

Introduction

The birth of child who has cerebral palsy is a potentially traumatic event for parents. It is one of the major health problems that have negative impacts on child and family throughout child life. In the past, those families were often told to put their child in an institution and forget about him/her. Hence, cerebral palsy is one of the chronic diseases that require specific care and attention from community care providers (*Bullough et al., 2004*).

Cerebral palsy is defined as difficulty in controlling the voluntary muscles due to damage to some portion of the brain. This damage is fixed, and does not become progressively greater (*Shu, 2004*). On the other hand, *Maloney et.al (2006)* defined cerebral palsy as a group of chronic conditions that affects body movements and muscle coordination.

The incidence of cerebral palsy is from 100 to 600 cases / 100,000 all over the world. There are almost 300,000 affected children in the United States (*Neff and Weiss, 2004*). In Egypt, several studies have been conducted trying to reach an estimate of the magnitude of the problem of disability. Because of lack of agreement and of standardization of definitions and procedures, variable estimates were reached. The estimated prevalence of disability varies between 5.6% and 11.8%, but no reliable data are available for cerebral palsy rates. It is generally

accepted that 5-10% of the populations have significant disabilities that need rehabilitation interventions (**WHO, 2008**).

Community-based rehabilitation is that care provided outside an institution such as a hospital or center of rehabilitation. It is based on understanding the problems that face people with disabilities in their daily lives, and the beliefs of the community people about them. Community-based rehabilitation is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services (**Shu, 2004**).

Community-based rehabilitation programs provide care outside the hospital and are aimed at preventive and health promotion to improve the health of disabled persons and help their families. Here the term based does not mean physical setting but means that upon which the care is founded (**WHO, 2008**).

As mentioned by **Maloney et al. (2004)**, management of the child with cerebral palsy is best accomplished by a nurse using a multidisciplinary health care team (community-based approach). The overall goal of multidisciplinary team should be to provide maximum quality of care while assisting the patient in obtaining his/her optimal level of wellness through mapping out a long-term program of development of these patients.

Moreover, the family caregivers play an important role in the educational process of their children with cerebral palsy. Caregivers can help in developing and carrying out educational goals and objectives. Because, the caregivers know the child, they are the best to carry their role effectively. So, caregivers must see themselves as equal partners with professionals in planning and implementation of programs for the child. They should be aware and confident in their role so as to make sure that the program plan is appropriate and effective, i.e. to obtain holistic care (*Sherill and Bernie, 2005*).

Significance of the study

Cerebral palsy is a serious health problem that threatens children and their caregivers throughout their lifetime. It is considered as one of the leading causes to child morbidity and mortality and of psychological stress for caregivers. Parenting a child with cerebral palsy is a hard task. It not only creates a myriad of physical and emotional problems for the child, but also an emotional and financial burden on the family.

Aim of the Study

The study aim was to investigate the effect of community-based rehabilitation program on children with cerebral palsy and their caregivers. This was achieved through the following objectives:

1. To assess the knowledge of caregivers who are caring for their children with cerebral palsy
2. To identify the activity of caregivers who are caring for their children with cerebral palsy
3. To adopt and adapt a program based on the needs and problems of children and their caregivers
4. To implement the program based on the needs and problems of children and their caregivers
5. To evaluate the effect of the rehabilitation program.

Research hypotheses

The researcher hypothesized that:

1. There is a relationship between demographic characteristics of the subjects and the types of needs and problems.
2. Poor management of cerebral palsy will affect children needs and development.
3. The intervention program will overcome the children and their caregivers' needs and problems, improve children growth and development, and empower their quality of life.

Review of Literature

Cerebral Palsy

Cerebral palsy (CP) is a group of disorders affecting the development of movement and posture that are believed to arise from non-progressive disturbances in the developing fetal or infant brain; it is related to a brain injury or to problems with brain growth. It causes reflex movements that a person can not control and muscle tightness that may affect parts or all of the body. These problems can range from mild to severe depending on the location and extent of the damage. Mental retardation, seizures, and vision and hearing problems can occur in people with CP (*Pellegrino, 2002; Betz, 2008*).

Cerebral palsy results from malfunction of the motor centers and pathway of the brain (*Nettina, 2002*). The term cerebral refers to the brain's two halves, or hemispheres, and palsy describes any disorder that impairs control of body movement. Thus, these disorders are not caused by problems in the muscles or nerves. Instead, faulty development or damage to motor areas in the brain disrupts the brain's ability to adequately control Cerebral Palsy. Meanwhile, the location in which brain damage occurs determines how functions are affected, as in Figure (1) (*Liptak, 2001*).

