**THE RESILIENCY OF FAMILY WITH CELEBRAL PALSY CHILDREN**

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Abstract

This studies aims to provide an overview of family resilience in families with Cerebral Palsy

Children who attend education at *YPAC* (Foundation for Disabled Children) which is the only

center for cerebral palsy services in Jakarta . This research used a qualitative approach with the

type of case study research, namely in three (3) families where each family has two (2) children

with Celebral Palsy. The result of this study describe risk factors and protective factors in families with children with Celebral Palsy with all their limitations. Risk factor is the condition of the informant, who has an economic income that is insufficient and unstable. On the other hand, family members also often receive stigmatized, and once becomes a victim of violence. Meanwhile protective factor is a source of strength that can be arise from the personality or values of each member, commitment among family members, support from the surrounding environments such as extended family, friendship groups, neighbors, and institutions. Social support becomes a source of strength for the family and keeps the family survive with their Celebral Palsy children.

Keywords : Celebral Palsy, Family resilience, risk factor, protective factor

1. **Introduction**

People with disabilities become one of the issues that need attention. According to the data from Central Bureau of Statistic in Health Ministry of Indonesia (2014), the highest percentage of disability in 2012 was multiple disabilities which reached 39.97%. One type of disability with a low percentage was Cerebral Palsy (CP) reaching 0.09%. However, according to Health Ministry of Indonesia (Health Ministry of Indonesia, 2014), Celebral Palsy is categorized as a type of severe disability. Likewise, based on research conducted by Witterberg and Saada (2013). Celebral Palsy is one type of disability that has quite heavy burden in childhood and has a large impact on the family and all its members (Valentina, 2014). They are paralyzed from birth or since the first five years of age can cause obstacle of child motor development (Bower, 2009) can also trigger difficulty in controlling the muscles as a result of paralysis or damage to the brain (Slaich, 2009).

Children with disabilities have similar rights as other children around the world (UNICEF, 2013). Based on Law No. 23 of 2002 concerning Child Protection, it is stated that every child has the right to live, grow, develop, and participate impartially and get protection from violence and discrimination. Similar to children with disabilities, children have the right to be free from discrimination and to obtain facilities or accessibility in obtaining their rights including their services.

The birth of Celebral Palsy children has an impact on the family on a health, social and economic basis (Wittenberg and Saada, 2013). Twenty hours parenting patterns and high costs must be spent to meet the needs of children with CP. Closest families and people on children with CP play a significant role in stimulating children's development and teaching children to explore new things, such as how to eat, talk, walk, and interact socially (Braga and Paz, 2006)

Some studies related to people with disabilities including a research conducted by Suharli, (2000), about the success of the CP Children Rehabilitation Process comes mainly from families. Research on disabled children from Melani (2014) about Evaluating Occupational Therapy Programs shows that children who are physically disabled, the majority of whom are CP people, must undergo therapy for the rest of their lives. While research related to family resilience from Apostelina (2012) on Family Resilience in Families with Autistic Children shows the importance of the role of family and extended family. Research from Satriyo and Yumpi (2017) illustrates the low ability of families who have children with Disintegrative Disorders in regulating emotions causing crises that include frustration, anxiety, shock, helplessness, anger, sadness, and resentment.

The description of some studies above shows the problems faced by families who have children with disabilities or children with special needs. Research shows a focus on resilience in the family. However, it has not shown how the environmental dimension supports family resilience. In a study conducted by Walsh (2016), it is known that if each individual has the potential to build resilience, the results of the study say if resilience can be strengthened through experience facing difficulties, in which the individual will build strength within (internal) while waiting for help from others (external), so that it can be said if resilience is a result of life experience.

Families who can adapt and carry out their functions in the midst of the problems face dare called families that have buoyancy or resilience (McCubbin, 1997 in Mawarpury and Mirza, 2017). Family resilience is the ability of the family as a functional system to survive and recover as in its original condition when facing difficult conditions (Walsh, 2016.) According to Patterson (2002), a family with disability members will be considered resilient if it can fulfill the family member's vulnerable protective function. The outcome of the function is family capability in providing care for children with special needs, making sure that there is no violence in the family, and not referring children to care institutions.

The most significant issue is how Celebral Palsy children obtain therapy and care for their entire life. The need of assistance and extra necessity in carrying out daily activities in CP children causes stress to the family (Valentina, 2014). Some families with CP children hire caregivers to help children mobilization. However, not all families with CP children can hire caregivers. Families who cannot afford to pay for caregivers must take care of their own children. The burden experienced by the family will be multiplied when the family has more than one child with CP. In addition, there was a lack of understanding and a lack of support from the neighborhood environment on disability issues, causing family members to experience stigma and becoming victims of verbal violence.

