PREDICTING FACTORS OF CAREGIVER BURDEN FOR CHILDREN WITH CEREBRAL PALSY

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR
THE DEGREE OF MASTER OF NURSING SCIENCE
(PEDIATRIC NURSING)
FACULTY OF GRADUATE STUDIES
MAHIDOL UNIVERSITY
2007

Thesis
Entitled

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ACKNOWLEDGEMENTS

I would like to express my sincere gratitude and deep appreciation to Associate Professor Rashanee Seeda, my major-advisor, for her kindness, support, excellent guidance, valuable advice, supervision and encouragement throughout the completion of this study. I am equally grateful to Associate Professor Dr. Kaimook Wichiencharoen and Associate Professor Srinual Chavasiri, my co-advisors, for their helpful support, guidance and encouragement throughout the study. I would like to thank Assistant Professor Dr. Jariya Witayasooporn, Lecturer Dr.

Wanlaya Thampanichawat, and Miss Ubonwon Wathanadilokul, M.D. for their conductive comments and valuable recommendations for this study.

Great appreciation is further expressed to all the staff of Siriraj Hospital, Sirindhorn National Medical Rehabilitation Center and the Foundation for Children with Disabilities for their cooperation throughout this study.

I am also deeply indebted to the caregivers and their children who so willingly participated in the study.

Special gratitude goes to all of the experts involved in assuring the validity of the study instruments and providing valuable suggestions. Moreover, I would like to thank the Pediatric Nurses Society of Thailand for financial support.

Finally, I would like to express my gratitude to my parents and relatives for their love, care and financial support. I would also like to thank Mr. Siratsapon Barakun, for his helpful support and valuable advice about how to overcome the computer using, and my classmates in Pediatric Nursing, Faculty of Nursing as well as my close friends for their great support throughout my graduate study.

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ABSTRACT

The purposes of this descriptive research were to examine caregiver burden and to investigate the predictive power of caregiver's age, family income, caregiver's health status, caregiving involvement, coping, and severity of disability on caregiver burden. The study sample consisted of 100 primary caregivers of children with cerebral palsy aged 6 month to 6 years. Data were collected by questionnaires. Descriptive statistics and multiple regression were used for data analysis.

The results revealed that the mean score of caregiver burden was low (Mean = 43.51, SD = 13.37). When considering each subscale, the mean score of the emotional burden was moderate (Mean = 2.54, SD = 0.80), while the mean scores of financial burden, physical burden and social burden were low (Mean = 2.20, SD = 0.91; Mean = 2.06, SD = 0.86; Mean = 1.89, SD = 0.85 respectively). Caregiving involvement, caregiver's health status, and coping could jointly explain 23.7 percent of the variance in caregiver burden with statistical significance (Overall $F_{(3, 96)} = 9.94$, $p<.001$). The caregiving involvement was the best predictor of caregiver burden.

These findings suggest that nurses should provide intervention to increase the caregiver's skill in providing care and coping, enhance support networks, and encourage and promote the health and well being of caregivers, so that caregivers can effectively and efficiently care for their children with cerebral palsy.

KEY WORDS: CAREGIVER BURDEN / CHILDREN WITH CEREBRAL PALSY

126 P.

ปัจจัยทำนายภาระของผู้ดูแลเด็กสมองพิการ (PREDICTING FACTORS OF CAREGIVER BURDEN FOR CHILDREN WITH CEREBRAL PALSY)

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บทคัดย่อ

การศึกษาครั้งนี้เป็นการวิจัยแบบบรรยาย เพื่อศึกษาภาระของผู้ดูแล และศึกษาอำนาจการทำนายของ อายุของผู้ดูแล ภาวะสุขภาพของผู้ดูแล รายได้ของครอบครัว การมีส่วนร่วมในการดูแล การเผชิญความเครียดในการดูแล และระดับความรุนแรงของความพิการ ต่อภาระของผู้ดูแลเด็กสมองพิการ กลุ่มตัวอย่างเป็นผู้ดูแลหลักของเด็กสมองพิการ อายุ 6 เดือน ถึง 6 ปี เก็บรวบรวมข้อมูลโดยใช้แบบสอบถามและวิเคราะห์ข้อมูลด้วยสถิติเชิงพรรณนาและการวิเคราะห์ความถดถอยเชิงพหุ

ผลการวิจัย แสดงให้เห็นว่า ค่าเฉลี่ยภาระของผู้ดูแลต่ำ (Mean = 43.51, SD = 13.37) เมื่อพิจารณาภาระของผู้ดูแลโดยจำแนกเป็นรายด้าน พบว่า ค่าเฉลี่ยภาระของผู้ดูแลด้านอารมณ์ปานกลาง (Mean = 2.54, SD = 0.80) ขณะที่ ค่าเฉลี่ยภาระด้านการเงิน, ภาระด้านร่างกาย และภาระด้านสังคมต่ำ (Mean = 2.20, SD = 0.91; Mean = 2.06, SD = 0.86; Mean = 1.89, SD = 0.85 ตามลำดับ)

การมีส่วนร่วมในการดูแล ภาวะสุขภาพของผู้ดูแล และการเผชิญความเครียด สามารถร่วมกันทำนายภาระของผู้ดูแลได้ร้อยละ 23.7 อย่างมีนัยสำคัญทางสถิติ (Overall $F_{(3,96)}$=9.94, p< .001) โดยการมีส่วนร่วมในการดูแลเป็นตัวแปรที่สามารถทำนายภาระของผู้ดูแลมากที่สุด

จากผลการวิจัยครั้งนี้มีข้อเสนอแนะว่า พยาบาลควรพัฒนาโปรแกรมเพิ่มความสามารถของผู้ดูแลในการดูแลเด็กสมองพิการ และสนับสนุนการให้สมาชิกในครอบครัวมีส่วนร่วมในการช่วยเหลือผู้ดูแลเด็กสมองพิการ, ส่งเสริมให้ผู้ดูแลเผชิญความเครียดอย่างมีประสิทธิภาพ และส่งเสริมภาวะสุขภาพของผู้ดูแล เพื่อให้ผู้ดูแลสามารถให้การดูแลเด็กสมองพิการได้อย่างมีคุณภาพสูงสุด

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CHAPTER I
INTRODUCTION

Background and Significance of the Study

Cerebral palsy (CP) has high incidence among children with disability. The estimated incidence of cerebral palsy in Thailand was 2 to 3 per 1000 births (Kanokpongsak, 1998). The statistics from the Queen Sirikit National Institute of Child Health was showed the number of children with cerebral palsy in 1996, 1997, and 1998 to be 1,616, 2,102, and 1,951, respectively (Hanprasitkam, 2000). Moreover the number of patients with cerebral palsy at Rajanukul Hospital in 2002, 2003, and 2004 was 1,186, 1,760, and 1,342, respectively. Since the survival rate of preterm infants has improved, the development of CP in these infants has become of greater concern. Furthermore, the improved survival rate of newborns with congenital health problems and brain injury is actually increasing the numbers of children with cerebral palsy (Bache, Selber, & Graham, 2003; Han, Bang, Lim, Yoon, & Kim, 2002; Pharoah, Cooke, Johnson, King, & Mutch, 1998; Rosen & Dickinson, 1992).

Cerebral palsy is a chronic condition that involves disorders effect movement and posture due to a defect or lesion of the immature brain and non-progressive pathology (Swaiman & Russman, 1999). Most of the children with cerebral palsy exhibit impaired motor function and limitations for self-care functions such as feeding, dressing, bathing, and mobility. The study of Jongjit, Komsopapong, and Chira-Adisai (2002) measured functional status in 80 Thai children with cerebral palsy as compared to that of 157 normal children with ages ranging from 6 to 100 months and found that children with cerebral palsy scored consistently lower in all areas of the WeeFIM: Functional Independence Measure for Children than normal children ($p<.05$). Children with CP are not always suffering profound handicap. CP can be managed, and individual potential of children with CP can be maximized. Caregivers, parents or relatives who care the CP children play an important role in long-term home care aimed at improving the quality of life of children.

CP, therefore, not only has an impact on children, but also on their families. There is a growing body of evidence to suggest that the care of children with disabilities is a source of psychosocial distress. The care of disabled children has increasingly become the responsibility of parents as caregivers devote time and energy to help these children with daily tasks that CP children are unable to perform alone; thus, the caregiver's time is limited for other activities or work. In fact, it is estimated that caregivers spend approximately 12-15 hours per day in caring for and helping cerebral palsy children (Brust, Leonard, & Sielaff, 1992; Hanprasitkam, 2000). Most caregivers, therefore, are obliged to change life styles in the areas of time management, employment and social duty wherein free time can also be affected (Hoyert & Seltzer, 1992). Caregivers of children with disabilities are unable to enter or maintain paid employment after the birth of their children because of the increased care needs and adjusted life styles necessary to accommodate child care (Dobson & Middleton, 1998). Moreover, some caregivers abandon hope of promotion by refusing transfers in their companies. The consequences include loss of family income while family expenditures for alimony and medical treatment increase (Curran, Sharples, White, & Knapp, 2001; Hirose & Ueda, 1990). In general, parents or caregivers have a variety of duties that can be categorized as personal, familial and social. Caregiving is a normal part of the parental role for the parents of any young child. So, the high level of care required for a child with long-term functional limitations can become burdensome and may impact the physical, psychological, social and financial well-being of the parents (Raina et al., 2004).

The burden of the caregiver is an individual's subjective perception of overload in one or more of physical, psychological, social or financial aspects through the caregiving process (Chou, 2000; Chou, Jiann-Chyun, & Chu, 2002; Chou, LaMonlagne, & Hepworth, 1999). Extraordinary care is required of the caregivers of children with cerebral palsy. This, in combination with various personal, familial and social duties causes caregivers to perceive that these tasks are overloading and burdensome; moreover, having a cerebral palsy child may impose multiple challenges on caregivers and is considered a major stressor or crisis in family life (Olsen et al., 1999). As a result, most caregivers have poor health that is often associated with long-term caregiving. Many specific health problems include lumbago, weakness, sore

muscles etc. (Hirose & Ueda, 1990; Dawis & Niskala, 1992). With regard to psychological distress, it has been found that the caregivers of disabled children exhibit higher levels of depression and anxiety scores than caregivers of normal children. Social isolation and loss of control over daily life are also indicated as many caregivers experience isolation from friends, community and even other family members. In addition, other family members may withdraw from the demands of caregiving, causing the primary caregiver to feel abandoned by the family (Given et al., 1990) and possibly resulting in family conflict. Finally, caring for a child with chronic medical problems has a significant effect on financial status of their families (Johnson & Oski, 1997). Eker and Tuzun (2004) evaluated the quality of life of mothers who looked after CP children at home. The findings of this study showed that the quality of life of mothers with CP children was quite different from those who had children with minor health problems; moreover, the severity of children's motor disability was associated with a decrease in the physical and psychological well-being of the mothers.

Caregivers who have health problems may be negligent or even ignore to care for children with cerebral palsy (Tangudommongkol, 1997). Watanasin, et al. (2001) studied caregiver capabilities and the condition of children with cerebral palsy at home and found that caregivers were unable to rehabilitate or stimulate motor function and other developments due to various duties. These caused deterioration in the child's health, increasing disability severity and the low intelligence quotient. Cerebral palsy children have several health problems, but they are capable of developing a capacity for self-care that depends on many factors i.e. clinical, health and related treatment, child-related and familial factors. Caregivers, therefore, are very important people for enhancing the self-care and capability of CP children at home.

As healthcare providers, nurses should recognize the caregiver burden in order to care for the caregivers of children with cerebral palsy as these caregivers may feel that the care of CP children is intolerable. Therefore, information about factors associated with caregiver burdens in relation to care for children with cerebral palsy can help nurses to develop realistic goals and strategies with the caregivers to alleviate their burden and also assist caregivers in sustaining themselves and their difficult responsibility. Moreover, understanding of the caregiver burden is the basis for nurses

in helping caregivers identify and describe important problems, needs, and strengths in developing intervention strategies to advocate the development of the best way to deal with day-to-day living and crises that arise.

The review of the literature revealed only a few studies on the topic of caregiver burdens related to the care of disabled children that were published both abroad and in Thailand, and no one has ever studied the caregivers of children with cerebral palsy in Thailand. As for overseas studies, only a few were found and these had limitations regarding sample size. The factors related to caregiver burden include coping (Chou, 2000; Chou, Jiann-Chyun, & Chu, 2002; Chou, LaMonlagne, & Hepworth, 1999; Ray & Ritchie, 1993; Witayasupon, 1996), family income (Bull, 1990; Montgomery, Gonyea, & Hooyman, 1985; Eamyingpanich, 1996), caregiver's age (Montgomery, Gonyea, & Hooyman, 1985; Pipatananond, 2001), severity of disability (Anglod, et al., 1998; Brust, Leonard, & Sielaff, 1992; Maes, Broekman, Dosen, & Nauts, 2003; Ow, 2003; Sayal, 2004), caregiver's health status (Bull, 1990; Montgomery, Gonyea, & Hooyman, 1985; Oberst, Hughes, Chang, & McCubbin, 1991), caregiving involvement and caregiving self-efficacy (Chou, 2000; Chou, Jiann-Chyun, & Chu, 2002; Chou, LaMonlagne, & Hepworth, 1999)

Caregiver burden comprises the experience of caregivers through the chronic illness of family members, the caring process and the phenomena of physical, emotional, social and financial dimensions (Chou, 2000). The caregiver burden concept of Chou has clearly and appropriately detailed the relationship factors affecting the caregiver burden and can be used as a guideline for studying the caregiver burden involved with chronic illness in children. For this reason, the investigator has chosen this concept as the conceptual framework for this study.

Research Questions

The following research questions guided this study:

1. What is caregiver burden in caring for children with cerebral palsy?
2. Can the caregiver's age, family income, caregiver's health status, caregiving involvement, coping and severity of disability predict caregiver burden?

Purposes of the Study

1. To examine caregiver burden involved in caring for children with cerebral palsy.

2. To investigate the predictive power of the caregiver's age, family income, caregiver's health status, caregiving involvement, coping and severity of disability on caregiver burden.

Hypotheses

Caregiver's age, family income, caregiver's health status, caregiving involvement, coping and severity of disability can predict the caregiver burden involved with caring children with cerebral palsy.

Conceptual Framework

In general, parents or caregivers have various personal, filial and social duties. Caregiving is a normal part of being the caregiver or parent of any young child; thus, providing the high level of care required by a child with long-term functional limitations can become burdensome and may impact upon the physical and psychological health, social and financial well-being of the caregiver (Chou, 2000; Raina et al., 2004).

The characteristics of caregivers, care-receivers and situations differ; therefore, caregivers perceive caregiving burdens differently. Chou (2000) stated that the factors influencing the caregiver burden consist of caregiving involvement, filial obligation, caregiving self-efficacy and coping. Moreover, the investigator reviewed literatures and found that other factors included caregiver's age, caregiver's health status, family income and severity of disability could predict caregiver burden. As follows:

Children with CP who have great limitations in self-care function, will require more caring from caregivers and can influence caregiver burden. A number of studies showed that decline in the child's functional limitations, such as performing activities of daily living, predicted caregiver burden (Maes, Broekman, Dosen, & Nauts, 2003; Sales, Greeno, Shear, Anderson, 2004; Sayal, 2004). Angold, et al. (1998) studied the predictors of perceived parental burden for 1,015 childhood and adolescent psychiatric

disorders in a longitudinal study which found that the significant predictors of perceived burden were levels of child symptomatology and impairment.

Caregiving involvement is defined as the frequency of caregiving tasks performed by the caregiver (Chou, Lamonlagne, & Hepworth, 1999). A number of studies showed that the caregivers provided care for the children with disability more than 12 hours per day (Hanprasitkam, 2000; Ray & Ritchie, 1993). Chou, et al. (1999) studied burden experienced by caregivers of relatives with dementia in Taiwan and found that the care-receiver's functional limitation, cognitive deterioration and degree of disturbance behavior had a significant a direct effect on caregiving involvement which had a significant a direct effect on caregiver burden. Caregivers may have less time to rest which may lead to physical disruptions, less opportunity for social activities, and less time to do outside work leading to burden as caregiving involvement increases.

Most caregivers of children with disabilities experience increased stress (Baird, MCConachie, & Scrutton, 2000; Cadman, Rosenbaum, Boyle, & Offord, 1991; Dyson, 1993; Hirose & Ueda, 1990; Hung, Wu, & Yeh, 2004; Ong, Afifah, Sofiah, & Lye, 1998; Piggot, Paterson, & Hocking, 2002; Saunders, 2003). However, caregivers who use effective coping strategies can reduce stress. The effectiveness of the coping strategy depends on the extent to which it is appropriate for the internal and / or external demands of the situation (Lazarus & Folkman, 1984) and several studies have showed that caregivers who cope effectively experience low levels of burden (Chou, 2000; Ray & Ritchie, 1993; Wittaya-suporn, 1996).

Caregiver's age is a basic conditioning factor of caregivers that affect their abilities and exercise to engage or manage dependent-care demand and maturing adults possess the capability for dependent-care action (Orem, 1995). Caregiver's age has been found to be correlated with caregiver burden (Horwitz & Reinhard, 1995; Stueve, Vine, & Struening, 1997). The caregiver's deterioration function increased with increasing age, while the demand of care-receiver assumed to be relatively stable or increase. Older children with CP continue to require dependent care from caregivers; moreover, caregivers tend to maintain their anxiety and concern about the disabilities of these children (Hirose & Ueda, 1990). In further support of this correlation, Pipatananond (2001) studied the caregiver burden predictive model by

application of the empirical test among caregivers of schizophrenics and found that caregiver's age had a direct positive effect on caregiver burden.

Health is a basic conditioning factor that affects caregiver abilities and exercise to engage or manage dependent-care demand (Orem, 1995). As a result, caregivers in poor health have been consistently found to have significantly higher burden levels than those in good health (Angold et al., 1998; Bull, 1990; Dowdell, 2004; Robinson, 1990; Sisk, 2000). Furthermore, caregivers in poor health have physical, emotional, cognitive and decision making functional limitations that result in low efficiency of caring. Therefore, caring for children with cerebral palsy who have more dependent care demands brings about caregiver burden.

Family income has been found to be the primary determinant of whether and how many services can be purchased to alleviate the burden of caregiving (Loomis & Booth, 1995). It has also been showed that insufficient income reduces the access to resources that might make caregiving more bearable. Fink (1995) stated that the financial expense of caregiving is one of the best predictors of caregiver burden.

In this study, the investigator studied the following predicting factors for caregiver burden in caring for children with CP included caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement and coping. Although, filial obligation and caregiving self-efficacy are also related to caregiver burden as the concept of Chou (2000), the investigator did not choose to include these factors in this study because the sample of the study shares membership in Thai society and culture. In addition, family members share similar views with regard to affection, reciprocity and filial obligation (Benja, 1994; Wongsit, 1992). The homogeneity of the sample will affect the significance of the results. The study of Kantana (2000) showed that the caregivers who were parents or not parents, caregiver burden did not differ because the Thai caregivers in this study shared the same positive relationship with the children in their care. Moreover, increasing the independent variables will affect or increase the number of questionnaires that may have an impact on the sample such as exhaustion and stress that leads to erroneous measurement. It is recommended, however, these factors should be studied in the future. For this reason, the predictive factors of caregiver burden in caring for children with CP which were chosen by the investigator for this study were included in Figure 1.

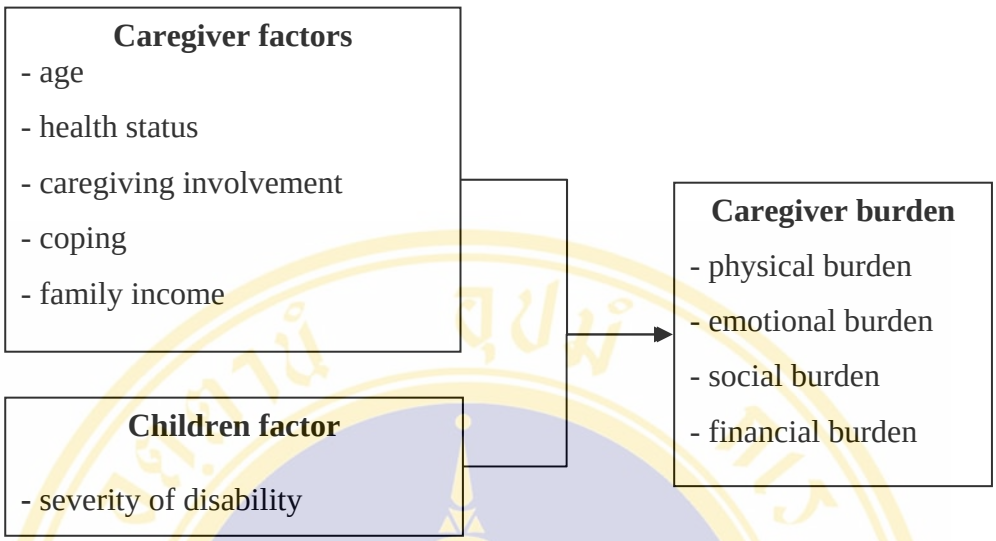

Figure 1: Conceptual framework

Scope of the Study

This study examined the predictive power of caregiver's age, family income, caregiver's health status, caregiving involvement, coping and severity of disability on caregiver burden. The sample for the study consisted of 100 caregivers who were taking care of CP children aged 6 months to 6 years and under out-patient follow-up at the Rehabilitation Department of Siriraj Hospital, the Developmental Department at Sirindhorn National Medical Rehabilitation Center and the Physiotherapy Department at the Foundation for Children with Disabilities.

Definition of Terms

Caregiver burden refers to the perception of caregivers regarding events, activities, or situations occurring in the process of caring for children with cerebral palsy and having an impact on the physical, emotional, social and financial status of caregivers as assessed by the Caregiver Burden Questionnaire that the investigator developed from structure of the Caregiver Burden Inventory designed by Novak and Guest (1989) to assess physical, emotional and social burdens. For assessment of the financial burden, the burden scale designed by Stommel, Given, and Given (1990) was applied.

Caregiver's age refers to the full number of years of age of caregivers of children with cerebral palsy from their birthday until the date of data collection.

Family income refers to the caregiver's monthly income in Thai currency (baht), or caregiver's income including the incomes of spouses in the case of marriage.

Caregiver's health status refers to the overall perception of caregivers about their personal health, which is an item of demographic characteristic form of caregivers and is assessed by a single-item of the self-rated health of the Stanford Patient Education Research Center.

Caregiving involvement refers to the caregivers' appraisal of the amount of time that they spend in providing care for children with cerebral palsy. Caregiving involvement is assessed by application of the Caregiving Involvement Questionnaire which the investigator developed from the questionnaire structure of maternal caregiving tasks for children with disability of Brust, Leonard, and Sielaff (1992).

Coping refers to the caregivers' appraisal of behaviors that they use to manage family life or stress when they have children with cerebral palsy. Coping with caring is assessed by the Coping Questionnaire that the investigator modified from the coping questionnaire on caring children for parents of Wittayasuporn (1996) who modified from Coping Health Inventory for Parents (CHIP) of McCubbin (1987).

Severity of disability refers to the degree or level of functional dependence and/ or independence as measured by the functional independence questionnaire of Sriseub (2000), which was developed and applied from the Functional Independence Measure for Children (WeeFIM) (Msall et al., 1994 cited in Sriseub, 2000) to assess the severity of disability, and it is classified as the following (Msall & Tremont, 1999).

1. Mild developmental disability includes independence in communication, self-care and mobility in which subjects are capable of reading and writing at the fifth-grade level.

2. Moderate developmental disability includes ability to communicate basic needs. Major academic challenges include middle elementary reading and written language activities.

3. Severe developmental disability includes dependence in mobility, some self-care competency and limited communication in which a range of behavior challenges requires much family support and accessible respite.