Parts of the brain affected in Cerebral Palsy

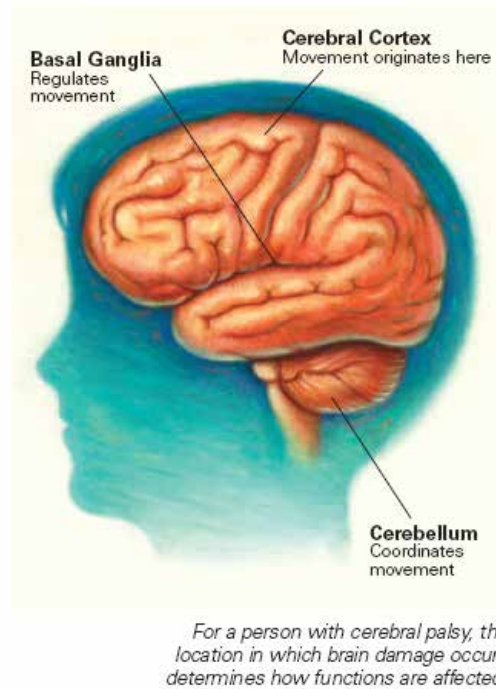


Figure (1): Different parts of the brain that might be affected in Cerebral Palsy (**Berker and Yalcin, 2005**).

This disease is a serious problem that leads to involuntary body movements, poor coordination, and stiff muscles (**Amir, 2005**). Children with CP have trouble when they try to walk, crawl or grab onto things. Some children may also have trouble with vision, speech, and hearing. Others may have seizures, poor mental ability, and trouble with bowel and bladder control, eating and feeding (**Basch, 2007**). This damage can happen before birth or up to the age of 5 years old. These children do not get better as they grow up. In most cases, no cause could be

found. There is no cure for CP but good care can help the person to function in the best way possible (**Behr, 2000; Sherill and Bernie, 2005; Youngblut, 2008**).

Prevalence

Cerebral palsy affects two to three per 1000 children and is the commonest cause of physical disability in early childhood (**Ashwill and Droske, 2002**). It was found that three per 1000 of those who participate in the National Collaborative Perinatal Project (NCPP) had CP (**Russman, 2007**). In the United States, 8,000 babies and 1,200 to 1,500 pre-school children are diagnosed with CP every year (**WHO, 2008**).

Worldwide, the incidence of CP is approximately 7/100,000 live births. The prevalence rates in children under 10 years of age are 2.2/1000, and 1.2/1000 in children 10 to 17 years old. The prevalence rates in boys are 2.0/1000, compared to 1.5/1000 in girls (**Stevenson, 2002**). The incidence of CP has not changed in more than four decades in USA, despite significant advances in the medical care of neonates (**Ashwal, 2004**). The incidence of CP is higher in areas with poor prenatal care with increased incidence among premature infants. About one in 100 babies who are small or premature have CP (**Merck, 2005**).

In Egypt, there is no definite incidence of CP (**Balkrishnan, 2002**). A total of 322 cases of CP were listed from 2004 to 2006 only in the registry of Ain-Shams Pediatric

Neurology out-patient clinic. Although the incidence may be declining, the prevalence may be increasing as technologic advances increase the infant survival rate (*Abou Fotouh et al., 2008*).

Despite advances in preventing and treating certain causes of CP, the number of children and adults it affects has remained essentially unchanged or perhaps risen slightly over the past 30 years (*Pines, 2008*). This is partly because more critically premature and frail infants are surviving through improved intensive care. Unfortunately, many of these infants have developmental problems of the nervous system or suffer neurological damage. Research is under way to improve care for these infants as in ongoing studies of technology to alleviate troubled breathing and trials of drugs to prevent bleeding in the brain before or soon after birth (*Aksu, 2003*).

Pathophysiology

Cerebral palsy is caused by damage to brain cells that control the movement of muscles. When those cells die, signals can no longer be sent to muscle cells. This loss of muscle control results in the symptoms of CP. The etiology of the cerebral insults includes vascular, hypoxic-ischemic, metabolic, infectious, toxic, teratogenic, traumatic, and genetic causes. The pathogenesis involves multifactorial causes, but much is still unknown. Different pathogenetic mechanisms of CP have been associated with preterm and term births. In many cases, a cause

cannot be accurately determined. Some believe that a pre-existing condition in some fetuses causes early birth and neurologic problems, as opposed to the prematurity itself causing CP (*Dillinton et al., 2000*).

