

Coping and Time Management in Mothers of Children with Autism Spectrum Disorder

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Abstract

Autism is a developmental disorder characterized by impaired social interaction, language, speech, and nonverbal communication, as well as repetitive and stereotypical movements. This disorder requires that children with autism always have a caregiver in their lives and usually caregivers are their mothers. Coping can be defined as the individual's resistance to events or factors that create stress for them and all of the cognitive, emotional and behavioral reactions to these situations. Social anxiety and isolation behavior are frequently observed in individuals with low coping skills. For this reason, studies were generally planned with the idea that mothers' coping attitudes and time management could change. In this review, studies in this perspective have been examined.

Key Words: Autism spectrum disorder, coping, time management, mothers.

Introduction

Autism is a developmental problem of the central nerve system associated with repetitive and stereotypical movements with retardation in social interaction, language, speech, and non-verbal communication (1). It is known that autism is a heterogeneous neuropsychiatric disorder that occurs with the interaction of many different environmental, biological and genetic factors. Numerous structural and functional neuroimaging studies have been conducted to investigate the possible etiologic factors, neuroanatomy, and pathophysiology of autism. Structural neuroimaging studies have revealed many different anatomical changes, which indicates a common disorder in neuronal networks in the early stages of development (2).

Coping can be defined as the individual's resistance to events or factors that create stress for them and all of the cognitive, emotional and behavioral reactions to these situations. Social anxiety and isolation behavior are frequently observed in individuals with low coping skills. Social anxiety is characterized by the fear of being an abstraction from society by other people (3). Lazarus and Folkman, who developed a model of coping methods, defined coping as "the

whole of cognitive, behavioral and emotional responses to reduce, eliminate or withstand the emotional tension caused by stressful events or situations". According to this model, coping includes all the successful or unsuccessful efforts of the individual against internal and external demands. Whether the ways used to cope with a particular stress situation are successful can only be determined by their effects on adjustment. According to the coping model, coping behaviors have purposes such as eliminating or reducing the source of discomfort, changing the evaluations of the stressful situation, and regulating the emotions that cause the discomfort (4). Time management is actually a self-management; is to control the events we experience and it is also the management of events by directing oneself (5) How time is perceived and used varies according to cultures and societies. In traditional societies, time is known as a very flexible and endless resource. For example, most of the economic activities in rural areas are seasonal, depending on the socio-economic and cultural structure of that region. For this reason, in traditional (agricultural) societies, time is generally expressed with seasons. With the mechanization of everything in modern (industrial) society, the only problem seems to be time limitation(5).

For this purpose, our study aimed to reveal the time management and coping attitudes of mothers of children diagnosed with autism by systematically examining domestic and international studies.

This review was conducted to examine the results of studies examining the relationship between time management and coping attitudes of the mothers of children with autism..

In order to collect data in the review, PubMed, Dergi Park and Google Scholar data tools were used to reach international publications.

The texts used in the study are accessed by scanning databases. Articles researched with data collection tools include studies published in recent years. Within the scope of the study, the publications related to the subject were published between 2000 and 2021 as "autism", "coping attitude", "mother", "parent", "time management", "autism", "autism spectrum disorder", "coping strategies". , "time management", "mother" and "parents" keywords were searched using combinations.

As criteria for inclusion in the review;

1-Academic studies made in Turkey and abroad.

2-Mothers with a child diagnosed with autism spectrum disorder.

3-Parents who voluntarily participated in the study

A total of 110 studies were reached by using the inclusion criteria. In the final phase of the literature review, the full texts of the remaining 27 studies were read, and 83 studies that did not meet the inclusion criteria according to their titles and abstracts were excluded. As a result, it was decided to continue with 12 studies.

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Within the scope of the review, a total of 12 studies were chosen, 5 of which were in the United States of America, 1 in England, 4 in Australia, 1 in Poland and 1 in Singapore.

