

The Journey Full of Emotions: Parents' Experiences in Raising Children with Cerebral Palsy

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Abstract: Raising a child with cerebral palsy (CP) is a formidable challenge for parents that can lead to tension and reality denial. This qualitative study aims to explore the parenting experience and the acceptance process of parents towards children with CP. This study used a qualitative design with semi-structured in-depth interviews. Three mothers and two fathers of children with CP were involved as interviewees. Data analysis was carried out using deductive thematic analysis technique. Common themes such as post-diagnosis denial; a long and emotional acceptance process; spouse's involvement in parenting; spiritual implication; the need for community support, are experienced by parents. Parental acceptance towards a child with CP is a long, complex, and emotional process. In conclusion, families that are able to achieve acceptance more easily adapting to family changes and dealing with stress. The findings of this study became an important milestone for the development of studies in the fields of family, disability, and social work.

Keywords: cerebral palsy; parental acceptance; family changes; community support.

INTRODUCTION

Cerebral palsy (CP) is one of the most common types of nervous system disorders occurring before or after birth and within childhood. These disorders can cause permanent disturbances in the development of movement and posture, cause limitations in activities and are often associated with non-progressive fetal or infant brain development disorders (Bulekbayeva et al., 2017; Oskoui et al., 2013; Kyeremateng et al., 2019). Motor impairment of CP is often accompanied by disturbances of sensation, cognition, communication, perception, and behavior (Hunt & Marshall, 1994; Rudebeck, 2020; Putri et al., 2021).

The prevalence of children with CP, which continues to increase from year to year, demands attention and must be addressed properly by all elements of society (Sellier et al., 2016; Kyeremateng et al., 2019). The estimated global prevalence of CP cases is 2-3 children for every 1000 live births (Braun et al., 2015; Oskoui et al., 2013; Kyeremateng et al., 2019). The results of the National Socio-Economic Survey (Susenas) conducted by Central Bureau of Statistics Republic of Indonesia indicate average percentage increase in the number of persons with disabilities (including CP) in Indonesia, which is around 1.42% annually (BPS RI, 2018). This large number of cases is certainly followed by difficulties experienced by families taking care of children with CP.

Cerebral palsy raises a multi-faceted impact throughout a child's life. Not only for the children, various complex impacts are also experienced by parents as caregivers (Majnemer et al., 2012; Kyeremateng et al., 2019). Parents who have and raise children with CP also experience severe psychological stress, including: post-traumatic stress disorder, anxiety, depression, feelings of loss and profound grief (Whittingham et al., 2013; Fernández-Alcántara et al., 2015). All of these may interfere parents' mental health, quality of life, and psychosocial well-being (Cheshire et al., 2010; Elangkovan & Shorey, 2020).

The experience taking care of a child with CP, in some ways, can be swayed by prevailing expectations or norms in society and culture. Giving birth to children with CP is still considered taboo, shameful, and perceived as God's punishment or negative karma for

their parents. Consequently, families who have children with CP often get rejection and stigmatization from society (Elangkovan & Shorey, 2020). These negative cultural norms and perspectives still occur, especially in Asia (Mohamed Madi et al., 2019). This rejection from the society also makes it difficult for parents and families to accept reality and adjust themselves to their children limitations (Paul & Nadkarni, 2017; Nurhastuti et al., 2019).

Parent's acceptance is an important thing that is needed in raising children with CP. If parents are able to fully accept their child's condition, negative emotions that are difficult to manage will be tolerated over time (McCracken & Eccleston, 2003; Nakamura & Orth, 2005). Conceptually, psychological acceptance is always associated with situations that are full of difficulties or experiences that are difficult to accept naturally (Herbert et al., 2008). Therefore, psychological acceptance theory is applied as a frame of reference in this study. Herbert (2014) defines psychological acceptance as a process that does not only involve focusing attention but is also shown by the individual's ability to embrace all available subjective experiences, without judgment or defense.

So far, there have been many quantitative studies that have found that the acceptance of parents and siblings has a positive impact on the socio-emotional development of children with disabilities (Freeborn & Knafl, 2013; Dickinson, 2021; Soemarna et al., 2023). However, in-depth findings are required to comprehensively understand the parents' experiences in raising and accepting their children disabilities. This qualitative study was conducted to explore more deeply the parenting experience and the acceptance process of parents who raise children with CP in Indonesia. The results of this study are very much needed as a reference in constructing rehabilitation programs for children with CP and family-based psychological well-being enhancement in Indonesia.

