

**"Babeş-Bolyai" University of Cluj-Napoca**  
**Faculty of Psychology and Educational Sciences**

**DOCTORAL THESIS**

**Predictors of perceived social support, stress level, coping strategies and  
resilience level for parents of autistic children**

**- SUMMARY -**

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# CONTENTS

## **Introduction**

### **1. Autism - conceptual delimitations**

- 1.1. The definition of autism
- 1.2. History of autism
- 1.3. Diagnostic criteria of autism
  - 1.3.1. Diagnostic criteria DSM - IV - TR
  - 1.3.2. Diagnostic criteria ICD - 10
- 1.4. Types of autism

### **2. Theories of autism**

- 2.1. Theory of Mind Deficit
- 2.2. Executive Dysfunction Theory
- 2.3. Central Coherence Theory

### **3. The family as a system. Functioning models applied to the family of a child with autism**

- 3.1. Transactional model
- 3.2. Family systems theory
  - 3.2.1. Family structure
  - 3.2.2. Family interaction
  - 3.2.3. Family functions
  - 3.2.4. The life cycle of a family
- 3.3. The ecological model
  - 3.3.1. Microsystem
  - 3.3.2. Midsystem
  - 3.3.3. Exosystem
  - 3.3.4. Macrosystem

### **4. Effects of autism on the family and its members**

- 4.1. Effects of autism on parents
- 4.2. Effects of autism on siblings
- 4.3. Effects of autism on grandparents
- 4.4. General effects on the family and its members

### **5. Evaluating families with autistic children**

- 5.1. Needs and wishes of the family

- 5.2. Family functioning style
- 5.3. Social support
- 5.4. Family systems assessment

## **6. Stress, coping, and resilience**

- 6.1. Psychological stress
- 6.2. Cognitive assessment
- 6.3. Personal and situational factors involved in cognitive assessments
- 6.4. Parental stress and ASD (Autism Spectrum Disorder)
- 6.5. Stress Management. Coping.
- 6.6. Approaches to coping
- 6.7. Coping strategies
- 6.8. Socio-cultural differences in coping
- 6.9. Coping resources
- 6.10. Coping efficiency
- 6.11. Resilience in families of children with ASD

## **7. Research methodology**

- 7.1. Research objectives
- 7.2. Research hypotheses
- 7.3. The participants involved in research
- 7.4. Description of research instruments

## **8. Research results, data interpretation, and discussion**

8.1. Study 1: Predictor variables and influences on social support perceived by parents of children with autism

8.2. Study 2: Predictor variables and influences on the level of stress perceived by parents of children with autism

8.3. Study 3: Predictor variables and influences on coping strategies used by parents of children with autism

8.4. Study 4: Predictor variables and influences on the level of resilience of parents of autistic children

## **9. Conclusions**

### **Bibliographical references**

### **Annexes**

**Keywords:** autism, resilience, coping strategies, stress levels, social support

## Introduction

Most researchers studying autism agree that autistic manifestations are a behavioural response to an organic substrate of their brains. In fact, autism is a complex developmental syndrome, comprising a heterogeneous group of individuals with similar symptoms but with multiple biological etiologies (Secară, 2006). Currently autism is described as a pervasive developmental disorder, affected individuals exhibiting deficits in the social interactions (using the nonverbal behavior in communication, social/emotional reciprocity), verbal and nonverbal communication and a restricted and stereotyped field of interests and activities (American Psychiatric Association, 1994; Myles, Cooper Swanson, Holverstott, Moore Duncan, 2007).

Autism is a developmental disorder with potentially harmful effects on the entire family. It is a chronic disability that occurs worldwide in all environments: racial, ethnic, cultural and social. A study in the USA found that autism is now ten times more prevalent than it was in 1980 (Blakeslee, 2003). Moreover, the number of children affected is growing by 10 to 17% per year (Autism Society of America, 2003). Because of the severity of this disorder, many families are struggling to adapt to the child's diagnosis and to adjust to having a child with special needs in their home. The motivation for this study is based on two factors, namely the increasing prevalence rates of the disorder and potentially harmful effects that it can have on family functioning. Therefore, the aim of this study was to identify the characteristics and the resources the families have, to enable them to adapt successfully.

The presence of an autistic child in the family can have negative effects on various areas of family life, including marital relationship, the relation between siblings and adjustment, socialisation practices in the family, and normal family routines. Because of the demands associated with caring for an autistic child, parents do not have much personal time (Court Appointed Special Advocate (CASA), 2003). The result can be a weak emotional bond between parents (Cantwell & Baker, 1984), depression, withdrawal of a parent's care responsibilities, or divorce.

Rivers and Stoneman (2003) found that many parental conflicts, as well as marital stress lead to behaviour problems, more difficult adjustment, lower self-esteem and higher rates of depression in siblings of children with autism. Other stressors for siblings include greater responsibilities, stigma, loss of normal interaction between siblings (Dyson, Edgar & Crnic, 1989), feelings of guilt and shame and changes in family roles, structure, and activities (Rodrigue, GEFFKEN, & Morgan, 1993).

Family routines are often dictated by the autistic child and must be often changed at the last minute to suit the child's needs. Other factors that cause isolation of families can include the difficulty of finding a trustworthy person to care for an autistic child, and fatigue or loss of energy due to the constant burden of care (Sanders & Morgan, 1997). Despite the challenges faced by families of children with autism, some families are able to cope remarkably well, although others have considerable difficulties in relation to these challenges.

The adjustment level of a family depends on many essential elements that interact, namely stress and its severity; family vulnerability; established patterns of family functioning and family typology; resistance resources; stress assessment; and problem-solving strategies and coping strategies of the family (McCubbin et al.).

