

Mothers' Coping Strategies for Children with Autism Spectrum Disorder

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Abstract: Autism is a severe developmental disorder that occurs throughout life, but this behavior can be reduced with proper handling and care from parents, family, and society. The right efforts made to autistic children will affect their growth and development to be better and more useful. The family, especially the mother, is a very important figure who influences the process of child growth and development. Mothers who educate and care for children with warmth will certainly have a more positive impact on children compared to mothers who do it as a duty or just an obligation without involving warmth. The purpose of this study was to determine the coping strategies of mothers who have autistic children and to determine the factors that influence coping strategies. This study uses a qualitative method. The subjects of the study or someone who provides information are mothers who have early childhood children and their neighbors by conducting interviews. Based on the results of the research and discussion that have been carried out, it can be concluded that the coping strategies used are problem focus coping in the form of exercised (cautiousness), emotional focus coping which is done by changing thoughts from being disappointed and sad and finally becoming an acceptance which is done by finding the meaning of the failure experienced by themselves and trying to be grateful (seeking meaning) and another form is escape avoidance or avoiding oneself, which is done in the early days when their child was diagnosed with autism which then tries to grow awareness of oneself of responsibility for the child (accepting responsibility). Factors that influence coping strategies are internal factors and external factors. Internal factors that influence are age and self-awareness of responsibility as a mother. The external factors are family support or social support, education level and economic conditions.

Keywords: Coping Strategy, Mother, Autism

INTRODUCTION

Autism or what is now better known as Autism Syndrome Disorder (ASD) is a pervasive developmental disorder that is quite severe. According to Mash & Wolfe (in Lubis, 2009) autism disorder is characterized by abnormalities in social, communication and language functions, as well as limited behavior and interests in children. Children with autism spectrum disorders need more attention. However, we must not forget the people who will educate children with ASD. Therefore, parents, especially mothers, must also receive attention from those around them in order to solve their problems. According to Beckman (1991), some families, including families with children with autism, a mother tends to experience more stress than the father. Mothers who have children with autism actually experience chronic stress that is comparable to the stress of combat fighters or soldiers, this is based on research conducted by Marsha Mailick Seltzer, Ph.D at the University of Wisconsin-Madison. This must be an important concern to be considered because mothers must still be able to maintain the survival of their children.

Poor psychological conditions experienced by mothers of children with autism do not necessarily make them free from responsibility for carrying out the task of caring for their children. Mothers need the ability to deal with stress and a healthy mentality to carry out their duties in caring for children. The condition of parents who have autistic children is likely to affect the psychology of the parents. If parents have poor psychology, it will affect the coping strategies of parents, especially

mothers, in caring for children.

I think it is important to conduct this research because autistic children need special attention and handling, especially from their mothers who are tasked with accompanying their growth and development. Parents need a strategy to face all these challenges which of course cause stress, this strategy is called a coping strategy. This autistic child will get the right treatment if the coping strategy used by the mother is appropriate. The usefulness of coping strategies is so that someone can continue their life even though they have problems, namely to maintain emotional balance, maintain a positive self-image, reduce environmental pressure or adjust to negative studies and continue maximum relationships with other people Firdaus (in Wardani, 2009). This coping strategy can be influenced by several factors, namely internal factors and external factors. Internal factors include personality and the coping methods used. Taylor (in Rahmawati 2018:24) suggests that an individual's reaction to stress and the coping strategies used can be influenced by personality. For example, people with optimistic personalities tend to problem focus coping, they will tend to be enthusiastic about finding solutions to problems because they believe that all problems have solutions while trying. External factors include time, money, education, quality of life, family and social support, and the absence of other stressors. Taylor (in Rahmawati, 2018) said that coping strategies tend to be more effective if there is support from people closest to them such as relatives, friends, and professionals who will make it easier to carry out the right coping strategies in solving problems.

