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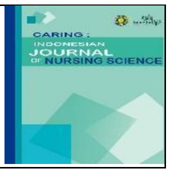

Mother's Perspective in Caring for Cerebral Palsy Children

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ABSTRACT

Cerebral palsy (CP) is a severe mental disorder that affects children. This disease can also lead to activity limitations in brain development, affecting a child's future intelligence pattern. Musculoskeletal issues, epilepsy, and sensory and behavioral disorders frequently accompany CP motor disorders. The purpose of this study was to explore mothers' perspectives on caring for children with cerebral palsy at the PNTC Colomadu Clinic. This investigation was qualitative. This investigation included five mothers with children with cerebral palsy and one therapist at the PNTC Colomadu clinic. Interviews, documentation, and observations were implemented to gather data. Data analysis was conducted through data reduction, data presentation, and conclusion. Source triangulation, method triangulation, and technique triangulation were implemented during the data validity assessment. 1) The findings indicate that cerebral palsy children require ongoing therapy and learning. 2) Children with cerebral palsy require learning, affection, and nurturing tailored to their unique requirements. 3) The goal of therapy is for the child to become independent. The CP advises parents to anticipate parental cooperation and family contribution to continue the development of abilities and provide children with education and enthusiasm.

Keyword: Cerebral Palsy, Children, Cognition, Motor Disorder, Perception

1. Introduction

Two words, cerebral (cerebrum), which refers to the brain, and palsy, which describes paralysis, form the etymology of cerebral palsy. CP is a term that refers to abnormalities in movement, attitude, and body shape, as well as disturbances in the coordination of crisis movements. Psychological and sensory disorders frequently accompany it, resulting from damage to brain development (Karisah, 2019).

The fundamental needs of children with CP are similar to those of children in general. However, the methods and proportions of meeting these needs vary because CP is characterized by motor disorders that are unique to each child. Good affection in CP children automatically optimizes treatment, therapy, and exercises. Parents demonstrate their acceptance of children not only by showing affection and attention but also by providing opportunities. Affection is synonymous with attachment, which refers to the bond of affection that forms between parents and children. Parents (father and mother) focus on their children, meeting all their needs out of a sense of responsibility to them. The child must learn and function effectively (Faisyahril, 2023).

Dr. Wintrop Phelp, an orthopedic surgeon, first described CP in 1957 as an abnormality in body movements associated with persistent brain damage. It leads to the brain's inability to develop pathologic abnormalities indicative of CP, which vary depending on the severity of the disorder or the extent of brain damage. The disorder is highly intricate and can manifest as either localized or systemic, depending on the specific brain region it affects. CP typically impacts the motor cortex, pyramidal tract, basal ganglia, brain shell, and cerebellum (Karisah, 2019).

CP is a collection of permanent movement disorders characterized by impairments in motor function and posture resulting from non-progressive disorders caused by lesions or abnormalities in the developing or immature brain, as per the current definition established by numerous international experts. Impaired motor function and posture manifesting in early toddlerhood and enduring indefinitely are the basis for five to seven CP diagnoses. The disorder is not progressive but may undergo modifications as individuals age (Sadowska et al., 2020).

The availability of research and manuscripts regarding mothers' perspectives on parenting children with cerebral palsy is severely limited. Glasscock (2000) conducted a literature review of 564 studies from 1980–200, primarily focusing on families living with children and infants with disabilities. The review included qualitative and quantitative studies that explored nursing, health, medicine, and psychology. Quantitative studies (529) dominated the review, focusing on physiology, epidemiology, pathophysiology, and treatment outcomes. Additionally, 405 studies focused on children with CP and their families. Researchers are interested in further investigating mothers' perspectives on parenting cerebral palsy children at the Paediatric and Neurodevelopmental Therapy Centre (PNTC) Colomadu clinic by employing a qualitative approach in a phenomenological manner, as indicated by the description above.