Reference	Country	Purpose	Methods	Data Tools	Sample Group	Findings
Leann E. Smith Æ Marsha Mailick Seltzer Æ Helen Tager- Flusberg Æ Jan S. Greenberg Æ Alice S. Carter (2007)	USA	Comparing the coping attitudes of mothers who have a child with ASD at 14-36 months and adolescence.	Questionnaires were continued to collect data on mothers' coping attitudes and well-being for 2-4 hours.	Center for Epidemiological Studies-Depression Scale (CES-D), Profile of Mood States (POMS), Scales of Psychological Well-being, COPE; Carver et al. 1989)	153 mothers with 14-36 month-old children with ASD and 201 mothers with adolescent children with ASD.	It has been observed that mothers whose children are in the younger age group successfully perform their coping attitudes.
Heather Miller Kuhaneck Tajhma Burroughs Jamie Wright Theresa Lemanczyk Amy Rowntree Darragh (2010)	USA	To examine the coping attitudes of mothers with children diagnosed with ASD.	Data were collected through open-ended individual semi-structured interviews by communicating with mothers through group meetings and e-mail.	Data were collected with semi-structured open-ended questions.	11 mothers with a child with ASD participated in the study. The mothers participating in the study had at least one biological child.	Time management, planning, burden, abundance and adequacy of information; It was concluded that these attitudes are important in coping.

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Karen Qian Ping Ang Pek Ru Loh (2019)	Singapore	This study is to examine the relationship between coping attitudes, gender and mental health of parents who have a child with ASD.	The data were collected by having the parents sign the consent form and fill in the questionnaires required for the study in such a way that the names of the parents remained anonymous	Depression, Anxiety, Stress Scales (DASS; Lovibond and Lovibond 1995), Brief COPE (Carver et al. 1989; Carver 1997), The Autism Treatment Evaluation Checklist (ATEC; Rimland and Edelson 1999)	106 mothers and 97 fathers with children diagnosed with ASD participated in the study.	It was observed that it strengthened the relationship between stress and depression in mothers and fathers who showed active avoidance of coping attitudes.
Shana R. Cohen Hye Kyung Lee Soojung Kim Alison Wishard Guerra (2020)	USA	This study is examine the effect of time use on positive emotions of Mexican immigrant mothers have a child with ASD.	Data were collected with the answers given by 32 Mexican immigrant mothers within 5 days.	Data were collected with semi-structured open-ended questions.	38 mothers with children with ASD were reached, and the interviews continued with the acceptance of 32 mothers.	It has been observed that mothers who can spend more time with their children experience more positive emotions.
D. E. Gray(2006)	AUSTRALIA	Seeing how coping attitudes evolve over time (10 years)	Parents' coping attitudes and how autism affects the family's social life were learned.	cope with a problem (Bury 1991; Thoits 1995), coping with illness (Bury1991)	28 parents (19 mothers-9 fathers) who have a child diagnosed with ASD.	Concluded families cope more easily with time and it becomes easier to live with it.

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RICHARD P. HASTINGS and FRIENDS. (2005)	UK	There is no reliable evidence that the relationship between the age of the child and the coping attitudes of the parents who have a child with ASD has changed, to examine them in more detail and to improve their coping attitudes, increase their reliability.	Parents were divided into two groups according to the age group of their diagnosed child: 1-preschool age group 2-school age group The same scales were applied to these two groups. Coping attitudes scale and anxiety and depression scales	COPE inventory (Carver et al., 1989) Hospital Anxiety and Depression Scale (HADS: Zigmond and Snaith, 1983), Questionnaire on Resources and Stress–Friedrich short form (QRS–F: Friedrich et al., 1983)	1st Group School-Age Child Diagnosed With Autism Spectrum Disorder 26 mothers 20 fathers 2.GROUP: 48 mothers and 41 fathers with a child diagnosed with pre-school age ASD.	It was seen that the coping attitudes of the second group parents were better due to the fact that school-age children continue their education in a boarding school, preschool children continue with formal education, and the time difference their families spend.
Monique Seymour Catherine Wood Rebecca Giallo Rachel Jellett (2012)	USA	Investigation of the relationship between maternal fatigue and coping attitude with the behaviors of her child diagnosed with ASD.	Data were collected through online interviews.	Demographic and Family Background Questionnaire The Brief Developmental Behaviour Checklist-P24 (DBC-P24; Taffe et al. 2007) The depression, anxiety and stress scale-21 (DASS-21; Lovibond 1995) Fatigue assessment scale (FAS; DeVries et al. 2003)	65 mothers with children aged 2-5 years diagnosed with ASD	It was observed that the mother's maladaptive coping attitude with fatigue had an effect on the behavior and stress of the child diagnosed with autism.

