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FATHER'S INVOLVEMENT IN PARENTING CHILDREN WITH CEREBRAL PALSY

Yubaedi Siron, Hana Sausan Ningrum, Lingga Gustiani, Fauziah Muaz
Universitas Islam Negeri Syarif Hidayatullah Jakarta
Corresponding e-mail: yubaedi.siron@uinjkt.ac.id

Abstract

Cerebral palsy children need special treatment from their parents. The optimal caring from father has a significant influence on the development of children with cerebral palsy. This study aims to explore the role of fathers in caring for children with cerebral palsy. This research uses a qualitative approach. This study uses semi-structured interviews with fathers who have children with cerebral palsy. The results of this study found that fathers play an active role in childcare. Fathers help build good relationships with children by inviting them to play, sing, and read a child's favourite storybook. Even though he is busy at work, the father always tries to fulfil the children's needs such as bathing, eating, giving medication, changing diapers and routine therapy. Each participant in this study had their parenting challenges. Although sometimes the participants feel unwilling to do therapy on children, what makes them enthusiastic is their high expectations.

Keywords : cerebral palsy; paternal involvement; parenting

Abstrak

Anak cerebral palsy perlu pengasuhan yang berbeda dari orang tuanya. Peran ayah dalam pengasuhan anak cerebral palsy yang dilakukan secara optimal mampu memberikan pengaruh yang besar dalam perkembangan anak cerebral palsy. Penelitian ini bertujuan untuk menggali tentang peran ayah dalam mengasuh anak cerebral palsy. Penelitian ini menggunakan pendekatan kualitatif. Peneliti memperoleh informasi dengan menggunakan wawancara semi terstruktur kepada para ayah yang memiliki anak dengan cerebral palsy. Hasil dari penelitian ini didapatkan bahwa ayah berperan aktif dalam pengasuhan anak. Ayah turut membangun hubungan yang baik dengan anak seperti mengajaknya bermain, bernyanyi, serta membacakan sebuah buku cerita favorit anak. Walaupun ditengah kesibukannya dalam bekerja, ayah selalu berusaha membantu memenuhi kebutuhan anak seperti mandi, makan, memberikan obat, mengganti popok dan terapi rutin. Setiap partisipan dalam penelitian ini mempunyai tantangan pengasuhan masing masing. Walaupun terkadang partisipan merasa berat hati untuk melakukan terapi pada anak, namun yang membuat mereka semangat adalah harapan mereka terhadap anak-anaknya yang begitu besar.

Keywords : cerebral palsy; keterlibatan ayah; pengasuhan

Introduction

Children with cerebral palsy are special so they need special treatment from their parents (Eliyanto & Hendriani, 2013). In Indonesia, according to the Basic Health Research conducted by the Ministry of Health of the Republic of Indonesia in 2010, the percentage of children aged 24-59 months with cerebral palsy is 0.09% (WHO, 2013). Parents have an essential role in developing children (Hill & Craft, 2003; Keown & Palmer, 2014; Paul, Hart, Augustin, Clarke, & Pike, 2020). The role of fathers in optimal parenting can significantly influence children's development (Appl, Brown, & Stone, 2008; Crespi & Ruspini, 2015; Frank, Keown, & Sanders, 2014). The active participation of the father, which is carried out continuously from the aspects of time, initiative, and personal empowerment in all aspects of development, is essential for children such as physical, emotional, social, spiritual, moral, and intellectual aspects (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Paul et al., 2020). Parents who have cerebral palsy children have a significant role as child educators. The presence of a child with cerebral palsy is not what parents want. Some parents even experience despair over their presence (Siron, Perdana, Saputri, & Hanifah, 2020). Successful communication in children with cerebral palsy requires parental involvement. Parents' responsibility also determines the successful development of children with cerebral palsy (Anindita & Apsari, 2020; Pradipta & Andajani, 2017; Whittingham, Sanders, McKinlay, & Boyd, 2013; Yuliyati, 2014).

Fathers involved in parenting make children have good social and cognitive abilities; children also have good self-confidence (Parmanti & Purnamasari, 2015). Fathers have a role in creating a peaceful atmosphere and providing opportunities for arguments for children. Fathers have an essential role in allowing children to do something, caring, provide support, and feel safe. Children with fathers who are actively involved in parenting will have good cognitive and social abilities and have a high sense of trust (Aisyah, Riana, & Putri, 2019; Appl et al., 2008; Astuti & Masykur, 2015). Fathers are expected to be actively involved in direct interactions with children (Appl et al., 2008). Involving fathers in childcare from infancy positively affects their development (Crespi & Ruspini, 2015; Frank et al., 2014; Li & Flee, 2015; Siron, 2019). This condition can be seen when a father gives his children love; their child will be close to his father. Besides, the father and son will grow to be more gentle and expressive (Appl et al., 2008; Frank et al., 2014; Putnick et al., 2012).

