here and their homeland. In this study, the participant's main source of help was their direct family members.

Family education material regarding a premature baby or an infant's illness should be efficiently utilized in any ICU to help parents understand their child's problem and the possible outcomes. The parents in this study reported the child's appearance as the most distressing source of stress for them and worry about child's illness and its future impact explained most of the variance in parental stress. A videotape that includes health care provider's explanation for the common problems, and other parent's experiences may be beneficial to parents to comprehend their own child's illness and possible outcomes. Most importantly, the material needs to be culturally and linguistically appropriate. Because of the different cultural backgrounds and the linguistic barriers, the messages that are passed between individuals may not necessarily always lead to better understanding. Language is a mode of thought but it is not simply an instrument that conveys and receives messages. Language is the central component of culture (Steven, 1985), and experiences are processed in the form of language in which they occurred (Speicher, 2000). For Chinese adults, some life experiences, such as

parenthood and child rearing, need to be re-experienced and explored in both Mandarin, the language in which they occurred in order to reach the deeper affective level of comprehension, and in English in order to integrate these experiences into their contemporary being.

Although many social resources exist, the immigrant may not be familiar with them or may hesitate to use those resources because of a difference in cultural background and understanding. Social support has been identified as a significant buffer and an important resource for families during stressful situations. Social support may not only enable people to cope more successfully with stress, but also may foster stress-related behaviors that can function proactively to eliminate stressful events before they occur or prevent a stressful event from intruding into other aspects of life (Lazarus & Folkman, 1984). Therefore, another important component of family education is the introduction of various social resources to immigrant families so that they can easily and willingly make use of social resources and receive other forms of appropriate support to maintain their physical and emotional health.

Education for Health Care Providers

To successfully achieve family education related to the sick child's illness and progress, health care providers must become knowledgeable of the parent's stress perceptions as well as their unique culture backgrounds. It is very important for health care providers to learn and develop comfort with assessing, encouraging, and assisting families in understanding their child's problem and treatment plan. Involving parents in their child's ICU care should be considered to promote parental feelings of competence and confidence in the parental role. Family and sibling support groups should be

organized and supported in every pediatric unit to help families cope as a unit with the sick child's crisis situation. The cultural issues in patient care need to be included in every nursing school's curriculum as well as in continuing education for health care providers.

Health care providers need to incorporate the importance of culture and consider cross-cultural relationships in the assessment and treatment of many clients and their family members. In other words, cultural competence is the foundation for health care providers to provide competent service. Culturally competent service includes a set of congruent behaviors, attitudes, and policies that work effectively in cross-cultural situations within a system or institution (Lu, 1996). To achieve this competency requires the assessment of cultural differences, the expansion of cultural knowledge, and a commitment to adapt services to meet culturally unique needs (Purnell & Paulanka, 1998; Mattson, 2000)

Cultural Interpreter's Utilization

Clinical research suggests that the utilization of language is an important communication tool between bicultural clients and their health care providers (Perez-Foster, 1996). Language is a mode of symbolic thought, not simply a way to convey and receive messages. Because of different cultural backgrounds and linguistic barriers, the messages that are passed between individuals do not always lead to better understanding. Language differences can exacerbate tensions between individuals in the same language community as well as in different language communities within a single country; they can also create inter-cultural problems that affect individuals from different countries. A translator not only translates the spoken words, but also more importantly must interpret

one's cultural values and beliefs. Cultural interpretation programs should be facilitated in the ICU to help parents to cope better with their child's illness (Bracht, Kandankery, Nodwell, & Stade, 2002).

Limitation of the Study and Implication for Future Research

This study is unique in two areas. First, this study introduces acculturation as a key variable in the exploration of Chinese-American parents stress experiences with a child in the ICU. And secondly, this was the first study to explore parents' sleep disturbances and perception of fatigue as responses to stress while their child is hospitalized in ICU. Although the study findings contribute to knowledge about Chinese-American parents' stress perceptions and stress responses, findings should be considered in light of the small sample size. Cohen suggests values of .13 and .26 as estimates of medium and large effect sizes for the overall population R-square. The multiple regression analysis utilized a sample of 30 mothers, with an alpha level of .05, and an overall $R^2 \geq .30$ for three predictors having a power of 80%, and with an overall $R^2 \geq .26$ for two predictors having a power of 80%. On the other hand, the multiple regression analysis employed a sample size of 25 fathers in this study, with an alpha level of .05, and an overall $R^2 \geq .34$ for three predictors having a power of 80%, and with an overall $R^2 \geq .31$ for two predictors having a power of 80% (Cohen, Cohen, West, & Aiken, 2003). In addition, the generalizability of the study findings is limited by the small sample size, the use of convenience rather than random sampling, the inclusion of only one racial group, the inclusion of parents of children who were admitted to ICU in teaching hospitals during the acute but stable stage of their illness, and the geographic location limited to urban west coast.

Certain factors identified in this study were the ICU stressors, parent's stress responses (sleep disturbances and fatigue), and the predictors for parental stress and stress responses during the acute phase of their ICU experience. In the current study, ICU stressors included child's appearance, parental role alteration, ICU environment, health care provider's behavior, and communication. Further research is needed to study the effects of these stressors over time into the convalescing or chronic phases of the ICU experience and recovery. This study should be replicated to include different geographic locations of Chinese-Americans, different generations of Chinese-American, populations in other minority ethno-cultural groups, more diverse socioeconomic groups, different health problems in different illness stages (acute and chronic) and child's different developmental periods. Other sources of stress identified from structured interviews in this study of Chinese-American included parental role incompetence, guilty feelings, family conflicts related to the sick child, and stress related to cultural beliefs. These sources of stress also need to be further explored with Chinese immigrants in future studies.

About one third of the parents in this study were living with their parents, and most of the two-parent families also had their parents from overseas to help out during the postpartum period. In addition, two grandmothers insisted on talking with the researcher about their concerns in relation to medical treatments and their conflicts with the Western health care system. Therefore, Chinese grandparents' perceptions regarding their sick grandchild and its effects on their children's stress levels also become a critical factor for researchers to examine when they conduct a study with Chinese parents who have a child hospitalized in ICU. This phenomenon also needs to be examined in other

Asian groups, especially Korean and Japanese who share so much cultural commonalities and family values with the Chinese.

Stress and strain has been conceived as a basis of ill/health (Lazarus & Folkman, 1984). Stressors elicit responses from a person's entire body, which includes three primary generic axes involved in the stress response: the neurological axis, the endocrine axis, and the immune axis (White & Porth, 2000). Further studies should include the biomarkers for various physiological components of the stress response (such as stress hormones like cortisol or heart rate variability) in addition the psychological stress responses involving perception of symptoms like insomnia or fatigue.

Studies have suggested that mothers with a high-risk newborn experience significantly more symptoms of posttraumatic stress than mothers of healthy term infants (DeMier, Hynan, Harris, Manniello, 1996; DeMier, Hynan, Hatfield, Varner, Harris, & Manniello, 2000). Some parents in this study also described their labor and delivery as a traumatizing experience, starting from the labor pain to the intense medical needs once the baby was born. The experience was further traumatizing because of the unfamiliar ICU setting. The relationships between the stress experienced with a sick child and the development of symptoms of posttraumatic stress disorder need to be further explored to identify potential risk factors contributing to the parental emotional distress and the effects on their bio-psycho-social health status. The results of this study indicate that both mothers and fathers experience less sleep time and more sleep problems after their child was hospitalized. Sleep disturbances and fatigue need to be further investigated to comprehend the relationships between sleep patterns and emotional well-being and

parent's learning capability and role competence in both the acute and chronic stages of their child's illness.

To provide the highest quality of care for patients and family caregivers, further interventions need to be developed for improving sleep and decreasing fatigue severity of parents with a sick child. In the short-term, sleep disturbances and fatigue can impact the parent's ability to perceive messages and to learn childcare skills and their daytime functioning should be carefully assessed. In the long-term, chronic sleep disturbances and fatigue can affect parent's health status and jeopardize parent-child relationships and family dynamics.

Current methods of research, practice, and training are challenged by multiculturalism (Constantine & Gloria, 1999). In the United States, fluency in English is a prerequisite for most research participation. As a result, non-English speakers in the U.S. are neither adequately nor accurately studied. Minority populations with different cultural backgrounds and language barriers may have increased vulnerability in coping with their child's illness. In the current study of Chinese parents, the SL-ASIA acculturation scores was significantly correlated with mothers and fathers overall stress level ($p < .05$), and belief in Asian values was found to significantly contribute to the variance in PSS:IH scores for both mothers and fathers. Further study is critical in order to distinguish the minority ethnic group's personal and family characteristics (especially acculturation as a variable) that influence parental stress, their stress responses, and utilization of available social resources.

Marin and Marin (1991) have made two critical points for recruiting and retaining research participants from minority groups, which include 1) adopting a translated

instrument for the participants and 2) using a same-ethnicity data collector. A low refusal rate (9.1%) for the current study is the best demonstration for benefits of using this research strategy. In addition, showing respect to the participant, providing help, and establishing ongoing relationships between researcher and participant (Demi & Warren, 1995; Marin & Marin, 1991) also contributed to a high participation rate in the current study. All of these methods should be utilized to study health behaviors and outcomes in other minority ethnic groups.

In summary, adopting a culturally-informed study is the foundation for research with ethnic minority groups. The identification of one's acculturation level, especially their ethnic-identity, is an important variable in promoting the understanding of Chinese immigrant parents' stress perceptions and stress responses. In any study of Chinese immigrants, family, as a unit, should also include grandparents as well as parents and children. The relationships between the child's gender and Chinese parent's perception of stress levels need to be further examined with a larger sample size. Longitudinal studies are needed to explore the parents' stress perceptions, stress responses, and family dynamics during transition from the sick child's acute stage to the chronic stage. The relationships between stress, sleep disturbance, fatigue, and parental role competencies need to be further explored for both hospitalized and non-hospitalized children and their parents.

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Appendix A
Research Approval

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH ADMINISTRATION, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
www.ucsf.edu/ora/chr

CHR APPROVAL LETTER

TO: Kathryn Lee, Ph.D.
Box 0606

Shih-Yu S. Lee, R.N., M.S.
Box 0606,

RE: Acculturation and ICU Stress Among Chinese/Chinese-American Parents

The Committee on Human Research (CHR) has reviewed and approved this application to involve humans as research subjects. This included a review of all documents attached to the original copy of this letter.

Specifically, the review included but was not limited to the following documents:
Consent Form, dated 8/6/02

The CHR is the Institutional Review Board (IRB) for UCSF and its affiliates. UCSF holds Office of Human Research Protections Federalwide Assurance number FWA00000068. See the CHR website for a list of other applicable FWA's.

CONDITION: Please respond in writing in a timely manner. First, before recruitment begins at Lucile Salter Packard Children's Hospital, a letter of approval from the Stanford IRB must be submitted to the office of the CHR. Second, the third paragraph under Procedures in your consent form should read: "You will be asked to keep a sleep log and to wear a watch-like motion sensor to monitor your sleep and activities continuously for 2 days. Any uncompleted portion of the interview can be completed when you return the monitor and the sleep log." Third, a Chinese translation of your consent form should be submitted as soon as it is available. The changes recommended in your English consent form should be made before you enroll any subjects. Please submit two copies of your revised English consent form, as well as the Stanford IRB letter and the translation when available, to Box 0962. Once these copies have been received and accepted, the status of this protocol will be changed from Conditional Approval to Approval.

APPROVAL NUMBER: H5464-21640-01. This number is a UCSF CHR number and should be used on all correspondence, consent forms and patient charts as appropriate.