From the description above is certainly a very important study that will later be used as one source of knowledge for mothers who have autistic children to understand how to carry out the right coping strategy in order to accompany their child's growth and development optimally with a healthy mental condition (can handle existing stressors) so that they can continue their lives with full acceptance and understanding of the problems being faced and how to overcome them. It is also important that this study is conducted to educate external factors that greatly influence the coping strategies carried out, namely social support. People in this category such as family, friends, people around them, or professionals if they understand their position and how much influence they have in the coping strategy carried out by mothers with children with autism disorders, of course, will greatly help its effectiveness.

METHODS

This study uses a qualitative approach. According to Bodgan and Taylor (in Moloeng, 2010:4) defines qualitative methods as research procedures that produce descriptive data in the form of written or spoken words from people and observable behavior. The subject of this study is the center of attention or target of the researcher. The subject of the study in this study was a mother with a child with mild autism disorder by involving people close to her (people who live in the same house as the informant or her neighbors). This informant was selected from several people who were truly trustworthy and knew the object being studied (Koentjaraningrat, 1993:130). In relation to the completeness of the information to be obtained, such as the completeness of information in accordance with the focus of the study, it is necessary to use data collection techniques. The data collection techniques are interviews, observation, and documentation. The data analysis technique used in this study is to use the concept given by Miles and Huberman. Miles and Huberman stated that activities in qualitative data analysis are carried out interactively and continuously until complete, so that the data is saturated. According to Miles and Huberman (in Emzir, 2010:129) there are three types of activities in qualitative data analysis, namely: data reduction, data models, and drawing conclusions. In qualitative research, research is the main instrument in collecting data interpreting

data guided by interview guidelines and observation guidelines. By conducting in-depth observations and interviews, we can understand social interactions, explore feelings and values reflected in the statements and behavior of respondents. In order for this research to be directed, the researcher first compiled a research instrument grid which was then used as a reference for creating observation interview guidelines. Validity is related to the issue of limiting or suppressing errors in research so that the results obtained are accurate and useful to be implemented (Suwarno, 2006:83). To determine the validity of data, an examination technique is needed. The implementation of the examination technique is based on a number of specific criteria. There are four criteria used, namely the degree of trust, transferability, dependence, and certainty (Moloeng, 2010:324). The examination technique used in determining the validity of the data in this study is to use triangulation. Triangulation is a data validity examination technique that utilizes something other than the data for checking purposes or as a comparison to the data (Moloeng, 2010:330). Denzin (in Moloeng, 2010:330) distinguishes four types of triangulation as an examination technique that utilizes the use of sources, methods, investigators, and theories. This study will use triangulation with sources. Triangulation with sources means comparing and checking the degree of trustworthiness of information obtained through different times and tools in Patton's qualitative research (in Moloeng, 2010:330).

RESULT AND DISCUSSION

Coping strategies are ways and efforts of a person to be able to overcome problems, the results of the study showed similarities and differences between one parent and another in dealing with autistic children, based on the data obtained from the results of the study, it can be seen that the coping strategies of mothers who have autistic children can be understood as a whole through the explanation given in the discussion of the research results interview. In the process of coping strategies include several aspects as follows:

Positive Emotional Maintenance

a. Considering alternative solutions to problems

Problem-solving skills include the ability to seek information, analyze situations, identify problems with the aim of generating alternative courses of action, then consider those alternatives in relation to the desired outcome, and finally carry out the plan by taking appropriate action.

Santrock (in Estria, 2008) stress management strategies (coping) can also be classified into 2, including approach strategies which include cognitive efforts to understand the causes of stress and efforts to deal with the causes of stress by facing the causes of stress or the consequences directly, such as seeking information and trying to solve problems with positive adjustments. From the results of the interview statements, parents carry out coping strategies by seeking solutions in the form of information on therapy places for their children. Another similar theory is according to Smet's theory (1994), coping that focuses on solving problems, which is called the Problem-focused coping theory in the form of Instrumental Action.

