

Knowledge, Attitude, and Behavior among Parents with Cerebral Palsy Children Visiting Dr. Hasan Sadikin General Hospital Bandung

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Abstract

Background: Cerebral palsy (CP) as a non-progressive syndrome of motor function and posture disturbance is caused by the abnormality or damage on the brain during its development. Children with CP usually have motor, sensory, communication, and intellectual disturbances. Medical rehabilitation is important; however, the environmental aspect is also crucial for their development. Parents as their caregivers may have good knowledge to assist their children during rehabilitation. This study aimed to explore the knowledge, attitude, and behavior among parents with CP children.

Methods: This study was descriptive quantitative study and conducted at the Physical Medicine and Rehabilitation Clinic of Dr. Hasan Sadikin General Hospital Bandung during September to October 2014. Parents of CP children were asked to complete a questionnaire that was specifically designed for this study after their consent was obtained.

Results: From a total of 31 parents, 51.6% had good knowledge about CP; 58.1% had good attitude toward CP children, and 51.6% had good behavior while taking care of their children.

Conclusions: The majority of parents with CP children have good knowledge, attitude, and behavior towards CP children. The knowledge of risk factors of cerebral palsy are poor, therefore, it is necessary for doctors and therapists to provide more education sessions on the risk factors and other related topics about cerebral palsy.

Keywords: Attitude, behavior, cerebral palsy, knowledge, parents

Introduction

Children with cerebral palsy (CP) have many disabilities and abnormalities that restrict their daily activities and development. Brain damage during its development is irreversible.¹ Management for CP mainly focuses on medical rehabilitation to manage their disabilities and to increase the quality of life.^{2,3} Social and environmental factors are also crucial for maintaining optimal development.^{2,3} Children with CP demand more intense care from their parents compared to normal children at their age.⁴⁻⁶ Therefore, family especially parents as their caregiver plays a crucial role in CP development milestone.^{2,3} Moreover, socioeconomic condition, marital conflicts, and other parental responsibilities give additional

burden to parents.⁶⁻⁸ Knowledge of the parents about CP may worsen these conditions.^{3,7} Poor knowledge will impact the attitude of the parents and their daily behavior, leading to failure in their children's development. Good knowledge develops a supportive and cooperative attitude, resulting in proper daily behavior and indirectly supporting the development of their children.^{3,7,9} The aim of this study was to explore the knowledge, attitude, and behavior among parents with CP children.

Methods

This study was a descriptive quantitative study, conducted from September to October 2014 at the Physical Medicine and Rehabilitation

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Table 1 Characteristics of Parents with Cerebral Palsy Children Visiting Dr. Hasan Sadikin General Hospital Bandung

Variables	Frequency (n=31)	Percentage (%)
Role in family		
Father	10	32.26
Mother	21	67.74
Age group (years)		
20–29	13	41.94
30–39	14	45.16
>40	4	12.90
Occupation		
Civil employee	1	3.23
Private employee	4	12.90
Entrepreneur	3	9.68
Farmer	5	16.13
Housewife	18	58.06
Education		
Elementary school	7	22.58
Junior high school	9	29.03
Senior high school	15	48.39
Parental status		
Parent with spouse	30	96.77
Single parent	1	3.23
Number of children in family		
1	14	45.16
2	13	41.94
3	2	6.45
>4	2	6.45
Child's age		
<1 year old	4	12.90
1–5 years old	18	58.07
5–12 years old	6	19.35
>12 years old	3	9.68
Patient type		
Control/Routine Therapy	30	96.77
Loss to Follow Up	1	3.23
Income (each month)		
< Rp1,000,000.00	11	35.48
Rp1,000,000.00–Rp5,000,000.00	15	48.39
Rp5,000,000.00–Rp10,000,000.00	5	16.13

Table 2 Knowledge, Attitude, and Behavior of Parents with Cerebral Palsy Children Visiting Dr. Hasan Sadikin General Hospital Bandung

Variables	Frequency (n=31)	Percentage (%)
Knowledge		
Good	16	51.61
Poor	15	48.39
Attitude		
Good	18	58.06
Poor	13	41.94
Behavior		
Good	16	51.61
Poor	15	48.39

Clinic in Dr. Hasan Sadikin General Hospital Bandung. This study was conducted after being approved by the Ethical Committee of Dr. Hasan Sadikin General Hospital.

The study subjects were parents with CP children. On descriptive sample calculation, the minimum subjects for this study were 30 and eligible parents were asked to participate using a consecutive sampling method.

Self-designed questionnaires were distributed, consisted of 12 questions for knowledge, 8 for attitude, and 9 for behavior. Other variables including a role in the family, age of parents, occupation, education, parental status, number of children in the family, age of CP children, and monthly income were collected. Each answer to the question had its score. The total individual score was then counted for the average value. Parents with individual same or more than the average value for knowledge, attitude, and behavior were categorized as "good", whereas parents with an individual score less than average value were categorized as "poor" group.

