CAREGIVERS' NEEDS FOR CARING CEREBRAL PALSY CHILDREN AT HOME

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Cerebral palsy is a common childhood disease that causes permanent physical disabilities. It is a group of nonprogressive encephalopathies which show many effects. The effects are seen by ages, and it invariably affects motor function. Many cerebral palsy children are dependent and often perceived as a burden. The patient needs endless caregiving. Caregivers also experience a high level of stress and need professional help in decreasing such a burden. This study aimed to investigate the caregivers' needs for caring for cerebral palsy children at home, and identify factors that predict their needs. This study was a descriptive research. The sample was composed of 140 caregivers of cerebral palsy children, below 6 years of age. Data was obtained from questionnaires: personal data, patient data and caregivers' needs. Data was analyzed using mean, standard deviation, Pearson's product moment correlation coefficient, and multiple regression.

The results of the study showed that the overall mean score and the mean scores of each section of caregivers' needs were in a moderate level. The sections of caregivers' needs included information, psychological, financial, spiritual, household management and physical needs. Caregiver characteristics (age, education level, marital status, number of children, workplace, family income, duration of caring) and patient characteristics (birth order, age, severity of disability) are unable to predict caregivers' needs.

The results from this study provide considerations for nursing practice. Nurses should coordinate with health care providers on how to best advise caregivers of cerebral palsy children. Nurses can support and provide education to the caregivers and family members about meeting the needs of these children, especially the spiritual and psychological needs. Nurses should also encourage the rehabilitation of the children to improve their functioning.

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จินตนา หาญประสิทธิ์คำ : ความต้องการของผู้ดูแลในการดูแลเด็กสมองพิการที่บ้าน (CAREGIVERS' NEEDS FOR CARING CEREBRAL PALSY CHILDREN AT HOME) คณะกรรมการควบคุมวิทยานิพนธ์: ไข่มุกข์ วิเชียรเจริญ, กศ.ด., รัชนี สีดา, ค.ม., ปนัดดา ปริยฑฤฆ, วท.ม., 109 หน้า, 974-665-028-9

โรคสมองพิการเป็นภาวะเจ็บป่วยเรื้อรัง เป็นกลุ่มอาการที่เกิดจากการทำลายของเนื้อสมอง ก่อนอายุ 5 ปี ซึ่งเมื่อเกิดขึ้นกับสมองส่วนใดแล้วก็จะมีผลต่อร่างกาย ทำให้เกิดความพิการชนิดต่างๆกันออกไปและจะคงอยู่เรื่อยไปตลอดชีวิต ทำให้มีข้อจำกัดในการช่วยเหลือตนเองและตอบสนองความต้องการของตนเองได้ ต้องพึ่งพาผู้ดูแล ในการดูแลเด็กอย่างถูกต้องไม่ให้เกิดภาวะแทรกซ้อนและสามารถแก้ไขความพิการที่เกิดขึ้นให้ลดลง ผู้ดูแลต้องเผชิญกับภาระการดูแลที่ยาวนาน มีผลกระทบต่อแบบแผนการดำเนินชีวิต ก่อให้เกิดความเครียดและความต้องการความช่วยเหลือในการแก้ปัญหาการดูแลผู้ป่วย การวิจัยครั้งนี้มีจุดมุ่งหมายเพื่อศึกษาความต้องการของผู้ดูแลในการดูแลเด็กสมองพิการที่บ้าน และปัจจัยที่สามารถทำนายความต้องการ กลุ่มตัวอย่างเป็นผู้ดูแลที่รับผิดชอบในการดูแลผู้ป่วยเด็กอายุ 0 – 6 ปีจำนวน 140 ราย เก็บรวบรวมข้อมูลโดยใช้แบบสอบถามความต้องการของผู้ดูแล วิเคราะห์ข้อมูลโดยหาค่าร้อยละ ค่าเฉลี่ย ค่าเบี่ยงเบนมาตรฐาน ค่าสัมประสิทธิ์ของเพียร์สัน ค่าสัมประสิทธิ์สหสัมพันธ์พหุ และวิเคราะห์การถดถอยพหุแบบขั้นตอน

ผลการวิจัยพบว่า ความต้องการของผู้ดูแลโดยรวมและรายด้านทั้ง 6 ด้านคือ ด้านข้อมูลในการดูแลผู้ป่วย ด้านการประคับประคองจิตใจ ด้านการเงินและวัสดุสิ่งของ ด้านการเสริมสร้างพลังทางจิตวิญญาณ ด้านการจัดการภายในบ้านและด้านการดูแลสุขภาพร่างกาย มีค่าเฉลี่ยอยู่ในระดับปานกลาง ปัจจัยของผู้ดูแลได้แก่อายุ ระดับการศึกษา สถานภาพสมรส จำนวนบุตร อาชีพ รายได้ของครอบครัว ระยะเวลาในการดูแล และปัจจัยด้านเด็กสมองพิการได้แก่ลำดับการเกิด อายุและความรุนแรงของโรค ไม่สามารถทำนายความต้องการของผู้ดูแลในการดูแลเด็กสมองพิการที่บ้านได้ จากการวิจัยมีข้อเสนอแนะคือ พยาบาลควรให้คำแนะนำแก่ผู้ดูแลและเป็นผู้ประสานงานขอความร่วมมือจากบุคลากรในทีมสุขภาพ ในการให้คำแนะนำแก่ผู้ดูแล ส่งเสริมให้กำลังใจในการดูแลผู้ป่วย นอกจากนี้ควรให้เวลาผู้ดูแลได้ซักถามปัญหาและส่งเสริมการฟื้นฟูสภาพร่างกายผู้ป่วย ให้สามารถช่วยเหลือตัวเองให้ใกล้เคียงกับพัฒนาการของแต่ละวัย

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CHAPTER I

INTRODUCTION

Background and Significance of the Study

In the past , many severity patients died from medical technology shortage, but advance in medical and surgical technology in health services over the past quarter century made many patients with very severe conditions live longer (Jackson & Vessel,1992: 3). Chronic patient survivors occurred impairment or disabilities as well (Newacheck, et al., 1986:178-184). Increasing survival rates of premature delivery and very low birth weight infants, however, is contributing to an upward trend in incidence of cerebral palsy. Approximately 78.1:1000 of infants whose birth weight below than 1000grams developed cerebral palsy (Pharoah, et al., 1998: 21-25).

A survey by the World Health Organization (WHO, 1976) found that mental retardation persons who had cerebral palsy were about 40 millions or 7.7 percents of all handicaps (Chintanapukdee, 1987: 2).According to a survey in Japan in 1990, 5 millions or about 4 percents of populations were handicaps (physical, psychological, and neurological handicaps), and about3.85 thousands who lived in welfare- house were cerebral palsy (Matsui, 1993: 35-41). A proposal of Thai Public Health Research Institution in 1996 stated that there were 4,825,681 handicapped persons or 8.1 percents of all population (Ministry of Labor and Social Welfare, 1999: 3-5). The incidence of cerebral palsy also reported as 1.9 to 2.3 in every 1000 live births (Wong,et al.,1999: 1966). Understandably, cerebral palsy is more common in developing countries which low facilities in pre and postnatal care, and high incidence in nutritional deficiency (Visuthipun & Jeamjunya, 1997: 232). The statistics from Queen Sirikit National of Child Health showed that cerebral palsy pediatrics in 1996 to 1998 were 1616, 2102, and 1951 persons, respectively. It found that the incidences in cerebral palsy between age 1 to 2 years was 41.5 percents, 3 to 4 years was 22.7 percents, 5 to 9 years was 17.2 percents, while the occurrence in the first year was 11.7 percents, and the rest was more than 10 year old. Pediatric patients in out-patient department of Rajanukul Hospital between 1996 to 1998 were 100, 103, and 104 cerebral palsy children, respectively.

Cerebral palsy is a chronic illness and can cause disabilities (Perrin & Thyen,1999: 335). It defined as a group of nonprogressive encephalopathies in an immature brain which can occur during prenatal, perinatal, or postnatal period. Its effects are obviously seen at age of 5 (Howle, 1999: 23). It affects motor function invariably. Cerebral palsy also has a risk of other deficits such as epilepsy, abnormal behavior, and difficulties in vision, speech, learning, eating, and gastrointestinal function (Back, 1999: 579). Mental and growth retardation which anticipate problem in children with cerebral palsy who are likely to interfere their daily activities. Therefore, many cerebral palsy children are still dependent and often perceive as a burden.

Family's members who take care of a cerebral palsy child at home often face a wide and burdensome series of tasks which are significantly different from those who take care of apparently healthy children (Perrin, et al.,1993: 31). Being cerebral palsy children in families can be develop to social and economics problems in the family and can be leave or neglect by their parents which had neglect children rate increases approximately 2 percent per year (Department of Social Welfare 1985 cited by Jintanapukdee,1987: 4-5).

Most typically, parents or other family members will be responsible for providing the child's care at home (Bowden, et al.,1998: 601). It is well known that the presence of a chronically ill child at home has practical and emotional effects on daily lives of all family members. Financial and work schedules also affect as illness-related costs and time taken from work. The interaction of family members with each other and with those outside home also changes. There are psychological strains on the individual members of the family, in both parents and siblings (Perrin & Thyen, 1999: 306-307). Being chronically ill will make children feel tired, withdraw from physical activity, and become restriction in terms of emotional distress. Other conditions result in progressive deterioration. Even though the exact course and timing of the deterioration is not always predictable (Eiser,1990: 3-43), these can extremely affect the caregivers as stressors (Perrin & Thyen, 1999: 306-307). Having vulnerable children is also one factor in increasing risk for child abuse and neglect. Although it seems paradoxical that parents who are concerned about a child's health could also do harm to their child. Thus, having a child with special needs can be a stress to their parents. With parents who do not have successful coping strategies, anger and frustration may vent on the perceived source, the child (Johnson & Oski, 1997: 50).

Nurses can play a vital role in helping the family to cope with their problems and to adjust to their life circumstances. The objectives of nursing care are to support family unity, to promote optimal adjustment, and to help integrate the child into the family and community (Bowden, et al.,1998: 608). This process begins by focusing not only on the parents' actual needs, but also on the "perceived needs" by health care professionals. Moreover, each family is unique. The experiences, coping styles, and pattern of family interactions differ from family to family. These differences must be respected and must be from the basis of individualized family care.

Having a child with disabilities creates a potentially wide set of challenges for families with subsequent needs in information and services that could assist coping and adaptation. Needs will likely vary according to individual family circumstances, but may include needs in information, ways of interacting with the child, family and social support, financial assistance, their child's condition explanation to others, respite or child care, community supports, and special professional services (Bailey, 1999: 437-451).

Wingate & Lackey's study focused on the needs of cancer patients' caregivers. They found that, first, psychological needs were needs for anything that preserved, supported, and/or developed one's emotions, thoughts, and relationships to others. Second,, household management needs related to managing /running a household and providing care to the patient. Third, information needs were needs for knowledge, information, and understanding that can be gained through education, experience, study, and assistance by explanation. Fourth, respite needs were needs for an interval of temporary rest or relief, and a need for reprieve. Fifth, physical needs were needs for anything that continued,, preserved, maintained, or retained the primary caregiver's bodily functions. Sixth, legal and/or financial needs were needs for those things that pertained to legal or financial matters. Seventh, spiritual needs were needs for anything that preserved, supported, and/or developed the nature of man's relationship to God. Last, other needs that did not fit into the seven other categories lists (Wingate & Lackey, 1989: 216- 225). Several studies stated that needs will likely vary according to individual caregiver factors and characteristics. Caregiver characteristics include:

1. **Age** is a major factor that makes an individual differ in cognitive and behavior. Younger mothers tend to have less knowledge, less positive attitudes, less control and less communication with their babies (Fry,1985: 47-55). Young adults want to achieve and are task-related, with a more competitive style in cognitive behavior. Older adults have more responsibly, with more reintegrative (Freiberg, 1992: 297). They require less psychological supports than younger mothers do.

2. **Parents' educational level** showed significant correlation between measurement of child health and well-being. Educational level reflected in their attitudes and assumptions (Mechanic, 1964 cited by Schor & Menaghan, 1995 :24). It found that mothers with a lower educational level tended to be more fatalistic about illness and less concern about detection in their children's health status, and took fewer precautions to protect their children's health.

3. **Marital-parent's status** included limitations of available resources: family income (more than 50% of this populations are below the national poverty level),time,, physical, and emotional energy. An effective network of social support is vital in helping single parents to meet multiple needs and roles that confront them (Tanner, 1999 :13).

4. **Members of children**: For parents with multiple children, tasks are more complicated in this family compared to the same amount of support that can generally be

afforded by a family with a single infant (Bowden, et al., 1998: 138).

5. **Workplace**: Parent's employment can influence their childbearing period in several ways. First, workplace conditions and job latitude are a degree of control over one's action on the job. The job influences emotional effects. This can cause working parents' to have difficult interactions with their spouses and children, and thus affect children's health and well-being. Unhappiness and stress at work can undermine self-esteem and emotional well-being of parents, who then act out their dissatisfaction at home. They may become abusive, coercive, unresponsive, insensitive, withdrawn, and, otherwise, dysfunctional (Schor & Menaghan ,1995: 26). It effects to economics support needs more than homemaking mothers.

6. **Family income** can threaten health by distorting human interactions and precluding participation in the most fundamental of societal activities (Wise,1999: 35).

7. **Duration of caring**: In an early phase of disability, change is less apparent because an immediate response takes time. As a disabled member moves into the rehabilitation phase, an influence of disabilities on the family will be more noticeable (Woodberry & Redd, 1984 cited by Fraley, 1995: 105).

Characteristics of cerebral palsy children

1. **Birth order**: Jacobs and Moss (1976 cited by Pichaipanich, 1999: 32) suggested that parents respond differently to first-born child than later-born child because : (a)more limited time and more work have a direct effect on caring for two children, (b) less novelty and excitement in having the second child, (c)a competition between the first-

born and the second-born on mother's attention, and (d) a mother has greater experience resulting in more efficient caregiving in the second born.

2. **Age**: An infant's major need is caring which promotes his or her complexity, multifaceted growth and development needs with a consideration for a unique affect on this process (Bowden, et al., 1998: 546).

3. **Severity of disability**: An inherent stress of caregiving, rather than a severity of disability, is often responsible for deficits in caregivers' health status, accounting for increased visits to physicians and a decrease in regular activities at work and at home (Dewis & Niskala, 1992:87-94; Williams,1994: 155-161).