4. Profound developmental disability includes dependence in self-care and communication with high rates of epilepsy and dysphagia which require interventions.

Expected Outcomes

1. The findings of this study can be of potential benefit in providing information to promote nursing awareness of caregiver burden involved in the care of children with cerebral palsy.

2. The findings of this study can be used to help nurses for effectively caring for children with cerebral palsy.

3. The findings of this study can be used as information for further research aiming to develop both educational and supportive programs as well as a competency development program for caregivers of children with cerebral palsy.

CHAPTER II
LITERATURE REVIEW

This study had the objectives to examine the caregiver burden and predicting factors of caregiver burden in caring for children with cerebral palsy. Related literatures on the following topics were reviewed:

- Cerebral palsy in children
- Caregiver burden
- Predicting factors of caregiver burden for children with cerebral palsy

Cerebral Palsy in Children

Cerebral palsy (CP) is not a specific diagnosis, but rather a collective term used to describe a large group of children suffering from a variety of motor impairments caused by non-progressive lesions in the immature brain (Bache, Selber, & Graham, 2003).

The majority of cerebral palsy cases are believed to be caused by intrauterine insults or structural abnormalities of the CNS (Nelson & Grether, 1999). The causes of cerebral palsy include a variety of prenatal, perinatal, and postnatal factors as follows:

Prenatal: Insufficient nutrients and oxygen can cause damage to the developing brain of the fetus (Ball & Bindler, 2003). Maternal infection, abnormal bleeding of maternal vagina, maternal exposure to certain medicines or toxins, and maternal malnutrition, all are risk factors to be cause of cerebral palsy.

Perinatal: Although the improved neonatal survival has decreased the risk of CP for neonates weighing more than 2500 grams, there has also been a trend toward higher survival rates in more immature, smaller and premature infants with medical complications. The survival of low-birth-weight and very low-birth-weight infants with higher CP risk has kept the prevalence of CP in childhood relatively constant.

Postnatal: Neonatal sepsis and hyperbilirubinemia place the child at higher risk. In young children, CNS infection and head trauma are the major sources of acquired brain injury and subsequent motor dysfunction (Ball & Bindler, 2003).

Classification of cerebral palsy

Cerebral palsy is classified into different categories according to types of impairment, the number of limbs involved and the severity of disability as follows:

1. Types of impairment/ the movement disorder (Howle, 1999; Steele, 1992):

1.1 Spasticity, is characterized by increased muscle tone, prolonged reflexes, exaggerated deep tendon reflexes, clonus, rigidity of the extremities during flexion and extension and a tendency to develop scoliosis and contractures. Spastic CP is the most common type of CP, combining with spastic hemiplegia and quadriplegia to make this group increase to up to 75 percent of all children with CP. Spastic CP is the result of effects on the motor cortex or white matter projections to and from the cortical sensory-motor in the brain.

1.2 Dyskinesia or Athetoid is a group of disorders in which movements are perceived to be uncontrolled and purposeless. This group includes athetosis, rigidity, and tremors. Athetosis is the most common type for dyskinesias and makes up 20 percent of all CP. Dyskinesia is associated with an impairment of basal ganglia and their connections to the prefrontal and premotor cortex.

1.3 Representing less than 10 percent of CP, ataxia is a primary disorder of balance and control in the timing of coordinated movements. Ataxia results from deficits in the cerebellum. Moreover, hypotonia, impaired force and power production during voluntary movement and impaired motor planning affecting sequencing for speech (dysarthria) and the rhythm and orderly progression for reciprocal gross (dysmetria and ataxia) and fine movements (dysdi-adochokinesia) are also present.

1.4 Hypotonia is characterized by a diminished resting muscle tension, a decreased ability to generate voluntary muscle force, and excessive joint flexibility as well as postural instability. Not related to a particular neural lesion, hypotonia is often seen as a transient stage in the evolution of athetosis or spasticity.

2. The number of limbs involved / topographical classification (Bache, Selber, & Graham, 2003; Howle, 1999; Steele, 1992):

2.1 Monoplegia: affects one limb, usually an arm, and results in difficulty with fine motor activities on the affected arm.

2.2 Diplegia: involvement of both lower limbs with minimal involvement of the upper limbs. Spastic paraplegia implies no upper limb involvement.

2.3 Triplegia: involvement of one side of the body, as in hemiplegia, combined with involvement of the contralateral lower limb; lower limb involvement is always asymmetrical.

2.4 Hemiplegia: involvement of one side of the body, either the right or left side, causing a range of difficulties in running, walking and using the hand on the affected side.

2.5 Quadriplegia: the increased muscle tone is generalized, affecting both the arms and the legs, as well as the trunk and neck. The result is difficulty in walking, running, using the hands, speaking, eating and toileting. A wheelchair may be needed for mobility.

3. Severity of disability (Msall & Tremont, 1999):

3.1 Mild developmental disability includes independence in communication, self-care and mobility in which subjects are capable of reading and writing at the fifth-grade level.

3.2 Moderate developmental disability includes ability to communicate basic needs. Major academic challenges include middle elementary reading and written language activities.

3.3 Severe developmental disability includes dependence in mobility, some self-care competency and limited communication in which a range of behavior challenges requires much family support and accessible respite.

3.4 Profound developmental disability includes dependence in self-care and communication with high rates of epilepsy and dysphagia which require humanistic interventions.

Assessment of disability severity for children with cerebral palsy

Several patterns of assessment of disability severity have been developed to categorize children with disabilities and grade the severity of CP based on the motor function of the children. The Gross Motor Function Classification System is widely

used for assessment of the severity of CP-related disability. It consists of a five level classification system based on the functional abilities and limitations of the child with emphasis on self-initiated movement leading to sitting and walking. This is designed for children <12 years of age with separate descriptions provided for children in various age bands (Wood, Rosenbaum, 2000). Such a classification helps in communication between physicians and is also an objective way of evaluation of any therapy.

However, the Gross Motor Function Classification System is based only on gross motor function alone, it is well known that motor function correlates well with disability and outcome on the other hand occasionally the effects of underlying neuropathology on other domains may be more disabling than motor function. Thus, a child with CP may be able to walk independently, but have severe epilepsy which may affect the quality of life. Due to the fact that CP is a changing disorder, it is evident that some limitations may not be evident early in life, but manifest at the school age or later. Therefore, it has been recommended that disabling conditions be evaluated on multiple axes-pathophysiology (underlying disease); impairment (clinically observable abnormality); functional limitations (effect on task performance); disability (effect on daily living) and societal limitations (effect on lifetime opportunities) (Aneja, 2004).

Assessment of disability severity in children with CP includes several methods that depend on objectives, timing and characteristics of disability that many researchers have categorized as follows:

Haley, Coster, and Ludlow (1991) assessed functional limitations in chronic ill and disabled children from 6 months to 7 ½ years of age in which three domains i.e. motors, self-care and social domains were used for assessment. However, this assessment is more detailed and requires a longer period of time (approximately 45 minutes) to administer.

Ketelaar and Vermeer (1998) reviewed functional assessment measures for children with cerebral palsy and found that 17 instruments that are used in paediatric rehabilitation and paediatric physical therapy. Seventeen measures were found: the Alverta Infant Motor Scale (AIMS), the Barthel Index, the Bayley Scales of Infant Development (BSID), the Browder Checklist, the Bruininks-Oseretsky Test of Motor Proficiency, the Functional Motor Assessment Scale (FMAS), the Gross Motor

Function Measure (GMFM), the Gross Motor Performance Measure (GMPM), the Kenny Self-Care Evaluation, the Miler Assessment of Preschoolers (MAP), the Motor Age Test (MAT), the Motor Development Checklist (MDC), the Movement Assessment Battery for Children (Movement ABC), the Peabody Developmental Motor Scale (PDMS), the Pediatirc Evaluation of Disability Inventory (PEDI), the Test of Motor Impairment (TMOI-H), and the Functional Independence Measure for Children (WeeFIM).

All the measures have difference, so the choice of the measure should be based on the characteristics of the measure, especially the target group of the measure with respect to diagnosis and age and the psychometric properties. For this study, investigator chose WeeFIM because it is appropriate with children with cerebral palsy, reflect main function which will finally reflect the need of care, can be administered in 15-20 minutes or less, and recent reports on the reliability and validity of this instrument indicate that the assessment has excellent consistency across raters and provides scores that are stable (Ottenbacher, Msall, Lyon, Duffy, Granger, & Braun, 1997). Moreover, Wong, Chung, Hui, Fong, Lau, Law, et al. (2004) found that WeeFIM has significant correlation with severity of cerebral palsy.

The Pediatric Functional Independence Measure (WeeFIM) was built on the conceptual and organizational format of the Functional Independence Measure for Adults (FIM) of the Uniform Data Set for Medical Rehabilitation that it was developed by Granger, et al. (1986). The WeeFIM (Msall, Rogers, Ripstein, Lyon, & Wilczenski, 1997) was developed by a team of physicians, nurses and therapists in the UDSMR at the University of Buffalo New York in 1987 to measure the severity of disability in children older than 6 months. Derived from the items of the FIM, this instrument was originally designed to assess severity of disability in adults. An initial framework for understanding the WeeFIM is the National Center for Medical Rehabilitation Research (NCMRR) classification scheme for pathophysiology, impairment, functional limitation, disability and societal limitations which was based on the first conceptual framework of the World Health Organization's disablement model of pathology, impairment, disability, handicap and the burden of care (Msall, DiGaudio, Rogers et al., 1994; World Health Organization, 1980).

The WeeFIM consists of a minimal data set that is discipline free (Wong et al., 2004). The goal of the WeeFIM instrument is to measure changes in function over time to weigh the burden of care in terms of physical, technological and financial resources (Braun & Granger, 1991). The WeeFIM is used to measure functional independence in children and focuses on evaluating disability by determining levels of functional independence. This instrument consists of 18 items in 6 subscales: self-care, sphincter control, transfer, locomotion, communication and social cognition. The self-care subscale includes 6 items: eating, grooming, bathing, dressing (upper and lower body), the perineal hygiene and adjustment of clothing required for toileting. Sphincter control involves bladder management and bowel continence. Transferring involves the ability to get in and out of chairs, on or off toilets and in or out of bathtubs or shower stalls. Locomotion includes walking in a standing position or self-directed mobility such as crawling or use of a wheelchair and complex locomotion such as going up and down a flight of 12-14 stairs. Communication involves comprehension of verbal and nonverbal information and the expressive use of language by demonstrating basic needs and ideas in gestures, words and sentences. Social cognition includes social interaction, problem solving and memory.

The WeeFIM instrument applies a scoring scale from 1 to 7 (1 = total assistance; 2 = maximal assistance; 3 = moderate assistance; 4 = minimal contact assistance; 5 = supervision; 6 = modified dependence; and 7 = complete independence) and can be administered in 20 minutes or less. Assessment levels of severity of disability are considered in relation to the mean of WeeFIM and standard deviation (SD) in age - group.

For this study, the investigator assessed levels of severity of cerebral palsy by using the Functional Independence Questionnaire of Sriseub (2000) who studied the quality of life of cerebral palsy children aged from birth to 6 years. Caregivers were interviewed in order to evaluate the quality of life of children by using the functional independence questionnaire, which was developed and applied from the Functional Independence Measure for Children (WeeFIM) (Msall et al., 1994 cited in Sriseub, 2000). The results showed the quality of life of cerebral palsy children to be lower than healthy children. The functional score of children increased with age and the

quality of life was significantly and negatively correlated to disability severity. This instrument could feasibly describe the severity of disease among Thai children with developmental disabilities and conformed to the WeeFIM which aimed at reflecting the degree of assistance a child required to complete daily activities and scoring the child's disability severity.

Impact on children with cerebral palsy

Children with cerebral palsy have disorder of movement and posture, and have a significantly high incidence of problems in other organ systems as follows:

1. Physical containment:

1.1 Eating disabilities: Feeding problems are thought to occur in approximately 40-50 % of children with cerebral palsy (Thommessen et al., 1990). Caused by several reasons depending on the extent of the disability, impaired self-feeding skills, oral-motor dysfunction and positioning difficulties all contribute to the problem. Poor sucking reflex and inability to chew or swallow are a result of the secondary involvement of the oropharyngeal muscles which result in abnormal muscle tone and functions of the tongue, lips and cheeks (Rubin & Crocker, 1989 cited in Steele, 1992). Abnormal posturing further contributes to difficulty in swallowing. In addition, respiratory function influences a child's eating abilities as children who have abnormal, irregular or insufficient breathing will have difficulties in coordination between breathing and swallowing.

1.2 Respiratory problems: Impaired self-feeding skills, oral-motor dysfunction and positioning difficulties can be complicated by aspiration and gastro-esophageal reflux disease. Coughing and choking, especially during eating, may be a predisposing cause of aspiration in a child with CP. Also, respiratory efforts may be uncoordinated and weak, which can result in inadequate gas exchange.

1.3 Dental problems: An increase in dental caries occurs as a result of (1) improper dental hygiene; (2) congenital enamel defects (hypoplasia of primary teeth); (3) high carbohydrate intake and retention; (4) dietary imbalance from poor nutritional intake; (5) inadequate fluoride intake and (6) difficulty in mouth closure and drooling in which spastic or clonic movements may interfere with the cleaning process. Gingivitis is secondary to inadequate dental hygiene and may be further complicated by the use of anticonvulsants (Wong et al., 1999).

1.4 Constipation: The increase in incidence of constipation at various ages results from various factors i.e. difficulties in chewing and swallowing, inadequate liquid intake, decreased intake of bulk foods, prolonged use of strained foods, decreased mobility, abnormality of muscle tone (including muscle-related peristalsis), medications, lack of an established toilet pattern, fear of using a toilet, instability of a child while sitting on a toilet, history of painful evacuations, inadequate positioning of evacuation and behavioral problems. Diarrhea and vomiting are frequent childhood symptoms as well.

1.5 Urinary tract infections: inadequate fluid intake, limited mobility, inadequate perineal hygiene, abnormal voiding patterns and chronic constipation are predisposing factors to Urinary tract infection (UTI). Girls also have a higher rate of vaginal infection that is related to UTI predisposing factors.

1.6 Hip dislocations, scoliosis and contractures: Children with spasticity have unbalanced muscle tone on either one or both hip joints which can cause unilateral or bilateral dislocations to occur at any age.

1.7 Safety: CP children, even those that are mildly affected, have balance and coordination problems. Therefore, it is important to prevent head injuries during ambulatory or play activities in the event that a seizure occurs.

2. Behavioral and emotional impact: The prevalence of disturbed behaviors or emotional maladaptation in different groups of children with CP has been reported to be from 30-80 % (McDermott et al., 1996). The stability of behavior problems over time was described by Breslan and Marshall (1985) in a 5 year study of 255 children with physical disabilities. They found that mental problems (items related to short-term memory and school performance) and isolation were consistent and significant problems for 82 CP children. In school-age CP children, other researchers have found that behavioral problems also include passivity, immaturity and anxiety (McDermott et al., 1996). Several studies have proposed that isolation and dependency can also be problems in children with CP (Blum et al., 1991; Livneh & Antonak, 1994).

3. Psychosocial development: Young children or teenagers with disabilities are often isolated from social contact and learning with peers because of limited motor skills and mobility. These children require extra time and energy-consuming therapy (Molnar, 1992). Spastic children may hesitate to make decisions or reach out for new

opportunities because the world seems overwhelming and somewhat threatening. These children, therefore, may find it easier to withdraw socially (Nelson, 1990a). Problems in psychosocial development can cause decreases in self-esteem, independence and social contact (Carrasco & Powell, 1989).

Impact on caregivers and family

The family is a group of interdependent people who engage in tasks aimed at eliminating the perceived physiological, psychosocial, emotional and spiritual burdens of another individual in the family (Rawlins, 1991). Caregivers are the spouses, parents, friends or significant others of a care recipient who play an important role in caring for an ill person, or dependent care recipient at home or in the community without monetary payment (Davis, 1992; Sirapo-ngam, 1996; Swanson et al., 1997).

Having a child with cerebral palsy may impose multiple challenges on families. This disease, therefore, is considered a major stressor or crisis in family life (Olsen et al., 1999) and includes the following issues:

1. Poor caregiver health is often associated with long-term caregiving and many specific health problems such as lumbago, arthritis, high blood pressure, heart disease and cataracts have been linked to caregiving. Aggravation of long- standing health problems, new stress and exertion-related problems such as hypertension, insomnia, sore muscles, nervousness and tingling of extremities may appear (Dewis & Niskala, 1992). Behavior problems in children are directly associated with poorer physical health in the mothers (Wallander et al., 1989).

2. In the area of psychological distress, mothers of disabled children have been found to achieve higher scores for depression and anxiety than those of normal children. This distress may be less related to psychological frailties or traits than to maternal stress arising from a realistic burden of care. Moreover, a child who depends on a family caregiver for activities of daily living will cause him have less time for his own recreational, cultural, social and work activities (Hallum, 1995).

3. Social isolation and loss of control over daily life are also presented. Most caregivers, especially those with severely ill children, feel regret and withdraw from the reality of their responsibility of the ill child’s care. Family life and morale are imbalanced by the unpredictability of the ill child’s conditions as families may feel they have lost control over their daily lives (Perrin et al., 1993). Typically, sleeping

schedules are disrupted and many families experience isolation from friends, family and even the community. Family functioning, especially in terms of communication and problem solving, gradually deteriorate over time as caregivers continue to experience family adjustments following rehabilitation (Evans et al., 1992). The longer the care is provided, the more likely the decline in family function. In addition, other family members may withdraw from the demands of caregiving, leaving the primary caregiver to feel abandoned by the family (Given et al., 1990). Siblings often report negative influences when they are required to accept a large portion of responsibility for the care of an impaired brother or sister. Other effects felt by siblings include competition for parent attention and feelings of neglect. Caregivers feel a need to compensate for the impaired sibling and confusion as well as a lack of communication about the handicapped condition may occur (Kilburg, 1992).

4. For marital relationships, the special needs of children with cerebral palsy lead to marital stress. The usual primary caregiver remains to be the mother who may feel captured in a 24 hours situation that provides little pleasure or satisfaction. Anger may be directed at partners who not only have more freedom to spend free time, but can also remain more objective about the child's problems. The partner with more freedom (usually the father), however, may resent the amount of attention given to the child and react with anger and hostility toward the spouse as well as the child with cerebral palsy (Fraley, 1995).

5. Financial status is altered as the care of a child with chronic medical problems significantly affects a family's financial resources (Jonhnson & Oski, 1997). Some fathers change their jobs to enable them to take better care of their children with cerebral palsy; moreover, they adjust their work to accommodate the care of the child and abandon promotion by refusing transfers in their companies (Hirose, 1990).

Caregiver Burden

The concept of caregiver burden

Over the past four decades, the concept of burden was interested several academics who defined burden as a negative field. Originally, the concept of burden was developed in 1966 and divided two parts that included subjective and objective burden. Subjective burden was referred to as feelings aroused in caregivers as they

fulfiled their caregiving functions, Objective burden refered to the events and activities associated with negative caregiving experiences (Hoenig & Hamilton, 1966 cited in Chou, 2000). This definition of burden, however, demonstrated a lack of clarity that made it difficult to use for research assessment. Subsequent academics, therefore, developed a concept of burden with increased clarity and understanding.

Zarit, Reever, and Bach-Peterson (1980) defined burden as the negative feelings of caregivers as assessed by physical and emotional health, social lifestyle and financial status through the caregiving process. They viewed burden as the product of a specific, subjective and interpretive process. This view depicts caregiver burden in a way that is not perceived as an unavoidable, negative consequence of providing care, but as the subjective perception of the caregivers regarding tasks performed by them for the impaired person or to personal and individualized reactions to the care-receiver's behavior.

Poulshock and Deimling (1984) argued that the concept of burden should refer to subjective and objective perceptions in relation to reactions to the experience of caregiving. Moreover, they reported that caregiver burden is identified by social activities, relationships with other family members and personal freedom which were all strongly affected by the task of caring for an elderly family member.

Klein (1989) defined the caregiving burden as a confrontation with substantial burden and pressure, viewing that the assessment of the level of caregiving burden depended on intellectual level as well as the moral and ethical development of individuals. Moreover, Klein considered caregiving as a form of stress assessed by the caregiving agents.

Bull (1990) stated that caregiving burden means the amount of caregiving demands and difficulties involved in providing care. The amount of caregiving demands can be evaluated and measured: therefore, it was called an objective burden. Difficulty in caregiving cannot be quantitative or measurable: hence, it was called a subjective burden.

Stommel, et al. (1990) defined the caregiver burden in terms of caregiving perception in the following areas: impact on finances, impact on health, impact on schedule, feelings of being abandoned by family and sense of entrapment.

Oberst (1990) accorded that caregiving burden is perceived according to the care given to the patients as follows:

Direct care: the caregiving activities that directly respond to the general, developmental and healthcare demands of patients.

Interpersonal care: the caregiving activities concerning interpersonal relations.

Instrumental care: general caregiving activities that may concern patients or any general business.

Orem (1991) defined the caregiving burden in terms of the outcomes of care arrangement for dependent persons wherein family members who were responsible for answering the demands of family members with illness had to improve their knowledge, skills and ability to establish interpersonal relationships while maintaining their willingness to care for dependent persons. At the same time, the caregiving agents had to be responsible for their own health conditions and well being.

Chou (2000) stated that burden is an individual's subjective perception of overload in one or more of four perspectives i.e. physical, psychological, social and financial, through the caregiving process. Moreover, Chou noted that critical attributes of burden include the following:

Subjective perception: Characteristics of caregiver / care-receiver and situations differ; caregivers, therefore, perceive different caregiving burdens.

Multidimensional phenomena (Bio-eco-psycho-social): The concept of burden generally covers four aspects: physical, financial, psychological and social. Burden resulting from caregiving can generate burden in several life domains of the caregiver. Nevertheless, the caregiver may not perceive all of the dimensions at one time.

Dynamic change: Burden is believed to change as demands and the extent of caregiving involvement change. Caregiver burden changes over time because of increasing disability of the impaired care-receiver and changes in the family's expectations of the patient. Thus, what might be considered burdensome at one time may change as the caregiver adapts and finds new ways to cope with the patient's impairment, or existing burden is replaced with new problems or crisis situations (Perlick, Clarkin, & Sirey, 1995).

Overload: Burden results from an imbalance of perceived demands and resources. These primary and associated demands may come from the care-receiver, other family members, work or society. The resources may originate with the caregiver or other informal or formal supports. Once the individual's resources become inadequate at meeting needs, the individual may experience overload in dealing with specific demands. The caregiver will feel burdened to the extent that he or she perceives the care-receiver's demands or other associated demands as outstripping the available resources.

A research concept, burden is a term that can take on different meanings. The review of literature supported the use of the burden concept for examining both personal reactions to caregiving and the effects of caregiving. In summary, caregiver burden is an effect of responsibility in caring for a family member with chronic illness that caregiver perceives as a problem or difficulty in which four perspectives i.e. physical, psychological, social and financial status are affected through the caregiving process.

For this nursing research, the concept of burden needs to be restricted in such a way as to give clear theoretical relevance. Therefore, the investigator has proposed the caregiver burden model of Chou (2000) as illustrated in Figure 2 which represents the conceptual model of burden and depicts the relationships among predisposing factors, mediators and consequences.

