CHAPTER II

ESSAY

PROBLEM OF CEREBRAL PALSY

2.1 Introduction

Cerebral palsy (CP) known to be one of the most causes of physical disability found among children in the world. It represents about one every three hundred babies inborn or developed cerebral palsy (WHO, 1993).

There are 10,000 new cases of cerebral palsy diagnosed each year in the United States, and for every 2,000 babies born in the United States, five have cerebral palsy. Approximately 5% of premature infants are diagnosed with this condition. The overall incidence of CP in USA is rising because premature babies who once would have died are surviving from advance in modern neonatal intensive care. A preemie's risk of cerebral palsy is 50 times higher than that of a full-term baby.

Reviewed literatures do not provide the number of CP children (aged 1-15 years old) for whole country in Thailand but there is a current trend of increasing rate of low birth weight infants survivors which has significantly improved in the past 10 years. Study of Mowhsuwan et al. (2000) reported that in year 2000, 14.2% of over 890,000

lifebirths in Thailand had low birth weight. The risk of cerebral palsy of these infants is 40-100 times higher than that of normal infants. In addition, meningitis infection is known as one of the causes of CP during childhood, and its incidence was reported at about 19-50 cases per 100,000 children in 1995 in the study by Suntaree (1995).

2.2 Operational definition of Cerebral Palsy

The terms of cerebral palsy have been defined with vary details depending on the objective of each study. The definition used in this paper was adjust from the definitions by WHO (1993) and Werner (1987) for comprehensive understanding to general public. It is an inclusive term that describes a group of non-progressive disorder, a difficulty in coordinating the muscle movement or maintaining a normal posture that is caused by a brain dysfunction. It is a disability of muscle control that affects movement and positioning of the body. It comes from the brain damage that occurred before the child was born, at birth or as baby. The muscles receive the wrong instructions from the damaged part of the brain. However, the movement and body position and related problems can be improved or made worse depending on how the child is treated and the degree of damaged on the brain.

2.3 What causes cerebral palsy?

Cerebral palsy is not a single cause disorder, like chicken pox or measles. It is a group of disorders with similar problems in control of movement, with different causes.

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Nobody knows the actual causes of cerebral palsy but the possible chance that a child would develop cerebral palsy may be during pregnancy, during labor, after premature labor, and in childhood as followings:

- a) During Pregnancy: A damaged placenta may interfere with fetal growth or movement and if prolonged, can cause CP. Other causes include: poor nutrition, expose to some toxic substances, infections, chromosome abnormalities, some biochemical genetic disorders, and chance malformations of the baby's brain. Even after intensive medical investigation many causes cannot be identified. Anything, which tends to produce a low birth weight (LBW) infant will increase the likelihood of cerebral palsy.
- b) During Labor: While being born, the baby's head may be squeezed or otherwise suffer mechanical trauma. Poor oxygen supply to the baby may cause metabolic disturbance (asphyxia) and destroy brain tissue. Infants whose CP is associated with difficulties in labor may require immediate help to breath, or will have symptom of injury such as seizures (convulsions), severe feeding difficulty, lack of responsiveness or movement, and signs of injury to organs such as the heart or kidneys.
- c) After Premature Labor: The brain of a prematurely born baby is not yet ready for the stresses of independent life. Despite all the advances in modern neonatal intensive care, it may be impossible to avoid some types of brain damage. Bleeding in to the brain, or not enough blood and /or

oxygen supply to particular part of the brain may occur.

 d) In Childhood: Some babies have brain hemorrhages or very high fevers. Infections (such as meningitis), head accidents, or poisonings account for the rest.

2.4 What are the Risk Factors?

Research scientists have examined thousands of expectant mothers, followed them through childbirth, and monitored their children's early neurological development. As a result, they have uncovered certain characteristics, called risk factors, that increase the possibility that a child will later be diagnosed with cerebral palsy:

- *Breech presentation;* Babies with cerebral palsy are more likely to present feet first, instead of head first, at the beginning of labor.
- Complicated labor and delivery; Vascular or respiratory problems of the baby during labor and delivery may sometimes be the first sign that a baby has suffered brain damage or that a baby's brain has not developed normally. Such complications can cause permanent brain damage.
- Low Apgar score; The Apgar score is a numbered rating that reflects a newborn's condition. To determine an Apgar score, doctors periodically check the baby's heart rate, breathing, muscle tone, reflexes, and skin color in the first minute after birth. They then assign points; the higher the score, the more normal the baby's condition. A low score at 10-20 minutes after

delivery is often considered an important sign of potential problems.

