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**Stress management in mothers of children with Autism Spectrum Disorder:
psychological characteristics, coping strategies and biological correlates**

Coordinatore:

Chiar.mo Prof. Tiziana Mancini

Tutor:

Chiar.mo Prof. Dolores Rollo

Dottorando: dott.ssa Elena Pattini

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PREFACE

A child with an autism spectrum disorder, which is characterized by severe difficulties in relationships, behavior and communication, forces the whole family system to handle a lot of stress due to the daily management of such a complex disease. For these reasons, parents need support that should be preferably tailored to the characteristics of their family background. To do this, it would be important to identify parameters related to the levels of stress in family members of patients with autism. The purpose of this study is to assess personality traits, coping styles and the ability to manage emotions in mothers of autistic children, and how these personal characteristics can be related to the individual reactivity to stressful situations, evaluated through biological correlates, such as cortisol levels and the heart rate variability. The aim of this work is also to reduce access to services for these subjects. Indeed, individual projects of parental support are a protective factor against the physical and psychological discomfort when implemented taking into account the individual variability in the above mentioned characteristics.

We approached this research with the dual personality of researchers and clinicians with the ultimate goal of ameliorating the type of support that is provided to parents of autistic children and also improving the well-being of the whole family context. This has an obvious and essential beneficial effect on their children as well, with and without disabilities.

CHAPTER 1

THE CHALLENGE OF RAISING A CHILD WITH AUTISM

Raising an autistic child is a long journey.

Looking back, Livia now understands that the signs made sense. Before her son Francesco was diagnosed with autism at the age of 3, he had been behaving differently from his older brother, Alessandro. Francesco was happy and affectionate, but “he developed pretty rigid routines that had to be adhered to or he would just totally fall part”. When Livia went to school with him, Francesco insisted on taking the same route and using the same entry to school every day. When he was asleep, his parents had to lay his blanket exactly in the same way, with the same edge touching his upper body. By the age of 2, Francesco did not speak any words, not even “Mum” or “Dad”. When Francesco was diagnosed with autism “it was one of the worst days of my life.” – Livia says - “I was paralyzed. I was numb and scared. I wanted to hide in my little house and just shut down. I was absolutely devastated and so was my husband, I had no idea what Francesco was going to be like”. (Kam, 2016)

1.1 Being a parent of a child with Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a life-long neurodevelopmental disorder, which affects a child’s communication, social interactions, and behavior patterns¹ (APA, 2014); its onset generally occurs before the age of three.

Persons with ASD represent a significant proportion of the world population, making ASD a global health issue.

¹ For the diagnostic criteria, see Table 1.

Through the world, caregivers find caring for children with ASD challenging. Family members must manage many aspects of caregiving, which is demanding, even overwhelming, and can affect family members' mental health (B. L. Baker, Blacher, & Olsson, 2005).

The pervasive and severe deficits often present in children with ASD are associated with many difficulties in caregivers, including decreased parenting efficacy, increased parenting stress, and an increase in mental and physical health problems compared with parents of both typically developing children and children with other developmental disorders. In addition to significant financial strain and time pressure, high rates of divorce and lower overall family well-being highlight the burden of having an autistic child in the family (Karst & Van Hecke, 2012).

Table 1. Diagnostic criteria for Autism Spectrum Disorder (APA, 2014)

Autism Spectrum Disorder	299.00 (F84.0)
Diagnostic Criteria	
A. Persistent deficits (currently or in the past) in social communication and social interaction across multiple contexts, as manifested by the following, examples are illustrative, not exhaustive, see text:	
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect, and failure to initiate or respond to social interactions.	
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language, deficits in understanding and use of gestures; or a total lack of facial expressions and nonverbal communication.	
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior depending on the social context, to difficulties in sharing imaginative play or in making friends and absence of interest in peers.	

Specify current severity:

Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities (currently or in the past), as manifested by at least two of the following; (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation for unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with visual details or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals with marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor

(**Coding note:** Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder

(**Coding note:** Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (**Coding note:** Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

Table 2. Severity criteria (APA, 2014)

Severity levels for autism spectrum disorder	
Level	3
"Requiring very substantial support"	
<u>Social communication:</u> Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	
<u>Restricted, repetitive behaviors:</u> Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.	
Level	2
"Requiring substantial support"	
<u>Social communication:</u> Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication.	
<u>Restricted, repetitive behaviors:</u> Inflexibility of behavior, difficulty coping with change or other restricted/repetitive behaviors appears frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.	
Level	1
"Requiring support"	

Social communication: Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. They may appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-from conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.

Restricted, repetitive behaviors: Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

The contribution of family context to disease progression plays a crucial role on the effectiveness of treatment. However, the majority of therapies for ASD has been evaluated only in terms of child outcomes, ignoring parent and family factors that may have a deep influence on both the immediate and long terms effects of intervention. Parents play an important role in intervention modalities and their changes, emotions, cognitions and behaviors have an important influence on their child well-being. Having a child with ASD forces families to change their projects for the future: in fact, a longitudinal study of parents of children with developmental disabilities showed that over 50% of parents aged 50 or older indicated that they still lived with their child, compared with a rate of 17% for typically developing children (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). The lifelong burden on parents and siblings of children with ASD may alter caregivers' perception of parenting, and likely decreases optimism about their own future, as well as the future of their affected child.

The experience of parenting any child can be stressful or anxious but generally family respond well and adjust in order to maintain stability and manage life's challenges. Conversely, families of a child affected by disability are negatively impacted and therefore they experience more instability

and dysfunction than “typical” families (Watson, Hayes, Coons, & Radford-Paz, 2013). Indeed, caregivers of people with ASD suffer more from depression, anxiety, somatic symptoms, and social dysfunction than the general population (De Andres-Garcia, Moya-Albiol, & Gonzalez-Bono, 2012). Mothers of children with ASD report greater emotional problems compared to mothers of children with intellectual disabilities rather than ASD and mothers of typically developing children (Totsika, Hastings, Emerson, Berridge, & Lancaster, 2011). It should be taken into account that these mothers usually have the major obligation of caring for their child (which include management of problematic behaviors), and balancing the stress associated with this task with the responsibility of overseeing the well-being of the rest of their family, frequently leads to experiences of mental fatigue, arguments, and stressful events (Smith et al., 2010).

