

# Parents' Resilience of Child with Cerebral Palsy

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*Abstract. Cerebral Palsy (CP) is a condition in which a child have damage to the brain which results in the absence of muscle control, posture abnormalities and movement barriers. CP is a condition that is suffered throughout lifetime. Nurturing children with CP certainly causes stress. So that to minimize it requires special competence in the parents. Resilience is considered as emotional and psychosocial strength, leading to courage and rationality in facing adversity. Resilience will help parents with CP children to adapt to unpleasant conditions. This study aims to describe the resilience of parents with CP children. Using qualitative methods, subjects were 2 mothers and had children with CP. Data collection used were interviews, techniques were phenomenological analysis and descriptive validation. This study describes that research subjects are able to apply the aspects of resilience namely causal analysis, emotional regulation, impulse control, optimism, self-efficacy, empathy and reaching out in caring for CP children so that they are assessed as resilient parents. In addition, they can be resilient due to other supporting factors such as learning, sincerity, support for family and environment, religiosity and proximity to God.*

*Keywords: Resilience, cerebral palsy, children, parent*

## Introduction

Children are a gift given by God, which must be nurtured, cared for, and educated well. The presence of a child has a very significant impact on the dynamics of a family. Parents who find one of their children is a child with disabilities, of course, faces more complex responsibilities in his life. They need more adaptation to be accepted in society.

One developmental obstacle that can occur in children is cerebral palsy. Cerebral palsy is a condition of paralysis of the brain which causes the absence of muscle control, posture abnormalities and motor movement barriers. A person can have cerebral palsy because there are several trigger factors, one of which occurs in the process of growth and development, namely TORCH infection (toxoplasma, rubella, cytomegalovirus, herpes). Cerebral Palsy is non-progressive, cannot be cured or can get worse if left untreated (Rye, 1989)

This certainly caused deep sorrow for parents after finding their child diagnosed with cerebral palsy. The cost of caring children with cerebral palsy is also greater than the costs they incur to support their normal children. In addition, the presence of more complex responsibilities makes parents with handicapped/disabled children potentially feel more depressed than parents with normal children. In line with the study, parents with handicapped/disabled children including parents of children with cerebral palsy have responsibilities and daily activities that are lived with a feeling of higher stress than parents of normal children. Various emotional reactions, and fatigue tend to disrupt their physical health conditions (Peer & Hillman, 2014)

Families who have children diagnosed with cerebral palsy will show various reactions, there are parents who

are disappointed and feel that their children are different from other normal children, on the other hand there are parents who want to accept special conditions for children and choose to exert their best efforts and responsible for caring for and educate children. This illustrates the condition of resilient individuals (Kalil, 2003). To be a resilient individual, everyone needs resilience, which is the ability to continue living after the unfortunate. Without resilience, there will be no courage, perseverance, no rationality (Reivich and Shatte, 2002).

Thus, resilience describes the ability to cope with and adapt to the severe events or problems that occur in life. That is, resilience will make parents with cerebral palsy child manage to adjust to dealing with stressful and unpleasant conditions while treating children with cerebral palsy conditions. From the description above, the researchers will assess the resilience of parents of children with cerebral palsy. It is intended that parents as the primary caregivers of children can figure out about their ability to carry out their responsibilities as parents and help their children grow optimally.

## Literature Review

### Resilience

Resilience is the ability to cope with and adapt to the severe events or problems that occur in life. Adapting to life stress, and overcoming the misery experienced in life (Reivich, K & Shatte, A, 2002). Resilience is the ability to bounce back from a stressful situation or event by making a new effort that is more adaptive when long efforts are deemed no longer suitable with existing conditions. Resilience motivates to deal with problems rationally, diligently and without violence, (Siebert, 2009). Seven abilities that form resilience are: control of

emotion, control of impulses, optimism, self-efficacy, causal analysis, empathy and reaching out (Reivich and Shatte, 2002).