Fathers can play a role in parenting and participating in children's daily activities (Appl et al., 2008; Erawati, 2009b; Keown & Palmer, 2014). The policies that previously focused on mothers began to provide opportunities and space for father figures to express themselves in the parenting process (Crespi & Ruspini, 2015; Hidayati, Kaloeti, & Karyono, 2011; Keown & Palmer, 2014). According to (Aisyah et al., 2019) (Aisyah et al., 2019), fathers' role in parenting is divided into direct

interaction, interaction with children when needed and responsibilities that are not involved in direct interaction with children. Father involvement is about building positive interactions and paying attention to children's development by providing comfort and closeness (Allen & Daly, 2007). A good relationship with a father indicates understanding and accepting their child's presence (Putnick et al., 2012; Rohner, 2014; Whittingham et al., 2013). The father's involvement also helps build empathy, love each other, and have good social relationships. Fathers also make significant contributions to children's development. The experience that the child experiences with the father will affect a child to adulthood later. The father's role and parenting behaviour affect the child's development and well-being and the transition to adolescence (Cabrera et al., 2000; Frank et al., 2014; Li & Fler, 2015).

The father's involvement is equally essential for the child with cerebral palsy (Siron et al., 2020). Cerebral palsy disorders are characterized by motor neurological disorders in the child's brain. Cerebral palsy disorders usually occur in prenatal, natal and postnatal (Rosenbaum P, Paneth N, Leviton A, 2007). Therefore, people with cerebral palsy need treatment in meeting their daily needs, such as bathing, eating and walking (Septiningsih & Cahyanti, 2014).

According to data held by the World CP Day Committee in Australia, 1 in 3 children with cerebral palsy cannot walk. 1 in 4 children with cerebral palsy cannot speak, 3 out of 4 children with cerebral palsy experience pain, 1 in 4 children with Cerebral Palsy has epilepsy. 1 in 4 children with cerebral palsy have behavioral problems, 1 in 2 children with cerebral palsy have intellectual impairment, 1 in 10 children with cerebral palsy have severe vision problems. 1 in 4 children experience defecation control disorders, and 1 in 5 children have sleep disturbances. Lastly, 1 in 5 children with cerebral palsy has trouble controlling saliva. Children with cerebral palsy are more at risk of having seizures, although the CP Day committee's data states that 1 in 4 children with cerebral palsy has epilepsy (Rovasita, 2017).

In the well-being psychological research in a single father with children with cerebral palsy, it was found that mothers have an essential role in caring for children with special needs, but the role of fathers is also essential (Septiningsih & Cahyanti, 2014). A single father needs to divide his time between earning a living and raising children with special needs. Also explained in the research on fathers' involvement in childcare (Astuti & Masykur, 2015), fathers are expected to work together in carrying out various roles, are accustomed to doing domestic tasks, and not rigid in the division of tasks between husband and wife.

Unfortunately, a father is usually rarely seen taking care of his children because of his busy work, so it is not uncommon for a father figure to look strange. A father's involvement is needed to build a positive relationship between father and son (Diadha, 2015; Erawati, 2009a; Keown & Palmer, 2014), especially for children

with cerebral palsy. Children with cerebral palsy disorders need the father's role to continue to provide support and encouragement to children. Generally, a father who has a child with cerebral palsy initially considers that caring for a child with cerebral palsy is not an easy thing so that sometimes there is internal anxiety (Varan, Rohner, & Eryuksel, 2008; Whittingham et al., 2013).

Given the importance of the father's role in children's care with cerebral palsy, the best practice form of paternity in children with cerebral palsy needs to be explored more deeply. This study aims to provide an overview of how fathers are actively involved in caring for children with cerebral palsy.