A great number of studies have examined the role of psychological processes as mediators of the impact of child problem behaviors on parental mental health: similar to what has been found in previous research on parents of children with intellectual disabilities (MacDonald & Hastings, 2010), greater psychological acceptance of difficult emotions and thoughts has been associated with fewer parent mental health problems. In fact, this adds to the growing literature indicating that problems that are chronic, stressful and not easily corrected through active problem solving may negatively impact a person’s process of psychological acceptance, which can lead to poorer adjustment (Weiss, Cappadocia, MacMullin, Vecili, & Lunskey, 2012). Indeed, for children with autism with more chronic behavior problems, or for multi-stressed parents, a problem-focused process, for example, may not be sufficient to ensure positive parent adjustment. In this regard, one of the most widely used parent management training program (Webster-Stratton, 2007) was found to significantly reduce the levels of externalization of autistic child behaviors, but it did not change maternal rate of depression (McIntyre, 2008). If problems are less manageable and/or support is less available, it may be futile for parents to focus exclusively on trying to change the situation. Instead, it the situation of the family should be understood and evaluated and parents should be offered multi-component interventions that have been shown to be more effective than either behavioural or cognitive interventions alone (Singer, Ethridge, & Aldana, 2007). In this kind

of situations, parents need strategies that allow them to acknowledge their current experience without trying to change it or avoid it.

1.2 Caregivers Mental Health and its influence on parenting practices

In addition to the effects on parenting self-efficacy and stress, raising a child with ASD appears to contribute to a general decrease in parental well-being and increase in mental health concerns (Ekas, Lickenbrock, & Whitman, 2010). Many studies have identified elevated levels of parent mental health problems, particularly depression and anxiety, in comparison with parents of typically developing children and parents of children with other developmental disabilities (Sawyer et al., 2010). For example, Davis and Carter's (Davis & Carter, 2008) assessment of maternal and paternal caregivers of 54 children with ASD suggested that 33% of mothers and 17% of fathers were in the clinical range for depression, with 6% of both groups reporting clinically significant anxiety symptoms. However, the mental health effects of having a child with ASD may not be limited to depression and anxiety, as a large study by Gau and colleagues (Gau et al., 2012) indicated that, parents of autistic children in Taiwan (versus parents of children without developmental concerns) demonstrated increased obsession-compulsion, hostility, schizoid traits and paranoia. These results were correlational and have not been replicated universally, but they highlight the need to explore the overall mental health status of caregivers. Furthermore, gender differences should be considered, as mothers of children with ASD and those with another developmental disability, seem to experience greater distress than fathers of children with ASD (Olsson & Hwang, 2001). Hastings (Hastings, 2003) also suggested that mothers were more affected by the health and functioning of their child and spouse than were fathers; mothers, in addition to domestic responsibilities, undertake complex activities which are not part of their routine, and caregiver burden can culminate in acute and chronic physical disorders, resulting in isolation and depression, as well as financial disequilibrium, reduction in libido and self-accusation (Macedo, da Silva, Paiva, & Ramos, 2015).

Recent literature has demonstrated that mothers have high scores for burden and low quality of life (Prudente, Barbosa, & Porto, 2010). This is in sharp contrast with what has been reported in parents of children with cerebral palsy, whose perception of quality of life resembles that of parents of children without disabilities (Allik, Larsson, & Smedje, 2006), challenging the pessimistic social and professional perspective which tends to underestimate the families' potential for adaptation. The cultural beliefs and prejudices about diseases like autism can lead to a greater vulnerability for the parents, in the experiencing of the positive perceptions regarding their lives and parenting (Carona, Crespo, & Canavarro, 2013). In fact, in a study comparing quality of life of mothers of autistic and healthy children, there were no significant differences in the domains of quality of life between caregivers, but mothers of the first group classified their health as bad as tending to worsen (Kheir et al., 2012).

It is important to notice that the mental health effects of parenting a child with ASD are largely contingent on specific parent and child characteristics. In a longitudinal study, Carter and his group of researchers (Carter, Martinez-Pedraza Fde, & Gray, 2009) found depressive symptoms in parents to be stable over time, from child's toddler age to early childhood. However, these researchers noted individual variability based on parental anxiety, efficacy, coping style and social support.

It may be important to understand how parental personality contributes to parental stress: Yamada and colleagues, (Yamada et al., 2007) showed that maternal stress was correlated with mothers' own neuroticism and agreeableness. Individual differences are fundamental in the impact of children with ASD on parent mental health. For example, a meta-analysis conducted by Yirmiya and Shaked (Yirmiya & Shaked, 2005) included 17 studies in which the psychiatric difficulties of parents of individuals with autism were compared to the psychiatric difficulties of other groups of parents. Parents of individuals with autism demonstrated more psychiatric difficulties than did the three other parent groups: parents of typically developing individuals, parents of individuals with Down Syndrome, and parents of individuals with Mental Retardation of unknown etiology. Parents of children with autism had more thought disorders compared to

parents of typically developing children, but less compared to parents of children with psychiatric disorders. These results leave the question of genetic versus environmental effects unanswered (because presumably no special emotional difficulties accompany raising a typical child). It is reasonable to assume, however, that genetic vulnerability to thought disorders would be more pronounced in families with a child suffering from psychiatric disorders including schizophrenia. The fact that no differences in thought disorders emerged between parents of children with autism and parents of children with Down Syndrome or Mental Retardation further complicates the picture, because these three groups vary in the degree of known genetic liability, and in the stresses and emotional difficulties involved in caring for these children. It is necessary to do further investigation in this direction.

Beyond this, it should be taken into account that individual differences have an influence on the relationship between mother and child, also in a disability context. The parent-child relationship, however, is a domain in which parents of children with ASD maintain relatively a healthy functioning. Mothers, despite increased stress levels and diminished quality of communication, reported higher levels of relationship closeness with their child compared with mothers in the general population (Montes & Halterman, 2007) and they did not differ from mothers of typically developing children for emotional closeness with their children (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). Mothers also report closer relationships with both adolescent and adult with ASD than fathers, despite similar self-reported levels of parenting burden (Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011). Hoffmann and colleagues (Hoffman et al., 2009), again, hypothesized that the diagnosis of ASD itself acts like a protective factor in the parent-child relationship, in that parents view the child less responsible for his or her behavior and so, they were less angry with their child and attributed most of their child's misbehavior to ASD symptoms, rather than their child's personality or temperament. However Hoffmann and colleagues (Hoffman et al., 2009) also noted that parents might blame themselves, rather than their child, for any misbehavior, which, in turn unfortunately, could contribute to decreased parenting efficacy and well-being. It can be notice that a good mother-child relationship could not be predictive of

change in maternal symptoms of depression. For example, as to better understand a complex family system, we need to evaluate the interplay between all the constructs like parent adaptability, relationship cohesion, dyadic relationship satisfaction, self-efficacy, parenting stress, psychological features and coping strategies, just to name a few.

With respect to this and an integrated model of parenting, also parental attitude and emotional control, within the scope of their interactions with their child, are two factors that can moderate the relationship between child emotional response and parenting practices (Karst & Van Hecke, 2012). Mindful parenting practices, which emphasize a clear, calm mind that is focused on the present moment (Singh et al., 2006), have been found to decrease aggressive behavior, noncompliance and self-injury in children with ASD. They are also related to increased maternal satisfaction with parenting skills and child interaction. However, every mother and every father of a child with ASD has a different personality, a different way to be a parent, different thoughts about parenting which can be the result of many psychological factors that should be investigated.