Family caregivers are the most important element of successful rehabilitation and long-term home care (Gaynor, 1990 cited by Holicky, 1996: 247-251). Having a child with mild cerebral palsy may have minimal affect on the family function. Time spent in providing care for a child with severe cerebral palsy will be different from that with mild cerebral palsy. Increased in physical care needs and prolonged years of dependency of their child may overwhelm families. Families need an assistance from whatever sources that are available, especially during the day. This way caregivers can meet personal needs of all family members. Respite care opportunities are essential for the overall health and well-being of the family (Steele, 1992: 164). Nurses play important role in interacting with caregivers and care recipients, so they can more likely be able to make an assessment of caregivers' needs (Cochran, 1994: 5-6).

From the above mentions, the researcher was interested to study the factors affecting the caregivers' needs. The researcher hopes that the results of this study will assist and support the caregivers for caring cerebral palsy children to have collect management. Therefore the cerebral palsy children will have a normal up bringing, development and quality of life, the same as normal children.

Purposes of the Study

1. To explore caregivers' needs for caring cerebral palsy children at home.

2. To study the predictive power of caregivers' needs for caring cerebral palsy children at home from the predictive variables such as the characteristic of caregivers and cerebral palsy children.

Conceptual Framework

This study used conceptual framework of caregivers' needs for caring cerebral palsy at home, which adapted from Wingate &Lackey's caregivers needs (1989: 216-225) according to their study was caregivers' needs in chronic illness the same as this.This conceptual framework included six categories: information, psychological, physical, spiritual, household management, and financial needs. Information need was a need for knowledge, information, or understanding that gained through education, experience, study, and assistance by explanation. Psychological need was a need for anything that preserved, supported, and/or developed one's emotions, thoughts, and relationships to other. Physical need was a need for anything that continued, preserved, maintained, and retained primary caregivers' bodily functions. Spiritual need was a need for anything that preserved, supported, and/or developed a mature of man's relationship to God. Household management need was a need related to managing/running a household and providing care to the patient. Financial need was a need for those things that pertained to financial matters. From the review of the studies and literature it may be concluded that caregiver's characteristics (age, education level, marital status, number of children, workplace, family income, duration of caring) and child's characteristics (birth order, age, severity of disability) are factors that probably influence caregivers' needs for caring cerebral palsy children at home. In this literature review, the conceptual framework mentioned above showed a form of the relationship between variables in diagram 1. This study only focused on the disability literature concerning with caregivers' needs for caring cerebral palsy children at home. Variables of interest were grouped into two conceptual domains: caregiver's and child's demography. Caregiver's demographic indicators included age, education level, marital status, number of children, workplace, family income, and duration of caring. Child's demographic indicators included birth order, age, and severity of disability.

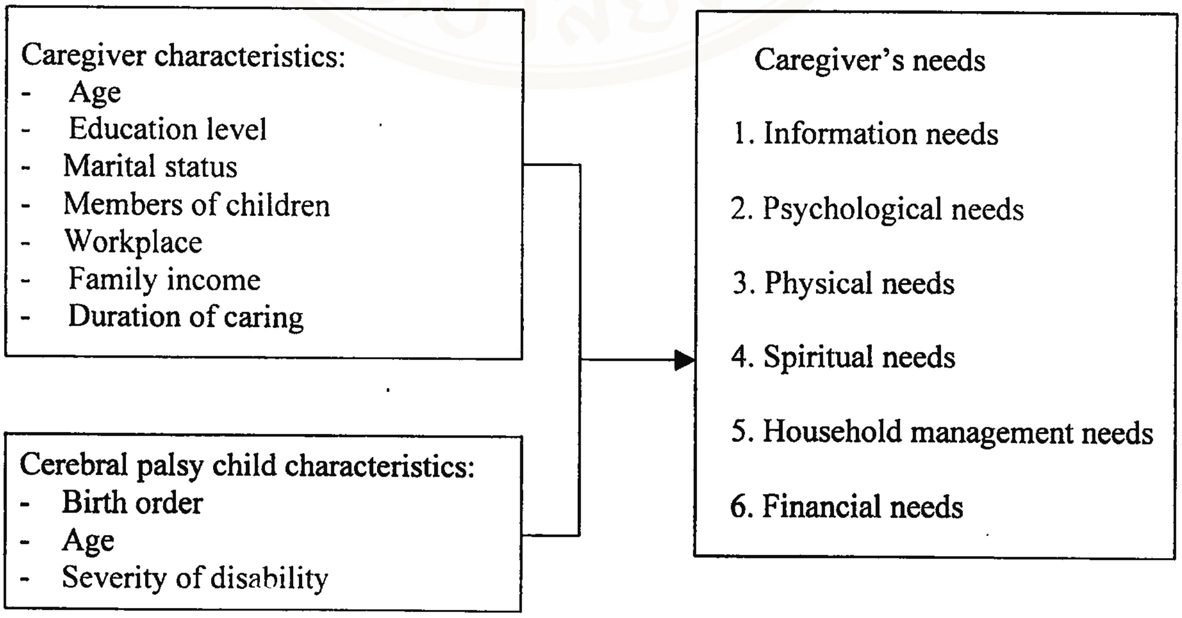

Diagram 1. Conceptual Framework

Hypotheses

1. Caregiver characteristics: age, educational level, marital status, members of children, workplace, family income, duration of caring are able to predict caregivers' needs for caring cerebral palsy children at home.

2. Cerebral palsy characteristics: birth order, age, severity of disability are able to predict caregivers' needs for caring cerebral palsy children at home.

Scope of the Study

This study was a study on the relationship between caregiver characteristics, cerebral palsy child characteristics and caregiver's needs for caring cerebral palsy children at home. The study was done in 120 caregivers who taking care of cerebral palsy children while followed up at physiotherapy department in Siriraj and Rajanukul hospital. Each caregiver had a cerebral palsy child whose age under 6 years old.

Definition of Terms

1. Caregivers' needs for caring of cerebral palsy children are needs that will facilitate them to care the child with cerebral palsy properly that are composed of:

1.1 Information need is a need for knowledge or information, caregivers concern about their abilities to provide optimal care for their cerebral palsy child.

1.2 Psychological need is a need for anything that preserves or supports to understand the role that caregivers play in caring cerebral palsy children.

1.3 Physical need is a need for anything that continues, preserves, maintains caregivers' bodily functions.

1.4 Spiritual need is a need for anything that preserves, supports, hopes, perceives self-esteem and/ or develops the nature of man's relationship to God.

1.5 Household management need is a need related to managing/ running a household and providing care for cerebral palsy children.

1.6 Financial need is a need for those things that pertains to financial matters.

2. Caregiver characteristics include:

2.1 Age: The number of years from the birth date of caregiver to the day of collecting data. A time period more than 6 months will be considered as a year.

2.2 Educational level: The highest level of education attained by caregivers according to the rules of The Ministry of Education and The Bureau of University Affair. In this study, numbers of years from the first year of primary education to the year of finishing education were also collected.

2.3 Marital status: The marital status of caregiver is divided into 2 categories: married and single (widowed, divorced, separated).

2.4 Number of children: Numbers of still alive children of the caregiver at the time of the study.

2.5 Workplace: A type of work that caregivers do for living and is a major source of income for the family. It can be divided as follows:

- Outside home consists of agriculture, employee, vendor, clerk in governmental or state enterprise sectors and others.

- Inside home, consists of housewife, vendor, employee, and others.

2.6 Family income: Caregiver's monthly incomes in Thai currency (baht), or caregiver's incomes which include his or her spouse's incomes in the case of marriage.

2.7 Duration of caring: The length of time in months since the first day that caregiver took care of cerebral palsy child at home. The starting date is the first date of caring cerebral palsy child from a diagnosis. Duration of caring is from the starting date to the day that the investigator collected the data. The days that exceed 15 days will be counted as one month.

3. Cerebral palsy child characteristics include:

3.1 Birth order: The order of the cerebral palsy child among the other alive children in the same parents.

3.2 Age: Ages of cerebral palsy children in full months and years from birth to the day of the study which is divided into 3 groups; 0-2 years old, 3-4 years old, and 5-6 years old.

3.3 Severity of disability: The capability of cerebral palsy child to perform daily activities. It is classified as (Nelson, et al., 1994: 472):

3.3.1 Mild cerebral palsy is defined as having consistent physical findings but having no limitation in ordinary activities.

3.3.2 Moderately cerebral palsy is defined as having definite difficulties in daily activities, often with the need for assisting devices or bracing.

3.3.3 Severe cerebral palsy is defined as having moderate to great limitations in daily activities.

Severity of disability was assessed by

From birth to 3 years assessment by using DDST (Appendix C)

From 3 years up using the functional independent assessment which is developed from the questionnaire for assessing the activities of daily living of disabled children (ADL). (Appendix C)

Expected Outcomes and Benefits

To help health team especially nurses to plan, promote and assist in effectively caring cerebral palsy children at home. Also, nurses could work with the caregivers who care for cerebral palsy children in order to meet their needs.

CHAPTER II

LITERATURE REVIEW

The research aim is to study caregivers' needs for caring cerebral palsy children at home. In this study, the related literature was reviewed using the outline as follows:

- Cerebral palsy
- Impact on cerebral palsy children
- Impact on caregiver and family
- Caregivers' needs for caring for a child with disabilities at home
- Factors that influence caregivers' needs for caring cerebral palsy children at home

Cerebral palsy

In past years, many severe ill children died. Several studies showed that advances in medical and surgical technology in the delivery of health services over the past quarter century made a large majority (over90%) of children, even with very severe conditions, helped children to live longer (Perrin & Thyen,1999: 336).Scientific advances also increased the longevity of children with many chronic conditions and disabilities (Sectish,2000: 17). Cerebral palsy is most common disease that causes permanent physical disabilities in childhood (Wong et al.,1999: 1966).

Cerebral palsy (CP) is defined as a static encephalopathy and nonprogressive disorder of postures and movements, often associated with epilepsy and abnormalities of speech, vision, and intellectual resulting from defects or lesions in a developing brain (Chesney,2000: 1843). The incidence is 1.9 to 2.3 in every 1000 live births (Wong, et al.,1999: 1966).

Etiology

A variety of prenatal, perinatal, and postnatal factors that contribute, both singly and multifactorially, to the etiology of CP (Table 1).

Table 1 Causes of cerebral palsy (Eicher & Batshaw,1993: 540).

Time (% of cases)	Causes
Prenatal (44%)	
First trimester	Teratogens, Genetic syndromes, Chromosomal abnormalities, Brain malformations
Second-third trimester	Intrauterine infections, Problems in fetal/ placental functioning
Labor and delivery (19%)	Preeclampsia, Complications of labor and delivery
Perinatal (8%)	Sepsis/CNS infection, Asphyxia,
Prematurity Childhood (5%)	Meningitis, Traumatic brain injury, Toxins
Not obvious (24%)	

Classification (Howle, 1999: 24-25; Steele, 1992: 148).

The American Academy for Cerebral Palsy and Developmental Medicine classification is the most widely used in descriptive system of classification and classifies the children by clinical types and topographic distributions of movement impairments as followings:

1. Types of Impairment

1.1 Spasticity, is characterized by having increased muscle tone, prolonged reflexes, exaggerated deep tendon reflexes, clonus, rigidity of the extrimities 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 makes this group increase up to 75 percent of all children with CP. Spastic CP also results from an insult to the motor cortex or white matter projections to and form the cortical sensorimotor 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 tremor. 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 Ataxia is a primary disorder of balance and control in the timing of coordinated movements. Ataxia represents less than 10 percent of CP. 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, an excessive joint flexibility, and a postural instability. It is often seen as a transient stage in the evolution of athetosis or spasticity. Hypotonia is not related to a particular neural lesion.

2. Topographic Distribution

The second part of a descriptive classification of CP is a topographic distribution of abnormal tone, posture, or movement. This includes diplegia which involves only the lower part of the body or only the upper part of the body. Hemiplegia involves an arm and a leg of one side of the body only. Quadriplegia involves the entire body, with equal or greater involvement of arms and upper body. The term double hemiplegia is sometimes used to indicate a type of quadriplegia in which an arm and a leg on one side are significantly more impaired than those on the other side.

Associated problems (Steele, 1992:153-154)

1. Mobility: Motor milestones are always delayed. Alterations in muscle tone and range of motion contribute to impairment in motor functions.

2. Intellectual problems: Fifty to seventy five % of children with CP have intellectual disabilities ranging degree from mild to severe mental retardation. Dyskinetic CP results in few limitations in intellectual abilities. Many CP children who have the most limiting physical symptoms are ones who have the least cognitive impairment. Severe motor involvement can delay speech production and the ability to exhibit intellectual capabilities unless the child has an access to appropriate technology to help transmit intellectual ability.

3. Visual impairment: More than 50%of children with CP have vision problems

(Rubin & Crocker, 1989). Refractive errors, strabismus, nystagmus, and amblyopia are common and often require surgery and lenses replacement for correction.

4. Hearing impairment: It can occur in 5 to15% of all CP children and 67%of the children with postbilirubin dyskinetic CP. Infants with motor problems may spend an inordinate amount of time in the recumbent position. Also, this predisposes them to increased episodes of acute and chronic serious otitis media which results in temporary conductive hearing loss.

5.Communicative disorders: a large number of CP children have delayed communication and communicative disorders. Poor quality of speech is a result from an inability to control muscles to provide oral-motor function. Language is affected by central processing difficulties.

6. Seizures: seizures are more common in the company of postnatal acquired hemiplegia. They are an unusual finding in athetosis and diplegia. The most common type of seizures is generalized tonic-clonic seizures.The peak incidence of onset is between 2 and 6 years of age (Wong, et al.,1999: 1968). Thirthy-five percent to fifty percent of children with CP have seizures (Steele, 1992: 154).

7. The manifestations of deficit-hyperactivity disorder may occur in children with CP. The primary presenting symptoms are poor attention, marked distractibility, hyperactive behavior, and integrative defects (Wong, et al., 1999: 1968).

8. Drooling: approximately 10% to 13% of CP children have drooling problems.

CP directly affects the pyramidal tracts, but often indirectly produces profound effects throughout the body. Early assessment and treatment is essential for a prevention of deformities and a provision of experiences required for a normal development but isdenied to the child with CP. The secret of success lies as much in the successful handling of the parents of the child (Levene,1990: 325).

Impact on cerebral palsy children

1.Physical containments:

1.1 Eating disabilities: Poor sucking reflex and an inability to chew or swallow are a result of secondary involvement of orophayryngeal muscles, resulting in abnormal muscle tone and functions of the tongue, lips, and cheeks (Rubin & Crocker,1989 cited by steele,1992: 153).Abnormal posturing further contributes to difficulty in swallowing. In addition, respiratory function influences on a child's eating abilities. Children who have abnormal, irregular, or insufficient breathing will have difficulties in coordinating in breathing and swallowing.