Based on various problems faced by families, The objective of this research is to understand the resilience of the families who have Celebral Palsy children but still survive in caring for their children, especially for families that do not have caregivers and have to take care their own children.

**2. Literature Review**

Cerebral palsy is a condition of paralysis in the brain that results in inhibition of individual motor development.( Bower, 2009) Every child who has cerebral palsy has different conditions, from mild to severe. Brain damage owned by people with CP can cause other obstacles, such as mental retardation, epilepsy, impaired vision or hearing, communication difficulties, and eating difficulties (Hinchcliffe, 2007; Bower, 2009). Barriers to body functions on people with CP can become more complex along with the increase of age, and there are several stages of child development that can be missed (Slaich, 2009).

Resilience can be defined as the ability to survive and recover after facing life difficulties (Walsh, 2016). Resilience is a dynamic process that develops an individual's adaptability when encountering adversity. Resilience is not just the ability to overcome and adjust to adversity, but the strength and resources that enable individuals to recover from a downturn and be able to continue their life well (Walsh, 2016).

According to Walsh there are two factors in looking at resilience : risk factor and protective factors. Factors that can threaten resilience are called risk factors (sources of difficulty). Risk factors are predictors or signs that make individuals vulnerable to future problems (Kaplan, 1999 in Kalil, 2013). Risk factors can occur at the level of individuals, families, communities, and even the wider community. Several risk factors that have been studied previously are job loss, poverty, divorce, death, chronic disease, and infertility (Kalil, 2013). However, although risk factors are one of the threats to resilience, not all individuals have the same risk factors. have the same resistance.

Vulnerability is a condition that makes families more susceptible to the adverse effects of a crisis. A family is said to be a vulnerable family if they experience the following conditions: a. insufficient and unstable economic income, where the family lives below the poverty line and is homeless; b). do not have access to health and education facilities; c) not getting social support from their environment, not getting help from other family members, neighbors, or relatives; d). being stigmatized, being a victim of stereotypes, being demeaned by their self-respect, being treated unfairly by those around them because they are considered different; e). have a family member who is sick or with a disability; f). have been a victim of physical or verbal abuse. (Myranska ,2013)

*Protective factors* are one of the factors that can strengthen resilience (Walsh, 2016). Protective factors are protection to minimize the impact of the problems that occur (Kalil, 2013). Protective factors can be in the form of a perspective on the environment, family warmth, family support, and children's support (Kalil, 2013). Futhermore the source of family strength like individuals with an external control center view that they have no role in changing fate and are easily influenced by the environment, whereas according to Juby and Rycraft (2004) individuals with an internal control center believe that they: (1) are able to control fate; (2) has the ability to change situations; (3) able to create the situations he wants( Benzies and Mychasiuk, 2009); emotion regulation and individuals who have spirituality will view their life positively. Acoording to Stewart social support refers to interpersonal interactions between families and their social networks, such as extended families that provide emotional support, real help, or information (Stewart, 1993 in Benzies and Mychasiuk, 2009).

**3. Research Method**

This research was conducted at Yayasan Penyandang Anak Cacat (YPAC), an educational institution, treatment, and shelter for children with cerebral palsy, the largest in Jakarta. YPAC has been around since 64 years. This study use qualitative approach. Creswell (2014) defines a qualitative approach as a research process with a particular methodology, in order to explore and understand the meaning of individuals or groups that are related to the phenomena to be studied.

In this study, researchers wanted to use case study research to understand and interpret family resistance with children with cerebral palsy. The study applied case study research that discusses privileges in several cases of individuals, groups, organizations, movements, events, or geographical units (Neuman, 2014). One of the strengths of case studies is that researchers can link an abstract idea into a concrete case (Neuman, 2014). As for this study, the researcher wanted to see the features of a family with cerebral palsy children, trying to connect the situation experienced by individuals with the pressure from the surrounding environment. How the situation faced by families with CP children and how the surrounding environment responded to the existence of CP children

**3.1.Data Collection**

Data collection techniques and information sources in this study were also carried out by depth interview, observation and documentation study related to the research topic.The literature study used in this research was carried out by utilizing library materials, such as books, online media, journals, legislation, and official government documents. Observation is a method of monitoring a social condition. Neuman (2014), Observations were made by looking at the conditions and activities of families who have children with celebral palsy

Purposive sampling was employed as the technique of selecting the informants. Purposive sampling is used to select informants who are difficult to reach and coming from special populations (Neuman, 2014). To get information about the resilience of families with cerebral palsy children, the informants in this study consisted of the Head of Development Unit and teachers at YPAC. Parents with cerebral palsy children, with the following criteria: a)has more than one child with cerebral palsy; b) does not have a babysitter; c) consists of parents who are not divorced; d) the family has a place to live and has no history of violence.

