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# Parenting Stress in Mothers and Fathers of Children with Autism Spectrum Disorders

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## 1. Introduction

A number of studies have demonstrated that parents of children with developmental disabilities experience higher levels of stress than parents of typically developing children (e.g. Hodapp et al., 2003; Johnson et al., 2003). Webster and colleagues (2008) found that the scores in the Parenting Stress Index were above 85<sup>th</sup> percentile in over 40% of parents of children with developmental delay, indicating significant parenting stress.

Parental stress is viewed as a complex set of non-specific, persistent and significant challenges associated with one of parents' most important roles, i.e. taking care of their child. Despite a considerable amount of data on stress in parents of children with disabilities, there is still no consensus on the conceptualization of this phenomenon (Perry, 2004). The theoretical framework adopted in a number of studies is the transactional model of stress and coping (Lazarus & Folkman, 1984). In this approach, stress is a particular type of an individual's relationship with the environment, which the individual appraises as putting certain demands or overextending his/her resources, and thus threatening his/her well-being (Lazarus & Folkman, 1984).

Parental stress is associated with the type of disability present in the child (Gupta, 2007). A number of authors have reported higher levels of stress in mothers of children with autism compared with mothers of children with other developmental disabilities, e.g. Down syndrome, fragile X syndrome, severe intellectual disability (Abbeduto et al., 2004; Weiss, 2002; White & Hastings, 2004), parents of children with special health care needs without developmental problems (Schieve et al., 2007) or typically developing children (Baker-Ericzén et al., 2005; Smith et al., 2001; Yamada et al., 2007). Tomanik, Harris and Hawkins (2004) found that two-thirds of mothers of children with autism in their study demonstrated elevated stress levels. Another revealing fact is that parents themselves often use the word "stressful" when talking about raising a child with autism (e.g. Gray, 2002a).

The present review of research on stress in parents of children with autism covers two main issues. In the first part, the most significant sources of parental stress in this group of parents are discussed and the results of research on stress profiles in mothers and fathers are presented. The second part offers an outline of individual determinants of parental stress, associated with personal characteristics of the parent (e.g., their sense of coherence, coping styles and strategies). Conclusion contains a brief account of the consequences of parental stress and potential implications of studies on stress for clinical practice.

## 2. Causes of stress in parents of children with autism

There are three major groups of factors that contribute to elevated stress in parents of children with autism: (1) child characteristics, in particular behavioural symptoms associated with autism and behavioural problems; (2) lack of adequate professional support and unsatisfactory relationships between parents and professionals from the stage of autism diagnosis to limited access to medical and educational services for the child; (3) social attitudes towards individuals with autism and lack of understanding for problems they and their families experience.

### 2.1 Child characteristics as a source of parenting stress

According to the currently available information, autism is characterised by the coexistence of three groups of symptoms: impaired social relations and communication, and restricted and repetitive patterns of behaviour (American Psychiatric Association, 2000). All of the above mentioned developmental difficulties may be severely distressing for parents.

So far there is no consensus on the relation between severity of children's impairment and stress in parents of children with autism. Some researchers report the presence of this relationship (e.g. Hastings & Johnson, 2001; Hoffman et al., 2008). Not all authors, however, have confirmed their results (e.g. Tobing & Glenwick, 2002), and some have even suggested that the severity of the child's autism symptoms is a relatively poor predictor of parental stress (Konstantareas & Papageorgiu, 2006). It seems that the root cause of this disparity in research findings are methodological issues, such as sample size, selection criteria and internal differentiation in the groups of parents and children in the studies, as well as the tools used to measure the children's developmental problems.

Furthermore, the role of particular types of the child's developmental and behavioural problems in the aetiology of parental stress is still unclear. Certainly, the most typical signs and symptoms of autism are pervasive deficits in socio-emotional development. They are especially apparent in limited ability of people with autism to initiate and maintain interaction (Volkmar et al., 2004). These difficulties may vary in form and severity, but even people with high-functioning autism (HFA) experience significant problems in interpersonal relations. Studies on parents of children with non-autistic developmental disorders show that low levels of the child's pro-social behaviour are related with the severity of parental stress (Richman et al., 2009). As Davis and Carter (2008) demonstrated in their study on parents of newly-diagnosed children with autism spectrum disorders (ASD), deficits in social relatedness may be a significant burden to parents. Similar results were obtained by Kasari and Sigman (1997), who found a relationship between the level of parental stress and child's responsiveness when interacting with the experimenter.

