# Research on family factors and support of children with cerebral palsy

(scientific paper)

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***Abstract:*** *Families are not only the main living area for such children with cerebral palsy but also their most reliable spiritual home. During the long-term care process, family members, especially those main caregivers are under diverse great pressure, the primary aim of this study was to examine family factors and support strategies used. Data regarding situation of children with cerebral palsy and their family factors were obtained from patient records. Results indicated that family coping styles associate with family factors and spiritual support was among the family coping strategies used most often. Not surprisingly social support was used least often, caregivers tended to seek out internal support (e. g. support from the extended family). Findings suggest the necessity to target policy makers, community supports, and attitude towards family rehabilitation. In the long run, to meet diversified needs of the child and their families, it's necessary to provide support services for the aim of enhancing children and parents' self-help ability.*

***Key words:*** *Family factors; Family support; School adjustment; Child characteristics*

## Introduction

According to the report of Chinese cerebral palsy net, the incidence rate in China was 1.8–4 ‰, an average of 3.25 ‰ among surviving infants in 2011. There are more than 6,000,000 patients with cerebral palsy (CP), the number annually increases with 4 to 5 million newborn infants. Adolescents account for more than 60 %, including at least 500,000 school-age children. Moreover, 70 % of these children lived in poverty. Families of children with CP are faced with various stressors stemming from daily care of rehabilitation and psychosocial challenges. The way families cope with these challenges can impact their physical and psychological well-being.

The field of cerebral palsy has a long history of observing and describing the medical techniques, the majority of literature on coping in families of children with cerebral palsy comes from medical rehabilitation other than family factors themselves or supports they used. The study assessing family functioning obtains information from primary caregivers in the family, which assumes that the primary caregiver brought more influence than other family members.

## Methodology

This descriptive study utilized data from multiple sources to gain a picture of family factors and support of children with CP, the author designed questionnaire for families with CP, and had face to face interviews with primary caregivers. Questionnaires were completed by the primary caregiver who generally spent the most time with the child (one of them was a hired nanny). A total of 14 families were contacted as respondents for the survey in Rehabilitation Center, the Disabled Federation of Sichuan Province, China. In these cases, the separate interview responses were compared, and respondents were re-contacted to clarify any discrepancies in the questionnaire provided.

Quantitative and qualitative data analysis techniques were used to extract themes. For the quantitative analysis, respondents were asked about research process of diagnosis, degree of illness and impact on families, as well as family coping styles and support used etc.

Qualitative analytic methods were used to analyze responses to the standard interview. The research team studied the interview responses carefully, looking for emerging themes of family factors and categories of support. A coding system was developed, and sound recording data were sorted according to “families of codes” (Bogdan & Biklen, 1998). The research team, together with respondents through focus group, discussed recommendations to guide future family coping and support development work.

## Findings

### Children characteristics in different families

No caregivers in the fourteen families refused to participate at the time of their children’s home rehabilitation. Thus, the total sample consisted of 14 families of children with CP range in age from 2 to 6 years. There are 9 in the class for younger children (mean age-3.5 years), 5 in the class for the elder (mean age-5.4 years). Just over half of the children were female (57.14 %), male (42.86 %). Significant relationships between parental and child coping have been found for both girls and boys (Kliewer

& Lewis, 1995), and among various illness groups (Brown et al., 1993; Kupst et al., 1995). Eleven children were born in the one-child family (78.57 %), another male and other females were not (21.43 %).

One significant question for the research was the age extent of children, family coping strategies and supports used discussing later might differ from each other because different age of definite diagnosis (see Table 1).

**Table 1:** Age of definite diagnosis

| Age (month) | Frequency | Percentage (%) | Accumulative (%) |
|---|---|---|---|
| Several days after birth | 1 | 7.1 | 7.1 |
| 1 | 1 | 7.1 | 14.3 |
| 3 | 1 | 7.1 | 21.4 |
| 7 | 1 | 7.1 | 28.5 |
| 8 | 1 | 7.1 | 35.6 |
| 12 | 2 | 14.3 | 49.8 |
| 13 | 1 | 7.1 | 56.9 |
| 14 | 1 | 7.1 | 64.0 |
| 15 | 1 | 7.1 | 71.1 |
| 16 | 1 | 7.1 | 78.2 |
| 18 | 1 | 7.1 | 85.3 |
| 26 | 1 | 7.1 | 92.4 |
| Uncertain | 1 | 7.1 | 99.5 |
| Total | 14 | 100 | Mean age = 11.08 |

As shown in Table 1, most children with CP were diagnosed before one year old (50 %), other got diagnosis before two years old (99 %). Such children have been in the rehabilitation center for training ranging in time from 1 month to 36 months (mean time-10.6 months). From the first day of the child, parents observed the change of children day by day, they took care of them carefully and noticed changes including twisting, sitting or crawling. Parents are the main original power to take children to the hospital while they noticed children's any abnormal behavior.