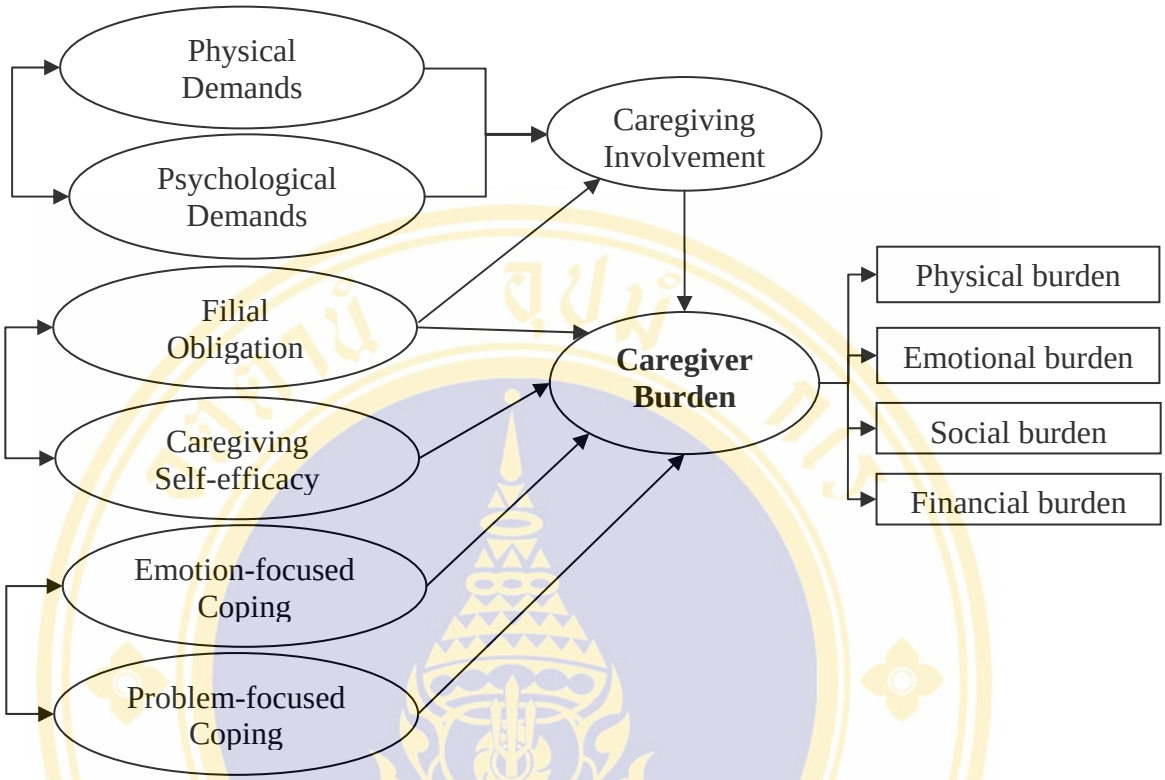

Figure 2: Structural model of the caregiver burden model (Chou, 2000)

Predicting factors of caregiver burden include the following: (Chou, 2000)

Caregiving involvement is defined as the number of caregiving tasks performed and the amount of time the caregiver spends performing them. Caregiving involvement is derived from the physical and psychological demands of care. Functional limitations are related to the care-receiver's functional capabilities that are measured by the activities of daily living and instrumental activities of daily living. Functional limitation may prevent the child from independently conducting activities of daily living (e.g., bathing, eating, dressing, walking, preparing snacks and taking medicine). The degree of functional limitation in the care-receiver (child) has been showed in some studies to be a significant variable with respect to the degree of burden experienced by the caregiver (Chou, LaMontagne, & Hepworth, 1999).

Filial obligation: the family system is an important base factor in response to the dependent care demands of family members. Obligation may be the potential motivating factor in the caregiving relationship and the caregiver sense of

responsibility for an ill child may support them for quality of care. Parents who reported positive relationships with their chronically ill child perceived a lesser degree of burden.

Caregiving self-efficacy: Individuals with a high sense of efficacy believe that they are capable of mastering different situations. Caregiving self-efficacy refers to the caregivers' ability to manage the caregiving tasks and the subjective perception that may be influenced by their self-efficacy expectations. Caregivers who have confidence in themselves, competence about responsibly caring for the patient and existence of motivation may perceive less caregiving burden.

Coping: When a family member has a chronic illness, caregivers or other family members appear stressed. The effectiveness of coping strategy depends on the extent to which it is appropriate for the internal and / or external demands of the situation (Lazarus & Folkman, 1984). If caregivers can effectively cope, they will have low level of burden.

Consequences / outcomes of burden

The burden resulting from caregiving can generate problems in several life domains of the caregiver, care-receiver, family and healthcare system as follows:

1. Caregiver: Deterioration in health status and occurrence of psychological problems.
2. Care-receiver: Poor health outcomes.
3. Family: Family/marital conflict and financial problems.
4. Health care system: Increasing cares expenditures.

Measurement of caregiver burden

When professionals successfully assist, care, and support caregivers, they must be able to assess caregiver problems as caregiver burden. As a rule, measurement of caregiver burden will be showed in caregiver responsibility for patient care that has impact on physical and emotional health as well as the social and financial status of the caregiver. A number of researchers have developed measurement instruments for caregiver burden as follows:

Bull (1990) used three measures of caregiver burden to assess subjective and objective burden in which Robinson's Strain Index was developed with a population of caregivers for persons with chronic illness. This instrument consists of 13 items that measure perceptions and feelings about providing care at home for which the Cronbach's alpha has been reported at 0.79. Information on objective burden was obtained by asking caregivers how much time they spent in caregiving on an average daily basis and what assistance-related activities they performed. Bartlett's test of sphericity confirmed that the inter-correlations among the measures of burden were significant and Cronbach's alpha for the total burden was 0.60.

Stommel, et al. (1990) developed measurement of the caregiver burden in caring dependent elderly relatives from five appraisals of the burden which were conceptualized as impacts and /or reactions to the processes and situations of caregiving. The measures were developed from an initial pool of 111 items with 5-point Likert-type response scales which assessed all mentioned areas of potential caregiver burden and were administered to a pilot sample of 99 caregivers. Following the initial exploratory factor analysis, the pool of items was reduced to 77, which was then administered to the current sample of 307 caregivers. In subsequent assessments, these measurements were reduced to a total of 27 items. Finally, the researcher made further modification in which a total of 31 items was retained to form five distinct subscales for caregiver burden measurement as having an impact on the following areas: finances, health, schedules as well as feelings of abandonment and sense of entrapment in which Cronbach's alpha scores were 0.72, 0.85, 0.81, 0.87, and 0.87, respectively.

Novak and Guest (1989) developed a diverse, multidimensional instrument, the Caregiver Burden Inventory (CBI), that measured the impact of burden on caregivers and in which the Caregiver Burden Profile (CBP) for each of 107 caregivers of cognitively impaired older people was based on their CBI scores. The CBP consists 24 items in the following areas of burden: time-dependent, developmental, physical, social and emotional. Eight items were selected from a review of the burden-related literature and sixteen items were chosen from the Novak

and Guest research. The Cronbach's alpha scores were 0.85, 0.85, 0.86, 0.73, and 0.77, respectively.

Chou (1999) measured caregiver burden in caring for patients with dementia by the Caregiver Burden Inventory, which was developed by Novak & Guest (1989). Part of the questionnaire was modified as Chou had the idea that problems concerning marriage were emotional, not social burdens. Moreover, Chou used CBI together with Cost of Care Index (CCI) which was designed to measure the personal, social, physical, emotional and economic dimensions of the cost of caregiving (Kosberg & Cairl, 1986 cited in Chou, 1999) in relation to financial burden. The total questionnaires comprised 44 items as the CBI had 24 items and the CCI has 20 items. Cronbach's alpha for physical, emotional, social and financial burdens were 0.93, 0.88, 0.82, and 0.93, respectively.

Application of these measurements alone; however, clarifies and appreciates the caregiver burden for only certain groups because health problems of care-receiver and individual characteristics of caregivers have difference. In this study, the investigator used the Caregiver Burden Questionnaire (CBQ) which the investigator developed in order to measure caregiver burden in caring for children with cerebral palsy. The CBQ was modified with respect to the physical, emotional and social burdens in the CBI of Novak & Guest (1989) and the financial burden in Burden in the scales of Stommel, et al. (1990). The CBQ was designed to measure the perceptions of caregivers regarding overload in one or more of the following four perspectives: physical, emotional, social and financial burden as a result of the caregiving process.

Caregiver burden in caring for children with cerebral palsy

Cerebral palsy possesses high incidence of physical disability, as the illness is not only chronic in nature but also leaves children with functional limitation. For children with cerebral palsy, independent living is impossible. Therefore, the burden of care is inevitably placed on their caregivers. There have been previous studies on the topic of caregiver burden in caring for children with chronic illness; however, these studies do not include the topic of the caregiving burden related to the care of

children with cerebral palsy. The following researchers who have studied the caregiver burden in caring for children with chronic illness:

Bull (1990) investigated factors influencing family caregivers' burden and health and determined changes in caregivers' burden and health outcome during the second week and 2 months post-discharge. The sample was 55 primary caregivers of chronic illness patients post-discharge, with functional status ranging from impairment of instrumental activity of daily living, such as shopping, to persons who were bed bound. The results revealed that caregiver's income, recipient's physical health and functional ability, caregiver's physical health, and size of the social network were inversely related to caregiver burden both at 2 weeks (r = -0.10, -0.67, -0.49, -0.05, and -0.06, respectively) and 2 months post-discharge (r = -0.39, -0.45, -0.59, -0.13, and -0.26, respectively). However, the significant values were not reported. Multiple regression analysis indicated that caregiver functional ability, recipients' functional ability, and size of social network explained 53 % of variance in caregiver burden at 2 weeks post-discharge (R^2 = 0.53, F = 17.19, p<.0001). However, caregiver burden at 2 months post discharge was 50 % explained by income, caregivers' functional ability, and recipients' functional ability (R^2 = 0.50, F = 13.16, p<.0001).

Brust, Leonard and Sielaff (1992) assessed the time commitment required in which 133 mothers of disabled children were asked to estimate by specific task categories the extra time required to care for the children. According to the findings, the total average of daily care time was reported at 12 hours and 6 minutes for household duties, child care, and vigilance with 6 hours and 30 minutes consumed in vigilant tasks i.e. watching a child who cannot be left alone and / or providing emotional support. The implication of these findings was confirmed by the study of Ray and Ritchie (1993) and Hanprasitkam (2000) in which it was showed that most caregivers of children with chronic illness spent more than 12 hours per day in caring for these children. The amount of time required by parents to care for their children with chronic illness necessitates lost opportunities that increase the burden of caring.

The findings of the study by Wittayasuporn (1996) showed that 74 parents received a moderate caregiving burden which was divided into two parts i.e. demand,

which was assessed by the time spent in caring for the child at each activity; and difficulty, which was assessed by difficulties in providing care for each activity. Parents perceived the most caregiving burden to be financial management, followed by surveillance against hazards or dangers, traveling to different places, medical care, dealing with behavior-related problems, communication with various persons, dealing with increased household chores, daily activity, emotional support for children, assistance, transporting the children and planning various activities, respectively. This study also found the average score for the amount of time used in caregiving to be higher than the score regarding caregiving difficulty.

Eamyingpanich (1996) investigated the caregiving burden and well-being in families of 100 mentally retarded children, finding that the activity which mothers perceived as the most demanding was managing the problematic behaviors of their children, followed by prevention of accidents and seeking sources of help. Time consuming activities included providing medical support and seeking help from various sources. The activity perceived as less demanding was caring for the children's general actions, such as walking, sleeping, exercising, etc.

Kantana (2000) studied caregiving burden in 100 caregivers of children with HIV and found that most caregivers of children with HIV perceive major burdens to be expenses, followed by feelings of abandonment, impact on schedule, impact on health, and sense of entrapment, respectively.

Angold, et al. (1998) examined the level of burden experienced by 1015 parents on account of their children's problems as a factor in propelling parents to seek help for their children's psychiatric disorders in which the Child and Adolescent Burden Assessment was used to assess caregiver burden. Parents were asked about 20 potential perceived burdens representing problems or difficulties in their own lives and perceived as being caused or exacerbated by their child's psychiatric symptoms and the following areas were covered: expenses and financial difficulties, problems in relationships with family or social network members, restrictions on activities and decreased feelings of well being and competence. The results showed that 10.7% of

parents in the general population perceived burden resulting from their children's symptomatology and that significant predictors of perceived burden were levels of child symptomatology, impairment and parental mental health problems. The effects of the severity of child disorder on specialty mental health service use appeared to be mediated by the level of burden induced.

Ow (2003) studied the burden of care for children with cancer from the experiences of 22 parents in an Asian context for a two-phase qualitative study in which the subjective burden of care was identified as parents'personal emotions i.e. distress, anxiety and sense of loss. The objective burden of care included disruption to family interactions, marital relations, childcare and housekeeping as well as need for information. The results of this study showed subjective burden to be consistently higher at both phases (initial phase of data collection and follow-up phase of data collection at three to six months later). The subjective burden of care was higher than the objective burden of care at the initial stage following diagnosis. As for the follow-up phase, parents with informal social support were generally adjusting well to the routine of managing additional household demands. Parental anxiety was associated with poor recovery as concern about relapse continued to render the subjective burden of care more imperative than the objective burden of care at this stage.

Maes, Broekman, Dosen, and Nauts (2003) studied the family burden in 66 persons with intellectual disability (ID) and severe behavioral or psychiatric problems. The family burden was assessed by acceptation, coping capacity, having problems, wanting a different situation, child-related burden, being on one's own, and having fun and good contact. The results showed that increasing behavioral or psychiatric problems in persons with ID are related to stronger feelings of dissatisfaction with the family situation. Parents consider the psychiatric or behavioral problems of their child to be an extra burden and feel it more difficult to raise and manage such a child in the family situation.

Dowdell (2004) studied the experience of 104 grandmothers parenting their grandchildren with health problems to determine the amount of caregiver burden involved. The Caregiver Reactions Assessment (CRA) was used to measure the

grandmother's caregiving burden and consisted of caregiver esteem, caregiver physical health and family support,as well as impact on schedule and finances. The results showed that grandmothers possess a rather high caregiving burden.

According to the literature review, the level of caregiver burden in caring for children with chronic illness differs. Although the burden of most caregivers is from a low to moderate level, this level depends on the burden assessment method, differing health problems of care-receivers and individual characteristics of caregivers. Thus, caregivers and children with CP who have individuality should be study.

Predicting Factors of Caregiver Burden for Children with Cerebral Palsy

The following predicting factors have been identified with caregiver burden: caregiving involvement, filial obligation, caregiving self-efficacy, and coping (Chou, 2000). Moreover, the review literatures were showed that other factors correlated with caregiver burden included caregiver's age, caregiver's health status, family income and severity of disabilities. This study examined selected factors comprising caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement, and coping. These factors may predict the caregiver burden in caring for children with cerebral palsy, as discussed in the details. As follows:

Caregiver's age

Age is a basic conditioning factor that affect caregiver abilities and exercise to engage or manage dependent-care demand and maturing adults possess the capability for dependent-care action (Orem, 1995) and is an important factor in mental status perception and ability to understand or make decisions about carrying out behavior. Caregiver age was found to be correlated with caregiver burden (Horwitz & Reinhard, 1995; Stueve, Vine, & Struening, 1997) as deterioration in caregiver function increased with age. Older caregivers seem less able to cope with the demands of the care-receivers, while the demand of care-receivers is assumed to be relatively stable or increased. Although children with CP become older, they continue to require dependent care from caregivers and caregivers have more difficulty coping with the problems of children. Moreover, caregivers maintain anxiety and concern about the

disabilities of their children e.g. parental anxiety over what will happen to their child after their death (Hirose, 1990). One study about predictive models for caregiver burden consisted of an empirical test among caregivers of schizophrenics by Pipatananond (2001) who confirmed that caregiver age had a direct positive effect on caregiver burden.

Caregiver's health status

Health is a basic conditioning factor that affects caregiver abilities and exercise to engage or manage dependent-care demand (Orem, 1995). Health perception affects the way people think and comprehend also events across their life and leads them to concern everything they perceive. It also motivates people to form behaviors from their perception.

Many of the health perception measures are lengthy. The length of most available instruments has prompted investigators to adopt surveys based on a few single-item measures. Consequently, the study has be attempted to determine if a single survey item can be used to measure self-rated health perceptions. One of the most widely used single measures of self-rated health perceptions ask respondents to rate their health as excellent, good, fair, or poor in response to the question (Ratner, Jonhson, & Jeffery, 1998). For this study, Health status was assessed by a single-item of the self-rated health of Stanford Patient Education Research Center. This instrument was taken from The Short-Form General Health Survey of the Medical Outcomes Study (MOS) which was developed by Stewart, Hay, and Ware (1988). The MOS-short form has 20 items about quality of life in which a typical question is "In general, would you say your health is Excellent or Very good or Good or Fair or Poor." The study of Cunny and Perri (1991) found that this question had a very high correlation coefficient with the total questionnaire ($r = 0.86$, $p < .0001$). In addition, Lorig, et al. (1996) assessed stability of measurement by the test-retest method in 51 subjects with chronic disease, finding the test-retest reliability to be 0.92. Self-rated health has the scores range from 1 to 5, with a higher score indicating poorer health. This single-item of self-rated health is recommended as an important indicator for the study of appraisal of health status. In addition, a single-item rating of health has been widely

used and has been showed to predict health outcome equally or better than more complex measures (Idler & Kasl, 1991).

Caregivers in poor health have consistently been found to have significantly higher burden levels than those in good health (Bull, 1990; Dowdell, 2004; Robinson, 1990; Sisk, 2000). Caregivers in poor health have functional limitation with regard to physical, emotional, cognitive and decision making aspects of caregivers; thus, low efficiency in caring. Therefore, caring for the dependent care demands of children with cerebral palsy brings about caregiver burden. According to Bull (1990), relationships between burden and health can change over time as the situation becomes more burdensome. Furthermore, the study of perceived caregiver burden involving 1015 children and adolescents with psychiatric disorders of Angold, et al. (1998) confirmed that parents with preexisting mental health problems perceived more burdens than those with no mental health problems.

Family income

Thoits (1995) has noted that money is an obvious coping resource that people draw upon their finances when coping with a variety of problems. Money is potential problem-solving resource; especially it pertains to health outcomes through increased access to medical care. Moreover, income is a significant component contributing to individual potentiality in caring for dependents and answering individual basic needs as caregivers who have high income can seek resources for better care of their children with health problems. So, caregivers who have monetary resources tend to be more confident that they can mobilize their money and provide other resources to meet their demands. This confidence contributes to a lower caregiving burden.

Previous findings from the studies of Eamyingpanich (1996), Robinson (1990), and Pipatananond (2001) all reflected the important issue that income had a negative correlation with caregiving burden in that people with high income have a variety of resources that can help them to provide effective care for dependant family members. Income is also a significant variable in determining a person's satisfaction toward different lifestyles and in providing sufficient resources leading to better health (Orem, 2001). In addition, the level of organizational involvement and service utilization increases with economic status (Comstock & Partridge, 1972 cited in

Pipatananond, 2001). However, Salleh (1994) studied 210 primary caregivers of Malay schizophrenic patients and found that caregiver's family income was not correlated with the amount of burden. However, the limitation of this investigation was the sample this study which included only those with low socioeconomic background.

Severity of disability

CP children with great limitations in self-care functions demand additional caring from caregivers as functional limitations may prevent the child from independently conducting the activities of daily living e.g., bathing, eating, dressing, walking, taking medicine, etc. For this reason, these caregivers spend more time, have more activity and have anxiety in caring for children with CP. These can become a caregiving burden. Angold, et al. (1998) studied the predictors of perceived parental burden for 1,015 children and adolescents with psychiatric disorders in a longitudinal study and found that significant predictors of perceived burden included levels of child symptomatology and impairment.

Caregiving involvement

Involvement in caregiving is defined as the number of caregiving tasks performed and the amount of time the caregiver spends performing them (Schott-Baer, 1993). Brust, Leonard, and Sielaff (1992) stated that mother caregiving tasks for children with disability are categorized as follows:

1. Child-care tasks directly related to providing personal or medical care (5 items):

1.1 Personal care (helping with bathing, grooming, eating, etc.).

1.2 Medical care (medications, tube feedings, wound care).

1.3 Escorting the child to health care.

1.4 Escorting the child to non-medical functions beyond what would have to be done if child was healthy (social activities, entertainment).

1.5 Waiting in doctors' offices.

2. Vigilant tasks (2 items):

2.1 Watching a child who cannot safely be left alone.

2.2 Providing emotional support when not doing other tasks (companionship, listening, giving encouragement).

3. Household tasks were defined as those not directly related to the child's personal care, but necessary for the provision of care (6 items):

3.1 Preparing special or extra meals and cleaning up afterward.

3.2 Extra or special shopping or errands (buying clothing, picking up medications).

3.3 Extra household chores (housework, yard work).

3.4 Managing the child's finances (dealing with insurance companies, finding special programs, filling out forms).

3.5 Monitoring and maintaining medical equipment.

3.6 Managing the child's medical conditions (scheduling doctor's appointments, talking to doctors, nurses and social workers).

These tasks are developed to be the Caregiving Involvement Questionnaire by investigator for this study. When caregivers have more caregiving involvement for children with chronic illness, they may have less time to rest which may lead to physical disruptions, less opportunity for social activities and less time to do outside work, thus leading to perceptions of being overwhelmed and burdened as caregiving involvement increases. In Taiwan, the study of Chou, LaMontagne, and Hepworth (1999) on the burden experienced by caregivers of relatives with dementia confirmed that caregiving involvement had direct positive effects on caregiving burden.

Coping

McCubbin and McCubbin (1996) described coping as involved complementary efforts of individual family members which fit together in a synergistic whole and create a balance between demands and resources that eliminates stresses and hardships at the same time. Families faced with crisis characterize the ways in which coping facilitates adaptation as identified by four broad headings as follows:

1. Direct action to eliminate or reduce the number and intensity of demands created by the illness.

2. Direct action to acquire additional resources not already available to the family.

3. Stress management for the tension associated with ongoing strains.

4. Family-level appraisal to create, shape and evaluate meanings related to a situation to make it more constructive, manageable and acceptable.

In summary, coping may be directed at the reduction or elimination of stress and hardship, acquisition of additional resources, ongoing management of family tension, and shaping the appraisal at both the situational and schema levels. These coping strategies are vitally important and often operate simultaneously.

When a child in a family is chronically ill or has a disability or handicap, the family is called upon to provide long-term care and support for the child as well as manage day to day family life. Such crisis situations threaten the family unit as the family is forced to adapt to achieve a new level of balance and fit. Health care providers work with families who have chronically ill children and need to assess parental coping to see whether these parents adapt successfully or need further assistance and professional intervention to enhance coping and improve family life. There is a need to assess and evaluate how each parent is coping and whether these coping behaviors are having a positive or deleterious effect on the chronically ill member and the family as a unit.

Coping strategies are not inherently good or bad. A strategy that is effective in one situation can be ineffective in another and, vice versa, the effectiveness of a coping strategy depends on the extent to which it is appropriate to the internal and / or external demands of the situation (Lazarus & Folkman, 1987). Assessment of parental coping should be administered in a non-threatening manner as health care providers contact these families. Therefore, the Coping Health Inventory for Parents: CHIP has been designed to assess parental perceptions of behaviors they are currently using to manage family life when they have a seriously or chronically ill child (McCubbin & Thompson, 1991).

The construction of CHIP was guided by the inclusion of important behavior items used in prior studies of family coping responses to stress with the development of additional behavior items focusing on: social support theory, family stress theory,

theories of the individual psychology of coping and family health care support (McCubbin & McCubbin, 1996).

The Quality of the instrument of McCubbin (1987) was tested by evaluating structure validity using the discriminated analysis of the interview data of one hundred and eighty five parents (95 mothers and 90 fathers) of children with cystic fibrosis. Although the original version of the CHIP instrument had 80 items, the results of the study showed that only 30 of the 80 items were rated by these parents as “not applicable”. They, therefore, eliminated an additional 5 items by using the criterion of minimal or negligible variance. The remaining 45 items were divided according to three coping patterns.

