

Stress Coping Strategies in Parents of Children With Autism Spectrum Disorder

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Abstract--- *Autism spectrum disorder is a neurodevelopmental disorder and can be a lifelong disorder. From the moment a diagnosis of autism is revealed, parents are obliged to take an important role and caring for children with autism spectrum disorder often presents challenges related to stress that parents can experience. Changes in behavior in one family member than will give effect to other family members. At present, in handling autism spectrum disorder, other than through interventions that are focused on stimulation of development and reduction of maladaptive behaviors, the other main consensus is to help families achieve appropriate care, obtain appropriate coping mechanisms and reduce stress on parents or caregivers. There are several measuring instruments that are often used to help clinicians determine the degree of stress in parents who have children with autism spectrum disorder including Parent Stress Index (PSI), Parental Stress Scale (PSS), and Autism Parenting Stress Index (APSI). Some strategies in dealing with stress in family especially parents of children with autism spectrum disorder are parental psychoeducation strategy, parent training strategy, useful parenting coping strategies, parents self care strategy, eco-map strategy, group therapy strategies, individual therapy for parents and social support strategy.*

Keywords--- *autism spectrum disorder, parents stress, coping strategies*

I. INTRODUCTION

Caring for children with autism spectrum disorder often presents special challenges related to stress that parents can experience. Parents or families can experience anxiety conditions, various symptoms of physical disorders, fatigue (burn out), the situation which is filled with quarrels, and even experience depression.

Bandura (1995), Bekhet et al. (2012), Benjak et al. (2009), Eisenhower et al. (2005), Higgins et al. (2005), Koegel et al.(1992), Kuhn & Carter (2006), Pakenham et al. (2004), Weiss (2002) all showed that these conditions will be related to a decrease in parenting abilities or parental competence in childcare (1).

Parents are obliged to take an important role from the moment a diagnosis of autism is revealed to their child. These roles include:

1. Determine therapy.
2. Monitor the development of their child including communicating with all therapists.
3. Seek and connect with educational institutions and clinical services.
4. Accompanying their children in interacting, communicating and behaving accordingly both at home and outside the home.
5. Acting as a case manager.

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Often, the condition of autism creates a burden and stress on parents. Stressful conditions in parents are consistently found in various studies (2)(3)(4)(5)(6)(7)(8)(9).

At present in handling autism spectrum disorder, other than through interventions that are focused on stimulation of development, reduction of maladaptive behaviors, the other main consensus is to help families achieve appropriate care, obtain appropriate coping mechanisms and reduce stress on parents or caregivers (1).

II. AUTISM SPECTRUM DISORDER

Parental knowledge about diagnosis can contribute to helping parents personally and is useful in determining intervention programs (1).

From various studies, autism spectrum disorder are understood as neurodevelopmental disorder which mean that there are some differences in brain development patterns (10).

Currently the diagnostic criteria that are often used in determining autism spectrum disorder are according to the DSM-5 (Diagnostic and Statistical Manual of Mental Disorder, 5th edition) where there are permanent defects in communication and social interaction in various aspects of life, not included in the Global Developmental Delay, manifested in at least 3 symptoms, then a pattern of behavior, interest or activity that is limited and repetitive, manifested in at least 2 of the 4 symptoms. Symptoms must appear early in childhood and cause disability in daily activities. And these signs and symptoms cannot be classified as a disorder of intellectual development or global developmental delay. Impaired intellectual development often occurs and appears as a comorbidity (11).

III. FAMILY SYSTEMS THEORY

McCubbin & McCubbin (1993), Hawley & DeHaan (1996), Walsh (1998) showed that parent or family efforts in dealing with stress conditions and caregiving demands on children with special needs depend very much on family belief systems that influence adaptation and resilience (12).

The theory that can be a reference in working with families with children with autism spectrum disorder is the theory of family systems. According to Bowen, family systems theory is a theory of human behavior that sees families as emotional units and uses systems of thought in explaining complex interactions within the unit. According to this theory, changes in behavior in one unit / family member will give effect to other units / other family members (13). Also found the role of a large system outside the family to help create balance.

Altieri and Von Kluge (2009) in their study determine several types of bonds in the family system and their relationship with the ability to deal with stress, as follows:

1. Families who express a strong attachment (enmeshed), apparently often use positive coping strategies, easily adjust to new situations and see their family members who experience conditions with autism will not change their families too much.
2. Families who express a lack of bonding (disengaged), often experience anxiety, are less adaptive and less able to work together in dealing with stress. Mothers often bear a greater burden in care and home arrangements.

