

COPING STRATEGIES OF FAMILIES WITH CHILDREN WHO SUFFER FROM AUTISM SPECTRUM DISORDERS (ASD)

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Abstract: *The main purpose of the current research is to identify the coping strategies adopted by the parents of children diagnosed with Autism Spectrum Disorders. The birth of a child with a disability, who strays from the ideal and does not correspond to the expectations of parents causes a shock, which triggers an ample and complex mourning process. Within families in the constellation of which there is a child with autism, a series of stressors and tensions manifests plenarily, difficulties arise, and that is why, for the stress and the diagnosis in itself to be managed as correctly as possible and to the benefit of the child, but also of the family, certain coping strategies are employed. The manner in which the parents choose to manage the stress, the manner in which they adopt and implement a certain coping strategy, the existing connection between coping strategies, and the stages of mourning are main aspects that will be treated in the current research.*

Key words: *coping strategies, mourning process, family with ADS children*

1. Introduction

Within the “Autism in Romania” conference organized by the Help Autism Association on the 6th of November 2019, the following statistics were presented: more than 1000 children are diagnosed with Autism Spectrum Disorder in Romania (according to the data published by the National Mental Health Institute, www.helpautism.ro). Autism is defined by Simion (2013) as a developmental disorder, considered to be one of the most severe neuropsychiatric disorders of childhood. Autism is a central disorder, within an entire spectrum of developmental disorders, known as the Autism/Autistic Spectrum Disorders or pervasive development disorders – a term used in the DSM IV and ICD 10 international classification systems. In order to diagnose Autism Spectrum Disorders, the specialist considers a series of criteria that are in accordance with the Diagnostic and Statistical Manual of Mental Disorders – DSM V (American Psychiatric Association, 2013).

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When a child is born, the parents radically change their functions within the family constellation. Studies have shown that the development of the family is simultaneous with the development of the child. Given his role within the familial system, it has been ascertained that a less than perfect child (diagnosed with an Autism Spectrum Disorder or another disability) can generate frustrations and discontentment within the family (Muntean, Sabău, & Zămoşteanu, 2007).

“The loss that the family deals with is that of the child they had dreamt of” (Moses, 1983, cit. in Roşan, 2015, p. 553). A child's diagnosis of autism can cause a powerful shock, marked by physical pain, the desire for isolation, and feelings of inner emptiness. Losing the child one has dreamt of for a long time can be associated with the mourning caused by a close person's death.

The literature highlights the fact that a diagnosis of Autism Spectrum Disorder significantly affects the parents' life, their career, their parental behavior and imposes the development of coping mechanisms (Mareş & Toth, 2015). Muntean and collaborators (2007) states the fact that, after the Pervasive Development Disorder diagnosis has been given, the family begins a labor of mourning which, in some cases, may be interminable, the death of the “ideal child” being often times impossible to accept. At that moment, the family's image of the child and various problematic situations that may arise can dramatically disturb the harmonious functioning of the family.

2. The stages of mourning and coping methods

When the diagnosis is discovered and throughout the evolution of the child with autism, the parents are under enormous stress (“stress” being a relationship between the person and the environment, in which the environment imposes conditions that require a person's inner resources and which interferes with the well-being felt by that person at a specific moment) called parental stress. Among the most powerful stressors, we mention here society's opinion regarding Autism Spectrum Disorder, the unknown etiology of autism, the absence of specialists and fragmented services, the feeling of powerlessness, the high costs of therapy, the emergence of conflicts at the level of the family, the child's characteristics (the severity of the diagnosis, auto-stimulations, stereotypes, etc.), parental perception differences, etc.

When the family feels the full extent of the emotions after learning the diagnosis, as well as the abovementioned stressors, an ample mourning process begins; these stages are fundamental for reaching the ideal, namely the acceptance of the diagnosis (the last stage of the mourning process), as well as an active involvement in the “battle” against the diagnosis. According to Kubler-Ross (1969), the stages of mourning are:

- *The denial and isolation stage* (“No, not me”; “I feel fine”; “This can't happen, not to me!”) – the family of the child diagnosed with Autism Spectrum Disorder pretends that the diagnosis doesn't exist and searches for possibilities to invalidate the diagnosis. Parents are distrustful of the diagnosis, the child with an Autism Spectrum Disorder representing a loss of the ideal child that they had long dreamt of. Most of the times, the family is prepared to accept the most obvious (socially visible) diagnosis, but profoundly denies the existence of less visible disorders (Roşan, 2015). Omer (2010)

defines denial as a buffer psychological mechanism.

