

ANALYSING THE FACTORS OF AFFECTING PARENTS' RESILIENCE IN FAMILIES OF A CHILD WITH AUTISM

Cvetanka Velkoska, Esra Baki, page 137-157

ABSTRACT

Having a child in the family, which has an important place in society, is an important life event that affects the entire family system and for many families, it can be a source of stress as well as a source of happiness. Parental stress is related to the type of disability present in the child. Autism is a neurodevelopmental disorder characterized by genetic and environmental factors, usually occurring in the early stages of life causing difficulties in social communication and interaction and the presence of restricted and repetitive behaviors. The fact that their children have autism causes families to experience difficulties in economical, psychological, emotional and social terms, the concept of resilience comes to the fore which makes it easier for families to overcome these difficulties. Social support systems and coping strategies that enable families with autistic children to cope with the difficult situations they experience and coping strategies that enable them to resist stressful events and situations increase the resilience of families, while also enabling them to look at their lives in a more positive way. The aim of this study is to conduct a comprehensive literature review on family resilience levels related to the problems experienced by families with autistic children and to what extent coping strategies, social support systems and perceived stress affect these resilience levels.

Keywords: Autism, Parenting Stress, Resilience Level, Coping Strategy.

Asst. Prof. Dr. Cvetanka Velkoska

International VISION University, Gostivar

e - mail:

cvetanka.velkoska@vision.edu.mk

Mr. Esra Baki

International VISION University, Gostivar

e-mail: esra.baki@vision.edu.mk

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INTRODUCTION

The smallest system of the society is the family, and each family creates subsystems within itself. While a new individual joins the family with the birth of a new child, many changes take place in the family system and the life of the family is reshaped accordingly. Roles, expectations and lives of mothers and fathers are changing. With the birth of a baby with autism, the family expecting a healthy baby is caught unprepared, this situation affects the whole process of the family system and family life is shaped accordingly.

Considering that autism, which is stated to occur with features such as language problems, introversion, repetitive movements, and limitation in relationships in the first three years of life, is a lifelong developmental condition, it is known that both children and their families are significantly affected by this process.

When children are diagnosed with autism, the process of living with a child with autism begins. Starting from the moment the child is diagnosed, the duties and responsibilities undertaken by family members may differ in all developmental periods of the child. In addition, family relationships, economic situations and social lives of family members can change to a great extent, and the family may face difficulties in many ways.

Families with autistic children need to be resilient in order to overcome the difficult situations they are in and to increase their capacity to solve their problems. At this point, we come across family resilience, which expresses the ability of families to overcome the difficulties they experience.

The social work interventions carried out aim to mobilize family resources and strengthen the family in order to cope with stress more effectively, both individually and as a relational system. At this point, developing families' coping skills, increasing their social support systems and reducing their perceived stress are important components to increase family resilience.

1. AUTISM:

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that appears in the first years of life and persists throughout life, manifested by marked delays in communication and interaction areas, and restricted and repetitive areas of interest (Kanner, 2016).

Many definitions of ASD have been made until today and various changes have been made in the diagnostic criteria of ASD. *Diagnosis and Statistical Manual of Mental Disorders*, which is the guide of the American Psychiatric Association (APA) in its last edition in 2013 (DSM-5), stated that ASD shows inadequacy and repetitive behaviors in social communication and interaction, insistence on sameness, hypersensitivity to affective stimuli or It was also defined as insensitivity, excessive adherence to routines, and resistance to changes, and it was stated that these characteristics should emerge in early childhood (APA, 2013).

Autism occurs in the first three years of an individual's life; It is a disorder that has symptoms that appear during the process of making eye contact, adjusting the tone of voice, and speaking (Korkmaz, 2005). Smith (2007) classified autism as a disability in social interaction, language and communication skills, and unusual behavior patterns.

According to the data of the American Centers for Disease Control Prevention (CDC), ASD is seen in 1 out of every 44 children in 11 states of the United States (Prevention, 2014). The increase in the incidence of ASD has led to the development of different perspectives on this subject and innovations in education and orientation.

Although the symptoms of ASD begin to appear in the first 12 months of life, they become more apparent after 18 months. Although the diagnosis of ASD is generally 2 years old, it is aimed to diagnose it from 18 months (Öner, III. Tohum Autism Foundation evaluation and development reports, 2020)

Some children may react very differently to sounds, while others may not respond at all. Although children do not look at many objects and people's faces for visual stimuli, it is known that they are very interested in rotating objects (N. Darica, 2017). It is known that children with autism

perform poorly in intelligence tests because they have difficulties in understanding the questions and conveying the answers even though they cannot fully pay attention. Children may have behavioral characteristics such as walking on their toes, persistence in certain movements, turning around for a long time and rocking.

