

# Need Assessment of Parents of Children with Cerebral Palsy Observed from Family Counselling

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Caring for a child with cerebral palsy can impact the quality of life of the parent. Raising a child with cerebral palsy is stressful for the parent because it requires intensive physical engagement, such as family counselling. Raising a child who has cerebral palsy creates fresh challenges for the whole family. Family counselling is a disability waiver service that includes counselling for the person and family members who serve as unpaid caregivers as identified in the individual plan of care. This study aimed to determine the needs of parents who have cerebral palsy children. The object of this research is 13 parents who have cerebral palsy children in Padang. A qualitative study was conducted utilising a grounded theory framework, with data collection through literature study, observation, and also using a questionnaire. The analysis tool used is explanatory research.

**Keywords:** *Need assessment, parents, family counselling*

## Introduction

Parents are responsible as the primary educators for the development of their children who experience cerebral palsy even though the presence of a child with cerebral palsy in the family is not something that is expected (Mumpuniarti, Sukinah, & Pujaningsih, 2017; Winarsih et al., 2013). Sometimes parents experience hopelessness in caring for children with cerebral palsy. Some parents feel shocked and cannot accept the fact that their child has a disability. Generally, they show a higher level of stress and worse mental health when compared to parents of children without developmental disabilities and the general population (Byrne, Hurley, Daly, & Cunningham, 2010; Barfoot et al., 2017).

A negative attitude towards disability from family not only impacts a child directly but also adds to the existing stress levels of a family. It can be concluded that the parental attitudes are assumed to be associated with the psychosocial development of children (Al-Dababneh & Al-Zboon, 2018; Terwiel et al., 2017). Parents of children with cerebral palsy experience

increased stress (Parkes et al., 2011), anxious and depressive symptoms (Lach et al., 2009) as well as increased burden of care (Sawyer et al., 2011), and an adaptive grieving process termed chronic sorrow (Ghoreyshyzadeh et al., 2017; Whittingham et al., 2013). The links between parental adjustment and child psychological health are well understood (Newland, 2015). Therefore, it is necessary to analyse the needs of parents who have cerebral palsy children.

Needs analysis is a constructive and positive tool for making changes. Needs analysis is the process of gathering information about gaps and determining priorities of these gaps to be resolved (Ghoreyshyzadeh et al., 2017; Myrhaug et al., 2016; Coyne et al., 2011; Wang et al., 2017). With this needs analysis, it is expected that parents who have cerebral palsy children can educate and develop cerebral palsy children to live independently and to be ready to get along in the community.

One way that can be done in the analysis of the needs of parents who have cerebral palsy children is by family counselling (Nurhastuti, Kasiyati, & Mega Iswari, 2019; Nurhastuti & Fatmawati, 2018). To understand how the needs of parents who have cerebral palsy children, it is important to use family counselling that is appropriate to the cultural background and socioeconomic level of the family. One of the goals of family counselling is to develop a tolerance for family members who are experiencing problems in life caused by the family itself or outside the family (Putri & Syukur, 2019; Rahayu, 2017).

Family counselling can be efficient when used in treating and improving there lotions' between parents and children struggling with a variety of issues. This modality is a complex form of counselling that often emphasises focus on communication between the therapist and members of the family, as well as between family members themselves. Many variables can compromise such communication. For example, when a family is too rigid, a negative feedback loop of unhealthy interactional patterns may exist. (Marchionda & Slesnick, 2013).

The starting point is always preparation. To prepare for the use of techniques to build healthy counselling and family communication patterns, there are structural pieces that are helpful to have in place. The first is to have clarity about and with the family as to the goals and expectations. The family has counselling as they pertain to the family as a whole as well as to each member. It is vital to have these ideas in mind and to clarify the possibilities, limitations, and structures necessary to achieve the family's desired outcome (McAdams et al., 2015; Ohlson, 1974).

## Methods

This research is qualitative analytical research because this research seeks to explain the needs of parents who have cerebral palsy children. At a higher level of abstraction, qualitative analytic research is concerned with why phenomena occur and the forces and influences that drive their occurrence. This research was conducted in the city of Padang with a sample of 13 parents who had cerebral palsy children. After doing family counselling for 13 parents who have cerebral palsy children, the questionnaire was spread to determine the needs of parents in carrying out education and guidance for their children with cerebral palsy. The questionnaire contained 114 questions concerning the needs of parents who have cerebral palsy children.

## Results and Discussion

### Results

This study has three measurement indicators, namely acceptance of parents who have cerebral palsy children, factors that influence parents in accepting children who have cerebral palsy, and problems and obstacles faced by parents in dealing with children who have cerebral palsy. The three indicators are described in the results of the study as follows.

