

## Article

# Survey of mothers of children with cerebral palsy

Zhang Jinming\* and Liu Jianjun

<sup>1</sup>Faculty of Rehabilitation, Capital Medical University, Beijing, China.

<sup>2</sup>Department of CRRC, Capital Medical University, Beijing, China.

Accepted 25 May, 2010

**Cerebral palsy (CP) is found in every country and in all types of families. It is difficult to estimate exactly how many people have CP. Many people with mild CP are never diagnosed, while others may have multiple disabilities, which overshadow their CP. About one in every three hundred babies born will have, or will develop CP. It is reported in China, that the occurring rate of CP is 1.5 - 5% and the total number of the CP children of age 0 - 6 is around 300,000. This group of CP children brings much burden to their families and the society. CP effects on children are life long. When a child is diagnosed with CP, all aspects of his/her parents begin to change.**

**Key words:** Mother, children, cerebral palsy, China.

## INTRODUCTION

Cerebral palsy (CP) is found every country and in all types of families. It is difficult to estimate exactly how many people have CP. Many people with mild CP are never diagnosed, while others may have multiple disabilities, which overshadow their CP. About one in every three hundred babies born will have, or will develop CP. It is reported in China, the occurring rate of CP is 1.5-5% and the total number of the CP children of age 0 - 6 is around 300,000. The group of CP children brings much burden to their families and the society. CP affects children lifelong. When a child is diagnosed as CP, all aspects of his/her parents start to be changed.

### The definition of cerebral palsy

CP is a term used to describe a group of disorders affecting body movement and muscle co-ordination. The medical definition of CP is "a non-progressive but not unchanging disorder of movement and/or posture, due to an insult to or anomaly of the developing brain."

Development of the brain starts in early pregnancy and continues until about age ten. Damage to the brain during pregnancy and one month early may result in CP. This damage interferes with messages from the brain to the body, and from the body to the brain. The damage to the brain does not get worse, but as the child gets older the

effects become more noticeable. For example, deformities can develop.

### *The causes of CP*

Any damage to the developing brain, whether caused by genetic or developmental disorders, injury or disease, may produce CP.

Anything, which tends to produce a low birth weight baby, will increase the likelihood of CP. Factors during pregnancy, which may cause CP, include: multiple births (twins or triplets), a damaged placenta which may interfere with fetal growth, infections, poor nutrition, exposure to toxic substances, etc; premature delivery, abnormal positioning of the baby (such as breech or transverse lie) which makes delivery difficult, rupture of the amniotic membranes leading to fetal infection. CP can occur if a young child suffers brain damage due to: infections such as meningitis, brain hemorrhages, head injury following falls, car accidents or abuse, lack of oxygen.

### *Treatment and management of CP*

CP is not considered to be a curable condition and the word "management" is used more often than "treatment". However, there is much that can be done to lessen the effects of CP and to help people with CP to lead independent lives.

CP children need various therapies for a long time.

\*Corresponding author. E-mail: [norwayuio@yahoo.com.cn](mailto:norwayuio@yahoo.com.cn).

Physical Therapy (PT) aims to help people achieve their potential for physical independence and mobility. PT includes exercises, correct positioning, and teaching alternate ways of movement such as walkers, bracing or handling a wheelchair. Occupational Therapy (OT) designs purposeful activities to increase independence through fine motor skills. OT helps children to use adaptive equipment such as feeding, seating and bathroom aids. Speech Therapy aims at improving communication. A child may need help to overcome a slight articulation problem, or she may not be able to communicate verbally and may require a non-verbal communication system. Music Therapy (MT) uses music for the treatment of neurological, mental or behavioral disorders. New therapies are being developed all the time.

## RESEARCH OBJECTIVES

The objectives of this research are:

- i.) To explore the attitudes of mothers with CP children to their children, family and to their own lives.
- ii.) To try to find out how much CP children affect their homes, especially their mothers.