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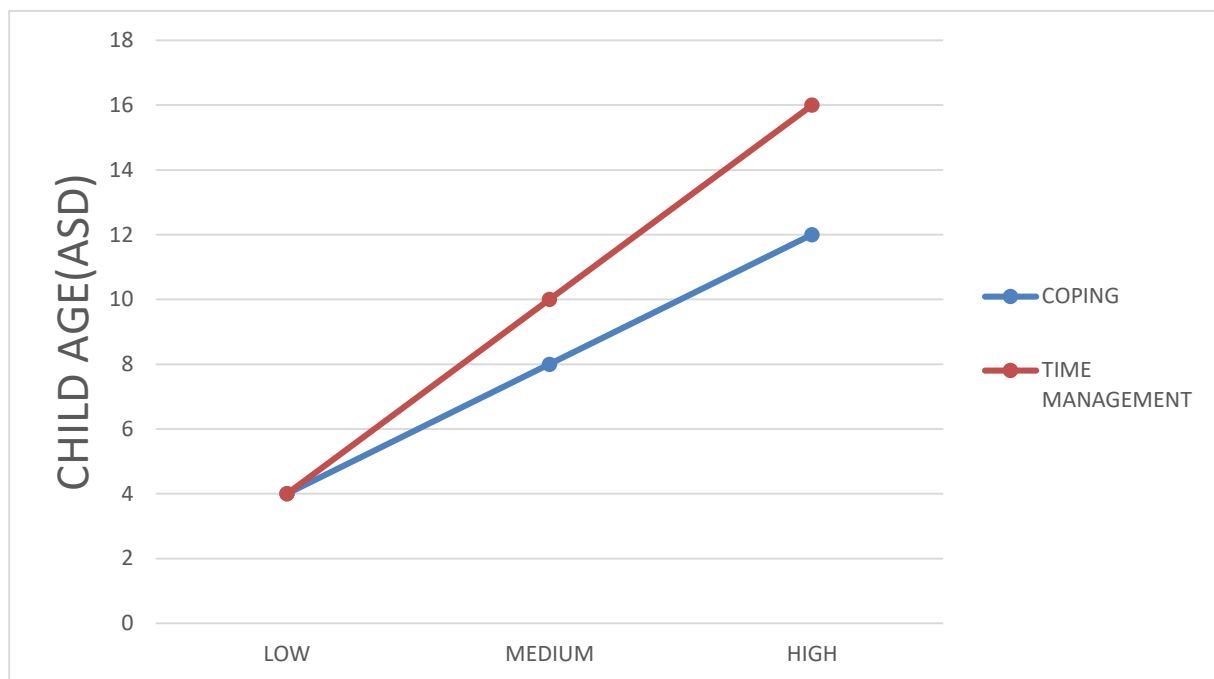
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Annette V. Joosten and Anneleise P. Safe (2014)	AUSTRALIA	To examine how mothers of children with ASD cope with the roles and emotions of their children.	Face-to-face and semi-structured interviews were conducted with mothers. These interviews lasted a minimum of 90 minutes and a maximum of 170 minutes.	Semi-structured open-ended interviews were conducted. Demographic survey was done.	7 mothers with a child diagnosed with ASD between the ages of 6-12.	It has been observed that mothers adapt to the situation. However, it has been observed that they develop these strategies for the expectations and stresses of others.
A.Dabrowska ve E. Pisula (2010)	POLAND	To examine the attitudes of parents of children with ASD, Down syndrome and typical development of coping attitude and stress.	Coping inventory stress questionnaires were administered to parents	Sociodemographic survey was done. Questionnaire of Resources and Stress (QRS) Families with Chronically Ill or Handicapped Members short form (Holroyd 1987) Coping Inventory for Stressful Situations – CISS (Endler & Parker 1990)	51 parents with children aged 2-6 years with ASD, 54 parents with children with Down syndrome and 57 parents with children typical development.	Stress levels of parents who have a child diagnosed with ASD were higher, and it was observed that mothers experienced more stress than fathers.
Benjamin Zablotzky Catherine P. Bradshaw Elizabeth A. Stuart (2013)	USA	In mothers of children diagnosed with ASD; to examine mental health, stress and coping attitudes.	Interviews were conducted remotely via telephone.	Sociodemographic survey and semi-structured interviews.	Mother with 91,642 children diagnosed with ASD.	It was observed that as the stress levels of mothers increased, the complications in their children with ASD

