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in Health, Educational, Social, and Organization Settings

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"Psychology in Changing Global Contexts"



**Faculty of Psychology
Universitas Airlangga**

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International Conference on Psychology in Health, Education, Social and
Organizational Settings (ICP-HESOS)
“Psychology in Changing Global Contexts”

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Mothers' Acceptance Process Towards Impaired Children With Cerebral Palsy

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Abstract.

This research examines acceptance process on mothers who have impaired children with cerebral palsy. Participants in this study are two mothers. Their children with cerebral palsy aged 12 and 14 years old, both live in Surabaya. Qualitative method with intrinsic case study was used to analyze both participants. The result indicates that coping strategy and social support play an important role in both mothers' acceptance process. Differences in coping strategy and social support fulfillment though resulting in unique acceptance condition for each mother. There are other factors, internal and external factor which influence differences in coping strategy conditions thus resulting in mothers' acceptance condition. Those internal factors are personality, religiosity, and value of having a child. Whilst, external factors are demographic and cultural background.

Keywords: acceptance, cerebral palsy, social support

INTRODUCTION

Not all mothers are blessed with normal children. Some of them are given children with special needs. Children fall on this category have several impairments, physical and/or cognitive. One of those special needs is cerebral palsy (CP). Cerebral palsy is a motoric disorder occur on the child due to brain damage before, during, or after labor. The brain damage affects motoric system resulting in insufficient coordination, poor balance, and abnormal movement pattern (Miller & Bachrach, 1995).

Cerebral palsy on children can be a significant stressor for a mother as the caregiver. Stressor comes from child's condition is revealed by Vijesh and Sukurmaran research (2007). From fifty mothers with CP children, 16 mothers were identified to have mild stress, 23 mothers are on moderate stress, and 11 are on high stress. Vijesh and Sukurmaran continued, the most affecting factor in the stress is pessimistic views towards their children disability and problems appear within their family.

Altindag, Iscan, Koksai, Ercin, and Ege research (2007) on 52 mothers with CP children also found high level of depression and anxiety. Not only that, Sajedi, Alizard, Malekkhosravi, Karimlou, and Vamegi (2010) on 43 mothers with CP children aged above 8 years old found that mothers with CP children on various types have a correlation with an increased on prevalence and severity level of depression symptoms.

Among mothers, it is common for them to deny or reject their children's condition. It is stated by Geralsis (1998) that a lot of parents continually deny their CP children's condition. They keep hoping that their children do not have CP. It was supported by a survey (Zhang & Liu, 2010) on 26 mothers with CP children which showed that most mothers could not accept their children having CP. They added, stress adding factor is the lack of information about CP.

Acceptance itself is a stage which an individual realizing that nothing could be done to change a reality into something desired other than accept it (Ross, as cited in Davis, 2009). With that, author predicts that mothers need a coping strategy as a way to help them while taking care and nurturing their children with CP. It is also wished to help mothers on fully accepting their children.

Coping is a stress management process for a situation deemed as difficult or overbearing individual's resources and a way to control enviromental and personal condition (Lazarus & Launier, as cited in Ogden, 2007). Its main goal is to reduce stressor faced by individuals. Ogden (2007) explains that coping, in relation with stress context, reflects individuals means in interacting with stress and trying to be back normal. Author predicts if mothers' coping are effective, it will help them to achieve



acceptance towards their children condition. In Pain research (1999), it showed majority of 20 parents, consisted of five pair of parents and ten mothers having children with certain disability, need other people to share their stories and to gain information as their emotional coping. Pain's research also showed parents need the presence of other people or it can be said social support is a coping as well.

Social support itself is a resources owned by someone to help them see that stressor they have is manageable (Ogden, 2007). In Heiman (2002) research, from 32 parents of children with special needs, most parents highlighted the need of social support and resources which would affect parental acceptance, optimism, realistic view towards children, and give positive affirmation for their children. This finding may express that social support is one of important factors needed by mothers to select coping strategy and to give positive impact on mothers' acceptance process towards their children condition with cerebral palsy.