It is known that individuals with ASD are recognized in the early stages of their lives and that appropriate education programs are offered, which positively affects the increase in the learning rate and the development of new skills in individuals with ASD (G. Baird, 2003).

It is possible for individuals with ASD to benefit from early and appropriate education by making their medical and educational diagnoses. The medical diagnosis is made as a result of the evaluations made by child psychiatrists in hospitals. Having a medical diagnosis is not considered sufficient for the individual to benefit from educational services.

According to the Guidance and Research Center Directive of the Ministry of National Education; The staff working in the special education departments of the guidance and research centers use the appropriate measurement tools to make the educational evaluation of the students, cooperate with other field experts in order to make appropriate decisions for the type and degree of disability, and inform the family. In line with the decision of the special education evaluation board, the student is directed to the school suitable for his/her educational diagnosis (Ministry, 2020)

1.1. EFFECTS OF AUTISM ON FAMILY:

A multifaceted process of influence begins starting from the moment a child with a developmental disorder such as autism is noticed in the family. Living with a child with autism significantly interrupts the normal developmental process of the family. The family, which has to undertake the lifelong care of the child, is faced with stressors and expectations specific to their own life cycle in their own life cycle (H.I. McCubbin, 2001). The stressors and expectations faced by these families differ from the families of normally developing children because most of

the daily and personal care of individuals with autism is provided by the family members.

Some of the difficulties experienced by families of children with autism; the feeling of loss and depression of the members, the decrease in leisure activities and entertainment opportunities that the family will spend together, some changes and personal sacrifices made in the relationships of the members that lead to loss of social support (C.E. Nealy, 2012). While a child with autism challenges the family in the areas related to the daily care and education of the children; it affects family members in areas such as self-esteem, belief and socialization (A. Turnbull, 2007).

With the diagnosis of autism, families often experience feelings of sadness, confusion, loss, denial, guilt and even depression (J.M. Altieri, 2009). Marcus, Kuncze, and Schopler (2005) These difficulties can cause families to list the stress factors experienced by families as follows:

- Not having enough information after the diagnosis and not knowing what to do,
- Having differences in the development of their children,
- Their children's appearances being normal,
- Their children's facing the problems in communication and behavior,
- Family members do not get the same answers to their approach to children,
- Behaviors that may leave the family in a difficult situation in the society,
- The need to communicate with many different experts,
- Having many therapies and the responsibility of deciding which therapy will be the most appropriate and beneficial for their child (ARSLAN, 2020).

Dale, Jahoda, and Knott (2006) state that mothers of children with autism have to assume more responsibility for their children, and this situation caused stress, helplessness and anxiety. As a result of mothers' taking more of this care and responsibility for their children, leisure activities and socialization are restricted (M.F. Morrell, 2006). As a result of mothers' taking more of this care and responsibility for their children, leisure activities and socialization are restricted (M.F. Morrell, 2006).

As a result of the researches, it was seen that the families were affected the most economically and psychosocially in the process after the diagnosis, and the coping methods they used before to live with a child with autism were insufficient.

In addition, it is noteworthy that families sometimes have difficulties in accessing services and the need of guidance. Starting a family and becoming a parent is one of the important events in human life. Parents who learn that they have a child with special needs go through certain stages of this acceptance. In this difficult process, parents both struggle with themselves and have to use the appropriate language to answer the curious glances and questions from outside (G. Baird, 2003) (G. Baird, 2003) (G. Baird, 2003) (G. Baird, 2003) (G. Baird, 2003) Emotional Explanations for accepting the diagnosis are shown in Figure 1.

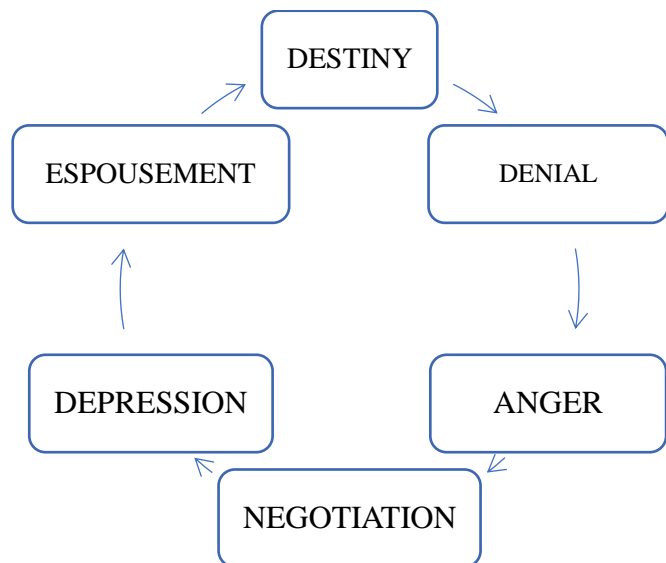


Figure 1. Emotional Explanations for Accepting the Diagnosis (MEMEDOVA, 2022).