APPROVAL DATE: September 12, 2002. **Full Committee Review**

EXPIRATION DATE: September 12, 2003. If the project is to continue, it must be renewed by the expiration date.

GENERAL CONDITIONS OF APPROVAL: Please refer to www.ucsf.edu/ora/chr/gen_cond_appvl.htm for a description of the general conditions of CHR approval. In particular, please note that prior CHR approval is required before implementing any changes in the consent documents or any changes in the protocol unless those changes are required urgently for the safety of the subjects.

QUESTIONS: Please contact the office of the Committee on Human Research at (415) 476-1814 or campus mail stop, Box 0962, or by electronic mail at chr@research.ucsf.edu.

Sincerely,

Victor I. Reus, M.D.
Chair
Committee on Human Research

cc:
CHR-SFGH

Appendix A
Research Approval

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
www.research.ucsf.edu/chr/index.htm
chr@research.ucsf.edu
(415) 476-1814

CHR APPROVAL LETTER

TO: Kathryn Lee, Ph.D. Box 0606 — Shih-Yu S. Lee, R.N., M.S. Box 0606,

RE: Acculturation and ICU Stress Among Chinese/Chinese-American Parents

The Committee on Human Research (CHR) has reviewed and approved this application to involve humans as research subjects. This included a review of all documents attached to the original copy of this letter.

The CHR is the Institutional Review Board (IRB) for UCSF and its affiliates. UCSF holds Office of Human Research Protections Federalwide Assurance number FWA00000068. See the CHR website for a list of other applicable FWA's.

APPROVAL NUMBER: H5464-21640-01B. This number is a UCSF CHR number and should be used on all correspondence, consent forms and patient charts as appropriate.

APPROVAL DATE: May 14, 2003 **EXPIRATION DATE:** September 12, 2003 **Expedited Review**

GENERAL CONDITIONS OF APPROVAL: Please refer to www.ucsf.edu/ora/chr/gen_cond_appvl.htm for a description of the general conditions of CHR approval. In particular, the study must be renewed by the expiration date if work is to continue. Also, prior CHR approval is required before implementing any changes in the consent documents or any changes in the protocol unless those changes are required urgently for the safety of the subjects.

HIPAA "Privacy Rule" (45CFR164): This study requires individual consent/authorization for use and/or disclosure of Protected Health Information (PHI).

Sincerely,

Victor I. Reus, M.D.
Chair, Committee on Human Research

cc:
CHR-SFGH

Appendix A
Research Approval

COMMITTEE ON HUMAN RESEARCH
OFFICE OF RESEARCH, Box 0962
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
www.research.ucsf.edu/chr/index.htm
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(415)476-1814

ORA CHR APPROVAL LETTER

TO: Kathryn Lee, Ph.D.
Box 0606

Shih-Yu S. Lee, R.N., M.S.
Box 0606,

RE: Acculturation and ICU Stress Among Chinese/Chinese-American Parents

The Committee on Human Research (CHR) has reviewed and approved this application to involve humans as research subjects. This included a review of all documents attached to the original copy of this letter.

The CHR is the Institutional Review Board (IRB) for UCSF and its affiliates. UCSF holds Office of Human Research Protections Federalwide Assurance number FWA00000068. See the CHR website for a list of other applicable FWA's.

APPROVAL NUMBER: H5464-21640-02. This number is a UCSF CHR number and should be used on all correspondence, consent forms and patient charts as appropriate.

APPROVAL DATE: August 21, 2003 **EXPIRATION DATE:** August 21, 2004 **Expedited Review**

GENERAL CONDITIONS OF APPROVAL: Please refer to www.ucsf.edu/ora/chr/gen_cond_appvl.htm for a description of the general conditions of CHR approval. In particular, the study must be renewed by the expiration date if work is to continue. Also, prior CHR approval is required before implementing any changes in the consent documents or any changes in the protocol unless those changes are required urgently for the safety of the subjects.

HIPAA "Privacy Rule" (45CFR164): This study does not involve access to, or creation or disclosure of Protected Health Information (PHI).

Sincerely,

Reese T. Jones, M.D.
Chair, Committee on Human Research

cc:
CHR-SFGH

California Pacific
Medical Center

Research Institute
A Sutter Health Affiliate

Street Address:
2200 Webster Street, Suite 514
San Francisco, CA 94115

INSTITUTIONAL REVIEW BOARD
2200 Webster Street, 5th Floor
San Francisco, CA 94115
(415) 600-3688
IRB Assurance NO: FWA00000921

TO: **David A. Lee, MD**

RE: **23.030, Acculturation and ICU Stress Among Chinese/Chinese-American Parents**

EXPEDITED REVIEW - REVISED CONSENT

DATE OF FINAL APPROVAL: **04/24/2003**
I have reviewed the consent form for the above research project that has been revised as requested by the IRB Committee. The protocol and revised consent, dated 04/23/2003 were **approved** as submitted. *Please have subjects who decide to participate in the research sign the attached stamped, approved consent form, version dated 04/23/2003 and HIPAA Authorization, version dated 04/23/2003.*

EXPIRATION DATE: **03/24/2004**
If the project is to continue, approval must be renewed and re-approved by this date.

MODIFICATIONS: Any modification to the consent form or protocol--including the title--must receive IRB approval prior to initiation; the request should be made in writing to the IRB Chairman at the above address.

COMPLICATIONS: All complications or untoward effects from the study must be reported immediately to the IRB.

Sincerely,

David F. Busch, MD
IRB Chairman
/mc

CRIB (Clinical risk index for babies)

Birth weight	
>1350	0
851-1350	1
701-850	4
≤700	7
Gestation	
>24 wk	0
≤24 wk	1
Congenital malformations	
None	0
Not acutely life-threatening	1
Acutely life-threatening	3
Maximum base excess in first 12 hrs	
> -7.0	0
-7.0 to –9.9	1
-10.0 to –14.9	2
≤ -15.0	3
Minimum approach FiO2 in first 12 hrs	
≤ 0.40	0
0.41-0.60	2
0.61-0.90	3
0.91-1.00	4
Maximum approach FiO2 in first 12 hrs	
≤ 0.40	0
0.41-0.60	1
0.61-0.90	3
0.91-1.00	5

Hospital mortality 0-5 (5%), 6-10 (40%), 11-15 (65%), >16 (90%)

RISM (Pediatric risk of mortality score)

Systolic BP (for infants) 130-160 or 55-65 (2), > 160 or 40-54 (6), < 40 (7)

Diastolic BP >110 (6)

HR (for infants) > 160 or < 90 (4)

RR (for infants) 61-90 (1), > 90 or apnea (5)

PaO2/FiO2 200-300 (2), < 200 (3)

PaCO2 51-65 (1), >65 (5)

Glasgow Coma Score < 8 (6)

Pupillary reactions Unequal or dilated (4), fixed and dilated (10)

PT/PTT 1.5 x control (2)

T Bili > 3.5 (6)

Potassium 3.0-3.5 or 6.5-7.5 (1), < 3.0, or >7.5 (5)

Calcium 7.0-8.0 or 12.0-15.0 (2), < 7.0 or > 15.0 (6)

Glucose 40-60 or 250-400 (4), < 40 or > 400 (8)

Bicarbonate <16 or > 32 (3)

Parents Demographic Data Form

Family ID: _____ Location of Interview: _____

Date: _____ Child's Admission Date: _____

1. You originally came from ___ China, ___ Hong Kong, ___ Taiwan, ___ U. S. A, or ___ other country, please specify _____.

2. You have lived in the United States since _____. The average time in U. S. for you is _____ (month per year).

3. Your age: _____

4. You are (child's name) _____father or _____mother.
   He/she is your ___ birth child, ___ stepchild, or ___ adopted child.

5. Do you have other children? ____No, ____Yes. If yes, how many boys and/or girls _____, and his/her age is _____.

6. The number of extended family members in your home is _____

7. Your highest education is ___ Elementary School, ___ Middle School, ___ High School, ___ College, or ___ Graduate School. The total years in school was _____

8. Have you attended school in the U.S.? _____No _____ Yes
   If yes, for how long _____ and when did you begin school in the U.S. _____

9. Is English your first language? ____ Yes, ___ No, please specify _____

10. Your occupation is _____.

11. Your current health status is ___ poor, ___ fair, ___ good, ___ very good, or ___excellent.

12. Did you have sleep problem before your child's hospitalization? ___ No, ___ Yes. If yes, please describe (include management)_____

13. Do you have sleep problem after your child's hospitalization? ___ No, ___ Yes. If yes, please describe (include management) _____

14. Your current financial status is ___ barely surviving, ___ getting behind, ___ breaking even, ___ moderately well off, ___ very well off.

15. Do you have financial difficulty because your child's hospitalization? ___ No, ___ Yes.

16. Which category best describes your family income from all sources before taxes?

___ Less than $20,000, ___ $20,000 to $40,000, ___ $40,001 to $60,000

___ $60,001 to $80,000, ___ $80,001 to $100,000, ___ more than $100,000

17. Your marital status is ___ Married, ___Divorce, ___Separated, ___ Living with a partner,

___ Widowed, or _____Single

18. Your current religion is ___ None, ___ Buddhism, ___ Taoism, ___ Christianity,

___ Catholicism, or____ other, please specify _____

19. The degree that religious belief helped you through your child hospitalized period is

____not at all helpful, ___ sometimes helpful, ___ generally helpful, ___ very helpful,

___ extremely helpful.

20. Do you have any previous experiences with intensive care unit? ___ No, ___ Yes.

If yes, who was in the ICU _____ and at _____.

21. How do you rate the severity of your child's illness condition while he/she admitted into the ICU? ___ not sick at all, ___ minor, ___ moderate, ___ sever, ___ extremely critical.

22. How do you rate your child's illness condition now?

___ not sick at all, ___ minor, ___ moderate, ___ sever, ___ extremely critical.

23. How do you rate your worrisome regarded to your child's illness and future impact to your child? ___ not worry at all, ___ a little worry, ___ moderately worry, ___ very worry,

___ extremely worry.

24. Do you seek for help while your child is sick? ___ No, ___ Yes. If yes, please specify the source of help _____

25. Do you have a special ritual, which relates to taking care your sick child? ___No, ___Yes.

If yes, please specify _____.

Child Data Sheet (Medical Record Review)

Family ID: _____ Chart Number: _____

Today's Date: _____

Hospital/Type of ICU: _____

Date of admission: _____

Child's date of birth: _____

Child's place of birth: _____

If born outside the U. S., how long in the U. S.: _____

Gender of the child: _____boy, _____girl, _____other

Primary Diagnosis: _____

Other Diagnosis:_____

Reason for admission: _____

_____

_____

Required oxygen at admission: ____ yes, _____no; ventilator: _____yes, _____no;

Ventilator's settings: _____

Requires oxygen at present: _____ yes, ____ no: ventilator: _____yes, _____ no

Ventilator's settings: _____

Surgical Procedure:_____

Parental Stressor Scale: Infant Hospitalization (PSS:IH)

We would like to know how much stress you have experienced as a result 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. Being separated from you child	1	2	3	4	5	N/A
2. Not being able to regularly care for your child (e.g., feed, diaper, hold)	1	2	3	4	5	N/A
3. Not having a chance to be alone with your child	1	2	3	4	5	N/A
4. Not being able to share your child with family and friends	1	2	3	4	5	N/A
5. Not being able to protect your child from pain and painful procedures	1	2	3	4	5	N/A
6. Not being able to comfort or help your child	1	2	3	4	5	N/A
7. The nurses and other staff seeming closer to the child than you are	1	2	3	4	5	N/A
8. Not being able to hold your child	1	2	3	4	5	N/A

We are also interested in how stressed you are by the way your child looks to you? How stressful is it:

	Not stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	Not applicable
9. Seeing your child with tubes or IV lines on him/her	1	2	3	4	5	N/A
10. Seeing your child in pain	1	2	3	4	5	N/A
11. Having your child look afraid, be upset or cry a lot	1	2	3	4	5	N/A
12. Seeing your child look sad	1	2	3	4	5	N/A

	Not stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	Not applicable
13. Seeing a needle or tube put in your child	1	2	3	4	5	N/A
14. Seeing your child have problems breathing	1	2	3	4	5	N/A
15. Seeing your child surrounded by machinery and having medical treatments	1	2	3	4	5	N/A
16. When your child can't respond to you	1	2	3	4	5	N/A

When you visit your child in the hospital, how stressful are the following things you might see or hear?