Departed from those notions, in this research, author wants to reveal mothers' process in achieving acceptance towards their children condition with cerebral palsy. During the whole process, it can be asserted that coping strategy and social support play a big role. This changing an achieving process in acceptance will be observed in this research.

METHOD

This research uses case study approach with interpretive paradigm. Author wants to observe from mothers' perspective on building meanings and understanding internal events within mothers for having children with CP. Thus, this research will not aim for generalization but on subjective meanings. Participants in this study is two mothers (called 'Fefe' and 'Fafa') of impaired children with CP, both children aged 12 and 14 years old in Surabaya. Data gathering techniques were interview and observation to both participants and significant others.

Fefe is 39 years old woman, has Chinese ethnicity, and has three kids. The youngest are twin daughters and one of them is having CP. The CP was identified when she was 7 months old and it was caused by a severe seizure when she was on her third month. Fafa is 50 years old woman, has Chinese ethnicity, and has two kids. The older is a daughter while the younger one (10 years age gap) is a son. Her son was diagnosed with CP when he was six months old. Fafa was in Samarinda during that time.

RESULT

Fefe and Fafa have children with different types of CP. Fefe's daughter has a hypotonic type marked with limp body and could develop to be spastic type. Hypotonic may also occur with seizure at any time. Fafa's son has a spastic and athetoid type. This type is marked with rigidity in body and facial muscle, difficulties in controlling movement, and speech. Fafa's son cognitive ability can be classified as normal, equal to children at his age while Fefe's daughter can be justified as non-functioning. Fefe's daughter need more attention and extra care because at any time she could experience seizure and as much as possible it has to be avoided. Seizure will damage the brain functions further. On the other hand, Fafa's son condition requires extra energy to carry her son for his mobility. This different characteristics of CP lead to a different acceptance stages. The following will be described how each mothers develop their acceptance on their children's condition.

Fefe and Her Social Cope

Fefe's daughter experienced a severe seizure when she was three months old. It caused a brain damage. Her daughter became regressed like a baby she was who could not do anything. Whereas before seizure, she could hold her head up. When it occurred, Fefe and her husband brought their daughter to a pediatric. The pediatric could not clearly explained her daughter's condition but suggested therapies. That time, Fefe believed that through therapies and medication her daughter could recover. Day by day, Fefe spent her time by taking care of her daughter and it changed her life completely. She became restless and agitated because unknowingly the seizure attack could happen on her child. Fefe felt distressed, tired, and confused. Luckily, her husband accompanied her during those times. Fefe and her husband didn't stay still and kept on looking for information about her daughter's sickness and what kind of treatment can be given. Information gathering was done through Internet, seminar, and friends.

This information gathering by Fefe was a part of coping strategy. It is a coping approach with problem-focused coping goal. Big support from her husband made Fefe felt lighter. Her husband also said that he felt the need to support his wife.

Based on information gathered, Fefe and her husband had predicted that their child was impaired with CP due to similar characteristics. But, they didn't dare to diagnose that because the doctor did say nothing. After looking for information from friends, Fefe and husband took the initiative to move the treatment to a doctor who specialize in handling children with special needs. From there, Fefe knew exactly that her daughter had CP and that time her daughter was 7 months old. After they knew it, they were not really surprised because they had the prediction before. Fefe still felt sad though but she could not runaway from the fact. Her daughter had CP. It took one month for Fefe to process herself to be open with her daughter's condition. She was supported by her husband and her own character that is open to unwanted things in her life.

Various therapies underwent for her daughter. Fefe even bought an expensive supporting tools. She bought an immensely expensive medicine to control the seizure. All those medications are within reach because Fefe's economic is considered as middle-up. She lives also in a big city which makes any current medications accessible. Fefe also was supported by her husband and her mother while taking care of her children. Fefe's mother often came up to look after her daughter with CP.

Material readiness and close support from relatives are factors supporting coping. Quinn and Gordon (2011) said that psychological support and material readiness give power to the mother during the initial process of taking care her child impaired with CP.

