

## An Overview of Assessment Instruments Used to Evaluate Stress and Parental Coping of Parents of Autistic Children

Venetike Merkaj

University of Tirana, Doctoral student

Email: [venetike@gmail.com](mailto:venetike@gmail.com)

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**Abstract:** A number of studies have demonstrated that parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children, others studies have shown that parents of autistic children shows more stress than parents of mental retardation children and down syndrome children. Parents of such children face more challenges in everyday living to cope with different stressful events. The aim of this study is to provide an overview of the different instrument used to evaluate stress of parents of autistic children and strategies that parents report aid them in coping with stress. The method of research of electronic databases on the internet has been used. Systematic review of research articles published in scientific journals having as search criteria and key words the terms: autism spectrum disorders, coping strategies, stress, parental stress, coping technique. The review report instruments that are used professionally in assessment of parental stress of parents of autistic children and report that parents used a variety of strategies to cope with stressors to having a child with autism. This review inspires a number of implications for clinical practice, it necessary when developing an interventional program for children with autism, to assess not only the child but also the parents, assessment of parental stress should became a routine part of child evaluation and practitioners can help parents to teach techniques for coping with stress.

**Keywords:** autism spectrum disorders, autism, coping strategies, stress, parental stress.

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### 1. Introduction

Autism is a complex developmental disability, it is characterized by severe and pervasive impairments in several important areas of development: reciprocal social interaction and communication as well as behavior, and imagination. (American Psychiatric Publishing, 2000). The definition of autism has evolved over the years and was broadened with the introduction in the 1980s of the terms *pervasive developmental disorder* (PDD) and *Asperger syndrome*. In the *Diagnostic and Statistical Manual of Mental Disorders IV-TR* (DSM- IV-TR), PDD is the umbrella term covering Autistic disorder, Asperger's disorder, Pervasive developmental disorder NOS (not otherwise specified), Rett's Disorder, Childhood Disintegrative Disorder. Having a child with autism means that the family suffers a crisis at the moment of final diagnosis and especially for parent's demands for coping with the disability means are determination of the roles in the family changes in social life and social roles, the mother abandoning her work and less free time for all family members. Research has shown that the parents of autistic children report more stress than parents of typically developing children or with others disabilities.

### 2. Literature Review

Research has shown that the major sources of parenting of autistic children are associated with irregular intellectual profile of autistic children, pervasive behaviors and long care to children's. (Bebko, Konstantareas, & Springer, 1987; R. L. Koegel, Schriebman, Loos, D. Wilhelm, Dunlap, Robbins, & Plienis, 1992; Moes, 1995; Moes et al., 1992). A study conducted with mothers of autistic children and mothers of mental retardation results that mothers of autistic children have higher level of stress than mothers of mental retardation children's. Children behavior problems is associated with increasing level of stress, and this study showed that most stressful for mothers were related with difficulties in relation to nutrition, clothing and behavior problems of autistic children. Parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (Hastings, 2002; Konstantareas 1991; Scorgie, Wilgosh & McDonald, 1998), others studies have shown that parents of autistic children shows more stress than parents of mental retardation children and down syndrome children. Parents of such children face more challenges in everyday living to cope with different stressful events. They have to face more financial strain to provide necessary medical expenses, have to pay more attention to the child and parental demands increase which in turn enhance psychological strain. (<http://www.autism-org/site/>). Robert Burton, in 1624 wrote of the sources of disease and melancholy (depression) in particular, emphasizing social stress as one of the greatest causes of malady. For the clinician in