## STUDY DESIGN

### The samples

We decided to make a survey study for this purpose. It was carried out in the CP pediatric department of China Rehabilitation Research Center (CRRC). CRRC is a state owned institute, established in 1988. It provides comprehensive rehabilitation and social services for persons with disabilities, carries out scientific research, offers professional training, and conducts information exchange and serves as a technical resource to the Chinese rehabilitation network. CRRC is situated in China capital city Beijing. It is the largest and most advanced rehabilitation center for persons with physical disabilities in China and should be the best place for a CP child to receive professional rehabilitation services.

Thirty six mothers whose children with CP stayed in CRRC for rehabilitation treatment were involved in this survey with their consents.

### Data collection

A questionnaire including 25 closed questions was designed as a tool for collecting data. The sample mothers of CP children were introduced to the survey before answering the questions and answered this questionnaire totally and separately. They could refuse to participate in the survey without any reasons. This survey is anonymous. The questionnaires with answers were kept by the survey conductors, and not to be made public.

## FINDINGS

### General findings

In this survey, the age range of 63.8% mothers of CP

children is 31 – 40; 30.6% is 25 - 30 while 2.8% is over 45. The education level of absolute majority of the mothers is above middle school. 8.3% of them are with primary school education or lower. Nearly half of the mothers have in income at 501 - 1000 RMB, and one quarter with income 1001 – 5000 RMB. 56.7% CP children are 1 - <6 years old and 33.3% with age 6 and above. Most of the children are the only one in their family.

### Most caregivers are children's mother

The result of the question "who is the main caregiver of your child?" 94.4% of mothers chose "myself". Grandparents usually are the caregivers of a child in China except parents. Nevertheless, a child suffering from CP, his/her mother takes more responsibilities of caring for the child naturally. In Chinese tradition, women are usually responsible for taking care of the children and home while the man work outside and make money. This phenomenon is more usual in rural than in urban area. This result reflects the conditions. Although the father is not the main caregiver of the child, we cannot say that the father is excused from the responsibility. The following result tells us that it is probably due to the fact that the father is spending much time on making money for his CP child. The role of caring for the child has to be taken by the mother.

### The rehabilitation cost for CP children are mostly from their fathers

The result shows that rehabilitation fee for CP children are from 63.9% fathers, 19.4% mother and 16.7% from other sources. It is known that the rehabilitation cost, especially in a professional institute, is quite high. Since CP is not incurable, the rehabilitation treatment lasts for lifelong. Undoubtedly it is a great burden for a family. It is reported that some of the mothers of disabled children give up job for taking care of children. The decision of quitting job must be a dilemma. They have more time for the child, but lose chance of making money at the same time.

### Absolute majority of mothers of CP children feel sorry for their children

Whatever causes CP, the quality of a CP child will be discounted greatly, which makes mother feel so much sorry for their child. The result shows that 88.9% mothers of CP children feel guilt to their children. Mothers' greatest anxiety is that nobody will take care of their disabled children after they get out of this world. Child is inculpable. But that the child becomes disabled is not the mothers' fault.

**Not more than one-third of mothers of CP children feel sorry for their husbands, and more than one-third of the mothers complain of their husbands in their hearts**

Compared with CP children, only 30.6% of the mothers of CP children feel sorry for their husbands, probably because the mother brings the baby to the world. Although a child is gestated by his mother, this does not mean that a child gets CP because of the mother, even without any relations to the mother. It is found in this survey, that 36.1% mothers have the complaining mentality to their husband. The reasons are maybe that the husband ignored her and the child while she was pregnant, maybe the baby's treatment was delayed by the husband or some reasons else.

**Over half of the mothers of CP children prove that they quarrel once in a while with their husbands by reason of the child and almost one-third of them never did**

It is found that 52.8% of mothers quarrel with their husbands once in a while, and that the rate of "never quarrels" is 30.6%. In other words, nearly one-third of parents of CP children are able to contribute together for their children, at least they did not spend time on dispute. From these findings, we can say a family life is affected distinctly by a disabled child.

**Nearly 90% of mothers think their CP children neither broke the relationship between themselves and their husbands, nor effected their marriage stabilization**

86.1% mothers don't think the CP child destroyed their relations. And 88.9% denied that disabled children affect marriage. From this result, we can see most parents can unite efforts for their disabled children and their family, although some parents divorce because of a disabled child.