Adapting the family includes a number of components oriented for adaptation and processes of resistance (McCubbin et al., 1996). These include:

- Vulnerabilities that may include additional day-to-day stress factors and changes that undermine or limit the family's ability to achieve a satisfactory level of adaptation;

- Resources, consisting of psychological, family-related, and social resources that families can use in the adaptation process;
- Evaluation, including factors that give meaning to changes in the family and plays a role in creating new models, affirming and eliminating old patterns. It involves the creation and use of available resources to cope, as well as the solving of, adaptation to, and adjustment towards the issues;
- Support, including intra-family and family-community support processes to facilitate adaptation;
- Models of operation that involves the removal, modification, and establishing of operational models in the family to bring balance and harmony, as well as adaptation (McCubbin et al.).

Walsh (2003) formulated a model of resistance process in the family and highlighted the qualities that can reduce stress and vulnerability to crises. It includes family belief systems, the approach of hardships as a "common challenge" (Walsh, p. 407), maintaining a positive outlook in adapting to stress and maintaining a common trust in an unfavourable situation. Furthermore, most families could find comfort, strength and guidance through connections to cultural and religious traditions (Walsh). Social and economic resources, including relatives and social networks, friends, community groups, and religious communities are important contributors to the strength of the family, especially if the stress is ongoing (Walsh). Communication processes involving content clarity, open emotional expression, collaborative problem solving and conflict management are vital to effective family strength (Walsh).

The above-listed and described are just some of the reasons that led to the choice of research topic named "Predictors of received social support, stress levels, coping strategies and the resilience level for parents of autistic children". This paper addresses a topic of great timeliness and impact on a global scale. At the same time, I believe that this research provides useful and interesting examples about parents of children with autism. It is also important to note that it's the first of its kind on a sample of the Romanian population that brings information not only on the mothers, but also on fathers. Studies made alongside all the data collected from the literature try to cover part of the gap in this area of research in Romania and could provide a basis for future studies.

## **Theoretical framework**

The first chapter (**Autism - conceptual delimitations**) provides a brief history of the term "autism" and an overview of the diagnostic criteria for autism, imposed by official diagnostic manuals (DSM -IV and ICD-10) and symptomatology. Within the symptomatology, deficits in the level of social interaction and communication (language), stereotyped and repetitive behaviours, sensorial development, are all expanded upon. Also, in this chapter the main types of pervasive developmental disorders are listed.

Autism is one of many developmental disorders that are collectively referred to as autism spectrum disorders. However, because of the difficulty in accurately diagnosing autism spectrum disorders, it is difficult to determine what proportion of these children have autism. While there was a great deal of research in autism, so far this has been largely focused on trying to understand the etiology of the disorder and finding explanations on the nature of deficits that they define. It is now well established that autism has a genetic component, although the mechanism by which it operates is not yet understood. However, it is suspected that several genes may act together to confer susceptibility (MRC, 2001).

In the absence of biomarkers for diagnosing autism, diagnostic criteria focus on identifying a number of symptoms of behaviour which are manifestations of qualitative social deficiency, communicative and imaginative development. The term "triad of deprivation" was coined to describe these main areas of deprivation (Wing & Gould, 1979).

The term pervasive developmental disorders of the autism spectrum is used as a generic term to refer to autism and all related disorders, including Asperger syndrome and pervasive development disorder.

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders [DSM - IVTR ] (APA, 2000) identifies pervasive developmental of autistic nature as part of a larger group of disorders known as developmental disorders (PDD). DSM-IV-TR recognizes five subtypes of autistic pervasive developmental disorders: (a) classic autism or autistic disorder (ASD); (b) Asperger syndrome (AS) or Asperger disorder (AD); (c) pervasive developmental disorder, not otherwise specified (PDD-NOS), (d) childhood disintegrative Disorder (CDD), and (e) Rett Syndrome (APA). The unique characteristics of each subtype offer professionals the data they need to diagnose the particular disorder (Sevin, Knight, and Braud, 2007).

Chapter two (**Theories of autism**) presents the main theories of autism having the purpose of explaining its characteristic cognitive deficits: Theory of Mind Deficit (ToM), executive dysfunction, and Weak Central Coherence (Rajendran & Mitchell, 2007).

**Theory of Mind Deficit** was proposed by Baron Cohen, (1995) and tried to bring some explanations about the socio-communicative deficits specific to people with autistic spectrum disorders. The author presumes "blind thinking" (mind-blindness) is a terminology that attempts to define the inability of individuals with ASD to conceive, understand, or predict other people's emotional states (Jurek, 2006). The opposite of empathy, mind-blindness is not necessarily caused by an inability to imagine an answer, but rather an inability to collect sufficient information in order to identify more possible answers (Baron-Cohen, 1995). In this way, the theory explains two of the three major deficits specific to ASD, respectively social deficits and deficits in the field of communication skills. Even in these circumstances, the author himself admitted one of the greatest of the theory's limits is the inability to explain the limited interest to activities and stereotyped and repetitive behaviour specific to autism (Baron-Cohen, 2009).

**Executive Dysfunction Theory** attempts to explain the palette repetitive behaviours, the strong desire for routine and the need for "unchanging" (Ozonoff, Rogers, Farnham and Pennington, 1994; Baron-Cohen, 2004, 2005 cit. Pennington et al, 1997 Russell, 1997; Secară, 2007; Peeters, 2009). This perspective explains the inflexibility present in individuals with autism, as well as the tendency for a specific stimulus to persevere. The term "executive function" encompasses a wide area of higher cognitive processes such as working memory, anticipation, planning, impulse control, inhibition, cognitive flexibility or adaptability to change, initiation and monitoring of actions (Secară, 2007).

**Central Coherence Theory (C.C.)** refers to perception and consists of the ability to integrate information into superordinate levels; more precisely, parts of a whole and its context. The C.C. deficit makes the autistic pay attention to detail and experience difficulty in integrating the ensemble of a figure; its contours often interfere with the context. "The concept of central coherence is the tendency for the average person to perceive and process information as a unit (proper context)" (Secară, 2007). A reduction of this tendency can be problematic for a summary, but it can also be beneficial in tasks that require attention to detail. The theory of central coherence, proposed by U. Frith (1989), explains aspects of preferences and desires of children with autism for local, partial details, at the expense of

global, general processing (Secară, 2007; Frith, 1989; Baron-Cohen, 2005 cit. Frith, 1989; Happe, 1996, 1997).