#### Cerebral palsy

Cerebral Palsy (CP) is a rudimentary motion and posture that is not progressive, and is caused by damage to motor cells in the central nervous system that is in the process of growth. CP is a permanent motoric defect, not progressive, which occurs due to brain damage due to trauma at birth. Disability is characterized by abnormal or late motor development, such as paraplegic athetoid, spastic or tetraplegic, which is often accompanied by mental retardation, seizures or ataxia (Rye, 1989)

Cerebral palsy has the following characteristics: muscle stiffness; there are uncontrolled movements in the legs, hands, arms, and facial muscles; loss of balance characterized by unorganized movements; muscle stiffness so like a robot when walking; the existence of small movements without realizing it; and children experience several mixed conditions (Rye, 1989)

#### Resilience of mothers with cerebral palsy children

Various reactions that parents might raise when facing the reality of their child with cerebral palsy. There are individuals who are angry and disappointed with this fact so that they commit violence against themselves, their children, and others (Physical violence), some are resigned and feel helpless, most blame God, the environment, or other things which they can blame for what happened to them.

In addition there are also some individuals who decide to face problems, adapt to reality and quickly overcome challenges. They managed to overcome their problems, even rose to become stronger individuals and found life better. They are said to be resilient individuals (Siebert, 2005).

Resilience was formed from the interaction between risk factors, namely everything that has the potential to cause problems or difficulties and protective factors. In this case, the disability in the cerebral palsy child, the perceived anxiety, the environment that does not support are the risk factors that must be faced by parents. While protective factors are things that strengthen individuals or families in dealing with risk factors. The process of good and successful adaptation to a problem reflects the strong influence of protective factors possessed (Luthar & Cicchetti, 2000)

Mothers who have cerebral palsy children have most stressful conditions that can disrupt the stability of their lives if they do not develop resilience in themselves. This is in line with the results of a study by Miodrag and Hodapp (2010) which found that mothers who have children with developmental disabilities are prone to high stress which has a negative impact on their health. The study explains that unresolved stress affects their ability to effectively become parents, which decreases the quality of parent-child relationships, poor psychological well-being, increased anxiety and depression (Cramm & Nieboer, 2011). The researchers concluded that parenting

stress can be a significant public health problem, because chronic health problems caused by stress can have a negative impact on the ability of mothers to care for children and interfere with parent-child relationships

Thus, resilience is considered a basic force for parents who have children with cerebral palsy, because it is effective in encouraging parents to have a positive character, build emotional strength, and maintaining their normal functions in life.

#### Method

This research is a qualitative research with a phenomenological approach that is a research process that intends to explore in detail related to one's personal life experience with the results of a description of how someone gives meaning to a phenomenon related to his personal and social world (Hanurawan, 2016). This model is used to understand the phenomenon of what is experienced by the subject of research such as behavior, perception, motivation, action, in a specific natural context and by utilizing various scientific methods (Moleong, 2005).

The subjects in this study were parents who were devoted to mothers who had cerebral palsy children. Consisting of 2 mothers aged 30-45 years, who have children with cerebral palsy.

Data collection in this study were using in-depth interviews. In-depth interviews are used with the aim that researchers obtain rich and in-depth information about the thoughts, beliefs, knowledge, motivation and feelings of the research subject (Hanurawan, 2016). The interview guidelines used are developed from developing aspects of resilience according to Reivich & Shatte (2002). The interview guide contains open-ended question which is an open question but still directed to the research objectives.

Data analysis techniques in this study are phenomenological analysis techniques (Hanurawan, 2016). In this case, the data generated through in-depth interviews by researchers is carried out reduction of ideas statements in the core themes, which in this case aspects of resilience, to describe the gist of each aspect of resilience in the subject.

#### Results

This study used 2 parents with children with cerebral palsy as subjects. Each subject has different experiences in applying aspects of resilience which are explained as follows.

##### Subject 1

She is a 45 year old, with a bachelor degree. She is a housewife with a husband who works as a private employee. Her family life is in the middle economic level. The application of aspects of resilience is as follows:

*Causal Analysis.* She can analyze the cause of the problem. She realized the son had cerebral palsy because

of toxoplasma and rubella virus infections and stress conditions and poor health during pregnancy. Even though they faced some difficulties in the beginning of adapting to caring for her son. But she does not regret this situation, she still accompanies the growth and development of her son by making the best effort.