Method

This study used a qualitative approach to describe the role of fathers who have children with cerebral palsy. The stages of this research were instrument preparation, resource search, interviews, and data processing. The data collection technique used in this study was to use interviews. This study involved three fathers who have children with cerebral palsy. Participant 1, father 30 years old, three years old child, works as an entrepreneur and domiciled in South Lampung. Participant 2, father 33 years, age 6 years 6 months, work as a private employee and domiciled in Bandar Lampung. Participant 3, father 35 years, age 9 years 11 months, works as a private employee and resides in Cikarang, Bekasi.

Table 1. Research Participant Data

No.	Father	Father's age	Children's Age
1	N1	30 years	3 years
2	N2	33 years	6 years 6 months
3	N3	35 years old	9 years 11 months

The interview instrument is the structured interview and consulted with experts before being used to collect data. Interviews conducted online to explore the experiences of 3 fathers in raising children with cerebral palsy.

Table 2. Interview Guidelines

No.	Question Guide
1	Activities that are usually done by father and son
2	The way the father divides his time between work and upbringing
3	The way the father divides his time between work and upbringing
4	Type of communication carried out by father and son
5	The way the father is actively involved in meeting the daily needs of the child
6	The way dad responds to other people's comments
7	The way the father teaches children with cerebral palsy
8	The way the father calms the child if something happens to the child
9	Challenges that fathers face in parenting children with cerebral palsy
10	Father's way of dealing with challenges

In this study, data analysis used (Miles & Huberman, 1994) by reducing data, verifying data, and displaying data. The data analyze at 3 stages, data reduction, display data, and conclusion (drawing/verifying data). Data reduction in this study focuses on data by the theme and provides codes for each aspect. All data classified according to the focus of the study.

The next stage is data presentation. The presentation of the data in this study intends to find meaning from the data obtained, then arranged systematically, from complex to simple but selective forms of information. Lastly is conclusion and verification. Conclusion in this research described in stages: a) check data representation; b) checking data on the influence of researchers; c) make data comparisons; d) use extreme cases in interpreting negative data. This study code the participant using n1, n2, n3 for initializing father as a participant to display the data.

Results and Discussion

Globally, studies related to father involvement measured several variations, such as paternal involvement, father involvement, and fathering quality. Most studies measure it by breaking down the variable of father involvement into more d

etailed indicators, for example, father support, father rigid control (paternal of disciplining children, paternal firm control), paternal didactic interaction, paternal of social activities, paternal of responsibility, paternal acceptance, child's time directly with father only (an activity with father, time with father), relationship quality, talking with father, the significance of father, father monitoring, father presence, nurturant fathering, dan expressive (Appl et al., 2008; Crespi & Ruspini, 2015; Erawati, 2009b; Filus & Roszak, 2014; Frank et al., 2014; Li & Fleer, 2015; Rohner, 2014).

This study coded the data into several categories that focused on fathers' involvement in parenting cerebral palsy. In the first category discussing the activities that fathers usually do with their children, fathers play an active role in fulfilling their needs, such as eating, bathing, routine medicine, therapy, and playing. (Septiningsih & Cahyanti, 2014) stated that people with cerebral palsy need treatment to fulfil their daily needs, such as bathing, eating, and walking.

Table 3. *Activities that are usually carried out by fathers with children*

Category 1	Code	Quote
Activities that are usually done by father and son	Fulfil daily activities, therapy and stretching (n1)	Eating, bathing, taking medication in routine, therapy play, stretching.
	Playing (n2)	Playing ball, driving car around
	Listening to music, praying and	Listening to music and praying

playing games (n3)	together, and playing games together
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In the second category, it discusses how fathers distribute their time between work and care. The three participants helped the wife's role in helping with domestic activities, bathing, and accompanying children before or after work. As stated by (Astuti & Masykur, 2015), fathers will work together in carrying out various roles, are accustomed to doing domestic tasks, and are not rigid in the distribution of tasks between husband and wife. The synergy between father and mother contributes positively to the child's development (Dyches & Smith, 2017; Jeong & Kim, 2016; Keown & Palmer, 2014; McFarland-Piazza & Saunders, 2012; Moss, 2012).