	Not stressful	A little stressful	Moderately stressful	Very stressful	Extremely stressful	Not applicable
17. Monitors and equipment in the room	1	2	3	4	5	N/A
18. The sudden sound of monitor alarms	1	2	3	4	5	N/A
19. The other sick children in the room	1	2	3	4	5	N/A
20. The large number of nurses, doctors, and other staff who work with your child	1	2	3	4	5	N/A
21. When other children in the hospital have a crisis	1	2	3	4	5	N/A
22. The needs of other parents in the hospital	1	2	3	4	5	N/A

We are also interested in your experiences related to health care providers' behaviors and communication.

Using the same rating scale, indicate how stressful health care providers' behavior for you:

1. Not stressful
2. A little stressful
3. Moderately stressful
4. Very stressful
5. Extremely stressful

Using the same rating scale, indicate how stressful of communication with health care providers for you:

1. Not stressful
2. A little stressful
3. Moderately stressful
4. Very stressful
5. Extremely stressful

How stressful in general, the experience of having your child in the ICU has been for you:

1. Not stressful
2. A little stressful
3. Moderately stressful
4. Very stressful
5. Extremely stressful

Pleas list any other experiences in your life that have been stressful to you and rate your stress level compare to your experience with your child's hospitalization.

_____

1. Less stressful than this experience with your child's hospitalization
2. Same stressful as this experience with your child's hospitalization
3. More stressful than this experience with your child's hospitalization

_____

1. Less stressful than this experience with your child's hospitalization
2. Same stressful as this experience with your child's hospitalization
3. More stressful than this experience with your child's hospitalization

General Sleep Disturbance Scale (GSDS)

How often in the PAST WEEK did you:

	Never							Every day
1. have difficulty getting to sleep	0	1	2	3	4	5	6	7
2. wake up during your sleep period	0	1	2	3	4	5	6	7
3. wake up too early at the end of a sleep period	0	1	2	3	4	5	6	7
4. feel rested upon awakening at the end of a sleep period	0	1	2	3	4	5	6	7
5. sleep poorly	0	1	2	3	4	5	6	7
6. feel sleepy during the day	0	1	2	3	4	5	6	7
7. struggle to stay awake during the day	0	1	2	3	4	5	6	7
8. feel irritable during the day	0	1	2	3	4	5	6	7
9. feel tired or fatigued during the day	0	1	2	3	4	5	6	7
10. feel satisfied with the quality of your sleep	0	1	2	3	4	5	6	7
11. feel alert and energetic during the day	0	1	2	3	4	5	6	7
12. get too much sleep	0	1	2	3	4	5	6	7
13. get too little sleep	0	1	2	3	4	5	6	7
14. take a nap at a scheduled time	0	1	2	3	4	5	6	7
15. fall asleep at a unscheduled time	0	1	2	3	4	5	6	7
16. drink an alcoholic beverage to help you get to sleep	0	1	2	3	4	5	6	7
17. use tobacco to help you get to sleep	0	1	2	3	4	5	6	7
18. use a herb to help you get to sleep	0	1	2	3	4	5	6	7
19. use an over-the-counter sleeping pill to help you get to sleep	0	1	2	3	4	5	6	7
20. use a prescription sleeping pill to help you get to sleep	0	1	2	3	4	5	6	7
21. use aspirin or other pain reliever to help you get to sleep	0	1	2	3	4	5	6	7

Suinn-Lew Asian Self-Identity Acculturation Scale (SL-ASIA)

The following questions are to collect information about the background of Asians who live in United States and their behaviors, which may be related to your cultural identity. Choose the one answer which best describes you.

1. What language can you speak?
   1. Asian only (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
   2. Mostly Asian, some English
   3. Asian and English about equally well
   4. Mostly English, some Asian
   5. Only English

2. What language do you prefer?
   1. Asian only (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
   2. Mostly Asian, some English
   3. Asian and English about equally well (bilingual)
   4. Mostly English, some Asian
   5. Only English

3. How do you identify yourself?
   1. Chinese, Taiwanese, Japanese, Korean etc.
   2. Asian
   3. Asian-American
   4. Chinese-American, Japanese-American, Korean-American, etc.
   5. American

4. Which identification does (did) your father use?
   1. Chinese, Taiwanese, Japanese, Korean etc
   2. Asian
   3. Asian-American
   4. Chinese-American, Japanese-American, Korean-American, etc.
   5. American

5. Which identification does (did) your mother use?
   1. Chinese, Taiwanese, Japanese, Korean etc
   2. Asian
   3. Asian-American
   4. Chinese-American, Japanese-American, Korean-American, etc.
   5. American

6. What was the ethnic origin of the friends and peers you had, as a child up to age 6?
   1. Almost all Asians, Asian-Americans.
   2. Mostly Asians, Asian-Americans.
   3. About equally Asian groups, Anglo groups, African Americans, and Hispanics
   4. Mostly Anglos, African Americans, Hispanics, or other non-Asians
   5. Almost all Anglos, African Americans, Hispanics, or other non-Asians

7. What was the ethnic origin of the friends and peers you had, as a child from 6 to 18?
   1. Almost all Asians, Asian-Americans.
   2. Mostly Asians, Asian-Americans.
   3. About equally Asian groups, Anglo groups, and African Americans.
   4. Mostly Anglos, African Americans, Hispanics, or other non-Asians
   5. Almost all Anglos, African Americans, Hispanics, or other non-Asians

8. Whom do you now associate with in the community?
   1. Almost all Asians, Asian-Americans.
   2. Mostly Asians, Asian-Americans.
   3. About equally Asian groups, Anglo groups, African Americans, and Hispanics
   4. Mostly Anglos, African Americans, Hispanics, or other non-Asians
   5. Almost all Anglos, African Americans, Hispanics, or other non-Asians

9. If you could pick, whom would you prefer to associate with in the community?
   1. Almost all Asians, Asian-Americans.
   2. Mostly Asians, Asian-Americans.
   3. About equally Asian groups, Anglo groups, African Americans, and Hispanics
   4. Mostly Anglos, African Americans, Hispanics, or other non-Asians
   5. Almost all Anglos, African Americans, Hispanics, or other non-Asians

10. What is your music preference?
   1. Only Asian music (for example, Chinese, Japanese, Korean, Vietnamese, etc.)
   2. Mostly Asian
   3. Equally Asian and English
   4. Mostly English
   5. English only

11. What is your movie preference?
   1. Asian-language movies only
   2. Asian-language movies mostly
   3. Equally Asian/English English-language movies
   4. Mostly English-language movies only
   5. English-language movies only

12. Where were you born? _____ please specify

12-1. In terms of being in the United States, circle the generation that best applies to you:
   1. 1st Generation = I was born in Asia or other
   2. 2nd Generation = I was born in U.S., either parent was born in Asia or other
   3. 3rd Generation = I was born in U.S., both parents were born in U.S, and all grandparents born in Asia or other
   4. 4th Generation = I was born in U.S., both parents were born in U.S, and at least one Grandparent born in Asia or other and one grandparent born in U.S.
   5. 5th Generation = I was born in U.S.; both parents were born in U.S., and all grandparents also born in U.S.
   6. Don't know what generation best fits since I lack some information.

13. Where were you raised?
    1. In Asia only
    2. Mostly in Asia, some in U.S.
    3. Equally in Asia and U.S.
    4. Mostly in U.S., some in Asia
    5. In U.S. only

14. What contact have you had with Asia?
    1. Raised one year or more in Asia
    2. Lived for less than one year in Asia
    3. Occasional visits to Asia
    4. Occasional communications (letters, phone calls, etc.) with people in Asia
    5. No exposure or communications with people in Asia

15. What is your food preference at home?
    1. Exclusively Asian food
    2. Mostly Asian food, some American
    3. About equally Asian and American
    4. Mostly American food
    5. Exclusively American food

16. What is your food preference in restaurants?
    1. Exclusively Asian food
    2. Mostly Asian food, some American
    3. About equally Asian and American
    4. Mostly American food
    5. Exclusively American food

17. What language do you read?
    1. Read only an Asian language
    2. Read an Asian language better than English
    3. Read both Asian and English equally well
    4. Read English better than an Asian language
    5. Read only English

18. What language do you write?
    1. Write only an Asian language
    2. Write an Asian language better than English
    3. Write both Asian and English equally well
    4. Write English better than an Asian language
    5. Write only English

19. If you consider yourself a member of the Asian group (Asian, Asian-American, Chinese-American, etc., whatever term you prefer), how much pride do you have in this group?
    1. Extremely proud
    2. Moderately proud
    3. Little pride
    4. No pride but do not feel negative toward group
    5. No pride but do feel negative toward group

20. How would you rate yourself?
    1. Very Asian
    2. Mostly Asian
    3. Bicultural
    4. Mostly Westernized
    5. Very Westernized

21. Do you participate in Asian occasions, holidays, traditions, etc.?
    1. Nearly all
    2. Most of them
    3. Some of them
    4. A few of them
    5. None at all

22. Rate yourself on how much you believe in Asian values (e.g., about marriage, families, education, work):
    1. Strongly believe
    2. Moderately believe
    3. Believe a little
    4. Mostly not believe
    5. Do not believe at all

23. Rate your self on how much you believe in American (Western) values:
    1. Do not believe at all
    2. Mostly not believe
    3. Believe a little
    4. Moderately believe
    5. Strongly believe

24. Rate yourself on how well you fit when with other Asians of the same ethnicity
    1. Fit very well
    2. Moderately fit
    3. Fit a little
    4. Moderately do not fit
    5. Do not fit

25. Rate yourself on how well you fit when with other Americans who are non-Asian
    1. Do not fit
    2. Moderately do not fit
    3. Fit a little
    4. Moderately fit
    5. Fit very well

26. There are many different ways in which people think of themselves.
    Which ONE of the following most closely describes how you view yourself?
    1. I consider myself basically an Asian person (e.g., Chinese, Japanese, Korean, Vietnamese, etc.). Even though I live and work in America, I still view myself basically as an Asian person.
    2. I consider myself as an Asian-American, although deep down I always know I am an Asian.
    3. I consider myself as an Asian-American. I have both Asian and American characteristics, and I view myself as a blend of both.
    4. I consider myself as an Asian-American, although deep down, I view myself as an American first.
    5. I consider myself basically as an American. Even though I have an Asian background and characteristics, I still view myself basically as an American.

Family Support Scale

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past week if a source of help has not been available to your family during this period of time, circle the NA (Not available) response.

How helpful has each of the following been to you in terms of take care of your child	Not Available	Not at All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's Parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's Relatives/kin	NA	1	2	3	4	5
5. Spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parents groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Church/Temple members	NA	1	2	3	4	5
14. My family or child's physician	NA	1	2	3	4	5
15. Early childhood intervention program	NA	1	2	3	4	5
16. School/day-care center	NA	1	2	3	4	5
17. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
18. Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
19. _____	NA	1	2	3	4	5
20. _____	NA	1	2	3	4	5

Structured Interview Form

ID _____

1. Is there anything else that was stressful for you during the time that your child has been in the intensive care unit?