CHIP is a self-report instrument consisting of a checklist of 45 specific behaviors. It has a rating scale from 0 meaning not helpful to 3 which means extremely helpful. The range of scores for the questionnaire was 0 to 135 in which a high score means that parents perceive the coping behavior as helpful at a high level, and a low score means that parents perceive the coping behavior as helpful at a low level. The CHIP has 45 items follow three coping patterns as follows:

Coping pattern I: Family Integration, Co-operational and An Optimistic Definition of the Situation is composed of 19 items.

Coping pattern II: Maintaining Social Support, Self esteem and Physical Stability is composed of 18 items.

Coping pattern III: Understanding Health Care Situations through Communication with Other Parents and Consultation with the Health Care Team is composed of 8 items.

The loading of each factor started at 0.48 to 0.74. These three factors were designated as coping patterns and represented 71.1 % of the variance of the original correlation matrix. Cronbach’s Alpha was computed for the items on each coping pattern and indicated reliabilities of 0.79, 0.79 and 0.71, respectively. McCubbin (1987) used an additional validity check by a discriminated analysis between low conflict and high conflict families who had a child with cerebral palsy. The results showed that both maternal and paternal use of all three coping patterns was significantly higher in high conflict families than low conflict families. This result was then tested for validity by the Correlation Matrix from the Family Environment Scale

(Moss, 1976 cited in McCubbin & McCubbin, 1996) and two indices of the health status of the chronically ill child after which it was hypothesized that all three coping patterns would be associated with dimensions of the family environment. The results of the study showed that there was a positive correlation between all three coping patterns and dimensions of the family environment which included cohesiveness, expressiveness, conflict, independence, organization and control. It was also hypothesized that the parents' use of the three coping patterns would have a positive correlation with improvements in the child's health status (McCubbin, 1987).

Phuchacram (1990) translated the CHIP in 1990, after which, the Content Validity was tested by 3 experts in a study of 60 parents of children with lymphoblastic leukemia in which Cronbach's Alpha for the CHIP was 0.80. Wittayasuporn (1996) modified the test again and the content validity was tested by 5 experts in a study of 74 parents of children with chronic illnesses in which the Combat' Alpha of the CHIP was 0.87.

Most caregivers of children with disabilities have high levels of stress. In a caregiving situation, coping strategies aimed at directly solving problems seem more effective at reducing stress. Moreover, several studies have showed that caregivers who cope effectively will perceive low level of burden (Chou, 2000; Chou et al., 1999; Ray & Ritchie, 1993). Similarly, Wittayasuporn (1996) studied caregiving burden in 74 parents of children with chronic illness and found that effective coping strategies had an effect on low caregiver burden.

Parental care of children with cerebral palsy is an enormous responsibility. Although impaired motor function is the hallmark of cerebral palsy, many children also experience sensory and intellectual impairments, and may have complex limitations in self-care function. These limitations can result in requirements for long-term care far exceeding the usual needs of children as they develop or the expectations of their families as parents. Therefore, providing the high level of care required by a child with long-term functional limitations can become burdensome and may impact the physical and psychological health as well as the social and financial status of caregivers. Moreover, the consequences of caregiver burden consist of poor health

outcomes in children with CP and caregivers, family conflict and increasing care expenditures in the health care system.

Although most of the caregivers adapt well to the situation of caring for children with CP, some do not. To understand caregiver situations in caring for children with CP, the complex nature of burden processes must be accounted for and factors that play a role in the caregiver burden must be considered. For this reason, the investigator studied the predicting factors of caregiver burden in caring for children with CP according to the caregiver burden concept of Chou (2000).

CHAPTER III
METHODOLOGY

Research Design

This was a predictive correlation study that aimed to investigate the predicting factors of caregiver burden in caring for children with cerebral palsy.

Population and Sampling

Population

The population of this study consisted of caregivers of children with cerebral palsy aged of 6 months to 6 years who received rehabilitation at the Department of Rehabilitation Medicine at Siriraj Hospital, the Sirindhorn National Medical Rehabilitation Center and the Foundation for Handicapped Children. The caregivers involved in this study were capable of communication and comprehension in the Thai language.

Sample

The sample of this study consisted of 100 caregivers who were selected by convenience sampling. Both caregivers and children with cerebral palsy lived in the same house and caregivers had been responsible for child care for more than 2 weeks. The children with cerebral palsy who have other health problems that are non-related to CP such as heart disease, diabetes mellitus, Down's syndrome were excluded from the study.

To determine the sample size that was a good representative of the population, power analysis for multiple regression (Polit & Beck, 2004) was applied as follows by using $\alpha = .05$, power = .80 and effect size as medium:

$$N = \frac{L}{\gamma} + k+1$$

N estimated the number of subjects needed

L tabled the value for the desired α and power analysis (Polit & Beck, 2004: 522). In this study, α = .05, power = .80 and L (from the table) = 13.62

k number of predictors (= 6)

ϒ estimated effect size between independent variable and dependent variable that can be calculated by the following formula:

$$\Upsilon = \frac{R^2}{1- R^2}$$

R^2 refers to the coefficient of effect size from previous studies as the medium coefficient = .13 (Witayasooporn, 1996). The outcome is:

$$= \frac{.13}{1-.13}$$

$$= .15$$

Apply .15 to the formula for computing the sample size as follows:

$$N = \frac{13.62}{.15} + 6+1$$

$$= 97.8$$

Thus, the estimated sample size was equal to 100 subjects.

Setting

This study was conducted at Siriraj Hospital, Sirindhorn National Medical Rehabilitation Center and the Foundation for Children with Disabilities. Settings were described as follows:

1. Department of Rehabilitation Medicine of Siriraj Hospital: The children with cerebral palsy were brought for rehabilitation from 8.30 a.m. to 4.00 p.m., Monday to Friday. The investigator collected data from the pediatric out patient department, pediatric physical therapy and pediatric occupational therapy clinics.

2. Sirindhorn National Medical Rehabilitation Center: The children with cerebral palsy were brought for rehabilitation from 8.30 a.m. to 12.00 p.m., every Tuesday and Thursday. The investigator collected data from the pediatric developmental stimulation clinic.

3. Foundation for Children with Disabilities (FCD): The Foundation for Children with Disabilities is a non-governmental organization whose purpose is to work with children with disabilities and their families. Target groups are children with disabilities with focus on children with cerebral palsy and parents of disabled children. Every Monday and Tuesday at 8.30 a.m. to 3 p.m., the Foundation for Children with Disabilities provides activities which include physical therapy, Thai massage for disabled children, Dao sa Hao movement, musical therapy, learning and play.

Instruments

The research instruments of this study consisted of five questionnaires which were administered to caregivers in the following 5 separate sections:

Section I: Demographic Characteristics Questionnaire included 2 components:

1. Demographic characteristics of caregivers included age, gender, education, marital status, total number of children, occupation, family income, adequacy of income, relation to cerebral palsy child, duration of daily care for the cerebral palsy child, caregiving assistants, and caregiver's health status.

Caregiver's health status was assessed by a single-item of self-rated health of Stanford Patient Education Research Center. This instrument was taken from The Short-Form General Health Survey of the Medical Outcomes Study (MOS) which was developed by Stewart, Hay, and Ware (1988). The MOS-short form has 20 items about quality of life in which a typical question is "In general, would you say your health is Excellent or Very good or Good or Fair or Poor." The study of Cunny and Perri (1991) found that item of self-rated health had a very high correlation coefficient with the total questionnaire ($r = 0.86$, $p < .0001$). In addition, Lorig, et al. (1996) assessed stability of this measurement by the test-retest method in 51 subjects with chronic disease, finding the test-retest reliability to be 0.92. This a single-item of self-rated health was arranged in five-point rating scale, ranging from excellent (1), to poor (5), with a high score indicating poorer health.

2. Demographic characteristics of children included gender, age, mean of medical payment.

Section II: Severity of Disability Scale was used to assess level of disability severity by the caregiver interview with regard to the functional abilities of children with cerebral palsy. The investigator took this instrument from the functional independence questionnaire of Sriseub (2000) who developed and applied the Functional Independence Measure for Children: WeeFIM (Msall et al., 1994 cited in Sriseub, 2000). This instrument consists of 18 items in three parts: self-care and sphincter control (8 items), transfer and locomotion (5 items) and communication and social cognition (5 items), all of which are on a rating scale for which the scoring system is based on a seven-level ordinal scale with high scores of 6-7 reflecting a child's ability to complete all components of a task without caregiver's help in a safe and timely manner. Low scores of 1 or 2 reflected that the child required at least half of the task components to be performed by a caregiver.

Level of scoring	Meaning	
7	Complete independence (timely, safe)	No helper
6	Modified independence (device)	
5	Supervision or setup	Helper
4	Minimal contact assistance (child ≥ 75%)	
3	Moderate assistance (child ≥ 50%)	
2	Maximal assistance (child ≥ 25%)	Complete dependence
1	Total assistance (child < 25%)	

Total scores of assessment ranged from 18 to 126 and the children were grouped by age as follows: 6-21 months, 22-45 months, 46-62 months, and 63-100 months according to Msall, et al. (1994). The investigator considered levels of disability severity from a mean of WeeFIM and SD in the age-groups as follows: (Jongjit, Komsopapong, & Chira-Adisai, 2002)

Age range	Mean± SD (WeeFIM scores)
6 - 21 months (14±5.61)	31 (3.0)
22 - 45 months (32±6.04)	74 (6.1)
46 - 62 months (54±8.01)	103 (6.9)
63- 100 months (73.5±7.24)	116.5 (7.0)

Level of disability (Msall & Tremont, 1999)

Mild developmental disability	WeeFIM scores within 1.5 SD of the mean for age group
Moderate developmental disability	WeeFIM scores 1.5-2.5 SD below the mean for age group
Severe developmental disability	WeeFIM scores 2.5-3.5 SD below the mean for age group
Profound developmental disability	WeeFIM scores more than 3.5 SD below the mean for age group

Meaning of scores as follows:

Children's age range: 6-21 months

Greater than 26.49	Mild developmental disability
23.50-26.49	Moderate developmental disability
20.50-23.49	Severe developmental disability
Lower than 20.50	Profound developmental disability

Children's age range: 22-45 months

Greater than 64.84	Mild developmental disability
58.75-64.84	Moderate developmental disability
52.65-58.74	Severe developmental disability
Lower than 52.65	Profound developmental disability

Children's age range: 46-62 months

Greater than 92.64	Mild developmental disability
85.75-92.64	Moderate developmental disability
78.85-85.74	Severe developmental disability
Lower than 78.85	Profound developmental disability

Children's age range: 63-100 months

Greater than 105.00	Mild developmental disability
98.01-105.00	Moderate developmental disability
91.01-98.00	Severe developmental disability
Lower than 91.01	Profound developmental disability

Section III: Caregiving Involvement Questionnaire

Caregiving involvement questionnaire which the investigator developed according to the question structure of mother caregiving tasks for children with disability designed by Brust, Leonard, and Sielaff (1992) and literature review. The question structure is categorized as follows:

1. Child-care tasks directly related to providing personal or medical care (7 items):

1.1 Personal care (helping with bathing, grooming, eating, etc.)

1.2 Medical care (medications, tube feedings, wound care)

1.3 Escorting the child to health care

1.4 Escorting the child to non-medical functions beyond what would have to be done if child were healthy (social activities, entertainment)

1.5 Waiting in doctors' offices

1.6 Managing the behavioral problem of child

1.7 Moving a child

2. Vigilant tasks (2 items):

2.1 Watching a child who cannot safely be left alone

2.2 Providing emotional support when not doing other tasks (companionship, listening, giving encouragement)

3. Household tasks were defined, as those not directly related to the child's personal care, but necessary for the provision of care (6 items):

3.1 Preparing special or extra meals and cleaning up afterward

3.2 Extra or special shopping or errands (buying clothing, picking up medications)

3.3 Extra household chores (housework, yard work)

3.4 Managing the child's finances (dealing with insurance companies, finding special programs, filling out forms)

3.5 Monitoring and maintaining medical equipment

3.6 Managing the child's medical conditions (scheduling doctor's appointments, talking to doctors, nurses and social workers)

The caregiving involvement questionnaire consists of 15 items that it is developed by 13 question structure of Brust, Leonard, and Sielaff (1992) and 2

literature review as managing the behavioral problem of child and moving a child. All of the questionnaires are rated on a scale of 5, ranging from little (1), to a great (4), in order to describe the amount of time associated with caregiving tasks. If activity is not used, the caregiver is asked to record (‘not doing’ as ‘0’). Criteria for scoring:

No action = 0 score
Low = 1 score
Moderate = 2 score
High = 3 score
Highest = 4 score

Score of caregiving involvement was a total score of all items of questionnaires, ranging from 0 to 60 scores. The higher score indicated that the caregivers held a higher level of caregiving involvement.

The level of caregiving involvement was judged as low, moderate, or high caregiving involvement by the average rating scores according to the following criteria:

The mean score of 0 to 1.34 means low caregiving involvement.
The mean score of 1.35 to 2.67 means moderate caregiving involvement.
The mean score of 2.68 to 4.00 means high caregiving involvement.

Section IV: Coping Questionnaire

The coping questionnaire for caregivers of children with cerebral palsy which the investigator modified from Wittayasuporn’s (1996) coping questionnaire for parental care of children originated by McCubbin (1987) and translated by Phuchacram (1990). This instrument consisted of a checklist of 45 and was categorized as follows:

Coping pattern I: Family Integration, Co-operational and Optimistic Definition of the Situation comprised 19 items: 1, 3, 6, 8, 11, 13, 16, 18, 21, 23, 26, 28, 31, 36, 38, 41, 43, 44, and 45.

Coping pattern II: Maintaining Social Support, Self esteem and Physical Stability comprised 18 items: 2, 4, 7, 9, 12, 14, 17, 19, 22, 24, 27, 29, 32, 33, 34, 37, 39, and 42.

Coping pattern III: Understanding the Health Care Situation through Communication with Other Parents and Consultation with the Health Care Team comprised 8 items: 5, 10, 15, 20, 25, 30, 35, and 40.

This instrument is a self-report instrument consisting of a checklist of 45 specific behaviors in which caregivers are asked to record how helpful (ranging from not helpful (0), to extremely helpful (3)), each behavior is in their particular family situation. If a coping behavior is not used, the respondent records why by either checking (a) I do not cope this way because I chose not to use it, or (b) coping behavior is not possible in our family, not applicable to us (scale = 0). Criteria for scoring:

Not helpful/ No use = 0 score
Minimally helpful = 1 score
Moderately helpful = 2 score
Extremely helpful = 3 score

The range of scores of the questionnaire was 0 to 135. The higher score indicated that the caregivers perceived a higher level of the usefulness coping behavior.

The level of coping was judged as low, moderate, or high coping by the average rating scores according to the following criteria:

The mean score of 0 to 1 means low coping.
The mean score of 1.01 to 2.00 means moderate coping.
The mean score of 2.01 to 3.00 means high coping.

Section V: Caregiver Burden Questionnaire

An operational measure of caregiver burden and a conceptualization of dependent-care demand, the Caregiver burden questionnaire for caregivers responsible in caring for children with cerebral palsy which the investigator developed from the structure of the Caregiver Burden Inventory designed by Novak and Guest (1989) to assess the physical, emotional and social burden. As for the part of financial burden, the assessment scale was designed by Stommel, Given, and Given (1990) in order to assess financial burden. It contained 19 questions separated into 4 parts:

1. Physical burden Items 1-4

2. Emotional burden Items 5-10

3. Social burden Items 11-15

4. Financial burden Items 16-19

Regarding response format and scoring, the identical 5-point likert response formats were used for demand subscales. Response choices ranged from disagree (1) to most agree (5), in order to describe caregiver burden. Criteria for scoring:

Disagree = 1 score

Slightly agree = 2 score

Moderately agree = 3 score

Strongly agree = 4 score

Absolutely agree = 5 score

The possible range of caregiver burden scale was 19 to 95. The higher score reflected that higher level of caregiver burden.

The level of caregiver burden was judged as low, moderate, or high caregiver burden by the average rating scores according to the following criteria:

The mean score of 1 to 2.33 means low caregiver burden.

The mean score of 2.34 to 3.67 means moderate caregiver burden.

The mean score of 3.68 to 5.00 means high caregiver burden.

Validity and Reliability

1. Validity: When the instruments were examined by three thesis committee, three validators (Appendix A), 1 physical medicine and rehabilitation physician and 2 pediatric nursing instructors, were asked to assure the content validity of the instruments which included the following: Demographic Characteristics Questionnaires, Severity of Disability Scale, Caregiving Involvement Questionnaire, Coping Questionnaire and Caregiver Burden Questionnaire. The validators also considered the research objectives, content and language used.

After the instruments had been reviewed, the investigator applied the opinions and recommendations of these experts to improve the instruments prior to trial implementation.

2. Reliability: The instruments were pilot tested with 30 caregivers with the same characteristics as the selected population in Siriraj Hospital, Sirindhorn National

Medical Rehabilitation Center, and the Foundation for Children with Disabilities. The Cronbach's Alpha coefficient was calculated as follows (Cronbach, 1984 cited in Polit & Hungler, 1999).

$$r = (k/k\text{-}1)\,[1-(\sum\sigma i^2/\sigma^2_y)]$$

When r = Estimated reliability

K = Total number of items in the instruments

$\sum\sigma i^2$ = Sum of variance of each individual item

σ^2_y = Variance of the total test scores

The Cronbach's Alpha coefficient of the Severity of Disability Scale, Caregiving Involvement Questionnaire, Coping Questionnaire, and Caregiver Burden Questionnaire were 0.98, 0.72, 0.80, and 0.87, respectively.

Data Collection

After the proposal of this study was approved by the Committee on Human Rights Related to Human Experimentation of Mahidol University and Siriraj Hospital, data were collected by the investigator by the following procedures:

1. A formal letter from the Faculty of Graduate Studies, Mahidol University was submitted to the Directors of Siriraj Hospital, Sirindhorn National Medical Rehabilitation Center and the Foundation for Children with Disabilities to obtain permission for data collection.

2. After receiving permission, the investigator met with the heads of the departments of these 3 settings to introduce herself and discuss the data collection procedures for the study.

3. The investigator selected the sample group from caregivers who personally accompanied their children to the hospital and were waiting for rehabilitation by the physical therapists. The investigator introduced herself to the caregivers, explained the objectives of the study and asked for their participation in gathering the data.

4. Caregivers who agreed to participate were invited to sit in a private place and sign an informed consent form. Afterward, the investigator interviewed them according to the recorded forms of Severity of Disability Scale. Prior to the interview, the investigator explained how to answer the questions then read the questions to the

caregivers and let them answer them. The investigator recorded the answers on the interview forms.

5. Next, the investigator handed out the Demographic Characteristics Questionnaire, Caregiver Burden Questionnaire, Caregiving Involvement Questionnaire and Coping Questionnaire to the caregivers, describing the methods for answering the questionnaires to them and allowing them answer the questionnaires by themselves. In cases where the caregivers had problems in answering the questionnaires because they could not read or write, the investigator read each question and let the caregivers answer item by item until the questionnaires were completed.

6. The investigator gathered the questionnaires and examined them for completeness of information.

7. All of the data from the questionnaires were analyzed by computer program.

Protection of Human Subjects

1. The study proposal was submitted to the Committee on Human Rights Related to Human Experimentation of Mahidol University and Siriraj Hospital. Moreover, the study was revised according to the committee's comments and suggestions.

2. After obtaining permission to collect data, the investigator started to recruit the sample by explaining the details of the study and the rights of the participants. Caregivers were invited to join the study and allowed freedom to make their decisions. They were assured that the collected data would be kept confidential and reported only as a group with no identification of any particular participants in the study. The participants were informed of their right to withdraw from the study at any time without any impact on the treatment, care and services their children would receive. They were also given an opportunity to ask any questions they had.

3. After the participants had read the information sheet and decided to participate in the study, they were asked to sign the consent form (Appendix C).

Data Analysis

The data were analyzed by using the statistical package for social science of the Windows program and setting the statistical significance at .05. The analysis procedures were as follows:

1. Descriptive statistics including frequency, percentage, mean and standard deviation were used to analyze the demographic data of caregivers and children, severity of disability, caregiver burden, caregiving involvement, and coping.

2. The assumptions of multiple regression analysis that were tested included normal distribution, homoscedasticity and multicollinearity (Appendix E).

2.1 Normal distribution: One-Sample Kolmogorov-Smirnov Test indicated that caregiver's age, caregiving involvement, coping and caregiver burden were normally distributed, while caregiver's health status, family income and severity of disability were not normally distributed. Histogram also showed that dependent variable, caregiver burden, was normally distributed.

2.2 Homoscedasticity: Scatter plot showed that the constancy of the residuals across values of the independent variables were spread at zero area, which indicated homoscedasticity in the multivariate case.

2.3 Multicollinearity: The pearson's product moment correlation was performed to examine the relationships among independent variables. The result of the analysis revealed that the highest correlation coefficient among the independent variables was 0.37. In addition, collinearity statistics showed that tolerance was more than 0.20 (0.73 to 0.94) and Variance Inflation Factor (VIF) was less than 4 (1.07 to 1.36). Multicollinearity was not a problem in this study (Garson, 2006).

3. Pearson's product moment correlation coefficient was used to generate correlation coefficient among 7 variables, which included caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement, coping and caregiver burden.

4. Multiple Regression Analysis was carried out to predict caregiver burden in children with cerebral palsy as follows:

4.1 All independent variables were entered in the equation.

4.2 Variables that could significantly predict the caregiver burden were entered in the equation by using stepwise multiple regression analysis to identify the predictability of these variables with caregiver burden in caring children with cerebral palsy in stages. In stage one, the independent variable that best predicted with the dependent variable was included in the equation. In the second stage, the remaining independent variables with the highest partial correlation with the dependent variable, controlling for the first independent variables, was entered. This process was repeated, at each stage partialling for previously entered independent variables, until the addition of a remaining independent variable does not increase R-squared by a significant amount.

CHAPTER IV
RESULTS

This study was conducted to examine the predicting factors of caregiver burden for children with cerebral palsy. The sample comprised 100 caregivers of children with cerebral palsy who received health care services at the Department of Rehabilitation Medicine of Siriraj Hospital, Sirindhorn National Medical Rehabilitation Center and the Foundation for Handicapped Children. Data were collected from September 2006 to December 2006 and the study findings have been presented in 2 parts as follows:

Part 1. Demographic characteristics and independent variables

1.1 Demographic characteristics of caregivers

1.2 Demographic characteristics of children with cerebral palsy

1.3 Caregiving involvement

1.4 Coping

Part 2. Caregiver burden

2.1 Caregiver burden

2.2 Correlation between independent variables and dependent variable

2.3 Predicting factors of caregiver burden for children with cerebral palsy

Part 1 Demographic Characteristics

1.1 Demographic characteristics of caregivers

In this study, the predicting factors of caregiver burden for children with cerebral palsy, there were 100 cases in the study sample. More than half of the caregivers were 21 to 40 years old (63%). Most caregivers (84%) were married status. More than half of the caregivers were mothers (66%). Caregivers held primary education (34%) and secondary education (34%). Forty-six percent of caregivers were housewife or unemployed. The majority of the caregivers had family incomes between 6,001 and 10,000 baht per month (32%). More than half of the caregivers (55%) had inadequate of income. About sixty-two percent of the caregivers had a daily duration of caring for children with cerebral palsy 17 to 24 hours. More than half of caregivers (51%) had duration of caregiving 1 to 3 years. Seventy-three percent of the caregivers had the assistant in caring for children with CP. Forty-six percent of caregivers had child 2 to 3 persons. Most caregivers described their health status as fair (41%) and good (39%). As presented in Table 1.