psychology and medicine, for the human resources professional in industry, and for educators in classroom, stress is a foundation concept as well. (Stevan E. Hobfoll 1998). The literature reflects researcher's belief that stress is a major factor affecting people lives and is related with mental health and with many problems of physical health. Stress is experienced when our subjective demands of a situation are incompatible with the ability of meeting and adapting to these demand and the internal perception of the ability to adapt or even respond when the demand impair the achievement of other important matters of survival. Four different conceptualizations or definitions of stress can be distinguished, and each has been applied to families of children with development disabilities. First, in one of the earliest theories stress is understood as the physiological and psychological reactions that an organism goes through, usually in stages, to adapt to a stressful situation. Although not universally accepted by parents or professionals, this definition has been quite widely applied clinically with families of children with development disabilities. A second conceptualization of stress is referred to as the "stressful life events" paradigm. This paradigm suggests that stressful life events have a negative impact on mental and physical health. This model has been extensively researched in many health areas and, generally speaking, the relationship between any particular stressful event (e.g., loss of job) and any particular outcome (e.g., depression) is weak because there are many intervening variables (e.g., what social supports the person has, what the job loss "means" to them, what coping strategies they use, and so on). A third approach to conceptualizing stress is the "daily hassles" paradigm, which suggests that it is not necessarily a major life event that is stressful but all the everyday frustrations and hassles associated with it. In the case of families of children with DD, this theory has been used extensively. It leads to the assumption that it is not the single life event of having a child with difficulties that is stressful but, rather, the cumulative effect of smaller day-to-day annoyances and hassles associated with caretaking (e.g., changing diapers on a big child, taking the child to various appointments, etc.). Thus, it is important to discriminate between stressors (stimuli) and appraisals of stressors. A fourth definition of stress involves the concept of a "resource imbalance" between the demands of a situation (stressors) and a person's resources or coping ability. In the case of families of children with development disabilities, this approach implies that stress is not simply a function of child characteristics (stressors). It is more than a single stressful life event or even a series of daily hassles. It depends to a large extent on the individual parent's coping abilities, the resources in the family, and the supports the family receives from others. (Adrienne Perry). Lazarus and Folkman defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person". (Stevan E. Hobfoll, 1998). Two basis categories of coping include efforts to alert the troubled person-relationship and efforts to regulate emotional distress. Problem- focused coping encompasses numerous specific coping strategies, such as defining the problem, generating, evaluating and selecting potential solutions and attempting to cognitively reappraise the situation by shifting level of aspiration, reducing ego involvement, finding alternative channels of gratification, or developing new standards of behavior. Emotion-focused coping includes strategies such minimization, positive comparisons, seeking positive value from negative events, selective attention, distancing, avoidance, exercise, and meditation, alcohol use, venting anger, and seeking emotional support. (Edwards, J. R., & Baglioni, A. J., Jr. (1999). Problem- focused and emotion focused coping are not exact opposites, but generally lie on either side of a continuum between active and passive responding. Most problem-focused coping is still as healthy because it acts to help achieve goals. This include active coping, planning, seeking support on task, and restraint coping to wait for proper timing. However, emotion- focused coping becomes divided into efforts that help sustain motivation or problem- solving versus emotion-focused coping that limits goal directed effort. Helpful emotion-focused coping might include acceptance and positive reinterpretation. Negative emotion-focused coping, involves avoidance, dwelling on negative emotion, or denial.

## 2. Methodology

This study aimed to provide an overview of different instrument used to evaluate stress of parents of autistic children and strategies that parents report aid them in coping with stress. The method of research of electronic databases on the internet has been used. There has been an extended research in articles published in scientific international journal, having as search criteria and key words the terms: autism spectrum disorders, autism, coping strategies, stress, parental stress as well as combinations of the above. The documentation of the data has been made on the basis of a table of data-input including:

The name of the first author of the study and the country of origin, the key words of the research, the publishing journal as well as the date of publication, the aim of the research, the measurements used (questionnaires, interviews). For the inclusion criteria the following were applied: the study should relate the parental stress and coping of children with autism, the study should be original, the study should have clear results regarding the parental stress and parental coping, the study should specify instrument that researcher have used to evaluate stress and parental coping. As exclusion criteria

are : the Language Limitation in the English Language because of the researcher's ability to study in this language, the limitation study focus in stress of parents of autistic children and in coping strategies that parents report aid them in coping with stress. Period of study September 2011- January 2012.