- Low birth weight and premature birth; The risk of cerebral palsy is higher among babies who weigh less than 2,500 grams (5 lbs., 7.5 oz.) at birth and among babies who are born less than 37 weeks into pregnancy. This risk increases as birth weight falls.
- *Multiple births;* Twins, triplets, and other multiple births are linked to an increased risk of cerebral palsy.
- Nervous system malformations; Some babies born with cerebral palsy have visible signs of nervous system malformation, such as an abnormal small head (microcephaly).
- *Maternal bleeding or severe proteinuria late in pregnancy;* Vaginal bleeding during the sixth to ninth months of pregnancy and severe proteinuria (the presence of excess proteins in the urine) are linked to a higher risk of having a baby with cerebral palsy.
- Maternal hyperthyroidism, mental retardation, or seizures; Mothers with any of these conditions are slightly more likely to have a child with cerebral palsy.
- Seizures in the newborn; An infant who has seizures faces a higher risk of being diagnosed, later in childhood, with cerebral palsy.

Knowing these warning signs helps doctors keep a close eye on children who face a higher risk for long-term problems in the nervous system. However, parents should not become too alarmed if their child has one or more of these factors as most of children who have such factors do not developed cerebral palsy.

2.5 How to Prevent Cerebral Palsy ?

Several of the causes of CP that have been identified through research are preventable or treatable. These are:

- Regular use of the child-safety seats and helmets and elimination of child abuse can prevent head injury. In addition, common sense measure around the household like close supervision during bathing and keeping poison out of reach can reduce the accidental injuries.
- Jaundice that can damage brain of newborn infants can be treated with phototherapy. Blood transfusion may needed in some cases.
- Rubella vaccination before becomes pregnant.

In addition, it is always good to work toward a healthy pregnancy through regular prenatal care and good nutrition and eliminating smoking alcohol consumption and drug abuse. Despite the best of parent and physician, however children still can be born with CP, since in most cases the causes of CP is unknown, little can currently be done to prevent it.

2.6 What are the Different Types of CP?

Professionals describe different type of CP according to the type of movement disorder and/or the number of limbs involved. Two children with the same type of CP may have different needs – because each child is different. With so many different

causes it's not surprising that CP takes many different forms. A number of types of CP are described in medical textbooks, but even specialists rarely agree about the right way to describe the cerebral palsy of an individual child. Each child with CP is unique individual. There is no good reason to insist on describing any child as having a particular type of CP. CP is not unchanging and it may take years for the types to stabilize. However, many professionals refer to types, so it helps to know the main descriptive terms.

*Classification by Tone or Movement Disorder:

<u>Spastic CP</u>

Spastic cerebral palsy, alone or mixed with other forms, is the most common type of CP. Spasticity may be very mild and affect only a few movements, or very severe, involving the entire body. The amount of spasticity usually changes over time. Spastic muscles have increased resistance to being stretched. They become overactive when used and produce clumsy or weak movements. Such muscles may also be called stiff, tight or hypertonic. Many children who have spasticity in their arms and legs may have decreased tone in their back and abdominal muscles, giving them a floppy trunk. Normal muscles work in pairs; when one group of muscle contracts, other groups will relax to allow free movement in the desired direction. Spastic muscles become active together and block effective movement. This muscular "tug-or-war" is called cocontraction. Spastic muscles become tight easily. For example: with the slightest attempt at movement, if the skin over them is touched lightly, in cold temperature, when the child is emotionally upset. These changes of spasticity reflect impairment in different part of the complicated systems in the brain and spinal cord, which control movement. You may notice spasticity:

- If changing a diaper is difficult because the muscles around your baby's hips are tight
- If your baby has difficulty suckling, there may be some spasticity in his or her tongue.
- When you try to move, soothe or cuddle your baby, his or her body stiffens.

Older children may experience spasticity when they attempt delicate movements (fine motor activities) such as bringing a cup to the mouth, or writing. Spasticity can be rendered by avoiding situations known to produce it. Secure seating that reduces trunk movements when attempting to balance may reduce spasticity in the upper limbs. Appropriate head supports can correct particular positions of the head, which may produce spasticity in the limbs. Inappropriate weight bearing may promote spasticity in the legs. Pediatric physical and occupational therapists are trained in managing spasticity. Drugs are sometimes used, and deformities can sometimes be reduced by stretching exercises or treated by surgery. Reducing spasticity is the subject of much on-going research. Spasticity is only one cause of high muscle tone. When tone (resistance, stiffness) is variable, the term dystonia may be used.