3. Families who express chaotic family conditions, where the family cannot determine a division of tasks / roles of each family member and lack of family rules so that they often experience high stress conditions related to conflicts in the family which then increase even more when there are family members diagnosed with autism spectrum disorder (14).

IV. STAGES OF PARENT RESPONSE

When children are diagnosed with autism spectrum disorder, parents can experience a feeling of great loss (15).

Kubler-Ross and Kessler (2005) identify 5 stages that a person can experience when dealing with the death of a loved one:

1. Denial.
2. Anger.
3. Bargaining.
4. Depression.
5. Acceptance.

Various studies show that not all individuals who experience loss will undergo the five stages. Losing is an ongoing process. When parents learn that their child has been diagnosed with an autism spectrum disorder, this condition can resemble a feeling condition like the child has died. Boss (1999) observes a condition he calls ambiguous loss. It is called ambiguous because because the loss condition is 'incomplete' where children with autism spectrum disorder are physically present but not psychologically (16).

The 'acceptance' condition for a child's diagnosis can occur when parents and family are able to move past conditions of previous feelings such as blame, guilt, anger and stop asking "Why me?" and moving forward to overcome the challenges of parenting, also realizing that parents can still enjoy life and accept these conditions as part of their lives.

In the field of child nursing, Elder and D'Alessandro (2009) identified 4 stages in parents who have children with autism spectrum disorder:

1. Shock and disbelief
2. Sad and angry
3. Disorganization and despair
4. Re-organization

V. THE CHALLENGES OF PARENTING CHILDREN WITH AUTISM SPECTRUM DISORDER

The following are the main challenges in caring for children with autism spectrum disorder :

1. Behavioral problems.

Behavioral problems are the most important indicators of stress on parents (17)(18). Included here is the child's attitude that is unpredictable, inappropriate and destructive (4).

2. Issues of socialization (17).
3. Cognitive problems.

Children with autism spectrum disorder often have problems with limited attention span and become easily frustrated if something does not match what they want (19) (17).

4. Lack of verbal communication (17).
5. Regulatory problems (sleep, eating and emotional regulation).

Children with autism spectrum disorder also often have sleep related problems (20). This condition often makes parents very tired (17).

Food-related conditions are often a challenge in parenting. Some studies state that this condition is generally associated with sensory sensitivity (18).

6. Non-functional repetition behavior.

In the study of Davis and Carter (2008), in addition to the problem of socialization and communication, the existence of stereotypic behavior and repetitions also become the main source of stress for parents. It also includes a child's need for the same routine over and over again (18)(4)(17).

7. Problems with sensory processes in children (4)(17).
8. Problems related to the child's physical condition.

Children with autism spectrum disorder often also have problems related to their physical condition. Consultation to the doctor to the hospital treatment is very possible.

9. Financial aspects in providing therapy for children (17).

According to Sharpley et al. (1997), the most significant sources of stress for parents who have children with autism spectrum disorder are (21) :

1. Sedentary conditions of disturbance.
2. Family and community members disapproval of the behavior exhibited by children. Parents often also feel a sense of 'being judged' by their environment who think that parents are not able to provide good care for children so parents will then choose to withdraw from social interaction (4)(15).
3. Lack of professional support.

Finding a daycare including child care can be a challenge. The more severe behavioral problems in children will cause difficulties for parents to get a day care or child care. Similar conditions occur when parents look for baby sitters.

Minnes and Woodford (2005) found that the two biggest things that parents pay attention to are access to social support groups and access to education for parents (9).

Lyons et al. (2010) states that a consistent predictor of stress in parents is the severity of symptoms in children with autism spectrum disorder (22).

VI. MEASURING INSTRUMENTS / INSTRUMENTS KNOWING THE PARENTAL STRESS DEGREES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

There are several measuring instruments that are often used to help clinicians determine the degree of stress in parents who have children with autism spectrum disorder, including:

VI.1. Parent Stress Index (PSI)

This measuring instrument was developed by Abidin (1995) to evaluate the level of stress in the relationship between parent and child. Initially this measurement tool was used in the relationship of parents with children who have a typical development but then many are also used in assessing the condition of parents of children with autism spectrum disorder. The type that is often used is the Parent Stress Index - Short Form (PSI-SF) (23).