Table 1 Demographic Characteristics of Caregivers (N = 100)

Caregivers' characteristics	Frequency	Percentage
Age (years)		
Less than 21	4	4
21-40	63	63
41-60	28	28
More than 60	5	5
Range = 17-71, Mean = 37.66, SD = 11.01		
Gender		
Male	10	10
Female	90	90
Marital status		
Married	84	84
Divorced / Widowed / Separated	13	13
Single	3	3
Relation to children with cerebral palsy		
Father	9	9
Mother	66	66
Relative / Sibling	8	8
Grandparent	17	17
Level of education		
None	3	3
Primary	34	34
Secondary	34	34
Diploma	13	13
Bachelor's degree	14	14
Master's degree	2	2

Table 1 Demographic Characteristics of Caregivers (N = 100) (Continued)

Caregivers' characteristics	Frequency	Percentage
Occupation		
Housewife or unemployed	46	46
Employee	22	22
Trader / Business owner	20	20
Civil service / State enterprise	9	9
Others (Agriculturalist, Student, Astrologer)	3	3
Family income (baht/month)		
Less than 6,001	25	25
6,001-10,000	32	32
10,001-20,000	15	15
20,001-30,000	12	12
30,001-40,000	9	9
More than 40,000	7	7
Range = 1,000-300,000, Mean = 19,662, SD = 32,386.56, Median = 10,000		
Adequacy of income		
Inadequate	55	55
Adequate without savings	42	42
Adequate with savings	3	3
Duration of daily caregiving for the children with cerebral palsy (hours)		
Less than 9	14	14
9-16	24	24
17-24	62	62
Range = 4-24, Mean = 18.62, SD = 6.90		
Duration of caregiving (years)		
Less than 1	5	5
1-3	51	51
4-6	44	44
Range = 0.6-6, Mean = 3.56, SD = 1.58		

Table 1 Demographic Characteristics of Caregivers (N = 100) (Continued)

Caregivers' characteristics	Frequency	Percentage
Assistants in caring for cerebral palsy children		
No	27	27
Yes	73	73
Husband	37	37
Wife	8	8
Relative / Sibling	6	6
Baby sitter	2	2
Parents	20	20
Number of children		
0	4	4
1	41	41
2-3	46	46
More than 3	9	9
Health status		
Excellent	1	1
Very good	12	12
Good	39	39
Fair	41	41
Poor	7	7

1.2 Demographic characteristics of children with cerebral palsy

This study found that more than half of the children with cerebral palsy were 4 to 6 years old (66%), and male (52%). For severity of disability, seventy-two percent of children with cerebral palsy had profound severity of disability. Seventy-five percent of the children had the universal coverage for health welfare as presented in Table 2.

Table 2 Demographic Characteristics of Children (N = 100)

Children with cerebral palsy' characteristics	Frequency	Percentage
Age (years)		
Less than 1	3	3
1-3	31	31
4-6	66	66
Range = 0.6-6 years, Mean = 3.77 years, SD = 1.61		
Gender		
Male	52	52
Female	48	48
Severity of disability		
Mild	19	19
Moderate	5	5
Severe	4	4
Profound	72	72
Mean of medical payment		
Universal Coverage	75	75
Reimbursement from government / State enterprise	10	10
Own expense	15	15

1.3 Caregiving involvement

The study indicated that the mean score of caregiving involvement was high (Mean = 42.09, SD = 9.08), with a possible range of 0 to 60 and an actual range of 17 to 60.

The numbers of the items for each subscale of caregiving involvement was unequal, and the results could not refer to differences in each subscale. Therefore, the investigator calculated the mean score of each subscale according to the rating scale of the questionnaire. The calculation of this mean score was performed by dividing the score of each subscale of caregiving involvement with a number of items of each subscale.

It was found that mean score of vigilant tasks was the highest (Mean = 3.49, SD = 0.58), while mean score of household tasks was the lowest (Mean = 2.65, SD = 0.78) as presented in Table 3. The higher score indicated that the caregivers held a higher level of caregiving involvement.

Table 3 Range, Mean and Standard Deviation of Caregiving Involvement Subscales of Caregivers (N = 100)

Caregiving involvement	Possible range	Actual range	Mean	SD
Child-care tasks (7 items)	0-4	0.86-4	2.75	0.70
Vigilant tasks (2 items)	0-4	2-4	3.49	0.58
Household tasks (6 items)	0-4	1-4	2.65	0.78

1.4 Coping

The mean score for the coping of caregivers was high (Mean = 87.36, SD = 12.51), with a possible range of 0 to 135 and an actual range of 53 to 117.

The numbers of the items for each subscale of coping was unequal and the results could not refer to the differences in each subscale. Therefore, the investigator calculated the mean score of each subscale according to the rating scale of the

questionnaire. The calculation of this mean score was performed by dividing the score of each subscale for coping with a number of items for each subscale.

It was found that mean score of coping pattern I: Family Integration, Co-operational and Optimistic Definition of the Situation was the highest (Mean = 2.37, SD = 0.29), while mean score of coping pattern II: Maintaining Social Support, Self esteem and Physical Stability was the lowest (Mean = 1.86, SD = 0.33) as presented in Table 4. The higher score indicated that the caregivers perceived a higher level of the usefulness coping behavior.

Table 4 Range, Mean and Standard Deviation of Coping Subscales of Caregivers (N = 100)

Coping	Possible range	Actual range	Mean	SD
Coping pattern I (19 items)	0-3	1.37-2.94	2.37	0.29
Coping pattern II (18 items)	0-3	1.12-2.69	1.86	0.33
Coping pattern III (8 items)	0-3	0.88-3.00	2.24	0.48

Part 2. Caregiver Burden

2.1 Caregiver burden

The mean score of the caregiver burden was low (Mean = 43.51, SD = 13.37), with a possible range of 19 to 95 and an actual range of 19 to 85.

The number of the items of each subscale of burden was unequal, and the result could not refer to differences in each subscale. Therefore, the investigator calculated the mean score of each subscale according to the rating scale of the questionnaire. The calculation of this mean score was performed by dividing the score of each subscale of burden with a number of items for each subscale.

It was found that mean score of emotional burden was the highest (Mean = 2.54, SD = 0.80), while mean score of social burden was the lowest (Mean = 1.89, SD = 0.85) as presented in Table 5. The higher score reflected that the caregiver perceived a higher level of burden.

Table 5 Range, Mean and Standard Deviation of Caregiver Burden Subscales (N = 100)

Variable	Possible range	Actual range	Mean	SD
Physical burden (4 items)	1-5	0.8-4	2.06	0.86
Emotional burden (6 items)	1-5	1.20-4.80	2.54	0.80
Social burden (5 items)	1-5	1-4.4	1.89	0.85
Financial burden (4 items)	1-5	0.8-4	2.20	0.91

When considering each item of each subscale of caregiver burden, it was found that mean score of “I’m physical tired” under the category of physical burden was the highest (Mean = 2.94, SD = 1.27), while mean score of “caregiving has made me physically sick” in the same category was the lowest (Mean = 1.87, SD = 1.15). The mean score of “I fear that my child will not be able to perform self-care when he grows up” in the category of emotional burden was the highest (Mean = 3.50, SD = 1.45), while the mean score of “I feel embarrassed over my child’s behavior” in the same category was the lowest (Mean = 1.26, SD = 0.69). The mean score of “I don’t do as good a job at work as I used to” in the category of social burden was the highest (Mean = 2.71, SD = 1.47), while the mean score of “I cannot meet with my friends” in the same category was the lowest (Mean = 1.59, SD = 1.01). The mean score of “I have increasing expenses” in the category of financial burden was the highest (Mean = 3.44, SD = 1.38), while the mean score of “I must borrow from some others” in the same category was the lowest (Mean = 2.16, SD = 1.35). These results are shown in Table 6.

Table 6 Possible Range, Mean and Standard Deviation of Each Subscale and Items of Caregiver Burden (N = 100)

Caregiver burden	Possible range	Mean	SD
Physical burden			
I'm physically tired.	1-5	2.94	1.27
I'm not getting enough sleep.	1-5	2.78	1.28
My health has suffered.	1-5	2.73	1.37
Caregiving has made me physically sick.	1-5	1.87	1.15
Emotional burden			
I fear that my child will not be able to perform self-care when he grows up.	1-5	3.50	1.45
I feel angry about my interactions with my child.	1-5	2.90	1.46
I feel easy upset.	1-5	2.08	1.07
I feel sad and/or pity myself.	1-5	1.62	0.97
I feel uncomfortable when I have friends over.	1-5	1.33	0.65
I feel embarrassed over my child's behavior.	1-5	1.26	0.69
Social burden			
I don't do as good a job at work as I used to.	1-5	2.71	1.47
I feel resentful of other relatives who could but do not help.	1-5	1.89	1.15
I don't get along with other family members as well as I used to.	1-5	1.66	1.17
I have had problems with my marriage or family.	1-5	1.62	0.97
I cannot meet with my friends.	1-5	1.59	1.01
Financial burden			
I have increasing expenses.	1-5	3.44	1.38
My financial resources are not adequate.	1-5	2.75	1.27
It is difficult to pay for child's health needs and services.	1-5	2.68	1.37
I must borrow from some others.	1-5	2.16	1.35

2.2 Correlation between independent variables and dependent variable

The correlation among all of the independent variables were low to mild (ranged from 0.03 to 0.37). Moreover, collinearity statistics was found that tolerance was higher than 0.20 (ranged from 0.73 to 0.94) and Variance Inflation Factor (VIF) was lower than 4 (ranged from 1.07 to 1.36). Therefore, multicollinearity was not a problem in this study, as showed in Table 7.

The correlation between independent variables and caregiver burden had been tested prior to multiple regression analysis and it was revealed in a bivariate analysis that the independent variables were positively and low to mildly correlated with caregiver burden included caregiving involvement ($r = 0.34$, $p<.01$), caregiver's health status ($r = 0.30$, $p<.01$) and severity of disability ($r = 0.18$, $p<.05$) while the independent variables that were negatively and mildly correlated with caregiver burden consisted of family income ($r = -0.27$, $p<.01$) and coping ($r =-0.26$, $p<.01$) as was showed in Table 7.

The mean score for caregiver's age was 37.66 years old; the mean score for caregiver's health status was 3.41 while the mean score for family income was 19,662 baht / month and severity of disability was 3.29. The mean score for caregiving involvement was 42.09, coping was 87.36 and caregiver burden was 43.51 as was showed in Table 7.

Table 7 The Intercorrelation, Mean and Standard Deviation for Variables Studied with Caregiver Burden (Correlation matrix) (N = 100)

Variables	1	2	3	4	5	6	7
1. Caregiver's age	1.00						
2. Caregiver's health status	.13	1.00					
3. Family income	.18*	-.20*	1.00				
4. Severity of disability	-.03	.29**	-.37***	1.00			
5. Caregiving involvement	-.10	.07	-.20*	.30**	1.00		
6. Coping	.09	-.04	.08	.13	-.10	1.00	
7. Caregiver burden	-.06	.30**	-.27**	.18*	.34**	-.26**	1.00
Mean	37.66	3.41	19662	3.29	42.09	87.36	43.51
SD	11.01	0.83	32386.56	1.2	9.08	12.51	13.37
Minimum	17	1	1000	1	17	53	19
Maximum	71	5	300000	4	60	117	85

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

2.3 Predicting factors of caregiver burden for children with cerebral palsy

Through multiple regression analysis, it was shown that all of the independent variables could jointly explain 26 percent of variance in caregiver burden (Overall $F_{(6, 93)}$ = 5.44, p<.001) whereas only three variables were able to predict caregiver burden. Caregiving involvement, caregiver's health status, and coping could significantly predict the caregiver burden (Beta = 0.27, t = 2.85, p<.01; Beta = 0.27, t = 2.58, p<.05; Beta = -0.20, t = -2.26, p<.05, respectively) (Table 8).

Table 8 Multiple Regression Analysis for Predicting Caregiver Burden (N = 100)

Variable	b	Beta	SEB	t
Caregiver's age	-.00	-.02	.11	-.26
Caregiver's health status	3.97	.27	1.53	2.58*
Family income	-.00	-.15	.00	-1.54
Severity of disability	-.10	-.01	1.15	-.09
Caregiving involvement	.39	.27	.14	2.85**
Coping	-.22	-.20	.09	-2.26*
Constant = 35.30, SE = 12.17**				

$R = .51$, $R^2 = .26$, R^2 adj = .21, Overall $F_{(6, 93)} = 5.44$***

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

When the investigator took the caregiving involvement, caregiver's health status, and coping, which could significantly predict the caregiver burden (p<.001, p<.05, p<.05 respectively) entered in the predictive equation. Stepwise multiple regression analysis was used to identify the predictability of caregiving involvement, caregiver's health status, and coping variables with caregiver burden in caring children with cerebral palsy. The result was showed that three variables together could jointly explain 23.7 percent of variance in caregiver burden (Overall $F_{(3, 96)} = 9.94$, p<.001). The caregiving involvement could explain 11.4 percent of variance in caregiver burden with statistical significance (Beta = 0.29, t = 3.33, p< .001). The caregiver's health status could explain additionally 7.5 percent of variance in caregiver burden with statistical significance (Beta = 0.26, t = 3.00, p< .01). The coping could explain additionally 4.8 percent of variance in caregiver burden with statistical significance (Beta = -0.22, t = -2.45, p< .05). These results are presented Table 9.

Table 9 Stepwise Multiple Regression Analysis for Predicting Caregiver Burden (N = 100)

Variable	R	R^2	R^2 Change	F Change	b	Beta	t
Caregiving involvement	.33	.11	.11	12.56	.44	.29	3.33***
Caregiver's health status	.43	.18	.07	9.02	4.32	.26	3.00**
Coping	.48	.23	.04	6.03	-.23	-.22	-2.45*
Constant = 22.61, SE = 6.02**							

Overall $F_{(3, 96)} = 9.94$***

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

The multiple regression equation

The raw score regression equation to predict caregiver burden is as follow:

1. Caregiver burden = 22.61 + 0.44 caregiving involvement + 4.32 caregiver's health status - 0.23 coping

The standard score regression equation to predict caregiver burden is as follow:

2. Z caregiver burden = 0.29 (Z caregiving involvement) + 0.26 (Z caregiver's health status) - 0.22 (Z coping)

CHAPTER V
DISCUSSION

The objectives of the study were to examine caregiver burden and investigate the predictive power of caregiver's age, family income, caregiver's health status, caregiving involvement, coping and severity of disability on caregiver burden. The study findings were discussed as follows:

Objective 1: To examine caregiver burden in caring for children with cerebral palsy.

This study found that the mean score of caregiver burden of the sample was low (Mean = 43.51, SD = 13.37, Possible range from 19 to 95). Possible explanation for this result might be due to more than half of caregivers (52%) had good health status to excellent health status. Sixty-three percent of the caregivers were from 21 to 40 years old who had abilities and exercise to engage or manage dependent-care demand, and maturing adults possess the capability for dependent-care action. Moreover, most caregivers were female (90%) who offered particularly gentle care for their children. More than half of the caregiver was mothers of children with cerebral palsy (66%) who loved and took sensitive care of their children.

Caregivers in this study were not new the role, with the duration of caregiving range from 1 to 6 years, with a mean of 3.56 years (SD = 1.58). The long period of caregiving time did not only reflected the adaptive function but also reflected caregivers' obligation and commitment that had contributed to the acceptance of the burden they carried. Furthermore, the majority of caregivers were married (84%) and had assistants (73%), primarily their husbands, to aid in the care of their children with cerebral palsy, which indicated that the caregivers had someone to share in both taking care of their children with cerebral palsy and household work.

This finding was consistent with the findings of other studies. For example, Eamyingpanich (1996) who studied mother's caregiving burden in the mentally retarded child found that the mean score of caregiving burden was low (Mean =

36.78, SD = 10.03, Range = 18.06 to 71). Thongpetch (2002) studied mother's caregiving burden in autistic child and found that the mean of caregiving burden was low (Mean = 38.93, SD = 9.75, Range = 15 to 75). The findings of this study were also consistent with the findings of the researchers abroad. In the longitudinal study findings of Angold, et al. (1998) who studied perceived parental burden and service use for child and adolescent psychiatric disorders among 1015 parents, found that the whole population had a weighted mean total burden score of 0.9 (SD = 3.3, range = 0 through 28). Piggot, Paterson, and Hocking (2002) studied participation in home therapy programs for children with cerebral palsy: A compelling challenge. They found that caring family member with chronic illness did not only have negative effect on the caregivers but also reflected caregiver positive feeling. With time and increasing knowledge, parents were able to learn and feel competent in their day-to-day handling of the child, thus enabling the development of habits that were self-fulfilling in terms of further improvement, such as involving other family members in the therapy regimes.

When considering each subscale, the mean score of the emotional burden was moderate (Mean = 2.54, SD = 0.80), while the mean scores of financial burden, physical burden, and social burden were low (Mean = 2.20, SD = 0.91; Mean = 2.06, SD = 0.86; Mean = 1.89, SD = 0.85) (Table 5). The mean score of emotional burden was moderate. This result can be explained in that the majority of the children with cerebral palsy (72%) had severity of disability at profound. The caregivers fear that children with CP would not be able to perform self-care when they grew up. Children with CP who have behavior problems and difficulty in caring may be a source of upset and dissatisfaction on the part of caregivers who feel angry about their interactions with their children with cerebral palsy. Leonard, Johnson, and Brust (1993) also found that severity of disability was related to parental stress. Furthermore, Hirose and Ueda (1990) who studied long-term follow-up of children with cerebral palsy and coping behavior of parents, and found that parents experienced the most stressful period during the child's infancy due to the shock from the diagnosis, difficulties in the care of the child. Their most difficult period occurred during the child's toddlerhood, school-age and adolescence due to difficulties in terms of the child's under-developed

motor activity. Additional concern resulted from parental anxiety over what would happen to the child after their death. Finally, the study of Mengel, et al. (1996) and Monsen (1999) confirmed that parents of children with chronic illness had anxiety and concern about the future of the children when the parents became older and were unable to care for their children.

The mean score of financial burden was low. This result can be explained that most caregivers did not pay for medical treatment of their children because most children had the universal coverage for health welfare (75%) and caregivers had the reimbursement from government or state enterprise (10%). Fifty three percent of the caregivers were employed. The majority of the caregivers had family incomes between 6,001 and 10,000 baht per month (32%). Mean of family income of the sample was 19,662 baht / month. Although some of the caregivers could not work as they used to, they were able to adapt and had other works to replace income lost. It was indicated that caregivers did not difficult to pay for child's health needs and services. Moreover, the marital status of most of the caregivers was married and had relatives for assistance in caring for children with cerebral palsy. It was also indicated that caregiver did not pay for this expense.

However, for severity of disability, the majority of the children with cerebral palsy had a profound severity of disability, requiring medical treatment in the form of the outpatient rehabilitation, but were not admitted to a hospital unless they had complications. Murphy, et al. (2006) studied the costs and complications of hospitalizations for children with cerebral palsy and found that children with CP demonstrated longer lengths of stay, higher total charges, more diagnoses and more procedures per admission than patients with other diseases such as disorders of the respiratory system, disorders of the digestive system, etc. Upon admission to the hospital, caregivers will have expenses such as food, fare, and miscellaneous expenses that do not necessarily apply to the current study, as the majority of children in this study were not admitted in hospital. This finding can be explained in that the mean of duration of caregiving for the caregiver-subjects was 3.56 years and caregivers may receive information about caring for their children from health care providers. The long duration of care and information received offered the caregivers a chance to develop their ability in the caring and rehabilitation for their children. Therefore, the

caregivers had no problems with this expense. However, caregivers incurred transportation expenses when they took their children to a nursing home or hospital. Therefore, in caring for children with cerebral palsy, the caregivers had incurred expenses that were not a problem.

The mean score of physical burden was low, although caring for children with cerebral palsy had a physical health impact on caregivers. Eker and Tuzun (2004) studied an evaluation of quality of life of mothers of children with cerebral palsy. The Turkish version of the Medical Outcomes 36-Item Short Form Health Survey (SF-36) was the most widely used general health status instrument in this study. They found that the mothers of children with cerebral palsy had significantly lower quality of life and the quality of life scores of mothers were significantly correlated with the severity of their child's motor disability. The study finding of Eker and Tuzun (2004), however, was not consistent with the finding of the present study. This may be explained in that most caregivers were 21 to 40 years old (63%) and mean of caregiver's age was 37.66 years old. Most caregivers had assistants (73%) for both taking care of their children with cerebral palsy and household work. More than half of the caregivers (52%) had good health status to excellent health status that indicated their physical competency. However, the average duration of daily caregiving for children with cerebral palsy of the sample came to 18.62 hours; they had little time to rest and were sometimes physically tired.

The mean score of social burden was low. This can be explained in that most caregivers were married (84%) and had assistants (73%) for the care of their cerebral palsy children. These assistants comprised husbands (37%), parents (20%) and relatives whom the caregivers trusted. It was also indicated that the caregivers had someone to share and consult with as well as boost their spirits in taking care of their CP children and dealing with caring problems. Moreover, more than half of the caregiver (66%) was mothers of the children with cerebral palsy; thus, they had more satisfaction and were willing to stay with their children rather than to go to meet with their friends or others. These study findings were consistent with the findings of Martinson, et al. (1995) who studied Chinese mothers' reactions to their child's chronic illness and found that mothers had social relationships with persons who could take care of their children or exercised will power. Some mothers stated that they

could not go out from home unless their children went with them because they felt anxious and concerned for their children.

Objective 2: To investigate the predictive power of caregiver's age, family income, caregiver's health status, caregiving involvement, coping and severity of disability on caregiver burden.

The results showed that, all of the independent variables could jointly explain 26 percent of variance in caregiver burden (Overall $F_{(6, 93)} = 5.44$, $p<.001$). There were only three variables, which were caregiving involvement, caregiver's health status, and coping that could significantly predict the caregiver burden (Beta = 0.27, t = 2.85, $p<.01$; Beta = 0.27, t = 2.58, $p<.05$; Beta = -0.20, t = -2.26, $p<.05$, respectively) (Table 8).

The investigator took the caregiving involvement, caregiver's health status, and coping variables entered in the predictive equation. Stepwise multiple regression analysis was used to identify the predictability of caregiving involvement, caregiver's health status, and coping variables with caregiver burden in caring children with cerebral palsy. The result was showed that three variables together could jointly explain 23.7 percent of variance in caregiver burden (Overall $F_{(3, 96)} = 9.94$, $p<.001$). These study findings were discussed as follows:

Caregiving involvement

The results showed that the mean score of caregiving involvement of the sample was high (Mean = 42.09, SD = 9.08, Possible range from 0 to 60). When considering each, the mean score of vigilant tasks and child-care tasks were high (Mean = 3.49, SD = 0.56; Mean = 2.75, SD = 0.70), while the mean score of household tasks was moderate (Mean = 2.65, SD = 0.78) (Table 3). These findings were similar to other studies (Brust, Leonard, & Sielaff, 1992; Ray & Ritchie, 1993; Wittayasuporn, 1996). For example, Brust, et al. (1992) assessed time commitment required in which 133 mothers of children with disabled were asked to estimate by specific task categories the extra time required to care for the children. They found that total average daily care time was reported at 12 hours and 6 minute, with 6 hours and 30 minutes consumed in vigilant tasks.

Caregiving involvement was positively correlated with caregiver burden ($r = 0.34$, $p<.01$) and could explain 11.4 percent of variance in caregiver burden with statistical significance (Beta = 0.29, t = 3.33, $p< .001$). This result indicated that caregivers with lower caregiving involvement had a lower caregiver burden. This can be explained that children with cerebral palsy who had limitations in self-care functions such as bathing, eating, dressing, walking, preparing snacks and taking medicine required caring for long-term from caregivers. For this reason, caregivers of children with CP perceived burden.