2. Have there been any communication issues between the health care providers and yourself that affect your understanding about your child's condition and treatment plan?

3. During this period of time, how do you feel physically, in your body?

4. During this period of time, what do you feel emotionally?

5. What helps you most to cope with this period of time?

6. What kind of assistance would you like to have to help you cope during this period of time?

Diary and Fatigue Scale

EVENING IFORMATION – FIRST NIGHT DATE ___/___/___

(Please complete prior to sleep)

---

1. I napped from: _____ to _____ ; from _____ to _____ ; from _____ to _____

2. Today, I did: _____ no activity (stay in bed, sat in chair, etc.)
   _____ basic activity (light housekeeping, showered, etc.)
   _____ mild exercise (walking, vacuuming, etc.)
   _____ moderate exercise (heavy housework, gardening, etc.)
   from _____ to _____; from _____ to _____
   _____ strenuous exercise (jogging, swimming etc.)
   from _____ to _____; from _____ to _____

3. Today, I ate: _____ my usual diet
   _____ an unusual diet (please describe): _____

4. Today, I ate: _____ my typical amount
   _____ less than usual
   _____ more than usual

5. Today, I felt: _____ not at all healthy
   _____ somewhat healthy
   _____ fairly healthy
   _____ very healthy

6. Today, I felt: _____ very happy
   _____ fairly happy
   _____ somewhat happy
   _____ not at all happy

7. Did you encounter any particular stress today? _____ Yes _____No
   Please describe: _____
   _____
   _____

8. Did you experience any uncomfortable symptom today? _____ Yes _____No
   Please describe: _____
   _____

9. Did you drink caffeine or alcohol beverages between your wakeup time and bedtime?

Approximate time	Type of beverage	Amount (cups)

We are trying to find out about your level of energy before your sleep. For each of items listed below, circle the number (from 0 to 10) to indicate how you are felling right now.

1. not at all tired/ fatigued	0	1	2	3	4	5	6	7	8	9	10	extremely tired/fatigued
2. not at all sleepy	0	1	2	3	4	5	6	7	8	9	10	extremely sleepy
3. not at all exhausted	0	1	2	3	4	5	6	7	8	9	10	extremely exhausted
4. moving my body is no effort at all	0	1	2	3	4	5	6	7	8	9	10	moving my body is a tremendous chore
5. concentrating is no effort at all	0	1	2	3	4	5	6	7	8	9	10	concentrating is a tremendous chore
6. carrying on a conversation is no effort at all	0	1	2	3	4	5	6	7	8	9	10	carrying on a conversation is a tremendous chore
7. I have absolutely no desire to lie down	0	1	2	3	4	5	6	7	8	9	10	I have a tremendous desire to lie down
8. not at all energetic	0	1	2	3	4	5	6	7	8	9	10	extremely energetic
9. not at all efficient	0	1	2	3	4	5	6	7	8	9	10	extremely efficient

PLEASE PUSH THE BUTTON ON YOUR WRIST MONITOR

BEFORE YOU TURN OUT THE LIGHTS

Appendix B
Questionnaire

MORNING INFORMATION – FIRST DAY DATE ___/___/___
(Complete soon after getting out of the bed)

PLEASE PUSH THE BUTTON ON YOUR MONITOR

1. Did you take something to help you fall asleep? ____ YES ____ NO

   If yes, please describe: _____

2. Last night I went to bed at: _____.

3. Falling asleep took _____ minutes, which was:
   _____ no time at all
   _____ usual amount of time
   _____ not the usual amount of time
   _____ longer than usual
   _____ way too long

4. During the night, I woke up _____ time(s).

   What awakened you? _____

   Were any awakens longer than 5 minutes? _____ No _____ Yes

   If yes, please describe: _____

5. The number of awakenings was:
   _____ fewer than usual
   _____ typical for me
   _____ more than usual
   _____ way too many
   _____ don't remember

6. The time spent awake was:
   _____ no time at all
   _____ less than usual
   _____ about the usual
   _____ longer than usual
   _____ way too long

7. I awoke this morning at _____ and got up at _____

   I awoke: _____ much too early
   _____ earlier than usual
   _____ the usual time
   _____ later than usual
   _____ way too late

8. I feel: _____ very alert
   _____ alert
   _____ somewhat drowsy
   _____ very drowsy

9. I feel: _____ very rested
   _____ rested
   _____ somewhat rested
   _____ not at all rested

10. My sleep was: _____ very poor
    _____ poor
    _____ fair
    _____ good
    _____ very good

11. I dreamed: _____ not at all
    _____ very little
    _____ a normal amount
    _____ more than usual
    _____ don't remember

We are trying to find out about your level of energy after your night of sleep. For each of items listed below, circle the number (from 0 to 10) to indicate how you are felling right now.

1. not at all tired/ fatigued	0	1	2	3	4	5	6	7	8	9	10	extremely tired/fatigued
2. not at all sleepy	0	1	2	3	4	5	6	7	8	9	10	extremely sleepy
3. not at all exhausted	0	1	2	3	4	5	6	7	8	9	10	extremely exhausted
4. moving my body is no effort at all	0	1	2	3	4	5	6	7	8	9	10	moving my body is a tremendous chore
5. concentrating is no effort at all	0	1	2	3	4	5	6	7	8	9	10	concentrating is a tremendous chore
6. carrying on a conversation is no effort at all	0	1	2	3	4	5	6	7	8	9	10	carrying on a conversation is a tremendous chore
7. I have absolutely no desire to lie down	0	1	2	3	4	5	6	7	8	9	10	I have a tremendous desire to lie down
8. not at all energetic	0	1	2	3	4	5	6	7	8	9	10	extremely energetic
9. not at all efficient	0	1	2	3	4	5	6	7	8	9	10	extremely efficient

家庭基本資料

家庭編號:_____ 會談地點:_____

日期:_____ 孩子入院日期:_____

1. 你最初從那個國家來 ___ 中國, ___ 香港, ___台灣, ___ 美國, 或
   ___ 其它國家, 請註明_____
2. 你自從何時住在美國 _____.
   你平均住在美國的時間是 _____(一年中有幾個月)
3. 你的年紀: _____
4. 你是(小孩名字)的 ___ 父親或 ___ 母親
   他/她是你的 ___ 親生孩子, ___ 繼子/女, 或 ___ 養子/女
5. 你有其他的孩子嗎? ___ 沒有, ___ 有。如果有, 有幾個男孩和/或女孩
   _____, 他/她的年紀 _____
6. 你家庭的成員總共有幾位 _____
7. 你最高的教育程度是 ___ 小學, ___中學, ___ 高中, ___ 大學, 或 ___ 研究所
   總共在學時間是 _____
8. 你有在美國念書嗎? ___ 沒有, ___ 有
   如果有, 有多久 _____ 從何時開始 _____
9. 英文是你的第一個語言嗎? ___ 是, ___ 不是, 請註明 _____
10. 你的職業是 _____
11. 你目前的健康狀況是 ___ 很差, ___尚可, ___ 好, ___ 很好, ____ 非常好
12. 在你小孩住院前你有睡眠的問題嗎? ___沒有, ___ 有。如果有, 請描述 (包括處
    理方法)_____
13. 在你小孩住院後你有睡眠的問題嗎? ___沒有, ___ 有。如果有, 請描述(包括處理
    方法)_____
14. 你目前的經濟狀況是 ___ 非常貧困, ___ 貧困, ___ 收入支出平衡, ___ 小康,
    ___ 富裕

15. 你有因爲小孩住院而有經濟上的困難嗎? ___沒有, ___ 有

16. 那一項最適合描述你家庭扣稅前的收入?

___ 少於$ 20,000, ___ $ 20,001 至 $ 40,000, ___ $ 40,001 至 $ 60,000

___ $ 60,001 至 $ 80,000, ___ $ 80,001 至 $ 100,000, ___多於 $ 100,000

17. 你的婚姻狀況是 ___已婚, ___ 離婚, ___ 分居, ___同居,

___ 寡居, ___或未婚

18. 你目前的宗教信仰是 ___無, ___ 佛教, ___ 道教, ___ 基督教,

___ 天主教, 或 ____ 其它, 請註明 _____

19. 宗教信仰對你在孩子住院期間的幫助是

___ 全無幫助, ___ 有時有幫助, ___ 有幫助, ___ 很有幫助, ___ 非常有幫助

20. 你在過去有加護病房的經驗嗎? ___ 沒有, ___有

如果有, 是誰住在加護病房 _____ 和在何處 _____

21. 你認爲你的孩子在剛住進加護病房時的病重程度是如何?

___ 一點也不病重, ___ 輕度病重, ___ 中度病重, ___ 嚴重, ___ 非常嚴重

22. 你認爲你的孩子目前的病重程度是如何?

___ 一點也不病重, ___ 輕度病重, ___ 中度病重, ___ 嚴重, ___ 非常嚴重

23. 你對你孩子目前的疾病對未來的影響的擔心程度是如何?

___ 一點也不擔心, ___ 一點擔心, ___ 中度擔心, ___ 很擔心, ___ 極度擔心

24. 你孩子生病時你有尋求幫助嗎? ___ 沒有, ___有。如果有,請註明幫助來源

_____

25. 你對照顧你的病孩有特別的儀式方法嗎? ___ 沒有, ___有。如果有,請說明

_____

下列的人或團體通常對家庭成員撫育幼孩有所幫助。這份問卷請你指出每個幫助來源對你家庭有多少的幫助。

請圈選最適合形容該幫助來源在過去一個星期中對你家庭有多少幫助的反應。如果該幫助來源在過去一個星期中並不存在請圈選不存在。

下列各個對你照顧小孩有多少的幫助	不存在	全無幫助	有時有幫助	有幫助	很有幫助	非常有幫助
1. 我的父母	不存在	1	2	3	4	5
2. 我配偶或同居同伴的父母	不存在	1	2	3	4	5
3. 我的親戚/親人	不存在	1	2	3	4	5
4. 我配偶或同居同伴的親戚/親人	不存在	1	2	3	4	5
5. 配偶或同居同伴	不存在	1	2	3	4	5
6. 我的朋友	不存在	1	2	3	4	5
7. 我配偶或同居同伴的朋友	不存在	1	2	3	4	5
8. 我自己的孩子	不存在	1	2	3	4	5
9. 其他的父母親	不存在	1	2	3	4	5
10. 同事	不存在	1	2	3	4	5
11. 父母團體	不存在	1	2	3	4	5
12. 社會團體/組織	不存在	1	2	3	4	5
13. 教會/廟寺分子	不存在	1	2	3	4	5
14. 我的家庭或孩子的醫師	不存在	1	2	3	4	5
15. 幼兒早期介入課程	不存在	1	2	3	4	5
16. 學校/托兒所	不存在	1	2	3	4	5
17. 專業幫助人員(社工、治療師、老師等)	不存在	1	2	3	4	5
18. 專業機構(公共衛生、社會服務、心理健康等)	不存在	1	2	3	4	5
19. _____	不存在	1	2	3	4	5
20. _____	不存在	1	2	3	4	5