**Table 2:** Types and pathogeny of ceberal palsy

| Sample | Pathogeny | | | | | | | | | Types |
|---|---|---|---|---|---|---|---|---|---|---|
| | Premature delivery | Dystocia | Asphyxia | Icterus | Low body weight | Hyperpyrexia | Multiple labor | Encephalic | Other | |
| 1 | | | √ | | | | | | | Convulsion |
| 2 | | | | | | | | | Unclear | Synthesis |
| 3 | | | | | | | | √ | | Convulsion |
| 4 | √ | | | | | | | | | Synthesis |
| 5 | √ | | | | | | | | | Convulsion |
| 6 | | | | √ | | | | | | Ataxia |
| 7 | √ | | | | √ | | | | | Low tension |
| 8 | | | | | | | | | Unclear | Low tension |
| 9 | | | | | | | | | Unclear | Convulsion |
| 10 | | √ | | | | | | | | Convulsion |
| 11 | | | | √ | | | | | | Athetosis |
| 12 | | | √ | | | | | | | Convulsion |
| 13 | √ | | √ | | | | √ | | | Convulsion |
| 14 | √ | | | | | | | | | Synthesis |

Table 2 summarizes the main pathogeny and types of the children with CP. Just 35.71 % children's illness were caused by premature delivery, followed by 21.43 % were caused by asphyxia, 14.29 % were caused by icterus. Cerebral palsy may results from many reasons like deprival of oxygen, cerebral hemorrhage, toxicosis or traumatic brain injury. According to intelligence test, the average intelligence quotient of children with CP is lower than that of common people.

## Family characteristics

To understand the family situation and supports used, it is necessary to examine the nature of family as a system. Some evidence suggests that family factors associate with patterns of family coping. Take Brazil & Krueger as an example, they did research on one-versus two-parent homes (2002). So does to the relationship of the caregiver, the biological versus alternative caregivers with the child (Rose & Clark-Alexander, 1998).

**Table 3:** Primary caregivers of children

| Frequence | People | Percentage (%) |
|---|---|---|
| 6 | Parents | 42.86 |
| 2 | Parents and father's mother | 14.29 |
| 1 | Parents and father's parents | 7.14 |
| 1 | Parents and four grandparents | 7.14 |
| 2 | Mother | 14.29 |
| 2 | Father and father's parents | 14.29 |

Background data were obtained through questionnaire at the on-study evaluation. Caregivers provided information on family environment factors including composition of the family (see Table 4), relationship of the child with the primary caregiver (biological, adoptive, foster, extended family). Since no family fell into the categories of foster parent family, we discussed two groups: biological versus extended family. Researchers have examined the primary caregiver the children lived with, as shown in Table 3, about 71.4 % children live with parents. About 28.5 % children live with grandparents. The percentage of children who live in the core family is 42.8 %, and the percentage of children who live in the reorganized or separated family is 7.1 %. Twelve of the main caregivers are female, seven of them are mothers, four of them are grandparents, and a nanny living in. Four of the main caregivers are male, two of them are fathers, and another two are fathers' fathers. Primary caregivers' mean year of education (8.3 years) is lower than that of parents (12.8 years).

More data indicates parents' characteristics of age as well as occupation. The youngest mother is twenty-eight years old, the oldest is thirty-four (mean age – 30.5). Nine of them have no career, another two mothers are farmers and three are workers. As to the father, the youngest is thirty years old, the oldest one is thirty-six (mean age – 32.4). Ten of them are workers, three are farmers, and one father carries on inoccupation. All parents are educated, however only 14.2 % graduated from university. Others are high school graduates (43 %) and primary school graduates (42.8 %).

The disease of CP influenced a small number of parents' marital status and most primary caregivers' personal relationship. In reverse, certain family environment factors have been found to influence child coping styles, such as parental supportiveness and the level of structure and organization within the home (Hardy et al., 1993).

**Table 4:** Marital status of parents

| Marriage | Frequency | Percentage (%) | Accumulative (%) |
|---|---|---|---|
| Harmonious | 2 | 14.30 | 14.30 |
| Normal | 9 | 64.30 | 78.60 |
| Unharmonious | 2 | 14.30 | 92.90 |
| Separate | 1 | 7.10 | 100.00 |
| Divorced | 0 | 0.00 | 100.00 |
| Total | 14 | 100.00 | 100.00 |

The primary caregivers gave response to relativity between children with CP and marital status in interviews actively. They assessed whether there was correlation between sample parents' marital status and children's CP illness by five-point scale (1 – strongly disagree, 5 – strongly agree). Good reliability and validity have been received. Two-parent homes are common, there isn't single-parent home, but one couple may agree to divorce each other after a long separation.