#### *Acceptance of parents who have cerebral palsy children*

Research questions about the acceptance of parents who have cerebral palsy children consist of several aspects, namely respecting children as a whole, understanding children uniquely, recognising the needs of children and loving children who are independent, and loving children without conditions. The results of the distribution of questionnaires about the acceptance of parents who have cerebral palsy children can be seen in the table below.

**Table 1. Recapitulation of Respondents' Answers on Parental Acceptance**

Indicator	Alternative Answers				Score
	Always	Often	Sometimes	Never	
Acceptance of Parents (Statement Items 1 - 35)	218 47.9%	146 32.1%	63 13.8%	28 6.2%	455 100.0%

Table 1 explained that in general that 47.9% of respondents have perfect acceptance of their children with cerebral palsy, 32.1% of respondents have good acceptance of their children with cerebral palsy. 13.8% of respondents have good enough acceptance of their cerebral children palsy, and 6.2% of respondents have poor acceptance of their children with cerebral palsy.

***Factors that influence parents in accepting children who have cerebral palsy***

Research questions about the factors that influence parents in accepting their children with cerebral palsy consist of several aspects, namely knowledge about cerebral palsy, knowledge about mentoring at home, and access to children's self-development information. The results of the distribution of questionnaires about the factors that influence parents in accepting children with cerebral palsy can be seen in the table below.

**Table 2. Recapitulation of Respondents' Answers on Factors Affecting Parents**

Indicator	Alternative Answers				Score
	Always	Often	Sometimes	Never	
Factors Affecting Parents (Item 36 – 61)	167 49.4%	108 32.0%	53 15.7%	10 3.0%	338 100.0%

Based on Table 2, it can be seen that in general, 49.4% of respondents understand the factors that influence parents in accepting their children with cerebral palsy, 32.0% of respondents understand the factors that influence parents in accepting children who have cerebral palsy, 15.7% of respondents are less understanding of the factors that influence parents in accepting children with cerebral palsy, and 3.09% of respondents do not understand the factors that influence parents in accepting children who have cerebral palsy.

***Problems and obstacles faced by parents in dealing with children who have cerebral palsy***

Research questions about problems and obstacles faced by parents in dealing with children with cerebral palsy consist of several aspects, namely internal and external. The results of the distribution of questionnaires about the problems and obstacles faced by parents in dealing with children with cerebral palsy can be seen in the table below.

**Table 3. Recapitulation of Respondents' Answers on Problems and Constraints Faced by Parents**

Indicator	Alternative Answers				Score
	Always	Often	Sometimes	Never	
Problems and Constraints Faced by Parents (Item 62 – 114)	265 38.5%	232 33.7%	108 15.7%	84 12.2%	689 100.0%

Based on Table 3 it can be seen that in general that 38.5% of respondents are very capable of understanding the problems and obstacles in dealing with their children with cerebral palsy, 33.7% of respondents can understand the problems and obstacles in dealing with their children who are cerebral palsy, 15.7% of respondents are less able to understand the problems and obstacles in dealing with children who have cerebral palsy and 12.2% of respondents are unable to understand the problems and obstacles in dealing with children who have cerebral palsy.

## **Discussion**

### ***Acceptance of parents who have cerebral palsy children***

The results showed that the majority of respondents were able to accept the existence of their children with cerebral palsy. However, some parents are less able to accept their children with cerebral palsy, especially about communication with children with cerebral palsy, lack of knowledge of the needs of children with cerebral palsy, and a lack of understanding of the feelings and expressions of children with cerebral palsy.

Based on these results, it is clear that the difficulty of parents in accepting children with cerebral palsy is related to communication, so this makes it difficult for parents to understand and accept the feelings felt by children with cerebral palsy. Therefore, related to these problems, parents need to communicate with cerebral palsy children.

Almasri et al. (2011) identify three subtypes of parental needs. The first subtype identified is based on requirements related to the child's health condition. This type of need includes information about the diagnosis, specifically cerebral palsy, and the state of development. A further component of this need consists of the necessity to explain to others their child's condition. The second subtype consists of needs related to family functioning, such as formal and informal support. The last subtype classifies consistent needs related to socialisation, community, and financial resources. Mikkelsen & Frederiksen (2011) found collaboration between family and provider consists of shared responsibility, parent autonomy and control, and negotiation and family support. These concepts are essential in acute care settings and have many ramifications. For instance, if a parent or parents try to obtain a more active role, power and control conflicts may arise. Such a dispute either tends to label the nursing staff "gate-keepers" or label parents as difficult.

### ***Factors that influence parents in accepting children who have cerebral palsy***

Cerebral Palsy children are at risk of disrupting growth and development in childhood, adolescence, and adulthood. Every child with special needs or not will continue to develop optimally according to their genetic potential. Under these conditions, parents must meet the basic rights and needs of children. Cerebral palsy children are not much different from most children. They can be creative, show creativity, and be productive (Wright et al., 2018). The diagnosis of cerebral palsy not only affects the child who has the disability but has ramifications for their family, friends, and others within their sphere of influence. Some factors influence parents in accepting children with cerebral palsy. Based on the results of the study, note that most parents understand the factors that influence him/her in accepting his/her child who has cerebral palsy. However, there are factors where parents do not understand the factors that influence themselves in accepting their children with cerebral

palsy, which are related to education and experience, the child expectancy factor, and socioeconomic and environmental factors.