1.2. REACTIONS OF PARENTS UPON LEARNING THAT THEIR CHILD HAS AUTISM:

The reactions of parents in the process of accepting their children with developmental disabilities consist of 3 phases.

STAGE 1; It is the stage of shock, denial and depression. Parents state that the problematic process begins when they realize that there is a difference in their children.

- **Shock:** In this period, indifference, feelings of isolation and crying often occur in the reactions of parents. Usually, parents state that they are completely unprepared for the news that their child has ASD. Parents often cut off communication with their immediate surroundings because they experience extreme sadness and feelings of helplessness during the shock period (N. Kaytez, 2015).
- **Denial:** During this period, parents may not accept the disability in order to protect themselves from the shocking feelings of the child's ASD. Parents may try to deal with their feelings by rationalizing them, or they may wait for the specialist to express that there is nothing wrong with their child. Parents go on a quest to prove that the child is normal and go from expert to expert. Parents have a lot of difficulty in explaining themselves during this period (Z.F. Ercan, 2019).
- **Depression:** In this period, parents realize that despite all their efforts, their child's disability does not disappear. Parents find themselves in a state of intense anxiety. For some parents, the period of depression can last a lifetime. Parents cut off their communication with their immediate environment and yearn for a normal child (H. İ. Özteke Kozan, 2019).

STAGE 2: It is the stage of Confusion, Guiltiness and Angriiness.

- **Confusion:** During this period, the burden of parents increases considerably. Children's constant need for care and frequent visits

to education and health institutions put parents in financial and moral distress. Therefore, the anger of the parents can be directed towards the child. While parents struggle with such troubles, they also love their children and take care to do the best for them. This situation causes complex emotions in parents (Akça F, 2019).

- **Guiltiness:** This period is the most difficult for parents to overcome among their feelings. Parents think that they are in any way causing the child to have ASD (watching TV, not being interested, working, leaving a caregiver) and that they are punished for their own past mistakes. Parents constantly complain about why this happened to us with a feeling of guilt. Parents may have unrealistic thoughts about their children having ASD (G. Kadan, 2015).
- **Angriness:** Anger is a major obstacle for parents to start accepting their children with ASD. Parents, why did it happen to us? He is looking for an answer to his question. At the same time, they begin to blame them by directing their feelings of anger to experts, teachers and therapists (H. Kırlioğlu, 2019).

STAGE 3: It is the phase of Negotiation, The Espousment and the Adaptation.

- **Negotiation:** All parentsres' only will is their child become as normal. Parents express that they are ready to agree with everyone (doctor, specialist, magician, wizard, etc.) in order for their child to become as normal (E. Hamarta, 2019).
- **Espousment and the Adaptation:** Parents who have passed the other stages and come to the stage of acceptance and adaptation accept their child / children with their illness. Parents are ready to adopt their child/children. Until this stage, parents begin to accept the strengths and weaknesses of themselves and their children with ASD. However, many parents may not reach the stage of acceptance and adaptation (A. Özyürek, 2019).

1.3.MENTAL AND PSYCHOLOGICAL PROBLEMS IN PARENTS WITH A CHILD DIAGNOSED WITH AUTISM:

ASD is associated with stress and depression for parents. It is stated that parents of children with ASD experience more stress, anxiety and depression than parents of children without this developmental disorder (M.A Almansour, 2013).

Children diagnosed with ASD fall into the group that requires special needs and intensive time in their daily care. Many factors such as daily care, education and health services, working family members, insufficient services provided to children with ASD, low educational level of parents and economic difficulties make the life of families difficult.

As a result of the researches, the risk of depression due to the intense stress experienced by caregivers or parents who care for children with ASD is higher than those who take care of normal children (A.K. Bekhet, 2018). Studies have shown that more than one third of people caring for a child with ASD have depression clinical scores above normal. In different studies, it has been observed that mental problems such as stress, depression, anxiety and anger occur in people who are responsible for caring for a child with autism (L.C. Lee, 2008).