- *The rage/anger and revolt stage* ("Why me? It's not fair!") - the family comes to terms with the situation, the diagnosis is no longer invalidated, but they focus on identifying the causes and the guilty parties. Roşan (2015) states that the search or revolt stage is marked by anger, aggression, and blaming others. The discharge of emotions is natural and, as long as it takes place in an adequate manner, the angry family can free their mind and body of the accumulated stress and may prepare for battle.

- *The negotiation or lamenting stage* ("Fine, it's me, but...") – the family gives up anger and revolt but hopes for some compensatory mechanisms. This stage is marked by emotional turmoil and contradictory feelings. "Guilt, followed by negotiation, is often felt by the parents of special needs children. Usually, the mother feels guilty for the cause of the child's problem, even if it is unknown, whereas the father blames himself for the inability to offer the family protection" (Luterma, 2004, cit. in Roşan, 2015). That is why it is characteristic in couples with an autistic child for the mother to assume the role of the child's personal assistant, of permanent caretaker, while the father takes care of the family's material well-being.

- *The depression stage* ("Yes, it's me...") – the family goes through moments when they have difficulties in living through the moment, maintaining social relations, having a reason to live, and feeling pleasure. Depression is natural and it represents the family's awareness of the diagnosis' implications. Feelings of hopelessness and despair are natural, the family has the tendency to isolate itself socially and that is why a specialist needs to detect the depression stage and come to the aid of the family (Omer, 2010). Mind you, we are not talking about depression as a psychological disorder, but depression as a stage in the mourning process.

- *The acceptance or resignation stage* ("Yes!"; "Life goes on"; "Everything will be alright") – the family resigns, it understands the situation rationally and resumes its activities and roles. In the acceptance stage, the focus is on developing certain mechanisms for solving the problem, within the family-therapist/specialist partnership (Omer, 2010).

To manage the stress and deal with the situation in a desirable and socially acceptable manner, the family of the child with an Autism Spectrum Disorder resorts to using coping mechanisms. "Coping is defined as a complex concept, the definition of which revolves around the notion of attempting to restore balance as a response to stress" (Muntean et al., 2007, p.41).

Lazarus and Folkman (1984) define coping as being a constant, cognitive, and affective effort to manage and/or get through certain challenges, from outside or inside, which are considered toxic or great consumers of energy. Lazarus and colleagues (1984) divide coping into two categories: coping focused on the problem (active or direct coping) and coping focused on emotions (passive or indirect coping).

Coping focused on the problem or active coping implies the formulation of situation management strategies (Preda, 2010). On the other hand, Popa-Velea (1999) states that direct coping is focused on analyzing and solving the problem, and if this is not possible, on minimizing the stressful situation; in this case, the accent is on confronting the

stressor. Carver, Scheier, and Weintraub (1989) elaborated the COPE questionnaire, which integrates the stress model created by Lazarus and Folkman (1984) and delimits within coping focused on problems the following manifestation dimensions: planning, elimination of concurrent activities, abstention from action and search of social support (Muntean et al., 2007). According to Lazarus and Folkman (1984), active coping is the rational way to control stress, meaning that negative emotions associated with stress are surpassed and the individual focuses his motivation and resources toward solving the problem.

Coping focused on emotions or passive coping is based on regulating emotions during stressful moments (Preda, 2010). Within the COPE questionnaire elaborated by Carver, Scheier, and Weintraub (1989), which integrates the stress model created by Lazarus (1984), passive coping falls under the following manifestation dimensions: search for emotional social support, positive reinterpretation, acceptance, denial, and orientation toward religion (Muntean et al., 2007). Folkman and Lazarus (1984) illustrate the fact that passive coping is a strategy through which the individual minimizes negative emotions by modifying his thoughts regarding the stressor, but without solving the problem. According to Popa-Velea (1999), indirect coping focuses on the individual and his/her ability or inability to deal with the stress.