Cognitive functioning in autism is characterized by a weak central coherence. This explains the analytical and zonal manner of processing information, presenting deficits of information integration consistent with the context and decoding the global meaning (Happe, 1997; Secară, 2007, Benga, 1997).

In chapter number three (**The family as a system. Functioning models applied to the family of a child with autism**) the family is shown as a system, as well as its main operating models, applicable for the family with an autistic child. So, this chapter presents the family as a stable system in continuous interaction, which allows it to conserve a certain permanence thanks to relations between members that are durable and important for everyone. The modification of one of the elements within the system entails, in effect, changing all other elements and the system as a whole, since there are no unilateral relations between its components. From this perspective, the presence of a child with autism in the family should be seen as an event or situation that will have repercussions on its members and the family as a whole.

Three models of family functioning had an important role in understanding families with autistic children, and a significant impact on working with these families: transactional model, family systems theory and ecological model.

The transactional model development is seen as resulting from the interaction between a body in continuous change and a changing environment (Bell, 1968, cited by Hornby, 1994). Considering this perspective, it is considered that families are affected by their members with disabilities, whom in turn are affected by the family they belong in.

Family systems theory states that the individual living within a family is a member of the social system, to which he must adapt. He can be addressed as part of the subsystem or system, but the whole must also be taken into account. In this respect, the individual responds to stress generated by other parts of the system and in turn may cause stress to other members of the system.

The ecological model states that human development and behaviour cannot be understood independently of the social context in which they happen. Therefore, children with disabilities do not live in isolation, but within a family, and the family lives in a broader context.

Buzolz and Whiren (1984) define an ecological approach in terms of physical and biological properties of the organism and its environment and in terms of psychological characteristics and interactions. The basic principle of the ecological model is that a change in any part of the system affects the sub-parts of the system, thus the need for balance. Ecological environments provide the necessary resources and build family social support systems. The nuclear family is considered to be the microsystem, parents and siblings influence each other. The variables associated with each family member affects the functioning of the family. The midsystem can be considered an important potential source of formal and informal support for the family of a child with autism. It includes extended family, friends, neighbors, teachers, classmates, different specialists, etc. The midsystem influences family microsystem. It, in turn, is influenced by the exosystem, it consisting of a series of social situations that indirectly affect the family, such as: education (educational alternatives for disabled people), organisations and non-governmental associations (e.g. financial support or other forms of help may be essential for some families), media (media influence on attitudes), etc. Macrosystem refers to the ideological system, beliefs, attitudes, and values of a particular society's institutions. Ethnic, cultural and religious values may affect how disability is perceived by family members.

Chapter Four (**Effects of autism on the family and its members**) presents major effects that the presence of a child with autism has on the family and its members overall, but also on each one, meaning the parents, the siblings, and the grandparents.

Robert Naseef, parent of a child with autism and at the same time a psychologist who specialises in working with families with disabilities, provides in his book "Special Children, Challenged Parents. The Struggles and Rewards of Raising a Child with a Disability" possibly the most complete list of potential responses of parents to a child's disability (Naseef 2001, 22).

shocked	anxious	unhappy	sorrowful	filled with remorse
unable of feeling anything else	worried	sad	furious	filled with regret
unable of thinking clearly	angry	negative	shaken	tainted
restless	agitated	crushed	irritable	undeserving of respect and attention
indifferent	unable of relaxation	disappointed	peevd	embarrassed
having slowed reactions	filled with unrest	hopeless	tense	victimised
devoid of emotion	scared	depressed	easily offended	cursed
lacking interest	tortured	discouraged	upset	guilty
confused	stressed	melancholy	nervous	ashamed
apathetic	uneasy	empty	in a foul mood	humiliated

"Inventory of Feelings" (Adapted from Naseef 2001)

Most studies that have aimed to investigate families with autistic children, of its effects on individual members, focused on the needs, perceptions, and maternal behaviour (Bailey et al., 1992). Fathers were evaluated in terms of the importance of the support provided to the mothers, and the importance for the mother of the father's reaction to having a child with autism (Damrosch and Perry, 1989).

Lamb and Meyer (1991) noted that mothers and fathers initially respond differently to the news that they have a child with autism. Fathers tend to respond less emotionally and are more concerned about the long-term problems, while women respond emotionally and are more concerned with their ability to cope with childcare. Fathers are more concerned than mothers of the child's development of a socially acceptable behaviour, especially when they have boys, and show greater anxiety in relation to the social status and the professional future of their child. Fathers also seem more affected than the mothers in regards to the degree of evidence of autism. The results of several studies show that mothers of children with autism experience a higher level of stress and depression than fathers (Beckman, 1991; Sloper and Turner, 1993; Timko et al., 1992). Mothers try to "absorb" family stress and to protect the rest of the family from stress, making them more vulnerable (Patterson, 1991). Fathers experience stress mostly related to the disposition of the child (Krauss, 1993), related to their degree of attachment to the child (Beckman, 1991; Cohen, 1999; Krauss, 1993), linked to the need to spend time with their wives, and their ability to meet the financial needs of the child (Elliot Brown and Barbarin, 1996; Cohen, 1999; Heaman, 1995). According to Heaman, both parents agree that the biggest stress is generated by issues of "the child's future".

Regarding support groups, it was concluded that mothers benefit more from the aid provided by support groups and that men were generally less willing to seek help (Heaman, 1995; Krauss, 1993). It is not unusual for parents to blame themselves for something they did or did not do before the birth of the child, which caused the child's autism. Every time they seek help for their child, parents hear a series of questions like: "When did you notice for the first time that something is wrong?", "How was the



pregnancy?", "What was your mental state during pregnancy?", "Are there similar problems in the family?". These questions can be painful for mothers because they make them wonder whether they even did something wrong during pregnancy. Parents who give birth to a child with autism tend to withdraw from the entourage. They are very sensitive to all the reactions of others to their child. According to Trout (1983), ambivalent feelings that parents face toward their child can make them very vulnerable to remarks coming from outside. Parents tend to attribute to their entourage their own perceptions and feelings about the child's problem, which complicates the relationship with others. This tendency to withdraw from the entourage may lead parents of children with autism to experience feelings of isolation (Pelchat-Borgeat, 1978; Kazak and Marvin, 1984, quoted Pelchat, 1988), reducing further still the network of social support which is significantly limited compared to families with children with no disabilities.