In addition to this, belief regarding parenting is also impacted by the diagnosis. Such parents are more likely to believe that they are not competent in their caretaking role compared with other parents (Hassall, Rose, & McDonald, 2005). We have already said that physical/developmental disabilities and parental mental health and parenting process interrelate in a bidirectional manner.

Some researchers suggest that these parents make more efforts to stimulate the development of their special children and use more specialized parenting behaviors compared with parents of other children (Lambrechts, Van Leeuwen, Boonen, Maes, & Noens, 2011). In line with this, Tsai and Lotus (Tsai, Tsai, & Shyu, 2008) found that parents of children with ASD integrate the role of coach with their role as caretaker. They often act like coaches to help their children on speech, motor and social skills and this dual role is an important feature of parenting in families of children with ASD, but the question is: How many parents feel that this kind of parenting is appropriate for them? Probably many of them find this way of being a parent stressful. Zhou and Yi (Zhou & Yi, 2014) found four pattern of parenting styles which varied in affiliation to the roles of caretaker

and coach. In this study, thirty-two parents from families of children with ASD in mainland China were interviewed.

Parenting styles were categorized into four types: training priority, relationship precedence, alternating and letting alone. The first, “training priority”, refers to a style in which parents placed priority on skills training for their child and so they spent a lot of time training their child and had great expectations for progress. They were usually highly demanding and strict and the most salient emotions of these parents was anxiety. Interestingly, they described, intensive training as a way to reduce parental anxiety. The second pattern, “relationship precedence”, emphasizes the importance of the parent-child relationship and puts the role of caretaker over the role of coach; parents spent much time playing with their child, took care of the child’s interests and needs carefully, and had high tolerance for the child’s problems. They tried to relax and to maintain positive mood. The third style was “alternating”, which means that parents swayed between the role of caretaker and the role of coach and struggled to find balance between the roles. The emotions they felt were fear, worry and confusion and they experienced low self-efficacy in parenting. The last type, “letting alone”, is a category in which parents had little hope for the child’s improvement and a little motivation to participate in any treatment.

Based on their experience, a sizable group of parents perceived that their own emotions influence the child’s emotions and his/her symptoms. It seemed that these four patterns were related to differences in the nature of emotion-symptom link: in the training priority pattern, parent’s anxiety, anger and frustration made the child stressed and therefore he/she exhibited more symptoms. On the contrary, in the “relationship-precedence” pattern: the child was more relaxed, showed fewer symptoms and made greater progress under the influence of parental relaxation and positive parenting (Zhou & Yi, 2014). Therefore, in a parent training program we have to take into account this kind of results and help parents manage their emotions, not only to pay attention to the child’s performance.

1.3 Parenting stress and resilience

There are many paradigms in family research aimed at capturing the experience of families of children with disabilities and, among them; the most widely investigated topic is that of parenting stress (Pisula & Kossakowska, 2010). Investigations of parenting stress are an important framework in which we can identify key variables that may contribute to the experience of stress. Understanding what contributes to stress will then lead to more targeted interventions to support families and facilitate family functioning (Hayes & Watson, 2013). However, what is really parenting stress? In a simple definition, it is the experience of distress or discomfort that results from demands associated with being a parent (Deater-Deckard, Pickering, Dunn, & Golding, 1998). Having a child with a severe impairment is absolutely a stressful condition, but stress-related alterations may arise for many reasons that are not always directly linked to having a child with a disability. For example, they can derive from personality factors, attitudes, cognitions, psychological characteristics and they mutually influence relationship between stress perception and adaptation.

According to Folkman and Lazarus (Folkman & Lazarus, 1985), stress results from the interaction of an individual (or a family) with the environment. When individuals deem that environmental stressors have overwhelmed their resources, they engage coping mechanisms to restore functioning. However, if the individual's coping mechanisms are either maladaptive or cannot meet the new demands, the outcome is stress (Hayes & Watson, 2013). The effects of stress may include physical and psychological symptoms such as depression, fatigue, restlessness, elevated activity of neural and hormonal pathways or increased risk for ulcers or heart disease (Carpenter & Steffen, 2004). Furthermore, parents of children with ASD have been reported to experience stress levels similar to individuals with Post-Traumatic Stress Disorder (Casey et al., 2012). It is important to notice that stress is an individual way to feel and react to life events and therefore is subjective. In the literature, many studies have compared measures of stress between families with and without children with ASD and have identified higher rates of stress markers in families of children with autism (Pisula & Kossakowska, 2010; Watson et al., 2013), coupled with higher incidence of

depression and anxiety (Eisenhower, Baker, & Blacher, 2005) and less overall well-being (Blacher & McIntyre, 2010). Researchers found that child characteristic and ASD symptoms severity are strongly associated with parenting stress levels. In particular, two diagnostic traits such as impairment in social communication (Davis & Carter, 2008) and restricted or repetitive behaviors (Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005) are reported as particularly stressful.

We should investigate how parents react to stressful events, because stress placed on families often contributes to exacerbate difficulties in children with ASD, supporting the idea that “children with autism...likely respond to their family environment in addition to acting upon it” (J. K. Baker, Fenning, & Crnic, 2011)². In line with this, there has been some evidence that parental stress and parenting self-efficacy influence the functional improvement of children. For example, Brinker and colleagues (Brinker, Seifer, & Sameroff, 1994) found that parental stress can predict the developmental level of children with intellectual disabilities, with a strong relationship between mother-reported stress and children’s progress in learning. In addition, it has been found that parental stress influences the effectiveness of early intervention in children with ASD (Osborne, McHugh, Saunders, & Reed, 2008).

Many studies have evaluated the negative consequences of caring for people with developmental disabilities. On the contrary, the ability to bounce back from the stress derived from care situations is far less studied. Preliminary evidence indicates that some caregivers show an ability to cope effectively with the stress of a care situation and are described as resilient (Bekhet, Johnson, & Zauszniewski, 2012). In addition, parents of children with ASD who possess indicators of resilience are better able to manage stress associated to growing up a child with a disease like autism (Bekhet et al., 2012).

Luthar and colleagues (Luthar, Cicchetti, & Becker, 2000) defined resilience as “*a dynamic process encompassing positive adaptation within the context of significant adversity*” (pp. 543). According to the resilience theory, a subject’s resilience is defined by balancing risk and protective factors.