2. RESILIENCE:

As mentioned above, the fact that their children have autism causes families to experience difficulties economically, psychologically, emotionally and socially, and the concept of resilience, which makes it easier for families to overcome these difficulties, comes to the fore. The concept of resilience, derived from the Latin word *resiliens*, refers to the bending or flexibility of a substance (R.R. Greene, 2002).

When the resilience is considered in terms of family, it is seen that some families cannot cope with risky situations and difficulties, while others cope more strongly in these difficult situations. In this respect, it can be said that family resilience, like individual resilience, is the ability to adapt, survive and maintain or develop healthy family functioning in the face of crisis (difficulty) (Patterson, 2002).

Family resilience is defined as the family's ability to cope and regain balance against the challenges and risks of life (Patterson, Family resilience to the challenge of a child's disability, 1991). Family durability; is based on family dynamics, mutual relations, social environment and the power of the family.

2.1.FAMILY RESILIENCE FACTORS: PROTECTIVE AND HEALING FACTORS:

As a result of the researches and studies, the main issue focused on families is to reveal the definition, conceptualization, measurement and validity of the protective and healing factors in the family system, which is faced with risk factors as well as crisis situations. Accordingly, protective and healing factors can be considered as follows (H.I. McCubbin M. M., 1997):

1. **Communication Regarding Problem Solving:** The fact that families are in communication against the events and changes in their lives provides the development of coping skills.
2. **Equality:** Self-confidence and independence taught within the concept of equality regardless of gender play a significant role in strengthening the harmony of families.
3. **Spirituality:** Religious or cultural beliefs allow families to interpret crises differently.
4. **Flexibility:** In crisis situations, families need to change their lifestyles, duties and responsibilities, family rules and roles in order to achieve harmony and balance.
5. **Outspokenness:** Balanced communication is the basis for families to maintain agreement and balance. It is seen that the communication in healthy families is direct, honest, open and authentic.
6. **Hope:** Families who are faced with events and changes that threaten or change the family system are more likely to be hopeless or uncertain about the future.
7. **Family Resilience:** When faced with crisis and risk factors, the limits of the family system are pushed. It is necessary for the family to cooperate by combining their common strengths and purposes and to trust themselves in this regard.

8. **Family Time and Habits spent Together:** All family systems try to spend time together and include daily activities in order to realize the stability and expectations that will create an environment of harmony and balance.
9. **Social Support:** Emotional support includes social support such as respect support, communication support, appreciation support and self-sacrifice support, such as a protective commitment and sense of belonging.
10. **Health:** It includes the physical and mental health and well-being of family members and the development of resilience.

In order to increase family resilience through the development of coping skills by overcoming the crisis situation of families with children with autism, families should use the above-mentioned protective factors and healing factors effectively.

2.2. MCCUBBIN AND MCCUBBIN FAMILY ARRANGEMENT AND ADJUSTMENT RESILIENCE MODEL

The Family Arrangement and Adaptation Resilience model is based on a systemic and ecological perspective and five key assumptions. These are:

1. The family faces stress and difficulties in its life cycle.
2. The family has the strength and ability to protect, help and recover under stress.
3. The family can receive or give social support under stress and in times of crisis.
4. As a group, the family seeks a common vision, meaning, and goal that will take it further.
5. The family seeks order, balance and harmony, even under great stress and crisis.

The developed model is based on the basic assumptions of family stress theories. These assumptions are as follows;

1. Changes in the family are natural and normal,
2. The family tries to maintain its self-balance (homoestatis) in the face of difficulties,
3. The family is flexible in the face of changes and difficulties,
4. There is a self-protection mechanism in the family as a unit,
5. There is a social support system in the family,
6. The functioning of the family has a rhythm and pattern,
7. The family needs to be considered in many dimensions,
8. The family can improve its functioning with problem-focused and empowerment-oriented approaches,
9. The family achieves self-control in the life cycle by using its own resources (McCubbin, 1988).

When the model is evaluated in the context of families with children with autism; In the process that begins with the diagnosis of autism in the child, families face numerous stresses and difficulties in their life cycle. Families have the power and ability to protect themselves, help themselves, and recover from this unexpected event. Families can receive or give social support from the society and their environment in times of crisis and stressful times.

Families seek meanings, goals, and shared views that will move their families forward. Even in the midst of great stress and crisis, families seek order, balance and harmony. At this point, it may be necessary to carry out studies focusing on the power of families in order to reveal these forces and end the search for meaning in some families. In this way, it can contribute to increasing the durability of families.