It is important to mention the fact that, throughout time, in the literature, a third category of coping strategies was circulated, given that the division of coping strategies into the two patterns, active and passive, is too simplistic and insufficient. Thus, within the COPE questionnaire elaborated by Carver, Scheier, and Weinteraub (1989), a third form of coping was introduced, namely dysfunctional or maladaptive coping, which has the following manifestation dimensions: discharge of emotions, mental passivity, behavioral passivity, and resorting to alcohol/drugs/medication/gambling (Muntean et al., 2007).

Muntean and colleagues (2007) reached the conclusion that the control locus as structural factor directly influences the coping strategies developed by the parents of children diagnosed with Autism Spectrum Disorders or other disorders. In the case of an internal control locus, the parent will form active coping strategies, focused on the problem, whereas if the parent has an external control locus, he will develop passive coping strategies, based on emotions. If the control locus is internal, then the parents of children with Autism Spectrum Disorders will blame themselves for their child's disability, they will attribute the cause of the disability at the level of their own parenting mistakes from before the diagnosis, they will consider genes and biological aspects as determining factors. If the control locus is external, then the parents of children diagnosed with Autism Spectrum Disorders will have the tendency to blame fate, divinity, their partner, or the pharmacological products they administered to the child before the diagnosis was given.

3. Research coordinates and design

3.1. Research questions

In the present research, the accent is placed on going through the mourning stages,

for each family, with the fundamental purpose of reaching the acceptance stage – the most desirable stage, which entails the parents' involvement in the therapeutic endeavor and in their child's inclusion process, but also the development of a balanced lifestyle. The starting point is the question: Is there a connection between the mourning stage that the family is in and the stress management strategy, the setbacks created by the diagnosis (coping methods) adopted by the family? At the same time, the research aims at identifying if there is a connection between the acceptance of the diagnosis and the manifestation within the family of a coping focused on the problem.

3.2. Hypotheses

As an objective, the research has aimed at establishing the connection between the mourning stage that the family is in and the coping methods adopted by the family. At the same time, the research aims at identifying if there is a connection between the acceptance of the diagnosis and the manifestation within the family of a coping focused on the problem.

We start from the hypothesis according to which: There is a connection between the mourning stage that the family of the child diagnosed with an Autism Spectrum Disorder is in and the coping strategy adopted by the family. Thus:

- The denial stage is associated with adopting a passive coping strategy by the family of the child with ASD.
- The anger stage is associated with adopting a dysfunctional coping strategy by the family of the child with ASD.
- The negotiation stage is associated with adopting a passive coping strategy by the family of the child with ASD.
- The depression stage is associated with adopting a dysfunctional coping strategy by the family of the child with ASD.
- The acceptance stage is associated with adopting an active coping strategy by the family of the child with ASD.

3.3. Method

The design of the present research is a descriptive one, seeking to explore the connection between the studied variables, namely the stages that the parents went through after learning the Autism Spectrum Disorder diagnosis and the coping strategies they used. At the same time, the design is transversal since there was a unique moment for collecting the necessary data.

The test sample for the research was made up of 85 participants, among whom 92.1% (79) being female and 7.1% (6) being male, with ages between 23 and 52. We attempted to make the group of participants as heterogeneous as possible. The main criterion for inclusion in the current study was the existence of at least one child diagnosed with Autism Spectrum Disorder in the family constellation. Whereas the exclusion criterion was the absence of a child with an Autism Spectrum Disorder.

The test sample for this research is not statistically representative constituted in a

nonrandom, convenience manner, the participation being voluntary. The participants in this research are parents who have children diagnosed with Autism Spectrum Disorder between 2000 and 2020 and who benefit from therapeutic assistance in: “Centrul de zi pentru copii cu autism și Sindrom Down Sfânta Maria”- Târgoviște, “Asociația Pro-Misiunea Socială” – Târgoviște, “Asociația Zâmbetul Otiliei”- Braşov as well as parents who are members of online groups dedicated to children with ASD, through social networks (Facebook, Twitter).