After Fefe could pass through her daughter's condition, Fefe could not resist that she made a vow. If her daughter's is cured, she will celebrate it. But then, she realized that she had to accept what is given to her by God. This view is supported by her religiosity and her faith on Buddhism teaching about accepting that is important part in living this world. The importance of accepting stressed by Fefe is coming from her faith. It is one of coping strategies which aimed on emotional focused coping.

"Yeah, given by God a child like Nana, it means God trusts me to have a child like Nana.. I think it that way to comfort myself..." (Monday, 23 July 2012)

With emotional focused coping which stressed on acceptance, it made Fefe easily living day by day taking care of her daughter. Up until her daughter reached 5 years old, Fefe continued to focus on taking care by her own. She could not freely go out and it was often she could not go out with the rest of the family because she had to take care her daughter.

After five years, Fefe opened up her mind that she had to live her own life. This was because her husband made her realize not to drowned with her daughter's condition. Fefe's younger sister also kept telling her the same thing. Fefe finally opened up and started to seek help from sitter to take care her daughter with CP so that she could take care of her other children and have activities with her own friends. This was also heavily supported by her trait, open to things and accepting. This kind of help is also a coping strategy, problem focused coping. Taanila, Syrjala, Kokkonen, and Jarvelin (2002) said that children sitter is a way of coping strategy and a right choice to support parents in adapting with their child's condition.

After Fefe believed and willing to seek for help from a sitter to take care her daughter, Fefe felt better. This better condition also affected Fefe's emotional state that could truly accept her child with CP presence. This acceptance was achieved because of those coping strategies applied by her and the presence of social support surrounding Fefe. Appropriate problem focused coping and emotional focused coping were used while taking care of her child. It is resulting a positive impact on her acceptance. It is as stated by Draper (2009), the more defence mechanisms used by the mother dealing with her child with CP, it will give more positive results. Draper continued, those conditions should also be supported by adequate facilities as the lack of facilities will influence mother's coping style. Other than that, Fefe was also supported by her neighbour. They emphasize and give encouragement to her. It is not rare Fefe's friend come to her house and lift up her spirit to accept her child's condition.

Fefe also valued on having a child as a mean to fulfill her loving nature, which Fefe does not ask for return. She just wishes her child to be in a better state, it makes her feels happy too. This value helps her to achieve a better acceptance. The chart below will explain:

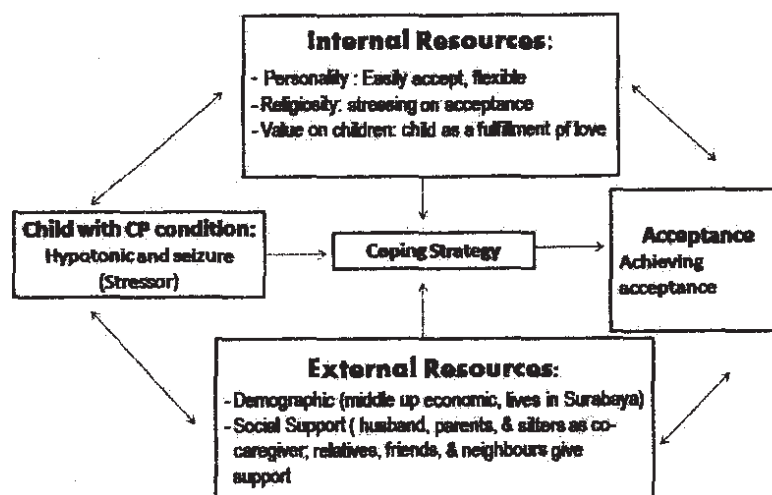


Figure 1. Fefe's conclusion

Fafa and Her Spiritual Cope

Fafa's happiness stopped abruptly and turned into deep sadness. When it was his sixth month, Fafa's son suddenly got diarrhea and feverish, 37.5°C. Fafa was in Samarinda that time and took her child to hospital right away. Next day, the diarrhea was stopped, but her son became like a baby again. The doctor who took care of her son did not explain anything but said her son got a CP due to virus. But, the doctor did not elaborate further what is CP and what had to be done. Fafa asked for explanation but the doctor replied harshly and even blamed her because she was late taking her son to hospital. Fafa was upset since she thought she was not late taking her son to hospital. She admitted that she felt messy, apprehensive, angry, confused, disappointed, and could not accept the reality. Crying was the only thing that Fafa did everyday. Luckily, on that condition, her husband accompanied her and tried to console her. But, Fafa and her husband did not understand what their son is going through.