### Family coping and support

Since a limited amount of research has suggested associations between coping and family factors, exploratory analyses will be conducted to assess relationships among these variables.

Conceptualizing coping strategies refers to passive and active techniques. When a person relinquishes control of a problem to others, passive coping techniques occur, while active coping involves an attempt to take a more active role in dealing with a problem (Brown & Nicassio, 1987). Research has demonstrated that use of denial is associated with more negative emotional impact at children with traumatic brain injury (Wade et al., 2001), suggesting that families' use of various coping strategies may influence the emotional burden of paediatric injuries.

To understand the effects that specific strategies can have on one's ability to cope with illness related stressors, past several studies have compared the effectiveness of passive versus active styles of coping. Most found little support for passive techniques with respect to physical and psychological outcomes.

Researchers did a survey of caregivers' friendly intercourse. Six caregivers usually asked help from extended family, three caregivers had good relationship with neighbors, two caregivers kept contact with friends. Table 5 illustrates primary caregivers' contact with family, specialists, friends and others, differentiating the emotion-focused support versus time-focused support.

**Table 5:** Primary caregivers' intercourse status

| Types | Examples | Frequency | Percentage (%) |
|---|---|---|---|
| Kinfolks | Siblings | 12 | 86 |
| Specialists | Teachers in rehabilitation center | 9 | 64 |
| Others | Neighbors | 5 | 36 |
| Friends | Colleagues | 4 | 29 |

Emotion-focused (Lazarus & Folkman, 1984) support occurs when an individual believes that nothing can be done to change the situation at the beginning of diagnosis and depresses under higher levels of distress during the long time of caring. Time-focused support is used when an individual views a stressful situation as amenable to take care of children.

To our knowledge, most support for family is associated with decreased emotional distress. Our study has specifically examined various rehabilitation or medical techniques among children with CP, and findings indicated that more serious degree of CP experienced more psychological distress than others. Combined emotion- and time-focused support, the primary caregiver have received assistance from different number of people (see Table 6).

**Table 6:** Number of people offering help

| Number of people | Frequency | Percentage (%) | Accumulative (%) |
|---|---|---|---|
| 0 | 2 | 14.30 | 14.30 |
| 1 | 1 | 7.10 | 21.40 |
| 2 | 3 | 21.40 | 42.80 |
| 3 | 3 | 21.40 | 64.20 |
| 4 | 1 | 7.10 | 71.30 |
| 5 | 2 | 14.30 | 85.60 |
| 8 | 1 | 7.10 | 92.70 |
| Invalidation | 1 | 7.10 | 92.70 |
| Total | 14 | 100.00 | 92.70 |

Checking the list of offering help, caregivers' parents are the most helpful ones (35.7 %), spouses' parents rank number two (22.3 %). Nurturing a child with CP is a great challenge including stress from psychology, spirit, and economy etc.

School-age children with CP in these cases did not go to school, thus, their expenses relate to daily expense, medical and rehabilitation fee. Three families (25 %) come from counties, and nine (75 %) are from countries. The lowest monthly family income is 1,500 RMB (215 US dollar), the highest is 8000 RMB (1143 US dollar). The family income averages 4278 RMB (611 US dollar) a month. With the rocketing up of consumer price index in China, more than 80 % respondents strongly agree with the heaviest burden for the family resulting from economy.

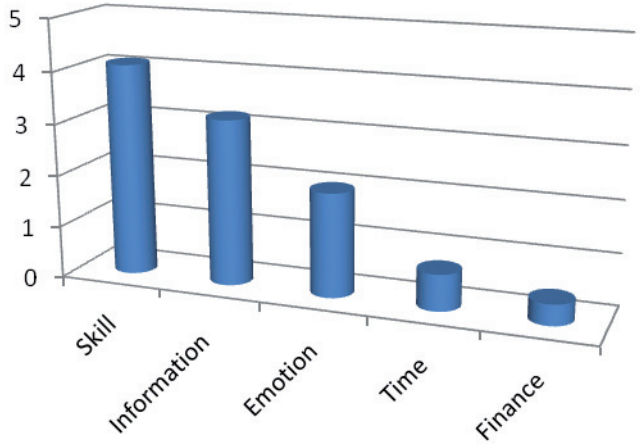

**Figure 1:** Types of social support

Among families of children with CP, it's obviously that social support as a means of coping is much less than the family self-support. (e. g. spiritual support from extended family). The lack of social support among illness populations is not a new finding, nor is it unique to individuals with CP. The research has demonstrated that children with chronic conditions report lower perceptions of support and smaller support networks than healthy children, and perceptions of social support may vary between illness groups (Ellerton et al., 1996). Classifying social support is apparent as shown in Figure 1, caregivers rated scores for some kinds of actual support like skills for rehabilitation from members of the medical team and information from mental health counselors or governmental offices etc. received. Study suggested that a considerable portion of caregivers spending little or no time socializing with friends and that lower perceptions of social support are associated with feeling. The child or the family's economy needs are far beyond the welfare financial support.