The findings of this study were similar to other studies. For example, Wittayasuporn (1996) studied caregiver burden of caregiver in caring children with chronic illness and found that the caregiver burden was positively correlated with the amount of time spent in caring ($r = 0.36$, $p< .001$). Chou, LaMontagne, and Hepworth (1999) studied burden experienced by caregivers of relatives with dementia in Taiwan and found that caregiving involvement had significant positive effects on caregiver burden (path coefficients of 0.60). The findings revealed that the caregivers may have less time to rest which may lead to physical disruptions, less opportunity for social activities, and less time to do outside work, thus leading to feelings of burden as caregiving involvement increases.

Caregiver's health status was positively correlated with caregiver burden ($r = 0.30$, $p<.01$) and could explain additionally 7.5 percent of variance in caregiver burden with statistical significance (Beta = 0.26, t = 3.00, $p< .01$), which indicated that caregivers who rated their current health as excellent or good had significantly lower burden scores than caregivers who rated their health as fair or poor. It can be confirmed that health is one of the basic conditioning factor of caregivers that affect their abilities and exercise to engage or manage dependent-care demand (Orem, 1995).

The findings of this study were similar to those of other studies. Sales, Greeno, Shear, and Anderson (2004) studied maternal caregiving strain as a mediator in the relationship between child and mother mental health problems which were measured by Medical Outcomes 36-Item Short Form Health Survey (SF-36), with higher scores indicating better health. They found that physical and mental health was negatively correlated with caregiver burden ($r = -0.45$, $p<.001$) which indicated that poor

maternal health related to high caregiver burden. Bull (1990) investigated the factors influencing family caregivers' burden and health, determining changes in caregivers' burden and health outcome during the second week and 2 months post-discharge. The sample comprised 55 primary caregivers of chronically ill post-discharge patients with functional status ranging from impairment of instrumental activity of daily living, such as shopping, to persons who were bed bound. The results revealed that caregiver's physical health was inversely related to caregiver burden both at 2 weeks (r = -.05) and 2 months post-discharge (r = -0.13).

Caregivers of children with cerebral palsy devoted time and energy to helping children with cerebral palsy by performing daily tasks that they would be unable to perform alone; thus, the caregiver's time is limited for other activities or work. This study found that caregivers spent approximately 18 hours per day in caring for and helping cerebral palsy children. The physical and psychological demand of children with CP may lead to exacerbate physical illness with caregivers. Sometimes caregivers were so involved in the caregiving that they neglected their own physical and mental well-being. This study indicated that caregivers who had good health status had a lower burden than caregivers had poor health status.

Coping

The results showed that the mean score of coping of caregivers was high (Mean = 87.36, SD = 12.51). When considering each subscale, the mean score of coping pattern I: Family Integration, Co-operational and Optimistic Definition of the Situation and coping pattern III: Understanding the Health Care Situation through Communication with Other Parents and Consultation with the Health Care Team were high (Mean = 2.37, SD = 0.29; Mean = 2.24, SD = 0.48), while the mean score of coping pattern II: Maintaining Social Support, Self esteem and Physical Stability was moderate (Mean = 1.86, SD = 0.33) as presented in Table 4. These findings were similar to other studies (Peeseak, 1999; Poltana, 2001; Ray & Ritchie, 1993). For example, Poltana (2001) studied crisis, coping, and family adaptive problems of the family with chronically ill children. The results showed that the subjects perceived coping behaviors was helpful at a high level for their children (Mean = 133.45, SD =

13.52). The family used the several coping behaviors and most used coping pattern I. The following was coping pattern III and coping pattern II, respectively.

The sample of this study used coping styles which emphasize performing with the children such as managing the children's appointment at the hospital, investing time and energy in caring, reading more about the medical problem of children, encouraging children with medical condition to be more independent, believing that children will get better etc. Folkman and Lazarus (1988) asserted that people seek to manipulate the environment and change stressful situations, using problem-focused coping to manage distress, and emotion-focused coping strategies are used more in situations that are perceived as unchangeable. This study found that caregivers used both problem-focused and emotion-focused coping strategies to manage stress because cerebral palsy is a chronic illness that generally non-progresses in stages and caregivers must adapt themselves to long-term situations. In this study, the severity of disability of most children with cerebral palsy (72%) was profound level. For this reason, caregivers used both problem-focused and emotion-focused coping strategies to manage stress.

In this study, coping was negatively correlated with caregiver burden ($r = -0.26$, $p < .01$) could explain additionally 4.8 percent of variance in caregiver burden with statistical significance (Beta = 0.22, $t = 2.45$, $p < .05$). It indicated that caregivers who perceived a higher level of the usefulness coping behavior, perceived a lower level of burden. McCubbin and McCubbin (1996) described coping as involved complementary efforts of individual family members which fit together in a synergistic whole and create a balance between demands and resources that eliminates stresses and hardships at the same time. Moreover, Poltana (2002) who studied crisis, coping and family adaptive problems of families with chronically ill children found that coping could explain 2.4 percent of variance in adaptive problem level with statistical significance (Beta = -0.15, $t = -2.18$, $p < .05$). It indicated that caregivers who perceived the helpfulness of coping behaviors at a high level, would have family adaptive problems at a low level, so they would have good adaptation. The caregiving situations for the children with cerebral palsy produced distress to caregivers. Therefore, the caregivers who cope effectively, would have low caregiver burden.

The finding of this study was similar to other studies. Wittayasuporn (1996) studied caregiving burden of 74 parents of children with chronic illness and found that effective coping strategies had affected low caregiver burden. Magliano, Fadden, Madianos, et al. (1998) studied burden on the families of patients with schizophrenia and found that relatives experienced higher levels of burden when they had poor coping resources and reduced social support networks. This was similar to study of Saunders (2003) who reviewed literature about families living with severe mental illness, and found that relatives in several countries experienced higher levels of burden when they had poor coping resources and reduced social support.

From the multiple regression analysis, it was found that severity of disability, family income, and caregiver's age were not significant predictors of caregiver burden in caring for children with cerebral palsy as shown in Table 8. The study findings are discussed as follows:

Severity of disability was correlated with caregiver burden with statistical significance ($r = 0.18$, $p<.05$), indicating that caregivers who take care children with CP who had mild severity of disability perceived lower burden than caregivers who take care children with CP who had profound severity of disability. This can be explained that CP children with greater limitations for self-care or severity of disability demanded high caring from caregivers. Thus, the caregivers spent more time and had more activity in caring for their children with CP, which could become a caregiving burden. The finding of this study was similar to Angold, et al. (1998) who studied the predictors of perceived parental burden for 1,015 children and adolescents with psychiatric disorders in a longitudinal study, finding that significant predictors of perceived burden included levels of child symptomatology and impairment.

From multiple regression analysis, all of the independent variables included caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement, and coping could jointly explain 26 percent of variance in caregiver burden (Overall $F_{(6, 93)} = 5.44$, $p<.001$). However, the severity of disability could not significantly predict the caregiver burden ($p>.05$) (Table 8). This can be explained that the severity of disability was correlated with family income, caregiver's

health status, and caregiving involvement with statistical significance (r = -0.37, p<.001; r = 0.29, p<.01; r = 0.30, p<.01). If the children with cerebral palsy had profound severity of disability, the caregivers would have increasing expenses in the form of health services, transportation for medical care and laundry or housecleaning related to the children with cerebral palsy and would have more caregiving involvement; moreover, caregiver's health status declined. In addition caregiver's health status and caregiving involvement could further explain of variance in caregiver burden than severity of disability (Beta = 0.27, t = 2.58, p<.05; Beta = 0.27, t = 2.85, p< .01; Beta = -.01, t = -0.09, p>.05). Thus, it might be possible that severity of disability had more indirect than direct effect on caregiver burden through caregiving involvement and caregiver's health status. For this reason, severity of disability could not explain variance in caregiver burden.

Family income was correlated with caregiver burden with statistical significance (r = -0.27, p<.01), which indicated that when the caregivers had high income, they had low burden. It can be explained that income was a significant component contributing to individual potentiality in caring for dependents and answering individual basic needs as caregivers who had high income could seek resources for better care of their children with cerebral palsy. So, caregivers who had monetary resources were confident that they could mobilize funds to provide other resources to meet their demand. On the other hand, lower income persons were less likely to access adequate resources.

These findings were consistent with a previous study by Eamyingpanich (1996) who studied mother's caregiving burden and family well-being in the mentally retarded children and found that mothers who had higher income indicated that these mothers held a lower level of caregiver burden. Moreover Pipatananond (2001) who studied caregiver burden predictive model: An empirical test among caregivers for the schizophrenic found that income had a negative direct effect on caregiver burden, and its statistical test did not reached a significant level. An explanation of this non-significant effect of income on caregiver burden may be that it has been attributable to the nature of the study phenomena that prevented caregivers from mobilizing their money to manage existing demands. Another explanation may be that even money can

be used as a resource to access important information resources to facilitate caregivers in understanding their burden via a variety of sources; the information they obtained was not sufficient or relevant to the management of the problems confronting them.

However, through multiple regression analysis, family income could not significantly predict the caregiver burden ($p>.05$) (Table 8). This can be explained that family imcome was correlated with caregiving involvement with statistical significance ($r =-0.20$, $p<.05$). In addition, caregiving involvement could explain more variance in caregiver burden than family income (Beta = 0.27, $t = 2.85$, $p<.01$; Beta = - 0.15, $t = -1.54$, $p>.05$). Thus, it might be possible that family income had more indirect than direct effect on caregiver burden through caregiving involvement. For this reason, family income could not significantly explain variance in caregiver burden.

Caregiver's age was not significantly correlated with caregiver burden ($r = -0.06$, $p>.05$), which indicated that caregiver's age differed whereas caregiver burden did not. This finding was not concurrent with the findings of the previous studies. For example, Cook, Lefley, Pickett, et al. (1994) studied age and family burden among parents of offspring with severe mental illness and found that age could significantly predict the cognitive dimension or continual thinking about the patient and the responsible dimension or feeling of ongoing responsibility (Beta = 0.16, $p<0.10$; Beta = 0.24, $p<.01$, respectively) because caregiver's age was based on the support of caregiver's ability to meet the demands of illness which decreased over time i.e. caregiver function deteriorated with caregiver's age. One study about predictive models for caregiver burden consisted of an empirical test among caregivers of schizophrenics by Pipatananond (2001) and confirmed that caregiver's age had a direct positive effect on caregiver burden. However, Greenberg, Greenley, McKee, et al. (1993) studied mothers caring for adult children with schizophrenia: The effects of subjective burden on maternal health and found that mother's age was significantly negatively correlated with burden ($r = -0.29$, $p<.01$) as caregivers began to accept the situation and care receivers recovered from illness.

From the above-mentioned studies and others, it was indicated that caregiver's age was both significantly negatively and positively correlated with caregiver burden,

which reflects a possible confounding factor in the relationship between caregiver's age and burden in the intensity of the crisis period for the ill relative when data were collected. The study findings of Greenberg, Greenley, McKee, et al. (1993) may be explained in that the adult child with schizophrenia constituted a crisis condition (exacerbation of symptoms), but that age was not related to burden when the adult child with schizophrenia was in stable condition because older caregivers might have more experience in dealing with symptomatic behaviors. One study that did not find a relationship between caregiver's age and burden was the study of Reinhard (1994) who studied living with mental illness: Effects of professional support and personal control on caregiver burden. Caregivers in the study of Reinhard (1994) cared for ill relatives in stable condition. In contrast, the finding of the study of Horwitz, and Reinhard (1995) studied ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses and found that increased parental age led to declining level of burden involved in caring for ill relatives recently admitted to a psychiatric setting.

According to the findings of this study, caregiver's age was not significantly correlated with caregiver burden ($r = 0.06$, $p>.05$); this can be explained by the lengthy duration of caregiving provided by caregivers (Mean = 3.56, SD = 1.58), which indicated that caregiving experience, thus age was not related to caregiver burden.

In conclusion, this study showed that factors included caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement, and coping were incorporated factors that explained 26 percent of the variance in caregiver burden (Overall $F_{(6, 93)} = 5.44$, $p<.001$). There were three variables, the caregiving involvement, caregiver's health status, and coping that could significantly predict the caregiver burden ((Beta = 0.27, t = 2.85, $p<.01$; Beta = 0.27, t = 2.58, $p<.05$; Beta = -0.20, t = -2.26, $p<.05$, respectively) (Table 8).These three variables were entered in the predictive equation and stepwise multiple regression analysis was used to identify the predictability of caregiving involvement, caregiver's health status, and coping variables with caregiver burden in caring children with cerebral palsy. The results showed that three variables together could jointly explain 23.7 percent of the variance in caregiver burden (Overall $F_{(3, 96)} = 9.94$, $p<.001$).

The caregiving involvement could explain 11.4 percent of variance in caregiver burden with statistical significance (Beta = 0.29, t = 3.33, p< .001). The caregiver's health status could explain additionally 7.5 percent of the variance in caregiver burden with statistical significance (Beta = 0.26, t = 3.00, p< .01). The coping could explain additionally 4.8 percent of the variance in caregiver burden with statistical significance (Beta = -0.22, t = -2.45, p< .05).

CHAPTER VI
CONCLUSION

Summary of the Study

This descriptive study had the objective to examine the predicting factors of caregiver burden in caring for children with cerebral palsy. The sample consisted of 100 caregivers of children with cerebral palsy whose children were brought to rehabilitate at the Department of Rehabilitation Medicine of Siriraj Hospital, Sirindhorn National Medical Rehabilitation Center, and the Foundation for Handicapped children. Data were collected from August 2006 to December 2006 by using Demographic Characteristics Questionnaire, Severity of Disability Scale, Caregiver Burden Questionnaire, Caregiving Involvement Questionnaire, and Coping Questionnaire.

The data were analyzed using the statistical package for social science of Windows program and the results of the study could be summarized follows:

1. The demographic data of the caregivers and children with cerebral palsy were as follows:

1.1 More than half of the caregivers were 21 to 40 years old (63%). Most caregivers (84%) were married status. More than half of the caregivers were mothers (66%). Caregivers held primary education (34%) and secondary education (34%). Forty-six percent of caregivers were housewife or unemployed. The majority of the caregivers had family incomes between 6,001 and 10,000 baht per month (32%). More than half of the caregivers (55%) had inadequate of income. About sixty-two percent of the caregivers had a daily duration of caring for children with cerebral palsy 17 to 24 hours. More than half of caregivers (51%) had duration of caregiving 1 to 3 years. Seventy-three percent of the caregivers had the assistant in caring for children with CP. Forty-six percent of caregivers had child 2 to 3 persons. Most caregivers described their health status as fair (41%) and good (39%).

1.2 More than half of the children with cerebral palsy were 4 to 6 years old (66%), and male (52%). For severity of disability, seventy-two percent of children with cerebral palsy had profound severity of disability. Seventy-five percent of the children had the universal coverage for health welfare.

2. Caregiver burden

2.1 The mean score of caregiver burden was low (Mean = 43.51, SD = 13.37). When considering each subscale, the mean score of the emotional burden was moderate (Mean = 2.54, SD = 0.80), while the mean scores of financial burden, physical burden and social burden were low (Mean = 2.20, SD = 0.91; Mean = 2.06, SD = 0.86; Mean = 1.89, SD = 0.85, respectively).

2.2 All of the independent factors which included caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement, and coping were incorporated to explain 26 percent of variance in caregiver burden (Overall $F_{(6, 93)} = 5.44$, $p<.001$). There were three variables, the caregiving involvement, caregiver's health status, and coping that could significantly predict caregiver burden (Beta = 0.27, t = 2.85, $p<.01$; Beta = 0.27, t = 2.58, $p<.05$; Beta = -0.20, t = -2.26, $p<.05$, respectively) (Table 8). These three independent variables could jointly explain 23.7 percent of variance in caregiver burden (Overall $F_{(3, 96)} = 9.94$, $p<.001$). The first variable was caregiving involvement which could explain 11.4 percent of variance in caregiver burden with statistical significance (Beta = 0.29, t = 3.33, $p< .001$), while caregiver's health status could explain additionally 7.5 percent with statistical significance (Beta = 0.26, t = 3.00, $p< .01$) and coping could explain additionally 4.8 percent with statistical significance (Beta = -0.22, t = -2.45, $p< .05$).

Implications and Recommendations

Implications for nursing practice

According to the results of this study, If caregivers of children with cerebral palsy have low caregiving involvement, excellent health status, and effecteve coping, they will have low burden. Therefore, nurses should use the findings as a guideline for the development of nursing care for caregivers of children with cerebral palsy as follows:

1. Nurses should develop intervention to increase the caregiver's skill in providing care, coping repertoire and enhance their support networks as follows:

1.1 Enhancing self-management of families and capable children with providing more information to families about CP as well as access to community resources.

1.2 Promoting and providing continuing group support as an exchange of knowledge and techniques to solve caring problems of the children with CP for caregivers.

2. Nurses should provide advice about various resources closer to the family's home thereby decreasing transportation time. These resources should be highly beneficial and relavant to the demands and problems of caregivers and children with CP.

3. Nurses should provide special services to families of children with CP by providing home visits and giving help to the caregiver and their children with consideration of personal factors that affect perceived caregiving burden. The services should be relevant to the demands and problems of caregivers and children so that the caregiver can deliver appropriate care to children with CP.

4. Nurse should encourage family members to share in the care of children with cerebral palsy and household work with caregivers. This would increase healthy relationships with all family members and also decrease stress and burden levels of the caregivers.

5. Nurse should encourage and promote the health and well-being of caregivers to support ability in caring their children.

Implications for further study

1. The burden model of Chou (2000) showed that caregiving involvement, coping, filial obligation, and self-efficacy influenced caregiver burden. Therefore, further study should examine other factors included filial obligation and caregiving self-efficacy that may influence caregiver burden in caring for children with cerebral palsy.

2. The study result showed that all of the independent variables, which included caregiver's age, caregiver's health status, family income, severity of disability, caregiving involvement, and coping were incorporated to explain 26 percent

of variance in caregiver burden. Therefore, further study should examine other factors that may influence caregiver burden in caring for children with CP such as children age and social support.

3. For the present study, the samples were caregivers who brought their children with CP to attend the rehabilitation at health service system. It was found that caregiver burden was low. Therefore, further studies should be conducted in the caregivers at home.

Limitations of the Study

This study implemented convenience sampling that had limitations in referring to the population. However the investigator managed this problem with the appropriate statistic use and the sample size calculation. Moreover, data were collected from three sites. For this reason, the result error and the external validity missing problem were decreased.

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APPENDIX

APPENDIX A

List of Content Validators

The content validity of the interviews and questionnaires used in this study was assured by three validators. Name list of content validators was as follows:

1. Assist. Prof. Jariya Witayasuporn,
   Ph.D. (Nursing)
   Department of Nursing
   Faculty of Medicine, Ramathibodi Hospital
   Mahidol University
2. Miss Ubonwon Wathanadilokul, M.D.
   Sirindhorn National Medical Rehabilitation Center
   Ministry of Public Health
3. Assist. Prof. Weeraya Jungsomjetpaisal
   M.S. (M.C.H. Nursing)
   Faculty of Nursing, Mahidol University

APPENDIX B

Documentary Proof of Ethical Clearance

Documentary Proof of Ethical Clearance from the Committee on Human Rights Related to Human Experimentation, Mahidol University

No. MU 2006-130

Documentary Proof of Ethical Clearance
The Committee on Human Rights Related to Human Experimentation
Mahidol University, Bangkok

Title of Project: Predicting Factors of Caregiving Burden for Children with Cerebral Palsy (Thesis for Master Degree)

Principle Investigator: Miss Wanid Duangdech

Name of Institution: Faculty of Nursing

Approved by the Committee on Human Rights Related to Human Experimentation

Signature of Chairman: .....
(Professor Dr.Srisin Khusmith)

Signature of Head of the Institute: .....
(Professor Dr.Pornchai Matangkasombut)

Date of Approval: 24 JUL 2006

Date of Expiration: 23 JUL 2007

Documentary Proof of Ethical Clearance from the Committee on Human Rights Related to Human Experimentation, Siriraj Hospital

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Siriraj Ethics Committee

Certificate of Approval COA no.Si 300/2006

Protocol Title : Predicting factors of caregiving burden for children with cerebral palsy.

SiEC number : 297/2549

Principal Investigator/Affiliation : Miss. Wanid Duangdech
Faculty of Nursing, Mahidol University

Research site : Faculty of Medicine Siriraj Hospital

Approval includes :

1. EC Submission form
2. Proposal
3. Participant information sheet
4. Informed consent form
5. Questionnaire

Approval date : November 14, 2006

Expired date : November 13, 2007

This is to certify that Siriraj Ethics Committee is in full Compliance with International Guidelines For Human Research Protection such as Declaration of Helsinki, The Belmont Report, CIOMS Guidelines and the International Conference on Harmonization in Good Clinical Practice (ICH-GCP)

(Prof. Sumalee Nimmannit, M.D.) November 15, 2006
Chair Person date

(Clin. Prof. Piyasakol Sakolsatayadorn) November 16, 2006
Dean of Faculty of Medicine Siriraj Hospital date

Sirindhorn National Medical Rehabilitation Center

บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล
คณะแพทยศาสตร์ศิริราชพยาบาล
อาคารรักษ์สิ่งแวดล้อม ชั้น 3 2 ถนนพรานนก
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โทร. 0-2411-2002 โทรสาร 0-2419-9485

ที่ ศธ 0517.02 (ศร)/

26 มิถุนายน 2549

เรื่อง ขอความอนุเคราะห์ให้นักศึกษาได้มาเก็บข้อมูล เพื่อประกอบการทำวิทยานิพนธ์

เรียน ผู้อำนวยการศูนย์สิรินธรเพื่อการฟื้นฟูสมรรถภาพทางการแพทย์แห่งชาติ

สิ่งที่ส่งมาด้วย แบบสอบถาม, แบบสัมภาษณ์ จำนวน 1 ชุด

ด้วย นางสาววานิด ด้วงเดช นักศึกษาบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล หลักสูตรปรัญญาโท สาขาวิชาการพยาบาลเด็ก คณะพยาบาลศาสตร์ กำลังเขียนโครงร่างวิทยานิพนธ์ เรื่อง "ปัจจัยทำนายภาระของผู้ดูแลเด็กสมองพิการ" อยู่ในความควบคุมของ รศ.รัชนี สีดา ซึ่งในการศึกษาวิจัยครั้งนี้นักศึกษามีความประสงค์จะเก็บข้อมูลจากผู้ดูแลเด็กสมองพิการที่มีอายุระหว่าง 6 เดือน – 6 ปี ซึ่งนำเด็กสมองพิการมารับการตรวจรักษา ณ งานกระตุ้นพัฒนาการเด็กของศูนย์สิรินธรเพื่อการฟื้นฟูสมรรถภาพทางการแพทย์แห่งชาติ โดยใช้วิธีสัมภาษณ์และส่งแบบสอบถามด้วยตนเอง ตั้งแต่วันที่ 1 สิงหาคม 2549 ถึงวันที่ 31 มีนาคม 2550

บัณฑิตวิทยาลัย จึงใคร่ขอความกรุณาจากท่านโปรดอนุเคราะห์ให้นักศึกษาได้เก็บข้อมูล เพื่อประกอบการทำวิทยานิพนธ์ ตามที่เห็นสมควรด้วย จักเป็นพระคุณยิ่ง

ขอแสดงความนับถือ

(ศาสตราจารย์ นพ.บรรจง มไหสวริยะ)
รองคณบดีฝ่ายวิชาการ
ปฏิบัติราชการแทน คณบดีบัณฑิตวิทยาลัย

เรียน ผู้อำนวยการ

(เฉลียว เฉื่อยจ่า)
พนักงานพิมพ์ดีด ชั้น 2
... ก.ค. 2549

ติดต่ออาจารย์ผู้ควบคุมวิทยานิพนธ์ รศ.รัชนี สีดา
โทรศัพท์ 0-2412-9079

Permission Letter for using instrument of Chiangmai University

ที่ ศธ 0515(013)/๑๗๖

บัณฑิตวิทยาลัย มหาวิทยาลัยเชียงใหม่
239 ถนนห้วยแก้ว อำเภอเมือง
จังหวัดเชียงใหม่ 50200