### 3. Findings

The various studies shows that parents of autistic children are more stressed than parents of developed children. Mothers of ASD children report significantly greater stress, greater depression, greater social isolation, and a lower level of marital intimacy when compared to mothers of normal children and mothers of Down's syndrome children (Bengt Sivberg, 2002). Mothers compared with fathers, were significantly more stressed, more involved, and reported higher levels of stress and coping related to car giving. (E. Tehee, R. Honan and D. Hevey, 2009). High levels of stress are present in mothers when their children are quite young, and also provides evidence that fathers of very young children share high levels of stress and depressive symptoms. Deficits/delays in children's social relatedness were associated with overall parenting stress, parent-child relationship problems, and distress for mothers and fathers. (N. O. Davis & A. S. Carter 2008). Other studies shows that the child's autism severity was the strongest and most consistent predictor of stress, and emotion-oriented coping moderated the relationship between pessimism stress and autism symptomatology, and distraction coping was a moderator between parent and family stress and autism symptoms. (A. M. Lyons, S. C. Leon, C. E. R. Phelps, A. M. Dunleavy. 2010). Mothers report more problem focused strategies more frequently than fathers and parents with preschool children reporting more frequent use of these coping strategies than parents of school - age children. (R. Hasting, H. Kovshoff, T. Brown, N. J. Ward, F. D. Espinosa, B. Remington, 2005). Acquiring social support and reframing were the most frequently used coping strategies on parents of autistic children. (Luther E. H., Canham D L, Y. Cureton V, 2005). One other effective ways that they coped as a family were in the areas of informal and formal social support networks. Parents used passive appraisal to cope. (Tway R, Connelly P.M., Novak JM, 2007). People do not approach each coping context anew, but rather bring to bear a preferred set of coping strategies that remains relatively fixed across time and circumstances, but the idea that such stable coping styles exist is controversial, Folkman and Lazarus have repeatedly emphasized that coping hold be thought of as dynamic process that shifts in nature from stage to stage of a stressful transaction. Such a view suggests that the development of a coping style would at best be counterproductive, because it locks the person into one mode of responding rather than allowing the person the freedom and the flexibility to change responses with changing circumstances (C. Carver, M. Scheier, J. Weintraub, 1989). This review is based in 18 published articles. These studies are coming from different country: United States of America (6), England (3), Israel (1), Ireland (1), Sweden (1), Japan (1), China (1), India (1), Canada (1), Poland (2) A number of assessment instruments have been created so that parental stress levels can be systematically measured and quantified, can provide information about the amount of stress a parent is experiencing. Once an instrument or a battery of instruments have been selected for the assessment of a parent's stress level, it is appropriate to administer the tests as part of the initial screening of the child. Instrument must: (1) measure the impact of a handicapped child on the family yet be broad in the issues and concerns addressed; (2) data must be available to support its technical qualities; (3) be easy to administer, score, and interpret; (4) the measure must be available and reasonable in price; and (5) the measure must require minimum administration time. (S. E. Mott, R. Fewell, M. Lewis, S. J. Meisels, J. P. Shonkoff, R. J. Simensson, 1986).

**1. Questionnaire on Resources and Stress (Short-Form) (Friedrich et al. (1983).** The measurement of stress in families of developmentally delayed or mentally retarded children has been a difficult task. QRS, Holroyd, 1974 was designed to answer this need, but the length and psychometric weaknesses of this instrument have interfered with more widespread usage. The original 285-item true/false scale was developed to measure the impact of a developmentally delayed, handicapped, or chronically ill child on other family members. Friedrich et al. (1983) recognized the problems of length and technical quality in the QRS and developed a shorter and psycho - metrically stronger inventory, the QRS-F52 items. These items were factor analyzed, and four distinct factors were found The QRS-F has four factors: (1) parent and family problems, (2) pessimism, (3) child characteristics, and (4) physical incapacitations. (F. WN, G. MT, C. K, 1983). Scores produce a total stress score (0-52). The internal reliability of the subscales ranges from 0.77 (Physical Incapacity) to 0.85 (Child Characteristics), with the internal reliability of the total stress score being 0.89. Researchers have previously used this tool for samples of parents of children with ASD in assessing stress in parents (Hastings & Johnson, 2001), and it allows comparison with previous studies. The total stress score from this scale has good reliability and validity for research with parents of young children with ASD. (L. A. Osborne, P. Reed, 2009). QRS-F has the following characteristics that suggest it is appropriate for use in programs for young handicapped children and their families, data are available to support its technical aspects, questionnaire is easy to give, available in the literature, and cost is minimal,

has been effective in measuring parent change resulting from intervention over time. (S. E. Mott, R. R. Fewell, M. Lewis, S. J. Meisels, J. P. Shonkoff, R. J. Simensson, 1986).