METHOD

This study employed a qualitative research design with semi-structured in-depth interviews. This study involved three mothers and two fathers of children with CP aged between 9-11 years who were living in Semarang City, Central Java, Indonesia and joined in the community of parents of children with disabilities. The participants were obtained by purposive sampling technique. Inclusion criteria: parents (father/mother); have children with CP living with them; and children's ages ranged from 5-12 years. Exclusion criteria: children with CP do not live with their parents (institutionalization). This study was approved and declared ethically feasible by the Health Research Ethics Commission of the Faculty of Nursing, Universitas Airlangga (Ethical Approval with number: 2811 – KEPK). Resource persons stated their willingness to be involved in this study through informed consent.

The interviews were conducted referring to the interview guide focusing on the parenting experience and parents' acceptance from the perspective of *psychological acceptance* theory (Herbert et al., 2008; Herbert, 2014). The questions asked to parents such as: (1) How are the experiences of caring for and raising children with CP; (2) How did the parents respond after their child was diagnosed with CP?; (3) How does the family process to deal with life changes and accepting the child's condition? Data collection was carried out once with an average interview duration of 90 minutes for each interviewee. The data analysis technique used deductive thematic analysis.

RESULT AND DISCUSSION

Result

All of three mothers were primary caregivers of children with CP. Two of them have husbands and the other one is single mother. The socio demographic profile of the participants is explained in table 1.

Table 1. Socio Demographic Profile

Participants	Age	Occupation	Children's age	Type of CP
Mother 1	38	Housewife	10	Quadriplegic
Mother 2	35	Housewife	11	Hemiplegic
Mother 3	50	Housewife	9	Quadriplegic-Athetosis
Father 1	41	Freelancer	11	Hemiplegic
Father 2	50	Craftsman	9	Quadriplegic-Athetosis

General themes such as post-diagnosis denial; a long and emotional acceptance process; spouse's involvement in parenting; spiritual implication; the need for community support, are experienced by parents. In addition to the five general themes, this study also found 11 specific themes that were very noteworthy. The summary of themes is explained in table 2.

Post-diagnosis denial

Limited understanding of children's needs

Most of parents experience confusion dealing with the diagnosis. Limited knowledge makes it difficult for them to understand the children special needs. A mother explained, *"This child is a bit difficult to raise. When she is calm, then everything feels easy, but when she is fussy then everything feels very heavy. It's hard to understand what she wants"*.

Stigmatization makes it difficult for parents to accept their children's limitations

One thing that makes it difficult for parents to accept children is negative judgment and treatment from neighbors or the community. This condition makes parents worse off and rejects reality. A mother explained: *"Many neighbors said bad things, as if this was all a very embarrassing thing. Over time, I decided that I had to be strong for my child."* A father also stated, *"We received a lot of bad words from neighbors; they were never in our position"*.

Feelings of despair

The high cost of caring for children with CP and unwealthy prognosis make the majority of parents feel hopeless. A mother explained: *"Our first child was normal, but our second child was born like this. The care needs are enormous. Why our child doesn't seem to be improving. I felt hopeless and wanted to give up on raising the child"*.

A long and emotional acceptance process

Reality denial

Most of parents experience a phase of rejection at the beginning of their role. The refusal appears in statements such as: *"Why am I going through all this? Why not someone else? What did I do wrong?"* In addition, the majority of parents also experience disappointment because their children have developmental disorders.

Profound grief

The initial feeling of rejection is due to the deep feelings of sadness that parents feel. The sadness arises because parents have lost their ideal child. Some of parents explained, *"I often cried when I prayed at night, thinking about what would happen when this child grows up"*.

Emotional fluctuations and exhaustion

Parental stress experienced by most of parents cause psychological tension which eventually appears in the form of emotional exhaustion. A mother explained: *“When I feel physically and mentally exhausted, I feel like screaming loudly and running away from this reality even if only for a moment. I need to refresh my mind and feelings. Exhausted and fed up going through this every day”.*

Acceptance from parents and family

A positive attitude in parenting is needed for parents who raise children with CP. This positive attitude can be realized if parents and families are able to accept the reality and limitations of their children. A mother explained: *“The key lies in parents and families acceptance. I used to cry a lot because my neighbors ridiculed me, but now I don't care about those negative judgments anymore. I look for a lot of activities so I won't be lost in sadness. When we were able to accept the condition of our child's limitations, everything felt lighter. I, my husband, and the children often discuss, if we die, it will be his/her brother/sister who will take care of this child. As long as we try, we believe that we can”.*