² p. 605

Risk factors predispose people to physical and mental health problems because they affect the way a person adapts to stress (Smith-Osborne, 2008). Risk factors for caregivers with ASD include symptom severity, marital quality, parents' anger and number of children with ASD. Two American studies have identified parent's anger as a factor that affected their emotional well-being (Benson & Karlof, 2009; Carter et al., 2009). The first study, conducted with 84 mothers and 6 fathers of children with ASD aged 3-7 years old, found that anger was related to symptoms severity, stress proliferation and parental depression (Benson & Karlof, 2009). The second study found a positive relationship between parental anger/hostile mood and depression severity in 143 mothers of toddlers with ASD (Carter et al., 2009). Protective factors in family members of children with autism include social support, age of the child, time since diagnosis, locus of control, cognitive appraisal and religious beliefs and spirituality (Bekhet et al., 2012). Social support, furthermore, buffered the effects of stress on parents' well-being if those providing the social support were perceived as competent (Sharpley, 1997). With respect to time since diagnosis, parents with older children reported less burden (they probably have more time for adaptation), which is positively correlated with maternal self-efficacy in 170 mothers of children with ASD (Kuhn & Carter, 2006). Acceptance is also one of the coping style patterns that helps parents be more resilient over time (Luong, Yoder, & Canham, 2009).

A few studies have examined the role of optimism and positive attitude in family members of persons with ASD. Ekas and colleagues (Ekas et al., 2010) found that optimism mediated the association between the quality of the mother's relationship to her child with ASD and her psychological/physical well-being (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Optimism is an important protective factor for resilience, but also for anxiety levels. In fact, optimism is a general tendency to get positive outcomes, and people who have higher levels of optimism and hope have fewer psychological problems, and therefore experience less anxiety. Overall, optimism is associated with better psychological and physical health outcomes. Having a positive attitude and positive emotions, as coping strategy, enable people to actively pursue their goals, even when

they are in a difficult, anxious and stressful mood (Zenger, Brix, Borowski, Stolzenburg, & Hinz, 2010).

Given the increasing prevalence of ASD (Rice, 2009) and its impact on the family, it is important to pay more attention to this vulnerable population, especially when therapists implement parent training programs. In fact, although individuals have less control over risk factors, such as symptoms severity, it is possible to strengthen their protective factors, for example by increasing positive cognition and positive emotion expression. This will result in greater resilience among caregivers of people with ASD that, in turn, will affect the care recipient. Managing parenting stress and enhancing their psychological well-being, at the end, has also a deep impact on the child' behaviors, disrupting the vicious cycle in which symptoms severity increases maternal depression and anxiety which, in turn, affect intervention efficacy.

1.4 Empathy and emotion recognition in parents of children with Autism Spectrum Disorder

A successful interaction requires the ability to understand others mental states in order to explain and predict their behavior (Attwood, Frith, & Hermelin, 1988). Representing the contents of one's own and other people's mind is so called Theory of Mind (ToM) and autism is characterized by a difficulty in this domain (Baron-Cohen, 1989). Empathy extends the ToM hypothesis by not only focusing on the attribution of another person's mental state, but also on the ability to respond to another's mental state with an appropriate emotion (Baron-Cohen, 2002). Empathy is a lens through which we can understand others' emotion and respond to them, including a cognitive component (identifying others' beliefs, intentions and thoughts etc...) and an affective component (responding to others' emotions in an appropriate emotional way) (Baron-Cohen & Wheelwright, 2004). In particular, the Empathising-Systemizing (E-S) Theory expands the concept of ToM comprising this affective component of empathy: this theory argues that the social and communication difficulties seen in autism can be accounted for by an empathy impairment

(including both cognitive and affective components) and the repetitive behaviors and narrow interests by an inclination for systemizing (the drive to understand and derive rules about a system), (Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009). A study of Sucksmith and colleagues (Sucksmith, Allison, Baron-Cohen, Chakrabarti, & Hoekstra, 2013) has explored self-reported empathy in parents of children with ASD. In fact, in these years first-degree relatives of individuals with ASD have been the subject of many studies to better clarifying the so called Broader Autism Phenotype (BAP) that is milder but qualitatively similar to the diagnosed autism phenotype. The BAP refers to heritable, sub-threshold autism-related traits and may be related to different genetic loading in families with autism (Hasegawa et al., 2015). In the study mentioned above, fathers but not mothers of children with ASD self-reported lower empathy than controls on the Empathy Quotient (a self-report measure of empathy). This suggests that lower self-reported empathy may be a reliable feature of the BAP in fathers only and some previous studies seem to confirm these results (Constantino et al., 2006; De la Marche et al., 2012). In a previous study, instead, Baron-Cohen and Hammer (Baron-Cohen & Hammer, 1997) found that both mothers and fathers of children with ASD showed deficits in emotion recognition ability, the test employed was "Reading the Mind in the Eyes" a tool that requires emotion recognition from just the eye region of the face and involves emotions beyond the basic ones. It should be taken into account that in the study of Sucksmith and colleagues (Sucksmith et al., 2013), parents of children with ASD were not significantly poorer than controls at identifying the six basic facial expressions of emotion. These discrepant findings may be explained by the fact that mild difficulties in basic emotion recognition performance could be compensated in parents of children with ASD, for instance, through differences at neurophysiological level (for example, by a reduced neural response to happy but not fear faces in some cortical areas as fusiform face area and superior temporal sulcus, despite non significant differences in performance on the facial emotion recognition task) (Spencer et al., 2011). However, understanding what occurs in such example of compensation should be further investigated.

Despite the growing interest for the presence of the BAP in relatives of individuals with ASD, there is no agreement on the definition of the traits/constructs that make up the BAP, recently one of the dimensions investigated is alexithymia. Alexithymia, (derived from the Greek language: a=lack, lexis=word, thymos=emotions) which literally means “having no words for emotions”, is not a diagnosis, but a construct useful to indicate individuals who have difficulty to understand the emotional feelings they experience, or to describe these feelings to others. Alexithymia is a personality trait that is associated with an increased risk of psychopathology (Franz et al., 2008; Szatmari et al., 2008). Given the recent findings about association between alexithymia and ASD (Hill, Berthoz, & Frith, 2004; Tani et al., 2004), some researchers (Szatmari et al., 2008) have hypothesized that parents of children with ASD could demonstrate more difficulties in emotion processing when compared to a control group. They assessed alexithymia by using the Toronto Alexithymia Scale (TAS-20), a reliable and valid self-report measure of emotion processing in adults, and ASD parents scored significantly higher (i.e. demonstrated greater alexithymia) than controls on the total score. These results are confirmed by Berthoz, Lalanne, Crane and Hill (Berthoz, Lalanne, Crane, & Hill, 2013), in fact, they found, in a sample of 87 parents of ASD individuals, a significantly greater percentage of parents were classed as alexithymic (TAS-20 criteria) than controls. However, we believe that these results should be interpreted with caution, in the light of certain considerations: (i) TAS-20 is a self-report measure and it could be reasonable to argue that individuals who recognize they have difficulty identifying feelings are able to do this better than those who have similar impairments but lack the insight that they do so; (ii) alexithymia is strictly associated with reduced empathy (Feldmanhall, Dalglish, & Mobbs, 2013) and (iii) it would be particularly relevant to investigate whether alexithymia and empathy can account for poor social exchanges in autistic individuals and if and to what extent these two constructs are related in a sample of parents of children with ASD, in order to better investigate the BAP characteristics.