*Emotional Regulation.* Initially she felt sad, shocked confused, weak, and afraid of having son with cerebral palsy. Then she overcomes this by thinking rationally, taking action to seek information, cooperatively in treatment

*Impulse control.* In dealing with disabilities that afflict her son, she decided to be more grateful and see the positives of what she is experiencing at the moment. When her emotions were uncontrolled because of her child's condition, she tried to understand the son's weaknesses. She is helped to control her emotions because she gets support from the family.

*Optimism.* She realized cerebral palsy was an incurable condition. Facing this reality, she continues to foster a positive belief that she is able to care and teaches good things for her son, trains her son to master independent tasks, understand cues, and provide the best nutrition.

*Self-Efficacy.* She has good self-confidence. She often invites her son to activities outdoor, stay in touch with family and neighbors and activities in public places.

*Empathy.* She has a good emotional attachment to her son. She can understand the wishes of the child only from the body language shown by her son. As a form of concern for parents who experience conditions similar to their own, she became the pioneer of the Parents of Child with Cerebral Palsy Community. She and the community members often share information and insights and accept and motivate each other.

*Reaching Out.* She assesses the son entrusted by God with special conditions for her care is "teacher" who trains him to have more insight, a strong person, patient in controlling emotions, being independent, not too idealistic, wiser in facing different judgements from people, devote greater affection to her son, and become more intimate with family.

## Subject 2

She is a 43-year-old with a high school degree. She is a housewife with a husband who works as a private employee. Her family life is in the upper middle class economy. The application of aspects of resilience is as follows

*Causal Analysis.* She can analyze the cause of the problem. She was pregnant in a diabetic condition, so the brain growth in her fetus became imperfect. She stated, having a child with cerebral palsy was the fate of God and she decides to think positively in living it.

*Emotional Regulation.* At first knowing that her daughter had cerebral palsy, she felt down and worried. She overcomes these feelings by being calm, cooperative in therapy and treatment and eager to actively stimulate motoric development of her daughter at home in accordance with what she learned at the therapist

*Impulse control.* Choosing to think more positively, understand the weakness of her daughter, not demanding, and be grateful for not being burdened with the more severe condition of cerebral palsy. She is also much closer to God.

*Optimism.* She has the determination to continue to provide whatever the daughter's right is. Such as best health care, recognition in the environment and family, being responsible for themselves, helping her daughter to be independent and communicate with simple gestures, and giving the right to education in inclusive schools.

*Self-Efficacy.* The development of her self-confidence is very good even though she has daughter with cerebral palsy. This is because her family, friends and neighbors provide full support and still invite her to socialize in the environment.

*Empathy.* She knows how to encourage the positive mood of her daughter who has cerebral palsy with music. Besides that she also taught her husband and her two other daughter to accept and how to care for their youngest child who has cerebral palsy. She wanted to be useful in the community, so that she joined the community Parents of Child with Cerebral Palsy, involved in listening to each other sharing activities and giving motivation to them.

*Reaching Out.* She believes that having a child with the condition of cerebral palsy is God's destiny that provides many changes in her life and her family. She feels that it is easy for human to think positively, more adaptable in various situations, not demanding in the family, appreciating small changes, find that her husband concerned about the family and devotedly worshiping and close to God, that the family becomes more intimate.

## Discussion

The information that has been conveyed, each subject has given an overview related to aspects of resilience in themselves. Both subjects have their own views and ways of applying every aspect of resilience in their lives.

Regarding to the analysis aspects of the causes of the difficulties experienced, both subjects have good understanding regarding causal analysis or the cause of their children who had cerebral palsy. Both of these subjects showed that they had a good causal analysis aspect in themselves, they fully realized the cause of their problem but did not give up and blame anyone, they still developed the belief that they could overcome and take action to overcome the adversity. In line with what is revealed in the theory that resilient individuals are individuals who have cognitive flexibility. They are able to identify all the causes of adversity that afflict them without feeling pessimistic that the condition is permanent in their lives and cannot be changed. Resilient individuals will not blame others for their mistakes in order to maintain their self-esteem or free them from guilt. They are not too focused on factors that are beyond their control, on the contrary they focus and take full responsibility for problem solving, slowly overcoming

existing problems directing their lives and achieving success (Reivich & Shatte, 2002)