**44.4% mothers of CP children deem they themselves donate for their children more than their husbands do, and over half of mothers think they do as much as their husband**

This is a subjective answer, however, the data reflect the attitude to their disabled child, and reflect the relation of the spouse as well. Namely around half parents have a good relation and make effort jointly for their disabled children. The result also shows that 2.8% mothers think their husband contribute for the child more than themselves.

**Over half of mothers of CP children think that the child is the most important member in her family**

It could be understood and accepted completely that suicide idea emerges instantaneously. A disabled child brings not only the family tremendous economical burden, but also an endless mental anguish. Mothers of CP children have not any way to escape the real-life. This survey shows 52.8% mothers have the idea of suicide. Whether she performs it or not, the result has already told us how much pressure a mother of CP children has upon her.

**61.1% of mothers of CP children are unwilling to talk about their children with others and 41.7% mothers of CP children are reluctant to take their child to the public**

It is very common that parents with disabled children don't want to talk about their disabled children with others. More than half of the mothers of CP children do so in this survey. As the social awareness is increasing, more and more disabled people take part in social activities. However, 41.7% mothers of CP children in this survey are still not able to take their disabled children to be with them in public.

**69.4% expressed that they neglected their own parents (grandparents of CP children); 80.6% mothers admitted that they became solitary and their social activities decreased**

A disabled child demands so much time and vigor that the mother cannot show consideration for their own parents. Although mother's parents never complain, there is guilt in a mother's heart. A disabled child changes the mother's life and character. 80.6% mothers isolate themselves and even reduce their social communications to as few people as possible.

**Regarding "having a disabled child arranged by fate", 55.6% mothers of CP children agreed with this standpoint, while 44.4% disagreed with it**

It is not hard to understand that mothers of CP children have no alternative in their hearts. They have to accept the reality. Over half of them agreed that a special life was arranged by a power outside the body, although 44.4% mothers don't agree with this standpoint. Mothers of CP children, whether they agree with this standpoint or not, clearly understand they should not concentrate on life's reasons, but put their hearts into their children's rehabilitation.

**Only one-third considered that their grief could be understood by others; 63.9% mothers would never give birth if they knew that the child will have a disability**

Only one-third of mothers admit that others are able to understand their grief. In other words, most people do not understand mothers of disabled children. This result indirectly implies that the society has not sufficiently understood the groups of disabled people and their families. "63.9% mothers would never procreate if they knew a disabled child in her life beforehand". This result shows that a disabled child greatly results in grief to the mother, although a child brings much happiness to his mother as he is growing.

**100% in the survey expressed that they are willing to replace children's health with their own life**

Maybe the question "if possible, would you rather replace non-disabled child with your life?" is regarded dispensable; whereas the result enable us understand the self-giving mother's love much more. Without doubt, all mothers' answers will be "yes".

## **DISCUSSION**

Every mother of a child with CP asks: "Did I do anything wrong? Why did this happen to my child?" In most instances, the answers to these questions will never be satisfied. We do not know the cause of most cases of cerebral palsy. That is, we are unable to determine what caused cerebral palsy in most children who have congenital CP. We do not know if the child who is at highest risk of developing CP is the premature, very small baby who does not cry in the first five minutes after delivery; and who has bleeding in his brain.

The rehabilitation given at CRRC is so rare in China. Absolutely most children with CP cannot receive professional rehabilitation services. Professional rehabilitation staff is quite few. The needs of CP children and their parents cannot be met. The findings of the survey have given us information about the general status of CP children and their mothers. We also know what and how much a CP child affects his/her family. Anyway, children are children with CP. Mothers of CP children are mothers. They are a special group, weak group, fragile group, longing for understanding, support, concern and assistance.

No research is perfect and endless. For this survey, mother informants are simply those who are in CRRC, the special place. Therefore, the representative is limited. The mothers whose economical condition is comparatively better have more possibility to be in CRRC at least, and easy to be as samples. Also, the findings will be richer if qualitative methods, such as interview, focus group discussions are used.