2. Methods

This qualitative research was descriptive and employed Miles and Huberman analysis. The Paediatric Neurodevelopmental Therapy Centre (PNTC) clinic, located at Perum Madu Indah III no. 2 Tohudan, Colomadu, Solo 57173 Central Java, Indonesia, hosted the research. The research was conducted from July 1 to July 17, 2023. In this study, the population consisted of 35 children diagnosed with cerebral palsy. The sample consisted of five mothers with children with cerebral palsy who were at least five years old, as well as one therapist who served as a triangulation. Observation, interviews, and documentation were employed to collect data in this study. The triangulation used entailed triangulating data, sources, and methods.

The sample in this study consisted of 35 mothers who had children with a diagnosis of cerebral palsy, all of whom were at least 5 years old. It ensured that the children had outgrown toddlerhood and received care from their mothers for an extended duration. Additionally, the children were routinely brought to therapy, making locating them at the PNTC clinic easier. The sample for this study consisted of five mothers who had children diagnosed with cerebral palsy and met the researchers' criteria, as well as one therapist who served as a triangulation material. The selection of therapists as a source of triangulation was determined by their overall knowledge of the study population and their extensive experience working in PNTC clinics. For the semi-structured interview, the researchers provided a list of questions but also posed additional questions that were not included. Interviews, documentation, and observation comprised the data collection methodology employed in this investigation. The researchers recorded the interview results and observations using a recorder. They also compared the interview results with the data owned by the object in the form of a track record of treatment and the results of the child's examination stored by the research object. The instrument's validity was assessed by triangulation of sources, techniques, and methods.

The data validity tests in this study were conducted by increasing persistence, member checks, and triangulation (sources, methods, and techniques). Data reduction, data presentation, and conclusions comprised the data analysis employed in this investigation. This study had no bias, as the researchers exclusively served as the researchers rather than subjects or therapists. The research ethics implemented were informed consent, anonymity, confidentiality, and ethical clearance from the ethics commission of Universitas 'Aisyiyah Yogyakarta with a number of No. 3046/KEP-UNISA/VII/2023.

3. Results

In this study, respondents are categorized into two categories: primary respondents and expert respondents. Table 1 below presents the characteristics of the primary respondents.

Table 1 Key Respondent Characteristics

Coding Respondent	Mother's Age	Children's Age	Level of Education	Types of Child CP
R1	59	20	Bachelor’s degree	Hemiplegia and ataxia
R2	41	9	Senior high school	Spastic Quadriplegia dan Microchepal
R3	52	12	Senior high school	Spastic Quadriplegia dan Athetoid
R4	36	7	Master’s degree	Spastic Diplegia
R5	45	6	Senior high school	Spastic Diplegia

Table 1 shows that the main respondents are mothers with children of various ages and different types of CP. During the interview, all respondents were quite cooperative, so the researcher could complete the interview process well.

Table 2 Characteristics of Expert Respondents

Coding Respondent	Age	Gender	Education	Period of Service	Department
R6	42	Woman	Diploma physiotherapy	17 years old	Assessor

Table 2 shows that the expert respondents consisted of an assessor who was a child physiotherapist at the PNTC clinic; respondents were very cooperative during the interview so that researchers could complete the interview process well.

3.1. *Results of field observations*

Basic needs are not only in the form of sharpening, loving, and nurturing children; therapy is also a basic need for people with CP; the intensity of therapy affects the level of muscle stiffness or weakness and tone, the child's immune system, breathing, heart work, to sleep disorders. The respondents in this study were mothers who migrated from various regions for their children's treatment and therapy because they were considered good and more optimal treatment was carried out at the PNTC clinic; they had a community of fellow parents of CP children.

Growth and development also occur in children slowly; interventions must be carried out as early and often as possible to improve physical abilities. Development in CP children depends on the capital that the child has; children with good cognition tend to develop their motor skills faster, and vice versa in children with CP whose cognition is impaired, then their motor development tends to be longer, expert respondents R6 explained that:

> *The motor development of CP children will increase depending on the intervention and capital of the child; capital here means the muscle tone, how is the cognitive state, whether there is an emotional disorder or not, whether the child is enthusiastic or not. If the muscle tone is good plus the cognition and understanding are good, especially if the child is enthusiastic, the motor skills will be better; for example, children who do not have eye contact are usually slower to lift their heads when compared to children who have active eye contact, their eyes are attracted so that there is a desire to hold their heads. In addition, a supportive environment is also the reason for the success of therapy in CP children; their families are supportive, at home they are also instructed to intervene and practice, the therapy is routine, God willing, the child will develop* (R6, 42 years old).