It is difficult to establish a precise location of neurologic lesions based on etiology or clinical signs because no characteristic pathologic picture exists. The hyperexcitability of the lower motor neuron is presumed to be the cause of spasticity. Some patients have evidence of vascular occlusion, atrophy, loss of neurons and degeneration. Anoxia plays the most significant role in the pathologic state of brain damage, which occurs frequently secondary to other causative mechanisms. In some instances, it is possible to establish a specific etiology of CP namely genetic syndromes, congenital malformations, and in utero or perinatal central nervous system infection (*Guisseppa et al., 2000*).

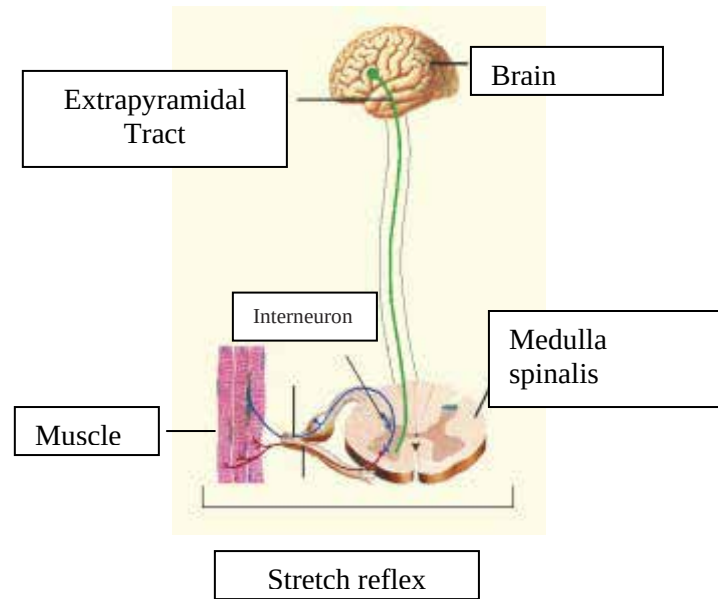


Figure (2): Pathophysiology of cerebral palsy
(Berker and Yalçın, 2005).

Specific brain lesions related to CP can be identified in most cases. These lesions occur in regions that are particularly sensitive to disturbances in blood supply and are grouped under the term *hypoxic ischemic encephalopathy*. Five types of hypoxic ischemic encephalopathy exist; parasagittal cerebral injury, periventricular leukomalacia, focal and multifocal ischemic brain necrosis (Figure 3), status marmoratus, and selective neuronal necrosis.

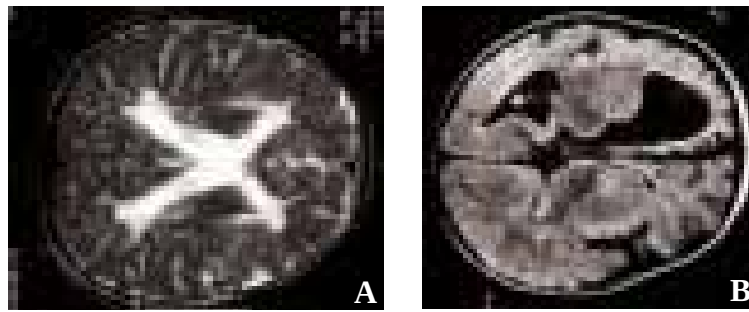


Figure (3): Specific brain lesions related to CP (A) Periventricular leukomalacia (PVL), (B) Multifocal ischemic brain necrosis (*Berker and Yalçin, 2005*).

Causes and Risk Factors

Cerebral palsy is caused by an insult to the immature brain from any time before birth up to the postnatal period. After the immediate postnatal period, CP often has an identifiable cause, e.g., hypoxic ischemic encephalopathy, which should be noted. The cerebral insult alters muscle tone, muscle stretch reflexes, primitive reflexes, and postural reactions. Other associated symptoms may be involved secondary to the neurologic insult, e.g., mental retardation, vision and hearing problems, seizures; but they are not part of the definition of CP (*Dillinton et al., 2000*). The risk factors associated with CP are grouped into prenatal, perinatal, and postnatal factors. Prematurity and low birth weight are the two most important risk factors in developed countries. Postnatal risk factors additionally play a major role in other countries (*Berker and Yalçin, 2005*).