1.5 Stress Physiology

Chronic stress has potential to cause health problems. Psychological stressors typically relate to social role and context (e.g., social expectations regarding parenting responsibilities), and these psychological stressors can activate the same physiological stress-response that is triggered in response to physical crises (Sapolsky, 2004). In order to maintain optimal bodily functioning, a process known as *homeostasis* regulates internal stability in response to environmental changes (Lovallo, 2005). Attempts to maintain homeostasis long-term in the face of chronic psychological stress can produce wear and tear, damaging the body. Chronic activation of the stress-response can increase, for instance, the risk of developing fatigue, hypertension (i.e., high blood pressure; BP), cardiovascular disease, peptic ulcers, cognitive decline, and damage to immune function (Sapolsky, 2004). However, physiological measures may not always correlate well with self-reported stress, and individuals who report the highest levels of stress are not necessarily those demonstrating the greatest negative outcomes (Romanczyk & Gillis, 2004). Relatively few studies, in fact, have investigated the effects of chronic stress in parents of children with ASD employing both physiological measures and psychological ones. Such studies could contribute to better understand the impact of parenting stress on health.

1.5.1 The Hypothalamus–Pituitary–Adrenal axis

The hypothalamus–pituitary–adrenal (HPA) axis is a central control and regulatory system of the organism that connects the central nervous system (CNS) with the endocrine system. This stress-responsive neuroendocrine system helps the organism adapt to increased demands and maintain homeostasis after challenge but is also vital for supporting normal physiological functioning. The end product, cortisol, has a wide range of physiological effects in the body; virtually all of the body's single nucleated cells are potential targets for cortisol. Cortisol plays a critical role in metabolism by mobilizing resources to provide energy. This helps to overcome the increased metabolic demand presented by a host of challenges. It also regulates or impacts on other important physiological systems, like the immune system, the sympathetic-adrenal-medullary (SAM) axis, the cardiovascular system, as well as affective and cognitive processes.

Under stress, the hypothalamus secretes corticotropin-releasing hormone (CRH), and this provokes the release of adrenocorticotrophic hormone (ACTH) from the pituitary. ACTH triggers the secretion of glucocorticoids from the adrenal cortex. In humans, the main glucocorticoid is cortisol. Cortisol is predominantly (90–95%) bound to binding proteins in blood, only 5–10% of the total plasma cortisol circulates as biologically active, unbound, “free” cortisol. Overall functioning is controlled by several negative feedback loops (Dallman, Akana, Bhatnagar, Bell, & Strack, 2000; Tsigos & Chrousos, 2002).

A dysfunctional HPA axis is associated with manifestations of psychosomatic and psychiatric disorders (Chrousos & Gold, 1992; Heim, Ehlert, & Hellhammer, 2000; Raison & Miller, 2003). For example, HPA axis hyperactivity is often found in major depression (Bjorntorp, 1996) and also seems to be associated with susceptibility to infectious diseases (Mason, 1991) and cardiovascular problems (McEwen, 1998). Hyporeactivity of the HPA axis system is associated with autoimmune processes such as lupus erythematosus (Weiner, 1991), neurodermatitis (Buske-Kirschbaum et al., 1997) or fibromyalgia, chronic fatigue syndrome, and rheumatoid arthritis (Tsigos & Chrousos, 2002). It is generally accepted that exposure to stress can foster the onset and/or progression of numerous diseases. It has been suggested that HPA axis functioning might serve as an indicator of allostatic load, an index of cumulative toll on the body. A high allostatic load might result from chronic overactivation of the stress response (McEwen, 1998), and result in a number of negative health outcomes in the long run, such as diabetes, hypertension, cancer, and cardiovascular disease (Kudielka & Kirschbaum, 2005).

1.5.2 Salivary cortisol

The HPA axis is a major homeostatic system and is activated in response to stress. Typically, basal HPA activity displays a robust diurnal pattern; levels of cortisol rise between waking and 30-40 minutes post waking (cortisol awakening response, CAR), decline across the day (diurnal cortisol slope) and reach a trough at around midnight (Pike et al., 1997). The endpoint of HPA axis activation in humans is the release of the glucocorticoid cortisol from the adrenal glands into the blood to exert multiple metabolic effects (Jacobson, 2005). Integrity of the HPA axis is essential to

life, and compromised performance through inappropriately low (e.g. Addison's disease) or high (e.g. Cushing's syndrome, chronic stress) production of cortisol can be life-threatening. A robust increase in cortisol secretion is necessary to determine appropriate behavioural reactions in response to the acute stress of psychological or physical threat, and resetting of the HPA axis with increased cortisol secretion is an important adaptive response influencing the onset, development and severity of inflammatory disease. Measurement of salivary cortisol has provided a great deal of experimental information on the activity of the HPA axis in health and disease and on the involvement of cortisol in the mechanisms determining our reactivity and adaptation to environmental changes. Salivary sampling is a well-established technique for cortisol measurement in adults (Al-Ansari, Perry, Smith, & Landon, 1982) and children (Woolston, Gianfredi, Gertner, Paugus, & Mason, 1983). Importantly, a strong positive correlation between salivary and blood cortisol levels has been reported (Bober et al., 1988; Porter, Gallagher, & O'Brien, 2007). A relatively non-invasive technique, salivary sampling has the dual advantage over blood sampling of (i) permitting cortisol to be measured without contamination of results by needle stress, and (ii) extending investigation beyond experimental laboratory studies through the ease of home sampling. These advantages may further serve to increase participation rates in studies from those who might be reluctant to provide blood samples, a particularly relevant issue in the study of children. Ethical issues are also substantially reduced by sampling saliva rather than blood (Jessop & Turner-Cobb, 2008).

In the literature, findings on cortisol levels in parents of autistic children are inconsistent. For example, in a cross sectional sample of young and middle aged caregivers of children with ASD and attention deficit hyperactivity disorder (ADHD) (n=56), compared against parents of typically developing children (n=22), diurnal patterns of cortisol secretion did not differentiate between the groups (Lovell, Moss, & Wetherell, 2012). Caregivers, however, scored markedly higher on all measures of psychological stress. According to other findings (Miller et al., 2008; Rohleder & Nater, 2009) caregivers have demonstrated increased psychological distress, but failed to observe disparities in cortisol secretion patterns. As one possible explanation, the HPA rebound effect