After coming back from hospital, Fafa took care of her son by her own because her husband had to go out of town for work. Fafa abandoned her activities such as selling stuffs, church activities, and gathering with friends. She focused on her son with CP while her first child, aged 10 years old that time, can take care of herself. Fafa did not need to pick her up in school, feed her, or helped her studying. She felt depressed continuously, but she could not express it to anyone. She only could mention it to her husband through phone. Whenever she was sad and needed to talk, she would call her husband. But, Fafa did not get a direct support which was a helping hand, an actual presence from her husband, by taking care and nurturing their children.

Fafa handled that thing alone. In the beginning, Fafa denied her son's condition and went to various doctors and alternative medications.

Fafa's effort to try various medications was a mean of problem focused coping. Luckily, Fafa has a good economics. Her husband also trusted the decision on Fafa to cure her son. For two years, Fafa was in anger state. Fafa was in an emotional roller-coaster because of her son's condition. It got worsen when the doctor and her mother blamed her. Fafa felt guilty and assumed she caused her son this problem.

Fafa's condition overwhelmed with anger is common to mothers who have children with CP. Geralis (1998) said that a lot of parents of children with CP tend to blame themselves as the source of the tragedy befall on their children.

Her guilt was worsen because in Samarinda, people saw her as the cursed one for having a child with CP. People built gap with her after they found out her child is not normal. It happened because on the 90s, Samarinda was under-developed and people there still believe in mystical things. Unsupportive social situation made Fafa felt even worse and she did not know where to go. She even blamed God about her son.

Fafa decided to go to Surabaya for one year after knowing about alternative Chinese medicine that she found from Internet. Fafa went to Surabaya for one year. She lived in rented house together with her son. This alternative medicine is a problem focused coping. Fafa tried various ways and her guts was affected by her character. She was ambitious and stubborn. She kept on trying to cure her son.

From the alternative medicine, Fafa acquired explanation about her son's condition. Fafa became

understand what is CP, how is her son's condition, and what need to do to maintain his condition. Palisano, Almars, Chiarello, Bagley, and Maggs (2009) research on 501 parents of children with CP showed that more than half participants need professionals service to guide them while nurturing and taking care their children. After one year, Fafa went back to Samarinda but she continued the therapy by buying therapy equipments for her son in Samarinda. Fafa also enrolled her son into a school for children with special need like autism, so her son can socialize.

As time goes by, her emotional state was still in up and down phase moreover she had to take care her child on her own. When she was tired, saturated, and upset, she felt downhearted. Crying was not a solution for Fafa any longer.

"I couldn't even cry now.... Now if I am being told to cry, I couldn't cry anymore. Truly. No tears. If people said, crying until tears drying out, that's true. I, I, now if crying, no tears come down. I can not cry any longer. (Monday, 30 July 2012).

When she felt down, emotional focused coping that she did was by going out of her house for a while or calling her husband. But she could only call her husband at night because her husband had to work. Other than her husband, she had no place to share because her mother was not supportive in dealing with her son's condition.