An important area in which the development of children with autism is untypical is the formation of interpersonal relations with parents. Studies have shown that the majority of these children's mothers consider their child's signs of attachment to be insufficient and rate their emotional reciprocity lower than mothers of children with other disabilities (Abbeduto et al. 2004; Hoppes & Harris, 1990). Even though mothers report that they would like their children to show more signs of attachment, this aspect of the child's functioning appears to be less salient in the emergence of parental stress than other difficulties experienced by mothers. Hoffman and colleagues (2009) found no differences in Attachment Subscale in Parenting Stress Index (PSI) between mothers of children with autism and mothers of typically developing children. Mothers of children with autism in the study reported high

levels of stress in all other PSI subscales (both in the Child Domain, and the Parent Domain); their scores in the assessment of demands resulting from relationships with the child were similar to those obtained by mothers of typically developing children. It should be mentioned that mothers of children with autism scored highest in the Child's Domain: their mean PSI scores in these subscales were in the 99<sup>th</sup> percentile.

Another potential child characteristic which may contribute to elevated parental stress is limited communication with the child. Communication deficits are seen across a range of verbal and nonverbal skills: gestures, intonation, melody, rhythm of utterance, facial expression and posture (Walenski et al., 2006). These children also have difficulties using communication to regulate social relations. Tomanik, Harris and Hawkins (2004) showed that in mothers of children with pervasive developmental disorders (mostly autism) aged 2-7 years, stress is associated with the child's ability to participate in interactions and communicate. Mothers of children with autism report higher stress when their children have poor communication skills (Konstantareas & Papageorgiu, 2006). It should also be mentioned that communication deficits are usually the primary reason why parents seek professional help (Charman & Baird, 2002).

Social relations and communication problems are associated with cognitive impairments affecting children with autism (e.g. Joseph et al., 2002). It appears, however, that intellectual development of the child is not a determinant of the level of parental stress. Parents of high-functioning children with autism or Asperger syndrome also experience elevated stress levels (Mori et al., 2009; Rao & Beidel, 2009).

Among the most important predictors of parents' stress are the child's behaviour problems (Bishop et al., 2007; Estes et al., 2009; Herring et al., 2006; Tomanik et al., 2004). Children with autism present with a number of such problems, including aggression and self-injury (Matson & Rivet, 2008). Self-injury, aggressive and otherwise destructive behaviour are the strongest predictors of parental stress (Dunlap & Robbins, 1994; Richman et al., 2009). The child's stereotyped and self-stimulating behaviours are also a source of distress for parents. The actual degree to which specific behaviour problems contribute to parental stress depends on the child's age. Parents of adolescents cite destructive behaviour and withdrawal from contact as the most significant causes of concern, while self-stimulation and tantrums are mentioned primarily by parents of preschool children (Dunlap & Robbins, 1994).

The child's challenging behaviours, apart from posing direct problems by endangering the safety of the child or others or causing material damage, may also lead to parents' community isolation (Worcester et al., 2008). In addition, parents often feel helpless, seeing that their child's responses to their attempts at calming him down are completely unpredictable and incomprehensible: *"What scared me the most was his crying, and I would do anything to prevent it. When he was crying, I felt lost, because I could not hold him or kiss him since he hated it"* (Grodzka, 1995, p. 217). Thus, the effect of challenging behaviours on parental stress can be complex. Better insight into the relationships between these phenomena would certainly help develop more effective ways of supporting parents.

Impaired adaptive functioning, including lower daily living skills, may also add to the burdens experienced by parents (Fitzgerald et al., 2002; Tomanik et al., 2004). Children with low level of self-care skills require more assistance in everyday tasks involved in getting dressed, eating and daily hygiene. With the accumulation of such demands along with other behavioural problems, it is no surprise that mothers evaluate taking care of a child with autism to be much harder than raising most children of the same age (Montes & Halterman,

2008). It should be noted, however, that although some authors have found a relationship between low adaptive functioning in children with autism and elevated parenting stress (Hall & Graff, 2011), other reports suggest that the child's adaptive skills' level is less significant than other factors in the context of parental stress (Beck et al., 2004). The longitudinal study by Lecavalier and colleagues (2006) demonstrated that the level of adaptive skills in children and adolescents with ASD is a weaker predictor of parental stress than, for example, externalizing behaviour.