Dyskinetic CP:

Here, the main difficulty is coordinating or controlling movements. Involuntary and unwanted whole body writhing movements are seen in athetoid CP. The word, athetosis, comes from a Greek word meaning to writhe like a snake. Once common as a result of Rhesus (blood type) incompatibility, athetoid cerebral palsy is now rare. Faster, dancing movements are described as choreiform and often accompany athetosis. These movements reflect impairments at the back of the brain, in the brain stem, located at the top of the spinal cord.

The most unusual type is ataxic CP resulting from impairments of the cerebellum, the brain's major center for balance and coordination, ataxic CP is associated with an unsteady, often lurching gait and unsteady hands. People who have ataxic CP may walk like someone who is drunk. They usually have poor muscle tone (referred to as hypotonic or floppy). Many progressive disorders, some now treatable, may imitate this type of CP. Medical investigations are usually necessary before diagnosis is confirmed.

Mixed CP:

Most commonly, spasticity is present along with other types of movement disorder.

*Classification by Number of Limbs Involved

When a child's arms and legs are affected by CP, the trunk is often also involved, either with decreased muscle tone, or as hemiplegia, because the child's body is lopsided.

<u>Diplegia:</u>

Both legs are affected much more severely than the upper limbs. If a premature baby has CP, it is usually diplegia.

<u>Hemiplegia:</u>

This is the most common distribution of CP; one side of the body (both arm and leg, from head to toe) is affected. The arm is more involved than the leg, and the child will usually learn to walk. The opposite side of our brain controls our limbs, so right spastic hemiplegia implies injury to the left side of the brain.

Double Hemiplegia:

Describes CP affecting both sides, (arms worse than the legs)

Triplegia:

Affects three limbs, while one is relatively unaffected.

Monoplegia:

Involves primarily only one limb.

Quadriplegia or Tetraplegia:

Involves all four limbs and the trunk.

As mention above, with so many causes that CP takes many different forms. So each child with CP is a unique individual and the treatment for each child is tailor-made and very specific for each child.

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2.7 What are the Secondary Conditions of Cerebral Palsy ?

In an effective health care system, much can be done to prevent secondary conditions. The following list is the most common health complications associated with

cerebral palsy and these conditions are found at various stages in the life of person with cerebral palsy. These are the conditions that we are attempting to prevent.

The list of secondary conditions associated with cerebral palsy

- Progressive contractions
- Mobility limitations
- Joint and muscle pain
- Problems with balance
- Pressure sores
- Spasticity changes
- Dental problems
- Seizures
- Obesity
- Bowel & Bladder incontinence and control
- Learning disabilities
- Depression
- Adjustments in social relationships

2.8 How is Cerebral palsy Managed?

Cerebral palsy can not be cured, but treatment or rehabilitation can often improve a child's capabilities. In fact, progress due to medical research now means that many patients can enjoy near-normal lives if their neurological problems are properly managed. There is no standard therapy that works for all patients. Instead, the physician

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must work with a team of health care professionals first to identify a child's unique needs and impairments and then to create an individual treatment plan that addresses them.

The rehabilitation services to improve CP children could be classified based on institution, community, and family levels as followings;

- 1) *Family based rehabilitation* (FBR) is another kind of service, where specialist visits clients at their families to identify a child needs and impairments and then create an individual treatment plan for each family, as so-called 'home management', to integrate with their children's activities.
- Community based rehabilitation (CBR) is a new approach of rehabilitation, which emphasis community involvement in development.
- 3) Institutional based rehabilitation (IBR) is the source or origin of rehabilitation services for people with disabilities, which is located in institution and work by many specialists. This kind of service relies on sophisticated equipment and spends high budget and normally focuses their work on welfare and charity rather than development.

The community based rehabilitation (CBR) and family based rehabilitation (FBR) are more appropriate and practical for the people in the remote area than the institutional based rehabilitation (IBR) as IBR is located in central area, which is difficult for rural people to access. Development by CBR takes long time depending on

the commitment and understanding of each community. It also needs support from government policy on rehabilitation. Implementation of CBR by either government or non government organizations found unsustainable in several locations such as CBR project in Huaysak subdistrict, ChiangRai province by Save the Children Fund (U.K.) and projects in NaKham and Aard-Samart subdistricts implemented by NakornPhanom Provincial Health Office in 1990-1992.