Table 4. *How fathers divide their time between work and care*

Category 2	Code	Quote
The way the father divides his time between work and care	Helping wife to do domestic activities (n1) (n2) (n3)	Before leaving for work, if the wife is cooking and doing housework, I will help to bath and feed the child, later in the afternoon or at night accompanying the child until he sleeps.
	Helping care in the afternoon after work (n1) (n2) (n3)	
	Accompanying children's play activities (n1) (n2) (n3)	

The third category discusses fathers who attend seminars or organizations related to cerebral palsy. Participant (n1) stated that they have attended a seminar and applied or practised the knowledge gained during the seminar for their children. Fathers can play a role in various circumstances, including parenting and participation in activities. The policy previously focused on mothers began to provide opportunities and space for father figures to express themselves in the parenting process. However, because the father works to fulfil the family needs, some fathers are not actively involved in organizations or seminars (Hidayati et al., 2011). The existence of community and parental training programs will positively contribute to parents' knowledge and ways in implementing child care (Hu, 2010; Lindsay, Proulx, Scott, & Thomson, 2014; McIntyre & Phaneuf, 2017).

Table 5. *Activities of fathers to increase knowledge related to CP*

Category 3	Code	Quote
Father's activities to increase knowledge related to CP	Attending the Seminar (n1)	Yes, I attended a CP seminar once. If any family gathering, the CP family also always come along. Yes, the knowledge is
	Attending a childcare	

organization/union (n1) (n2)	with CP	practised a little bit, for example how to stretching
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The fourth category considers the type of communication made by the father with the child. All the participants often ask about the child's activities for the whole day while the father is working. Sometimes fathers also take the opportunity to read a child a book. Fathers expected to be actively involved in direct interactions with children. Fathers involved in childcare since infancy positively affect their development (Kleemans, Peeters, Segers, & Verhoeven, 2012; Paul et al., 2020).

Table 6. *Type of communication between father and son*

Category 4	Code	Quote
Type of communication carried out by father and son	Ask about children's activities (n1) (n2) (n3)	Yes, I like to ask about the child's activities all day long when he is away from work, even though the child does not understand and cannot speak yet, sometimes he also reads books.
	Read a book (n1) (n2) (n3)	
	Train conversation (n1) (n2) (n3)	

In the fifth category, it presents the father's involvement in fulfilling the child's daily necessities. Participants (n1, n2) show that fathers fulfil their children's needs by working because by working, they can fulfil their every need. Meanwhile, the participant (n3) was directly involved in fulfilling children's basic needs, such as giving milk, changing clothes, and diapers. People with cerebral palsy need treatment to meet their daily necessities (Ikasari & Kristiana, 2017; Prasastiwi & Hardjanta, 2017; Puspitarini, 2017; Septiningsih & Cahyanti, 2014; Whittingham et al., 2013).

Table 7. *The way the father is actively involved in fulfilling the daily needs of the child*

Category 5	Code	Quote
The way the father is actively involved in fulfilling the daily needs of the child	Work (n1) (n2)	Yes, with work, so that we can fulfil children's needs.
	Give milk, change clothes and diapers for children (n3)	Yes, if you have free time or if you're not working, sometimes you come home from work to help feed the child's milk, sometimes change the child's clothes + diapers

The sixth category discusses how fathers respond to people's judgments. All participants responded to people's comments to him by explaining if someone asked questions about their child's condition, not all parents accepted what people said

about their children; many people commented irritably, but the three participants had better not to listen. People tend to think of them as disabled children who have no future (Megalonidou, 2020). Parents have an essential role in educating and caring for a child with cerebral palsy. The mother's role is needed, but a father's role is also essential (Keown & Palmer, 2014; Putnick et al., 2012).

Table 8. *How fathers respond to other people's comments*

Category 6	Code	Quote
The way dad responds to other people's comments	Do not care and explain if asked (n1) (n2) (n3)	Yes, if the person asks/comments, I will explain well or just ignore it

The seventh category describes the way fathers educate their children. Participants teach their children to share (n3), sharing and discussing with each other (n1), and raising self-confidence (n2). Fathers are involved in providing children opportunities to do something, care, provide support and a sense of security. Children with fathers who are actively involved in parenting will have good cognitive and social abilities and have a high sense of trust (Aisyah et al., 2019; Appl et al., 2008; Astuti & Masykur, 2015). The father's involvement also helps build empathy, love each other and have good social relationships with others (Allen & Daly, 2007; Appl et al., 2008; Crespi & Ruspini, 2015; Keown & Palmer, 2014).

Table 9. *How fathers teach their children with cerebral palsy*

Category 7	Code	Quote
The way the father teaches children with cerebral palsy	Share to other (n3)	I teach children to share, for example, like yesterday I got a Diapers 4 packages from other and I said, "Sir, the pampers asked for 1 for the older brother. Allowed or not?". Brother answered "yes".
	Sharing and discussion (n1)	The way we teach us is almost the same because we like to share discussions first.
	Raising Confidence (n2)	By asking him out and don't be embarrassed so that the child becomes confident.