The COPE questionnaire and teste were distributed electronically to parents of children with Autism Spectrum Disorders on social networks, pages dedicated to ASD children, or pages/groups belonging to centers, associations, or NGOs (private groups) that provide therapeutic service dedicated to children with ASD.

The collection of data was performed with the informed consent of all participants in this study. The data was collected with the aid of several instruments using online communication channels. The instruments of the research were elaborated electronically (Google Forms) and subsequently distributed on several socialization pages dedicated to parents and children with Autism Spectrum Disorders or (private) socialization groups belonging to the abovementioned associations/centers/ NGOs.

3.4. Instruments

In order to obtain data regarding the mourning period in which parents of children diagnosed with Autism Spectrum Disorder were, a questionnaire was used, entitled: Questionnaire regarding “The characteristics of families of children diagnosed with ASD”, a questionnaire created based on theoretical information collected in the first part of the research. The title of the questionnaire does not refer to the subject of the present research, in order to avoid the respondents’ contamination and answers stemming from social desirability. This instrument is made up of 23 items with closed questions and open questions.

The second section of the instruments is used to obtain data regarding the coping strategies used by the parents of children diagnosed with Autism Spectrum Disorder and the COPE Test was applied. The COPE test was elaborated by Carver, Scheier, and Weintraub in 1989 and it integrated the stress model created by Lazarus (Lazarus & Folkman, 1987).

The COPE test is adapted to and validated on the population of Romania, the psychometric properties of the test being the internal consistency coefficient of scales between .62 and .92, and the test-retest coefficient between .48 and .83 (Carver et al., 1989). The questionnaire targets 14 forms of coping that may have a predominantly active (focused on problems), passive (focused on emotions), or dysfunctional character. The instrument is made up of 53 statements, each form of coping being evaluated through 4 items, except for coping through resorting to alcohol or medication, which is measured through a single item.

The participants were instructed to carefully read the presented statements, to think about how they feel and how they act in relation to the autism diagnosis that characterizes their child's condition and check the answer that corresponds to their

situation.

The last part of the instrument had the role of collecting demographic data, the purpose of which is to facilitate the analysis of the quantitative data obtained in stages and systematically. The participants are assured again that their personal data will be treated with respect and confidentiality. The required demographic data is: initials of the name, age, gender, and the year in which the child was diagnosed with Autism Spectrum Disorder (in order to observe the inclusion and exclusion criteria for the present research).

4. Results

We started from the assumption that there is a connection between the mourning stage in which the family of the child diagnosed with Autism Spectrum Disorder is and the coping strategy adopted by the family. Thus, the following chart illustrates the relations identified between the mourning stage and the coping strategy adopted by the family, as follows:

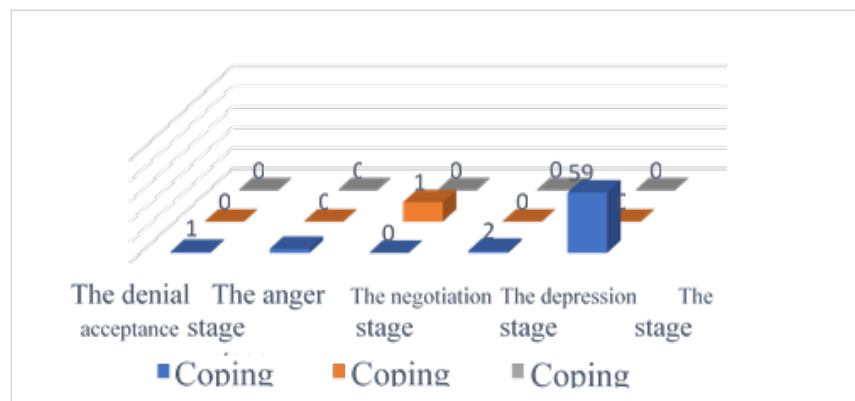


Fig. 1. *The crosstab distribution of mourning stages with the identified coping methods*

With regard to the first working hypothesis according to which: The denial stage is associated with adopting a passive coping strategy (marked with yellow in Figure 1) by the family of the child with ASD, it could not be empirically verified, because the collected data is insufficient, the test sample for the research does not manifest characteristics for this studied variable. The existence of a relation between the two variables may only be highlighted through the extrapolation of the results of the research in ensemble, in a speculative rather than empirical manner.