Family base rehabilitation serves individual needs of clients, which then strengthen family's ability to build their own confidence. Family based health care service by public health providers is an existing service nationwide in the community. Such service is a part of their public service in their respective assigned agency. That emphasizes on family based health care service alone. FBR project was launched to be integrated in the family based health care services which was initiated in Rasrisalai district by Rasrisalai Community Hospital and Srisaket Provincial Health Office in 1995 .The result of the project was success.

2.9 Family Based Rehabilitation and Home Management

In general family based rehabilitation for CP child, it needs to concern the childparental interaction. Suggestion on <u>home management</u> is the main role to develop these CP children. Mayo (1981) concluded that mothers of more severely disabled infants found that their involvement in home management made their lives more manageable. Parental involvement in home management may increase the parents' knowledge of

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their child's condition and may facilitate parent-child interactions (Breiner & Beck, 1984; Connor, Williamson, & Siepp, 1978; Parette & Hourcade, 1985; Provence, 1985; Ross, 1984). When the mothers carries their children in proper way, that means the children are guided and assisted in development on a daily basis and within a daily routine. Further, parental involvement in treatment may relieve stress and improve the family's health (Burden, 1980; Wendt et al., 1984). In addition, many parents want to become involved in their child's treatment (Lipton & Savarstad, 1974).

2.10 Operational definition of Home Management of Cerebral Palsy Children

In general, the earlier treatment begins, the better chance a child has of overcoming developmental disabilities or learning new ways to accomplish difficult tasks. WHO's treatment guidelines for all types of children with cerebral palsy are as followings;

- Encourage movement in as normal way as possible.
- Use both sides of the body.
- Follow up the developmental stages.
- Encourage the child to learn by doing activities related to daily life.
- Position and handling the child straight in lying, sitting, kneeling and standing.
- Prevent deformities.

According to this WHO's treatment guidelines and home management guidelines for cerebral palsy by Finnie (1975), this study defines home management for cerebral palsy children as a set of appropriate activities for taking care of CP child, which includes handling, positioning, prevention of contractures and deformities and encouraging child's skills for daily activities such as seating, sleeping, toileting, bathing, dressing, feeding, and self-care. Details for each activity are as follow;

- *Handling*; is a way of supporting and guiding a child so that her movements become more normal. It relaxes the stiff child. It supports a floppy or athetoid child. It allows ataxic and athetoid children to control their movements more.
- Positioning; A good positioning enables a child to do more for him in a normal way. Allow the child some movement rather than fixing him completely with equipment. Too much support does not allow him to learn to move. The mother / caretaker should change his position regularly and choose the position which correct the child best position.
- Prevention of Contractures and Deformities; A contracture is a shortened muscle which prevents the full range of movements being carried out at a joint. The join becomes stiff. A deformity is an abnormal position of a joint. Eventually the joint may not move at all. Contractures and deformities caused by too little movement or muscle imbalance. The mother should check the range of movement at each joint and use correct handling and positioning for relaxing the child muscle. In order to prevent contractures and deformities, the mother/ care taker should encourage the child to move by himself within good positions, which will stretch the tight muscles.

• Encouraging child's skill for daily activities and self- care; A child with cerebral palsy will get abilities later than other children. They may not achieve everything, and may not always walk. The mothers/ caretakers should help the child become as independent as possible in eating, dressing, washing, toileting and in meeting other daily needs.

2.10.1 What are the Factors affecting home management?

Physical and occupational therapists use home management as a treatment method extensively in the rehabilitation of children with cerebral palsy (Parette&Hourcade, 1985). The focus of home management may go beyond the daily management of the child to prescribe the routines to the mothers/caretakers on the care, handling, and treatment of their child.

The factors affecting home management are degree of disability of the individual child, the extent of the mothers/caretakers involvement, and involvement of the health personals.

• The degree of disability of individual child

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Home management vary according to the specific child's disabilities, some child may need intensive home management and some may just need to integrate some part of home management to his daily activities.

• The extent of mothers/caretakers involvement

The effectiveness of home management for CP child depends on the degree of mothers/caretakers involvement and the factor associated with mother-child interaction, mother's self-esteem and depression, family's size, family income,

education and occupation of mothers/caretakers, and knowledge, attitude of mothers/caretakers on home management.