stipulates that, over time, persistent elevation of cortisol can, as a function of increased feedback sensitivity or pituitary corticotrophin (CRH) receptor down regulation, cause HPA output to rebound to normal and, with time, below normal levels (Gunnar & Vazquez, 2001). In addition, meta-analyses have demonstrated an inverse relationship between time since stressor onset and HPA activity (Miller, Chen, & Zhou, 2007). According to this information about time since stressor onset, De Andrès-García and colleagues (de Andres-Garcia, Sarinana-Gonzalez, Romero-Martinez, Moya-Albiol, & Gonzalez-Bono, 2013) reported a difference in stress response between caregivers of ASD children and those of ASD adolescents and adults. The age of patients may modulate the cortisol response of caregivers to stress: in fact, caregivers of older offspring had lower cortisol levels than caregivers of younger care recipients. This result can be explained by the fact that a persistent and chronic stress exposure had caused a persistent dysregulation of the system that no longer works as it should and responds to a lesser extent to environmental stress, in this case, the lower cortisol values would be an index of a chronic dysregulation of the whole system. Therefore, the caregivers of adolescent or adult patients do not react physiologically to challenges that are present in their daily lives. In another study (Foody, James, & Leader, 2015), parents of children with ASD (19 mother-father dyads) had lower than average post awakening levels of cortisol (Wust et al., 2000). Wong et al. (Wong, Mailick, Greenberg, Hong, & Coe, 2014) provided the same result: in their study, mothers of children with autism had lower awakening cortisol levels than comparison mothers. These results, again, provide an evidence of a dysregulation of the HPA-axis. Findings from Dykens and Lambert's study (Dykens & Lambert, 2013) reported two distinctive daily cortisol trajectories in a sample of 91 mothers of children with ASD and other disabilities (ASD, n=30; Down syndrome, n=11; Prader-Willy syndrome, n=25 and Williams syndrome, n=25): blunted (63%) or steep (37%), the majority of mothers of children with ASD (89%) were assigned to blunted type. The "blunted" group include lower mean cortisol values, higher stress levels and lower health ratings than their counterparts, and a markedly blunted pattern of cortisol values throughout the day. The second trajectory ("steep") had higher cortisol values and steeper cortisol changes. This atypical cortisol awakening response and evening rise were differentially associated with anxiety, depression and health problems. Maternal dysregulation of evening cortisol may be

associated with a build-up of stress throughout the day, or with specific challenges of evening dinner or bedtime routine. Methodological differences such as the nature of the stressor investigated and the procedure in the estimation of the cortisol response may be relevant for the interpretation of results and the extraction of conclusions. It would be important to clarify the actual role of psychological variables and their interactions on cortisol response in order to better understand caregiving stress.

1.5.3 Cardiovascular response in caregivers of children with ASD

Coping with multiple challenges associated with raising a child with ASD could represent a threat to homeostasis in the caregivers. Alterations in homeostasis are mediated by impaired allostasis, defined as a set of processes that allow organisms to maintain homeostasis while adapting to the demands of the environment. The purpose of these adjustments, is to keep some crucial parameters (pH, temperature, oxygen tension) in a state of homeostasis. But, when the stressor becomes chronic these adjustments increase in quantity and intensity and may lead the body to overload which if allowed to continue can have serious health consequences (McEwen, 2007). The major system involved in the process of allostasis is the autonomic nervous system (ANS) whose (re)activity is reliably obtained by measuring heart rate and blood pressure variability (HRV, BPV). In the general population sympathetic activity is increased during a stress episode, with marked vagal withdrawal (Delaney & Brodie, 2000). In people under chronic stress results are inconsistent: some studies found an increased sympathetic activity during a stressor, while others reported blunted sympathetic reactivity (Gump, Matthews, & Raikkonen, 1999). For example, subjects with a diagnosis of Post-Traumatic Stress Disorder showed higher sympathetic activity during laboratory stress than controls (Keary, Hughes, & Palmieri, 2009). It can be hypothesized that caring for a child with ASD alters the activity of the ANS and thereby modulates the stress response and health of caregivers. In a sample of parents with ASD, Ruiz-Robledillo and Moya-Albiol (Ruiz-Robledillo & Moya-Albiol, 2015), found a positive relationship between sympathetic activation to an experimentally-induced acute stressor and the number of self-reported somatic symptoms. In another study of Ruiz-Robledillo, Bellosta-Batalla and Moya-Albiol (Ruiz-Robledillo, Bellosta-

Batalla, & Moya-Albiol, 2015), caregivers had lower sympathetic reactivity to acute stress in the laboratory than non-caregivers and this lower response was particularly evident during the stressors (e.g. arithmetic tasks). This result shows an alteration in the functioning of the ANS that could be due to the effects of chronic stress exposure. According to Inoculation Theory (and Stress Inoculation Therapy)³ (Meichenbaum & Novaco, 1985), we should consider that chronic stress exposure would result in cardiovascular adaptation to stress and this would provide a reasonable explanation of the blunted sympathetic reactivity to acute stress observed in caregivers (Carroll, Phillips, Ring, Der, & Hunt, 2005). In any case, higher cardiovascular responsivity may lead individuals, including caregivers, to develop more somatic symptoms, while a blunted cardiovascular response could also have negative consequences for health, as a result of the loss of the physiological ability to cope with stress. The lack of consistency in the results, i.e. the fact that negative effects of chronic stress have been related to both higher and blunted cardiovascular reactivity could be due to the type of stressor and other psychological and contextual variables of participants that require further investigation.

³ Stress Inoculation Therapy (SIT) is a psychotherapy method intended to help patients prepare themselves in advance to handle stressful events successfully and with a minimum of upset. The use of the term "inoculation" in SIT is based on the idea that a therapist is inoculating or preparing patients to become resistant to the effects of stressors in a manner similar to how a vaccination works to make patients resistant to the effects of particular diseases (Meichenbaum & Novaco, 1985).

CHAPTER 2

Stress management in mothers of children with Autism Spectrum Disorder: psychological characteristics, coping strategies and biological correlates

Aim of the Present Study

In this study, we address three research questions. Firstly, we investigate in mothers of children with ASD the impact of caregiving on (i) parent-reported stress, anxiety, personality factors, perception of the child, coping strategies, empathy and alexithymia, and (ii) physiological reactivity to a laboratory stressor. Secondly, we evaluate how psychometric variables are related to one another. Thirdly, we explore possible associations between individual psychological characteristics and physiological measurements at rest and in response to a laboratory stressor. With respect to the psychological assessment, we expect to find higher levels of parenting stress and anxiety in the group of parents of children with ASD versus controls and a difference in personality traits, in particular as far as the emotional expressiveness is concerned.

METHODS

PARTICIPANTS

Recruitment methods:

"Controls" subjects (parents of typically developing children) were recruited from kindergartens and primary schools of the region through an awareness campaign carried out by mail to the parents' representatives, with the cooperation of the principals of some public schools. Later, parents were invited to a meeting in which we discussed the main topics of the study and the type

of collaboration required. Participants received a sociodemographic checklist in which they were asked for information needed to establish their possible inclusion in the sample.