在上個星期你多常有：

	從來沒有							每天
1. 困難入睡	0	1	2	3	4	5	6	7
2. 在你睡眠週期的中途醒來	0	1	2	3	4	5	6	7
3. 在睡眠週期結束前太早醒來	0	1	2	3	4	5	6	7
4. 睡覺的週期結束醒來時感覺休息足夠	0	1	2	3	4	5	6	7
5. 睡的不好	0	1	2	3	4	5	6	7
6. 在白天時覺得想睡	0	1	2	3	4	5	6	7
7. 在白天需要掙扎來保持清醒	0	1	2	3	4	5	6	7
8. 在白天時覺得易怒	0	1	2	3	4	5	6	7
9. 在白天時覺得累或疲倦	0	1	2	3	4	5	6	7
10. 對你的睡眠品質感到滿意	0	1	2	3	4	5	6	7
11. 白天時感覺敏捷有活力	0	1	2	3	4	5	6	7
12. 睡太多	0	1	2	3	4	5	6	7
13. 睡太少	0	1	2	3	4	5	6	7
14. 在預定安排的時間稍睡片刻	0	1	2	3	4	5	6	7
15. 在非預定安排的時間睡著了	0	1	2	3	4	5	6	7
16. 喝含有酒精的飲料來幫助你入睡	0	1	2	3	4	5	6	7
17. 用煙草來幫助你入睡	0	1	2	3	4	5	6	7
18. 用草藥來幫助你入睡	0	1	2	3	4	5	6	7
19. 用安眠成藥來幫助你入睡	0	1	2	3	4	5	6	7
20. 用處方安眠藥來幫助你入睡	0	1	2	3	4	5	6	7
21. 用阿斯匹林或其它減輕疼痛的藥物來幫助你入睡	0	1	2	3	4	5	6	7

下列問題是爲瞭解居住在美國的亞洲人，在種族文化方面的自我認同及作法，請自各題選出最符合你的一項。

1. 你會說那些語言？
(1) 只會亞洲語言 (例如中國話、日語、韓語、越南話等)。
(2) 通常用亞洲語言，但也使用少許英語。
(3) 並用亞洲語言及英語 (兩種語言大致一樣好)。
(4) 通常用英語，但也使用少許亞洲語言。
(5) 只用英語。

2. 你喜歡使用什麼語言？
(1) 只喜歡使用亞洲語言 (例如中國話、日語、韓語、越南話等)。
(2) 比較喜歡使用亞洲語言，但也會用英語。
(3) 亞洲語言及英語都喜歡。
(4) 比較喜歡使用英語。
(5) 只喜歡用英語。

3. 你自認屬於那種族群？
(1) 中國人，台灣人、日本人、或韓國人等。
(2) 亞洲人。
(3) 亞裔美國人。
(4) 美籍華裔、美籍日裔、美籍韓裔等。
(5) 美國人。

4. 令尊 (你的父親) 自認他屬於那一種族群？
(1) 中國人，台灣人、日本人、或韓國人等。
(2) 亞洲人。
(3) 亞裔美國人。
(4) 美籍華裔、美籍日裔、美籍韓裔等。
(5) 美國人。

5. 令堂 (你的母親) 自認她屬於那一種族群？
(1) 中國人，台灣人、日本人、或韓國人等。
(2) 亞洲人。
(3) 亞裔美國人。
(4) 美籍華裔、美籍日裔、美籍韓裔等。
(5) 美國人。

6. 你六歲以前的玩伴、同輩們屬於什麼族群？
(1) 幾乎都是亞洲人、亞裔美國人。
(2) 大部份是亞洲人、亞裔美國人。
(3) 亞洲人、白人、非裔美國人、以及西班牙人等均等。
(4) 大部份是白人、非裔美國人、西班牙人或其它非亞洲人。
(5) 幾乎都是白人、非裔美國人、西班牙人或其它非亞洲人。

7. 六歲至十八歲之間，你的玩伴、同輩們屬於什麼族群？
(1) 幾乎都是亞洲人、亞裔美國人。
(2) 大部份是亞洲人、亞裔美國人。
(3) 亞洲人、白人、非裔美國人、以及西班牙人等均等。
(4) 大部份是白人、非裔美國人、西班牙人或其它非亞洲人。
(5) 幾乎都是白人、非裔美國人、西班牙人或其它非亞洲人。

8. 現在社區裏與你交往的人是屬於什麼族群？
(1) 幾乎都是亞洲人、亞裔美國人。
(2) 大部份是亞洲人、亞裔美國人。
(3) 亞洲人、白人、非裔美國人、以及西班牙人等均等。
(4) 大部份是白人、非裔美國人、西班牙人或其它非亞洲人。
(5) 幾乎都是白人、非裔美國人、西班牙人或其它非亞洲人。

9. 如果你在社區裏可選擇交往的對象，你會選什麼族群的人？
(1) 幾乎都是亞洲人、亞裔美國人。
(2) 大部份是亞洲人、亞裔美國人。
(3) 亞洲人、白人、非裔美國人、以及西班牙人等均等。
(4) 大部份是白人、非裔美國人、西班牙人或其它非亞洲人。
(5) 幾乎都是白人、非裔美國人、西班牙人或其它非亞洲人。

10.你喜歡那種音樂？
(1) 只喜歡亞洲的音樂 (例如中國、日本、韓國、越南等的音樂)。
(2) 大多只聽亞洲的音樂。
(3) 亞洲和西洋的音樂均喜歡。
(4) 大多只聽西洋的音樂。
(5) 只喜歡西洋的音樂。

11.你喜歡何種語言配音的電影？
(1) 只喜歡看亞洲語言的電影。
(2) 大多看亞洲語言的電影。
(3) 亞洲語和英語的電影均喜歡。
(4) 大多只看英語的電影。
(5) 只喜歡看英語的電影。

12.你在那裏出生？

_____ (請寫出那個國家)

12-1.那麼你是在美國的第幾代？
(1) 第一代 (我生於美國以外的地方)。
(2) 第二代 (我生於美國，父母之一是生於亞洲或其它美國以外的地方)。
(3) 第三代 (我生於美國，父母生於美國，祖父母都是生於亞洲或其它美國以外的地方)。
(4) 第四代 (我生於美國，父母生於美國，祖父母之一生於亞洲或其它美國以外的地方，令一個生於美國)。
(5) 第五代 (我生於美國，父母及祖父母均生於美國)。
(6) 不知自己屬於第幾代，因缺乏相關資料。

13.你在那裏長大？
(1) 完全在亞洲。
(2) 大多在亞洲，部份時間在美國。
(3) 在亞洲與美國的時間各半。
(4) 大多在美國，部份時間在亞洲。
(5) 完全在美國。

14.你與亞洲有何種接觸？
(1) 有一年以上的成長時間是在亞洲。
(2) 在亞洲居住不到一年。
(3) 偶爾去亞洲訪問。
(4) 偶爾與在亞洲的人以書信、電話等聯繫。
(5) 從未與在亞洲的人接觸或聯繫。

15.你在家用餐時，比較喜歡那種菜式？
(1) 只吃亞洲菜式。
(2) 大部份亞洲菜式，少部份爲美式。
(3) 亞洲菜式與美式各半。
(4) 大部份是美式。
(5) 只吃美式。

16. 你在外用餐時，比較喜歡那種菜式的餐館？
(1) 只吃亞洲菜式。
(2) 大部份亞洲菜式，少部份爲美式。
(3) 亞洲菜式與美式各半。
(4) 大部份是美式。
(5) 只吃美式。

17. 你的閱讀能力如何？
(1) 只能閱讀亞洲的文字。
(2) 閱讀亞洲文字的能力比英文強。
(3) 閱讀亞洲文字及英文的能力相當。
(4) 閱讀英文的能力比亞洲文字強。
(5) 只能閱讀英文。

18. 你的書寫能力如何？
(1) 只能書寫亞洲的文字。
(2) 書寫亞洲文字的能力比英文強。
(3) 書寫亞洲文字及英文的能力相當。
(4) 書寫英文的能力比亞洲文字強。
(5) 只能書寫英文。

19. 如果你自認是亞洲族群的一員 (無論以東方人、亞洲人、亞裔美國人或華裔美國人等自稱)，你的自豪程度有多少？
(1) 非常引以爲榮。
(2) 多少會引以爲榮。
(3) 僅有少許榮耀感。
(4) 不以爲榮，但對身爲此一族群也無反感。
(5) 不以爲榮，但對身爲此一族群有反感。

20. 你如何看待自己？
(1) 道地的亞洲人。
(2) 七、八成的亞洲人。
(3) 兩種文化背景的人。
(4) 七、八成西化的人。
(5) 非常西化的人。

21.你是否會參與亞洲人的傳統節慶及假日等活動？
(1) 幾乎參與所有活動。
(2) 參與大部份的活動。
(3) 參與某些活動。
(4) 參與少數的活動。
(5) 從不參與活動。

22. 你對亞洲人傳統的習俗觀念 (例如婚姻、家庭、教育、工作) 有何看法？
(1) 十分重視。
(2) 中等重視。
(3) 少許重視。
(4) 大致不重視。
(5) 完全不重視。

23. 你對美國人 (西方) 傳統的習俗觀念 (例如婚姻、家庭、教育、工作) 有何看法？
(1) 完全不重視。
(2) 大致不重視。
(3) 少許重視。
(4) 中等重視。
(5) 十分重視。

24. 你和同一族群的亞洲人一起時有何感覺？
(1) 十分自在。
(2) 大致自在。
(3) 少許自在。
(4) 相當不自在。
(5) 完全不自在。

25. 你和不屬於亞洲人的一般美國人一起時有何感覺？
(1) 完全不自在 。
(2) 相當不自在。
(3) 少許自在。
(4) 大致自在。
(5) 十分自在。

26. 人們對自己有種種不同的看法，你認爲那一項最接近你的？
(1) 我認爲基本上我是亞洲人 (中國人，台灣人、日本人、韓國人或越南人等)，雖然我在美國生活和工作，基本上我還是認爲自己是亞洲人。
(2) 我認爲我是亞裔 美國人，雖然我內心裡總是知道自己是亞洲人。
(3) 我認爲我是亞裔 美國人，我具有亞洲人和美國人的特質，我是個具有兩方面特質的人。
(4) 我認爲我是亞裔 美國人，雖然內心裡我首先把自己看成是美國人。
(6) 我認爲基本上我是美國人，雖然我有亞洲人的背景，但是我還是認爲自己是美國人。

我們想知道因爲你孩子的生病和住院帶給你多少的壓力經驗。我們指的壓力是那些導致你感到焦慮、懊惱、或緊張的經驗。

下列是一些描述當你小孩在醫院時你會有的經驗。閱讀每一項然後圈選代表你壓力經驗的號碼。請圈選 "0" 如果該項不適用於你的情況。

身爲住院小孩的父母，下列經驗帶給你多少的壓力？

	沒有壓力	一點壓力	中度壓力	很有壓力	極度壓力	不適用
1. 與你的孩子分開	1	2	3	4	5	0
2. 無法規律的照顧你的孩子 (例如：餵食、換尿布、抱)	1	2	3	4	5	0
3. 沒有機會與你的孩子單獨在一起	1	2	3	4	5	0
4. 無法與你的家人和朋友分享你的孩子	1	2	3	4	5	0
5. 無法保護你的孩子免除疼痛和痛苦的程序	1	2	3	4	5	0
6. 無法安慰或幫助你的孩子	1	2	3	4	5	0
7. 護士和其他的工作人員似乎比你還親近你的孩子	1	2	3	4	5	0
8. 無法抱你的孩子	1	2	3	4	5	0

我們也有興趣於你孩子的樣子給你帶來的壓力有多少？壓力的程度是:

	沒有壓力	一點壓力	中度壓力	很有壓力	極度壓力	不適用
9. 看見你孩子身上的管子或靜脈點滴管	1	2	3	4	5	0
10. 看見你的孩子有疼痛	1	2	3	4	5	0
11. 你的孩子看起來害怕、懊惱或哭的很多	1	2	3	4	5	0
12. 看見你孩子悲傷的樣子	1	2	3	4	5	0