**2. The Parenting Stress Index-Short Form (PSI-SF)**, is a brief version of the Parenting Stress Index (Abidin, 1995), a widely used and well-researched measure of parenting stress. The PSI-SF has 36 items from the original 120-item PSI. The version was developed in response to clinicians' and researchers' need for a shorter measure of parenting stress, that measures stress directly associates with parenting role. PSI-SF, is one of the most widely used instruments for measuring parenting stress in families of children with ASD. Although it was not devised specifically for assessing parents who are raising a handicapped child, the items have a great deal of face validity for this group. Another important consideration is that the PSI not only captures family characteristics pertaining to stress-financial stress, the family's emotional and physical state -but also provides for the assessment of specific characteristics of the child. PSI-SF is also a clinical tool that is widely used to identify parents in need of counseling services. (A. Zaidman-Zait, P. Mirenda, B. D. Zumbo, S. Wellington, V. Dua, K. Kalynchuk, 2010). The instrument yields scores for several factors (parent/child dysfunctional interactions, parent distress, difficult child) in a addition to a total stress score.

**3. The Coping Health Inventory for Parents Mc.Cubbin et al., 1983** is, a self-administered questionnaire, 45- item used to asses parents perception of how he or she manage family life with a child with a chronic illness. 45- items are divided into three sub-scales 1. Family Integration, Cooperation and an Optimistic Definition of the Situation; 2. Maintaining Social Support, Self Esteem and Psychological Stability; 3. Understanding The Health Care. The scale uses a four-point Likert-type scale, ranging from 'not helpful' (0) to 'extremely helpful' (3). The authors report the internal consistency of all three subscales to be satisfactory. The instrument can be used to develop intervention strategies and measure change in parent's ability to cope when faced with parenting a child with chronic illness.

**4. Perceived Stress Scale.** The PSS (Cohen, Kamarck, T., and Mermelstein, R. 1983) is a 14-item questionnaire, is the most widely used psychological instrument for measuring the perception of stress. It is a measure of the degree to which situations in one's life are appraised as stressful. The items are easy to understand, and the response alternatives are simple to grasp. Instruments that assess stress based on the number of stressors present in a person's life fail to take into account the way that people interact with those stressors and the influence that coping resources may have on the actual experience and perception of stress. Although the PSS does not measure the amount of coping resources available to a respondent or the skills necessary to effectively utilize those resources, by assessing how stress is being perceived, the effects of those resources are measured indirectly. Responses are scored from 0 to 4 on a Liker-type scale. (Cohen et al., 1983). The PSS provides an assessment of the amount of stress individuals believe they are experiencing, which for some purposes may be a more effective tool than an instrument that measures the number of stressors present in an individual's life. This scale might be especially appropriate for identifying parents who need training in the effective use of coping resources. (Lessenberry, Beth M. Rehfeldt, Ruth Anne, 2004).

**5. The Coping Orientation of Problem Experience Inventory (COPE) (Carver et al., 1989)**, the instrument has had a good deal of use, there were some problems with its length, as a consequence, is created an abbreviated version of the COPE, called the Brief COPE. 60 items was developed to assess a broad range of coping responses, several of which had an explicit basis in theory. Respondent indicate what he or she usually do when experience a stressful event. The inventory includes some responses that are expected to be dysfunctional, as well as some that are expected to be functional. The items have been used in at least 3 formats. One is a "dispositional" or trait-like version in which respondent's report the extent to which they usually do the things listed, when they are stressed. A second is a time-limited version in which respondents indicate the degree to which they actually did have each response during a particular period in the past. The third is a time-limited version in which respondents indicate the degree to which they have been having each response during a period up to the present. The COPE inventory is divided into 13 scales Focus on and venting of emotions, Use of instrumental social support; Active coping; Denial; Religious coping; Humor; *Behavioral disengagement*; Restraint; Use of emotional social support; Substance use; Acceptance; Suppression of competing activities; Planning. (Carver, C. S., Scheier, M. F., & Weintraub, J. K., 1989).