It can be concluded that they did problem focused coping that is, they seek solutions to their problems so that the problems are resolved. Another coping strategy that is used is to do emotional focus coping namely by changing the mind from being disappointed and sad about the condition of his child who was not as normal as other children to thinking that there are still many children whose condition is below his child, with this state of mind, the subject

feels calmer and there is still hope for his child's condition. The theory related to emotional focus coping namely: According to Lazarus and Folkman, There are two types of strategies for dealing with stress, namely behavioral and cognitive in the form of problem focus coping and emotional focus coping, while what is in accordance with mother X2's actions is that she carries out emotional focus coping in the form of overcome the negative emotions that accompany it. This strategy is to reduce individual emotions caused by stressors (sources of stress), without trying to change a situation that is the source of stress directly.

Subject 1 hereinafter referred to as mother X1, subject 2 hereinafter referred to as mother X2 and neighbor X1 hereinafter referred to as mother Y1. The actions taken by subject mother X2 fall into the category of emotional focus coping, namely seeking meaning, mother X2 tries to take wisdom or lessons from the problems she is facing, mother X2 tries to be grateful for her child's condition because there are still many children whose conditions are worse than her child's. According to Lazarus and Folkman in their journal (Maryam, 2017) explains about problem-focused coping strategies, namely modifying emotions by making efforts without making efforts to change the stressor directly. Usually someone uses emotional focus coping if the person feels unable to change the stressor and can only accept it because the resources they have cannot overcome the stressor.

The type of stress and problems faced will determine which coping strategies Evans & Kim will use (Maryam, 2017). The parameters of the success of using a type of coping strategy can be seen from the reduced stress and the fulfillment of various expected demands (Rutter, 2013; Compas, et al., 2014).

In this case, Mrs. X2 tries to create a positive meaning by remaining grateful for her child's condition, because there are still many mothers out there whose children's conditions are worse, so it can be concluded that Mrs. X1 uses a positive reappraisal type of coping (giving a positive assessment). In addition, Mrs. X2 also does coping in the form of emphasizing responsibility (Accepting responsibility), namely by raising awareness of everything as it should be. Mrs. X2 realizes that children are entrusted to her, so whatever is given by Allah must be the best for her.

Even his father is very supportive of all the good things about his son, they realize that they only need to focus on solutions rather than having to drag on and mourn the problem, they believe that God's gift is the best because no one knows the future. They also do not want to waste their childhood and want to maximize their efforts, they think about their child's future, if they do not try the best for their child in childhood then it is feared that their child will be late in getting treatment and the consequences are pitiful. In terms of emphasizing the responsibility of mother X2 trying to understand her role by giving full support to her child, she realizes her role as a responsible mother. On the other hand, mother X2 also realizes that if she does not support her child later she will fail.

However, before Mrs. X2 realized her responsibility, there was a time when Mrs. X2 experienced shock to the point of not leaving the house for about a month. During this time, Mrs. X2 experienced confusion about her child's condition regarding the future and what she should do. From the results of Mrs. X2's statement, it can be concluded that Mrs. X2 carried out emotional focus coping in the form of escape avoidance, namely by avoiding herself from the problem she is facing. Mrs. X2 did not want to have contact with other people for a month because she was worried about questions from people around her.

So positive reappraisal or giving a positive assessment based on the results of the discussion above is a reaction by creating a positive meaning that aims to develop oneself in religious matters such as always thinking positively and taking wisdom from everything that happens.