Results

In total, thirty-one parents were included in this study, and the characteristics of those parents were shown in Table 1. The age of subjects was in the range of 21–50 years old, with an average of 32.52 years old with most of them was in the age group 30–39 years old. The majority (48.39%) had finished their senior high school education. Most of these parents (45.16%) only had one child, the one with CP, aged predominantly between 1–5 years old, and they came to the hospital with

their CP children for routine therapy.

Most of the subjects (48.39%) had income Rp1,000,000.00 to Rp5,000,000.00 each month, however, all of these parents had used National Health Insurance (*Badan Penyelenggara Jaminan Sosial Kesehatan*, BPJS) for the therapy of their CP children.

The questionnaire result revealed an average score for knowledge was 8.42, for attitude was 25.7, and for behavior was 28.03. More than half (51.61%) of the parents had good knowledge, good attitude (58.06%), and good behavior (51.61%).

Most subjects gave the right answer about knowledge; such as they knew the cause of cerebral palsy, however, only a few knew the term of their children's condition. Most of the subjects did not know the risk factors of CP. Most of them realized the importance of frequent and long term rehabilitation, but only a few understood the goal of the rehabilitation programs for their children. They believed that medical rehabilitation might cure their children of CP. They did not understand the goal of rehabilitation is to maximize their children's daily function, but they realized that their children need special care, more than other children.

As for attitude, 58.06% of parents showed good attitude toward CP children. From the interview, they stated that their children's condition had added financial burden and reduced their time. The parents came to the rehabilitation doctor at least once for consultation monthly. The majority of fathers tended to have lower knowledge, attitude, and behavior score compared to mothers, although no statistical analysis had been

performed. Subjects from the age group 20-29 years old had the highest knowledge level as well as for attitude and behavior. As for the education level, higher education showed better knowledge, attitude, and behavior.

Discussions

Parents with CP children play a significant role in taking care of their CP children as these children demand more intense care. Good knowledge, attitude, and behavior may give these parents an aid to handle their situation. Our study has shown that the majority of the parents, especially the mothers are housewives, similar to other studies in India¹⁰ and Africa.¹¹ Majority of mothers have had worked previously, but they quit their job because of their children's condition.^{10,11}

Knowledge levels of all parents were good, however, few subjects know the terminology for their children's condition. The parents often misuse the disease terminology or name of the disease as CP, instead, the parents use part of the symptoms to explain the disease, including the children 'can't walk', are 'failure to thrive', or have 'seizure'. This result is similar to a study in India; that only 45.3% of parents know that 'Cerebral Palsy' as the name of the disease.¹²

The parents in our study also have low knowledge about the risk factors of CP. This may be due to a lack of information about the related topics from medical officers such as doctors, nurses, or therapists, as also reported in various studies.^{12,13} Same as the importance of medical rehabilitation for CP children, only a few understand the goal of rehabilitation. Therefore, the information about rehabilitation therapy to parents is important. An educational film could be given to the parents to increase the level of knowledge. This increases knowledge of the parents at all educational level.¹²

Most of the parents mention that the CP child gives a financial burden and a decrease in personal time. The CP children are included in the BPJS program, yet, for each visit to Dr. Hasan Sadikin General Hospital Bandung, extra cost for such as transport expense, meal, and others is needed. There is also no pattern of increasing knowledge based on the level of income. This result was supported by another study, that stated socioeconomic status does not have an impact to increase knowledge about CP in parents.¹²

Interestingly, the duration time at home or with their children also give a big impact

on knowledge, attitude, and behavior level of the parents.⁸ For example; fathers tend to have lower knowledge, attitude, and behavior level than mothers. Mothers were the main caregivers and spend more time with their children than the father.^{5,6,8} Similar to the type of job; outside the house jobs, such as civil employees and farmers spend more time outside the house and thus may have additional burden leading to decrease attention to their children.⁶⁻⁸ Importantly, being a single parent, it seems that the knowledge, attitude, and behavior scores were below the average. Chronically ill children have its pressure, leading an increase of stress level and eventually, decrease of attitude and behavior.¹⁴

Parents with CP children aged 12 years or older has a low attitude and behavior score. This may due to longer exposure to CP children, including all of their disabilities, financial problems, and all other consequences. This situation leads to increased stress and indirectly impacts parents' attitude and behavior.⁶⁻⁸ When the CP children growing older, parents will face more difficult.¹⁵ This includes worsening of physical problems, more difficult to maintain social relationship with the community, negative impacts on parents' job, and more financial problems.¹⁵

The limitation of this study is that questionnaire used is self-designed and not validated yet. There is also no standard yet for the good and poor level of knowledge, attitude, and behavior as we use this average score. Furthermore, we did not compare the level of knowledge, attitude, and behavior with various variables. Further study to explore these parameters is needed to assess the knowledge, attitude, and behavior among parents with CP children to increase the quality of life of both parents and children.

To conclude, even though the majority of parents with CP children in this study have good knowledge, attitude, and behavior, it is important to educate the parents as the main caregiver of Cerebral Palsy children as well as the community about the risk factors and other related topics about CP.

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