Regarding to the regulatory aspects of emotion, both of them gave a statement that they did not drag on into sadness and gave up on the situation. They show the ability to overcome difficult conditions and the stressors they face by being cooperative, taking focused and consistent steps to support the family, seeking information, consulting experts. Their ability to adapt to the emotions they feel and take steps and determine a rational attitude to overcome their problems proves good emotional ability. This is in line with the theory revealed by Reivich and Shatte (2000) where someone who has good emotional regulation will be responsible for monitoring, evaluating, and modifying emotional reactions, especially the intensity and timeliness to achieve a goal

The results of previous studies also support this, a study exploring the role of social support as a factor that strengthens resilience in a person (Heiman, 2002). Good social support can encourage individuals to openly discuss concerns with family and professionals and correlate with the high resilience of parents with disabled children. Research by Freedman, Litchfield, and Warfield (1995) found formal social support to be a major stress management factor for working parents of children with developmental disabilities.

In the regulation of emotions applied by both subjects they were able to show calmness and focus to overcome the stressors they faced. Reivich and Shatte (2002) reveal that two skills can make it easier for individuals to regulate emotions that are calm and focused. So that individuals who are able to manage both of these things can take advantage of their potential to relieve existing emotions. This ability helps individuals to improve control of the stressors they face. In focus skills, it is easier for individuals to find solutions to existing problems

During nurturing children and adapting to children in everyday life, both subjects showed good emotional control. In various conditions that give rise to resentment and anger, both subjects always think clearly before raising their attitudes towards children, practice gratitude, understand children's weaknesses, minimize negative emotions by remembering religious rules such as submission and have proximity to God.

The behavior that is shown by both in order to face of the environment that gives negative attitudes and sayings to their children who have CP is to respond patiently and calmly by giving a simple explanation regarding the actual condition of the child, because both understand that the other person's questions that intersect those feelings are due to ignorance they have about the condition of a CP children. They are increasingly motivated to train their children to be friendly and teach them to interact. The ability to respond with positive emotions shows that both subjects are able to function aspects of impulse control properly. This is in line with the results of the study that resilience correlates with high flexibility in dealing with difficult situations, low

negative emotions and increasing life satisfaction (Kaboudi, Abbasi, Heidarisharaf, & Dehghan, 2018)

In addition, both subjects were considered to have good optimism in caring for their children in the midst of the condition of children with CP. Both subjects have a positive belief that by intensely guiding children and teaching everything that is good, their children will try to master independent tasks in serving themselves in their daily lives. Parents show good responsibility by giving children's rights in the form of love, care, therapy, cooperatively stimulating children's motor skills at home, and still strive to give children the right to get the education in the midst of their limitations. Both subjects felt a better progress towards the efforts they had made so far with confidence.

Optimistic individuals believe that a difficult situation will someday turn into a good situation. They have hope for their future and they believe that they are in control of the direction of their lives (Reivich & Shatte, 2002). The two subjects illustrate that they have good optimism in caring for children with CP, they instill confidence that their children will be able to achieve certain targets in their development and in realizing that, confidently exert every effort they can such as medicine, therapy stimulation and creating supportive conditions such as cooperation and support every day to achieve their expectations.

Regarding self-efficacy, both subjects were considered to have good self-efficacy. Destined to have children with CP does not make them socially isolated and becomes a barrier for them to continue to actively interact with the surrounding environment. They live close to each other, and their relationships with families is good. Both subjects often invited their children to meet with neighbors, family, recitation, and walk around to public places. One subject also remained active in social media, he often uploaded photos of her child. As for the subject's conviction by doing this the child believes that they are receiving sincere reciprocity from their parents.

In the aspect of empathy, both subjects were able to show good empathy in everyday life. Both subjects have very good emotional attachment to children which makes children very dependent on them. Both subjects acknowledged that they were able to recognize the child's emotional needs and conditions only from their body language and eye contact. Likewise, the two subjects admitted that their children seemed able to understand the very simple prohibitions and orders they conveyed to children and the children showed an attitude of obedience to what they said. Meanwhile, having children with CP was considered by both subjects as making them to have greater empathy for others, especially those who have similar fate with them.