Asking for other people's opinions

Wardani (2009) stated that coping consists of cognitive and behavioral strategies. It can be concluded that mothers X1 and X2 made efforts after their children were diagnosed with autism, they wanted to do their best. They looked for therapy information everywhere as stated by Mother X1. Mother X1 also looked for therapy information from her neighbor who had the same case as her, therefore a common thread can be drawn between the conclusions of mothers X1 and X2 taken with the theory expressed by Lazarus and Folkman that mothers X1 and X2 carried out coping strategies in the form of Problem focus coping, namely strategies used to overcome stressful situations by solving the problems faced, so that individuals are immediately free from their problems, narrowing down to the form of problem focus coping, the efforts that have been made are a form of exercised caution (cautiousness), namely the individual thinks and considers available alternative solutions to problems, asks for other people's opinions, is careful in deciding problems and evaluating strategies that have been done. In addition, another form of problem focus coping that is in line with the efforts made by mothers X1 and X2 is in the form of Instrumental Action, namely individual actions that directly solve problems, and prepare steps to be taken. This is as concluded in the research journal, namely efforts that lead to problem focus coping, in the form of seeking information about medical treatment and knowledge about the disease, making decisions to provide appropriate treatment even though it has a fairly high risk. While other forms of coping in the form of other actions (problem focused coping) are shown by trying to find references and more knowledge about the disorders experienced by the child. In addition, seeking the best treatment for the child is done for the child's recovery. Likewise with mother X2 who seeks information on social media and the internet regarding the information needed. Some of them also decided to stop any activities outside the home in order to care for their children. Margaretha (2014) from the statement is relevant to the action of Mrs. X1 who stopped working to take care of her child. In addition to stopping her work, Mrs. X1 is also more often at home to take care of her autistic child than doing activities outside. In terms of asking for advice from her family, especially her husband, Mrs. X1 tends to be dominant because her husband fully surrenders her child's education and therapy, her father focuses on earning a living. Based on the statement above, it states that Mrs. X1 is independent in making decisions, this is in line with the problem focus coping theory of Lazarus and Folkman (Guntara & Saepul Rohmat, 2020) in an introspective form, namely having to act alone to solve the problem.

Based on the statement above, it states that mother X1 is independent in making decisions, this is in line with Lazarus and Folkman's problem focus coping theory. Guntara & Saepul Rohmat (2020) in the form of Intropersitive, namely having to act alone to solve the problem. Mother X2 who gave up her job to take care of her child, she did not want to waste her child's golden age in vain, Mother X2 was very enthusiastic about the information she received regarding her child's progress, this could be for the development and progress of their lives because they have the same rights as normal children, as stated in Ma'rifah, Suryantini, & Mardiyana, R. (2018) that parents who are expected to still seek information to expand their parental knowledge on coping strategies for parents of autistic children and parenting patterns to provide special attention to children with autism for their development and progress in life because they have the same rights as other normal children.

Evaluate previously used strategies

Be careful in deciding to solve the problem

Mrs. X1 considered several aspects for the effectiveness of her child's development. From Mrs. X1's actions, it can be seen that she monitored her child's development. After finding out that her child was not being effective at the therapy institution, Mrs. X1 stopped the therapy and looked for alternatives elsewhere. This means that Mrs. X1 was careful in deciding on issues related to her child's development.

Likewise, X2's mother saw her child's progress, so she moved her child from the PKMB program to the regular program. From the statements of both Mrs. X1 and Mrs. X2, it can be concluded that they evaluated their strategies by choosing effective education for their children.

Immediate problem solving

Taking direct action to solve problems or seeking information related to solutions to problems being faced is a form of problem-focused coping strategy according to Lazarus and Folkman. In eliminating stressors, problem-focused coping strategies directly address the problem. This coping strategy is usually used when the situation is considered changeable by the individual. The results of the dialogue above show that mother X1 handled it directly by sending her child to school to study. In addition, Mother X1 also applied her child as an effort to make her child better as confirmed by statements from neighbors. Meanwhile, mother X2 handled it directly by providing alternative therapy and massage as a form of maximum effort made by her father and mother.

Direct efforts have been made since the beginning of their child being diagnosed with autism by seeking alternative information in the form of therapy or choosing a school. In terms of instrumental support, mother X1, in addition to receiving support from her family with her family's acceptance of her autistic child, mother X1 also seeks social support by joining a community. In the community, mother X1 can share with other mothers related to her child's development, education, or obstacles faced. What is more important is that they remind or motivate each other.

Arrange the steps that will be used

Mother X1 thought of avoiding her problems by shifting the responsibility of raising her child to a boarding school.

Mother X2 plans education for her child for the sake of efficient growth and development of her child's education, Mother X2 wants her child to be able to focus on her education so that the results are more optimal, this is done by planning inclusive education for her child.