Parental stress is also associated with the child's regulatory difficulties. These problems affect a number of areas, including emotional and affective regulation, and circadian rhythm. Studies have shown that, according to parents, children with autism demonstrate more negative emotions than children with mental disability and typically developing children (Capps et al., 1993). There is a relationship between such child characteristics as irritability, social withdrawal, hyperactivity and non-compliance, and the level of stress in mothers (Tomanik et al., 2004). In a study by Konstantareas and Papageorgiou (2006), the most powerful determinant of mothers' stress was the child's temperament, and in particular, the child's general level of activity, low flexibility and low mood.

One of the sources of problems experienced by parents are also the disturbances in the child's circadian rhythm. A number of children with autism have sleeping problems, such as excessively short sleep time, trouble falling asleep, waking up multiple times at night, problems getting out of bed in the morning and drowsiness during the day (e.g. Goodlin-Jones et al., 2008). These problems cause significant fatigue in parents, sometimes bordering on exhaustion, and are associated with parents' elevated stress and sleeping disorders (Hoffman et al., 2008).

Parents are also troubled by the child's untypical behaviour resulting from sensory problems, such as fixation on some and avoidance of other objects, paradoxical responses to stimulation and susceptibility to sensory overload (Ben-Sasson et al., 2007; Tomchek & Dunn, 2007). For parents who are not educated about autism-specific deficits in sensory processing, such behaviours may seem incomprehensible and lead to elevated levels of stress.

A contributing factor to behavioural unpredictability is the child's asymmetrical development in various areas: from relatively typical development, through regression, to severe developmental delay (cf. Marcus et al., 1997). An illustrative example is a girl described by Moreno and Donnellan (1991), who was able to define words such as "perigee" and "apogee" at the age of seven, but was unable to communicate her everyday needs.

The above developmental and behavioural problems illustrate how tough a challenge parents of children with autism are facing. Standing up to that challenge is impossible without professional support. Unfortunately, interactions with professionals can also be a major source of parental stress.

## **2.2 Problems with diagnosis, relations with professionals and parental stress**

One of the most significant causes of stress experienced by parents of children with autism is lack of adequate professional support (Bishop et al. 2007; Sharpley et al., 1997). Parents face problems receiving help from healthcare professionals already at the stage of diagnosis of their child's developmental deficits. Suffice to say that, on average, the child is assessed by more than four professionals before diagnosis, with mean time to diagnosis being approximately 2-3 years (Siklos & Kerns, 2007). Among the multiple factors contributing to this situation, a major cause is the general lack of education about the course of young

children's development and its disorders among professionals (including physicians and psychologists), and insufficient knowledge of symptoms indicating significant developmental difficulties. Another important issue is the small number of diagnostic and treatment institutions offering specialised services to individuals with ASD.

As noted by Norton and Drew (1994), autism is usually diagnosed only when parents insist on careful assessment of their child. This finding was confirmed by data from Canada, indicating the presence of a relationship between the mother's education and the child's diagnosis of autism (Croen et al., 2002). Information collected from parents suggest that they initially become concerned with their child's development in the first half of his/her second year of life (De Giacomo & Fombonne, 1998). They are usually worried by the child's communication difficulties, in particular the lack of speech, as well as unusual social behaviour and play patterns (Charman et al., 2001; Goin-Kochel & Myers, 2005).

Parents are frustrated by delayed and drawn-out diagnostic process and disappointed with the level of professionals' knowledge about autism spectrum disorders (Brogan & Knussen, 2003; Mansell & Morris, 2004; Osborne & Reed, 2008). Their stress associated with fear for their child may be further compounded by the way they are treated by professionals. They are forced to long waiting times at specialised institutions, and they receive conflicting information on how to help their child. Their problems are exacerbated by poor interpersonal skills of some professionals.

Support for parents is also inadequate during and immediately after the diagnostic process. Parents find it difficult to cope with their child's diagnosis of autism. Their responses range from relief that the situation is finally clear, through shock, disbelief or denial, to profound sadness and depressed mood (Avdi et al., 2000; Midence & O'Neill, 1999). Many are unable to deal with the situation on their own and require professional support (Wachtel & Carter, 2008).