Feeling not alone

The majority of parents explained that by growing the awareness that they are not alone, this further relieves the psychological pressure they are experiencing. All parents feel the same way. This feeling has a positive impact and supports parents to more easily accept their children's limitations. Some of parents explained: *“In the end I realized that I am not alone,” ... “Many parents have and take care of children with CP, even more severe ones than mine.”*

Gratitude

The feeling of gratitude when the parents see many other parents who are less fortunate than them, strengthens the parents even more. Most of parents explained: *“I feel fortunate as it turns out that there are many children who are worse off than mine”*, A father explained: *“There are also many couples who have not been blessed with children. If I get one like this, I should be grateful that we can still take care of him”.*

Spouse's involvement in parenting

Spouse's support

Support from a spouse is very important and has a positive impact on the mental health of parents as caregivers for children with CP. A mother explained: *“My husband has always been supportive, he is calmer than me. He understands that a mother may be a lot more occupied, so he never burdens me.”*

Shared parenting

Parents who take care of their children together are perceived more positively than if only one parent plays a nurturing role. A mother explained: *“I'm pleased if my spouse is willing to help take care of the children, even if my portion is still much greater”.*

Spiritual implication

The majority of parents explained that there are some experiences that can only be interpreted spiritually, such as: *“Who do you want to blame? I just believe that this is God's will”*. Some parents also explained: *“Just be grateful and believe that this is my road to heaven by taking care of a child who has a disability for the rest of his life”.*

The need for community support

In addition to the support of spouses and families, the majority of parents also explained that they needed support from the community. Meeting friends who have the same experiences can strengthen parents in overcoming the challenges of parenting a child with CP. A mother explained: “*The existence of community support makes it easier for me to accept and lighten my role as a caregiver. The stress is reduced since I can meet friends who share the same fate*”.

Table 2. Themes Metrics

General Themes	Specific Themes
Post-diagnosis denial	<ul style="list-style-type: none"> a. Limited understanding of children's needs b. Stigmatization makes it difficult for parents to accept their children's limitations c. Feelings of despair
A long and emotional acceptance process	<ul style="list-style-type: none"> a. Reality denial b. Profound grief c. Emotional fluctuations and exhaustion d. Acceptance from parents and family e. Feeling not alone f. Gratitude
Spouse's involvement in parenting	<ul style="list-style-type: none"> a. Spouse's support b. Shared parenting
Spiritual implication	
The need for community support	

Discussion

In general, this study discusses the findings in two phases: *first*, the phase immediately after receiving the diagnosis; and *second*, the phase of parents' adjustment towards life changes. In the first phase, the majority of parents experience confusion dealing with the diagnosis. Limited knowledge makes it difficult for them to understand the children special needs. This phase persists quite long, between three to four years after the diagnosis.

During the early years after the CP diagnosis is being concluded, parents are required to immediately learn to understand their child's limitations. But at the same time, they also have to struggle to face negative judgments and different treatment from neighbors and society. Some cultures, especially in the Asian context, consider having a child with CP is an embarrassment and a karma/punishment from God (Mohamed Madi et al., 2019). The negative stigma like this is actually perceived as an obstacle for parents in taking care of children with disabilities and makes it increasingly difficult for them to accept the reality they are facing (Feaster & Franzen, 2021). According to the findings of a study on the experiences of stigmatization among caregivers in Ghana, stigma is supported and enhanced by prevalent or internalized communal values. Stigma arises not just from the family's outside milieu, but also from inside the family, such as extended family, mothers/fathers in-laws, and relatives. Several variables, including low levels of education, the status of caregivers in the community, and poverty, might intensify stigma (Zuurmond et al., 2020).

Taking care of a child with CP is perceived as a daunting challenge for the majority of parents. Parents realize that children with CP will depend on them in the long term. Many supporting facilities are needed by children, ranging from health facilities, mobility aids, and special education facilities which are quite difficult for parents to achieve. The complexity of these challenges has an impact on physical and mental health disorders. In addition, the impact of financial difficulties is also experienced by parents. The high cost of treatments for children with CP and unwealthy prognosis make the majority of parents feel hopeless. These findings support the results of previous studies examining the psychological

difficulties and challenges in taking care of children with CP (Sunardi, 2017; Earde et al., 2018; Dieleman et al., 2019; Kyeremateng et al., 2019). It is undeniable that many parents try to negate reality and feel very depressed about the conditions they have to face. This is in line with what was submitted by Elangkovan in his systematic review study (Elangkovan & Shorey, 2020).