The U.S. Department of Health and Human Services, Health Resources and Services Administration, (Lu, 2014) reports several support needs to be asked for by families of children with special health care requirements. 6.7% of parents said they needed respite care, 12% reported a need for family counselling to help deal with stresses involved in having a child with special health care needs, and 7.2% reported at least one unmet support service need. The goal of the following literature review is to look at current literature, research studies, and the latest understanding of how a diagnosis affects a family and point out evidence of the need for a family advocate and counsellor, trained in meeting the mental health needs of the patient and his or her family, who can walk with the family on their journey through diagnosis, treatment, and therapy.

Family counselling that incorporates mindfulness (nonjudgmental psychological contact with present-moment experience), experiential acceptance (psychological contact with emotions, cognitions, and memories), and valued action (engagement in meaningful, values-driven activities), to enhance psychological flexibility (Coyne et al., 2011). Parenting style predicts the child's quality of life in children with CP and there is vast literature demonstrating links between family and child well-being. Further, it reinforces the family-centred care philosophy, in describing the impact of a family intervention on a child's quality of life (Newland, 2015).

### ***Problems and obstacles faced by parents in dealing with children who have cerebral palsy***

The results of research on problems and obstacles faced by parents in dealing with children who have cerebral palsy show that most can understand the problems and obstacles in dealing with children who have cerebral palsy. However, there are several items of statement of problems faced by parents in dealing with children with cerebral palsy, namely the physical, psychological, emotional, social relations, communication, and learning aspects; aspects of providing motivation and ideals life; and elements of the type of opportunity for work or career placement.

Some literature studies revealed in Dillon-Wallace et al. (2016) say that cerebral palsy, as well as other chronic conditions, tends to cause various psychological effects. It includes feelings of guilt and a sense of responsibility experienced by parents for their child's health, feeling depressed and helpless, as well as excessive anxiety and being too protective. Siblings of cerebral palsy children also sometimes show hatred and even risk showing behavioural problems, low self-esteem, shame, committing a crime, and low levels of education. (Empati et al., 2018) The explanation indicates that in addition to the psychological effects experienced by parents of children who have cerebral palsy, psychological effects are also

experienced by siblings and are a source of family stress. The situation certainly requires the ability of parents with children with cerebral palsy to make psychological adjustments.

Darrah et al. (2012) review three crucial concepts that are vital when discussing rehabilitation services for children with cerebral palsy. The first concept places emphasis on family-centred care and services. The second concept emphasises therapy goals that focus on a child's success in completing functional activities that are meaningful to the child and the family. The final concept centres on cerebral palsy existing throughout the lifespan and the importance of the transitions that exist as the child grows. While the second and third concepts can stand alone, the literature suggests such services originate from family-centred care (Ghoreyshyadeh et al., 2017).

Wilkinson & Hanna (2018) studied the implementation of family-centred care in practice. The study consisted of interviews from managers of rehabilitation facilities, therapists, and families. Managers have individually been interviewed regarding their facilities' mission statement in regards to FCC and parents representation on advisory boards. Darrah et al. (2012) found that 55.3% of facilities studied had an advisory board, and less than half of those had parental participation. 68.4% of the mission statements included a reference to family-centred services.

## **Conclusion**

There are several aspects of the needs of people who have cerebral palsy children. Judging from the indicators of acceptance of parents who have cerebral palsy children, it shows that some parents are less able to accept their children with cerebral palsy. Especially in communication with children with cerebral palsy, less understanding of the needs of children with cerebral palsy, and lack of understanding of the feelings and expressions of cerebral palsy children.

Judging by the indicators of factors that influence parents in accepting their children who have cerebral palsy shows that there are factors where parents in accepting their children who have cerebral palsy that is related to education and experience factors, the child expectancy factor, and socioeconomic and environmental factors. As for the indicators of problems and obstacles faced by parents in dealing with children who have cerebral palsy, it shows that there are several items of statement of problems and obstacles of parents in dealing with children with cerebral palsy; namely physical, psychological, emotional, social relations, communication, and learning aspects; aspects of providing motivation and ideal life; and elements of the type of opportunity and work/career placement.

Based on these explanations, it is clear that the fulfillment of parents who have cerebral palsy children is important for every parent. Therefore, family counselling has a positive role in this



problem. Through family counselling it can be seen that some of the needs of parents who have cerebral palsy children are related to the acceptance of parents who have cerebral palsy children.

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