It should also be emphasized that regardless of how parents respond initially, diagnosis is only the first step in their adaptive process. Siegel (1997) notes that coming to terms with the child's autism is a long-term process, due to, among other things, absence of any signs of disability in the child's appearance, which means that even after the diagnosis some parents remain sceptical as to its correctness. In the course of "arriving" at the final diagnosis, they live a life of uncertainty, which is made worse by the fact that they usually receive contradicting information about the nature of their child's problems and prognosis for further development. Even when the diagnosis is final, many parents are not aware of its consequences for the child and family. Lack of proper support significantly hampers their adaptation to the new situation.

Although autism has been diagnosed in children for many years, accessibility of autism-specific services and professional support is still unsatisfactory. This problem is present in many different countries, as demonstrated by research conducted e.g. in the USA (Wachtel & Carter, 2008), Belgium (Renty & Roeyers, 2004), and Poland (Rajner & Wroniszewski, 2000). Consequently, the task of arranging proper support, as well as medical, educational and other services for the child often falls to the parents (e.g. Renty & Roeyers, 2006; Sharpley et al., 1997; Weiss, 2002), who are left alone to coordinate, advocate for, and make decisions about treatment (Wachtel & Carter, 2008). As a result, they are overburdened with duties, sometimes feeling incompetent and anxious whether they have made the right choice of intervention for their child.

A significant cause of parents' dissatisfaction with professionals are problems in obtaining specific information about autism and instructions on how to take care of the child. A study by Rhoades and colleagues (2007) showed that as few as 40% of physicians who give the child the diagnosis of autism follow up with additional information about the disorder for parents, and only approximately 15-34% give advice on choosing a medical/educational program. The results of research by Hall and Graff (2011) suggest that parents expect professionals to have up-to-date knowledge on available sources of support and to be able to direct the family so as to save it from being overloaded with unnecessary and unneeded activities. However, the results of studies on professionals show that they are uncertain about the aetiology of autism, diagnosis and the best types of intervention for affected children (e.g. Mavropoulou & Padeliaou, 2001). Additionally, they often lack qualifications when it comes to working with children with autism (Casella & Colella, 2004).

When analysing issues in the relationships of parents of children with autism with professionals, one must mention another aspect of those relations, associated with dated and unproven concepts of parental contribution in the aetiology of their child's autism. According to current consensus, autism belongs to neurodevelopmental disorders, and its aetiology is determined by neurobiological mechanisms (see: Moldin & Rubenstein, 2006). Thus, our knowledge about the causes of this disorder has progressed a long way since the "refrigerator mother" hypothesis, popular in the 1950's (cf. Marcus et al., 1997). However, as Schreibman (2005) observes, theories of psychogenic aetiology of autism have left a climate full of suspicion and distrust in the relationship between parents and professionals. This remark was confirmed by the findings of Avdi, Griffin and Brough (2000), who demonstrated that parents suspected professionals of withholding information, being judgemental and controlling.

Another challenge for parents is the lack of adequate respite services. Additional demands over typical childcare duties mean that parents are tired and lack time for other tasks and for satisfying their own and their family's needs. This also has direct effects on employment choices. In the Montes and Halterman study (2008), nearly 40% of parents of children with ASD reported claimed that problems associated with childcare significantly affected their employment decisions and careers. The proportion was much lower in the case of parents of high risk and typically developing children.

Another source of stress for parents related to lack of adequate support is the sense of neglecting other children by not spending enough time with them. Here is an excerpt from a letter written by a mother of Janek, published in Grodzka (1995): *"As parents of two sons – the older one healthy, and the younger who is sick – for ten years we were so focussed on the younger one that our healthy boy, although only two years older, had anything but a rosy childhood. Only now are we starting to realize that. Can we ever make it up to him? I don't know. Our older son loves his brother very much, and it shows. But he is also fighting for equal treatment"* (p. 223).

As the above review suggests, not only are parents faced with inadequate support, but their relationship with healthcare professionals may actually place additional burden on them. In order to avoid painting a one-sided picture of the parents-professionals relationship, it should be pointed out that studies conducted in Great Britain show that over 60% of parents whose children with autism benefit from educational services at schools express their satisfaction with those services (Whitaker, 2007). Their positive assessment involves the belief that school staff understands their child's difficulties and responds to them with empathy and from their perception that the school is able to respond flexibly to the child's needs. The level of satisfaction is also related with the quality of communication between the family and school.