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Damhnat McCann, Rosalind Bull and Tania Winzenberg (2012)	AUSTRALIA	To examine the time that parents of children with complex needs devote to daily activities.	Four electronic databases were searched.	Electronic literature search was conducted for related research. Searches were also made using the names of key researchers in the field and "Related articles".	32 studies were reviewed.	These families need counseling due to the overload
Michael G. Sawyer Michael Bittman Annette M. La Greca Angela D. Crettenden Taylor F. Harchak Jon Martin (2009)	AUSTRALIA	Examination of the relationship between maternal mental health and time pressure when the mother of the child diagnosed with ASD.	Two interviews were made over the phone. In the first interview, a daily activity record was requested. In the second interview, this activity record was get from the mothers.	Australian Bureau of Statistics (ABS)(1998) Time Crunch Scale (Robinson and Godbey 1997) The 30-item Interpersonal Support Evaluation List (ISEL; Cohen et al. 1985) 25-item Strengths and Difficulties Questionnaire (SDQ) (Goodman 1997; Goodman 2001)	Interviews were made with 216 mothers who had children between the ages of 6-17 who were diagnosed with ASD.	The relationship between the age of the child with ASD, the mother's social support, the child's behavior and timing with the mother's mental health problems were found to be significant.



Leann E. Smith et al. aimed to compare and contrast the coping attitudes of mothers who have a child diagnosed with ASD at 14-36 months and adolescence. Questionnaires were conducted to collect data on mothers' coping attitudes and well-being for 2-4 hours. Center for Epidemiological Studies-Depression Scale (CES-D), Profile of Mood States (POMS), Scales of Psychological Well-being, COPE; Carver et al. (1989) scales were used. The study was conducted with 153 mothers with a child diagnosed with ASD between 14-36 months of age and 201 mothers with a child diagnosed with ASD in adolescence. It was seen that mothers of these children were in the young age group successfully performed their coping attitudes (19).

Heather et al. examined the coping attitudes of mothers of children diagnosed with ASD. Data were collected through open-ended individual semi-structured interviews by communicating with mothers through group meetings and e-mail. A total of 11 mothers participated in the study. It was taken into account that the mothers participating in the study had at least one biological child. It was concluded that time management, planning, sharing the burden, abundance and adequacy of information were important in coping (17).

Karen Qian Ping Ang and Pek Ru Loh examined the relationship between coping attitudes, gender and mental health of parents with children diagnosed with ASD. The consent form was signed by the parents, and the necessary questionnaires for the study were filled in such a way that the names of the parents remained anonymous, and the data were collected. 106 mothers

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and 97 fathers participated in the study. It was concluded the relationship between stress and depression were in mothers and fathers who showed active avoidance of coping attitudes (23).

Shana R. et al. Studied about the effect of time use on positive emotions of Mexican immigrant mothers with a child diagnosed with ASD. Data were collected with the answers given by 32 Mexican immigrant mothers within 5 days. 38 mothers were reached, and the interviews continued with the acceptance of 32 mothers. It has been observed that mothers who can spend more time with their children experience more positive emotions (24).

D. E. Gray et al. conducted a study to learn how coping attitudes evolve over time (over a 10-year period). Parents' future expectations, parents' coping attitudes, and how autism affects the family's social life were sought. Cope with a problem (Bury 1991; Thoits 1995) and coping with illness (Bury 1991) scales were used. 28 parents (19 mothers and 9 fathers) participated in this study. It was found that families cope with time more easily and it becomes easier to live with it (15).

Richard P. Hastings et al. carried out a study to demonstrate the relationship between the age of the child and the coping attitudes of the parents. Parents were divided into two groups according to the age group of their diagnosed child: 1-preschool age group and 2-school age group were included in the study. COPE inventory (Carver et al., 1989) Hospital Anxiety and Depression Scale (HADS: Zigmond and Snaith, 1983), Questionnaire on Resources and Stress–Friedrich short form (QRS–F: Friedrich et al., 1983) scales were used for data collection. 26 mothers and 20 fathers with children diagnosed with ASD in the first group, 48 mothers and 41 fathers in the second group preschool age were included in the study. It was stated that the coping attitudes of the second group were better due to school-age children continuing their education in a boarding school, preschool children continuing with formal education, and the difference in the time they spent with their families (16).