• Involvement of health personnel

Health personnel such as physical and occupational therapists play an important role in providing home management for mothers/caretakers with CP children. Some therapists, in their attempt to provide the best possible treatment for the child, may recommend extensive home management (Wendt et al, 1984). Other therapists recommend activities that are both helpful in their daily routines and can be easily integrated into a normal mothers/caretakers role, but do not specifically recommend that mothers/caretakers actively treat their child in a complex way at home (Anderson & Hinojosa, 1984; Wilson, 1984). Therefore, mothers/caretakers may feasible integrate home management into their daily activities also depend on the ability of the health personnel in justifying the appropriate home management to the individual CP children.

2.11 Associated Variables Affecting Mothers' Practice on Home Management of Cerebral Palsy Children

As above mentioned, it could be concluded that mother plays an important role toward home management for CP child. The internal variables affecting mother's practice on this home management include family 's income, family's size, motherchild interaction, mother's self-esteem and depression, educational level of mother, and knowledge, attitude of mother on home management. The external variables from community include knowledge of home management, knowledge of how to participate in support of family with CP child, social norms and beliefs. Other variables from service providers are availability of information, education, and communication as well as inaccessibility of specific services by mothers/ caretakers, including capability of health providers in home management's guidance.

2.11.1 Internal Factors Associated with Mothers/ Caretakers

Internal factors associated with mothers/ caretakers include the cognitive and affective dimensions of knowing, feeling, valuing and having self-confidence or a sense of efficacy in performing knowledge, attitudes, beliefs, values, cultural modes. Demographic factors such as age, gender and family size and socioeconomic factors such as education, income and occupation are also predisposing determinants of behavior that facilitate or hinder a person's motivation to change and can be altered through direct communication.

Knowledge is an essential factor that decides every individual whether to use or not use certain practices. It also brings a positive association towards change. Therefore, it can be assume that if there is an increase in knowledge, there could be a possibility of change in practice.

In developing countries, lower maternal self-esteem and depression has been associated with poverty and lack of financial resources (Brody and Flor, 1997).

Depression and low maternal self-esteem interfere with mother and child interaction. In most cases, depressed mothers are less responsive to their children's needs and less able to interact with them (Cox et al, 1987). These character and personality of the mothers with CP children become more emotional in coping up their CP children and may influence their capability to practice home management.

Low maternal self-esteem and depression, knowledge, attitude and belief need long term intervention and need a continuous effort for improvement. These factors have also a strong influenced to the mothers / care takers. Such factors categorizes the socioeconomic determinants such as mother's education, occupation, income, and number of children, and age. Improvement of socioeconomic determinants needs a strong commitment of the government to uplift the socioeconomic determinants, large allocation of fund, and time. Therefore, improvement of these factors is rather complex and very difficult to intervene, so socioeconomic factors was not be emphasized in this study.

2.11.2 Factors Associated with Health Providers

Factors associated with health providers refer to the availability, accessibility and affordability of health care facilities and resources necessary for behavioral and environmental outcomes to be realized. They also include skills that a person or organization needs to carry out to change in behavior or to change the environment. These factors can be changed primarily through training for skill and organization for barriers and resources.

Lack of these factors such as access to education services on home management and materials on home management, have a direct effect on the knowledge and practice of mothers/caretakers in home management. The accessibility to home management education plays an important role to raise awareness among mothers.

2.11.3 Factors Associated with Community

Factors associated with community comprise of the different types of feedback and rewards that those in the target population receive, which may either encourage or discourage them in the changing their behavior. Thus, the factors include social support, peer influences for the continuation or discontinuation of a behavior. These factors can be change mainly by indirect communication with family, peers and teacher, employer and other who control social rewards.

Several researchers (Bejer and Green, 1975; Kaplan, 1977) have noted the importance of social support for behavior change and its relationship to health.

These authors suggested that one form of social activity should be included in interventions such as: a support group, or peer education, or social network. For example: support of community members such as formal or informal village leaders, and communication among mothers is important in the Thais social setting.

2.12 Consequences of Inappropriate Practice of Mothers/ Caretakers in Home Management of children with Cerebral Palsy

The child potential growth and development appear to depend upon the

presence of caring and a challenging environment, which is related to the practicing of mothers/care takers. For CP child, the mother needs to practice appropriate home management because of their potential for physical, intellectual, psychological and social growth. An appropriate home management is one of the most critical requirements for improving the children's development and capacities and may help

The consequences of inappropriate practice of mothers/ care takers in home management of children with CP affect directly to the child. They may hinder child's development, increase contractures and deformities, pressure sore and delay formal schooling. These consequences can then burden to the family and public health care. Study in USA indicated that CP cause substantial economic burden on both medical and non-medical resources for caring and support of the CP children (Waitzman, 1995).