Regarding the second working hypothesis, the data collected within the current study – the low number of participants to fall within the anger stage – does not allow generalizations.

Regarding the third working hypothesis, 22% (19) of the participants fall within the negotiation stage. The main characteristic of these participants is that they renounced their anger and have contradictory feelings. The emotional turmoil felt by the families

following the discovery of the Autism Spectrum Disorder diagnosis is a powerful one, contradictory emotions arise, emotions of varying intensities, most of the times very strong, and a fundamental need to share these emotions is noticed. Most of the times, parents feel the need to discuss freely about the stressful situation that is affecting their life, to ask for advice and suggestions, to identify with people going through similar situations and emotionally discharge. In this case, there is a relation between = the negotiation stage that the family is in after learning the Autism Spectrum Disorder diagnosis and the family's adopting a passive coping strategy. Thus, 22% (19) of participants are in the negotiation stage and adopt a passive coping strategy. The studied test sample included in the passive coping strategy is characterized by searching for socio-emotional support, positive reinterpretation, acceptance, denial, and orientation towards religion. The participants who are in the negotiation stage adopt passive coping strategies, according to the COPE Test all participants obtained scores between 30 and 76, which positioned them in the passive coping strategy (the score in this strategy being the largest).

With regard to the fourth working hypothesis, by individually analyzing the cases, we have identified the fact that, in the case of participants to the present research, it cannot be studied and analyzed in depth, because within the test sample of the research, only 2% (2) of participants fall within this stage. It is particularly important to mention that depression in this research refers to the mourning stage and does not have the traits of a psychological disorder. Thus, parents were included in this category because they stated that they felt emotions such as "frustration, confusion, fatigue, unfulfillment" or "I feel despair, I don't know how to calm her down when she has a fit" (negative feelings that are based on difficulties to manage certain deviant behaviors), but most importantly, they feel deep sadness.

The fifth working hypothesis illustrates the fact that: There is a relation between the acceptance stage that the family is in after learning the Autism Spectrum Disorder diagnosis and the family's adopting an active coping strategy (marked with blue in Figure 1). 70% (59) of participants fall within the acceptance stage. This is possibly due to the fact that the test sample is a convenience one, made up of parents who have a history with regard to the therapeutic assistance that their child diagnosed with Autism Spectrum Disorder receives. This stage is based on the rational understanding of the situation, thus the parent in the acceptance period reaches the stage where he/she feels resigned and at peace with the situation, and although the situation causes them stress and discomfort, they can naturally manage their emotions and direct their efforts in view of solving the situation that is causing great stress (the therapeutic intervention necessary for the child with Autism Spectrum Disorder).

5. Conclusions

The current research aimed at exploring the connection between the mourning stage that the family is in after learning the Autism Spectrum Disorder diagnosis and the coping strategy adopted by the family. Given the nature of the test sample's composition, all the hypotheses suggested for the current research could not be

empirically verified. However, we may speculatively conclude that, if there is a relation between the negotiation stage of mourning and the passive coping strategy variable and between the acceptance stage of mourning and the active coping strategy variable, then, through extrapolation, we may take into consideration the fact that there is a relation between the other variables (denial, anger, and depression mourning stage and the passive and dysfunctional coping strategy), which must be verified through ameliorations of the test sample's composition: expansion, diversification, representation.

Going through the mourning stages represents an ample, complex process that requires time and emotional and psychological support, which varies from one individual to the next. Specific for these stages are a series of emotions and feelings illustrated within the current research, but also the participants' adopting certain coping strategies. There is no pre-set time interval during which the parent should reach the acceptance of the diagnosis, but the sooner this happens, the stronger the influences and benefits for the child. The acceptance of the diagnosis represents a necessary premise for the inclusion of the family as a team, by involving the parent in therapy and turning him into a co-therapist, into an active support.

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