VI.2. Parental Stress Scale (PSS)

This measurement tool was developed by Berry and Jones (1995) which aims to measure the level of stress experienced by parents and see the positive and negative aspects that occur in parents from caregiving.

This measuring device consists of 101 items of stress assessment on parents but a short version of this measuring tool has also been developed into 18 items to measure:

1. Positive aspects experienced by parents in caring for children such as:
 - a. Emotional gain.
 - b. Personal development.
2. Negative aspects that parents feel in parenting such as:
 - a. Parenting demands.
 - b. Limitations of personal activity.

Parents will judge the items indicated by the 5-point Likert scale that is strongly disagree, disagree, not make a choice, agree and strongly agree (24).

VI.3. Autism Parenting Stress Index (APSI)

Autism Parenting Stress Index (APSI) was made by Silva and Shalock. This measuring instrument is intended for:

- a. Measuring stress in parents is related to the main symptoms and comorbidities that are often found in autism spectrum disorder.
- b. Identify which areas are needed to improve parenting skills.
- c. Assess the effects of interventions on stress experienced by parents.
- d. Provides information for clinicians in determining how parents develop abilities towards various aspects of parenting demands with autism spectrum disorder. The clinician can then determine which areas are needed by parents in developing their skills.

The symptom areas assessed by APSI were obtained through interviews with 100 parents who have children younger than 6 years with autism spectrum disorder.

These symptoms are then rated by parents as the symptoms that most stress the parents. These symptoms are then grouped into 3 large groups, namely symptoms of social difficulties, behaviors that are difficult to overcome and physical problems.

Compared with other instruments in assessing parental stress degrees, APSI is a reliable instrument for measuring stress related to parenting to children with autism spectrum disorder (25).

VII. STRATEGIES FOR OVERCOMING STRESS IN PARENTS WHO HAVE CHILDREN WITH AUTISM SPECTRUM DISORDER

VII.1. Parental Psychoeducation Strategy

The intervention model that is promoted from current research for parents who have children with autism spectrum disorder is a psychoeducational program (focusing on emotional evaluation and understanding and its impact on parental social intelligence) and intervention area therapy programs stabilizing the emotional condition of parents through various types of psychotherapy (26).

Psychoeducation interventions through the development of parental understanding of the behavior of their children who experience autism spectrum disorder will teach parents, for example about the cognitive basis experienced by children that affect their behavior. Through this understanding, it is expected to have a positive influence on parents in viewing behaviors that are often difficult to overcome. Parents will also learn to understand the function or meaning behind their child's behavior which will shape parents to develop positive parenting patterns (12).

VII.2. Parent Training / Workshop Strategy

Parental training is an educational intervention that empirically can support children who have problematic behavior related to autism spectrum disorder. Parent training gives parents specific techniques for managing their child's behavior problems (27).

Mancil et al (2009) states that parental training is one of the most effective strategies in dealing with stress in parents who have children with autism spectrum disorder (28).

Sessions that can be considered as part of parental training are (27):

1. Exercise identifies the function of behavior through the analysis of events that occur before the emergence of the behavior (antecedents) and analyzes the events after a behavior (consequences).
2. Presentation of strategies to prevent destructive behavior, for example, practices creating a routine visual schedule.
3. Presentation of positive reinforcement strategies for expected behavior, ignoring planning for inappropriate behavior and techniques promoting compliance.
4. Training new skills for parents such as communication skills and daily activities.

VII.3. Parent's Coping Strategy

Just as each child with an autism spectrum disorder is unique, so every parent will have a unique way of responding to the child's condition. This will be seen in the parent coping strategy where the parent coping ability will be greatly affected by the following factors (15) :

1. Belief or religion.
2. Education level.
3. Financial status.
4. Culture-related norms.
5. Living conditions in urban or rural areas.

Here are some things related to parent coping strategies and examples of coping strategies that are often used by parents who have children with autism spectrum disorder:

i. Resilience

Bayat (2007) in his study stated that parents who show resilience have a great ability in coping conditions that occur in their children.

Resilience is the capacity to endure difficulties while becoming stronger and producing more resources. Bayat identifies 3 main factors that contribute to family resilience, namely:

1. Ability to understand problems.
2. Recognize the strengths owned and have the ability to see the positive things behind the situation.
3. Have a strong belief system.