In the second phase, some parents experience emotional fluctuations on their journey in accepting and in peace with the reality. The feeling of denial arises at the beginning is one or other influenced by the experience of deep sadness or grief that felt by the parents. Parents feel that they have lost the ideal child they had hoped for. This experience is similar to the results of a previous study that identified the development of feelings of loss in fathers and mothers of children diagnosed with infantile CP (Fernández-Alcántara et al., 2015). According to the perspective of Kubler-Ross grief theory, denial from parents marks the start of a series of self-acceptance processes (Kubler-Ross et al., 1972; Upton, 2012). This is also experienced by the majority of parents involved in this study. Parents question the situation and have a hard time accepting this heartbreaking reality.

The process of accepting children by their parents is long and dynamic. The emotional dynamics experienced by parents, among other things, are influenced by the condition of the child's disability, support from a spouse, community support, spiritual implication, and family resources. When the child does not experience too many health problems, parents will be calmer in taking care of the child. Parents' stress in caring for a child with CP might grow if there is a need for additional care that is unpredictable and difficult to manage (Rapisa & Kusumastuti, 2022), particularly if it is tied to the family's financial situation (Cavanagh & Ashman, 1985). Likewise, if the spouse is willing to be involved in parenting, it will further relieve the psychological tension they feel. This finding supports the results of previous studies on the factors that influence parents' acceptance (Gusrianti et al., 2018; Ramanandi et al., 2018).

In addition to the support of spouse and families, the majority of parents also clarify that they need support from the community. Meeting friends who are going through the same matter can strengthen parents. In line with the results of other studies stating that feeling accepted by the environment and feeling that they are not alone is very important to grow faith and self-confidence as a parent. This feeling of assurance also creates closeness with the child and in the end parents can accept the child's condition (Kutsunugi et al., 2021). Parents who get support from all of the family members and society will show loving, supportive, understanding, and non-discriminatory parenting (Paul & Nadkarni, 2017). Moreover, support from the community can improve family well-being (Majid et al., 2018).

The unique finding of this study is the spiritual implication of parents regarding the condition of children with CP. The majority of parents express that there were some experiences that could only be interpreted spiritually, such as the faith that being a parent of a child with CP is God's will. Some mothers convey that being an attendant or caregiver for a disabled child is a road to heaven. This finding is similar to the concept of psychological acceptance which explains that acceptance is an individual's ability to embrace all existing subjective experiences, without judgment or defense (Herbert, 2014). This concept is of course different from the concept of *learned helplessness* that we know so far. Psychological acceptance is indicated by positive behavior to change the situation.

CONCLUSION

The experiences of parenting and raising children with CP is perceived by parents as a life-changing event that causes shock and tension. Along the way, parental acceptance is needed as the main gate to a better adjustment as a functioning family. The process of

accepting a child with CP by parents is a long, emotional, and dynamic process. In the process, parents need support from their spouse, family, community, and cannot be separated from spiritual values. Parents' acceptance in this study is indicated by an attitude of being at peace with reality and positive conduct to change difficulties to be more easily tolerated. Acceptance is one of the stages in which parents adjust to the challenges of parenting disabled children. Self-empowerment is possible if parents are willing to accept their situation. Acceptance as part of the parent's process of adapting to change is closely related to the resources that parents have. Adjustment will be easier to achieve when parents have resources that are proportional to the difficulties they are experiencing. The resources referred include knowledge, finance, support from other family members and the extended family.

LIMITATIONS

As we knew, a small sample size is not a limitation in qualitative research (Smith, 2009) as it enables more attention to the ideographic nature of the accounts with an in-depth inquiry into rich data. Further studies are needed to ensure contributions from other cities. The sample is homogeneous in the sense that it represents a group of parents of children with CP obtaining services from a disabled child community in a semi-urban area. However, it is unknown whether parents who live (or continue to live) in outlying rural areas or those who do not receive any services have a different lived experience. The sample is diagnostically heterogeneous, with three different types of CP represented. The heterogeneity of the sample allowed this study to learn more about the experiences of parents whose voices are rarely heard, allowing for a more complete picture to be captured. The findings also serve as a guide for future research and may lead to an improvement in the well-being of parents. We acknowledge that the precise etiology of the children's CP was unknown, which would have helped contextualize the findings.

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