Abandonment

Mother X2 did not do permanent neglect, only for a short time. Mother X1 sometimes did temporary neglect by ignoring her child first by not responding to him so that her child would calm down first when having a tantrum, she considered tantrums to be a normal thing for her child so it was not a serious problem, just face it calmly. Likewise, mother X2 did it by doing temporary neglect by leaving it for a while, leaving it to play with her cellphone or watching television. This is also one of the coping strategies put forward by Lazarus and Folkman (in Wardani, 2009) that coping consists of cognitive and behavioral strategies. Among the coping strategies to overcome the negative emotions that accompany it (Emotion Focused Coping) is in the form of Minimization (Ignorance). The act of avoiding problems by assuming that the problem being faced is much lighter than it actually is. For mother X2, she did not ignore after having full awareness/full acceptance of her child's condition.

Blame yourself

Self Blame(Self-Blame) is a passive strategy that is more directed inward, rather than an effort to get out of the problem. Mrs. X1 did not blame herself because there was no autistic descendant in her family and the family also did not blame Mrs. X1. Including what was put forward by Pareek (in Pastonjee, 1992) that there are eight coping strategies that are commonly used, namely impunitive (assuming there is nothing more that can be done in the face of external pressure), Intropunitive (self-blame when facing problems), Extrapunitive (committing aggressive actions when having problems), Defensiveness (doing denial or rationalization), Impersistive (feeling optimistic that time will solve the problem and the situation will improve again), Intropersistive (expecting others to help solve the problem), and Interpersistive (believing that cooperation between oneself and others will be able to solve the problem).

Pray

How does mother X1 involve God and teach her child the religious aspect by teaching her to read the Koran and memorize the hadith because Mother X1 understands that her child has an advantage in the memorization aspect. An individual's way to manage stress and other life problems by using their beliefs, including here in dealing with autistic children, this was stated by Wong-Mc Donald and Gorsurh (in Nisa, 2017). Likewise, Mother X2 surrenders everything that has been attempted to God, she believes that what is given by God is the best. Mother X2 uses emotional focus coping in the form of seeking meaning. Mother X2 still feels grateful because there are still many conditions of children under her. Mother X2 tries to find the meaning or wisdom from the incident that not everyone is blessed with children like that, only chosen people are entrusted with special children.

Coping strategy process

Primary appraisal (first assessment)

Primary appraisal is one of two stages of assessment of potential stressors besides secondary appraisal. Primary appraisal or main assessment is an assessment that is personal, whether the event has a negative relationship and implication. This assessment is a process to determine the meaning of whether the event is perceived positively, neutrally or negatively so that it allows harm to occur, treator challenge. Harm is an assessment of the danger of an event that occurs. Treat is an assessment of the occurrence of a bad assessment or threat from an event that occurs. Challenge is a challenge and the ability to face what happens. Mrs. X1 conducted a primary appraisal by interpreting the event as "harm" because there was an assessment of the danger of the event that occurred, the mother felt shock. Likewise, X2's mother was very shocked by her child's condition at that time. X2's mother locked herself at home for approximately one month.

Secondary appraisal

After the initial acceptance that had initially eluded people, over time, mother X2 found the meaning of life so that she could accept her child's condition and could make herself aware of her responsibility towards her child so that she reached the stage of complete acceptance.

Supporting Factors for Coping Strategies

Internal Factors

Parental self-control is influenced by problems that arise in raising autistic children. The level of individual self-control can be seen based on self-control factors from Ghufon & Risnawati (in Nisa, 2017), namely internal factors and external factors. The internal factor that influences is age. In an interview with Mother X1, it was found that Mother X1 did not play physically and chose to be patient.

In addition, Mother X1 also chose to stop working online in order to focus more on educating her child.

Not only did mother X1 quit her job, mother X2 also stopped her career to take care of her child. This shows self-awareness of her responsibility towards her child, namely realizing that while her child is still small, it is not too late to give her proper attention, care or education so that she will not be pitiful when she grows up.