Respondents recalled the days when they knew the illness of children and described their feeling by many negative words such as "worry, fear, rage, self-accusation, sin" and hence. A feeling of utter helplessness washed over every family member. Comparing with emotional burden among them in the early days of diagnosis, caregivers felt more peaceful at present (see Figure 2).

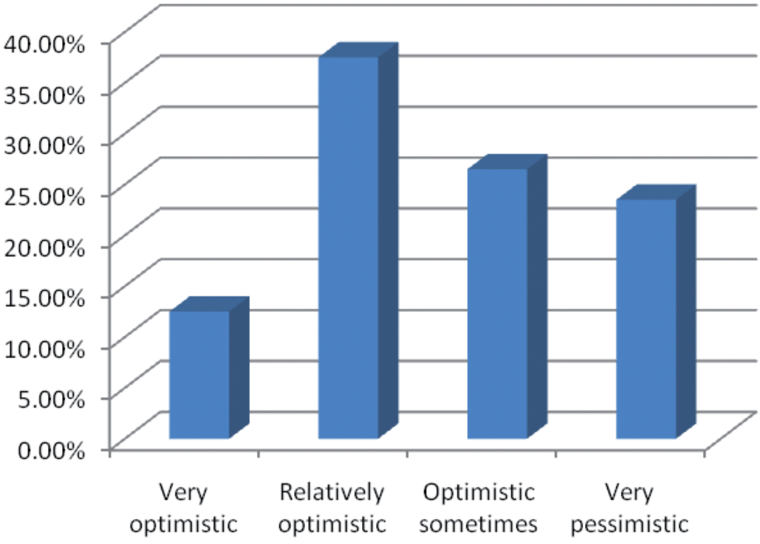

**Figure 2:** Primary caregivers' mentation

During the time of parenting the child with CP, some families at present are characterized by close relationship and mutual support, but without any self-help organization for caregivers or parents. The research demonstrated that both the degree of altruism and tolerance toward difference increased, they tend to offer more help than before. For the very pessimistic caregiver, a sense of fatigue for a long time and deteriorating economic status washed them over because of the child's illness.

## Discussion

This finding did not reach specific statistical significance in regional difference of family. This may be partly due to the fact of the limitation of a small sample. While previous studies have examined family variables as they relate to coping in the individual with the illness, whereas this study assesses coping in the family. It's necessary because economic status here may differ from there, one hypothesis of which is associated with social support from local governments. Another possibility is that the physical and emotional impact of their own disease makes it difficult for caregivers to obtain appropriate support services for their child. Follow-up research is needed to compare economic status of families from different districts. Further studies should also be needed for the impact of parents' unemployment and economic stress on social support.

Families who use passive coping may feel helpless regarding to their ability. Those families may relinquish control of decisions about the child's disease to others, such as the medical team, rather than worry about these problems themselves. This may be helpful in some situations, but could potentially lead to problems if caregivers are not independent.

Active coping strategies positively impact the child's medical status and the family. Items about passive coping styles in questionnaire reflect an avoidance of problem situations or the tendency to relinquish control of one's problems to others.

We failed to find significant relationships between characteristics of the maternal caregiver and family coping styles. However, many studies have put forth evidence that family composition (two-parent families versus single-parent families) is related to coping styles. Moreover, past research with healthy families has found that single mothers use more strategies related to accepting responsibility compared with mothers in two-parent families (Compas & Williams, 1990).

The external support most frequently endorsed by families in our study included actual and spiritual support. Means of actual support mainly relates to medical skill, information and financial way, spiritual support is associated with time and emotion. The spiritual dimension is important for families' quality of life and its implications for caring practice. The data indicated that caregivers tended to seek out help from the extended family or friends for spiritual support. Comparing with developed countries, social welfare policy needs to be advanced for servicing children with special needs and their families in parts of China. The finding demonstrated that families of children with CP or primary caregivers tended to seek out less support from community resources than extended families. The support resources should be enlarged including community support. To make full use of community resource, promoting community involvement aimed at respecting and supporting the family of children with CP. Moreover, exploratory analyses revealed the necessity to advocate lifelong family rehabilitation for children with CP.

Given that social support can be a valuable resource in maintaining the emotional health of families dealing with chronic illness (Neville, 1998), it is concerning that families of children with CP are not relying on social resources more often. While this is certainly a valid concern, the absence of external support could negatively affect psychological and physical well-being. Thus, there is a need for interventions aimed at helping caregivers effectively seek out and utilize supportive social relationships. In addition, it's important in the long run to improve the ability for the family taking an active role in overseeing their child's development.

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