Monique Seymour et al. conducted a study to examine the relationship between maternal fatigue and coping attitude with the behavior of her child diagnosed with ASD. Data were collected through online interviews. Demographic and Family Background Questionnaire The Brief Developmental Behavior Checklist-P24 Demographic and Family Background Questionnaire (DBC-P24; Taffe et al. 2007) The depression, anxiety and stress scale-21 (DASS-21; Lovibond and Lovibond 1995) Fatigue assessment scale (FAS; DeVries et al. 2003) scales were used for data collection. 65 mothers with children aged 2-5 years participated in the study. It was concluded that the maladaptive coping attitude of the mother with the fatigue had an effect on the behavior and stress of the child diagnosed with autism (14).

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Annette V. Joosten et al. researched to examine how mothers of children diagnosed with ASD cope with the roles and emotions of their children. Face-to-face and semi-structured interviews were conducted with mothers. These interviews lasted for a minimum of 90 minutes and a maximum of 170 minutes. Data were collected through demographic questionnaires and semi-structured open-ended interviews. Seven mothers between the ages of 6-12 were included in the study. It was observed that mothers adapted to the situation by developing strategies. However, they stated that they developed these strategies not according to the needs of themselves and their children, but based on the expectations and stresses of others(13).

A.Dabrowska et al. examined the attitudes of parents of children with Down syndrome and typical development of children diagnosed with ASD of coping and stress. Sociodemographic survey was done. Questionnaire of Resources and Stress (QRS) Families with Chronically Ill or Handicapped Members short form (Holroyd 1987) Coping Inventory for Stressful Situations – CISS (Endler & Parker 1990) scales were used to collect data. The study included 51 parents with children aged 2-6 years diagnosed with ASD, 54 parents with children with Down syndrome, and 57 parents with children with typical development. The stress levels of parents who have a child diagnosed with ASD were higher, and they stated that it was concluded that mothers experienced more stress than fathers (22).

Benjamin Zablotsky et al conducted a study in mothers of children diagnosed with ASD. They aimed to research mental health, stress and coping attitudes. Interviews were made remotely via telephone. A sociodemographic questionnaire and semi-structured interviews were used to collect data. 91,642 mothers with children diagnosed with ASD were included in the study. It was found that as the stress levels of mothers increased, the complications of their children increased (18).

Damhnat McCann et al. examined the time that parents of children with complex needs to caregiving at daily activities. Data were scanning four electronic databases. 32 studies were examined in this research. It was concluded that these families needed counseling due to the overload (21).

Michael G. Sawyer et al. carried out a study to examine the relationship between maternal mental health and time pressure, when the mother of a child diagnosed with ASD cares for her child. Two interviews were made over the phone. In the first interview, it was requested to keep a daily activity record. In the second interview, this activity record was taken from the mothers. Australian Bureau of Statistics (ABS)(1998)Time Crunch Scale (Robinson and Godbey 1997) The 30-item Interpersonal Support Evaluation List (ISEL; Cohen et al. 1985) 25-item Strengths

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and Difficulties Questionnaire (SDQ) (Goodman 1997; Goodman 2001) The 30-item version of the General Health Questionnaire (Goldberg 1978) scales were used to collect data. It was concluded that the age of the child, the social support of the mother, the behavior of the child and the timing were significantly associated with the mental health problems of the mother(20).

This systematic review aimed to examine the time management and coping attitudes of mothers of children diagnosed with autism and to identify common results that will guide future research in order to improve the quality of data in this area. As a result of the studies discussed, it has been seen that there is limited number of studies about this issue and there are more studies from abroad. The number of studies conducted in our country is not sufficient, the data could not be generalized.

In the studies examined, it was observed that the age of the children had a significant effect on the mother's coping attitude and time management. The results differ when autism is accompanied by another disease. When the data were generalized, it was concluded that the mother's coping attitudes and time management improved over time.

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