But stress is the strongest imprint disability leaves on parents. Parents are subjected to enormous stress during the period of suffering that accompanies a birth problem or disability diagnosis. Stress, its causes, and its consequences were probably studied most extensively in relation to families with children with autism. As Westwood, Palmer and Owens (1998) emphasised, factors that cause pressure on parents and can cause stress are: coping with profound grief and bearing "chronic pain"; coping with social prejudices; lack of time; finding time for themselves; inability to rest enough, sleep disorders; expectations they have on various educational programs, on targeted therapies performed by various specialists, contact and connecting with specialists; understanding assessments and reports on the child's progress; developing habits of cooperation and teamwork with specialists; marital conflicts.

Siblings suddenly have to adapt to their brother or their sister who, because of the situation they are in, they can necessitate a lot of time, attention, money, and psychological support from the family (Lobato, 1990; Powell and Gallagher, 1993 cited by Seligman, 1997). The reactions of children without disabilities to their brother or sister with a disability can influence the overall adaptation and developing self-esteem of both parties. Actions and feelings of siblings without disabilities towards their brother or sister with autism are not static, but tend to change over time as they get used to having a brother or sister with autism, and attempt to face the daily realities. Siblings with autism can experience stress themselves, as family members. They may feel frustrated that they are unable to make themselves understood, may be unhappy that they are allowed to play alone, can be withdrawn due to lack of social skills. They may have low self-esteem, can feel anger generated by their inability to make things as easily and quickly as their siblings do effortlessly.

The parents' attitude plays a significant role in the process of adaptation to siblings' disability. Parents can have a tendency to be overly indulgent with children with autism to "compensate" for the disability. On the other hand, they can formulate their unrealistic expectations of their other children without autism to accept their sibling as someone "normal".

When parents provide proof of acceptance of children with autism, siblings tend to react the same way. The ability of parents to communicate openly on the subject of autism and tensions that may exist in the family are very important for the siblings.

It is very difficult, if not impossible, to make a clear distinction between the effects of child disability on family and the family adapting to the situation. Most effects are closely related to the adaptation process. The birth of a child with a disability has an impact on parents and other family members primarily in various spheres of their adaptation. The following are some theories of adaptation to disability.

In the context of the fifth chapter (**Evaluating families with autistic children**) an assessment of families with children with autism is made, presenting the needs and aspirations of the family, its functioning style, as well as social support that each family member, but also the whole family, needs. In the perspective of Dunst, Trivette and Deal (1988) those who offer help to a family must assess: needs, aspirations, family operation style, support, and resources. Family needs and aspirations, its skills and capacities (family operation style), social support and resources are seen as separate but interrelated parts of the process of assessment and intervention. The behaviour of offering help to families creates ways in which families are given the opportunity and the power to acquire and use skills to find support and to mobilise resources to meet the needs.

Evaluation of family and intervention should include: specifying the needs, aspirations, and projects of the family, identifying the family's skills and capacities, identifying sources of support and resources for needs and projects, and proactive roles of specialists, members of a team of intervention, in helping families to mobilise resources to meet needs.

The birth of a baby with a defect is a painful and traumatic event that shakes the family balance. Psychological stress is intense and regular mechanisms employed to solve problems prove often ineffective to restore family balance. In my opinion, any attempt to explain the variability in family adaptation to a child's disability must appeal to three research areas: stress, coping, and individual resilience, these things are presented in chapter six (**Stress, coping, and resilience**).

So far, a definition of stress has not been formulated to satisfy most researchers in this field. The definitions of stress today highlight the relationship between the individual and the environment, taking into account the characteristics of the individual on the one hand and on the other the nature of events.

In 1966, Lazarus suggests that stress should be approached as a concept that helps us understand a wide range of phenomena of great importance in adaptation. He defines psychological stress as a response to anticipating the threat of danger and placing the individual in a position to mobilise and use their own resources and those available in the environment to withstand the threat (Roskies and Lazarus, 1980).

The diagnosis of a child with ASD affects not only the person diagnosed, but also its caregivers, family, teachers and community (Karst and Van Hecke 2012). Autism is unique among childhood disorders, this due to the fact that it is often undetected and undiagnosed, even after the child started attending kindergarten (Beauchesne and Kelley 2004). A cause or treatment was not identified, and children develop normally and then usually regress (Landa and Garrett-Mayer, 2006). As such, caring for a child with autism spectrum disorder or living with one is a challenge for the entire family system and the effects of this experience are truly pervasive. According to studies, about 85% of people with ASD have cognitive or adaptive cognitive that often place restrictions on independent living skills, leading to the possibility of requiring some care measures or assistance from parents or families throughout life. What was established clearly is that parents of children with autism experience higher levels of emotional distress (Hamlyn-Wright, Draghi-Lorenz, and Ellis, 2007; Lecavalier, Leone, and Wiltz, 2006). The researchers also found that having and raising a child with autism can lead to depression (Benson, 2006; Hastings, Kovshoff, Ward, Espinosa, Brown, and Remington, 2005 Pakenham, Sami Sofronoff, 2005) and anxiety (Pakenham and al., 2005) both for the mother and for the father (Jones, Ttsika, Hastings, and Petalas, 2013).