Based on the results of observations made by the researcher, it was found that the research subjects were all from outside Karanganyar, Central Java, but were willing to temporarily rent a house around the PNTC clinic so that they could routinely bring their children for therapy, from where it can be seen that the persistence of parents to strive for motor development in children with cerebral palsy.

Parenting CP children is very different from caring for healthy children. Children with CP need different assistance for each child, according to their respective physical conditions; for example, assistance to CP children who cannot lift their heads will be different from assistance given to children who can already sit or to children who can walk. Training, community, and knowledge provision to mothers who have CP children help them to have relationships and comrades-in-arms; these activities also help them increase knowledge about care and training for CP children at home and reduce the stress experienced by mothers in caring for their children.

Education for CP children is carried out in various schools; CP children attend SLB, homeschooling, and inclusion schools by bringing their respective accompanying teachers (Shadow Teachers). Good parenting, complete affection, and a good education can increase self-confidence and enthusiasm in carrying out treatment and therapy activities in children, leading to improved health and therapy success in CP children.

3.2. *Results of interviews with respondents*

The researchers' observations revealed that parenting children with cerebral palsy is significantly different from raising healthy children. Each child requires unique assistance based on their abilities. For instance, the assistance provided to CP children who cannot lift their heads will differ from that provided to children who can sit or walk.

Based on the results of interviews on the research subjects, it was found that therapy and learning in CP children is a continuous process that must be carried out. R6 expert respondents explained that:

> *The motor development of CP children will increase depending on the intervention and capital of the child, capital here means how the muscle tone, how is the cognitive state and whether there is an emotional disorder or not, whether the child is enthusiastic or not. If the muscle tone is good plus the cognition and understanding are good, especially if the child is enthusiastic, the motor skills will be better, for example, children who do not have eye contact are usually slower to lift their heads when compared to children who have active eye contact, their eyes are attracted so that there is a desire to hold their heads. In addition, a supportive environment is also the reason for the success of therapy in CP children, their families are supportive, at home they are also instructed to intervene and practice, the therapy is routine, God willing, the child will develop* (R6, 42 years old).

CP children need sharpening, loving and nurturing according to their individual needs. The basic needs of CP children are the same as those of healthy children, but in different proportions. It includes nutritional needs, balanced nutrition, basic care, clothing, board, food, need to feel safe, affection, attention, and also education. The fulfillment of basic care for healthy children can be done independently sometimes with the help of parents, but in people with CP it is done with full help from parents or caregivers. As the R5 respondent explained:

> *If the needs of a child are the same as normal children, they need to be cared for, they need to eat, clothes and study, but for my child the way is different, eating must be fully helped, because his hands cannot be used independently, he still uses diapers to defecate and urinate, he is still helped to sit, I still help everything, unless he wants to roll over, The problem is that he can only roll around, that's all I am very grateful for. If my education doesn't dare to take it to school, because his physical condition is still like this, he still needs a lot of therapy first, he just participates in educational classes at the clinic, sings and learns with his teacher, at home I also like to take care of simple things such as, this is a pillow, this is a bolster, it's already in my opinion* (R5, 45 years old).

Parenting in CP children requires patience and a long time, instilling understanding in CP children must be done repeatedly and frequently. As explained by the R1 respondent:

> *Actually, the basic needs of children are the same, the only difference is how to give them, depending on the circumstances of each child, my child who even though he understands what I am wearing, he cannot immediately practice, it needs a lot of practice and continuously, if I want my child to be strong, every morning after dawn I have to force him to practice using the planting bike for example 5 minutes, Later I increased the duration, at first he was angry that he didn't want to, after a while he got used to it and didn't feel heavy. For school, I have moved a lot from kindergarten, sometimes it is not suitable so I move, the school is included with shadow teachers, home schooling has also been, until now I am also trying to be in SLB, wherever the knowledge is still entered. For my child's school age, he has just graduated from high school even though he is 20 years old, that's because I entered school late, I first pursued his motor development* (R1, 59 years old).