Both subjects joined the parents of child with cerebral palsy community, in the community the two subjects gave a positive contribution where each of their actions was motivated by the concern of fellow parents and CP children, both subjects acknowledged that they were often involved in sharing insights and providing support to other members. The attitude shown by both shows

their ability to empathize. As explained in the theory that individuals who are able to empathize will be quite proficient in interpreting nonverbal languages that are shown by others, such as faces, voice intonation, body language and being able to capture what others think and feel. Therefore, someone who has the ability to empathize tends to have positive social relationships (Reivich and Shatte, 2002)

In the aspect of Reaching Out, both of them have their own meanings related to the positive aspects they get during exerting their efforts to live the reality of being a parent with cerebral palsy child. Both subjects interpreted that the child entrusted by God with special conditions for them to care taught many positive attitudes and maturity in addressing life and the environment.

Both subjects have good reaching out abilities, they can adapt to the stressors they face and get positive meaning in the process. This is in line with the explanation of the theory that one of the characteristics of good resilience in a person is his ability to achieve positive aspects of life after the affliction that afflicts. Good reaching out in individuals becomes a factor that helps in the meaning to change threats into opportunities to grow, develop and improve one's ability to adapt, and help someone explore and discover new qualities in his life through the process of facing adversity (Reivich and Shatte, 2002).

Their intermediate economic status do not become obstacles in overcoming stressors while caring for children with CP, both subjects have the motivation to seek all abilities amid the limitations they have. The process they go through forms a good mindset and dominance of positive feelings. This shows the development of aspects of good resilience.

Based on the level of education, 1<sup>st</sup> subject who has a bachelor degree has a greater initiative in applying aspects of empathy in her, as seen from her initiative to be a pioneer in forming Parents Child Cerebral Palsy Community, actively sharing current insights and motivating other community members. 2<sup>nd</sup> subject who has a high school degree is also considered to have quite good empathy skills, only so far her involvement in the community is limited to providing support to fellow members.

Before becoming a resilient individual, the two subjects experienced dynamics within themselves until they finally proceeded towards resilience. Based on this explanation, it was known that subject 1 and subject 2 were resilient individuals. In every aspect of resilience, most have in common. Resilience in the second self is influenced by several factors such as the learning process, actively seeking information, acceptance of the full situation, support from family and environment, religious beliefs.

Overall, both subjects in this study showed good ability to apply each aspect of resilience. This is illustrated by how they think about their problems, how to process emotions to choose actions that mostly lead to positive actions while maintaining children with CP conditions.

This is in line with the study by Skehill (2001), who found that resilience is related to the high use of effective and useful coping strategies. In explaining these results, it can be said that people with high resilience are directly involved with problems when faced with situations that suppress and use all their strengths; this condition makes their mind and reduce their emotional parental stress. In addition, the use of resilience skills in stressful situations leads to a focus on the individual's problems and efforts to solve them as a result of this intellectual coherence and identify sources of stress, which makes the source of stress seen conditionally (Skehill, 2001).

In this case, even if the problem is not resolved, identifying stress sources of parents on the one hand increases awareness and feelings of control over stress on the other hand, this is what helps improve mental health. Improving endurance skills, activates individual mental processes, and this cognitive activity enhances an individual's view of the problem and source of Parental Stress (Kaboudi et al., 2018).

### Conclusion

Based on the results of descriptive qualitative research on the resilience of parents who have children with cerebral palsy, it was concluded that both subjects applied causal analysis, emotion regulation, impulse control, optimism, self-efficacy, empathy and reaching out aspects well in their lives so that they could have resilience in maintaining children with cerebral palsy.

Before becoming a resilient individual, both subjects experienced dynamics within themselves until they finally proceeded towards resilience. Resilience in both subjects is influenced by supporting factors such as the learning process, acceptance of the situation, support from family and environment, religious beliefs.

Based on the results of this study it can be seen that it is important for parents to develop resilience in life. Because resilience helps in encouraging the ability to control the pressures of everyday life and encourages someone to find positive meaning in the problems that occur.

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