Among the most important factors of stress for families with autistic children can be identified: difficulties in finding educational services, appropriate medical and therapeutic intervention, financial hardship related to the costs of childcare, and emotional

aspects involved in caring for a child with disability (Plant and Sanders, 2007). In the studies of Woodgate and his collaborators (2008), parents reported experiencing feelings of loneliness because they think society does not understand autism, they do not have a normal life, their children resist their intentions to get closer, their spouses are not on the same page, and they cannot access the system of professionals and agencies that could help them. In addition, difficult behavioural manifestations of autistic child contribute significantly to causing the feeling of self-isolation within the family (Woodgate, Ateah, and Secco, 2008). In these circumstances, parents should adapt to the experience of illness and try to mitigate the impact of the disorder on both the child and themselves. Parents build a representation of this disease that can guide them in adapting to interaction with the child and the decision about what treatment to follow (Al Anbar, Dardennes, PradoNetto, Kaye and Contejean, 2011), the mother's perception playing an important role in the dynamics of the couple relationship (Lickenbrock, Ekasia, and Whitman, 2011).

As variables mediating the relationship between different psychological variables such as depression, stress, and parental competence, some parents' beliefs related to their effectiveness as parents can be identified (Coleman and Karraker 1997; Teti, O'Connell and Reiner, 1996). Social support is identified as a contributing factor in removing negative effects of stress. Social support develops relationships and interactions among individuals, family, groups of friends and social systems (Boyd, 2002). Building on previous research showing that parents of children with autism experience higher levels of emotional distress, depression, and anxiety, and that the increased stress in parents of children with autism is closely linked to the uninvolved behaviour of the child in social interactions and resistance to the intentions of parents to approach the child, a first question to ask is whether the child's behaviour as perceived by parents influence his or her psychological condition. That perceptions of parents on the child's illness with autism influence the decisions they take regarding the treatment or other aspects of their own psychological state, another question that needs an answer is whether a partner's perceptions about the illness have a connection with both his or her personal state as well as the state of the other partner.

The mechanisms for the prevention and adaptation to stress are known in the literature as stress coping or management. Lazarus and Folkman (1984) define coping as "cognitive and behavioural efforts constantly changing to meet specific external and internal requirements which are assessed as taxing or exceeding the resources of a person". This definition distinguishes between coping and automated adaptive behaviour, limiting coping to requirements which are assessed as exceeding individual resources. As a result, the boundary limits coping to conditions of psychological stress, which requires mobilisation of resources and excludes automated behaviorus and thoughts that do not require effort. Also, coping is seen as a process that changes, a process during which the person must rely at times more on a form of coping, such as defensive strategies, and at other times on others, for example on problem-solving strategies, as the person-environment relationship changes. The dynamic and change that characterise coping are not random. They are the result of ongoing assessments and reassessments of the change in person-environment relationship.

Over time, coping approaches have been different. Three major approaches are frequently mentioned in the literature and appear to have significantly influenced research in this area: approach per person, situation-based approach, and cognitive approaches.

In the literature we find multiple classifications of coping mechanisms. Lazarus and Folkman (1984) classified the strategies of coping in strategies focused on issues and strategies focused on emotions. Scheier, Wintraub, and Carver (1986), and Endler and Parker (1990) propose a more complex classification into three categories. Thus, along

with coping strategies centered on the problem, arise coping strategies centered on emotions, divided into strategies that reflect an affective and cognitive "state" in a stressful situation (centered on emotions/ approach), and strategies through which confrontation with the stressor is avoided (centered on emotions/ avoidance).

Mikulincer and Florian propose four categories of coping: problem-centered strategies, reevaluation, reorganization, and avoidance strategies. Reassessment involves the use of selective attention on positive information, creating positive illusions and partially negating unpleasant aspects of reality (Lazarus and Folkman, 1984; Taylor and Brown, 1988). Reorganization involves a series of intrapsychic steps (acceptance, experience management, and restructuring of internal structures) entailing a better adaptation to reality. Coping strategies such as avoidance can initially have beneficial effects by reducing distress, but have long-term negative effects on adaptation efforts (Lazarus, 1983; Roth and Cohen, 1986, quoted Mikulincer and Florian, 1996).

Another smaller group of coping strategies aims at increasing emotional suffering. Some individuals need to feel worse before they can feel better. To heal they first need to live acute suffering and for this they blame themselves or engage in other forms of self-punishment. Thus, individuals may deliberately increase emotional suffering in order to mobilise for action (Lazarus and Folkman, 1984).

Most parents of children with disabilities reach coping strategies centered on emotions due to the "unsolvable" nature of their child's disability. They accept their child unconditionally and reinterpret him/her as something that has the utmost need for love, support, and little else. Other parents, on the other hand, react to a child's disability by mobilising all resources to help their child learn to walk, talk, be integrated into the community and eventually to become at least partially independent. These parents will appeal to social support in order to successfully achieve objectives. So, along with coping strategies centered on emotions, parents will engage coping strategies centered on the problem (Seligman, 2000).

As pointed out by Lazarus and Folkman (1984) coping strategies themselves are not good or bad, adaptive or maladaptive. An effective strategy in one situation may be ineffective in another. The efficiency of a coping strategy depends on how appropriate it is in relation to internal or external requirements of the situation. The same applies to cognitive assessments. Assessments related to threat, loss, or challenge or to the irrelevant nature of situations are not themselves right or wrong, effective or ineffective. Their effectiveness depends on what actually happens and any judgement is better made in the context of the situation. Coping efficiency also depends on the secondary assessment of resources during the events. Most assessments do not match perfectly with the course of events. The ambiguity of stressful situations, certain models of engagement of the person and, implicitly, the selective vulnerability, cause this mismatch. Most situations are ambiguous for one reason or another. Whether the information is missing, or unclear, or both. Vulnerability is the predisposition of a person to interpret certain types of situations as stressful and goes hand in hand with commitments - as the commitment is stronger the more a person cares more or is more vulnerable to a stressful event or situation.

In time, several studies have been conducted on the adverse consequences on parents' health, as they care for children with developmental disorders, such as those in the autism spectrum. Thus, research shows that people who take care of children with ASD suffer a greater measure of depression, anxiety, somatic symptoms and social dysfunction than the general population (De Andres-Garcia, Moya-Albiol and Gonzalez-Bono, 2012).