**4. Result and Disscusion**

Each of the three family have two children with Celebral Palsy, that were classified as those having moderate cerebral palsy (30%), in which people with cerebral palsy had very limited activities and mobility. Their children had multiple disability (deaf and mentally disabled), had a quite severe mental disorder making it difficult to communicate, experienced impaired vision and paralysis of their hands and feet. That is why having CP children takes up time and energy for parents, especially mothers since CP children badly need assistance from people around forever.

Physical limitations make CP children dependent on their parents, especially in doing mobilization in their daily activities. The three informants had an improper sleep pattern because the range of sleep time was less than 5 hours, and as a result their chores that also became their responsibility had to be delayed to take care of their CP child all day long. According to Wittenberg and Saada (2013), families who care for CP children experience pain in the body due to helping children mobilization, have sleep disorders, are unable to move freely at home and feel the unhealthy pattern of work.

In the middle of their hustle and bustle and limitations they have, the family still spent time for children and tried to meet the educational needs of children. CP children attended education at *YPAC* (Foundation for Disabled Children) Jakarta.

Walsh (2016) mentions that like all individuals, every family has different sources of difficulty and sources of strength in facing a crisis. According to Patterson (2002), the source of difficulties and sources of strength exist in all layers, such as individuals, families, and communities.

The three families experienced a crisis in the form of excessive worry and sadness on their way to raise CP children. For that, families need adaptability so that they can carry out their functions in the midst of the problems at hand (McCubbin, 1997 dalam Mawarpury dan Mirza, 2017. Families who can adapt and carry out their functions in the midst of the problems face dare called families that have buoyancy or resilience (McCubbin, 1997 in Mawarpury and Mirza, 2017). Family resilience is the ability of the family as a functional system to survive and recover to its original condition when faced with difficult conditions (Walsh, 2016), where family resilience can be determined through sources of difficulty and sources of strength owned by the family (Patterson, 2002).

Myranska, et al. (2013) stated that a family can be categorized as a vulnerable family if the family has CP children, has an economic income that is insufficient and unstable, does not have access to health and education facilities, does not receive social support from its environment, is stigmatized, and once becomes a victim of violence. Vulnerability is a condition that makes families more easily affected by the crisis. The three families had limitations in the economy.The irregular income has put the family into economic difficulties. However, having CP children requires a great amount of money for the continuity of life-long therapy. One of the informants experienced rejection by not being permitted to access one of the hospitals because she could not pay for medical expenses. The dismissal, expensive fees, and conditions of the child who did not improve made parents feel traumatized to get further medical treatment. Later on the three families obtained services at *YPAC* (Foundation for Disabled Children) Jakarta.

Stigma problems experienced by informants could be in the form of verbal talk and the look when looking at children with CP. According to Myranska (2013), being stigmatized is being victimized by stereotypes, lowered self-esteem, and unfairly treated by people around them because they are considered different. This is in accordance with the recognition of one family who got a pitiful and dislike view from the people around it. The families received a variety of negative responses, and because of that condition the family became reluctant to socialize in the community, close themselves, and maintain a distance when being together with family members who also had cerebral palsy children. In addition, one of the normal children even experienced verbal bullying or violence in school due to having siblings with Celebral Palsy

The protective factor in family resilience can be seen by how families adapt. Resilience is formed and learned through experience in dealing with misery (crisis). Every individual has different sources of difficulty and sources of strength when facing a crisis (Walsh, 2006). The resilience of each family can change as time changes. Thus, it can be determined that family resilience is assessed as a process and not an outcome (Rutter, 1999 in Benzies and Mychasiuk, 2009).

The experience of having CP children had triggered a psychological impact as felt by all family informants, namely sadness and resentment over the condition of their children. They felt sad about the condition of their children who could not be independent in adulthood. They also felt worried about the survival of their children if both of the parents died. In addition, parents also sometimes felt annoyed with children's limitations in understanding something.

However, parents did not burst their anger to children because they realized that these limitations were not the things desired by everyone. They tried to regulate and manage their emotions. According to Shaffer, et al (2005) in Benzies and Mychasiuk (2009), by having the ability to regulate and manage emotions, family members can think calmly in the midst of perceived stress. Families focus more on the care of their children compared to the feelings of sadness or annoyance.

The ability of parents to regulate emotions becomes one of the sources of strength (protective factors), as a protector to minimize the impact of problems that occur. In this condition, the source of strength can help families to adapt and overcome problems (Kalil, 2013). The source of strength can arise from the personality or values ​​of each family member (individual), values ​​and commitments among family members, and support from the surrounding environment such as extended family, friendship groups, neighbors, and institutions.

Support from partners is the best support that can improve the ability to overcome family economic and social problems (Van Doesum, et al, 2005 in Benzies and Mychasiuk, 2009, p. 106). Support provided from husband to wife or vice versa is attention and cooperation in caring for children. It was very helpful for mothers who did not have caregivers in caring for children with CP.