A number of difficult experiences of parents are caused by attitudes and behaviour towards their child demonstrated by others.

### **2.3 Social attitudes towards people with autism as a source of parental stress**

There is no doubt that parents of children with autism must cope not only with problems resulting from their child's developmental disability and challenging behaviours, but also with distressing responses of others to the child's behaviour, as well as general lack of knowledge about autism.

The contrast between the child's appearance, which betrays no signs of disability, and his behaviour, which is perceived as abnormal and "strange", frequently puts parents in very unpleasant situations (e.g. Gray, 2002b; Portway & Johnson, 2005). The child's behaviour is often taken to be a symptom of poor upbringing: *"You're being a bad mother. He's behaving like that because you don't discipline him. If you did it this way you wouldn't have problems.' That kind of stuff...you know, it doesn't help"* (Farrugia, 2009, p. 1018). Social disapproval for the child's behaviour often leads to stigmatization, experience of shame for parents, and their exclusion from normal social activities (Farrugia, 2009).

One of the aspects that determine the attitudes and behaviour towards people with autism is lack of awareness about the disorder. Autism still remains an unknown condition (e.g. Huws & Jones, 2010). There is plenty to be done in this area in order to change negative attitudes towards people with autism, especially since it has already been demonstrated that the scope and manner of providing information about the disorder significantly affects the attitudes and the level of acceptance for people with this disability (Iobst et al., 2009).

Boyd (2002) found that informal support plays a particularly important role in the adaptation of mothers of children with autism. Unfortunately, availability of this type of help also tends to be limited. Problems with the child's functioning often mean that parents are left to care for their children alone, deprived of help even from close family members. The burden of childcare often takes its toll on their relationships with friends and acquaintances. Their social circle is usually significantly reduced (Farrugia, 2009).

Still, it should be noted that professionals declare positive attitudes towards people with autism (e.g. Weil et al., 2011), as suggested by the results of the study conducted by Horrocks et al. (2008), in which principals of public schools in Pennsylvania were asked about their views on placing a child with autism at their schools. In one study, people training for various health and social professions were asked about their opinions on working with individuals with autism. It was assessed as difficult, challenging, and frustrating but also rewarding, important and an opportunity for personal and professional growth (Werner, 2011).

Some stressors listed in this section are unique to parents of children with autism (e.g. burdens associated with their child's difficulties in social relatedness, atypical attachment behaviour), while others are also experienced by parents of children with other developmental problems (e.g. behavioural problems or negative social attitudes towards the child and its family members). The list of challenges faced by parents presented here is by no means exhaustive. It leaves out a number of important issues which are not specific to autism, such as the parents' sense of guilt or anxiety about the child's future, which are shared by parents of children with various developmental disabilities. However, the exceptional circumstances of parents of children with autism are present in these issues as well. Parental self-blame for their child's autism may be rooted in certain aetiological

concepts, such as the “refrigerator mother” hypothesis mentioned above. On the other hand, anxiety about the child’s future is related to the fact that problems in social interaction put people with autism at increased risk of isolation and lack of support from friends to a much greater degree than individuals with other disorders. With time, the question of their child’s social relations and having even a small circle of friends become increasingly important for the parents.

As it has already been mentioned, parental stress is a multifaceted phenomenon. It is influenced by many factors which may affect its profile and severity, as well as its implications for the parents’ and child’s well-being and family life. The factors that determine the level of stress in parents of children with autism have been the focus of research for over 30 years. The following section of the article looks at some of those factors.

### **3. Individual determinants of parental stress**

Important factors determining the stress of parents of children with autism include parent’s sex and a number of individual characteristics (such as coping strategies and style, and sense of coherence). The role of these factors in the context of stress experienced by parents is discussed below.

#### **3.1 Parental stress in mothers and fathers of children with autism**

The majority of studies on parental stress associated with raising a child with autism have focused on mothers. The idea was to find a stable, and at the same time group-specific stress profile. In one of the first investigations on the topic, Holroyd and McArthur (1976) compared stress experienced by mothers of children with autism and mothers of children with Down syndrome. Apart from common problems related to health, depressive mood, sense of being overburdened, pessimistic view of the future and limited family opportunity, mothers of children with autism reported stress associated with taking the child to public places, the child’s almost complete dependence on care and lack of access to specialised services. Later research also showed that mothers of children with autism have a less positive future perspective than mothers of children with Down syndrome (Abbeduto et al. 2004).