Generally it takes an average of 2 years for a family to adjust to all the needs and changes related to parenting with autism spectrum disorder (29).

Milshtein et al. (2009) describe several types of coping that can be sought by parents who have children with autism spectrum disorder such as:

ii. Resolved parents

This coping has an active effort and accepts all abilities and limitations of children, does not revolve only on the idea of looking for what causes the conditions that their children experience and always tries to see positive things despite the challenges of certain parenting difficulties (30).

iii. Insightful parents – child focused

Oppenheim, Koren-Karic, Dolev, and Yirmiya (2009) found that in addition to the resolution aspects of resolving conflicts in the family, insightfulness or efforts to understand things from the child's point of view are important aspects in reducing stress on parents.

The Oppenheim et al (2009) study observed that insightfulness depends on the capacity of parents to recognize signs of child behavior and also depends on the child's capacity to show these signals and communicate their needs (31).

iv. Thinking-oriented parents

Process-oriented parents focus on finding information, actively engaging in groups, having realistic expectations of children's abilities, and being a staunch supporter of their children so they will always try to have optimistic feelings about the child's future (32).

v. Task-oriented parents

In the study of Lyons, Leon, Phelps, & Dunleavy (2010), parents who use task-oriented coping have less stress than emotionally oriented parents. This coping strategy focuses on existing problems and uses concrete actions through behavioral and cognitive analysis in reducing stress (22)(33).

vi. Regulating emotions and compromising attitudes

Pottie and Ingram (2008) identify coping strategies for emotional regulation and compromise attitudes that can lead to positive moods for parents and a lack of stress. Obrien and Daggett (2006) propose what parents can do as emotional responses when they find children diagnosed with autism spectrum disorder: Parents who focus on 'what is' compared to the attitude of parents who focus on 'what might have been' and focus on 'what could be'. Parent who focus on 'what is' will take a positive and realistic approach to children, seeing children as unique individuals and not comparing with other children. Parents then focus on the developments that occur from day to day even though they realize that there are various problems related to care being undertaken (33) .

vii. Reframing / redefinition an event by using various resources

Pottie and Ingram (2008) also observed that coping strategies through reframing by looking at events from a positive perspective / 'frame' will make parents have positive emotional conditions, reduced stress and are not prone to depression (33).

In the Tway, Connolly, and Novak (2007) study, observing 3 levels of resources that can be used by families and enabling families to reframe or redefine various events, such as individual abilities, resources from family units and resources from the community (34).

viii. Reevaluation of parental careers (especially in mothers)

Parents, especially mothers, can reevaluate career goals while at the same time having care responsibilities for children with autism spectrum disorder. Parents who are not too focused on their careers and pay great attention to caregiving and families are found to have a great ability to enjoy life and feel less stress in caring for children with autism spectrum disorder (35).

ix. Increase the understanding of others about the potential of children and parents' active response in the community

Through efforts to increase awareness in the community about autism spectrum disorder in terms of potential strength in children, the needs of children and their limitations can lead to positive attitudes towards the community about children with autism spectrum disorder (15).

A study conducted by Harandi and Fischbach (2016) found that parents who actively responded to the rudeness directed at their children turned out to show low levels of stress and not isolate themselves compared to passive parents. Therefore Harandi and Fischbach's study recommends the need for education to the public about

autism spectrum disorder to reduce stigma and increase understanding, tolerance and acceptance of children and their families (36).

x. Support strong social networks and strong religious beliefs

Mancil, Boyd, and Bedesem, (2009), Altiere and Von Kluge, (2009), Tway, Connolly, and Novak (2007), Pottie and Ingram (2008) find that parents of children with autism spectrum disorder who have strong social assistance networks shows a great ability in coping and can adapt to various challenges in parenting. Coping strategies through social support are also proven to increase feelings of satisfaction in parents undergoing daily activities with children (9)(14)(34)(33).

