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Caring for Cerebral Palsy Children: Indonesian Parents' Experience

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Abstract

Children with Cerebral Palsy (CP) will need help from others to meet their day-to-day needs, which will cause high parental dependence for a long time, and will be physically, mentally, socially and economically burdensome. This study aims to obtain in-depth information on the experience of parents in caring for children with CP. The research method is based on qualitative research with a phenomenological study approach. The participants in the study were ten mothers who had children with CP. Participants were selected using a method of objective sampling. Data collection techniques were carried out through in-depth interviews; data were analyzed using an inductive approach based on Braun & Clarke's six-phase thematic analysis. There are eight themes identified in this study, namely: 1) Psychological Impact on Parents, 2) Parents' Efforts, 3) Child Dependency, 4) Support, 5) Mother's Routine Changes, 6) Parents' Expectations on Children with CP, 7) Success of Treatment, 8) Financial Impact. Further researchers are expected to be able to seek more in-depth data on the categories identified in this study, namely in the category of sincerity, increased worship and external support for maternal activities in the children's community with CP.

1. Introduction

CP is a disorder that occurs due to brain damage in fetal or infant development which causes limitations in movement, body posture and is even accompanied by psychological and sensory

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disorders (Armand & Bonnefoy, 2016; Desiningrum, 2016). Basic Health Research in 2010, shows that the percentage of children aged 24 -59 months with CP is 0.09%. The National Survey of Children's Health (NSCH) and the National Health Interview Survey (NHIS) in 2011-2013 obtained the prevalence of CP based on parental reports among children aged 2-17 years. The survey found a prevalence per 1000 live births that ranged from 2.6 in NSCH and 2.9 in the NHI (Stavsky, M., Mor, O., Mastrolia, SA, Greenbaum, S., Than, NG, & Erez, 2017).

Children who experience CP will need help from others in meeting their daily needs. It causes high dependence on parents for a long time, so that parents who care for children with CP need help, especially in understanding their child's behavior, parents will look for appropriate sources of support and interventions that can improve children's abilities, every parent will have experience different in treating children with CP (Magalhães et al., 2019). Based on the preceding, the authors are interested in exploring the experiences of parents in caring for children with CP, so that the needs of parents and families in caring for children with CP can be described.

Libryani (2015) states that CP is a conditioning group that affects motor function and posture due to non-progressive lesions of brain development that can be caused by antenatal (80%), intrapartum (10%), and postnatal (10%) factors. In the brain, three different parts work together in carrying out and controlling the work of the brain which influence the function of movement and posture, where if there is damage to this part of the brain it can make a person suffer from CP, the parts of the brain are Cortex; spastic CP, causing muscle stiffness or muscle tension, slow and awkward movements. Gangliabasal; athetoid CP (athetosis choreoathetosis), which causes uncontrolled movements, found in the legs, arms, hands and facial muscles. Cerebellum; CP attention, characteristics are, shaking movements, and affects balance as well as awareness. (Terri, 2018). Melunivic. M., Catibusic. F. Bilalovic., Rahmanovic, S., Dizdar, (2017) said that children with CP are people with severe motor disorders that significantly affect body weight when compared to healthy children. One of the causes is orthomotor dysfunction.

Therapeutic management in children with CP is to help the child achieve optimum development and function within the limitations of the disease. Therapy is primarily preventive, symptomatic and supportive (Rahmana et al., 2020). Medical management focuses on increasing mobility through the use of therapeutic mobility and drugs. The use of therapeutic modalities, such as physical therapy, occupational therapy, and speech therapy is important in increasing mobility and development in children with CP (Terri and Susan, 2018). CP is a lifelong disorder that can result in severe physical and cognitive impairment.

In some cases, physical distress necessitating intensive daily care of the child, by providing intense daily care, can result in fatigue in the parents. Adapting to the demands of a multidimensional disease is difficult. Children are often hospitalized and have to undergo several corrective surgeries that can burden the family, including the financial aspects (Terri and Susan, 2018). Research conducted by Ferreira et al. (2016) stated that caring for children with CP who have minor damage is a serious challenge and overburdens for parents. Emotional problems were twice as likely in children with CP; this increases stress levels on their parents and caregivers so that they have poor health both physically and psychologically. The purpose of this study was to obtain in-depth information about parents' experiences in caring for children with CP.

2. Materials and Methods

This research is a qualitative study with a phenomenological study approach to finding out the experiences of parents in caring for children with CP. The data obtained by the researcher will be triangulated with the data to key participants, namely, the husband of the main participant and also the physiotherapy officer. Participants in this study consisted of ten mothers who had children with

CP as the main participants, while for the key participants, there were ten fathers and one physiotherapist who was responsible for child therapy. Participants were selected by purposive sampling, which is determined through predetermined criteria; parents who accompany children in physiotherapy and care for their children independently will better understand and be able to communicate their experiences. Basically, qualitative research does not pose a risk to participants, but researchers still pay attention to the rights of participants, including; The researcher explains to the participants the benefits of the research conducted. The researcher explains and guarantees that the confidentiality of the participants is given priority by not displaying the information and identity of the participants.