The eighth category is the father's method of quieting the child if something happens to the child. In participants (n3) the father promised a reward so that the child would stop crying, to participants (n1, n2) by giving hugs and touches because according to the participants a hug was the most important. This method saw that when a father gives love to his children, the child will undoubtedly be close to his father, and the father's figure will grow to be a braver and more expressive person. Fathers will give more love and do their best to please their children (Keown & Palmer, 2014).

Table 10. *The father's way of comforting the child*

Category 8	Code	Quote
The way the father calms the child if something happens to the child	Promised reward (n3)	a At that time, my child cried. When I came home from work I carried him and talked to him. When my child wanted to stop crying, I promised him an ice cream. And Alhamdulillah, my child stopped crying.
	Give Hugs and Touches (n1) (n2)	More to a hug, if suddenly confessed his body, I immediately picked him up and hugged him. Because I can't communicate verbally yet, so my touch is the most important for him.

The ninth category considers the challenges that fathers face in caring for children with cerebral palsy. In participant (n3), the challenge experienced is that parents must continue to be enthusiastic in facing it when a child was getting unwell. Participants (n1) experienced many challenges, such as pursuing children's independence, fighting laziness to do routine therapy at home, and when the child was the hospital. In participants (n2), the child's challenges were when the child cried, and as parents did not understand what the child wanted. The role of parents in caring for cerebral palsy children is complicated. Children have imperfections, so they need help in carrying out activities. Parents' role is essential in bathing, take him to the therapy place, and help during the therapy process (Sakdiyah, 2012).

Table 11. *Challenges faced by fathers in caring for cerebral palsy children*

Category 9	Code	Quote
Challenges that fathers face in parenting children with cerebral palsy.	When the child is getting sick (n3)	The most difficult challenge in our life when our child is sick.
	Against laziness (n1)	here are lots of challenges; the most challenging is pursuing the child's independence, the challenge of fighting laziness to treat children at home routinely, the challenge of often going in and out of the hospital, especially if the child has had seizures
	Teaching independence (n1)	
	When the child has a seizure (n1)	
	Trying to understand the character of the child (n2)	Sometimes children with cerebral palsy often cry. As parents, we do not understand what our children want

the tenth category, it addresses the father's way of dealing with the challenges that occur. Each participant has their difficulties, but the focus of all their challenges is to be more sincere, patient, and accept God destiny. Every parent has their parenting challenges, especially parents who have children with special needs. Parents have a good acceptance in order to face these challenges (Dwairy, 2009; Fernández-García, Rodríguez-Menéndez, & Peña-Calvo, 2017; Machado, Machado, Neves, & Fávero, 2014; Meiza, Kardinah, Rahman, & Puspasari, 2019; Putnick et al., 2012; Whittingham et al., 2013).

Table 12. *Father's way of dealing with challenges*

Category 10	Code	Quote
Father's way of dealing with challenges	Sincere, Accept destiny (n3)	More sincere, trying to accept God destiny.
	Be patient and consistent (n1) (n2)	The main point of facing the challenges is patience because if you can't wait, you will definitely give up, for example, after 3 years of therapy, you still can't lift your head, if you can't wait, we will definitely stop therapy, if you face laziness, the children at home will return to our hopes. For one day our children can be independent. If we are lazy, it is impossible to achieve our dreams. If we face a seizure, we have to take care of the child's eating, which triggers us to avoid seizures, consistently take the child's routine medicine, etc.

Conclusion

The discussion above concludes that the three participants are actively involved in caring for children with cerebral palsy. This result indicates that the three participants often help their spouses in their spare time by fulfilling their children's daily needs such as eating, giving medication, routine home therapy, bathing, and changing children's diapers. Participants also did many enjoyable activities with their children, such as playing, storytelling, and singing together. Each participant has difficulties carrying out or dealing with cerebral palsy children, but the participants think they should face those conditions with patience and sincerity. The participants felt a sense of heaviness to do child therapy, but what made them excited again was that their children's hopes were exceptional.

The limitation of this study is the researcher's depth of focus due to the limited time available. Besides, the relatively small number of participants still requires to explore more extensive and in-depth data. The description of fathers' involvement with children with cerebral palsy will be more comprehensive and in-depth if more participants are involved, and further research focuses on the varieties of father involvement.

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