1.2 Respiratory problems: Coughing and choking, especially while 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 occurres as a result from (1) an improper dental hygiene, (2) congenital enamel defects (hypoplasia of primary teeth), (3) a high carbohydrate intake and retention, (4) a dietary imbalance from poor nutritional intake, (5) an inadequate fluoride intake, and (6) a difficulty in mouth closure and drooling. Spastic or clonic movements may interfere with a cleaning process. Gingivitis is secondary to inadequate dental hygiene and may be further complicated by the use of anticonvulsants (Wong et al., 1999: 1969).

1.4 Constipation: The increase in incidence of constipation in various age results from various factors: difficulties in chewing and swallowing, an inadequate liquid intake, a decrease in the intake of bulking foods, a prolonged use of strained foods, a decrease in mobility, an abnormality of muscle tone (including muscles related peristalsis), medications, a lack of an established toilet pattern, a fear of using a toilet, an instability of a child while seating on a toilet, a history of painful evacuations, an inadequate positioning of evacuation, and behavior problems. Diarrhea and vomiting are frequent symptoms during childhood as well.

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

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

1.7 Safety: CP children, even those that are mildly effected, have balance and coordinating problems. When trying to ambulate or during play activities, it is important to prevent head injuries, if a seizure should occur.

2. Behavioral and emotional impact: The prevelancence of disturbed behaviors

or emotional maladaptations in different groups of children with CP have been reported to be from 30-80% (McDermott, et al.,1996: 447-463). 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 were significant problems for 82 CP children. In school-age CP children, other researchers found that behavioral problems also included passivity, immaturity, and anxiety (McDermott, et al.,1996: 447-463). Several studies proposed that an isolation and a dependency can be problems in children with CP (Blum, et al.,1991:280-285; Livneh & Antonak,1994: 201-230).

3. Psychosocial development: A young child or a teenager with disabilities is isolated from social contact and learning with peers because of limited motor skills, and mobility. These children need extra time and need energy-consuming therapy (Molnar, et al., 1992: 122). A spastic child may hesitate to make a decision or reach out for a new opportunity because the world seems overwhelming and somewhat threatening. A child may find it easier to withdraw socially (Nelson,1990a: 255). Problems in psychosocial development can cause a decrease in self-esteem, security, independence, and social contact (Carrasco & Powell, 1989: 401-402).

Impact on caregiver and family

The family is a group of interdependent people who engage in tasks aimed at eliminating perceived physiological, psychosocial, emotional, and/or spiritual burdens of another individual in the family (Rawlins,1991: 213). Caregivers are a spouse, parents, friends, or significant others of a care recipient who are important people in caring for an ill, infirm, and dependent care recipient at home or in the community, and without payment (Davis,1992: 2; Sirapo-ngam,1996: 86; Swanson, et al.,1997: 65).

Family functioning (Ludwig & Rostain,1999: 162).Although there are many specific and specialized family functions, they can be divided in those pertaining to childrearing into three general categories: Supply of physical needs; provide developmental, behavioral, and emotional needs and socialization or teaching about relationships.

Having a cerebral palsy child may impose multiple challenges to families. It is considered as a major stressor or crisis in family life (Olsen, et al.,1999: 275-291). These issues include:

1. Poor caregivers' health is often associated with long-term caregiving. Many specific health problems have been linked to caregiving, for example arthritis, high blood pressure, heart disease, and cataracts. Aggravation of long-standing health problems, new stress and exertion-related problems such as hypertension, insomnia, sore muscles, feelings of nervousness, and tingling of extremities may occur (Dewis & Niskala, 1992; Sexton & Munro, 1985 cited by Holicky, 1996: 247-252). Behavior problems in children are directly associated with poorer physical health in the mothers (Wallander, et al.,1989: 371-387).

2. In psychological distress, mothers of disabled children were found that they had higher depression and anxiety scores 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 (especially the mother) for activities of daily living will make her/ him have less time for her/ his own recreational, cultural, social, and work activities (Hallum,1995: 12-50).

3. Social isolation and loss of control over daily life are also presented. Most parents, especially those with very severe ill children, feel regret and withdrawn from the reality of their responsibility for their child's care. Family life and morale are imbalanced by the unpredictability of the ill child's conditions. Families may feel they lost control over their daily lives (Perrin, et al.,1993: 32). Typically, sleeping schedules are disrupted (Burr et al.,1983 cited by Perrin, et al.,1993: 32). Many families experience isolation from friends, family, and even the community. Family functioning, especially in terms of communication and problem solving, gradually worsen over time as caregivers continue to experience family adjustments following a rehabilitation (Evans, et al.,1992: 140-144). The longer the care is provided, the more likely the family functioning declines. In addition, other family members may withdraw from the demands of caregiving, leaving the caregiver feeling abandoned by the family (Given et al.,1990: 77-85). 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. Parents feel the need to compensate for the impaired sibling; and confusion and lack of communication about the handicapping condition may occur (Kilburg,1992: 68).

4. Marital relationships, the special needs of the cerebral palsy child leads to

marital stress. In spite of recent changes in American society, the usual primary caregiver still is the mother. She may feel captured in a 24-hour situation that gives little pleasure or satisfaction. Anger may be directed at their partner, who not only has more freedom to spend her/ his free time but also can 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 and the cerebral palsy child (Fraley,1995: 95-96).

5. Financial, caring for a child with chronic medical problems has a significant effect on families' financial status (Johnson & Oski,1997: 48-50). Hidden costs along with lost opportunities, lost work time and lost chances to pursue in one's career or their school (Stein,1989: 66).

Caregiver's needs for caring a child with disabilities at home

Having a child with disabilities may impose multiple challenges to families. It is considered as a major stressor or crisis in family life. Family hardiness also has been explored as a significant factor in health promotion, specifically among families dealing with children with chronic illnesses (Olsen, et al.,1999: 276).

Changes in technology not only increased a complexity of health care, but also changed the practice in acute care settings and in home care setting. Presently, patients stay in the hospital in shorter periods and then return to their homes while still requiring special care (Boyd & Hanson,1995: 375). Early discharge from the hospital make many families face complicated caregiving (Francis,1994: 149). However, the majority of care will continue to be given by family members (Lundh,1999: 582-588). Family-centered models of care involve a general change in attitudes among health care professionals who provide care to children with disabilities. This new philosophy moved from an institution/agency approach to a child-centered approach, then to a family-centered approach (Castiglia & Harbin,1992: 442). Family caregivers may be the most important element of a successful rehabilitation and long-term home care (Gaynor,1990 cited by Holicky,1996: 247-252).

In general, the family caregiver's role and responsibilities are classified into four categories as follows (Davis,1992 ; Sirapo-ngam,1996 cited by Wonjumlonsin,1999: 20):

1. Direct care services, which are personal care services that help with daily activities, and provide services for behavior problems and a specific care for each disease.

2. Emotional support, which is psychological supporting services by assessing patient's feelings, avoiding things that may decrease the patient's self-esteem, and taking the patient's developmental status into consideration.

3. Mediating with formal organizations, which are services that include managing financial resources, contracting a service for home repairs, and filling out legal forms and other documents.

4. Financial assistance, which supports medical expenses.

CP is a chronic disease that needs a long period of time and adherence in treatment and rehabilitation. Whenever family members take a role of a cerebral palsy child's caregivers, they have to prepare themselves to learn how to care and manage with the patient's problems. Moreover, they might be face with behavioral and emotional changes from the patient and long term care throughout their child's lifespan. These may cause them stress, eventhough they have skills, knowledge, and experience in caregiving.

Need can be defined in various ways. According to Kozier and Erb (1979), a need is defined as basic human needs as those necessary things which are required by human beings in order to maintain physiological and psychological homeostasis. Yura and Walsh (1983), cited that human needs referred to those needs that all people satisfy to enhance their images of themselves as persons.

Abraham Maslow (1970 cited by Freiberg,1992: 339-340) proposed a hierarchy of needs which is common to all humans. The highest needs for self- actualization, self-understanding, and an understanding of others can emerge only when lower needs are satisfied. The hierarchy of needs, from the lowest level to the highest level, includes the followings :

1. Physical needs: Food, drink, sleep, activity and relief from pain and discomfort.

2. Safety needs: Freedom from threats to supplies or life; secure, orderly and predictable environment.

3. Belonging and love needs : Acceptance and affectionate relations with others.

4. Esteem needs : Competence, confidence, task mastery, recognition, prestige; respect and approval from others.

5. Self-actualization: Realize ones potential; feeling that one is what one is capable of being.

According to Maslow, gratification of a need makes a person feel good, but deprivation causes illness (mental or physical). A deprived person will prefer gratification of a missing need over everything else under conditions of free choice. When the family has a child with disabilities at home, the family system must adjust to equilibrium in order to maintain roles and responsibilities at the same time in caring for their child as well. This shows that caregivers or parents of children with disabilities have several needs as follows:

Having a child with a disability makes a potentially wide set of challenges for families with subsequent needs for information and services that can assist in coping and adaptation process (McCollum & Hemmeter,1997: 549-578).

Family needs were assessed using the Family Needs Survey (Bailey & Simeonson,1988: 117-127). This survey consisted of 35 items reflecting needs which are commonly expressed by parents of children with disabilities (for example: how to teach my child, and babysitter agencies that are available).

Parents consider a scale to be useful and valid means of expressing needs. A clinical usefulness of a measurement in various settings had been documented in several studies (Barnhart, et al.,1994; Cooper & Allred,1992; Garshelis & McConnell, 1993). The items are organized into seven empirical derived clusters; information, family and social support, financial needs, explaining to others, childcare, professional support, and community services.

Needs will likely vary according to individual family circumstances, but include needs for information, ways to interact with a child, family and social support, financial assistance, ways to explain their child's conditions to others, respite or child care, community support, and special health care services (Bailey, Blasco, & Simeonsson,1992: 1-10).

Bailey, et al. (1999: 437-451) studied relationships between formal and informal support in mothers and fathers of children with developmental disabilities. The study showed that, for both mothers and fathers, family and formal support was significantly higher (more supportive) than that support from friends or informal support. Informal support was related significantly higher than support from friends.

Families with special needs can use two support networks: informal social networks and formal support systems. Formal support systems include agencies as well as professionals that provide services to families and individuals who need assistance. Informal support networks refer to a family's relatives, neighbors, friends, coworkers, and social groups who share emotional support, goods, services, and information (Valentine, 1993: 107-121).

Hall's studied an exploration of parental perception of the nature and level of support needs in caring for a child with special needs, in 25 parents (1996, 512- 521). Neither of the older children had received the services of a pediatric community nurse, whereas the parent of the youngest child had found it a great help. The nurses taught the multiple and complex skills required on a daily basis to maintain life for a severely disabled child. One of the comments from a mother of the oldest child in the sample was "I needed someone to work with me at home to show me how to do something in a different way because my child had a feeding problem". The only father discussed during the interview that his overall needs related to improved respite care. What he received was infrequent and did not allow him to finish his work, have a holiday, or even take time off from his child. He felt that it was unfair because he did not receive these types of services while others did. He did not consider nursing support as he had never been offered any, but he stressed how physically demanding it was to care for his son's basic needs.

Twenty parents engaged in caring for a child 2 to 14 months after renal transplant were studied (Fedewa & Oberst, 1996: 402-407). Increased housework, errands, providing emotional support, transportation, and monitoring / reporting symptoms were the most demanding tasks in this study. Housework, emotional support, and managing behavior problems were the most difficult to manage.

Wingate and Lackey's study (1989: 216-225) said the identifying need were twofold: (1) to identify needs of a non-institutionalized patient with cancer which is defined by patients, primary care givers, and nurses, and (2) to identify needs of the primary care giver which is defined by the same three groups of subjects. From this study, primary care giver's needs found that, first (29.5%), psychological needs is a need for anything that preserves, supports, and/or develops one's emotions, thoughts, and relationships to others. Second (18.6%), household management needs relate to managing/running a household and providing care to the patient. Third (17.8%), information needs is a need for knowledge, information, or understanding that can be gained through education, experience, study, or assistance by explanation. Fourth (12.5%), respite needs is a need for an interval of temporary rest or relief; a need for reprieve. Fifth (8.3%), legal and/or financial needs is a need for those things that pertain to legal or financial matters. Sixth (5.3%), other needs that did not fit into the seven other categories listed. Seventh (4.2%), spiritual needs is a need for anything that preserves, supports, and/or develops the nature of man's relationship to God. And eighth (3.8%), physical needs is a need for anything that continues, preserves, maintains, or retains the primary care giver's bodily functions.

From a literature reviewed, the researcher developed questionnaires from Lackey - Wingate is model for the categorization of needs of caregivers of patients with cancer at home (1989). Caregivers' needs for caring for cerebral palsy children at home had six categories. It included 1) information needs 2) psychological needs 3) physical needs 4) spiritual needs 5) household management needs and 6) financial needs as follows :

1. **Information needs** are need categories for caregiver to learn and safely perform necessary procedures and treatment regimens that can effective care for cerebral palsy children as:

1.1 Caring in daily activities of living include the following: self-care deficits–bathing/hygiene, dressing/grooming, feeding, toileting related to neuro- muscular impairment or cognitive deficit; altered growth and development; altered growth and development related to a disability and educational program.

1.2 Psychological caring includes the following: self-concept disturbance related to body image, self-esteem, role performance, personal identity and social isolation related to the disability.

1.3 Self from impact on cerebral palsy children includes the followings: high risk for impaired skin integrity, respiratory tract, gastro-intestinal tract, and urinary tract infection, a joint contracture related to immobility and high risk for injury related to uncoordinated movements. Families need to recognize their contributions to their child's care and their level of expertise regarding a child's condition and needs (Bowden, et al.,1998: 608).

2. Psychological needs: The responsibilities of caring for children with cerebral palsy are real issues. Parents often feel anger, guilt, grief, fear, concern for the future, and overwhelming fatigue. Families of children with CP need a lot of support during the initial diagnosis, subsequent well-child visits, hospitalizations, and long-term care (Castiglia &Harbin,1992: 450). The identification of families' strengths promotes family adaptation such as support from family members, friends, or organizations. The process of connecting was conceptualized as creating a bond of relationship, cooperation or mutual effect. It was a basic social process that enabled caregivers to realize a fulfillment of their needs for help, hope, and happiness. Caregivers learned that lay people could master technical skills and could function well in assisting a patient when they were informed and aware.

3. Physical needs: Respite is essential for families who have a child with a disability. The physical and emotional demands of raising a child with special needs can be overwhelming and place tremendous responsibilities on the parents in all aspects of their lives (Castiglia & Harbin,1992: 465). Caregivers needed help in giving direct care to the dependent person at home, and family members were expected to offer this help. Caregivers expressed the need for respite or relief from the burdens of caregiving and perceived respite as positive, vital, and "at the top of the list of needs" (Rawlins,1991: 213-220).