Although most studies have assessed the disorder in terms of the health condition of people caring for children, recently, researchers have taken interest positive adaptation to the care situation. In this context, some people demonstrate skills to effectively cope

with stressful care situations, a phenomenon described as resilience (Gaugler, Kane, and Newcomer, 2007). The term resilience is used to explain positive adaptation of individuals to stressful situations (Bonanno, 2012). However, in terms of conceptualising this term, there is a lack of homogeneity. So the definition is not unanimous for all studies, although, in general, resilience is understood as a dynamic process, an efficient capacity of recovery after stressful situations. This definition refers to resilience as a way to cope in an adaptive manner. In this respect, resilience for people who care for children is a set of features that promote efficient adaptation to the situation of care without affecting their health (Fernandez-Lansac, CrespoLopez, Caceres, and Rodríguez-Poyo, 2012; Lin, Rong, and Lee, 2013).

Considering this, resilience is not a static and stable skill, and caregivers can be helped with increasing their level of resilience. Resilience involves effectively coping with stress without experiencing negative consequences, but yielding positive, beneficial results from stressful situations. This process leads to an increase in the ability to cope successfully with stress (Bayat, 2007). It is obvious that resilient people show positive changes in different areas of life, and some have adopted a positive view regarding the process of care (Fernandez-Lansac and Crespo, 2011). Dale, Jahoda, and Knott (2006) examined how families manage to cope with stress related to ASD, and the results indicated that feelings of anger, shock, denial, self-blame, and guilt were reported upon receiving diagnosis. Moreover, single mothers who tended to autistic children suffered from depression and isolation. Researchers also discovered that the role of social support and access to support services have significantly reduced the mother's stress levels. Dale and his colleagues (2006) have also noted the characteristics of families, including perceived self-efficacy, ability to adapt positively to stress, and coping strategies that help develop a strong sense of accomplishment, and a positive state for the family (Dale, Jahoda, and Knott, 2006). Social support is one of the most analyzed variables in relation to resilience, being defined as a resilient factor that repels the consequences of stress which appears when caring for people with ASD and is associated with less anxiety and depression, and diminished somatic symptoms (Boyd, 2002).

## **Research methodology**

In this part of the present thesis, we have started off in setting goals and hypotheses based on a few studies that have investigated the impact a child with ASD within the family in general and on the level of perceived stress, the utilised coping strategies, the social support available, and the relation between these and resilience.

### **Research objectives**

This research is based on quantitative methods and analyses, and has the following objectives:

1. Identifying issues that may affect the level of parental stress associated with the presence of a diagnosis of autism.
2. Analysing coping mechanisms developed by parents of children with autism.
3. Evaluating resilience levels exhibited by parents of children with autism.
4. Identifying the needs for social support among parents of children diagnosed with autism.
5. Identification of predictive models of parental stress, use of coping mechanisms, social support, and the level of resilience.

To achieve the stated objectives, we conducted four studies:

1. Predictor variables and influences on social support received by parents of children with autism.
2. Predictor variables and influences on the level of stress perceived by parents of children with autism.
3. Predictor variables and influences on coping strategies used by parents of children with autism.
4. Predictor variables and influences on the level of resilience of parents of children with autism.

### **Research hypotheses**

1. One of the predictors of received social support is the parent's biological gender.
2. Low levels of parental stress causes the perception of social support as being high.
3. There are significant differences in the perception of social support depending on the age of the parents.
4. The equation for predicting parental stress includes social support.
5. There are significant gender differences in the perception of parental stress levels.
6. The high level of social support causes low levels of parental stress.
7. Parental stress predicts the total score on the coping scale.
8. Mothers of children with autism develop positive coping strategies, such as seeking social support, while fathers of children with autism use negative coping strategies, such as avoidance.
9. Parents who perceive greater social support have adaptive coping strategies.
10. The parental stress variable is part of the equation for predicting the resilience capacity.
11. Parental stress levels affect the capacity for resilience of parents of autistic children.
12. The existence of another child in the family increases the likelihood that parents have a high level of resilience.

### **The participants involved in research**

The research included a total of 114 participants, all parents or people caring for children with ASD. Of these, 54% are women/ mothers and 46% are men/ fathers. People who participated in this study are parents of children diagnosed with ASD, who were included in their specific intervention programs in Gorj and Bucharest.

### **Description of research instruments**

In this research the following tools will be used: Multidimensional scale of perceived social support, The resilience scale, Parenting Stress Index - Short Form (PSI), Strategic Approach to Coping Scale (SACS).

**Strategic Approach Coping Scale (SACS)** is a multidimensional questionnaire designed to identify behavioural coping strategies in a social context, that someone uses after having lived through negative events or circumstances. So, it is a tool that assesses behavioural coping, taking into account the social aspects of the strategies through which one faces stressful situations. In contrast to other questionnaires of coping that do not make explicit distinction between a person's thoughts and real activity, SACS refers exclusively to the way a person reacts behaviourally actively/passively, prosocially/antisocially, directly/indirectly, after he lived through a negative experience. SACS is a self-assessment questionnaire with 52 items and 9 assessment scales of behavioural coping strategies. The evaluated strategies refer especially to the general tendency of tackling issues, using a

specific set of behaviours. This tendency is fairly stable over time. SACS distinguishes nine behavioural coping strategies:

Assertive action by which the situation is approached firmly, spontaneously, honestly, and directly, without the person withdrawing in the face of problems and which pursues interests without harming others (the *active-passive* dimension).

Social relating, through which the person joins others to face the situation together or through which they help others, taking into account their needs (*prosocial-antisocial* dimension).

Seeking social support, through which the person turns to others for help and emotional support and seeks advice from family and friends about what to do (*prosocial-antisocial* dimension).

Prudent action, in which a person takes every precaution before acting, and evaluates their options carefully, to protect themselves from any danger (*prosocial-antisocial* dimension).

Instinctive action, where the person relies on their intuition and reacts according to the momentary impulses to solve problems (*prosocial-antisocial* dimension).

Avoidance, through which the person engages in other activities that do not deal with the problem (*active-passive* dimension).

Indirect action, where the person handles the situation to make others believe that they are in control, while the person solving the problem, intransparent (*direct-indirect* dimension).

Antisocial action through which the person pursues interests, even if they harm others (*prosocial-antisocial* dimension).