According to Benzies and Mychasiuk (2009), a good relationship between husband and wife is characterized by good communication between those two, so that it can create a comfortable environment for children to develop. Partner support can relieve stress because spouse is the closest and most comfortable person to share stories about problems that are experienced daily.

The assistance received by the family is not necessarily only from the nuclear family but also from extended families. According to Benzies and Mychasiuk, (2009), social support from the extended family can be in the form of instruments, emotional, or practice that become a factor that can help families to deal with problems. According to Stewart (1993) in Benzies and Mychasiuk (2009), social support of extended family can also be in the form of emotional support, real help, or information. The three families in this study received emotional support and real help from their extended family. Extended families helped them to take care in the hospital and take turn in keeping their children at home. Two of the three families in this study also received financial assistance from their extended family.

According to Benzies and Mychasiuk (2009), family resilience is not only influenced by characteristics and interactions within the family but also influenced by the community and the physical environment around the family. Family involvement in the community opens up the family's opportunity to obtain information about health and education services and increases the emotional ties between community members. In this study, the three families were not involved in the organization, but they had informal friendship groups that helped them to obtain information. The friendship group was the parents' friendship group of students at *YPAC* .

According to Criss, et al (2002) in Benzies and Mychasiuk (2009), acceptance of friendship groups was the strongest source of strength when compared to other community social interactions. In this study the three families received good acceptance from the parents of students at *YPAC*, even the friendships became very close as they had become the part of real family. Their CP children also got good acceptance and could socialize in the school environment. This friendship group worked together to reduce the financial burden of each family, such as holding joint activities and helping to find donors to financially support the parents in need.

In addition, good access to children's education and health services is marked by the opening of opportunities for children to obtain education and health services. According to Patterson (2002), families with disability children can be categorized to have resilience when families provide care for children with special needs; there is no violence in the family, and children are not referred to childcare institutions. The three families in this study had good access to education and health services at *YPAC* and received cost subsidy and financial assistance from donors

People with CP who lived in Jakarta Special Province got assistance from Regional Government of Jakarta in the form of ownership of the Jakarta Smart Card (KJP). With assistance from *YPAC* (Foundation for Disabled Children) and Regional Government of Jakarta Special Province, families with low economics could still carry out their protection functions and build family resilience.

Furthermore, the families also had a source of strength from the neighborhood. Safe living environments include low crime rates and large numbers of infrastructure facilities, and supportive neighbors (Benzies and Mychasiuk, 2009). In this study, two out of three families had supportive neighbors who accepted their children existence and reinforced each other. Neighbors became helpers when one of the families in this study was stigmatized by other neighbors. Responses from neighbors were influenced by the relationship made by the informant and the time duration the informant lived in the area.

The survival of the family in dealing with various crises occurs through processes originated from individual factors and environmental factors. Family resilience is not only supported by factors from the family but also showed from how families relate to their environment.Available social support can help individuals to survive. The meeting point between individual needs and social support is a source of strength in the family in which positive social support can be the key to family resilience Harms (2010), The survival of families with Celebral Palsy children comes from individual parents, as well as from the support of extended families, neighborhood environment, friendship communities and *YPAC* (Foundation for Disabled Children) institutions.

5. **Conclusion**

The purpose of this study was to investigate the resilience of families who had children with CP and how the environment became a part of family resilience. Families with CP children had different sources of difficulty and sources of strength, but fulfilling the therapeutic needs and education for children with disabilities became the top priority for the family.

The main source of difficulty came from each family member. The existence of these difficulties had led to other sources of difficulty coming from the surrounding environment or community. Taking care of CP children required a lot of time and energy especially for families that did not have caregivers, so all management activities had to be carried out by parents

The family had to continue to adapt by using the source of power that they owned, so it could continue to carry out their functions. The strength of each family member was different, but the most prominent or strengthening was the source of strength that came from within the parents, such as the internal control centre, emotional regulation, belief system, helping the family to accept their child's condition, so the family members could reduce their sadness and focus on caring for their children. All informants regulated their sadness and negative emotions into something positive, and focused more on the treatment of their children

The sense of responsibility upon the family members made parents to become motivated to continue and to provide care for their children and continue to work to finance the treatment. The survival of the family to continue the care for their children was inseparable from the support of the environment, including cooperation, commitment, social support, and financial assistance. All of the sources of family strength helped them to continue to take care of their children. Sources of strength came from extended families, communities, acceptance of friendship groups, education and therapy facilities from *YPAC* (Foundation for Disabled Children) and assistance from the local government. When families were well received and supported by people around them, the family would be more motivated in caring for their children and easier to maintain their resilience.

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