4. **Spiritual needs**: Disconnection also occurred when caregivers struggled in finding sources of hope that served in their life's circumstances. Even though they expressed that faith in God was a support in their burdens, it was difficult for hope to be ever present in their thinking. Family caregivers used another category of statements, such as "looking for strength inside" and "God uses these situations in order to build strength". One caregiver stated that "she needed to hear that there was always hope".

5. **Household management needs**: The role of women has always been inextricably interwoven with the family because society consideres the responsibility of women is to take care of family members who fell ill. In their house- keeping role, women provide an environment for the maintenance of health and wellness (Bomar,1996: 6). Family members nurture a child based on their ability to provide food, shelter, health care, and a stimulating and safe environment for a child to explore and learn (Hertzberg,1999: 98).

6. **Financial needs**: The cost of caring for a child with disabilities is not limited only in medical expenses. Expenses in medical needs may include transportation, clothing, day care or respite care, dental and visual services, and home remodeling" (Edwards, 1999: 206).

Factors that influence caregivers' needs for caring cerebral palsy children at home.

Factors of cerebral palsy children that influence on caregivers' needs include:

1. Birth order: Research on the significance of family size and birth order on children's personality, adjustment and cognitive development is complicated by the fact that birth order and family size are related to social class differences (large family size is associated with lower social class). In contrast, a possible disadvantage of being first-born for socio-emotional development was that the former children have a slight advantage over later-born children in terms of their scholastic achievement and verbal IQ (Rutter, 1985b cited by Dunn,1994: 123). Recent research showed that there was a clearest correlation between the number of siblings in a family, rather than birth order, and cognitive development (Blake,1989).

2. Age: The handicapped newborn infant's care is not different from that of a normal baby, even when special equipment needs or feeding problems occur and take time in training. Bonding between mother and child is facilitated by interaction. It is more difficult for the parents when the baby is not able to respond by smiling, cooing, and bodily movements. As the baby grows up in the first year, early motor skills may lack, but the parents are controlled by the infant's needs expressed by his or her behavior the same way as a normal child. The toddler years set the stage for the rest of development, as the child learns to communicate, control, act on his or her own, relate to others, and play. Communication is the most important skill that establishes early because it is a basis of learning and social relationships. In pre-school aged children, a participation in playing with other children is often limited by their physical difficulty. It is important that the handicapped child have opportunities to interact with peers at age- appropriate levels in

whatever way is feasible. This interaction is needed to establish a foundation for social skills needed later in school and work (Molnar, et al.,1992: 126-128). Parents of the maturing disabled adolescent also cope with an increase in the size of their child. As the adolescent becomes taller and heavier, parents report more stress related to the physical burden of care (Hallum,1995: 12-50). Hall's study (1996:512-521) showed that "An exploration of parental perception of the nature and level of support needed to care for their child with special needs" in the parents of children from birth to 19 years of age. It found that a mother of the youngest child who invariably needed all the details repeated again, or worse, asked for another assessment. The parents of the older children needed both information about what would be offered for their children after they left school.

3. Severity of disability: Caregiver stress results from various sources, including physical demands of caregiving, a conflict over completing roles, role difficulty, a difficulty in managing care-receiver behavior, a loss of companionship, and a lack of support (Williams,1994: 155-161). In fact, it found that the more a child is dependent on others in performing daily living activities, the more psychological distress that was reported by their mother. This relationship can be explained in different ways. Providing care which is more than daily living activities can be physically and emotionally draining and cause psychological distress (Wallander & Venters, 1995: 619-632). Somatic complaints, anxiety, and depression are most common symptoms of well spouses (Evans, et al.,1992: 140-144; O'Brien,1993a: 105-112). Severity of disability has a predictable impact on growth and development, on children's psychological status, and on their families. Even though each condition has its own clinical idiosyncracies, families raising a

child with severity disabilities face a common set of problems in coping, psychological and family support, and in finding an appropriate broad range of health care services and related services (Perrin,1999: 304).

Factors of caregivers that influence on caregivers' need include :

1. Age: It is important in mental status perception, and ability to understand or make decisions about carrying out behavior (Srangnok,2000: 27-28). Hass (1990: 145-146) found that the age of a parent influences the power and ability of a parent to care for a sick child. Young parents have more difficulty in caring for a handicapped child than older or more experienced parents. Because of inexperience, young parents have difficulty in reviewing how much activity their child needs and what toys are appropriate (Pillitteri, 1981: 948).

2. Parents' educational level: More education and higher emotional health perhaps better equips caregiving responsibilities and may even benefit from this role. College-educated women who reported higher life satisfaction had a higher rate of caregiving than those with less life satisfaction (Moen, et al.,1995: 259-273). Parents who have a higher level of education are more knowledgeable and capable in helping their children to perform health practices (Sherman, et al.,1995: 26-28).

3. Marital-parent's status: It appears that family stress is not directly related to being a single parent. McCubbin (1989 cited by Hall,1996: 512-521) studied 397 families who had a child with cerebral palsy. He measured parental coping using the Coping Health Inventory for Parents (CHIP). The results showed no significant differences in each group of parents, but single parents showed their vulnerability in financial terms.

These parents had less income and financial reserves to overcome crises, even though they were more flexible than two parent families.

4. Number of children: The size of the family, family expectations of the individual members, and the resources available for use by the individual family members have a conditioning effect on an individual's self-care requirements and means of meeting them. A person who grew up in a large family may have very different requisites in solitude and social interaction than that a person raised in a small family. They may need to develop different action strategies to meet the demand for solitude (Orem, 1995: 362). Tarvis (1972 cited by Freiberg,1992: 346) also indicated that the more children a woman has, the less satisfied she becomes with her home-working role.

5. Workplace: In a rural setting, most females engaged in agricultural jobs. Women's employment also tends to take place in or near home, that makes child-care less problematic and allows household work that can be shared by other family members (Ariadi,1995: 28). Limitations for engagement in result-achieving courses of action within the investigative and production phases of self-care, including limitations for self-management, are associated with human functional states and with environmental conditions and circumstances (Orem,1995: 238-239). The Inability or limitations in ability to control body movements in the performance of required actions are in either or both phases of self-care. These may be a lack of sufficient energy for sustained action in the investigative and production phases of self-care.

6. Family income: It is one of the best predictors in poor health outcomes for children, besides mortality, activity limitations, and utilization of health care (Schor &

Menaghan,1995: 24-26). Families from lower socioeconomic groups may lack knowledge or resources to provide a safe, stimulating, and enriched environment that fosters optimum development for children (Orem,1991 cited by Wenhui,1997: 25-26).

7. Duration of caring: Ray, et al. (1982: 385-395) indicates that a person spends a phase of time to develop skills of adaptation and ability to face problems. Duration of caring influences the adaptation of caring because human nature needs a timing phase to learn and adapt (Friendland & McColl, 1987: 517-522). Caregivers feel bored, stressful and dejected, which decrease their abilities to take care of sick children due to chronic sickness (Ruanlapanun, 2000: 31).

In related literature, it can be concluded that cerebral palsy children have an impact not only directly on themselves but also on families and caregivers. CP is a chronic disease that needs a long period of time and adherence with their treatment and rehabilitation. Whenever family members take a role as caregivers of a CP child, they have to prepare themselves to learn how to help and how to manage with the patient's problems. Moreover, they might be faced with behavioral or emotional changes in the patient and long term care, which may not show results over a short time. These may cause them to need more in information needs, psychological needs, physical needs, spiritual needs, household management needs, and financial needs. All of these needs have individual differences that depends on two main categories: (1) caregiver factors, such as age, educational level, marital status, number of children, workplace, family income and duration of caring; (2) cerebral palsy children factors, such as birth order, age, and severity of disability. Nurses play important role in interacting with the caregivers, therefore, they are more able to make an assessment of family's needs. This assessment will guide nurses and health teams to plan, promote, and assist in caring for cerebral palsy children at home effectively and to meet caregivers and cerebral palsy children's needs.

CHAPTER III

METHADOLOGY

Research Design

This study is a descriptive research. The objectives were to explore and describe caregivers' needs for caring for cerebral palsy children at home and the factors that predict the caregivers' needs for caring for cerebral palsy children at home.

Population and Sampling

Population of this study consists of caregivers of cerebral palsy children between the age of 0 – 6 years, who brought their children to rehabilitate at the physiotherapy department in Siriraj Hospital and Rajanukul Hospital.

Sample selection: Purposive sampling had the same characteristics as those of the population that was selected as the main caregiver to whom the cerebral palsy child had been his/ her major responsibility throughout the prior month. The sample size was 140 caregivers of cerebral palsy children and was calculated by Biddle & Marlin's formula (Biddle & Marlin, 1987: 4-17).

$$n = 10(k+2)$$

when n = number of sample

k = number of independent variables such as caregiver characteristics (age, education level, marital status, number of children, workplace, family income and duration of caring), and cerebral palsy child characteristics (birth order, age and severity of disability)

In this study, there were ten independent variables, therefore:

$$n = 10(10 + 2) = 120 \quad \text{samples}$$

And in this study, the researcher collected to 140 samples.

Setting

This study was conducted at Siriraj Hospital and Rajanukul Hospital. Siriraj Hospital where the researcher has been working from 1987-until the present. And Rajanukul Hospital is the specific rehabilitation of cerebral palsy children. The patients followed up on Monday-Friday at 8.00-12.00 pm.

Instrumentation

Instruments

The questionnaire used to collect the data for this study consisted of two parts: the demographic data form and the caregivers' needs for caring cerebral palsy children at home questionnaires. The questionnaires were described as follows:

Part I: Demographic data of subjects

1.1 Caregiver's demographic data form such as age, gender, education, marital status, total number of children, occupation, family income, relation to cerebral palsy child, duration of daily care giving for the cerebral palsy child and assistants of the caregiver.

1.2 Cerebral palsy child's demographic data form such as birth order, age, duration of illness, and severity of disability which was assessed by the psychotherapist and the researcher based on two criteria of the cerebral palsy children as follows:

From birth to 3 years: the development assessment by using DDST (Denver Developmental Screening Test) from birth to 3 years. It identifies developmental lags. The severity of disability is assessed from the percentage in the average scores of four developmental areas on this age scale (in Appendix C) (Jaikamwong, 1999).

51% - 80%	as	mild cerebral palsy
25% - 50%	as	moderate cerebral palsy
less than 25%	as	severe cerebral palsy

From 3 years up: the functional independence assessment which is developed from the questionnaire for assessing the activities of daily living of disabled children (ADL)(Grant & McGrath, 1991: 638-648 cited by Wongchanta,1997). It consists of a three-point scale to assess the range of complete independence to dependence in 9 subdomains. These 9 subdomains represent the 4 domains of mobility (item 1), communication (items 2.1-2.2), self care (items 3.1-3.4), and social cognition (items 4.1- 4.2).

The answer has a rating scale with 3 levels. The scoring of answer is as follow:

Answer A is rated a 3 score, indicating complete dependence.

Answer B is rated a 2 score, indicating moderate dependence.

Answer C is rated a 1 score, indicating complete independence.

The total score is cumulative across the items, thereby assessing severity of disability.

Total score of 22 – 27 means the child has mild cerebral palsy.

Total score of 16 – 21 means the child has moderate cerebral palsy.

Total score of 9 – 15 means the child has severe cerebral palsy.

Part II: Caregivers' Needs for Caring Cerebral Palsy Children at Home Questionnaire.

This questionnaire was developed by the researcher based on the needs of cancer patients and their primary caregivers (Wingate & Lackey, 1989). It consists of 60 positive items divided into six dimensions: information needs (items 1-24), psychological needs (items 25-34), physical needs (items 35-41), spiritual needs (items 42-49), household management needs (items 50-55), and financial needs (item 56-60).

The answer has a rating scale with 4 levels. The scoring of items was 1 as any need, 2 as a low need, 3 as a moderate need, and 4 as a high need. The level of caregivers' needs was judged as never, low, moderate or high need by the average rating scores according to the following criteria:

The average score of 1.00 – 1.50 means the caregiver had never had this need.

The average score of 1.51 – 2.50 means the caregiver had a low need.

The average score of 2.51 – 3.50 means the caregiver had a moderate need.

The average score of 3.51 – 4.00 means the caregiver had a high need.

Content Validity

The content validity of instruments were tested for clarity and appropriateness for language usage by a five panel experts, as follows:

- Pediatric neurology physician

- Two pediatric nurses educators
- Psychological nurse educator
- Expert in cerebral palsy pediatric nursing.

The researcher took the opinion and recommendations of these experts to improve the instruments before trying out the instruments .

Reliability

The instruments were pilot tested with 30 caregivers with the same characteristics in a select population in Rajanukul Hospital. The Cronbach's alpha coefficient was calculated for as follows (Cronbach, 1984 cited by Polit & Hungler,1999: 415).

$$r = (k / k\text{-}1)\left[1 - (\Sigma\, \sigma i^2 / \sigma y^2)\right]$$

When r = The estimated reliability

k = The total number of items in the instruments

σi^2 = The variance of each individual item

σy^2 = The variance of the total test scores

Σ = The sum of

The obtained results of calculated reliability of the questionnaire = .94

Data collection

1. The researcher sent a letter of Graduate Studies, Mahidol University to the Director and the committee on human rights related to research involving humans of Siriraj Hospital, and the Director of Rajanukul Hospital for permission to collect the

data due to the following schedule :

- Siriraj Hospital	Wednesday and Thursday	9.00 – 12.00 p.m.
- Rajanukul Hospital	Monday, Tuesday, and Friday	9.00 – 12.00 p.m.

2. After receiving permission, the researcher met with the heads of the physical therapy departments of 2 hospitals to introduce herself and discuss the data collection procedure of this study.

3. The researcher selected the sample group of caregivers who brought their children by themselves from the recorded cards of cerebral palsy children and took note of their names.

4. The researcher requested to meet the caregivers whose children's names were recorded, while the caregivers and their children were waiting for rehabilitation by the physical therapists. The researcher introduced herself to the caregivers and explained the objectives of the study to them. The researcher asked for cooperation to gather the data. The caregivers of cerebral palsy children could refuse or stop giving information at any time during the interview and responding to the questionnaire.

5. When the caregivers agreed, the researcher asked the caregivers to sit in a private place and interviewed them according to the recorded forms on the personal data and the interview forms on caregivers' needs for caring cerebral palsy children at home. Before the interview, the researcher explained how to answer the questions and then read each question to the caregivers and let them answer it. The researcher recorded the answers on the interview forms.

6. Next, the researcher handed out the questionnaires of caregivers' needs for caring cerebral palsy children at home to the caregivers and described the method in answering the questionnaires to them. The researcher let the caregivers answer the

questionnaires by themselves. In case that the caregivers had problems in answering the questionnaires because they could not read or write, the researcher read each question for them and let them answer item by item until the questionnaires were completed. The researcher recorded the answers on the questionnaires.