2.13 Conclusion

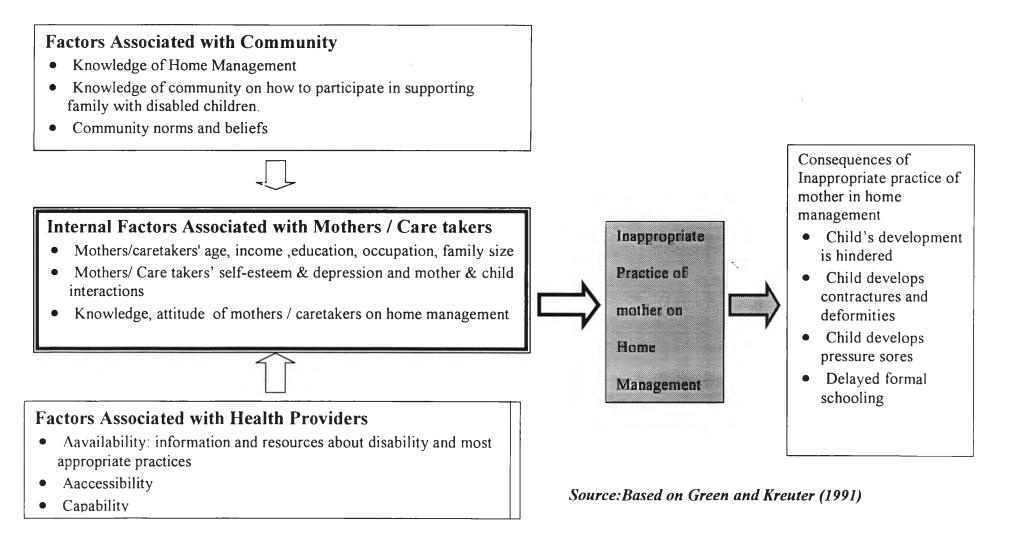
Cerebral palsy (CP) is a condition. It results from damage to the brain before, during, or after birth .It is not a progressive condition, which means it won't get worse over time. The main causes of CP is unknown but there are several factors that are associated with CP such as a lack of oxygen, premature birth, low birth weight, blood type incompatibility, infection, or central nervous system problems put a child at a risk for CP. Today there are an increasing number of measures that can be taken prenatal to reduce the risk of CP. Preventing prematurely can decrease the incidence of CP, but for most cases we don't know how. The best advice is to get medical care as soon as you know you are pregnant. Although CP can't be cured, treatment or rehabilitation can often improve a child's capabilities and lead a more functional life. In health care service, there are three levels of rehabilitation institute, community, and family. The most effective health care service for CP child is family based rehabilitation, which family plays the main role in performing home management for CP child

The practicing of mothers in home management of children with cerebral palsy is associated with several factors which are influence the knowledge, attitude and practice of mothers in home management such as: socioeconomic, demographic, and environmental factors. Key factors can be defined as internal and external factors. These factors not only directly and indirectly affect the knowledge, attitude and practice of the mothers in home management, but factors also have the inter-relationships and interactions and this is important.

A comprehensive strategy requires community cognition about home management. There is a need for participation of community to support, organize and develop appropriate solutions. Mothers themselves do not recognize their inappropriate knowledge and practice. Consequently, they are not aware of the need to gain knowledge and improve practice in absence of support from community members e.g., village leaders, health staff and other mothers.

One of the internal resources that could be used is the existing health care service and networks available in the community. Making full use of available resources in the community can take more effective to mobilize manpower, e.g. village leaders, health staff. In conclusion, the practicing of mothers in home management for children with cerebral palsy is a problem that need to be addressed of., It is important to be concern on home management because the vast consequences such as hindered of child's development, increasing of contractures and deformities, occurring of pressure sore and delay for formal schooling and increased cost of health care of the family. What is needed is a comprehensive development strategy .The next chapter will describe in details as on a possible strategy that can intervene the consequence of inappropriate practice of mothers/ care takers on home management for CP children.

Figure 2.1 Casual Relationship of Associated Variables Affecting Mothers/Caretakers' Practice on Home Management of Cerebral Palsy Children



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