**6. Coping Inventory for Stressful Situations (CISS, Endler, Parker 1990).** The weakness of most of the measures lies in their unsatisfactory psychometric properties, unstable factor structures, and lack of cross-validation. These shortcomings have been overcome with the CISS, that was developed in an accurate and rigorous way and in a balanced approach, including rational and empirical steps. CISS include 48 item, with 16 items per scale. A general

instruction was used, aiming at a "typical" coping response ("...how much you engage in these types of activities when you encounter a difficult, stressful, or upsetting situation"). Coping behaviors were compiled that fitted the two generally accepted coping functions problem solving and emotion regulation. Factor analyses, performed for men and women separately, yielded three factors: task-oriented, emotion-oriented, and avoidance-oriented coping. The avoidance dimension could be further subdivided into a Distraction scale and a Social Diversion scale. Very good psychometric properties were identified in several validation samples. Construct validity was documented by appropriate correlations with the WCQ and various personality traits. The instrument is disposition-oriented and, therefore, covers only one facet of coping.

**7.The Family Stress and Coping Questionnaire (FSCQ-A, Tehee, Honan & Hevey, 2009)** was adapted from the Family Stress and Coping Interview is a questionnaire designed to quantitatively and qualitatively, which measures perceived stress and coping related to caregiving in families of individuals with developmental disorders across the lifespan (J.S. Nacheshen, L. Woodford & P. Minnes, 2003). Specifically, the FSCQ-A elicited responses from parents regarding their level of perceived stress in the following areas: (1) the diagnosis and the cause of their child's ASD, (2) explaining ASD to family, friends, community and interacting with them, (3) dealing with health professionals / health board / teachers / education system, (4) creating friendship / leisure opportunities for their child, (5) deciding on the best level of integration for their child, (6) meeting the needs of their other children, (7) meeting their own personal needs, (8) meeting the needs of their partner, (9) maintaining their own personal friendships, (10) dealing with their child's sexuality, (11) concerns about present/future work/employment for their child, (12) concerns about present/future long-term accommodation for their child, (13) planning wills/trusts/guardianships, (14) planning emotional and social support for their child, (15) planning assistance with care, (16) attaining respite care, and (17) dealing with financial issues. It consists of 26 self-report using a 4-point Likert scale, Open-ended questions requested parents to list the top three sources that cause them most stress at present. (E. Tehee, R. Honan and D. Hevey, 2009).

**8.The Parental Stress Scale (PSS)** is a self-report scale that contains 18 items representing pleasure or positive themes of parenthood and negative components, it is intended to be used for the assessment of parental stress of children with and without clinical problems. Respondents are asked to rate each item on a five-point scale. The PSS demonstrated satisfactory levels of internal reliability (.83), and test-retest reliability (.81). The scale demonstrated satisfactory convergent validity with various measures of stress, emotion, and role satisfaction, including perceived stress, work/family stress, loneliness, anxiety, guilt, marital satisfaction, marital commitment, job satisfaction, and social support. (Berry, J.O. & Jones, W.H., 1995).

**9.The Ways of Coping Questionnaire (WCQ)** is based on Lazarus model of stress and coping. In the 1970s, the stress and coping research group of Lazarus developed the Ways of Coping Checklist (WCC) in line with the transactional phenomenological stress theory that suggested two main functions of coping: problem solving and emotion regulation. From 68 items with a yes-no response format, 40 items formed the problem-solving subscale, and 24 the emotion-focused subscale. Since this classification did not reflect the complexity and richness of coping processes, a series of factor analyses with different data sets were carried out, generating over time the current version of the instrument now called WCQ, it consists of 50 items (plus 16 fill items) within eight empirically derived scales. A difficulty with the instrument has always been that the number of extracted factors changed from sample to sample or from stressor to stressor, but this seems to be a general problem with most coping measures, reflecting the unresolved disposition versus situation issue.