Similar results were obtained by Bouma and Schweitzer (1990) in their comparison of mothers of children with autism and children with a physical disability and healthy children. Mothers of children with autism experienced more strain from problems related to the child’s cognitive development, the need for constant supervision, and the perspective of their child’s continued dependence on care. Behaviour problems of their child with autism also featured as a significant contributor to stress.

Koegel et al. (1992) described a fairly stable pattern of difficulties experienced by mothers of children with autism, independent from the child’s age, intellectual development, geographical region or cultural background. The core stress was associated with the child’s future, his/her cognitive development, dependence on care and social exclusion.

In another study (Pisula, 2007), mothers of children with autism showed higher stress levels than did mothers of children with Down syndrome on seven of the 15 subscales of the Questionnaire of Resources and Stress (Holroyd, 1987). The largest differences between groups were found for overprotection / dependency of the child and child's difficult personality characteristics. Mothers of children with autism were also more concerned about

their child's dependence on external care. Similar results were obtained by Dale, Jahoda and Knott (2006).

There is no doubt that bringing up a child with autism may also be a significant challenge to fathers. However, our knowledge of how they experience problems related with the child's developmental deficits is still limited. In a study dating back almost twenty years, Rodrigue et al. (1992) demonstrated that fathers noticed the child's effect on family members' opportunities to satisfy their own needs and on overall family activity. Later studies found that the level of stress in fathers of children with autism is higher than in fathers of typically developing children (Baker-Ericzén et al., 2005).

Very few research projects to date have compared the stress profiles of mothers and fathers. Tehee et al. (2009) found that mothers were significantly more stressed than fathers. As stated Moes et al. (1992), mothers experienced more stress in four areas: parenting problems, the child's self-sufficiency, behaviour, and physical development. Other findings suggest that stress in mothers is interrelated with their child's social skills, while no such relationship was found in fathers (Baker-Ericzén et al., 2005). Hastings (2003) showed that stress level in mothers was associated with the child's behavioural problems and the father's mental health, while the stress in fathers was not related to either the child's behaviour or mother's mental health. Other researchers (Knusen & Sloper, 1992) have also shown that mothers were particularly affected by behavioural problems demonstrated by the child, as well as his/her dependency, anxiety and poor communicative skills, while fathers, apart from communication problems, were most affected by the child's physical disability and presence of other stressful life events (e.g. career-related or associated with family finances). As for behavioural problems, fathers were mostly distressed by the child's externalizing problems, while mothers were more affected by the child's regulatory problems (Davis & Carter, 2008). A supplement to these findings is the information that mothers perceived significantly more stigmatizing behaviours of other people than did fathers (Gray, 2002b). Thus, it would seem that mothers are more sensitive to hostile behaviour of others towards the child than are fathers.

In the light of the above account, it is clear that we still know very little about the differences between mothers and fathers of children with autism in terms of parental stress they experience. Research has shown that mothers experience more stress and that their stress is more pervasive than stress experienced by fathers: scores are elevated in more domains measured in these studies.

### **3.2 Individual personal characteristics of parents and parental stress**

Stress experienced by parents may significantly affect their adaptability to the demands of bringing up a child with developmental disability. Successful adaptation of parents depends on a range of factors, including their coping strategies and styles (McCubbin & Petterson, 1983).

The nature of challenges resulting from the child's developmental deficits affects the type of coping strategies used by parents. Some results indicate that parents of children with ASD employ more strategies that involve distancing and escape than parents of non-autistic children, and that they are less likely to use strategies involving self-control, seeking social support, and problem solving (Sivberg et al., 2002). Tway et al. (2007) found that parents of children with autism aged  $\leq 12$  often resorted to strategies that included reframing and seeking social support.

The way parents cope with stress is correlated with their stress level (Hastings & Johnson, 2001). It should be noted, however, that the interrelations between parental stress in parents of children with autism and their stress coping in general have not been sufficiently researched. In one of only a handful of studies on the subject, Lyons and colleagues (2010) analysed the effect of autism severity and parents' coping strategies on parental stress. The most powerful predictor of stress was the child's autism severity. However, coping strategies also play an important role for the well-being of parents of children with autism. Smith et al. (2008) concluded that the well-being of mothers of toddlers with autism correlated with using less emotion-focused coping and more problem-focused coping, regardless of the severity of the child's deficits.