Gray (2006) analysed in a 10-year study the dynamics of various coping strategies used by parents who have children with autism spectrum disorder. In his study it was seen that parents used coping strategies that were not too many but effective. Two coping strategies that seem consistently used by parents are social support and strong religious beliefs (37).

xi. Get positive things from caring for children with autism spectrum disorder

Although parents often perceive that many negative aspects are found in the care of children with autism spectrum disorder, parents also find various positive aspects of care, for example, parents report the conditions they experience strengthen aspects of their faith that are spiritually religious (29). Parents also gain internal strengths that keep them moving forward, including getting a greater perspective of life, having more empathy and compassion for others, increasing tolerance, being easy to help people, strengthening relationships as a married couple, finding new people who together being in a support group, and raising confidence in various other areas of life (15).

VII.4. Parents' Self Care Strategy

Parental self-care has an understanding of the decisions and actions taken by parents to improve health, prevent disease and restore health (38).

Generally, other forms of self-care activities undertaken by parents are (34)(39) :

- a. Get social assistance / support from closest friends or from extended family.
- b. Parents will also try to seek help from other parents who also have children with autism spectrum disorder. It was found that as many as 93% of parents would seek to seek advice from other families who have the same care issues.
- c. Maintain good physical and mental health.
- d. Maintaining a beneficial activity outside the parenting situation.
- e. Use relaxation methods.
- f. Using stress control methods

The biggest challenge in self-care when parents feel they do not have time to pay attention to themselves (Dzubay, 2011).

VII.5. Eco-Map Strategy

Eco-map is a diagram that shows all the systems that are around a particular individual. Generally used in family counseling. The eco-map was introduced by Hartman in 1975 to show an ecological system that directs the family system.

By using eco-maps, parents can identify resources that can help overcome the tensions that arise due to caregiving (38).

Symbols commonly used in eco-maps are used, such as:

1. At the center of the eco-map are individuals or families.
2. Lines are made that connect the eco-map center with other individuals or other systems.
3. Thick lines show strong relationships.
4. Red lines or dashed lines are usually used to show relationships that are full of stress.
5. The arrow that leads to the center of the eco-map shows the system that is very influential on the client / individual / family.
6. Arrows that point to a particular system show a large influence from the client / individual / family to the system.
7. Arrows that point in both directions describe the two-way relationship of the mutual influence of the client / individual / family with other systems.

VII.6. Group Therapy Strategy

Izadi-Mazidi et al (2015) in their study showed the effectiveness of cognitive therapy in group behavior in dealing with stress in parents. Cognitive behavioral therapy in this group includes education about autism spectrum disorder, joint discussions of cognitive aspects and cognitive distortion and relaxation practices (40)(41).

VII.7. Individual Therapy Strategy in Parents

In addition to psycho-educational programs, individual therapy interventions through various types of psychotherapy are suggested by various recent studies in stabilizing the emotional condition of parents (26).

VII.8. Social Support Strategies

Mancil et al (2009) stated that social support is a very effective strategy in dealing with stress in parents who have children with autism spectrum disorder (9)(28).

Social support will improve the emotional psychological condition of parents, provide a place for mutual discussion, provide informal social networking, reduce the isolation that parents often do and provide mutual support for each other on issues that are equally felt (41).

VIII. CONCLUSION

Caring for children with autism spectrum disorder often presents special challenges related to stress that parents can experience. Stressful conditions in parents who care for children with autism spectrum disorder are consistently found in various studies.

Research states that parents who have children with autism spectrum disorder experience greater stress than parents who have children with other special needs.

Parent or family effort in dealing with stress conditions and caregiving demands on children with special needs is very dependent on the family belief system that affects adaptation and individual resilience.

Various challenges can arise when caring for children with autism spectrum disorder and some strategies in dealing with stress in parents of children with autism spectrum disorder are:

1. Parental Psychoeducation Strategy
2. Parent Training / Workshop Strategy
3. Useful Parenting Coping Strategies include:
 - a. Resilience.
 - b. Resolved parents.
 - c. Insightful parents - child-focused parents.
 - d. Thinking oriented parents.
 - e. Task-oriented parents.
 - f. Parents who focus on "what is".
 - g. Reframing / redefined an event by using various resources.
 - h. Reevaluate parental careers (especially in mothers).
 - i. Increase the understanding of others about the potential of children and parents active response in the community.
 - j. Support strong social networks and strong religious beliefs.
 - k. Get the positive things from caring for children with autism spectrum disorder.
4. Parents Self Care Strategy.
5. Eco-Map Strategy.
6. Group Therapy Strategy.
7. Individual Therapy Strategy for Parents.
8. Social Support Strategy.

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