	沒有壓力	一點壓力	中度壓力	很有壓力	極度壓力	不適用
13. 看見針頭或管子插進你孩子的身上	1	2	3	4	5	0
14. 看見你的孩子有呼吸問題	1	2	3	4	5	0
15. 看見你的孩子被機器環繞和接受醫療	1	2	3	4	5	0
16. 當你的孩子無法對你有所反應	1	2	3	4	5	0

當你探視你在醫院中的孩子時，下列你可能會看到或聽到的事項對你所造成的壓力程度有多少？

	沒有壓力	一點壓力	中等壓力	很有壓力	極度壓力	不適用
17. 房間裏的監測器和設備	1	2	3	4	5	0
18. 監測器突然的警報響聲	1	2	3	4	5	0
19. 房間裏的其他病童	1	2	3	4	5	0
20. 大量的護士、醫生、和其他照顧你孩子的工作人員	1	2	3	4	5	0
21. 當醫院中其他孩子有危機	1	2	3	4	5	0
22. 醫院中其他父母親的需求	1	2	3	4	5	0

我們對於醫療照護人員的行爲以及你與他們的溝通所帶給你的經驗也有興趣。

使用同樣的量表，指出醫療照護人員的行爲帶給你的壓力有多少：

1. 沒有壓力
2. 一點壓力
3. 中度壓力
4. 很有壓力
5. 極度壓力

使用同樣的量表，指出與醫療照護人員的溝通帶給你的壓力有多少：

1. 沒有壓力
2. 一點壓力
3. 中度壓力
4. 很有壓力
5. 極度壓力

你小孩在加護病房的經驗給你帶來的整體壓力有多少：

1. 沒有壓力
2. 一點壓力
3. 中度壓力
4. 很有壓力
5. 極度壓力

請列出任何其它帶來緊張壓力的生活經驗並與你孩子住院帶來的緊張壓力經驗做比較。

例 1:_____

1. 比你孩子住院的經驗較沒有壓力
2. 與你孩子住院的經驗同等的壓力
3. 比你孩子住院的經驗更有壓力

例 2:_____

1. 比你孩子住院的經驗較沒有壓力
2. 與你孩子住院的經驗同等的壓力
3. 比你孩子住院的經驗更有壓力

晚間的資料 — 第一晚　日期 ___/___/___
〈請在睡前完成〉

---

1. 我小睡從: _____到_____; 從 _____到_____; 從 _____到_____

2. 今天, 我做: ____ 完全沒有活動 (留在床上, 坐在椅子等)
____ 基本的活動 (輕度的家事, 沖澡等)
____ 輕度的活動 (走路, 吸塵等)
____ 中度的活動 (繁重的家事, 園藝工作等)
從_____到 _____;從_____到 _____
____ 費力的活動 (跑步, 游泳等)
從_____到 _____;從_____到 _____

3. 我吃: _____ 我平常的飲食
_____ 不是平常的飲食 (請描素): _____

4. 我吃: _____ 平常的食量
_____ 少於平常的食量
_____ 多於平常的食量

5. 今天, 我覺得: _____ 一點都不健康
_____ 有幾分健康
_____ 健康
_____ 很健康

6. 今天, 我覺得: _____ 很快樂
_____ 快樂
_____ 有點快樂
_____ 一點都不快樂

7. 你今天有遭遇任何特別的緊張壓力? _____ 有 _____ 沒有

請描述: _____

_____

_____

8. 你今天有經驗任何不舒服的徵候? _____ 有 _____ 沒有

請描述:_____

_____

9. 你在醒來和睡覺之前有喝含咖啡因或酒精的飲料?

大概的時間	飲料的種類	量(杯)

我們想知道你睡覺前的活力狀況。在下列各項，圈選號碼 (從 0 到 10) 來代表你現在的感覺。

1. 一點都不累/疲倦	0	1	2	3	4	5	6	7	8	9	10	極度累/疲倦
2. 一點都不想睡	0	1	2	3	4	5	6	7	8	9	10	極度想睡
3. 一點都沒精疲力盡	0	1	2	3	4	5	6	7	8	9	10	極度精疲力盡
4. 動我的身體一點都不費力	0	1	2	3	4	5	6	7	8	9	10	動我的身體需非常費力
5. 集中注意力一點都不費力	0	1	2	3	4	5	6	7	8	9	10	集中注意力需非常費力
6. 與人交談一點都不費力	0	1	2	3	4	5	6	7	8	9	10	與人交談需非常費力
7. 我完全不想不想躺下來	0	1	2	3	4	5	6	7	8	9	10	我非常想躺下來
8. 一點都沒活力	0	1	2	3	4	5	6	7	8	9	10	極度有活力
9. 一點都沒效率	0	1	2	3	4	5	6	7	8	9	10	極度有效率

在你關燈之前請按下你手腕監測器的按鈕

早上的資料 — 第一天　　日期 ___/___/___
(請在起床後立刻完成)

請按下你的監測器的按鈕

1. 你有吃什麼東西來幫助你入睡? _____有 _____ 沒有

如果有，請描述：_____

2. 昨晚我上床的時間: _____

3. 入睡花費我 _____ 分鐘，那是：
_____ 不費任何時間　　_____ 比平常多點時間
_____ 和平常一樣時間　　_____ 太長的時間
_____ 不是平常的時間

4. 在晚間，我醒來 _____ 次
什麼使你醒來？_____
醒來有沒有超過五分鐘？_____ 沒有 _____ 有

如果有，請描述：_____

5. 醒來的次數：
_____ 少於平常次數
_____ 和平常一樣
_____ 比平常多點時間
_____ 次數太多
_____ 不記得

6. 醒來的時間：
_____ 極短
_____ 少於平常的時間
_____ 和平常一樣
_____ 比平常時間長
_____ 太長的時間

7. 我今天早上醒來的時間是 _____ 起床的時間是 _____
我醒得: _____ 太早　　_____比平常晚
_____ 比平常早　　_____ 太晚
_____ 和平常一樣時間

8. 我覺得: _____ 非常清醒
_____ 清醒
_____ 有點昏昏欲睡
_____ 非常昏昏欲睡

9. 我覺得: _____ 休息得非常好
_____ 休息得很好
_____ 有休息
_____ 一點也沒休息

10. 我睡得: _____ 非常不好
_____ 不好
_____ 還可以
_____ 好
_____ 非常好

11. 我做夢: _____ 一點也沒有
_____ 非常少
_____ 和平常一樣多
_____ 比平常多
_____ 不記得

我們想知道你晚上睡覺之後的活力狀況。在下列各項，圈選號碼 (從 0 到 10) 來代表你現在的感覺。

1. 一點都												極度
不累/疲倦	0	1	2	3	4	5	6	7	8	9	10	累/疲倦
2. 一點都												極度
不想睡	0	1	2	3	4	5	6	7	8	9	10	想睡
3. 一點都沒												極度
精疲力盡	0	1	2	3	4	5	6	7	8	9	10	精疲力盡
4. 動我的身體												動我的身體
一點都	0	1	2	3	4	5	6	7	8	9	10	需非常
不費力												費力
5. 集中注意力												集中注意力
一點都	0	1	2	3	4	5	6	7	8	9	10	需非常
不費力												費力
6. 與人交談												與人交談
一點都	0	1	2	3	4	5	6	7	8	9	10	需非常
不費力												費力
7. 我完全不想												我非常想
不想躺下來	0	1	2	3	4	5	6	7	8	9	10	躺下來
8. 一點都												極度
沒活力	0	1	2	3	4	5	6	7	8	9	10	有活力
9. 一點都												極度
沒效率	0	1	2	3	4	5	6	7	8	9	10	有效率

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT
Chinese/Chinese-American parents Experiences with a Hospitalized child

A. PURPOSE AND BACKGROUND

Ms. Shih-Yu Lee, a doctoral student in the Department of Family Health Care Nursing at University of California and Kathryn Lee, RN, PhD, in the Department of Family Health Care Nursing at University of California, San Francisco are conducting a research study to help us understand more about parent's experiences of having a child in an intensive care unit. The results of this study will help health care providers to offer culturally relevant care for parents when their child is seriously ill.

You are being asked to participate in this study because you are of Chinese background, and you have a child hospitalized in the intensive care unit.

B. PROCEDURES

If you agree to be in this study, the following will happen:

1. Researcher will review your child's medical record to collect information.

2. You will be interviewed one time. The interview will last about 60-90 minutes. You will be asked about the experiences with your critically ill child in the intensive care unit, your cultural background and your sleep pattern in the past week. The interview will be held at a location and time that is convenient for you. The interview can be done in two sessions if you feel it is too much burden for you.

3. You will be asked to keep a sleep log and to wear a watch-like motion sensor to monitor your sleep and activities continuously for 2 days. Any uncompleted portion of the interview can be completed when you return the monitor and the sleep log.

C. RISKS/DISCOMFORTS

This time period in your life may be very difficult, and you may feel uncomfortable or upset during the interview. If this happens, you may refuse to answer a particular question, or you may stop the interview completely. You may choose to withdraw from the study at any time.

There is a slight risk or rash from wearing the watch-like motion sensor on your wrist. If you have a metal allergy or develop an allergy during the study, you should remove the watch-like motion sensor immediately and call the investigator.

Participation in research will involve a loss of privacy, but information about you will be handled as anonymously as possible. Neither your or your child's name will be used in any published reports from this study.

D. BENEFITS
There will be no direct benefit as a result of your participation, but you will provide information to help health care providers better understand the experiences of Chinese parents with a critically ill child. This knowledge will help them to provide more culturally sensitive and appropriate care in the future.

E. ALTERNATIVES
There are no alternatives to participation in this study.

F. COSTS
There will be no costs for you to participate in this study.

G. PAYMENT
You will not be paid for taking part in this study. You will receive a small gift for you child as a token of appreciation for your participation.

H. QUESTIONS
Ms. Shih-Yu Lee has explained this study to you, and your questions have been answered. If you have any other questions about the study, you may call Ms. Lee at (415) 476-4435 or her advisor Dr. Lee at (415) 476-4442.

If you have any comments or concerns about participation in this study, you should first talk with the researchers. If for some reason you do not wish to do this, you may contact the Committee on Human Research, which is concerned with the protection of volunteers in research projects. You may reach the committee office between 8:00 and 5:00, Monday through Friday, by calling (415) 476-1814, or by writing: Committee on Human Research, Box 0962, University of California, San Francisco/San Francisco, CA 94143.

I. CONSENT

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to participate or to withdraw at any point in this study without jeopardy to your child's medical care.
If you agree to participate, you should sign below.

Name of Child: _____

_____
Date Parent's Signature

_____
Date Person Obtaining Consent

CALIFORNIA PACIFIC MEDICAL CENTER AND UNIVERSITY OF CALIFORNIA, San Francisco CONSENT TO ACT AS A RESEARCH PARTICIPANT

You are being asked to take part in a research study being conducted by David A. Lee MD (Neonatologist at CPMC), Kathryn Lee RN, PhD (Professor in School of Nursing at UCSF), and Shih-Yu Lee RNC, MS (Doctoral student in School of Nursing at UCSF).

Because you are of Chinese background and you have a child hospitalized in the intensive care unit, you are being asked to participate in this study.

A. WHAT IS THE PURPOSE OF THIS STUDY?
The purpose of doing this study is to understand parent's experiences of having a child in an intensive care unit. The results of this study will help health care providers to offer culturally relevant care for parents when their child is ill.