2.3.COPING IN FAMILIES OF CHILDREN WITH AUTISM:

According to Eskin (2014), coping is a basic psychological process. It is about how a person deals with the problems and troubles he encounters in his life and what he does with them. In this context, although the life is stressful, what matters is not the difficulties and problems, but how the person copes with these difficulties and problems (Eskin, 2014).

The biggest problem that families will experience is that they do not know how to approach their children and are insufficient in how to guide them. Most families with autistic children are worried about not knowing how to live with their children. In the study of Olsson and Hwang (2001) comparing mothers with mentally retarded and autistic children, it was concluded that mothers with children with autism experienced more distress than mothers with children with mental disabilities (Olsson, 2008).

Hasting et al. (2005), one of the studies on families of children with autism, reported that families of children with autism who use problem-focused coping have higher levels of well-being than those who use emotion-focused coping. In addition, some families with children with autism stated that they experience higher levels of psychological problems, develop problem-focused coping strategies, and that their family functioning is adversely affected due to family conflicts (Stoner, 2010).

Another study examined the pressure on the family system and compared the coping behaviors of parents of children with autism with parents of children without autism. The results support the hypothesis that there are differences in the types of coping behaviors practiced. Parents of children with autism scored higher on distancing and escapism, behaviors aimed at withdrawing from a stressful situation. In contrast, parents in the control group scored higher in the use of self-control, social support, and problem solving (Sivberg, 2002).

According to the results of the research, it is seen that resilience has a significant relationship with both social support and coping. Coping styles of families show parallelism with social support systems. Having

adequate social support systems of families makes them stronger against the effects of the problems they experience (Bayraklı, 2009).

In the study of Elçi (2004) on families with children with autism; determined that optimistic coping strategy and stress affect the personal success of mothers (Elçi, 2004).

In his study, Çelimli (2009) that he examined the differences in parental stress, coping methods and family functions variables in Turkish and American families with a child diagnosed with autism at preschool age, stated that Turkish and American mothers did not differ in terms of parental stress levels, but differed in coping ways and family functions (Çelimli, 2009). According to the research, it was found that Turkish mothers used more problem-focused coping ways than American mothers.

The fact that families have adequate social support systems makes them stronger against the effects of the problems they experience. Since children with autism are not easily understood by their physical appearance, they can be found strange because of their behavior that is considered strange by the society. This situation causes families to limit their social circle.

The psychosocial well-being of families experiencing these and similar problems, the social support provided by the families in the difficulties they experience, and the coping strategies that enable them to resist the difficulties will increase the resilience of the families. In this context, it is important to reveal the strengths of families by emphasizing their abilities, values, interests, beliefs and resources and develop their coping skills.

CONCLUSION AND RECOMMENDATIONS

As a result of studies carried out in recent years professionals including biological, psychological and social factors; It has been observed that they reduce the negative effects of stressful events and turn to the concept of resilience, which helps individuals and families cope with difficult life events. When the studies conducted in this context are examined, it is understood that coping strategies that focus on the solution of the problem come to the fore. Families with autistic children tend to accept the situation and solve their problems rather than denying the situation they are in.

The resilience of families does not only mean that they overcome their difficulties, but also that they become stronger by overcoming difficulties. Therefore, it is necessary to focus on the strength and resources of families instead of focusing on the problem they experience by collaborating with families. Thus, by revealing the current abilities and resources of families; It will be ensured that their environment, internal and external resources (social support systems) are activated, the stress they experience is reduced, their coping skills are developed and the resilience of families is increased.

The reports of the Guidance Research Center and the Special Needs Report for Children are decisive for the education of children with autism. The presence of a social worker in this structure will allow the child to be evaluated within his own system. In this way, the picture of the situation of the family and the child can be revealed more clearly and the needs can be determined more accurately. As a result of the researches, it has been observed that there is a need for social workers who will serve as mediators, trainers, guides and consultants, especially for families. For these reasons, the involvement of social workers and serving the needs of families, children and institutions gives very effective results.

It can be ensured that families are in contact with professionals from many different disciplines such as psychiatrists, child psychiatrists, psychologists, speech therapists, psychological counselors, social workers. Thus, a center where families can consult when needed and get

support for their children and themselves will also help families reduce their stress, improve their coping skills and increase their resilience.

As a result of the compilation I have made in this article, since there is a lack of information on the prevalence of autism and the problems experienced by families in different geographical regions, studies can be planned to cover the resilience of siblings and family elders, including different regions. At the same time, studies can be planned dealing with the life experiences of families of adults with autism.

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