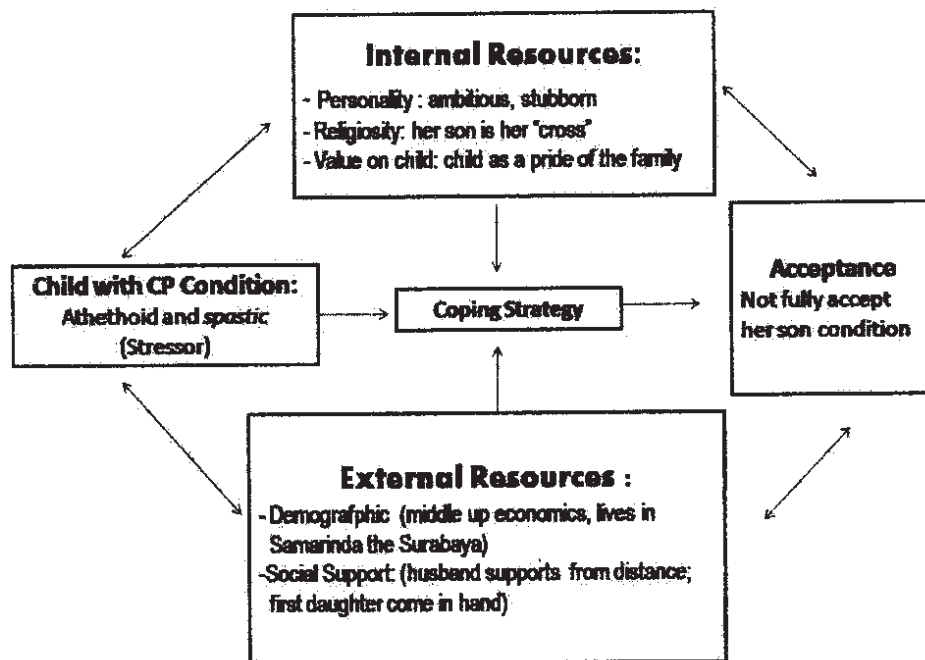
After 7 years in Samarinda, Fafa's first daughter wanted to continue her study in Surabaya. That time, Fafa thought that if she moves to Surabaya, she could seek for better treatment. In Surabaya, she found a school for children with CP, which was a YPAC (institution for disabled children). In this place, her questions were answered and it opened up her mind to accept her son's condition. Fafa could see there are a lot of people have children with worse condition and she felt that she have a community to accept her, gather together with other parents of children with special needs. Here, Fafa could find a place for herself and her son because while they were in Samarinda, she rarely

saw parents of children with special needs. They tend to hide their children.

From the institution (YPAC), Fafa could see that her child is her little cross that is given by God and she should carry it. She grew her spiritual perspective on her problem. This emotional focused coping brought positive impact on Fafa. She became calmer by seeing that Lord Jesus carried heavier cross and her son is only a smaller cross for her to carry. Whenever she felt down again, Fafa often begged to God to strengthen her. Fafa would pray to God and asked His consolation.

Fafa's openness to her son's condition and her emotional focused coping made her started to accept the condition. But, Fafa still could not completely accept her son's condition. It was caused by her desire that exacted better progress from her child, to be more independent without realizing that it is difficult to achieve for her son. Fafa's wish is backed by her age. She is 50 and she realizes that she is not as agile as before, to take care her son such as carrying her son. But she insists to not using a sitter for her son. Fafa does not want to use a sitter because she thinks that raising the child on her own could redeem her guilt. More than that, the value of having a child as something that she could be proud of is another reason why she wants her son to be more independent compared to other children with CP. This value to view a child as parents' pride is influenced by family ethnicity and background. Chinese family tends to see sons as the pride of the family.

Jersild (1974) said that individual with acceptance could accept their own self, have realistic view on their condition, and valued themselves while calculating their own limitation. Based on explanations above, it could be seen Fafa's acceptance is incomplete. She wants her son to have unrealistically better condition. Beside that, the lack of support from her significant others makes her stands still with her decision and conviction. This condition admitted by Fafa makes her feels tired and affects her emotions. It makes her feels even more down hearted. Further explanation see chart below:



DISCUSSION

and values on children. External factors are demographic and cultural background. Differences in fulfilling those factors could affect mothers' acceptance process. It could bolster or even hamper the process and changes in one factor could impact other factors. With that, it can be said that one factor to another are closely related thus it affects acceptance process on mothers toward their children's condition.

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