Aggressive action, where the person acts decisively and quick to take the others by surprise assume control (*prosocial-antisocial* size).

Each person evaluated by SACS indicates a scale of five points, where 1 means "Not at all what I do" and 5 means "Definitely, it's what I do" concerning the behaviour described in each item. To obtain a subscale score, the sum amount of item quotas included in the scale is calculated. Among the items that make up a subscale, more than one answer cannot be absent. In this case, the missing score will be replaced by the average of other scores.

### **Parenting Stress Index-Short Form (PSI-SF)**

According to Abidin (1995) PSI-SF contains 36 statements organised into three subscales: parental distress (PD), dysfunctional interaction between parent and child (P-CDI), and child difficulties (CD). Scores obtainable are between 36 and 180 and indicate the global amount of stress experienced as parent as a function of the three subscales.

PSI-SF was evaluated 5 points according to Likert scale, ranging from 1 (strongly disagree) to 5 (disagree). The scale was punctuated by rearranging items so that 5 = 1, 4 = 2, 3 = 3, 2 = 4, and 1 = 5 to determine subscale (PD, P-CDI, or CD) and the total score for stress, all scales were summed taking into account the overall score indicating the overall level of stress. In the analysis, the highest score indicates the highest level of stress, while the lowest score indicates the lowest stress. Within PSI-SF, stress levels considered normal are between 15 and 80%. Scores of 90% indicate that the individual is experiencing high stress levels. It should be noted that the total score regarding PSI-SF show only the overall level of stress perceived by the subject in his role as parent and does not take into account the level of stress that an individual may perceive outside this role.

It is also important to remember that the total score in the PSI-SF reflects the stress associated with parenting and interaction between parent and child. Each subscale contains

12 questions. PD subscale reflects the level of distress as a result of the combination of personal factors with the requirements of a growing child.

### **Resilience Scale (RS)**

One of the most utilised tools worldwide, in research on resilience. The RS is the first instrument developed to measure resilience and can be applied to different age groups, from teenagers to elderly people. Resilience Scale measures the individual resilience, which is considered an important characteristic of personality that increases an individual's ability to adapt. It was created by Gail Wignild, RN, PhD and Heather Young, PhD, FAAN, GNP, in 1987, and has 25 questions that can be answered on a Likert subscale from 1 to 7, where 1 means "it does not suit me at all" and 7: "it totally suits me." Possible scores are between 25 and 175, where 175 represents the highest level of resilience.

Resilience Scale's internal consistency ranged between 0.76 and 0.91. Test-retest fidelity varied between 0.67 and 0.84 at a series of intervals of one month, three, four, and then another four months (Li, 2008).

### **Multidimensional scale of perceived social support (MSPSS)**

Multidimensional scale of perceived of social support (MSPSS), developed by Zimet, is a scale composed of 12 items. It is very easy to use, as it is a self-reporting tool, used to measure perceived social support and perceived social support adequacy from 3 sources: family, friends and other people significant to the topic.

In the first phase, the scale was designed with 24 items which referred to family, friends, and other significant people. Each item could be measured with a maximum of 5 points from strongly disagree (1) to strongly agree (5). Taking into account the results of several pilot tests and repeated factor analyses, the items that did not directly concern perceived social support, or that did not lead to clear results, were excluded. The current version and revision of this scale consists of 12 items, and to increase the variability of answers and minimise the capping effect, and evaluation was implemented using a Likert scale of 7 points from strongly disagree (1) to very strongly agree (7). The 12 items are divided into 3 groups of 4 items each depending on perceived sources of support - family, friends, or other significant people. The largest cumulative scores show higher perception of social support. Within this scale, scores can vary between 7 and 84 points. Scores between 69 and 84 indicate a strong social support. Scores between 49 and 68 indicate a moderate social support, and scores between 12 and 48 indicate a low social support. Studies have shown that mothers who score between 12 and 48, benefitting from a low social support, are predisposed to depression and other diseases with adverse health effects.

## **Research results, data interpretation, and discussion**

### **Study 1: Predictor variables and influences on social support perceived by parents of children with autism**

The first study envisages highlighting the main variables on the degree of perceived social support and the scores on subscales (family support, the support of friends and the support of significant others). It is also interesting to identify a predictive model, and connections to other variables.

There are numerous variables that influence the perception of social support, both globally and in terms of its size. Thus, it is noted that the coping level is the only variable that influences how parents of children with ASD perceive family support. The more they use coping strategies to a greater extent, the less family support is felt. This is probably due



to the fact that they use their own ways to solve problems and no longer seek or pay attention to the support provided by family.

I also noticed that low parental stress causes the perception that support from a significant person is high and is associated with children who are masculine.

Another conclusion is that the child's age is important for the perception of different modes of social support: parents of children aged up to 10 years (inclusive) felt greater support from a person, and those whose children have more 10 years perceive more support from family and friends.

Both the age of the parent and the child influence the perception of social support from a significant person and friends. Therefore, the chances of a parent to perceive higher social support increases when younger than 30 years old, and the child younger than 5 years old.

Looking at gender differences, we found that women believe to a greater extent that they benefit from global social support than men, as well as from friends and significant others.

We highlighted the existence of regression equations from which we can predict the score that a person might get on this scale. Thus, if the parent is feminine, her parental stress level is low and if the child was diagnosed before the age of three years, will certainly get a higher score of perceived social support.

### **Study 2: Predictor variables and influences on the level of stress perceived by parents of children with autism**

The second study prioritizes parental stress as the dependent variable, both globally and in its dimensions (DR - defensive response, PD - parental distress, P-CDI - parent-child dysfunctional relationship, CD - child difficulties).

First, one can distinguish the great importance both the resilience level and social support have for the degree of stress, especially for defensive response and pressure associated with parenting. Thus, if parents have a low resilience capacity or perceive to a lesser extent the existence of social support, the likelihood that they feel a greater pressure caused by the parental role increases, as well as the need to hide the negative aspects of the relationship with their children.