This research emphasizes data credibility testing; it is conducted by extending observations, increasing research persistence, triangulation, discussions with peers, negative case analysis, and member checks (Sugiyono, 2010). Identification of research themes is carried out through a data analysis process using an inductive approach following six phases of analysis according to Braun, V., & Clarke, (2006) to find important themes from the results of interviews that describe the knowledge, feelings, experiences, support, barriers, and the expectations of parents in caring for children with CP. the analysis phase is by; 1) preparation of transcripts, 2) Identification of patterns and assigning codes, 3) Arranging categories, 4) Reviewing and improving initial themes, 5) Name of themes, and 6) Reporting on analysis results.

3. Results and Discussions

The first theme is the psychological impact on the mother as the main participant, experiencing psychological, spiritual and social changes. Psychological changes experienced by mothers in the form of feelings of sadness, shock, spiritual change is a mother's condition that increases worship and has feelings of sincerity and patience by having CP children, social changes, this is related to mothers who care for children with CP towards the home environment and children's activities. This is in line with Devina's research (2016), which states that a mother who cares for a child with CP often experiences stressful situations, so a mother who is the main caregiver for a child with CP needs a personality that can make her survive the situation. which stressed him out. Mother's acceptance of the child's condition by increasing feelings of sincerity and patience, and increasing worship cannot be explored more deeply, how in the end mother can be sincere and patient, and increase worship more broadly can be a reference for more in-depth interviews.

The second theme describes the efforts made by parents in fulfilling care and treatment that supports the recovery of children with CP, these efforts are in the form of medical and non-medical treatment, using alternative medicine with prayer water to support the recovery of children with CP, for medical treatment in line with Purnomo's research. D., Kuswardani (2018), which states that handling cases of CP diplegia spastic, the physiotherapy modality used is *bobath* exercise therapy, namely inhibition and facilitation which is considered effective with conditions of functional standing and walking disorders. Alternative medicine is a new category in research, so this category needs to be followed up.

The third theme is dependence on children with CP due to motor and speech disorders experienced by children. Based on the movement damage that occurs in CP children, the research was conducted by Usman. H., (2017) that fifty percent of children suffering from CP have the inadequate eating ability. This feeding problem is related to the common oral motor dysfunction in CP patients. The fourth theme describes the support that mothers get in caring for children with CP. It is under research conducted by Valentine, (2014) that social support provided from family, neighbours, health services are one of the factors that can help parents adapt to the condition of children with CP. In the theme of support, researchers only find that as long as This is the family and

husband who have a big role, while other external support cannot be explored more deeply for all participants regarding support in the community for parents with children with CP, related to activities carried out in the community.

The fifth theme is a change in the mother's routine which illustrates the changes faced by parents in caring for CP children originating from the mother's condition and mother's activities. Valentine, (2014), states that continuous effort and builds parental resilience. Stress and fear not only arise at the time of the initial diagnosis but can also arise due to fatigue in caring for children. The sixth theme, the results of the study show that parents with CP children have a desire that their children can be like other normal children, fully recovered, be healthy, can walk, and there are health facilities in the form of health insurance that can help with the cost of treating children with CP, Research conducted by Kusumah (2017), one of the themes found in his research is the expectation of mothers while caring for CP children, this theme consists of two categories, namely, the hope of the child's recovery, expressed by the four participants in this study, this hope is expressed that they have a desire for their child to recover.

The seventh theme, the success of treatment, is a theme that describes changes in children's physical activity as well as speech changes where each participant states the success of the physiotherapy that has been undertaken, this is following the research conducted by Purnomo. D., Kuswardani (2018) which states that the treatment of CP cases with spastic diplegia physiotherapy modalities used is the Bobath method of exercise therapy, namely inhibition and facilitation which are considered effective with conditions of functional standing and walking disorders. The Bobath method can help teach normal posture and movement patterns and maintain normal tone qualities. The eighth theme, financial impact, describes the statements of parents, even though there is health insurance provided by the government, they still require medical expenses outside of medical care. CP children require treatment over a long period, and also during their lifetime. It is in line with research conducted by, Glinac, A., Matovic, L., Delalic, A., Mesalic, (2017) which states that mothers of CP children experience not only psychological pressure but also experience financial factor problems, related to; transportation, child care, therapy, adaptive equipment. Researchers suggest that the results of this study can be used as initial data regarding the experiences of parents caring for children with CP, further researchers can seek more in-depth data about the categories obtained in this study, using the same or different methods.

4. Conclusion

This study found one of the categories, namely parents' efforts to treat children with CP in addition to medical use of prayer water, in addition to the mother's coping in accepting the child's condition with an increase in worship and feelings of sincere. Researchers suggest that the results of this study can be used as preliminary data regarding the experiences of parents caring for children with CP, the next researcher can look for more in-depth data about the categories obtained in this study, namely in the category of sincerity, increased worship and external support related to mother's activities in the community.

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