"Case" subjects (parents of children with ASD) were recruited from the Center for Care, Diagnosis and Study of Communication and Socialization Disorders (Local Health Authority, Parma) and from the Children Autism Foundation in Fidenza (Pr). Parents were informed by telephone of the opportunity to participate. In collaboration with the Head of the Centre and the Foundation, we conducted an informative meeting with parents that agreed on participating. Similarly to control subjects, they were asked to fill out a socio-demographic checklist to evaluate their possible inclusion in the sample.

INCLUSION CRITERIA

Controls (parents typically developing children):

Being a parent of a 3 to 11 years-old child

Age between 30 and 50 years-old

Does not have children with chronic conditions or disabilities

Does not have partners with chronic conditions or disabilities

Does not suffer from chronic diseases or disabilities

Has not suffered in the last year from particularly stressful events such as deaths, serious accidents, dismissal or divorce.

Has not have cared in the last year for a family member (e.g., a parent) with a serious illness.

Does not use drugs

Cases (parents of children with ASD)

Being a parent of a 3 to 11 years old child with Autism Spectrum Disorder according to DSM-IV TR criteria. The boy/girl must have been diagnosed at an accredited center, after the administration

of the ADOS (Autism Diagnostic Observation Schedule) (Rutter, di Lavore, & Risi, 2002) and ADI-R (Autism Diagnostic Interview-Revised) (Rutter, Le Couteur, Lord, & Faggioli, 2005); tests which are indicated by the guidelines as essential tools for the diagnosis of autism (Levi et al., 2005).

Does not have other children with disabilities or chronic diseases

Does not have a partner with disabilities or chronic diseases

Has not suffered in the last year from particularly stressful events such as deaths, serious accidents, dismissal or divorce.

Age from 30 to 50 years-old

Living with the child with ASD.

Subjects who failed to meet these prerequisites were excluded from the study.

SAMPLE

We recruited:

1. 9 mothers of children (3-11 years-old) diagnosed with autism spectrum disorder
2. 14 mothers of typically developing children (3-11 years-old)

The demographic data of mothers are shown in Table 3.

Table 3. Mean, Standard Deviation and percentage of the demographic information relative to mothers of children with ASD (n=9) and mothers of typical development children (n=14)

	MCASD	MCTD
	Mean (Std.Dev.)	Mean (Std. Dev.)
Mothers' Age	39,22 (1,56)	38 (3,08)
Child's age	5,23 (0,70)	5,71 (0,72)
Smokers	50%	30%

Mothers' employment (% employed full-time)	0%	70%
Body Mass Index (kg/m ²)	27,53 (1,82)	25,68 (1,72)

Level of Education:

High School	70%	40%
University	30%	60%

MCASD=Mothers of Children with Autism Spectrum Disorder

MCTD= Mothers of Children Typical Development

INSTRUMENTS

Below we listed the measures we used for psychological assessment followed by those for the psychophysiological assessment.

PSYCHOMETRIC MEASURES

Parenting Stress Index-Short Form (PSI-SF)

The PSI-SF is a 36-item, self-report instrument that measures stress related to the role of parenting (Abidin, 1990). It contains statements related to parenting such as “I feel trapped by my responsibilities as a parent”. Individuals rate their level of agreement with each statement on a 5-point Likert scale from 1 (strongly agree) to 5 (strongly disagree). It yields an overall parenting stress score from three different subscales: parental distress (PD), parent–child dysfunctional interaction (PCDI), and difficult child (DC). However, because an item analysis has identified that PD is the only valid subscale for parents of children with ASD (Zaidman-Zait et al., 2010), only the PD subscale was included in the present study. PD examines the extent to which the parent experiences stress in his/her role as a parent.

State-Trait Anxiety Inventory (STAI)

The State-Trait Anxiety Inventory (STAI) is a commonly used measure of trait and state anxiety (Spielberger & Gorsuch, 1983). It can be used in clinical settings to diagnose anxiety and to distinguish it from depressive syndromes. It is also often used in research as an indicator of caregiver distress. Form Y, its most popular version, has 20 items for assessing trait anxiety and 20 for state anxiety. State anxiety items include: "I am tense; I am worried" and "I feel calm; I feel secure." Trait anxiety items include: "I worry too much over something that really doesn't matter" and "I am content; I am a steady person." All items are rated on a 4-point scale (e.g., from "Almost Never" to "Almost Always"). Higher scores indicate greater anxiety. The STAI is appropriate for those who have at least a sixth-grade reading level.

Internal consistency coefficients for the scale have ranged from .86 to .95; test-retest reliability coefficients have ranged from .65 to .75 over a 2-month interval (Spielberger & Gorsuch, 1983). Studies also have shown that it is a sensitive predictor of caregiver distress over time, and that it can vary with changes in support systems, health, and other individual characteristics (Elliott, Shewchuk, & Richards, 2001; Shewchuk, Richards, & Elliott, 1998).

Coping Orientation to Problems Experienced (COPE-NVI) (Elliott et al., 2001; Shewchuk et al., 1998)

To assess coping strategies, we administered the new Italian Version of the Coping Orientation to Problems Experienced (COPE-NVI), (Sica et al., 2008). It is a 60-item, self-report instrument that evaluates four independent dimensions of coping: social support; avoidance strategies; positive attitude; task-oriented and transcendental orientation. All items are rated on a 4-point scale: 1 = I usually don't do this at all; 2 = I usually do this a little bit; 3 = I usually do this a medium amount; 4 = I usually do this a lot

Subscales:

-Avoidance strategies (very heterogeneous scale, which includes the use of denial, substance use, behavioral and mental detachment).

- Positive attitude (attitude of acceptance, containment and reinterpretation of negative events).
- Orientation to the problem (use of active strategies and planning).
- Social support (search for understanding, information and emotional outburst).
- Orientation transcendent (the items refer to religion and the absence of humor).

Empathy Quotient (EQ)

The Empathy Quotient (EQ) is a self-report measure of empathy (Baron-Cohen & Wheelwright, 2004). This is a 40-item, self-report instrument. Full endorsement of all items gives a score of 80, with higher scores which are indicative of a better capacity to empathise. All items are rated on a Likert response scale with four response options: 'strongly agree', 'strongly disagree', 'slightly agree' and 'slightly disagree'.

Ten Item Personality Measure (TIPI)

The TIPI is a 10-item measure of the Big Five (or Five-Factor Model) dimensions (Gosling, Rentfrow, & Swann, 2003). To meet the need for a very brief measure, the Ten Item Personality Measure (TIPI) was developed. A 10-item measure of the Big Five dimensions is offered for situations when very short measures are needed, personality is not the primary topic of interest, or researchers can tolerate the somewhat diminished psychometric properties associated with very brief measures.

Toronto Alexithymia Scale (TAS-20)

The TAS is a 20-item instrument that is one of the most commonly used measures of alexithymia (Bagby, Parker, & Taylor, 1994). Alexithymia refers to people who have trouble identifying and describing emotions and who tend to minimise emotional experience and focus attention externally.