7. The researcher gathered and examined for completeness of information from all of the questionnaires.

8. The researcher analyzed the answers gathered from the interview forms and the questionnaires statistically.

Protection of Human Subjects

The consent form explained the details and the objectives of the study and asked for cooperation. The subjects had the right to make their decision to participate in this study or not. If they did, they could cancel or withdraw from the study at any time. The data which was taken from the subjects would be kept confidential. After the subjects received the data of the consent form, then the researcher started to interview. (Details in Appendix B)

Data Analysis

The data was analyzed by using the statistical package for the social science for windows (SPSS 7.5/FW) program and set the statistical significance of .05. The steps were as follows:

1. Demographic data was analyzed by using frequency and percentage.

2. Scores of caregivers' needs for caring cerebral palsy children at home were analyzed by using mean and standard deviation.

3.The relationship between the predictive factors including caregiver characteristics (age, education level, marital status, numbers of children, workplace, family income and duration of caring); cerebral palsy child characteristics (birth order, age and severity of disability); and caregiver's needs for caring cerebral palsy children at home were analyzed using Pearson's product-moment correlation coefficient.

4.Calculated the multiple correlation coefficient of the criterion and the predictor.

5.Found out the best equation for variable prediction by using the stepwise multiple regression technique.

CHAPTER IV

RESULTS

This descriptive study was aimed at assessing caregivers' needs for caring cerebral palsy children at home. One hundred and forty samples of caregivers of cerebral palsy children, in the physiotherapy departments at Siriraj Hospital and Rajanukul Hospital were purposively selected. The results are presented as follows:

Part I Demographic data of the caregivers and demographic data of the cerebral palsy children.

Part II Caregivers' needs for caring for cerebral palsy children at home.

Part III The relationship between selected factors including caregiver characteristics: age, education level, marital status, number of children, workplace, family income and duration of caring and cerebral palsy child characteristics: birth order, age and severity of disability; and caregivers' needs for caring for cerebral palsy children at home.

Part I Demographic data of caregivers and Demographic data of cerebral palsy children.

Table 1 Frequency and percentage of the caregivers categorized by sex, age, marital status, occupation, and religion (n = 140).

Characteristic		Frequency	Percent
Sex:	Male	17	12.1
	Female	123	87.9
Age: (years)	Under 20	2	1.4
	20 – 40	103	73.6
	41 – 60	31	22.1
	Above 60	4	2.9
Marital status:	Married	119	85.0
	Singled/Widowed/Divorced	21	15.0
Workplace:			
	Outside home	47	33.6
	Inside home	93	66.4
Religion:	Buddhism	127	90.7
	Islamism	8	5.7
	Christian	5	3.6

Table 1 showed that most of the caregivers, 87.9 percent were female, age between 20 – 40 years old 73.6 percent, married 85 percent, 66.4 percent have workplace inside home, and the most common religion was Buddhism 90.7 percent.

Table 2 Frequency and percentage of the caregivers categorized by family income, and sufficient income (n = 140).

Characteristic	Frequency	Percent
Education:		
No education	4	2.9
Primary	57	40.7
Secondary/Vocational Certificate	45	32.1
Diploma/Higher Vocational Certificate	7	5.0
Bachelor's Degree or Higher	27	19.3
Family income/month (baht)		
Below 5,000 baht	43	30.7
5,000 – 10,000 baht	52	37.2
10,001 – 30,000 baht	41	29.2
30,001 – 60,000 baht	4	2.9
Sufficient income:		
Sufficient savings	39	27.9
Sufficient with no savings	49	35.0
Insufficient without debt	17	12.1
Insufficient with debt	35	25.0

Table 2 showed that most of the caregivers, 40.7 percent had a primary education, sufficient income with no savings (35.0 percent), and most of the samples had a monthly income of 5,000 – 10,000 baht (37.2 percent).

Table 3 Frequency and percentage of the caregivers categorized by relationship to cerebral palsy child, number of children, and duration of caring (n = 140).

Characteristic		Frequency	Percent
Relationship to cerebral palsy child:			
Parent		119	85.0
Grandfather, Grandmother		11	7.9
Aunt, Uncle, Sister		10	7.1
Number of children:	0	9	6.4
	1	53	37.9
	2	44	31.4
	Above 2	34	25.3
Duration of caring:			
Under 6 months		2	1.4
6 months – 1 year		6	4.3
Over year – 3 years		45	32.2
Over 3 years		87	62.1
Daily duration of caring in:			
Less than 6 hours		14	10.0
6 – 10 hours		17	12.1
11 – 15 hours		20	14.3
More than 15 hours		89	63.6

Table 3 showed the majority of the caregivers (85.0 percent) were parents, had one child (37.9 percent), a duration of caring was over 3 years (62.1 percent) and the daily duration of caring more than 15 hours (63.6 percent).

Table 4 Frequency and percentage of the caregivers categorized by experience for caring for cerebral palsy children, assistants of caregivers, and kind of helping (n = 140).

Characteristic	Frequency	Percent
Experience for caring:		
None	131	93.6
Have	9	6.4
Assistant:		
None	47	33.6
Parent	28	20.0
Spouse	22	15.7
Relative	22	15.7
Baby-sitter	21	15.0
Kind of helping:		
Nurture	76	54.3
Rehabilitation	4	2.9
Bathing	7	5.0
Feeding	6	4.3

Table 4 showed that most of the caregivers,(93.6 percent) were not experienced for caring for cerebral palsy children 66.4 percent had assistants and the assistants helped the caregivers to nurture the child at 54.3 percent.

Table 5 Frequency and percentage of the patients categorized by age, birth order , duration of illness, and severity of disability (n = 140).

Characteristic	Frequency	Percent
Age: (years)		
Under 2	24	17.1
2 – 4	53	37.9
Over 4	63	45.0
Birth order:		
First	73	52.1
Second	44	31.5
Over second	23	16.4
Duration of illness:		
Under 6 months	7	5.0
6 months – 1 year	9	6.4
Over 1 year – 3 years	47	33.6
Over 3 years	77	55.0
Severity of disability:		
Mild	12	8.6
Moderate	23	16.4
Severe	105	75.0

Table 5 showed that most of the patients, over 4 years of age was at 45.0 percent, 52.1 percent were the first order child, 55.0 percent had the duration of illness over 3 years and 75.0 percent had a severe level of disability.

Part II Caregivers' needs for caring for cerebral palsy children at home.

Table 6 Mean, standard deviation and the Interpretation of the mean scores of caregivers' needs clarified in each category.

Needs	$\bar{X}$	S.D.	Interpretation
Information needs	3.30	0.53	Moderate need
Psychological needs	3.16	0.59	Moderate need
Financial needs	3.06	0.84	Moderate need
Spiritual needs	3.05	0.70	Moderate need
Household management needs	2.85	0.76	Moderate need
Physical needs	2.58	0.80	Moderate need
Total needs	3.10	0.52	Moderate need

Table 6 showed that the caregivers had the over all mean score of information needs in the highest level, the mean was 3.30 and the standard deviation was 0.53. The lowest level of the needs were physical needs ($\bar{X} = 2.58$, S.D. = 0.80). Total needs were at the moderate level ($\bar{X} = 3.10$, S.D. = 0.52).

Table 7 Mean, standard deviation and the Interpretation of the mean score of the information needs of caregivers.

Needs	$\bar{X}$	S.D.	Interpretation
Information needs:	3.30	0.53	Moderate need
- Patient's developmental	3.83	0.41	High need
- Know continuing treatment	3.81	0.46	High need
- Seizure management	3.74	0.66	High need
- Rehabilitation resources	3.74	0.67	High need
- Knowledge about prognosis	3.73	0.52	High need
- Knowledge about disease	3.71	0.69	High need
- Managing Behavior	3.69	0.60	High need
- Education	3.69	0.65	High need
- Supportive	3.61	0.73	High need
- Help in walking	3.46	0.88	Moderate need
- Defend the accident	3.34	0.87	Moderate need
- Helping with constipation	3.29	0.98	Moderate need
- Mouth care	3.21	0.91	Moderate need
- Take a seat	3.21	1.06	Moderate need
- Take the position	3.14	1.08	Moderate need
- Medication	3.11	0.95	Moderate need
- Helping with diarrhea	3.11	1.00	Moderate need
- Feeding	3.06	1.09	Moderate need
- Take to the chair	3.06	1.14	Moderate need
- Bring to the bed	3.01	1.11	Moderate need
- Helping with vomit	3.00	1.05	Moderate need
- Care of the skin	2.93	1.08	Moderate need
- Clean the reproductive organ	2.49	1.12	Low need
- Take a bath	2.41	1.15	Low need

Table 7 showed that the caregivers' needs had the average score of the information needs in the high need for 9 items, in the moderate need for 13 items and in the low need for 2 items. The highest score item was the information need in the developmental ($\bar{X}$ = 3.83, S.D. = 0.41). The low needs were information need in taking the child for a bath ($\bar{X}$ = 2.41, S.D. = 1.15) and cleaning the reproductive organ of the child ($\bar{X}$ = 2.49, S.D. = 1.12).

Table 8 Mean, standard deviation and the Interpretation of the mean scores of the psychological needs of caregivers.

Needs	$\bar{X}$	S.D.	Interpretation
Psychological needs:	3.16	0.59	Moderate need
- To be accepted by physicians	3.62	0.71	High need
- To be accepted by nurses	3.59	0.76	High need
- To be welcomed by physicians	3.56	0.70	High need
- To be welcomed by nurses	3.39	0.82	Moderate need
- Family solve problems	3.27	0.94	Moderate need
- Consulting with members of the family	3.19	0.93	Moderate need
- Participating in the activities of the family	3.05	0.98	Moderate need
- Relaxation	3.01	1.05	Moderate need
- Vacation sometimes	2.52	1.05	Moderate need
- Relations visit	2.38	0.99	Low need

Table 8 showed that the caregivers' needs had the average of the psychological needs in the high need for 3 items, in the moderate need for 6 items and in the low need for 1 item. The highest score was to be accepted by physicians about caring for the patient when the caregiver took him to the hospital ($\bar{X}$ = 3.62, S.D. = 0.71). The low need was relations visiting the patient and caregiver sometimes ($\bar{X}$ = 2.38, S.D. = 0.99).

Table 9 Mean, standard deviation and the Interpretation of the mean scores of the financial needs of caregivers.

Needs	$\bar{X}$	S.D.	Interpretation
Financial needs:	3.06	0.84	Moderate need
- For rehabilitation resources	3.79	0.56	High need
- For the medical expenses	3.04	1.08	Moderate need
- For the expenses of daily living of the patient	2.88	1.14	Moderate need
- For the transportation's expenses	2.83	1.16	Moderate need
- For the expenses in family	2.77	1.13	Moderate need

Table 9 showed that the caregivers' needs had the average score of the financial needs in the high need for 1 item, in the moderate need for 4 items, but none in the low need. The highest score was to help from sources that provide instruments for the rehabilitation of the patient ($\bar{X}$ = 3.79, S.D. = 0.56).

Table 10 Mean, standard deviation an the Interpretation of the mean scores of the spiritual needs of caregivers.

Needs	$\bar{X}$	S.D.	Interpretation
Spiritual needs:	3.05	0.70	Moderate need
- Patient was perceived to caregivers' feelings	3.73	0.61	High need
- To perceive self-efficacy	3.42	0.88	Moderate need
- Emotional supportive	3.20	0.95	Moderate need
- Family and patient were known caregivers' efficacy	3.06	1.03	Moderate need
- To know there is hope	3.02	1.12	Moderate need
- Be happy from caregivers' regardness	2.86	1.06	Moderate need
- To pray and go to church	2.59	0.94	Moderate need
- To accept the handicapped patient	2.55	1.09	Moderate need

Table 10 showed that caregivers' needs had the average score of the spiritual needs in high need for 1 item, in the moderate need for 7 items. The score was highest in the patient was perceived to caregivers' feelings of interest and loves the patient very much ($\bar{X}$ = 3.73, S.D. = 0.61).

Table 11 **Mean, standard deviation and the Interpretation of the mean scores of the household management needs of caregivers.**

Needs	$\bar{X}$	S.D.	Interpretation
Household management needs:	2.85	0.76	Moderate need
- be helped from community resources	3.28	0.94	Moderate need
- Someone care for the patient when caregiver is busy	3.14	0.98	Moderate need
- Family gets the patient to see the doctor	2.89	1.09	Moderate need
- Helping to cook the food	2.74	1.01	Moderate need
- Helping to wash the clothing	2.64	1.06	Moderate need
- Helping to clean the home	2.41	1.00	Low need

Table 11 showed that the caregivers' needs had the average score of the household management needs in moderate need for 5 items, in the low need for 1 item, but none in the high need. The highest score was to connect with the community resources that can solve the family's problems ($\bar{X}$ = 3.28, S.D. = 0.94). The low need was helping to clean the home ($\bar{X}$ = 2.41, S.D. = 1.00).

Table 12 Mean, standard deviation and the Interpretation of the mean scores of the physical needs of caregivers.

Needs	$\bar{X}$	S.D.	Interpretation
Physical needs:	2.58	0.80	Moderate need
- Having good health	2.91	1.01	Moderate need
- Have time to take care for themselves	2.71	0.95	Moderate need
- Have time for respite	2.64	1.01	Moderate need
- Check up themselves	2.56	1.05	Moderate need
- Have time for self care	2.49	0.99	Low need
- Have time for sleeping	2.43	1.07	Low need
- Have time for exercise	2.37	1.04	Low need

Table 12 showed that the caregivers' needs had the average score of the physical needs in the moderate need for 4 items, in the low need for 3 items, but none in the high need. The highest score item was to have good health ($\bar{X}$ = 2.64, S.D.=1.01). The low needs were to have time for self care ($\bar{X}$ = 2.49, S.D. = 0.99), have a time for indoor exercise ($\bar{X}$ = 2.37, S.D. = 1.04), and have time for sleeping more than this ($\bar{X}$ = 2.43, S.D. = 1.07).

Part III The relationship between selected factors including caregiver characteristics: age, education level, marital status, number of children , workplace, family income and duration of caring and cerebral palsy child characteristics: birth order, age and severity of disability ; and caregivers' needs for caring cerebral palsy children at home.

Table 13 Mean, standard deviation, minimum, maximum of variables and matrix of correlation coefficient among the variables.