In a study on coping strategies in parents of preschool and school-aged children with autism, Hastings et al. (2005) distinguished four main coping dimensions: active-avoidance coping, problem focused coping, positive coping, and religious/denial coping. Out of those dimensions, active-avoidance coping was associated with a high level of stress and psychopathology in both mothers and fathers.

Some data also suggest that elevated level of parental stress is associated with religious coping (Tarakeswahr & Pargament, 2001). Lower stress, in turn, is associated with using coping strategies that involve reformulation and seeking informal support (Hastings & Johnson, 2001), problem-oriented coping (Lustig, 2002), as well as coping by focusing on family integration and co-operation (Jones & Passey, 2005). It has also been shown that adaptation of mothers of children with autism is facilitated by active coping patterns, while self-blame for the handicap is associated with poorer adaptation (Bristol, 1987).

Most studies on coping with stress in parents of children with autism focus on coping strategies. Much less is known about coping styles defined as a dispositional variable which refers to relatively stable characteristics of an individual (Endler & Parker, 1990). In a study on parents of high functioning children with autism, Lee (2009) found that they demonstrated lower adaptive coping skills than parents of typically developing children. Any analysis of stress coping in this group of subjects should take into account findings about a certain typical characteristics in their functioning. They suggest that there is a similarity in psychological functioning of the child and parents. Parents demonstrate higher rates of social difficulties (e.g. impaired friendships, aloofness, shyness, impairments in confiding relationships, social phobia) (e.g. Murphy et al., 2000; Piven, 1999), higher scores in aloof personality, rigid personality, and pragmatic language difficulties (Hurley et al., 2007). In addition, some of them show some cognitive features similar to the cognitive functioning of their children (e.g. Briskman et al., 2001). These characteristics may affect their ability to cope with the difficulties associated with the child's developmental problems.

Individual characteristics important in the context of parental stress and how parents cope with it also include sense of coherence (SOC), defined as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (a) the stimuli deriving from one's internal and external environments in the course of living and structured, predictable, and explicable (*comprehensibility*); (b) the resources are available to one to meet the demands posed by these stimuli (*manageability*); (c) these demands are challenges worthy of investment and engagement (*meaningfulness*)" (Antonovsky, 1987, p. 19). SOC has been shown to be closely associated with individual's health and psychological distress (e.g. Antonovsky, 1998; Olsson et al., 2008). Very few studies so far focused on the

sense of coherence in parents of children with autism. From the few that have been conducted, it appears that they have weaker SOC than parents of children with other disabilities and parents of typically developing children (Olsson & Hwang, 2002; Pisula & Kossakowska, 2010; Sivberg, 2002). In the context of these findings, the results of the study by Mak, Ho and Law (2007), who analysed the relationship between SOC and parental stress in mothers of children with autism are particularly interesting. The study showed that mothers with stronger SOC perceived lower stress, regardless of the severity of their child's developmental difficulties.

Other factors that may potentially be related to parental stress include parents' lower control locus, lower levels of self-esteem, and vulnerability to mental health problems. However, the results of studies on the relationship between these variables and parental stress conducted so far are inconclusive. For example, Hamlyn-Wright et al. (2007) did not find locus of control to mediate the relationship between stress and anxiety or depression in parents of children with autism. Dunn et al. (2001) also failed to obtain a relationship between locus of control and parental stress. In addition, the level of stress in parents of children with autism is also determined by the factors mentioned in the first part of this section, i.e. availability of social support, social attitudes towards the child with autism, family's financial standing, family cohesiveness and marital satisfaction.

#### 4. Conclusion

To summarize the present review of research on stress in parents of children with autism, significant sources of stress include, among others, lateness and difficulty in obtaining diagnosis, untypical and inconsistent development of the child, and behavioural problems, with particular emphasis of challenging behaviour in public. Parents are also hampered by the lack of systemic solutions for people with autism, ignorance of professionals, and general lack of understanding for their problems. The situation is further complicated by the fact that people with autism require considerable and wide-ranging support for a significant portion of their lives, and that currently used intervention methods fall short of expectations. These problems affect various individuals to different degrees and may actually be untypical in a particular case, which is why the experiences of different families can be so divergent.