B. WHAT HAPPENS TO YOU AND OTHER STUDY PARTICIPANTS?
The following procedures will be performed:

1) Researcher will review your child's medical record to collect information.
2) You will be interviewed one time. The interview will last about 45-60 minutes. You will be asked about the experiences with your child in the intensive care unit, your cultural background and your sleep pattern in the past week. The interview will be held at a location and time that is convenient for you. The interview can be done in two sessions if you feel it is too much burden for you.
3) You will be asked to keep a sleep log and to wear a watch-like motion sensor on your wrist to monitor your sleep and activities continuously for 2 days. Any uncompleted portion of the interview can be completed when you return the monitor and the sleep log.
4) About 100 participants from CPMC and UCSF affiliated hospitals will take part in this study.

C. WHAT ARE THE RISKS OF THIS STUDY?
You may feel uncomfortable or upset during the interview. If this happens, you may refuse to answer a particular question, or you may stop the interview completely. You may find it is inconvenient to wear the wrist monitor. If you develop rash during the study, you should remove the watch-like motion sensor immediately and call the investigator.

D. WHAT ARE THE POTENTIAL BENEFITS TO YOU AND OTHERS?
There will be no direct benefit to you from participating in this study, but you will provide information to help health care providers better understand the experiences of Chinese parents with a critically ill child. This knowledge will help them to provide more culturally sensitive and appropriate care in the future.

E. ARE ALTERNATIVES AVAILABLE?
Non-participation in this study is an alternative.

F. WHAT HAPPEN IF YOU ARE INJURED OR HARMED IN SOME WAY BY THE STUDY?
You have been advised that California Pacific Medical center and the Investigators have no special program to provide compensation if injury occurs during research. If you are injured as a result of participation in this study, treatment will be made available. Under certain circumstances, University of California will pay for the cost of medical care for any injury you might suffer as a result of this research. In the event of a research-related injury, you should contact Dr. David Lee's research partner, Ms. Shih-Yu Lee, at (415) 476-4435. This is a 24-hour number.

G. HOW CONFIDENTIAL ARE YOUR RECORDS?
Your information and your child's records of treatment will be kept confidential according to standard medical practice. Any information that is obtained in connection with this study that can identify you will remain confidential and will be disclosed only with your permission or as required by law.

Neither your or your child's name will be used in any published reports from this study. Study information will be coded, and kept in locked file at all times. Only study personnel and California Pacific Medical Center Institutional Review Board (Committee established for the protection of rights of research participants) will have access to the files.

An authorization describing how health information about you/your child may be used and to whom it will be disclosed by the principal investigator and the research team will be provided to you. Federal and state law requires that patients must give authorization for use of their protected health information in order to participate in this research study. Please refer to the attached "Patient Authorization for the Use and Disclosure of Protected Health Information for Research" form.

H. STATEMENT OF VOLUNTARY PARTICIPATION
Your participation in this study is voluntary. Without any prejudice to your child's future medical care, you free to take part in, or withdraw from the study at any time.

I. SUBJECT PAYMENT
You will not be paid for taking part in this study. You will receive a small gift, lullaby CD, or blanket, for your child as a token of appreciation for your participation.

J. COST TO THE SUBJECT
There will be no costs for you to participate in this study.

K. NEW FINDING
You will be told of any significant findings developed during the course of this study, and you can ask for study results at its conclusion.

L. EXPERIMENTAL SUBJECT'S BILL OF RIGHTS
A copy of the Experimental Subject's Bill of Rights and a copy of this consent form will be given to you for your own use.

M. INVESTIGATOR'S NAME AND NUMBER
Dr. David Lee's research partner, Ms. Shih-Yu Lee, discussed this information with you. She will answer any further questions you may have concerning this study or the procedures.
You can reach Dr. David Lee, Dr. Kathryn Lee, and Ms. Shih-Yu Lee at (415) 476-4435.

N. IRB HOURS AND NUMBER
Should you have any questions about your rights as a research participant, you may call the Institutional Review Board which is concerned with protection of volunteers in research projects, between 9 a.m. and 4 p.m. Monday through Friday, by calling (415) 600-3688 or by writing: California Pacific Medical Center Research Institute (CPMCRI) Institutional Review Board Office, P.O. BOX 7999, SF CA 94120

SUBJECT'S STATEMENT: My signature below means that I have read the above information about the study and have had a chance to ask questions. I have been given a copy of this consent form; the Subject's Experimental Bill of Rights; and a copy of the Authorization for the Use and Disclosure of Protected Health Information for Research form. I have been told that by signing this consent form I am not giving up any of my legal rights.

Printed Name of Participant	Name of Child
Participant's Signature	Date
Signature of Person Obtaining Consent/Printed Name	Date

加州大學，舊金山分校
研究參與同意

1. 研究目的與背景

加州大學，舊金山分校家庭健康護理系博士班學生李時雨女士與該系李凱瑟琳教授要進行一項研究以幫助瞭解小孩在加護病房時父母親的感受經驗。此研究結果會幫助醫療照護人員對重病孩童的父母提供合於文化背景的照護。

你被邀請參與這項研究是因爲你有中國人的背景，以及你的孩子在加護病房中。

2. 研究過程

如果你同意參與這項研究，以下的事會發生：

〈1〉研究人員會查閱你孩子的病歷以收集資料。

〈2〉你會被訪問一次。訪問時間大概會是六十至九十分鐘。你會被問及有關你對小孩在加護病房的感受經驗、你的文化背景、以及你在上個星期的睡眠的情形。如果你覺的這個訪問給你的負擔太重，可以將此會談分成兩次。

〈3〉你會保留一份睡眠日誌和戴一個類似手錶的動作感覺器以便連續監測你兩天的睡眠與活動。任何未完成的會談可以在你歸還睡眠日誌和動作感覺器時完成。

3. 參與研究可能會有的危險/不適

你的生活在這段期間可能很困難，在會談中你可能會感覺不安或懊惱。如果這些現象發生，你可以拒絕回答某一特別的問題或者你可完全終止會談。

在手腕戴類似手錶的動作感覺器可能會有輕微的危險。如果你對金屬過敏或在研究期間產生過敏反應，你應立刻拿下該類似手錶的動作感覺器同時與研究人員聯絡。

參與研究可能會喪失隱私，但有關你的所有資料會盡可能以不記名來保密。你與你孩子的名字都不會出現在有關這個研究所發表的報告。

4. 參與研究的利益

你的參與研究不會帶給你直接的利益，但是你提供的資料將會幫助醫療照護人員瞭解中國父母與重病孩子的經驗。這些知識會幫助他們將來提供更合宜文化背景的照護。

5. 變更取代參與研究

沒有其它的變更取代參與這個研究的方法。

6. 費用

你不需付費用來參與這項研究。

7. 報償

參與這項研究你不會得到報償。你會收到一個給你孩子的小禮物以象徵我們對你參與研究的感激。

8. 疑問

李時雨女士已對你解說這項研究並回答你的問題。如果你仍有有關這項研究的疑問，你可打電話給李女士(415) 307-8824或他的指導教授李博士(415) 476-4442。

如果你對參與這項研究有任何的意見或顧慮，你可先與研究人員洽談。如果因爲一些因素導致你不願意如此做，你可以接洽人類研究委員會，該會是關心和保護自願參與研究的人員。你可在星期一至星期五的八點到五點之間接洽該委員會辦公室，你可打電話(415) 476-1814或寫信至
Committee on Human Research
Box 0961, University of California, San Francisco
San Francisco, CA 94143

9. 同意

參與此項研究是志願性質。你有權利在任何時候拒絕或退出這個研究而不會危及你孩子的醫療照護。
如果你同意參與，請在下面簽名。

孩子的姓名: _____

_____ _____
日期 父；母簽名

_____ _____
日期 獲取同意書者簽名

加州太平洋醫療中心及加州大學，舊金山分校
研究參與同意

加州太平洋醫療中心新生兒專科醫師李大衛以及加州大學，舊金山分校護理系博士班學生李時雨女士與該系李凱瑟琳教授要進行一項研究。你被邀請參與這項研究是因爲你有中國人的背景，以及你的孩子住在加護病房中。

1. 此項研究的目的是什麼？

此項研究的目的是要瞭解小孩在加護病房時父母親的感受經驗。此研究結果會幫助醫療照護人員對重病孩童的父母提供合於文化背景的照護。

2. 參與研究會經歷什麼？

如果你同意參與這項研究，以下的事會發生：

〈1〉研究人員會查閱你孩子的病歷以收集資料。

〈2〉你會被訪問一次。訪問時間大概會是四十五至六十分鐘。你會被問及有關你對小孩在加護病房的感受經驗、你的文化背景、以及你在上個星期的睡眠的情形。如果你覺得這個訪問給你的負擔太重，可以將此會談分成兩次。

〈3〉你會保留一份睡眠日誌和戴一個類似手錶的動作感覺器以便連續監測你兩天的睡眠與活動。任何未完成的會談可以在你歸還睡眠日誌和動作感覺器時完成。

〈4〉總共大約有100個人(來自加州太平洋醫療中心及加州大學舊金山分校附屬醫院)會參與這項研究。

3. 參與研究可能會有什麼危險?

在會談中你可能會感覺不安或懊惱。如果這些現象發生，你可以拒絕回答某一特別的問題或者你可完全終止會談。

你可能會感覺有些不方便當你戴類似手錶的動作感覺器。你在戴類似手錶的動作感覺器時如果有紅疹過敏反應，你應立刻脫下它同時與研究人員聯絡。

4. 參與研究有什麼利益?

你參與此研究不會帶給你直接的利益，但是你提供的資料將會幫助醫療照護人員瞭解中國父母與重病孩子的經驗。這些知識會幫助他們將來提供更合宜文化背景的照護。

5. 是否有其它取代參與研究的方法?

不參與這個研究是變更取代的方法。

6. 如果因參與研究而受傷要如何處理?

加州太平洋醫療中心以及研究人員沒有特別的賠償方法來處理你因參與研究的受傷。如果你因參與研究而受傷，你會得到治療。在某些情況下，你的受傷是因參與研究而造成，加州大學會支付你的醫療費用。在因參與研究而造成受傷，你需打電話給李大衛醫師的研究同事李時雨女士(415)476-4435，這是個24小時的熱線電話。

7. 你提供的資料有多少的隱秘度?