๑ กุมภาพันธ์ 2549

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน ประธานกรรมการบริหารหลักสูตรพยาบาลศาสตรมหาบัณฑิต มหาวิทยาลัยมหิดล

อ้างถึง หนังสือ ที่ ศธ 0517.05(พย.ม.)/043 ลงวันที่ 25 มกราคม 2549

ตามที่ประธานกรรมการบริหารหลักสูตรพยาบาลศาสตรมหาบัณฑิต มหาวิทยาลัยมหิดล มีความประสงค์จะขออนุญาตให้นางสาววานิด ด้วงเดช นักศึกษาหลักสูตรพยาบาลศาสตรมหาบัณฑิต สาขาการพยาบาลเด็ก คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล นำเครื่องมือวิจัยในวิทยานิพนธ์ของพึงพิศ ศรีสืบไปใช้ในงานวิจัยนั้น

บัณฑิตวิทยาลัย มหาวิทยาลัยเชียงใหม่ พิจารณาแล้วไม่ขัดข้อง และยินดีอนุญาตให้นำเครื่องมือดังกล่าวไปใช้ประโยชน์ในการศึกษาวิจัยได้

จึงเรียนมาเพื่อโปรดทราบ

ขอแสดงความนับถือ

(รองศาสตราจารย์วราภรณ์ ปัณณวลี)
รองคณบดีฝ่ายวิชาการ ปฏิบัติราชการแทน
คณบดีบัณฑิตวิทยาลัย

งานบริการการศึกษา
โทร. 053-942423
โทรสาร 053-892231

APPENDIX C

Information Sheet and Informed Consent Form

คำอธิบายโครงการวิจัย

หัวข้อเรื่องที่จะทำการวิจัย

ปัจจัยทำนายภาระของผู้ดูแลเด็กสมองพิการ

วัตถุประสงค์และวิธีการวิจัย

วัตถุประสงค์

1. เพื่อศึกษาภาระของผู้ดูแลในการดูแลเด็กสมองพิการ
2. เพื่อศึกษาอำนาจการทำนายของตัวแปรอิสระได้แก่ ปัจจัยด้านผู้ดูแล ได้แก่ อายุ รายได้ของครอบครัว ภาวะสุขภาพ การมีส่วนร่วมในการดูแล และ การเผชิญความเครียดในการดูแล ปัจจัยด้านเด็ก ได้แก่ ระดับความรุนแรงของความพิการ ต่อภาระของผู้ดูแลเด็กสมองพิการ

วิธีการวิจัย

การวิจัยนี้เป็นการศึกษาความสัมพันธ์เชิงทำนาย (Predictive Correlation Studies) เพื่อศึกษาอำนาจการทำนายของตัวแปรอิสระได้แก่ ปัจจัยด้านผู้ดูแล ได้แก่ อายุ รายได้ของครอบครัว ภาวะสุขภาพ การมีส่วนร่วมในการดูแล และ การเผชิญความเครียดในการดูแล ปัจจัยด้านเด็ก ได้แก่ ระดับความรุนแรงของความพิการ ต่อภาระของผู้ดูแลเด็กสมองพิการ

เหตุผลที่เชิญชวนให้ผู้ยินยอมตนให้ทำการวิจัยเข้าโครงการวิจัย

เนื่องจากภาระของผู้ดูแลเด็กสมองพิการ เป็นปัญหาที่สำคัญและเป็นสิ่งที่เข้าใจยาก เพราะเป็นประสบการณ์ตรงของผู้ดูแลเด็กสมองพิการ ผู้รักษาพยาบาลมักไม่เข้าใจสถานการณ์ที่ผู้ดูแลประสบและไม่ทราบว่ามีปัจจัยใดบ้างที่เกี่ยวข้องกับภาระของผู้ดูแลเด็กสมองพิการ ทำให้ไม่สามารถให้การดูแลช่วยเหลือผู้ดูแลได้อย่างถูกต้อง และมีประสิทธิภาพ

ระยะเวลาที่ต้องการทำการทดสอบในผู้ยินยอมตนให้ทำการวิจัย

ผู้ยินยอมตนให้ทำการวิจัยแต่ละคนจะต้องใช้เวลาในการตอบคำถามและตอบแบบสอบถามประมาณ 45-60 นาที

ประโยชน์ที่คาดว่าจะเกิดขึ้นทั้งต่อผู้ยินยอมตนให้ทำการวิจัยและต่อผู้อื่น

1. พยาบาลตระหนักถึงภาระของผู้ดูแล
2. พยาบาลได้แนวทางในการวางแผนช่วยเหลือผู้ดูแลที่ต้องรับภาระในการดูแลเด็กสมองพิการ ให้สามารถปรับตัวกับภาระการดูแลเด็กสมองพิการได้อย่างเหมาะสม
3. เป็นข้อมูลในการทำวิจัยที่เกี่ยวข้องต่อไป

ความเสี่ยงหรือความไม่สบายใดที่คาดว่าจะเกิดขึ้นกับผู้ยินยอมตนให้ทำการวิจัยในการเข้าร่วมการศึกษาวิจัย

เนื่องจากการวิจัยนี้เป็นการวิจัยแบบบรรยาย เก็บรวบรวมข้อมูลจากผู้ดูแลเด็กสมองพิการโดยใช้แบบสอบถาม ซึ่งไม่ก่อให้เกิดอันตรายต่อผู้ยินยอมตนให้ทำการวิจัย อย่างไรก็ตามหากผู้ยินยอมตนให้ทำการวิจัยรู้สึกไม่สบายใจ กังวลใจในการตอบแบบสอบถาม ผู้วิจัยจะให้ผู้ยินยอมตนให้ทำการวิจัยพักการตอบแบบสอบถามไว้ก่อน และดูแลผู้ยินยอมตนให้ทำการวิจัยอย่างใกล้ชิดจนกว่าสบายใจขึ้น หากดีขึ้นแล้วและยินดีที่จะตอบแบบสอบถามต่อ ผู้วิจัยจะให้ผู้ยินยอมตนให้ทำการวิจัยได้ตอบแบบสอบถามต่อไป แต่ถ้ายังมีความไม่สบายใจอยู่และไม่ยินดีที่จะตอบแบบสอบถามต่อ ผู้ยินยอมตนให้ทำการวิจัยสามารถยกเลิกการเข้าร่วมการวิจัยต่อไปได้ทันที

การเตรียมผลิตภัณฑ์ หรือกระบวนการรักษาที่พิสูจน์จากการทำวิจัยแล้วว่าปลอดภัย และมีประสิทธิผลไว้ให้ผู้ยินยอมตนให้ทำการวิจัยอย่างไร

เนื่องจากการวิจัยนี้เป็นการศึกษาแบบบรรยายและเก็บรวบรวมข้อมูลโดยการสัมภาษณ์ และใช้แบบสอบถาม ซึ่งไม่ก่อให้เกิดอันตรายหรือความเสี่ยงต่อสุขภาพของผู้ยินยอมตนให้ทำการวิจัยแต่อย่างใด

ทางเลือกในการรักษาหรือวิธีการตรวจวินิจฉัยอื่น ที่อาจเป็นประโยชน์แก่ผู้ยินยอมตนให้ทำการวิจัย

เนื่องจากการวิจัยนี้ เป็นการศึกษาแบบบรรยายและเก็บรวบรวมข้อมูลโดยการสัมภาษณ์และใช้แบบสอบถาม ซึ่งไม่ก่อให้เกิดอันตรายหรือความเสี่ยงต่อสุขภาพของผู้ยินยอมตนให้ทำการวิจัยแต่อย่างใด

ขอบเขตการดูแลรักษาความลับของข้อมูลต่าง ๆ ของผู้ยินยอมตนให้ทำการวิจัย

ข้อมูลที่ได้จากผู้ยินยอมตนให้ทำการวิจัยทั้งหมดจะถูกเก็บเป็นความลับและจะไม่เปิดเผยชื่อ-นามสกุลใด ๆ ทั้งสิ้น ซึ่งข้อมูลทั้งหมดจะถูกวิเคราะห์และสรุปออกมาในภาพรวม

การดูแลรักษาที่ผู้วิจัยจะจัดให้

เนื่องจากการวิจัยนี้เป็นการวิจัยแบบบรรยาย เก็บรวบรวมข้อมูลจากผู้ดูแลเด็กสมองพิการโดยใช้แบบสอบถาม ซึ่งไม่ก่อให้เกิดอันตรายต่อผู้ยินยอมตนให้ทำการวิจัย อย่างไรก็ตามหากผู้ยินยอมตนให้ทำการวิจัยรู้สึกไม่สบายใจ กังวลใจในการตอบแบบสอบถาม ผู้วิจัยจะให้ผู้ยินยอมตนให้ทำการวิจัยพักการตอบแบบสอบถามไว้ก่อน และดูแลผู้ยินยอมตนให้ทำการวิจัยอย่างใกล้ชิดจนกว่าสบายใจขึ้น หากดีขึ้นแล้วและยินดีที่จะตอบแบบสอบถามต่อ ผู้วิจัยจะให้ผู้ยินยอมตนให้ทำการวิจัยได้ตอบแบบสอบถามต่อไป แต่ถ้ายังมีความไม่สบายใจอยู่และไม่ยินดีที่จะตอบแบบสอบถามต่อ ผู้ยินยอมตนให้ทำการวิจัยสามารถยกเลิกการเข้าร่วมการวิจัยต่อไปได้ทันที หรือหากขณะตอบแบบสอบถามผู้ยินยอมตนให้ทำการวิจัยมีอาการผิดปกติ เช่น หน้ามืด ,ใจสั่น ,คล้าย

จะเป็นลม เป็นต้น จะได้รับการช่วยเหลือโดยนำส่งห้องฉุกเฉินหรือห้องพยาบาลเพื่อรับการปฐมพยาบาลทันที

กรณีเกิดอันตรายหรือผลไม่พึงประสงค์จากการศึกษาวิจัย ผู้ยินยอมตนให้ทำการวิจัยจะได้รับการดูแลรักษาโดยไม่ต้องเสียค่าใช้จ่ายอย่างไรบ้าง

เนื่องจากการวิจัยนี้ เป็นการศึกษาแบบบรรยายและเก็บรวบรวมข้อมูลโดยการสัมภาษณ์และใช้แบบสอบถาม ซึ่งไม่ก่อให้เกิดอันตรายหรือความเสี่ยงต่อสุขภาพของผู้ยินยอมตนให้ทำการวิจัยแต่อย่างใด

ในกรณีเกิดอันตรายจากการทำวิจัยถึงขั้นพิการหรือเสียชีวิต ผู้ป่วยหรือทายาทจะได้รับการชดเชยอย่างไร

เนื่องจากการวิจัยนี้ เป็นการศึกษาแบบบรรยายและเก็บรวบรวมข้อมูลโดยการสัมภาษณ์และใช้แบบสอบถาม ซึ่งไม่ก่อให้เกิดอันตรายหรือความเสี่ยงต่อสุขภาพของผู้ยินยอมตนให้ทำการวิจัยแต่อย่างใด

สิทธิผู้ยินยอมตนให้ทำการวิจัยจะถอนตัวออกจากโครงการวิจัยได้ทุกเมื่อโดยไม่กระทบต่อการดูแลรักษาที่พึงได้รับตามปกติ

หากขณะตอบคำถามและตอบแบบสอบถามผู้ยินยอมตนให้ทำการวิจัยไม่สะดวกหรือสบายใจที่จะตอบคำถาม หรือมีอาการผิดปกติ เช่น หน้ามืด ,ใจสั่น ,คล้ายจะเป็นลม เป็นต้น ผู้ยินยอมตนให้ทำการวิจัยสามารถถอนตัวออกจากการวิจัยได้โดยไม่มีผลกระทบต่อการดูแลรักษาที่พึงได้รับตามปกติจากโรงพยาบาลหรือสถานบริการ และจะได้รับการช่วยเหลือทันทีที่เกิดอาการผิดปกติ

ชื่อ ที่อยู่ และเบอร์โทรศัพท์ของแพทย์ ที่ผู้ยินยอมตนให้ทำการวิจัยสามารถติดต่อได้สะดวก ทั้งในและนอกเวลาราชการกรณีมีเหตุจำเป็นหรือฉุกเฉิน

นางสาววานิด ด้วงเดช
คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล
ถนนพรานนก เขตบางกอกน้อย กรุงเทพฯ 10700
หมายเลขโทรศัพท์ที่สามารถติดต่อได้ตลอด 24 ชั่วโมง 085-9373798

วานิด ด้วงเดช
ผู้วิจัย

Informed Consent Form

แบบฟอร์มใบยินยอมให้ทำการวิจัย โดยได้รับการบอกกล่าวและเต็มใจ

การวิจัยเรื่อง ปัจจัยทำนายภาระของผู้ดูแลเด็กสมองพิการ

วันที่ให้คำยินยอม วันที่.....เดือน.....พ.ศ.....

ก่อนที่จะลงนามในใบยินยอมให้ทำการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจากผู้วิจัยถึง วัตถุประสงค์ของการวิจัย วิธีวิจัย อันตราย หรืออาการที่อาจเกิดขึ้นจากการวิจัยหรือจากยาที่ใช้ รวมทั้งประโยชน์ที่จะเกิดขึ้นจากการวิจัยอย่างละเอียด และมีความเข้าใจดีแล้ว

ผู้วิจัยรับรองว่าจะตอบคำถามต่าง ๆ ที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบังซ่อนเร้น จนข้าพเจ้าพอใจ

ข้าพเจ้ามีสิทธิที่จะบอกเลิกการเข้าร่วมโครงการวิจัยนี้เมื่อใดก็ได้ และเข้าร่วมโครงการวิจัยนี้โดยสมัครใจ และการบอกเลิกการเข้าร่วมการวิจัยนี้จะไม่มีผลต่อการรักษาโรคที่ข้าพเจ้าจะพึงได้รับต่อไป

ผู้วิจัยรับรองว่าจะเก็บข้อมูลที่เกี่ยวกับตัวข้าพเจ้าเป็นความลับ และจะเปิดเผยไว้เฉพาะในรูปที่สรุปผลการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่าง ๆ ที่เกี่ยวข้องกระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ผู้วิจัยรับรองว่าหากเกิดอันตรายใด ๆ จากการวิจัยดังกล่าว ข้าพเจ้าจะได้รับการรักษาพยาบาลโดยไม่คิดมูลค่าตามมาตรฐานวิชาชีพ และจะได้รับการชดเชยรายได้ที่สูญเสียไประหว่างการรักษาพยาบาลดังกล่าว ตลอดจนเงินทดแทนความพิการที่อาจเกิดขึ้น

ผู้วิจัยรับรองว่าหากมีข้อมูลเพิ่มเติมที่ส่งผลกระทบต่อการวิจัย ข้าพเจ้าจะได้รับแจ้งให้ทราบโดยไม่ปิดบังซ่อนเร้น

ข้าพเจ้าได้อ่านข้อความข้างต้นแล้ว และมีความเข้าใจดีทุกประการ และได้ลงนามยินยอมในใบยินยอมนี้ด้วยความเต็มใจ

ลงนาม..... ผู้ยินยอม

ลงนาม..... พยาน

ลงนาม..... พยาน

APPENDIX D

The Instruments

Part 1 เลขที่แบบสอบถาม.....

วันที่.....

ชุดที่ 1 แบบสอบถามข้อมูลส่วนบุคคล

คำชี้แจง: กรุณาตอบแบบสอบถามเกี่ยวกับตัวท่านโดยทำเครื่องหมาย ถูก (✓) หน้าข้อความ หรือเติมคำใน ☐ ช่องว่าง

ข้อมูลของผู้ดูแลเด็กสมองพิการ

อายุ..... ปี (นับเต็มปีจนถึงปัจจุบัน)

เพศ ☐ หญิง ☐ ชาย

สถานภาพสมรส ☐ คู่ ☐ หย่า ☐ แยก ☐ อื่น ๆ ระบุ.....

ความสัมพันธ์ของท่านกับเด็กสมองพิการ

- ☐ บิดา
- ☐ มารดา
- ☐ ญาติ ระบุ.....
- ☐ อื่น ๆ ระบุ.....

จำนวนบุตร .....คน

การศึกษาสูงสุดของท่าน

- ☐ ไม่ได้เรียน
- ☐ ประถมศึกษาปีที่.....
- ☐ มัธยมศึกษาปีที่.....
- ☐ ประกาศนียบัตรหรืออนุปริญญา
- ☐ ปริญญาตรี
- ☐ สูงกว่าปริญญาตรี

อาชีพ

- ☐ ไม่ได้ประกอบอาชีพ
- ☐ รับจ้าง ระบุ .....
- ☐ ค้าขาย

☐ เกษตรกรรม

☐ รับราชการ

☐ พนักงานรัฐวิสาหกิจ

☐ อื่น ๆ ระบุ.....

รายได้ของครอบครัว.....บาท/เดือน

ความเพียงพอของรายได้

☐ ไม่เพียงพอ

☐ เพียงพอ

☐ เหลือเก็บ

ในภาพรวมสุขภาพโดยทั่วไปของท่านในปัจจุบันเป็นอย่างไร

☐ สุขภาพดีเยี่ยม

☐ สุขภาพดีมาก

☐ สุขภาพดี

☐ สุขภาพพอใช้

☐ สุขภาพไม่ดี

ระยะเวลาที่ท่านดูแลเด็กสมองพิการ เป็นเวลา.....ปี..... เดือน

ให้การดูแลเด็กสมองพิการโดยเฉลี่ยกี่ชั่วโมงในหนึ่งวัน..... ชั่วโมง

มีผู้ช่วยเหลือในการดูแลเด็กสมองพิการหรือไม่

☐ ไม่มี

☐ มี ได้แก่ .....

ข้อมูลของเด็กสมองพิการ

อายุ..... ปี.....เดือน

เพศ ☐ หญิง ☐ ชาย

เมื่อท่านนำเด็กสมองพิการมารักษาที่โรงพยาบาล ท่านชำระเงินด้วยวิธี

☐ จ่ายเงินเอง

☐ ใช้สิทธิ์ข้าราชการหรือพนักงานรัฐวิสาหกิจ

☐ บัตรประกันสังคม

☐ ใช้บัตรประกันสุขภาพถ้วนหน้า (บัตรทอง 30 บาท)

☐ บัตรสงเคราะห์คนพิการ

☐ อื่น ๆ ระบุ.....

ชุดที่ 2 แบบสอบถามภาระของผู้ดูแลเด็กสมองพิการ

คำชี้แจง: ภาระของผู้ดูแล เป็นการรับรู้ หรือความรู้สึกของท่าน ต่อเหตุการณ์ กิจกรรม ที่เกิดจากการดูแลเด็กสมองพิการ ว่ามีผลกระทบต่อท่านในด้านร่างกาย อารมณ์ สังคม หรือด้านการเงิน

แบบสอบถามนี้ ต้องการทราบว่าภาระในการดูแลเด็กสมองพิการของท่านเป็นอย่างไร ขอให้ท่านอ่านข้อความแต่ละข้อ แล้วพิจารณาว่าข้อใดตรงกับความรู้สึกของท่านมากที่สุด โดยใส่เครื่องหมายถูก (✓) ลงในช่องทางขวามือที่ตรงกับความรู้สึกของท่านเพียงช่องเดียว โดยแต่ละข้อคำตอบมีความหมาย ดังนี้

ไม่เห็นด้วย หมายถึง ข้อความนั้นไม่ตรงกับความรู้สึกของท่านในการดูแลเด็กสมองพิการเลย

เห็นด้วยเล็กน้อย หมายถึง ข้อความนั้นตรงกับความรู้สึกของท่านในการดูแลเด็กสมองพิการเล็กน้อย

เห็นด้วยปานกลาง หมายถึง ข้อความนั้นตรงกับความรู้สึกของท่านในการดูแลเด็กสมองพิการปานกลาง

เห็นด้วยมาก หมายถึง ข้อความนั้นตรงกับความรู้สึกของท่านในการดูแลเด็กสมองพิการมาก

เห็นด้วยมากที่สุด หมายถึง ข้อความนั้นตรงกับความรู้สึกของท่านในการดูแลเด็กสมองพิการมากที่สุด

ตัวอย่าง

ข้อความ	ไม่เห็นด้วย	เห็นด้วยเล็กน้อย	เห็นด้วยปานกลาง	เห็นด้วยมาก	เห็นด้วยมากที่สุด
ก. ครอบครัวของฉันมีค่าใช้จ่ายมากขึ้นเมื่อต้องดูแลเด็กสมองพิการ				✓	

จากคำตอบ

ก. แสดงว่าท่าน รู้สึกเห็นด้วยมาก ว่าครอบครัวของท่านมีค่าใช้จ่ายมากขึ้นเมื่อต้องมาดูแลเด็กสมองพิการ

ข้อความ	ไม่เห็นด้วย	เห็นด้วยเล็กน้อย	เห็นด้วยปานกลาง	เห็นด้วยมาก	เห็นด้วยมากที่สุด
1. การดูแลเด็กสมองพิการ ทำให้ฉันนอนหลับไม่เพียงพอ					
2. การดูแลเด็กสมองพิการ ทำให้ฉันรู้สึกเหน็ดเหนื่อย หรืออ่อนล้ามากขึ้น					
3. สุขภาพของฉันแย่ลงกว่าเดิม เมื่อฉันต้องมาดูแลเด็กสมองพิการ เช่น ปวดหลัง เป็นหวัดบ่อย					
4. การดูแลเด็กสมองพิการ ทำให้ฉันเจ็บป่วยจนต้องไปรับการรักษาบ่อยขึ้น					
5. ฉันรู้สึกอับอายต่อท่าทางหรือพฤติกรรมของเด็กสมองพิการ เช่น ก้าวร้าว ดื้อรั้น เอาแต่ใจตนเอง ต่อต้าน เกร็ง					
6.					
7.					
.....					
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.....					
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18					
19.....					

ชุดที่ 3 แบบสอบถามการมีส่วนร่วมในการดูแลเด็กสมองพิการ

คำชี้แจง: การมีส่วนร่วมในการดูแลเด็กสมองพิการ เป็นการประเมินปริมาณเวลาที่ใช้ในการดูแลเด็กสมองพิการของผู้ดูแล

ขอให้ท่านอ่านข้อความแต่ละข้อ แล้วพิจารณาว่าการดูแลเด็กสมองพิการที่ท่านรับผิดชอบอยู่ในขณะนี้ท่านต้องใช้เวลาในการดูแลเด็กสมองพิการในแต่ละกิจกรรม มากน้อยเพียงใด ขอให้ท่านใส่เครื่องหมายถูก (✓) ลงในช่องที่ ตรงกับความรู้สึกของท่านในเรื่องปริมาณเวลาที่ใช้ในการดูแล และหากว่าท่านไม่ได้ให้การดูแลเด็กในข้อนั้น ๆ ขอให้ท่านใส่เครื่องหมายถูก (✓) ลงในช่อง **ไม่ได้ทำ**

ตัวอย่าง

กิจกรรมในแต่ละวัน	**เวลาที่ใช้ในการดูแล**				**ไม่ได้ทำ**
	น้อย	**ปานกลาง**	**มาก**	**มากที่สุด**	
ก. การให้กำลังใจ ปลอบโยน และอยู่เป็นเพื่อน เล่นกับเด็กสมองพิการ			✓		
ข. การจัดกิจกรรมนอกบ้านให้กับเด็กสมองพิการ เช่น พาไปเที่ยว พาไปเยี่ยมญาติ					✓

จากคำตอบ

ก. แสดงว่าท่านใช้เวลาในการให้กำลังใจ ปลอบโยน และอยู่เป็นเพื่อน เล่นกับเด็กสมองพิการ มาก

ข. แสดงว่า ท่านไม่ได้จัดกิจกรรมนอกบ้านให้กับเด็กสมองพิการ เช่น พาไปเที่ยว หรือพาไปสถานที่พักผ่อนต่าง ๆ

กิจกรรมในแต่ละวัน	เวลาที่ใช้ในการดูแล				ไม่ได้ทำ
	น้อย	ปานกลาง	มาก	มากที่สุด	
1. การดูแลเกี่ยวกับการรักษาพยาบาล (รับประทานยา ทำแผล ให้อาหารทางสายยาง ทำกายภาพบำบัดและอื่นๆ)					
2. การดูแลกิจวัตรประจำวัน (การอาบน้ำ การแต่งตัว การรับประทานอาหาร การขับถ่าย และอื่น ๆ)					
3. อยู่เป็นเพื่อนกับเด็กสมองพิการขณะให้การรักษาพยาบาล (รับประทานยา ทำกายภาพบำบัด ให้อาหารทางสายยาง)					
4.					
5.					
....					
....					
....					
15.....					