Variables	1	2	3	4	5	6	7	8	9	10	11
1. Caregiver's age	1.000										
2. Education level	-.121	1.000									
3. Marital status	-.021	.063	1.000								
4. Number of children	.394**	-.010	.272**	1.000							
5. Workplace	.085	-.156	.083	.051	1.000						
6. Family income	.268**	.404**	.260**	.221**	-.173*	1.000					
7. Duration of caring	.218**	.061	.154	.108	.036	.032	1.000				
8. Birth order	-.018	-.053	-.075	.425**	-.002	.055	-.020	1.000			
9. Patient's age	.201*	.025	.164	.076	.018	-.004	.906**	-.053	1.000		
10. Severity	-.010	.021	.030	-.040	.091	-.042	-.014	-.157	.026	1.000	
11. Caregiver's needs	-.010	-.125	-.033	.044	-.022	-.117	-.003	-.096	.026	.139	1.000
$\bar{X}$	35.34	9.57	.24	1.85	.34	11417.14	43.86	1.7	45.67	2.66	3.10
S.D.	9.43	4.77	.61	1.17	.47	9579.47	19.58	.88	16.84	.63	.52
Minimum	17	0	0	0	0	0	1	1	8	1	2.37
Maximum	65	16	1	8	1	60000	72	4	72	3	3.83

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

Table 13 showed that the minimum, maximum, and average caregiver's age was 17, 65 and 35.34 years old respectively, with a standard deviation of 9.43. The minimum, maximum, and average education level was 0, 16 and 9.57 years with standard deviation of 4.77. The minimum, maximum, and average marital status was 0, 1 and 0.24 respectively, with a standard deviation of 0.61. The minimum, maximum, and average the number of children was 0, 8 and 1.85 persons respectively, with a standard deviation of 1.17. The minimum, maximum and average workplace was 0, 1 and 1.34 respectively, with a standard deviation of 0.47. The minimum, maximum, and average family income was 0, 60000 and 11417.14 baht with standard deviation of 9597.47. The minimum, maximum, and average duration of caring was 1, 72 and 43.86 months respectively, with a standard deviation of 19.58. The minimum, maximum, and average birth order was 1, 4 and 1.7 respectively with a standard deviation of 0.88. The minimum, maximum, and average patient's age was 8, 72 and 45.67 months respectively, with a standard deviation of 18.64. The minimum, maximum, and average severity of disability was 1, 3 and 2.66 respectively, with a standard deviation of 0.63. In addition, it was found that the caregiver's age, education level, marital status, number of children, workplace, family income, duration of caring, birth order, patient's age, and severity of disability did not a relationships with caregivers' needs at a statistically significant level of .05. There was a relationship among the predictive variables, which were a positive relationship of caregiver's age with number of children, family income, duration of care and patient's age at a statistically significant level of .01, .01, .01 and .05, respectively.

There was a positive relationship of education level with family income at a statistically significant level of .01, and a positive relationship of marital status with number of children and family income at a statistically significant level of .01. A positive relationship of number of children with family income and birth order at a statistically significant level of .01, and a positive relationship of duration of caring with patient's age at a statistically significant level of .01. A negative relationship of indoor workplace with family income at a statistically significant level of .05.

Table 14 The Regression coefficient between the predictor which are caregiver characteristics: age, education level, marital status, number of children, workplace, family income and duration of caring and cerebral palsy child characteristics: birth order, age and severity of disability; and caregivers' needs for caring cerebral palsy children at home.

Variables	b	Beta	SE	F
1. Caregiver's age	-.005	-.091	.006	-.837
2. Education level	-.013	-.122	.011	-1.242
3. Marital status	-.122	-.084	.144	-.848
4. Number of children	.085	.191	.051	1.675
5. Workplace	-.037	-.034	.098	-.385
6. Family income	-.000	-.053	.000	-.493
7. Duration of caring	-.002	-.079	.005	-.387
8. Birth order	-.098	-.167	.060	-1.637
9. Patient's age	.002	.107	.006	.525
10. Severity of disability	.094	.115	.072	1.323
Constant	3.277		.356	

$R = .263$ $R^2 = .069$ adj $R^2 = -.003$ $SE = .5210$ $F = .962$

Table 14 showed that the predictors, which were included in the analysis, were 10variables of caregiver's age, education level, marital status, number of children, workplace, family income, duration of caring, birth order, patient's age and severity of disability, all of which did not a relationship with caregiver's needs at a statistically significant level .05.

It described that total independent variables including caregiver's age, education level, marital status, number of children, workplace, family income, duration of caring, birth order, patient's age and severity of disability were not able to predict caregivers' needs for caring cerebral palsy children at home ($R = 0.263$, $p > .05$).

CHAPTER V

DISCUSSION

The hypotheses of this study was that caregiver characteristics: age, education level, marital status, number of children, workplace, family income, and duration of caring, and cerebral palsy child characteristics: birth order, age, and severity of disability can be used as predictors on caregivers' needs in caring cerebral palsy children at home. Description of the results according to the purposes and the hypothesis are shown in details below.

Purpose I : To describe caregivers' needs in caring cerebral palsy children at home.

From this study, the researcher found that mean of caregivers' needs in caring cerebral palsy children at home in overall and in each aspect was ($\bar{X}$ = 3.10, S.D.= 0.52) as showed in Table 6. It showed that six needs were at moderate need's level.

1. Information needs: It found that mean of information needs was at a moderate level ($\bar{X}$ = 3.30, S.D. = 0.53). According to Orem, an agent who performs an action must have " sensory knowledge" and an " awareness" of a situation; and an agent "reflects" on that knowledge and then " makes decisions" (Orem, 1991: 79 – 86). It found the caregivers had high level for these needs. They included a method to support the patient's development ($\bar{X}$ = 3.83, S.D. = 0.41), continuing treatments for the patients that should be received ($\bar{X}$ = 3.81, S.D. = 0.46), information in seizure

management ($\bar{X}$ = 3.74, S.D. = 0.66), and knowing the resources that can help their problems in caring the child ($\bar{X}$= 3.61, S.D.=0.73). These items can groups into 3 categories (need to know support and developmental, about treatment and the supportive resources). It is important for caregivers to know and be informed that most treatments are useful and usually used to maintain a physical and emotional balance (Pachter, et al., 1995: 982 – 988). About 50 – 70 % of children with cerebral palsy have intellectual disabilities with varying degree from mild to severe mental retardation. And 35 – 50% of those also have seizures (Steele, 1992: 153 –154). In this study, most of the severity of disability (75%) was severe. Moreover, these children and their caregivers need appropriate information in their development and what is going on around them. Bailey, et al's studied (Bailey, et al., 1999: 437 – 451) needs and supports that were reported by Latino families of young children with developmental disabilities. They found that the most common expressed needs were information about services for their child, both in the present time and in the future; information about their child's disability; and information regarding how to teach their child and how to manage their child's behaviors. Furthermore, information that make caregivers feel confident in performing their role and feel more important in providing a continuous child care in their community is also essential (Thoits, 1986: 416 – 423). The lowest needs were a method of cleaning patient's genitalia ($\bar{X}$ =2.49, S.D.= 1.12), a method of taking a bath or sponge bath ($\bar{X}$ = 2.41, S.D. = 1.15), and information about comfortable patients' care. Most of caregivers (62.1%) had a duration of caring more than 3 years. After living with the patient with chronic illness condition and learning its nuances and management, the caregivers had more understanding in chronic illness (Mahon, 1992: 19). It made caregivers to have the low level of this need. In each item of caregivers' needs, it found that caregivers had a moderate level of the needs in 13 items.

2. Psychological needs: It found that mean score of psychological needs was at a moderate level ($\bar{X}$ = 3.16,S.D. = 0.59). It found that the caregivers needed acceptance from physicians and nurses in patient care when they took their child to the hospital ($\bar{X}$ = 3.62, S.D. =0.71; $\bar{X}$ = 3.59, S.D. = 0.76, respectively). Caregivers had a need to be welcomed from physicians in asking information ($\bar{X}$ = 3.56, S.D. = 0.70). Besides the social support from their family members, caregivers also need social support especially from health care teams. They reported that physicians and nurses should have time for them to ask questions when they take their child to the hospital. One possible reason is that public hospitals in any area in Thailand have an insufficient and an inappropriate ratio of health care professionals to parents. Therefore, time and frequency of communication with caregivers by health care professionals are limited. According to Thai culture, health clients always think of others more and feel that health care providers are in higher level in society. When health care clients met with health care professionals, the health care clients will keep quiet even if the health care professional is busy or not (Chontawon, et al., 2000: 56-71). That explained why caregivers' needs in these items were at a high level. This finding concurs with the study of Snowdon and Kane (1995: 425-428) that parents need information from the professionals especially physicians and nurses. Psychological needs are needs for anything that preserves, supports, develops one's emotions, thoughts, and relationships to others (Wingate & Lackey, 1989: 221). In addition, this study had the same finding as Lundh's study (1999: 58 – 588), that nearly 90% of caregivers needed emotional support from their families. This

emotional support will make caregivers feel more valuable and are a part of their society. Cerebral palsy in children is considered a chronic illness that needs long-term care. The longer time it takes one cares for these children, the more stress it can cause to their caregivers. To learn more about these caregivers' needs, nurses can help the caregivers have appropriate problem solving. From this study, it found that cerebral palsy children's caregivers are mostly female and are mothers as showed in Table 1 and 3. These same results were found in many other studies (Hass, 1990 ; Hatton, et al., 1995: 569 – 577 ; Keller & Nicolls,1990: 73 – 80 ; Ray & Ritchie, 1993: 217 – 225). The role of women has always been in exitricably interwoven with the family. Among society, it seems that the responsibility in taking care of family members, who are ill, falls to the women (Bomar, 1996: 6). In this study, it also found that most caregivers' assistants were parents, spouses, and sisters (51.4 %) (Table 4). Furthermore, in traditional Thai culture, most family structures are nuclear families which have strong relationships among their relatives and neighborhoods. Although, presently, the family's structure is changing to have more single families, the relatives and family members are still willing to help to take care of a sick member (Suparb, 1994: 9 – 14). Rawlins' study also showed the same result as this findings (1991: 213 – 220) that caregivers needed help in direct care for the disabed person at home. family members were the people who were suppose to offer this help. It is on the top (number such as one, five, ten) on the list of needs. A care for a sick member in a family without any help from family members makes caregiver feel frustrated (Williams,1994: 155 – 161). Nevertheless, caregivers stiill receive help from their family members as well. It made caregivers to have a low level of the need in relation visiting the patient and caregiver sometimes ($\bar{X} = 2.38$, S.D.= 0.99).

3. Financial needs: It found that the mean score of financial needs was at a moderate level ($\bar{X}$ = 3.06, S.D.= 0.84). However, the caregivers had high a level need in the sources that can provide instruments for the rehabilitation of the patient ($\bar{X}$ = 3.06, S.D.= 0.56), even though the sources may be limited. It can be explained that financial assistance is an essential factor in patients' care. Financial factors include costs of treatment during hospitalization, rehabilitation at home, transportation, instruments used during rehabilitation period and miscellaneous costs. The study showed that 87.9percent of caregivers were female (Table1). About 35percent of family incomes were only sufficient with no saving. According to this findings, it means that there were individual differences in caregivers' needs in social support. In families with low incomes, they often need help in financial support from social welfare (Wittaya-Sooporn, 1996: 117). Therefore, financial needs in this group showed moderate level. Although they received help from their families' members and the social welfare, they still had needs in financial support related to their child's conditions.

4. Spiritual needs: It found that the mean score of spiritual needs was at a moderate level ($\bar{X}$ = 3.05,S.D. = 0.70). The caregivers had a high level need in that patients were perceived to caregivers' feelings and interest and their loves the patient very much ($\bar{X}$ = 3.73, S.D. =0.61). It can be explained that 85 percent of caregivers were the parents (Table 3). Naturally, mothers do love their babies. Taking care of their children, seeing them grow and develop into fine people, gives most parents their greatest satisfaction in life (Marshall, 1991: 69-70). Most of the caregivers are Buddhism (90.7%). And 73.6 percent of them have age between 20–40 years (Table1). Adulthood is the phase to complete education, achieve economic independence

through vocation, select relationship partner and lifestyle, contribute to society (Potter & Perry, 1993 cited by Peters, 1998: 27). Decisions that adults make are accurate and easy to understand.Adults have a greater attention span and they try to achieve a cure. In this study, among each variable, it found that caregivers need to be full of contentment and rejoice in the action of caregivers ($\bar{X}$ = 2.86, S.D. = 1.06). A need to pray, do their practices, and go to a church were what caregivers wanted to do ($\bar{X}$ = 2.59, S.D. = 0.94). These needs had a moderate level. It can be explained that Buddhists have hope and the caregivers are the parents caring for the illness child and also the family members have responsibilities in caring for the ill child (Phupaiboon, 1994: 72). When considering the items that have a high level, perceiving self-efficacy in caring for the patient ($\bar{X}$ = 3.42, S.D. = 0.88); and need in emotional support from family members also showed high score ($\bar{X}$= 3.20, S.D.= 0.95). They were motivated in relation to others and received love from others and help each other (Boonthong, 1990; Chunngam, 1991 cited by Chuangsawadsak, 1998: 56). It showed that responsibility in patient care was not easy if caregivers had to deal with the rapid changes psychologically, emotional, and behavior. These caused caregivers stress and made them need more psychological support from their family members to empower their role.

5. Household management needs: It found that the mean score of household management needs was at a moderate level ($\bar{X}$ = 2.85, S.D. = 0.76). It explained that household management is an activity of the family. In the realm of decision making about the patient's health, finding a source of the remedy and choosing people and procedures help in providing the patient's remedy (Noelker, 1994cited by Cheewapoonphon, 1998: 20). Needs in seeking community resources that can help

them solve problems in their families was at a moderate level ($\bar{X}$ = 3.28, S.D. = 0.94). The needs of being helped by family members were helping in cooking, doing the laundry, and cleaning the house. These activities make the family neat (Meekanon, et al., 1989: 9 – 11). These functions are often done by females. This study found that 87.9 percent of caregivers were females, and 66.4 percent of caregivers lived at home (Table 1). Most of the time that the caregivers spent at home is when the caregiving assistants had their activities done outside the home and could not help the caregivers to take care of the patient. From this study, the need to have someone who can substitute as the caregivers in taking care of the patient when they have to do some businesses outside the home was at a high or moderate level ($\bar{X}$ = 3.14, S.D. = 0.98). Because of the time spent in giving care was more than 15 hours per day (63.6 percent of time) as showed in Table 3, and the rest of time was for the other activities inside home. It was considered the responsibility of caregivers that they should not leave the patient at home and go out to do any business, even their own personal business. Change in caregivers' daily activities made some of them leave their jobs, which directly affected their lifestyle. The present study showed the same result as Periad & Ames's study (1993: 252 – 256). Periad & Ames stated that lifestyle changes among caregivers of stroke survivors was related to quitting their jobs in order to have more time to take care of the patient. The need in helping to bring the patient to see the physician by family members was at a moderate level score ($\bar{X}$ = 2.89, S.D. = 1.09). The reason of this need was that most patients were in pre-school age, and their growth was not fully developed, which made them to be dependent. This made the caregivers themselves unable to bring the patients to the hospital. Therefore, sometimes, caregivers needed this help from family members and also to feel that they are not alone.