你的所有資料以及你孩子的治療記錄會被保密。有關你的資料會被保密，除非經過你的允許或法律的需要才會公開。

你與你孩子的名字都不會出現在有關這個研究所發表的報告。資料會使用代號上鎖保存。只有研究人員和加州太平洋醫療中心的審核委員會(保護參與研究人員的委員會)可以使用這些資料。

一份描述如何使用你/你孩子健康資料的授權書會提供給你。聯邦和州法要求病人必需授權使用你/你孩子的健康資料以便參與研究。請看〝病人給研究單位使用被保護的健康資料授權書〞

8. 參與此項研究是志願性質
參與此項研究是志願性質。你有權利在任何時候拒絕或退出這個研究而不會危及你孩子的醫療照護。

9. 報償
參與這項研究你不會得到報償。你會收到一個給你孩子的小禮物，一個安眠音樂帶或一條毯子，以象徵我們對你參與研究的感激。

10. 費用
你不需付費用來參與這項研究

11. 新發現
在研究期間你會被告知新的發現，你可以在研究結束時要求知道研究的結果。

12. 參與研究者的權利
參與研究者的權利書及這份同意書會留給你個人使用。

13. 研究人員的名字及電話
李大衛醫師的研究同事李時雨女士已對你解說這項研究並回答你的問題。如果你仍有有關這項研究的疑問李女士會進一步回答你的問題。
你可打電話給李大衛醫師, 李凱瑟琳教授,以及李時雨女士(415) 476-4435。

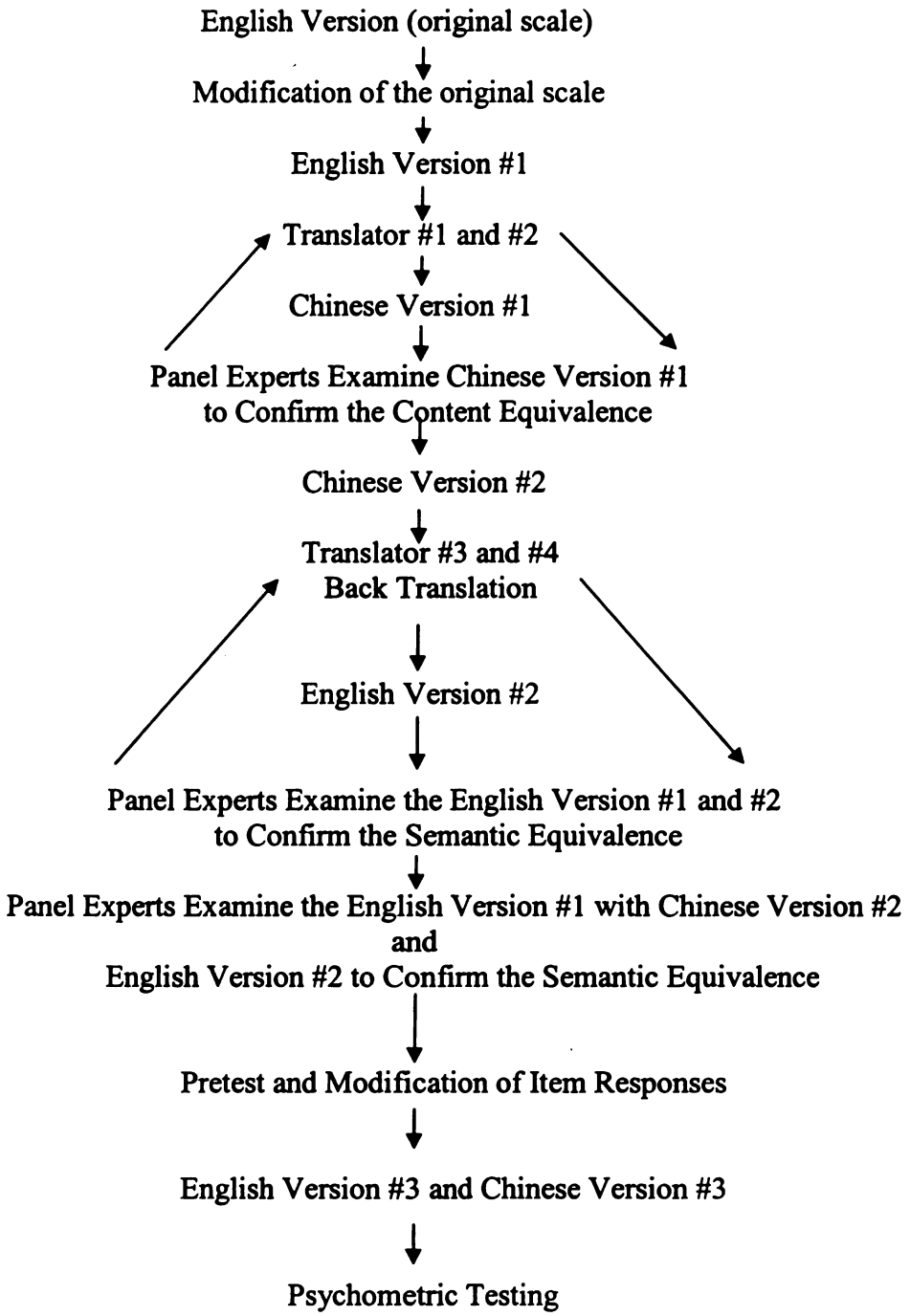
14. 審核委員會的辦公時間及電話
如果你對參與研究者的權利有任何疑問。你可以與審核委員會聯絡，該會是關心和保護自願參與研究的人員。你可在星期一至星期五的上午九點到下午四點之間接洽該委員會辦公室，你可打電話(415) 600-3688或 寫信至California Pacific Medical Center Research Institute (CPMCRI) Institutional Review Board Office, P.O.BOX 7999, SF CA 94120
參與者的聲明：我的簽名代表我已閱讀以上有關此研究的資料和有機會提出問題。我有拿到一份同意書、病人權利書、以及病人給研究單位使用被保護的健康資料授權書。我知道簽此同意書我沒有放棄我的法律權利。
如果你同意參與，請在下面簽名。

_____ _____
參與者姓名 小孩姓名

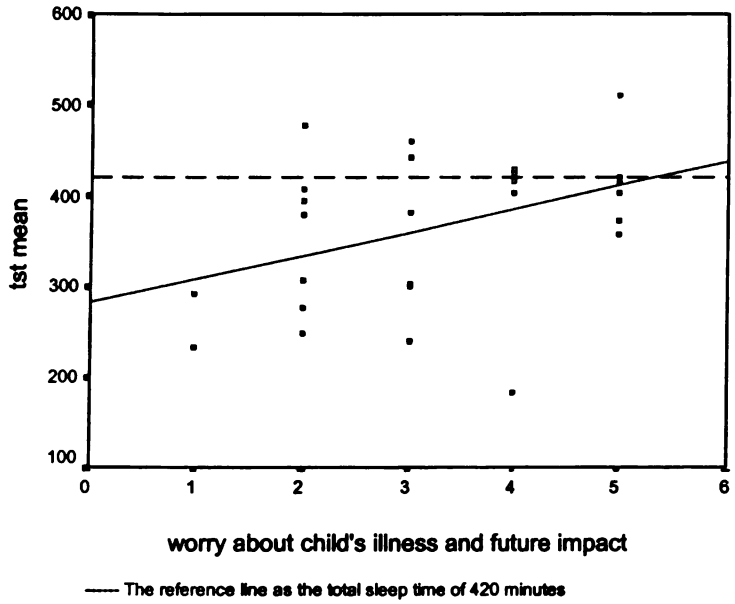
_____ _____
參與者簽名 日期

_____ _____
獲取同意書者簽名/ 姓名 日期

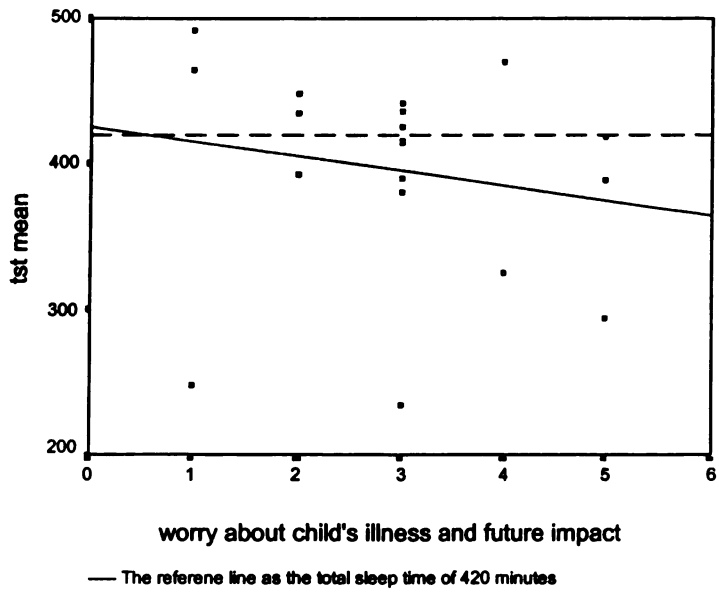
Translation Procedure

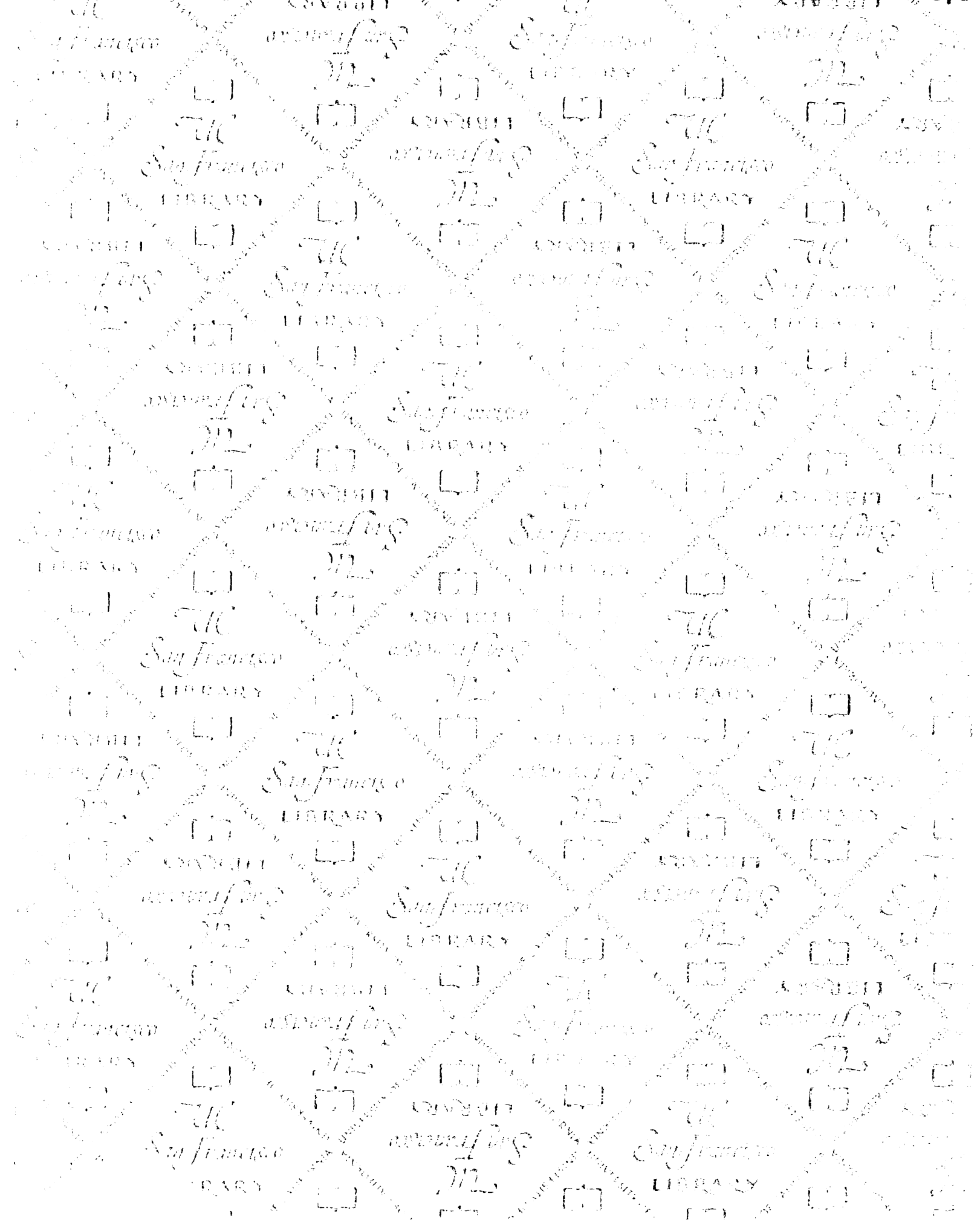


Mothers' Total Sleep Time and Worry about Child's Illness and Future Impact



Fathers' Total Sleep Time and Worry about Child's Illness and Future Impact

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