The success and goal of therapy is the independence of CP children.The respondents of this study agreed that the main goal of the series of therapies carried out by CP children is to achieve independence, in the sense of being able to carry out daily activities independently without the help of others, to achieve this goal, CP children must receive intense therapy, both in health care places such as clinics, or by parents at home, as revealed by R1:

> *I hope that my son can live independently, in the sense that if he needs to eat, he can bribe himself, can urinate and defecate on his own, and other life skills, because we don't know how old he is, as much as possible he must be independent, Alhamdulillah, because of Allah's permission and plus the therapeutic efforts of the baby, my child can walk on his own when he is 2 years old, It's just a step, even though until now he is 20 years old I still train so that his path is strong and there are still many other small motors that he can't do, just talk about it still needs therapy until now, he used to do therapy really every day, now he has at least 4 therapies a week, because his school time is now a lot, he is still physiotherapy, occupational therapy, speech therapy, hydrotherapy are also still, every day I still practice using a stationary bike at home, I still invite them to run, learn to climb stairs, etc., this really requires diligence and patience* (R1, 59 years old).

4. Discussion

Sharpening, loving, and nurturing are fundamental requirements for all children, regardless of whether they have regular or special needs, such as cerebral palsy. The only difference is that these requirements are similar to those of a cerebral palsy child. Therefore, the provision of nurturing and support is also unique.

The basic needs of CP children, which include sharpening, loving, and nurturing, are similar to those of children. However, CP children fulfill these basic needs in varying proportions and ways because the conditions affecting CP children, such as motor disorders, can vary from child to child. The fulfillment of good affection in CP children automatically increases the optimization of the treatment, therapy, and exercise provided to CP children. Faisyahril’s (2023) research aligns with this. Faisyahril (2023) clarifies that parental acceptance of children is not solely characterized by the provision of love and attention but also by the provision of opportunities.

The study's findings indicated that parents had the opportunity to engage with the subject matter. Parents provide opportunities for their children by allowing them to establish relationships and communicate with their extended family, neighbors, and the broader community. It is a positive response. Faisyahril and Wibowo (2023) elucidate that affection is synonymous with attachment, which refers to the bond of affection that forms between parents and children. Parents (father and mother) focus on their children, meeting all their needs out of a sense of responsibility. Parents do this to facilitate the learning process and ensure its smooth operation. In addition to offering love and attention, parents who accept their children's conditions will also provide opportunities for their children to engage in a variety of activities that can facilitate their development (Faisyahril, 2023).

One of the most influential factors in any child's mental and social development is the relationship between parent and child. In order to promote maternal mental health, intervention programs must address parenting and parent-child relationships, as well as provide parents with the necessary support to acquire the necessary strategies and skills to manage their child's behavioral and mental issues (Ashori Mohammad et al., 2019).

Regardless of their differences, all children, including those with special needs, have the same opportunity to receive an education. Article 31, paragraph (1) of the UUD 1945 regulates this. In essence, every citizen has an equal right to educational services. It demonstrates that children with typical development and those with special needs must receive proper education to maximize their potential (Jazim, 2016).

Faisyahril's (2023) research, "Parental Acceptance of Children with Cerebral Palsy Disabilities at the Special School Part D of the Bandung Disabled Children Development Foundation," reveals that parental acceptance of children encompasses not only the provision of opportunities but also the expression of affection and attention. The study's findings indicated that parents had an opportunity to engage with the subject matter. The method of providing opportunities to subjects is that parents provide a positive response by granting permission for the subject to establish relationships and communicate with extended family, neighbors, and the broader community.