**10.Family Crisis Oriented Personal Evaluation Scales (F-COPES: McCubbin, Olson, & Larsen, 1987).** The F-COPES is a 30-item, self-report questionnaire used to assess ways that families cope with stress. The measure uses a 5-point Likert Scale with responses ranging from "strongly disagree" to "strongly agree." There are five subscales: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and seek help, and passive appraisal. This measure has good internal consistency and an overall alpha of 0.86. The overall test-retest reliability is 0.81. The alphas for the subscales range from 0.61-0.81, and the test-retest values range from 0.61-0.95.

#### 4. Discussion

The objective of this review was to offer some information related with instrument used for assessment of parenting stress and coping of parent of autistic children. Some assessment instrument may be more useful and effective than

others, some can be more effective for some intervention program. For example, the PSI seems to be attractive, as it assesses a variety of outcomes. PSS appears to be an effective tool for assessing the level of stress that can be attributed to the parenting role. Other scales, such as the QRS-F, may be adequate for some programs, but may be too narrow to tap the outcomes of others, other have a number of advantages for using in clinical practice, for example Family Stress and Coping Questionnaire is developed in collaboration with families, uses qualitative and quantitative research methods, addresses issues across the lifespan. COPE is not the final word on what aspect of coping should be measured, because there are too many different ways to deal with life's adversity. Diversity among measures of coping should be constrained only by limits on insight into the nature of coping process. Which coping functions are important and which are not can be determined only by measuring and testing them. (C. Carver, M. Scheier, J. Weintraub, 1989). The need to include complementary outcome measures seems particularly relevant to the area of family assessment, and users should gather additional information about them. Researcher has been used different instrument to evaluate stress and coping strategies of parents of autistic children. These studies are important for specialist that work with children and families of children with autism, they can offer a different perspective not to focus only to autistic child but to focus to family system on impact that autistic children have at family system, and in mental health of their parents. It's necessary that professions that work in institution that offer services for child and families of autistic children to have information about instrument that are used to evaluate stress and coping strategies and to have a better coordination in order to use these instrument for evaluating parenting stress and as a measure of programs effectiveness that operate in a variety of service settings that serve families of autistic children. If we refer Albanian Institution that offer services for children and families of autistic children, specialist of multidisciplinary team that work with parents of autistic children don't use any instrument to evaluate stress and coping strategies of parents of autistic children. (S. E. Mott, R. R. Fewell, M. Lewis, S. J. Meisels, J. P. Shonkoff, R. J. Simensson, 1986). The instruments could potentially be used to determine the effectiveness of experimental treatments or interventions, as well as to compare the overall effectiveness of existing interventions for autistic children and to improve services provide to the families of autistic children.

## 5. Conclusion And Recommendation

1. This review is based in 18 published research article, studies showed that autism is a source of parental stress all over the world.
2. The instrument described in this review are very effective for evaluating stress and identified coping strategies of parents of autistic children.
3. Institution that provide services for families of autistic children it's necessary to ensure that a child and his or her family is receiving the best treatment. An initial step in this process is evaluation of stress and coping strategies of parents of autistic children.
4. Assessment of stress and parental coping should be part of child screening and evaluation in Albania institution, if we want to offer the best treatment in context of family system in order to minimize health problems of parent.
5. The instrument reviewed used to evaluate stress and coping strategies can be used in combination with other instrument in order to get more information about amount of parental stress and coping strategies.
6. Assessment of parental stress and coping strategies would be used to assess changes in parent stress level and coping strategies after a course of child involvement in a therapy.
7. Assessments of stress and coping are necessary because according to results of instrument practitioner can identify needs of parents, and can design counseling program or training program on stress reduction and coping strategies.

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