ชุดที่ 4 แบบสอบถามพฤติกรรมเผชิญความเครียดของผู้ดูแลเด็กสมองพิการ

คำชี้แจง : พฤติกรรมการเผชิญความเครียดเป็นวิธีการที่ท่านใช้ในการแก้ปัญหา กับเหตุการณ์หรือสถานการณ์ที่ทำให้ท่านเกิดความเครียด ซึ่งเป็นผลจากการดูแลเด็กสมองพิการ

ขอให้ท่านอ่านข้อความในแต่ละข้อ และพิจารณาว่าพฤติกรรมการเผชิญความเครียดในแต่ละข้อนั้น มีประโยชน์กับท่านในการดูแลเด็กสมองพิการ และ/หรือ ลดความตึงเครียด ได้มากน้อยเพียงใด ขอให้ท่านทำเครื่องหมายถูก (✓) ลงในช่องทางขวามือที่ตรงกับการรับรู้หรือความรู้สึกของท่านว่าพฤติกรรมเผชิญความเครียดนั้น ไม่มีประโยชน์เลย มีประโยชน์เล็กน้อย มีประโยชน์ปานกลาง หรือมีประโยชน์มาก เพียงข้อใดข้อหนึ่งเท่านั้นและหากพฤติกรรมใดที่ท่านไม่ได้ปฏิบัติ ให้ใส่เครื่องหมายถูก (✓) ลงในช่องไม่ได้ปฏิบัติ โดยพิจารณาว่าเหตุผลที่ไม่ได้ปฏิบัติ เป็นเพราะท่านทำไม่ได้ หรือไม่คิดทำ เพียงข้อใดข้อหนึ่งเท่านั้น

ตัวอย่าง

พฤติกรรมการเผชิญความเครียด	ได้ปฏิบัติและมีประโยชน์ต่อผู้ดูแล				ไม่ได้ปฏิบัติเนื่องจาก	
	มาก	ปานกลาง	น้อย	ไม่มีประโยชน์	ทำไม่ได้	ไม่คิดจะทำ
ก. ปรึกษากับ แพทย์ พยาบาล หรือนักสังคมสงเคราะห์ เมื่อพาเด็กป่วยมาตรวจ		✓				
ข. ระบายความวิตกกังวลใจกับเพื่อนสนิท					✓	

จากคำตอบ

ก. แสดงว่าท่านรับรู้ว่าการปรึกษากับแพทย์ พยาบาล หรือนักสังคมสงเคราะห์ เมื่อพาเด็กสมองพิการมาตรวจ ว่ามีประโยชน์กับตัวท่านในระดับปานกลาง

ข. แสดงว่า ท่านไม่ได้ระบายความวิตกกังวลใจกับเพื่อนสนิท เนื่องจาก ไม่สามารถทำกิจกรรมนี้ได้

พฤติกรรมการเผชิญความเครียด	ได้ปฏิบัติและมีประโยชน์ต่อผู้ดูแล				ไม่ได้ปฏิบัติเนื่องจาก	
	มาก	ปานกลาง	น้อย	ไม่มีประโยชน์	ทำไม่ได้	ไม่คิดจะทำ
1. ระบายความรู้สึกส่วนตัวกับคู่สมรส หรือเพื่อนสนิท						
2. สร้างความสัมพันธ์กับเพื่อน เพื่อให้รู้สึกว่าตัวเองสำคัญ						
3. ไว้วางใจ หรือเชื่อใจคู่สมรส/เพื่อนสนิท/ญาติให้ช่วยดูแลตัวเองหรือเด็กสมองพิการ						
4. นอนหลับ						
5. ปรึกษาความคับข้องใจ เรื่องต่าง ๆ กับแพทย์ พยาบาล หรือนักสังคมสงเคราะห์เมื่อพาเด็กสมองพิการมาตรวจรักษา						
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45.....						

Part 2

แบบประเมินที่.....
วันที่.....

Severity of Disability Scale

แบบประเมินความรุนแรงของความพิการ

คำชี้แจง

แบบประเมินชุดนี้เป็นแบบประเมินความรุนแรงของความพิการ ซึ่งผู้วิจัยจะทำการสัมภาษณ์ผู้ดูแลเด็กสมองพิการถึงความสามารถของเด็กสมองพิการในการทำกิจกรรมที่เกี่ยวกับการดำเนินชีวิตประจำวัน โดยแบบประเมินมีทั้งหมด 18 ข้อ และในแต่ละข้อจะให้คะแนนได้ตั้งแต่ 1-7 โดยมีเกณฑ์และรายละเอียดการให้คะแนน ดังนี้

เกณฑ์การให้คะแนน

7 คะแนน หมายถึง เด็กสามารถทำกิจกรรมตามทักษะเพื่อช่วยเหลือตนเองโดยไม่มีผู้ช่วยเหลือได้อย่างปลอดภัยและใช้เวลาเหมาะสม

6 คะแนน หมายถึง เด็กสามารถทำกิจกรรมตามทักษะเพื่อช่วยเหลือตนเองได้โดยไม่มีผู้ช่วยเหลือ แต่มีการใช้เครื่องมือ หรืออุปกรณ์ช่วยได้อย่างปลอดภัย และใช้เวลามากขึ้น

5 คะแนน หมายถึง เด็กสามารถทำกิจกรรมได้เอง โดยมีผู้ดูแลเด็กเป็นผู้ให้คำแนะนำ หรือช่วยจัดเตรียมสิ่งของ/อุปกรณ์ให้กับเด็ก

4 คะแนน หมายถึง เด็กสามารถทำกิจกรรมได้เอง 75%- 99% และมีผู้ดูแลช่วยในการทำกิจกรรม ไม่เกิน 25%

3 คะแนน หมายถึง เด็กสามารถทำกิจกรรมได้เองครึ่งหนึ่ง ประมาณ 50%-74% และมีผู้ดูแลช่วยทำกิจกรรมครึ่งหนึ่ง ประมาณ 26%-50%

2 คะแนน หมายถึง เด็กสามารถทำกิจกรรมได้เองน้อยกว่าครึ่งหนึ่ง 25%-49% และผู้ดูแลช่วยทำกิจกรรมมากกว่าครึ่งหนึ่ง ประมาณ 51%-75%

1 คะแนน หมายถึง เด็กสามารถทำกิจกรรมได้ 0%-24%เองทั้งหมดหรือทำกิจกรรมได้เล็กน้อย 0%-24% และผู้ดูแลช่วยทำกิจกรรมนั้นตั้งแต่ 76% ขึ้นไป

ความสามารถ	7	6	5	4	3	2	1	รวม
ด้านการดูแลตนเอง 1. เด็กสามารถรับประทานอาหารโดยใช้ช้อน (ส้อม) และใช้อุ้งมือประคองถ้วย								
2. เด็กสามารถแปรงฟัน หวีผม และล้างมือ ล้างหน้า								
3. เด็กสามารถอาบน้ำโดยการฟอก ล้าง เช็ด ส่วนที่ต่ำกว่าระดับเอว								
4. เด็กสามารถสวมและถอดเสื้อ								
5. เด็กสามารถสวมและถอดกางเกง								
6. เด็กสามารถทำความสะอาดร่างกายหลังขับถ่าย และสวม/ถอดกางเกง								
ด้านการควบคุมการขับถ่าย 7. เด็กสามารถควบคุมปัสสาวะ								
8. เด็กสามารถควบคุมอุจจาระ								
ด้านการเคลื่อนย้ายตนเอง 9. เด็กสามารถเคลื่อนย้ายตนเองไป-กลับเก้าอี้หรือรถเข็น (โดยการเดินหรือใช้รถเข็น)								
10.เด็กสามารถเคลื่อนย้ายตนเองไป-กลับโถส้วม (โดยการเดินหรือใช้รถเข็น)								
11. เด็กสามารถเคลื่อนย้ายตนเองไป-กลับที่อาบน้ำ (โดยการเดินหรือใช้รถเข็น)								
ด้านการเคลื่อนไหว 12. ( ) การเดิน ( ) การคลาน ( ) การใช้รถเข็น								
13. การขึ้นลงบันได (12-14 ขั้น)								
ด้านการสื่อความหมาย 14. เด็กสามารถเข้าใจความหมายของสิ่งที่มองเห็น หรือ ได้ยิน								

ความสามารถ	7	6	5	4	3	2	1	รวม
15. เด็กสามารถสื่อสาร ( ) คำพูด ( ) แสดงท่าทาง								
ด้านการเรียนรู้ทางสังคม 16. เด็กสามารถเล่นร่วมกับเพื่อน และแบ่งของเล่น								
17. เด็กสามารถแก้ปัญหาง่าย ๆ เช่น เช็ดพื้น เมื่อทำน้ำหก หรือ รับโทรศัพท์ หรือซื้อของ								
18. เด็กสามารถจดจำสิ่งที่คุ้นเคย ได้แก่ บุคคล สถานที่ เพลง วันหยุด หรือวันเกิด								

หมายเหตุ : แบบประเมินความรุนแรงของความพิการ เป็นลิขสิทธิ์ของบัณฑิตวิทยาลัย มหาวิทยาลัยเชียงใหม่ เป็นเครื่องมือวิจัยในวิทยานิพนธ์ เรื่อง คุณภาพชีวิตของเด็กสมองพิการ ของ พึงพิศ ศรีสืบ 2543 ห้ามนำมาใช้ก่อนได้รับอนุญาต

APPENDIX E

Testing Assumptions of Multiple Regression Analysis

The assumptions that were tested before using multiple regression analysis included normal distribution, homoscedasticity, and multicollinearity. The results for each assumption were presented as follows:

1. Normal distribution was assessed by using histogram of standardized residuals. The dependent variable was showed as normally distributed (Figure 3). The plotted values did fall close to the line of normal probability (Figure 4).

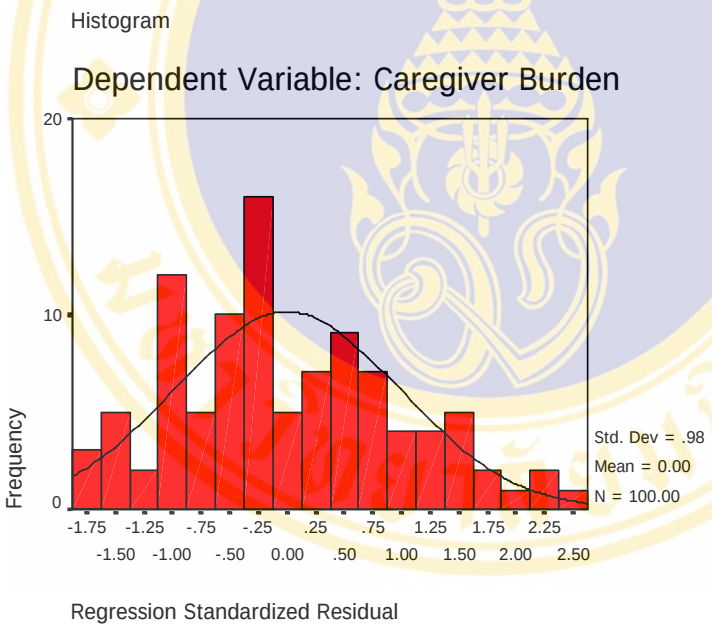

Figure 3 Histogram of Standardized Residuals

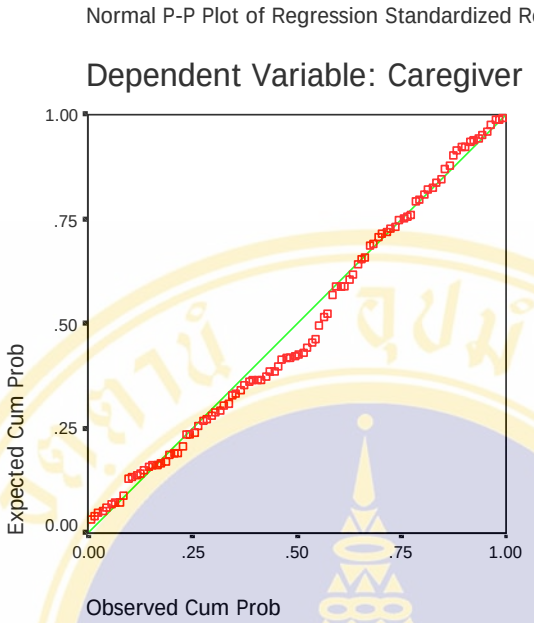

Figure 4 Normal P-P Plot of Regression Standardized Residual

One-Sample Kolmogorov-Smirnov test showed that caregiver's age, caregiving involvement, coping and burden were normally distributed, while caregiver's health, family income and severity of disability were not normally distributed (Table 10).

Table 10 One-Sample Kolomogorov-Smirnov Test (N =100)

One-Sample Kolmogorov-Smirnov Test

		caregiver age	caregiver health	caregiving involvement	coping	family income	disability severity	caregiver burden
N		100	100	100	100	100	100	100
Normal Parameters[a,b]	Mean	37.66	3.41	42.09	87.36	19662.0	3.29	43.51
	Std. Deviation	11.01	.83	9.08	12.51	32386.6	1.21	13.37
Most Extreme Differences	Absolute	.102	.241	.096	.052	.283	.442	.056
	Positive	.102	.209	.084	.043	.216	.278	.056
	Negative	-.066	-.241	-.096	-.052	-.283	-.442	-.044
Kolmogorov-Smirnov Z		1.016	2.414	.957	.522	2.828	4.416	.556
Asymp. Sig. (2-tailed)		.254	.000	.319	.948	.000	.000	.916

a. Test distribution is Normal.

b. Calculated from data.

2. Homoscedasticity

This assumption was tested by scatter plot (Figure 5). It showed that the constancy of the residuals across values of the independent variables were spread at zero area, which indicated homoscedasticity in the multivariate case.

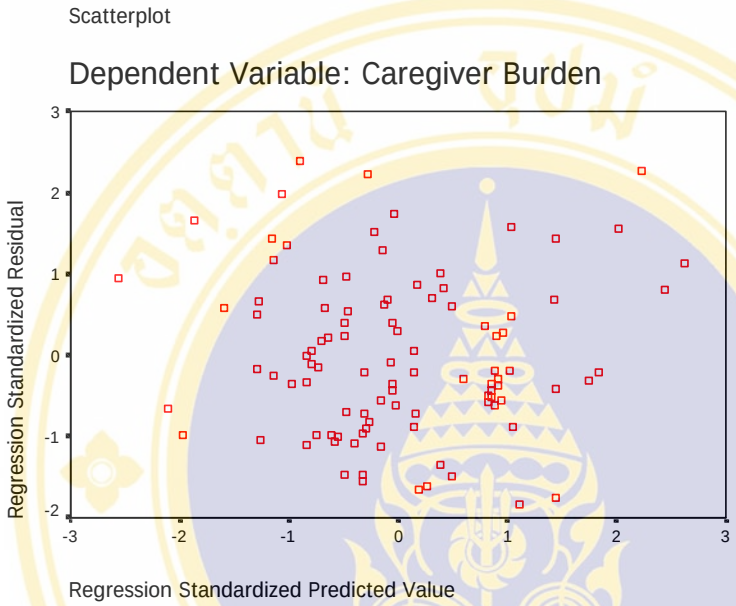

Figure 5 Scatter Plot between Regression Residuals and Regression Predicted Value

3. Multicollinearity

The Pearson's Product Moment Correlation was performed to examine the relationships among independent variables. The results revealed that the highest correlation coefficient among the variables was .37 (Table 11). In addition, the tolerance and VIF of a variable were used as a measure of collinearity. The tolerance values were .73 to .94 and VIF values were 1.07-1.36 (Table 12). Therefore, the multicollinearity was not a problem in this study.

Table 11 Correlations of Independent and Dependent Variables (N = 100)

Correlations

		caregiver burden	caregiver age	caregiver health	caregiving involvement	coping	family income	disability severity
Pearson Correlation	caregiver burde	1.000	-.062	.296	.337	-.258	-.273	.175
	caregiver age	-.062	1.000	.134	-.095	.087	.180	-.030
	caregiver healt	.296	.134	1.000	.065	-.036	-.197	.293
	caregiving involvement	.337	-.095	.065	1.000	-.095	-.201	.297
	coping	-.258	.087	-.036	-.095	1.000	.077	.125
	family income	-.273	.180	-.197	-.201	.077	1.000	-.371
	disability sever	.175	-.030	.293	.297	.125	-.371	1.000
Sig. (1-tailed)	caregiver burde	.	.269	.001	.000	.005	.003	.041
	caregiver age	.269	.	.092	.173	.195	.037	.385
	caregiver healt	.001	.092	.	.261	.362	.025	.002
	caregiving involvement	.000	.173	.261	.	.174	.023	.001
	coping	.005	.195	.362	.174	.	.224	.108
	family income	.003	.037	.025	.023	.224	.	.000
	disability sever	.041	.385	.002	.001	.108	.000	.
N	caregiver burde	100	100	100	100	100	100	100
	caregiver age	100	100	100	100	100	100	100
	caregiver healt	100	100	100	100	100	100	100
	caregiving involvement	100	100	100	100	100	100	100
	coping	100	100	100	100	100	100	100
	family income	100	100	100	100	100	100	100
	disability sever	100	100	100	100	100	100	100

Table 12 Collinearity Statistics of Independent Variables (N = 100)

Coefficients[a]

Model		Collinearity Statistics	
		Tolerance	VIF
1	Caregiver age	.929	1.077
	Health status	.872	1.146
	Caregiving involvement	.883	1.132
	Coping	.942	1.062
	Family income	.806	1.241
	Severity of disability	.732	1.366

a. Dependent Variable: Caregiver burden

APPENDIX F
Score of Severity of Disability

Table 13 Frequency, Range, Mean, and Standard Deviation of Severity of Disability of Children with Cerebral palsy (N = 100)

Age range (months)	Frequency	Actual Range	Mean	SD
6-21	**14**	**18-89**	**30.07**	**18.99**
Mild	5			
Moderate	1			
Severe	2			
Profound	6			
22-45	**35**	**19-111**	**43.42**	**26.90**
Mild	7			
Moderate	1			
Severe	1			
Profound	26			
46-62	**30**	**18-123**	**62.26**	**30.91**
Mild	6			
Moderate	2			
Severe	1			
Profound	21			
63-100	**21**	**18-123**	**40.38**	**29.26**
Mild	1			
Moderate	1			
Severe	0			
Profound	19			

Caregiving Involvement

Table 14 Mean, and Standard Deviation of Each Subscale and Items of Caregiving Involvement (N=100)

Caregiving involvement	**Mean**	**SD**
Child care		
1. Personal care (helping with bathing, grooming, eating, etc.).	2.92	0.92
2. Medical care (medications, tube feedings, wound care).	2.91	1.01
3. Escorting the child to health care.	2.90	1.03
4. Escorting the child to non-medical functions beyond what would have to be done if child were healthy (social activities, entertainment).	2.74	1.18
5. Waiting in doctors' offices.	2.70	1.15
6. Managing the behavioral problem of child.	2.62	1.17
7. Moving a child.	2.44	1.20
Vigilant tasks		
1. Watching a child who cannot safely be left alone.	3.52	0.70
2. Providing emotional support when not doing other tasks.	3.45	0.68
Household tasks		
1. Preparing special or extra meals and cleaning up afterward.	3.07	0.95
2. Extra or special shopping or errands.	2.82	1.08
3. Extra household chores (housework, yard work).	2.82	1.03
4. Managing the child's finances.	2.65	1.13
5. Monitoring and maintaining medical equipment.	2.54	1.14
6. Managing the child's medical conditions.	1.99	1.47

Coping

Table 15 Range, Mean, and Standard Deviation of Coping of Caregivers: Pattern I (N = 100)

Coping	Mean	SD
1. Having my child with the medical condition seen at the clinic/hospital on a regular basis.	2.86	0.47
2. Investing myself in my child.	2.84	0.49
3. Believing that my child is getting the best medical care possible.	2.84	0.49
4. Encouraging my child with medical condition to be more independent.	2.71	0.57
5. Believing that things will always work out.	2.66	0.59
6. Believing that my children will get better.	2.65	0.58
7. Doing things with my children.	2.56	0.67
8. Trying to maintain family stability.	2.55	0.69
9. Telling my self that I have many things that I should be thankful for.	2.37	0.72
10. Believing that the medical center/hospital has my family's best interest in mind.	2.27	0.70
11. Building a closer relationship with my spouse or relative.	2.05	0.91
12. Doing things with family relatives.	2.03	0.93
13. Trusting my spouse or relative to help support me and my children.	1.97	1.00
14. Believing in god.	1.88	0.97
15. Taking good care of all the medical equipment at home.	1.78	1.15
16. Doing things together as a family.	1.67	0.97
17. Getting other members of the family to help with chores and tasks at home.	1.61	1.00
18. Showing that I am strong.	1.59	1.07
19. Talking over personal feelings and concerns with spouse or relative or friend.	1.53	1.10

Table 16 Range, Mean, and Standard Deviation of Coping of Caregivers: Pattern II (N = 100)

Coping	Mean	SD
1. Becoming more self reliant and independent.	2.68	0.51
2. Develop my self as a person.	2.40	0.72
3. Investing time and energy in my job.	2.19	0.91
4. Building close relationships with people.	2.05	0.80
5. Eating.	1.97	0.86
6. Concentrating on hobbies.	1.88	0.97
7. Going out with my spouse or relatives on a regular basis.	1.72	0.97
8. Sleeping.	1.67	0.84
9. Keeping with self in shape and well groomed.	1.59	0.08
10. Working, outside employment.	1.57	0.79
11. Involvement in social activities with friends.	1.36	1.12
12. Allowing myself to get angry.	1.21	0.98
13. Being able to get away from the home care tasks and responsibilities for some relief.	1.17	0.90
14. Purchasing gifts for myself and other family members.	1.12	0.83
15. Talking to some one (not professional counselor/doctor) about how I feel.	1.10	0.98
16. Getting away by my self.	1.02	0.99
17. Engaging in relationship and friendship which help me to feel important.	0.89	0.92
18. Entertaining friends in our home.	0.73	0.89

Table 17 Range, Mean, and Standard Deviation of Coping of Caregivers: Pattern III (N = 100)

Coping	Mean	SD
1. Reading more about the medical problem which concerns me.	2.79	0.50
2. Being sure prescribed medical treatments for child are carried out at home on a daily basis.	2.49	0.70
3. Talking with the doctor about my concerns about my child with the medical condition.	2.28	0.89
4. Talking with other parents in the same type of situation and learning about their experiences.	2.14	0.93
5. Talking with other individuals/parents in my same situation.	2.07	0.88
6. Talking with the medical staff when we visit the medical center.	1.92	1.00
7. Reading about how other persons in my situation handle things.	1.64	0.98
8. Explaining our family situation to friends and neighbors.	1.29	1.00

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