6. Physical needs: It found that mean score of physical needs was at a moderate level ($\bar{X}$ = 2.58, S.D. =0.80). It explained that caregivers were aware of the physical care that would promote and maintain human well being. Taking care of cerebral palsy patients, is a heavy task, time consuming and with much responsibility. Long-term care definitely affects caregivers' lifestyle. Thus, caregivers need appropriate adaptation for their lifestyle. This study showed that 62.1 percent of cerebral palsy children had more than 3 years in their duration of illness (Table 3). Duration of illness included the period both in acute illness and in a rehabilitation. Caregivers learned to adjust their lifestyles. The study of Adkin (1993: 144 – 154) found that the adaptation and lifestyle change occurrs to care for the ill child first, but caregivers' needs will change forever. Long term care made caregivers fatigued, tired and have stress (May, 1993: 270). It makes caregivers need respite from their burdens. They need to exercise and to be healthy also. In this study, it showed that the caregivers know how to maintain their healthy status, their need to have a annual check up, and their need to have time to do indoor exercise was at a moderate level ($\bar{X}$ =2.91, S.D. = 1.01, $\bar{X}$ = 2.56, S.D. = 1.05, and $\bar{X}$ =2.37, S.D. = 1.04, respectively). The reason was that most caregivers focused on taking the best care of patients, more than themselves. Moreover, most of the time they spent in taking care of their patients. Thus, to do indoor exercise at home was the best way to maintain a healthy life for these caregivers. They also thought that taking care of patients was exercise in itself. They also thought that their mild illness was not a problem. Some caregivers also complained that they still need to see the physician, but had no time. The study of

Harrington and co-worker (Harrington, et al., 1996: 118 – 125) also showed the same results of these findings. They studied needs of caregivers in hospice-cancer patients. They found that although caregivers perceived their health status was important, but the patients' health condition was the first priority. The study showed that 87.9 percent of caregivers were female (Table1). The woman is typically the caretaker of the family who places the needs of family members before her own (Burbansstipanov, et al., 1997: 411-435). It made caregivers to have a low level of the need in have time for self care, have time for sleeping and have time for exercise ($\bar{X}$= 2.49, S.D.=0.99; $\bar{X}$=2.43, S.D.=1.07; $\bar{X}$=2.37, S.D.=1.04, respectively).

Purpose II: Factors that predict caregivers' needs in caring cerebral palsy children. The hypothesis is caregiver characteristics: age, education level, marital status, numbers of children, workplace, family income, and duration of caring, and cerebral palsy child characteristics: birth order, age, and severity of disability can be used as predictors on caregivers' needs in caring cerebral palsy children at home.

The results showed that these factors could not predict caregivers' needs in caring for cerebral palsy children at home because there was no relationship between these factors and caregivers' needs. Thus, they cannot used as predictors in caregivers' needs. The results are discussed, as folllows:

Age: The results showed that there was a negative relationship between caregiver's age and caregivers' needs in caring for cerebral palsy children at home. There was no statistical significance ($r = -.010$, $p > .05$) (Table 13). This meant that a difference in caregiver's age had no difference in the caregivers' needs, which was opposite to Orem's concept (Orem, 1991: 239 – 246). Orem stated that age is one factor that affects a demand in self-care and a person responsibility. The capability of caring for a person gradually increases with age and reaches an optimum level when a person is an adult. This capability will decrease when a person is old. In this present study, there was 73.6 percent of participants were between age 20 – 40 years old and 22.1 percent of them were between 41 – 60 years old. The average age in this study was 35.34 years old as shown in Table 13, which accounts for the caregivers being mature, able to have self-care and be a responsible person. Therefore, caregivers' needs in caring for cerebral palsy children had no difference. According to the study of Oberst and co-workers (Oberst, et al., 1991: 71-78), they also found that caregiver's age had no relationship in the need for caring.

For educational level, this study found that there was a negative relationship between educational level and caregivers' needs in caring for cerebral palsy children at home. There was no statistical significance (r = - .125, P>.05) (Table 13). This means that a difference in educational level made no difference in caregivers' needs. In contrary, the concept stated that education will affect in seeking information, learning style and considering decisions. Having higher education should make a person have more reasonable responses in specific and different situations by using their knowledge. Furthermore, education will make people perceive more self-esteem and use it's strength to support themselves to adapt in any situation (Moen, et al., 1995: 259 – 273). Oberst and co-workers (Oberst, et al., 1991: 71 – 78) also proposed that an educational level of a caregiver had no relationship with the need in caring for a disabled person. The result are congruent with the study of Fildey and Shuman (cited by Hass, 1990: 59 – 63). They found that there was no relationship between educational level of the parent and power components of dependent care. Therefore, caregivers' needs in cerebral palsy care had no difference. Furthermore, information which caregivers need, was limited, and health care information from the healthcare professionals was not different.

Marital status: The study found that there was a negative relationship between a marital status and caregivers' needs in caring cerebral palsy children at home. There was no statistical significance (r = - .033, P >.05) (Table 13). This means that a difference in marital status makes no difference in caregivers' needs. It was opposite to the concept that family is an important source in social support for caregiver because family members will help in patient care. They shared in the situation that made caregivers have more self-esteem which empowered them in patients' care (Cheewapoonphon, 1998: 39). In a single-parent, he/ she was supposed to have both father and mother roles and, sometimes, friends or relatives also involved in participating in some appropriate tasks (Peters, 1998: 32). In Thai society, family members provide help each other when they have problems. In a single-parent family, the relatives are also supposed to help. Orem (1995: 267) stated that a family is a dependent care unit which contains at least 2 people: dependent member and dependent care agent. Dependent care agent may be one person as the mother, and many persons as father, mother, and/ or relatives. Thus, dependent care agent contains some or all of family members, but often have only 2 or 3 people. They relate to the health care of the dependent member all times and they may change their functions among family members.

Number of children: This study found that there was a positive relationship between number of children and caregivers' needs in caring cerebral palsy children at home. There was no statistical significance (r = .044, p >.05) (Table 13). This means that a difference in the number of children makes a difference in caregivers' needs. It showed the opposite result in Eamyingpanich (1996)'s study, that number of children had no relationship in caring. It means that mothers who have only a few children will use a little time and energy in taking care of their other normal children. Therefore, she perceives the care of the cerebral palsy child is not difficult. On the contrary, mothers who have many children will spend more time in taking care of children. Actually, normal children need's for care are met by their mother as their basic need. It does not include care that involves in health deviations of cerebral palsy. Energy and time that is used in cerebral palsy child care are not different. It may be most of the studied sample group had only a few children (69.3%) (Table 3).A homogeneous sample may find no relationship between factors.

Workplace: The study found that there was a negative relationship between workplace and caregivers' needs in caring for cerebral palsy children at home. There was no statistical significance (r = - .022, P > .05) (Table 13). According to this finding, a difference in workplace does not make any difference in caregivers' needs. Orem (1995: 267) stated that limitations for engagement in result-achieving courses of action within the investigative and production phases of self-care, including limitations for self-management, are associated with human functional states, environmental conditions and circumstances. Mothers who work outside the home must find caregiving assistant who can care for their child at home. There was no different between care that was provided by mothers who worked outside home and those who worked at home.

Family income: The study found that there was a negative relationship between family income and caregivers' needs in caring for cerebral palsy children at home. They was no statistical significance (r = - .117, p > .05) (Table 13). It means that a difference in family income does not make any difference in caregivers' needs. This is opposite to Orem's concept (Orem, 1991 cited by Wenhui, 1997: 25 – 26). Orem stated that the socioeconomic level of children's families apparently has a significant impact on self-care practices. Families from a lower socioeconomic group may lack of knowledge and resources in providing a safe and stimulating environment that fosters optimum children development. The family income of the sample group in this study were: insufficient, sufficient with no saving, and sufficient with saving (37.1%, 35.0%, 27.9%,respectively) (Table 2). Nevertheless, in Thailand's health care system, those with low income could receive medications for free. The medications are provided by social welfare services (which is paid by the government) every time they come to the hospital. Schuman (1987 cited by Hass,1990: 22) also found that the ability of caregivers in caring for a dependent person does not correlate with caregiver's income. In contrast, Hileman and co-workers (Hileman, et al.,1992: 771-777) found that there was a negative relationship between family income and household management's needs. This means that a family with high income had low household management needs.

Duration of caring: This study found that there was a negative relationship between a duration of caring and caregivers' needs in caring cerebral palsy children at home. There was no statistical significance (r = - .003, p >.05) (Table 13). It means that a difference in duration of caring makes no difference in caregivers' needs. This is opposed to Orem's. Orem (1985: 106) proposed that a capability to take care of person who depends on the others will vary among person's experiences. The one who has few experience will need more information than another who has a lot of experiences needs. It is the nature of humans that it takes time to know something. As time passed by, he/ she will know and learn more. Oberst and co-workers (Oberst, et al., 1989: 209 – 215) studied that there was a positive relationship between duration of illness and care responsibility. This means that the longer duration of illness is the more responsibility and the higher caregivers' needs are. On the contrary, Cumming and co-workers' study (Cumming, et al., 1996cited by Ruanglapanun, 2000: 73) showed that, in a short period of time, mothers of chronically ill children do not have more psychological abnormality than those whose children have an acute illness. This means that the difference in duration of caring does not make any difference on caregivers' needs. In this study, only 1.4 percent of the participants had duration of caring under 6 months. Most of them, 62.1 percent, had duration of caring more than 3 years. Therefore, the subjects had already had experiences in caring for their ill child for a longtime. This helped them to develop an ability to solve the problems appropriately. Thus, there was no relationship between these factors.

Birth order: this study found that there was a negative relationship between birth order and caregivers' needs in caring for cerebral palsy children care at home. There was no statistical significance ($r = -.096, p > .05$) (Table 13). It means that the difference in birth order does not make any difference in caregivers' needs. Thampanichawat's (1990: 85) also found that birth order had no relationship with behavioral adjustment in preschool children. Arunyapoom's study (1999 : 88) showed that birth order of a child did not correlate with a father's role in child care. Regardless of birth order of a cerebral palsy child, the mother still spends more time and gives more love, interest, and care to her sick child. Parents may have an overprotective behavior to their child and do everything they could for their child to feel better (Amico & Davidhizar, 1994: 213 – 218).

Patient's age: This study found that there was a negative relationship between patient's age and caregivers' needs in caring cerebral palsy children at home. There was no statistical significance (r = .026, p > .05) (Table 13). This means that the difference in the patient's age does not make any difference in caregivers' needs. The patient's age between 2-4 years old and between 4-6 years old which the developmental age is responded from their mothers had not difference between them. In this study, patient's ages are between 2-4 years old and between 4-6 years old, which in this developmental age the children respond from their mothers and they had not differences between them. In this study, the patient's ages were between 2-4 years old and between 4-6 years old (37.9%, 45%, respectively). Because most of them are near preschool age, the need to respond in basic conditioning shows there was no difference between them.This study showed the same result as the study of Pakdeto (1997: 52). It found that the difference in patient's age does not make any difference in responding to the mother in meeting the basic needs of her child. The result was also congruent with the study of Puangchan (1995: 71). Puangchan also found that patient's age had no relationship with mother's capabilities in child care.

Severity of disability: This study found that there was a positive relationship between the severity of disability and caregivers' needs in caring for cerebral palsy children at home. There was no statistical significance (r = .139, p > .05) (Table 13). This means that the difference in severity of disability does not make any difference in caregivers' needs. The period of instability can be extended indefinitely when the family has a child with a chronic illness or disability. In this situation, roles may need to be adjusted simultaneously as the needs of a child change. A family who cares for a child with a disability usually experiences numerous role changes. The degree of change depends on characteristics of family members and a severity of the disability that the child has (Youngblood, 1999: 136). The longer time care is provided, the more likely family functioning declines. In addition, other family members may not perform caregiving assistant's role. This can cause caregivers to feel abandoned by the family (Given, et al., 1990 cited by Holicky, 1996: 247 – 252). Chaigosol (1993: 53) also found that there was no relationship between severity of illness and mother's care behavior in nephrotic syndrome children.

The concept framework of this study is caregiver characteristics: age, education level, marital status, number of children, workplace, family income, and duration of caring, and cerebral palsy child characteristics: birth order, age, and severity of disability can be used as predictors on caregivers' needs in cerebral palsy children care at home. From the study's results, it found that these factors were unable to predict caregivers' needs in caring cerebral palsy children at home. In a nursing practice, it is necessary to use these factors as data in nursing care plan and to assist the mothers or caregivers in caring for cerebral palsy children at home correctly. For the other group patients, the relationship between results and these factors may be different and may affect on caregivers' needs in patient care at home. This needs further studies to be done.

CHAPTER VI

CONCLUSION

Summary of the Study

This was a descriptive research that studies caregivers' needs in cerebral palsy children care at home and investigate the relationships between caregivers' needs in caring for cerebral palsy children at home, the caregiver and cerebral palsy child characteristics.

The sample of this study were 140 caregivers of cerebral palsy children, under 6 years old, who brought their children for rehabilitation at the physiotherapy department, Siriraj hospital and Rajanukul hospital. Participants were selected by the purposive sampling technique.

The instruments used in this study were the demographic data form and a severity of disability of cerebral palsy children and caregivers' needs in cerebral palsy children care at home questionnaire. Researcher collected the data herself. The data was analyzed using SPSS 7.5 FW as follows:

1. The demographic data was analyzed by using the method of frequency distribution and percentage.

2. The mean, and standard deviation of caregivers' needs in cerebral palsy children care at home were calculated.

3. The Pearson's correlation coefficient was calculated between caregivers' characteristics (age, education level, marital status, members of children, workplace, family income, duration of caring) and cerebral palsy child characteristics (birth order,

age, severity of disability); and caregivers' needs in cerebral palsy children care at home.

4. The multiple correlation coefficient of the criterions and the predictors was calculated.

Implications and Recommendations

The results are as follows:

1.Demographic data of the caregivers and of the patients were as follows:

1.1 Caregivers' demographic data: It found that 87.9percent of caregivers were female and were mothers. About 66.4 percent work at home or being a housewife. And 37.2percent had family monthly income between 5,000 –10,000 baht. Thirty-five percent of those families had sufficient income with no saving. Most of participants (85%) are married, 69.3 percent of caregivers had 1-2 biological children. Most of subjects (63.1%) had duration of caring over 3 years. The majority of caregivers (63.6%) spent over 15hours per day giving the child care. Most of them had no experience in caring for cerebral palsy child before (93.6%), and 66.4 percent had caregiving assistant as showed in Table 1, 2, 3, 4.