The need for a positive parent-child relationship and denial of dysfunctional aspects that fall outside this pattern is a stronger pressure experienced by parents in rural areas.

Gender differences are also important, as fathers feel greater pressure than mothers to mask problems in relation to their children, whom they consider to be difficult.

Regression analysis confirmed the child's biological gender and social support as significant predictor variables for stress levels. According to the equation, the stress level decreases when the parents have a girl or if they believe they do not benefit from social support.

### **Study 3: Predictor variables and influences on coping strategies used by parents of children with autism**

This study aims, in the first phase, to discover variables which influence coping and its dimensions (AS - assertive action, SR - social relating, CSS - social support, PA - prudent action IA - instinctive action, A - avoidance INA - indirect action ANA - anti-social action and AA - aggressive action), then of a predictive model and relations to other variables involved in the study.

To utilise coping strategies, both main effects and regression analysis attest to the significant impact of the child's age at diagnosis and parental stress levels. Therefore, a

person will get a high score on the coping scale if the child's diagnosis was made during the first three years of life or as parent stress level decreases.

Child age currently affects some coping strategies. Indirect action, antisocial action, and assertive action and seeking social support are means of coping used especially by parents of children less than 5 years old.

Regarding social support, the results show that the perception of high social support leads to the use of means of coping connected to social relating and social support. If they lack social support from their family, parents move towards instinctive actions.

Another important influence is the environment from which the respondents come. Parents from urban areas prefer as coping strategies: instinctive action, indirect action, antisocial action, and aggressive action, while those in rural areas seem inclined to seek social support to overcome their problems.

We can add that social relating is mostly used by parents who have boys, and those of them who have not reached 30 seek support from others more.

#### **Study 4: Predictor variables and influences on the level of resilience of parents of autistic children**

The fourth study focuses on resilience, emphasising on main influences and relations between study variables and outlining a predictive model. The most important effects on resilience are due to the three variables encompassed in the regression model of this dependent variable: total scores on scales of stress and use of coping strategies, and the existence of other children in the family. Therefore, people are more resilient if they have lower stress levels, use coping in greater measure, or there are other children in the family.

Moreover, people with high resilience scores prefer social relating, indirect action and prudent action as means of coping.

We also find gender differences in the sense that women are more resilient than men. The child's age at diagnosis is also important, increasing the likelihood that parents are more resilient if the child's diagnosis was made until reaching age 2.

The influence of social support on resilience is not very clear.

The four studies have highlighted the importance of parents' biological genders on perceived social support, parental stress, use of coping strategies and resilience.

Moreover, this variable is a predictor of perceived social support, together with the level of stress and age of the child at the time of diagnosis. Therefore, the first research hypothesis was confirmed. Perceived social support is high if the parent is a woman, parental stress level is low, and the child was diagnosed in the first three years of life.

Men experience higher levels of stress than women, they perceive the child as difficult (DC) and try to mask the negative aspects of their relationship (DR). The Doctoral research hypothesis is partially confirmed, given that we have no influence on the overall level of stress, and significant differences arise on the two dimensions of scale.

Correlation analyses revealed relation between the gender of the parent and coping mechanisms used. Thus, mothers addresses the issue in an assertive manner and seek social support to solve it, using positive means of coping, as we assumed in the research hypothesis. There is, however, no empirical evidence that fathers use avoidance or other negative strategies, only that they prefer all the above to a smaller extent.

Also, the fourth study showed that women are more resilient than men.

Secondly, through regression analysis, we found that parental stress is a good predictor of resilience capacity in conjunction with the usage of coping means, and having another child in the family. According to the predictive equation, resilience capacity is increased if parents use means of coping to a great extent, adapting them according to the situation, they feel a low level of parental stress and have other children. So, the tenth and

twelfth working hypotheses were confirmed. Also, hypothesis eleven is confirmed, in accordance with the main effect of stress on resilience; people who experience greater stress have a smaller resilience capacity, compared to those who experience little or no stress.

Stress also has significant effects on social support, in that social support is perceived to be higher if the stress level is lower, which confirms the second research hypothesis.

Low stress also determines the use of positive means of coping to a greater extent, such as solving the problem in an assertive manner or using intuition. Moreover, the regression equation for predicting the score on the coping scale includes stress level and the child's age at diagnosis. Thus, using coping strategies to a greater extent is predicted by the perception of a low stress level or the existence of a diagnosis the first three years of the child's life.

It also noted that parents who perceive a high level of social support feel to a lesser extent the stress associated with parenthood (PD) and don't try to hide the negative aspects of the relationship with their children (DR). There are no main effects on the overall level of stress, but social support is one of the predictors of stress, along with the child's biological gender. The stress felt is greater if perceived social support is low, and the child is female.

Furthermore, parents who believe they have a high level of support from others use social relating and seek social support more, which are adaptive coping strategies. Moreover, the perception that there is a person that supports them is associated with problem solving in an assertive manner.

The age of the parent influences the perception of social support, those up to 30 years old felt a greater degree of support from others, in comparison with subjects from other age groups. Incidentally, they are also the ones who seek social support to overcome difficulties.

Other variables with significant effects are the current age of the child and the child's age at diagnosis.

In conclusion, the research hypotheses were confirmed completely or partially, identifying predictive models for social support, parental stress, use of coping and resilience capacity.

At the same time, we believe that this research provides useful and interesting examples about parents of children with autism. It is also important to note that it's the first of its kind on a sample of the Romanian population that brings information not only on the mothers, but also on the fathers. Studies made alongside all the data collected from the literature attempt to cover part of the gap in this area of research in Romania and could provide a basis for future studies.

Among the limitations of this research could be the relatively small number of cases, their demographic characteristics, the inclusion of parents only, lack of a social desirability scale. Doctoral research methodology is a quantitative one, and most studies on families with a member with autism usually rely on qualitative research methods. Therefore, a combination of quantitative and qualitative methods to explore the mechanisms through which family members reach a better adaptation may be an appropriate approach in the future. Based on these limits, another future direction of research involves the development of projects or programs that include members of families with autistic children in as many areas of the country as possible.

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