External Factors

External factors include educational factors. Likewise, individuals with higher education tend to use problem-focused coping strategies (Billing & Moos in Holahan & Moos, 1987). According to Billing & Moos (in Holahan & Moos (in (Minari & Widyarini, 2015))) that higher education influences individuals to choose coping strategies, and highly educated individuals tend to use problem focus coping strategies. Mrs. X1 with a bachelor's degree in education planned effective and affordable education for her child despite economic limitations. Mrs. X1, who previously underwent therapy and education at a therapy center, when evaluating the results, it turned out not to be as expected, finally Mrs. X1 stopped her therapy and education at the institution and decided to look for other more effective alternatives with various considerations. From the description, Mrs. X1 always makes efforts to overcome her child's problems in order to get the best. In addition, there are economic factors. Mrs. X1 experienced economic difficulties so she had to reconsider matters regarding Mrs. X1's child's education and therapy. In addition to economic factors, other external factors are family support or social support. Mrs. X1 received family support, she did not feel blamed by her family for the presence of her child. From the dialogue stating that Mrs. X1 asked for her family's opinion, it means that Mrs. X1 feels comfortable with her family. The environment accepts Mrs. X1's child by understanding their circumstances. From the interview statement of neighbor X1, it can be concluded that the neighbors accept the condition of the child of mother X1, they understand the condition of mother X1 who has an autistic child. It can be concluded that mother X1 gets social support from her neighbors.

For mother X2, support from the family was very minimal, initially the family blamed mother X2 but she tried to explain so that the family finally understood her child's condition. Instead of getting support, X2's family blamed her, which made mother X2 even more anxious, although some of the family did not support her, but there was a husband who fully supported her. The support from her husband changed her view from being confused to being shocked to a positive view. It can be concluded from the statement above that mother X2 received support from her family, namely from her husband, so that it influenced her view from being negative in the form of shock, confusion, and negative acceptance to positive acceptance and that had an impact on mother X2's strength to face her problems.

Family support is one of the things that influences coping strategies. Family members are one source of social support. Every family is required to be more focused in dealing with a problem. Thus, families need adequate adaptation development or what is called Ostlund & Persson's coping strategy (in Maryam 2017). This is also supported by Friedman (in Maryam, 2017) which says that family coping is a positive behavioral response to solve a problem or reduce the level of stress caused by a particular problem. In this case, the family is very much expected to solve a problem through an effective strategy by considering the coping strategy with the problem being faced. Family functioning will be carried out well if the family is able to cope well too Shidow, Henry, Tolan, & Strachan (in Maryam 2017). In contrast, if the family does not carry out its function well, the family cannot cope well. In the case of mother X2, her husband was very supportive and very accepting of her child, but on the other hand, other family members such as her grandmother initially did not accept and blamed mother X2, this made mother X2 feel restless and guilty.

CONCLUSION

Based on the results of research and discussions that have been carried out regarding the coping strategies of mothers with children with autism disorders, it can be concluded that the mother's coping strategy used is problem focus coping, which is a solution that focuses on the problem by directly solving the problem. The forms of problem focus coping used include exercising caution (cautiousness), which is the individual thinking and considering available alternative solutions to the problem, asking for other people's opinions, being careful in deciding the problem and evaluating the strategies that have been carried out. Another coping strategy used is emotional focus coping, which is an individual's effort to control emotional responses to conditions that are very stressful (Folkman, 2013). Among the forms of emotional coping used is by changing thoughts from being disappointed and sad and finally becoming acceptance. This is done by finding the meaning of the failure he experienced and trying to be grateful by finding the wisdom contained in the incident in emotional coping called seeking meaning. Another emotional focus coping used is escape avoidance or avoiding oneself, this is done by the subject to calm himself in the early days when his child was diagnosed with autism. Many negative thoughts emerged and made him restless so that he was encouraged to withdraw temporarily from the social environment. After accepting his child's condition, the next strategy the coping used is accepting responsibility namely emphasizing responsibility by fostering awareness that what is given by God, including children, is the best and children are a gift from God that must be looked after as well as possible so that parents will do anything for the good of their children with the awareness that has grown.

Factors that influence coping strategies are internal factors and external factors. Internal factors that influence are age and self-awareness of responsibility as a mother. External factors are education level, family support or social support and economic conditions.

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