Severe stress experienced by parents of children with autism has profound consequences for their health, well-being, interactions with the child and family life. Nevertheless, it is still difficult to pinpoint the exact mechanism behind these consequences. It has been demonstrated that parents of these children have poorer health and lower sense of psychological well-being than parents of children with other dysfunctions (e.g. Abbeduto et al., 2004; Kasari & Sigman, 1997). Phetrasuwan and Miles (2009) have also shown that mothers of children with ASD who reported higher stress, presented with more symptoms of depression and lower levels of well-being than mothers with lower stress. It is not clear, however, whether autism is unique in that respect, or if other disorders affect parents' well-being similarly. Greenberg and colleagues (2004) found no differences in terms of depression, well-being and health between mothers of adults with autism, Down syndrome and schizophrenia.

Studies have also shown that parental stress affects such aspects of family life as spending time together, capacity for spontaneous and flexible planning and marital relationship

(Hutton & Caron, 2005), and lower the efficacy of early interventions in children with ASD (Osborne et al., 2008).

Richard Hastings (2002) put forward a theoretical model combining the child's behaviour problems with developmental disability, parental stress and parenting behaviour. The model proposes the following chain of relations: (1) child's behaviour problems lead to parent's stress, (2) parental stress affects the way parent acts toward the child, (3) the parent's behaviour towards the child reinforces the development and persistence of behaviour problems. The model has not been fully tested yet, but some data partially support its validity (e.g. Estes et al., 2009). Kasari and Sigman (1997) proposed a similar model for interpreting the interrelations between the behaviour of a child with autism and parental stress, supplementing it with the shape of parent-child interactions. They suggest that elevated stress in the parent affects her behaviour toward the child, and, as a result, the course of their interactions.

There is no doubt that the application of the stress-coping paradigm in research on the circumstances of parents of children with autism has yielded a lot of interesting and important results, improving our understanding of the difficulties they must face. These findings help develop better methods of supporting families of children with autism. However, data in this field are often inconsistent, most likely due to methodological issues. Adequate tools for assessing parental stress still need to be designed, as shown by validity analyses of existing questionnaires (e.g. Zaidman-Zait et al., 2010).

The present article offers a comprehensive analysis of information about the challenges faced by parents who raise a child with autism. It should be noted, however, that parents also report positive aspects of their parenting experience. What's more, with time, as they adapt to the situation, their sense of well-being improves. Gray (2002a) analysed parents at two instances, 8-10 years apart. In the second study, parents reported better mood, fewer health problems and lower stress levels than at the initial assessment. They also noticed improvement in their relationship with extended family and significant reduction in stigmatizing towards the child. Similar results were obtained by King et al. (2006), who found that with time parents achieved better sense of coherence and control. Their values and goals changed, which facilitated adaptation to the demands resulting from the child's developmental difficulties. Research on the factors that facilitate parents' adaptation to the unique challenges posed before them by their child's autism is still an important branch of scientific inquiry.

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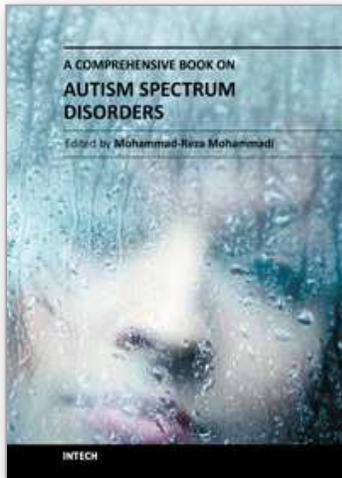
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The aim of the book is to serve for clinical, practical, basic and scholarly practices. In twentyfive chapters it covers the most important topics related to Autism Spectrum Disorders in the efficient way and aims to be useful for health professionals in training or clinicians seeking an update. Different people with autism can have very different symptoms. Autism is considered to be a "spectrum" disorder, a group of disorders with similar features. Some people may experience merely mild disturbances, while the others have very serious symptoms. This book is aimed to be used as a textbook for child and adolescent psychiatry fellowship training and will serve as a reference for practicing psychologists, child and adolescent psychiatrists, general psychiatrists, pediatricians, child neurologists, nurses, social workers and family physicians. A free access to the full-text electronic version of the book via Intech reading platform at <http://www.intechweb.org> is a great bonus.

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