1.2 Cerebral palsy children's demographic data: It found that 45 percent of patients' age were between 4 – 6years old. About 52.1percent of these children were the first born, 55 percent of them had duration of illness more than 3 years and most of them were severe ill (75%).

2.Caregivers' needs in caring cerebral palsy children at home, are as follows:

2.1. Caregivers' needs had the overall mean score at a moderate level.

2.2. Caregivers' needs in each category had mean score in the moderate level as follows:

2.2.1 Information needs: Caregivers' needs had a high average score in 9 items of information needs. Receiving information in health care is one of the strategies to provide appropriate care according to the patients' development. Being a part of treatment and discharge planning, managing patients'behaviors, spasticity, and other problems, seek the resources for rehabilitation, providing appropriate patient education and helping the caregivers to understand the patient's conditions and prognosis are the other items with a high average score.

2.2.2 Psychological needs: Caregivers' needs had a high average score in 3 items of psychological needs. They want to be accepted by physicians in managing patient's problems when they go to hospital, to be accepted by nurses in managing patient's problems when they go to hospital and physicians should have time for caregivers to ask questions.

2.2.3 Financial needs: Caregivers' needs had a high average score in 1 item of financial needs. It was to help with resources to provide instruments for patient's rehabilitation.

2.2.4 Spiritual needs: Caregivers' needs had a high average score in 1 item of spiritual needs. It was to perceive in caregivers' feeling of interest and love the patient very much.

2.2.5 Household management needs: Caregivers' needs had a moderate average score in 5 items of household management needs. The highest score was to feel connect to community resources that can help them solve problems.

2.2.6 Physical needs: Caregivers' needs had a moderate average score in 4 items of physical needs. The highest score was to know how to maintain a healthy status.

3. Factors that predict caregivers' needs in caring cerebral palsy children at home are as follows: It found that caregiver's characteristics: age, education level, marital status, members of children, workplace, family income, duration of caring, and cerebral palsy child characteristics: birth order, age , severity of disability had no relationship with caregivers' needs in cerebral palsy children care at home. And they are unable to predict caregivers' needs.

Implications and Application of Research Findings

1. Nurses are an excellent source for such information. Knowledge in growth and development of their child will help the caregivers to provide appropriate care regarding the child's age. Education and training programs can provide caregivers the understanding of child developmental processes through their life span in both physical and psychosocial aspects. It also helps caregivers to understand normal and disease-related changes. Therefore, they can effectively deal with possible problems, make appropriate decisions among their families, seek available community resources, and feel more confident.

2. Nurses should collaborate and consult with therapists to establish if any communication problem exist. Nurses and therapists can assist a family in selecting and using a communication system, and allow time for a child to use this system.

3. Nurses can suggest appropriate and available resources for each caregiver and their families. Nurses can discuss these issues with families, and encourage caregivers to participate in support groups and community services agencies.

4. Nurses should provide information about the expected age-related tasks and development, encourage self-care activities for the patients and provide time and opportunity for the child to participate in appropriate play and recreational activities with other children. Nurses should encourage to participate in a group support for caregivers of cerebral palsy children.

Implications for Further Studies

1. Further study on caregiving is required in several areas for several reasons. According to this study's findings, further research should study the quality of the caregiver in the hospital and community. Successful interventions can help caregivers to take care of patients appropriately.

2. This study focused only on caregivers of cerebral palsy children, under 6 years old. Future research should be conducted in a different sample, with age limitation of the children. More longitudinal research will be helpful in determining how caregivers' needs and problems change over time. This information can help to solve the problems of child care.

3. Further study should study in depth detail as the qualitative approach to the needs of caregivers who do and do not take the cerebral palsy children to the hospital.

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APPENDIX

APPENDIX A

LIST OF EXPERTS

APPENDIX A

LIST OF EXPERTS

The experts who had validated the questionnaires of the caregivers' needs for caring cerebral palsy children at home are as follows:

1. Mr. Tawatchai Jaikamwang, M.D.,

   Head of Rehabilitation Section Rajanukul Hospital

2. Assoc. Prof. Wilai Leesuwan,

   Department of Nursing, Faculty of Medicine Ramathibodi Hospital

3. Asst. Prof. Wilai Lerdthumthevee,

   Department of Pediatric Nursing, Faculty of Nursing, Mahidol University

4. Asst. Prof. Chomchuen Somprasert, Ph. D.,

   Department of Psychiatric Mental Health Nursing,

   Faculty of Nursing, Mahidol University

5. Miss Chantima Chintakovit, B.N.,

   Head of Community Research Work, Rajanukul Hospital

APPENDIX B

CONSENT FORM

คำชี้แจงและการพิทักษ์สิทธิ์ของผู้ดูแลเด็กสมองพิการ
เพื่อขอความร่วมมือในการเข้าร่วมการวิจัย

ดิฉันนางสาว จินตนา หาญประสิทธิ์คำ เป็นนักศึกษาพยาบาลปริญญาโท มหาวิทยาลัยมหิดล กำลังศึกษาวิจัยเกี่ยวกับความต้องการของผู้ดูแลในการดูแลเด็กสมองพิการที่บ้าน โดยมีวัตถุประสงค์ของการวิจัยคือ ศึกษาความต้องการของผู้ดูแลเด็กสมองพิการที่บ้านและปัจจัยที่สามารถทำนายความต้องการของผู้ดูแลผู้ป่วย

ถ้าคุณเข้าร่วมในการวิจัยครั้งนี้ ดิฉันจะให้คุณตอบแบบบันทึกข้อมูลส่วนบุคคลของผู้ดูแลและผู้ป่วย แบบสอบถามความต้องการของผู้ดูแลซึ่งจะใช้เวลาประมาณ 25 – 30 นาที

หากคุณมีข้อสงสัยประการใดเกี่ยวกับงานวิจัยครั้งนี้ ดิฉันยินดีตอบให้คุณเข้าใจและไม่ว่าคุณจะเข้าร่วมในการวิจัยครั้งนี้หรือไม่ก็ตาม ผู้ป่วยยังได้รับการรักษาพยาบาลจากเจ้าหน้าที่ของโรงพยาบาลตามปกติ คุณมีสิทธิ์ที่จะตอบรับหรือปฏิเสธการเข้าร่วมในการวิจัยครั้งนี้ และถึงแม้ว่าคุณยินยอมเข้าร่วมในการวิจัยแล้ว คุณยังมีสิทธิ์ยกเลิกการเข้าร่วมการวิจัยนี้ได้ตลอดเวลาโดยไม่มีผลต่อการรักษาพยาบาลผู้ป่วยหรือผลกระทบใดๆ

สำหรับผู้เข้าร่วมวิจัย

ข้าพเจ้าได้รับการอธิบายตามรายละเอียดข้างบน มีความเข้าใจและยินดีเข้าร่วมการวิจัย

ลายเซ็น ....

( )

วันที่ .... เดือน .... พ.ศ. ......

APPENDIX C

INSTRUMENTS

ส่วนที่ 1

แบบบันทึกข้อมูลส่วนบุคคล

คำชี้แจง : ข้อความต่อไปนี้เป็นแบบบันทึกข้อมูลส่วนบุคคล ลักษณะผู้ป่วยที่ให้การดูแล และระดับความรุนแรงของความพิการ กรุณากรอกข้อมูลและทำเครื่องหมาย (/) ในช่องที่ตรงกับความเป็นจริง

1.1 ข้อมูลส่วนบุคคลของผู้ดูแล

1. อายุ .... ปี
2. เพศ ( ) หญิง ( ) ชาย
3. สถานภาพ ( ) คู่ ( ) โสด ( ) ม่าย หย่าหรือแยก
4. จำนวนบุตร .... คน
5. ศาสนา ( ) พุทธ ( ) คริสต์ ( ) อิสลาม
6. สำเร็จการศึกษาระดับ
   ( ) ไม่ได้เรียน ( ) ประถมศึกษาชั้น ....
   ( ) มัธยมศึกษาหรืออาชีวศึกษา ( ) อุดมศึกษา
7. อาชีพ
   ( ) ทำงานในบ้าน ระบุ ....
   ( ) ทำงานนอกบ้าน ระบุ ....
8. รายได้ของครอบครัว .... บาท / เดือน
9. ความเพียงพอของรายได้
   ( ) มีพอใช้และมีเงินเหลือเก็บ ( ) มีพอใช้แต่ไม่มีเงินเหลือเก็บ
   ( ) ไม่พอกับค่าใช้จ่ายแต่ไม่มีภาระหนี้สิน ( ) ไม่พอกับค่าใช้จ่ายและมีภาระหนี้สิน
10. ความสัมพันธ์กับผู้ป่วย ....
11. ระยะเวลาที่ผู้ดูแลดูแลผู้ป่วย .... ปี .... เดือน
12. ให้การดูแลเฉลี่ยกี่ชั่วโมงในหนึ่งวัน .... ชั่วโมง
13. ประสบการณ์ในการดูแลผู้ป่วยลักษณะนี้ ( ) ไม่มี ( ) มี
14. มีผู้ช่วยเหลือในการดูแลผู้ป่วยที่บ้านได้แก่ ....
15. ผู้ช่วยเหลือให้ความช่วยเหลือในด้าน ....

1.2 ข้อมูลลักษณะผู้ป่วยที่ให้การดูแล

1. ลำดับที่ของการเกิด ....

2. อายุของผู้ป่วย .... ปี .... เดือน
3. ระยะเวลาที่เจ็บป่วย .... ปี .... เดือน

1.3 ระดับความรุนแรง .... (เจ้าหน้าที่กรอก)

แบบประเมินระดับความรุนแรงของความพิการ

1.3.1 การวัดระดับความรุนแรงของโรคในเด็กสมองพิการอายุ 0 – 3 ปี

ตัวอย่าง เด็กชายเออายุ 2 ปี ได้รับการทดสอบ DDST พบว่าระดับพัฒนาการที่สามารถทำได้ผ่านสูงสุดในแต่ละด้านมีดังนี้คือ

ด้าน personal-social ทำได้เท่ากับ 14 เดือน
ด้าน fine motor-adaptive ทำได้เท่ากับ 9 เดือน
ด้าน language ทำได้เท่ากับ 9 เดือน
ด้าน gross motor ทำได้เท่ากับ 8 เดือน

เมื่อนำมารวมกันได้ = 40 เดือน แล้วหาค่าเฉลี่ยคือ 40 / 4 = 10

นำมาคิดเป็นเปอร์เซ็นต์โดยเทียบกับอายุจริง (เดือน) = 10 × 100 / 24 = 41.67

เมื่อเปรียบเทียบกับคะแนน จะพบว่าอยู่ในช่วง 25% - 50%

ดังนั้น เด็กชายเอมีความรุนแรงของโรคสมองพิการอยู่ในระดับ ปานกลาง

1.3.2 แบบประเมินระดับความรุนแรงของโรคในเด็กสมองพิการอายุ 3 – 6 ปี

คำชี้แจง : กรุณาขีดเครื่องหมายถูก(✕) ลงในแต่ละข้อที่ตรงกับความเป็นจริงเกี่ยวกับเด็กของท่าน

1. ความสามารถด้านการเคลื่อนไหว
   - การเคลื่อนไหว
     ก. เดินได้ ข. ลุกขึ้นนั่งได้ ค. อยู่ในท่านอน
2. ความสามารถด้านการติดต่อสื่อสาร
   2.1 การมองเห็น
     ก. ปกติ ข. มองเห็นไม่ชัด (ใส่แว่น) ค. ตาบอด
   2.2 ภาษา
     ก. พูดได้ ข. แสดงท่าทาง ค. ไม่สื่อความหมาย
3. ความสามารถในการกระทำกิจกรรมส่วนตัว
   3.1 รับประทานอาหาร
     ก. รับประทานอาหารเอง ข. ผู้ใหญ่ป้อน ค. ใส่สายยาง
   3.2 ปัสสาวะรดที่นอน (กลางคืน)

ก. ไม่มี ข. 4 ครั้ง / สัปดาห์หรือน้อยกว่า ค. มากกว่า 4 ครั้ง / สัปดาห์

3.3 ทำความสะอาดหลังขับถ่ายอุจจาระ

ก. ทำได้ด้วยตนเอง ข. ต้องช่วย ค. ทำไม่ได้

3.4 ถอดเสื้อผ้า

ก. ทำได้ด้วยตนเอง ข. ต้องช่วย ค. ทำไม่ได้

4. ความสามารถด้านสังคม

4.1 ความสัมพันธ์กับเพื่อนบ้าน

ก. มีเพื่อน ข. ไม่มีเพื่อน ค. ถูกแกล้ง

4.2 พฤติกรรม

ก. ไม่มีปัญหา

ข. ซึมไม่ทำอะไรหรือทำร้ายตนเองเฉพาะเวลาโกรธ

ค. ทำร้ายตนเองตลอดเวลา

ส่วนที่2

แบบสอบถามความต้องการของผู้ดูแลในการดูแลเด็กสมองพิการที่บ้าน

คำชี้แจง : กรุณาทำเครื่องหมาย √ ลงในช่องที่ตรงกับระดับความต้องการของท่านเมื่อรับผิดชอบในการดูแลผู้ป่วยที่บ้าน โดยพิจารณาว่า ท่านมีความต้องการในสิ่งเหล่านี้มาน้อยเพียงใด โดยแบ่งเป็น 4 ระดับ เลือกตอบให้ตรงกับความคิดเห็นของท่านมากที่สุด

มาก	หมายถึง	มีความต้องการมาก
ปานกลาง	หมายถึง	มีความต้องการปานกลาง
เล็กน้อย	หมายถึง	มีความต้องการเพียงเล็กน้อย
ไม่ต้องการ	หมายถึง	ไม่มีความต้องการ

ความต้องการ	ระดับความต้องการ			
	มาก	ปานกลาง	เล็กน้อย	ไม่ต้องการ
1. ฉันต้องการทราบวิธีการทำความสะอาดปากฟัน				
2. ฉันต้องการทราบวิธีการอาบน้ำหรือเช็ดตัวผู้ป่วยให้สะอาด				
. . . .				
60. ฉันต้องการคำแนะนำแหล่งที่ฉันสามารถขอความช่วยเหลือในการจัดหาอุปกรณ์ที่ช่วยในการฟื้นฟูให้กับผู้ป่วย				

BIOGRAPHY

NAME	**MISS JINTANA HANPRASITKAM**
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RESEARCH GRANT	**PARTIAL SUPPORTED BY THE THESIS GRANT, PEDIATRIC NURSES SOCIETY OF THAILAND**
POSITION & OFFICE	**1987-PRESENT: ANANDHAMAHIDOL V UNIT PEDIATRIC NURSING DEPARTMENT SIRIRAJ HOSPITAL** **POSITION: REGISTERED NURSING**