Faisyahril (2023) clarified that affection is synonymous with attachment, which refers to the bond of affection that forms between parents and children. Parental attention is the process by which parents (fathers and mothers) focus on their children to meet their needs. Parents do this out of responsibility to enable their children to learn and thrive. In addition to offering affection and attention, parents who acknowledge their child's condition will also provide opportunities for their children to engage in various activities that can facilitate their development.

Children with CP measure the success of their series of therapies by their independence. The potential for independence in CP children can be bolstered by intensive therapy tailored to the child's circumstances and requirements, physician treatment if the child continues to require treatment, and home exercises that parents, families, or carers can administer. Parents play a significant role in therapy success in children by offering moral and material support, affection, and positive parenting. Furthermore, the child's physical health and well-being are significant factors in therapy success (Agarwal dan Verma, 2012).

Assistance services, specifically physiotherapy, are necessary to mitigate obstacles in the physical condition of CP children. The primary goal of physiotherapy is to treat and rehabilitate health conditions. The primary goal of this physiotherapy is to mitigate the challenges that children with disabilities face in terms of their locomotor abilities (bones, muscles, and joints), as well as to enhance motor skills that are highly functional in daily life, particularly in order to facilitate their education (Ulaiqoh Nida, 2016). Young children with cerebral palsy need to start treatment and rehabilitation as soon as possible because the brain is very flexible (able to adapt and change based on functional needs) in the early stages of developing the central nervous system. It means that people with cerebral palsy can make significant strides in motor development (Sadowska et al., 2020). In the interim, if children with cerebral palsy do not receive intervention, their circumstances will deteriorate. Spasticity is the most prevalent symptom experienced by children with cerebral palsy. This condition is characterized by increased muscle tension, which restricts the range of passive and active joint motion and contributes to developing joint contractures.

Spasticity can impede the process of rehabilitation, treatment, and patient self-care, as well as cause pain, low self-esteem, and a poorer quality of life. It can also contribute to permanent contractures, joint deformities, bedsores, thrombosis, and infections. Spasticity adversely affects the development of motor function. Pharmacotherapy, physiotherapy, or surgical intervention may be employed to facilitate systematic rehabilitation in the event of spasticity. The selection of pharmacological treatment methods is contingent upon the severity and location of the disease (Sadowska et al., 2020).

Individuals or groups receive physiotherapy as a health service to develop, maintain, and restore body movement and function throughout their lifespan. It entails manual handling, equipment (physical, electrotherapeutic, and mechanical), body function training, and communication (Indonesian Physiotherapy Association, 2022). Individuals or groups receive physiotherapy as a health service to develop, maintain, and restore motion and body function throughout their lives. Physiotherapists perform this service using manual handling, motion improvement, physical, electrotherapeutic, and mechanism equipment, body function training, and effective communication. Conversely, medicine cannot cure the condition of CP (Sulistyawati dan Mansur, 2019).

This information is based on Permenkes No. 65 of 2015, which pertains to physiotherapy service standards. Using wheelchair aids, leg braces, and other therapeutic methods and technology can alleviate and assist children with CP conditions in surviving. Pediatric physiotherapy to treat cerebral palsy improves the child's gross motor skills, improving their quality of life. Physiotherapy snacks can help maintain and enhance movement function in the body despite the permanent brain damage associated with CP. If CP is not treated, it can lead to challenges in maintaining balance and correct walking patterns, maintaining gross motor skills, maintaining balance, strengthening the heart and lung muscles, developing muscle contractures, joint stiffness, scoliosis, and deteriorating posture (Sopandi & Nesi, 2021).

5. Conclusion

The PNTC clinic provides physiotherapy, occupational therapy, speech therapy, and hydrotherapy to children with cerebral palsy. The therapy uses NSMRD & S (Neuro Senso Motor Reflex Development & Synchronisation) techniques. CP children's fulfillment of basic needs is similar to that of other children, but the proportions differ. Love and nurturing play a crucial role in achieving this. The barometer of therapeutic success in children with cerebral palsy is the independence they achieve in meeting their daily needs independently.

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