§ Prenatal Causes:

In many cases, the exact cause of CP is not known. Cerebral palsy can be caused by problems from being born too early (premature); not getting enough blood, oxygen, or other nutrients before or during birth; a serious head injury; multiple births; maternal illness; a serious infection that can affect the brain, such as meningitis; exposure to toxic or teratogenic agents; and/or some genetic problems that affect brain development (*Murphy, 2000; Pellegrino, 2002*).

A fetus's risk for developing a brain abnormality or injury that leads to CP increases when the mother has certain problems during her pregnancy. These problems may include infections, such as German measles, cytomegalovirus infection, and toxoplasmosis. When these infections occur during the first six months of pregnancy, the fetus is especially at risk. Infections in mother's uterus or vagina may cause inflammation in the placenta, which can disrupt the normal growth of a fetus's brain. Other problems include exposure to certain medications, such as thyroid hormones or estrogen; use of alcohol, and some prescription medicines; and other problems, such as bleeding in uterus in last trimester, proteinuria, or high blood sugar (*Winnicott and Wong, 2006*). In addition, mothers with any of maternal hyperthyroidism, mental retardation, or seizures are slightly more likely to have a child with CP (*DeCarlo, 2001*).

Some babies born with CP have visible signs of nervous system malformation, such as microcephaly. This suggests that problems occurred in the development of the nervous system while the baby was in the womb (*DeCarlo, 2001*). It has been reported that CP is found in infants that have a blood type or a blood factor that is different from their mothers and those with jaundice soon after birth (*Merck, 2005; Stevenson, 2002*). Babies born to teen mothers or to mothers age 35 and older have a higher risk for CP (*Dowdorth, 2006*).

§ **Perinatal Causes:**

Risk factors identified during the labor and delivery include vaginal bleeding on admission and placental complications such as abruptio, premature rupture of membranes, and breech presentation. Many of these risk factors are significant only if a baby weighed less than 2500 grams at birth. In addition some of the risk factors such as oxytocin augmentation, or cord prolapse were relevant only if associated with low Apgar scores (*Velasco et al., 2000*). Prematurity, birth weight less than 2500 gm, growth retardation, intracranial hemorrhage, trauma, bradycardia and hypoxia, infection, seizures, and hyperbilirubinemia are other risk factors for CP during perinatal period (*Kockrow, 2004*). Also, babies with CP are more likely to present feet first (*Amir, 2006*).

Between 40% and 50% of all children who develop CP (CP) are born prematurely. Approximately 11% of premature

babies who survive in neonatal intensive care units develop CP. In addition, the risk of a baby having CP increases as the birth weight decreases. A baby who is born prematurely usually has a low birth weight, less than 5.5lb, but full-term babies can also have low birth weights (Figure 4). It is estimated that 70-80% of children with CP experienced a disruption in the normal development of their brain during fetal growth (*Werner, 2007*).



Figure (4): Premature babies (*Berker and Yalçin, 2005*).



Figure (5): Multiple pregnancies (*Berker and Yalçin, 2005*).

Multiple-birth babies are more likely than single-birth babies to be born early or with a low birth weight (**Werner, 2007**). In vitro fertilization results in multiple pregnancies and increases the risk of CP. Twins, triplets, and other multiple births (Figure 5) are linked to an increased risk of CP (**DeCarlo, 2001**).

§ Postnatal Causes:

Trauma, infection, intracranial hemorrhage, head injuries, brain lacerations, and hemorrhage account for approximately 18% of postnatal CP; while brain infection such as meningitis, toxic condition, viral infection and toxic chemicals such as lead poisoning together account for 57% of postnatal CP. Sudden spontaneous brain hemorrhage occur in children and most often produce a spastic hemiparalysis (**Kockrow, 2004**). CP risk is increased if the young child does not get enough fluid and becomes dehydrated, or gets a bad infection of the brain or spinal cord, or had a bad car accident, or had a bad fall (**Zoltan and Pedretti, 2005; Merck, 2005**). Serious head injury from an accident or fall includes injury to a baby from shaking, throwing, or other force (**Dowdorth, 2006**).

Classifications and Characteristics

Cerebral palsy is classified into four broad categories: spastic, athetoid, ataxic, and mixed forms. Based on which limbs are affected, the names are given to these types combine a Latin description of affected limbs with the term plegia or