The TAS-20 has 3 subscales:

- Difficulty Describing Feelings subscale is used to measure difficulty describing emotions. 5 items – 2, 4, 7, 12, 17.
- Difficulty Identifying Feeling subscale is used to measure difficulty identifying emotions. 7 items – 1, 3, 6, 11, 9, 13, 14.
- Externally-Oriented Thinking subscale is used to measure the tendency of individuals to focus their attention externally. 8 items – 5, 8, 10, 15, 16, 18, 19, 20. Scoring: Items are rated using a 5-point Likert scale whereby 1 = strongly disagree and 5 = strongly agree. There are 5 items that are negatively keyed (items 4, 5, 10, 18 and 19). The total alexithymia score is the sum of the responses to all 20 items, while the score for each subscale factor is the sum of the responses to that subscale. The TAS-20 uses cut-off scoring: equal to or less than 51 = non-alexithymia, equal to or greater than 61 = alexithymia. Scores of 52 to 60 = possible alexithymia.

Italian Questionnaires on Temperament (Questionari Italiani del Temperamento, QUIT)

The Italian Questionnaires on Temperament (QUIT) are a battery of instruments that measure the temperament of the child, from the first month after birth to eleven years of age (Axia, 2002). The QUIT investigates six temperamental dimensions: social orientation (pleasure in social situations and interactions with others), inhibition to novelty (emotional reaction to novelty experience), the level of motor activity (gross motor activity, speed reaction to environment experience), positive emotionality (intensity of positive emotional reactivity and expression), negative emotionality (intensity of negative emotional reactivity and expression) and attentional capacity (ability to focus attention and to shift attention from one focus to another). These dimensions have been created from the international research on temperament and have proven particularly suited to the Italian context. The scale ranges from "almost always" to "almost never", on a 6-point scale. Each questionnaire has a sheet of encoding that allows the calculation of the value reached by the individual child in every dimension.

Type D Personality Test (DS 14)

In recent years the type-D construct has been established as a predictor of adverse clinical events and cardiac prognosis in patients after an acute coronary syndrome or revascularization, and in patients with chronic heart failure (Denollet, Pedersen, Vrints, & Conraads, 2006; Denollet et al., 1996). Type D stands as an acronym for the distressed personality, which was first formulated and introduced by Johan Denollet in 1995 (Denollet, Sys, & Brutsaert, 1995). The type-D pattern is defined by high levels of negative affectivity and high levels of social inhibition. The DS14 consists of two 7-item subscales: negative affectivity (e.g., “I am often irritated”) and social inhibition (e.g., “I find it hard to start a conversation”) (Denollet, 2005). Previous validation studies have demonstrated high correlations between the subscale NA and other constructs of negative affectivity and neuroticism, and between the subscale SI and low extraversion and shyness (Barnett, Ledoux, Garcini, & Baker, 2009; Denollet, 2005; Grande et al., 2004; Pedersen et al., 2009). Participants are instructed, “Please give a statement about how you feel generally”, and each item is rated on a 5-point Likert-type scale ranging from 0 to 4. The anchors are false, rather false, neutral, rather true, and true. Subjects scoring above the cut-off score of 10 on both the subscale negative affectivity (NA) and social inhibition (SI) are categorized as type D.

PSYCHOPHYSIOLOGICAL ASSESSMENT

Psychosocial Stress Test

The psychosocial stress test, adapted from the Trier Social Stress Test (Frisch, Hausser, & Mojzisch, 2015) (Fig.1), consists of a brief interview lasting 5 minutes, followed by an arithmetic task of the same duration; during both phases, the subject seats in front of an interviewer and in the presence of a small audience. The TSST is a stress protocol used to induce a state of moderate psychosocial stress in healthy subjects and in clinical populations, in order to study its physiological correlates. It is a paradigm that combines an uncontrollable factor with social-evaluative threat (social component of psychological stress in which performance could be judged

negatively by others). The TSST usually consists in a simulated job interview. The TSST has been found to reliably activate the hypothalamic–pituitary–adrenal (HPA) axis and trigger a two- to three-fold release of cortisol (compared to non-stress control conditions) in about 70–80% of participants (Dickerson, Gruenewald, & Kemeny, 2004; Kudielka, Bellingrath, & Hellhammer, 2007). Moreover, various other indicators confirm the stress-inducing potential of the TSST. The activity of the sympathetic–adrenal–medullary (SAM) axis—the other main stress axis besides the HPA axis—can be assessed by changes in cardiovascular parameters (Kirschbaum, Pirke, & Hellhammer, 1993) or in salivary alpha amylase (Rohleder & Nater, 2009). Additionally the TSST has also been shown to affect immunological parameters (e.g., interleukins, see (von Kanel, Kudielka, Preckel, Hanebuth, & Fischer, 2006)) and leads to high levels of self-reported stress and anxiety (Hellhammer & Schubert, 2012).

In the modified version adopted in this study, the subject is required to answer a series of questions about its personality in a social context. The stress interview is followed by a phase of five minutes of arithmetic task. In this phase, the subject is asked to count backward from 2083 in units of 13. Every time the subject fails, it is asked to start over. In the 90 minutes prior to testing in the laboratory, the subject does not have to practice excessive exercise nor eat, drink only water and pay attention to hour of awakening. Through the experimental session, ECG recordings are performed to investigate cardiac autonomic activity and saliva samples are collected to assess cortisol levels (Fig. 1).



Fig. 1. Example of a laboratory setup during the Trier Social Stress Test

In the present study, saliva samples were collected from under the front of the tongue using Salimetrics Oral Swabs (SOS; Salimetrics Europe, Suffolk, UK). Participants were advised not to schedule data collection for at least 2 days after any dental work and to avoid alcohol consumption for 24h before collecting saliva, tooth-brushing, smoking, eating, drinking and exercising in the 60 minutes before collecting saliva samples. Besides these restrictions, subjects were otherwise free to follow their normal daily routines on the sampling day. They were instructed to open the plastic container and remove a single cotton roll at each designated sampling time. Subjects were told that the swabs had to remain in the container until usage to ensure valid hormone analysis in the laboratory. After saliva collection, each wet swab was stored in a plastic Salivette tube labeled with the designated sampling time by the experimenter. Subjects were instructed to collect eight saliva samples throughout 2 day before coming to the laboratory for the Stress Test (immediately after awakening, 30 minutes after awakening, at lunch time (12am) and before sleeping). Saliva were retrieved from participants, and stored frozen at -20°C until they were assayed for cortisol. The eight morning saliva samples were assayed in duplicate for salivary cortisol by enzyme immunoassay using the Salimetrics salivary cortisol assay kits (SOS; Salimetrics Europe, Suffolk, UK). The test requires 25µL of saliva, and it has a range of sensibility from .003 to 3.0 µg/dL. Samples were excluded if there was not enough saliva in the sample to perform the assay. Cortisol samples were also collected before, during and after the session in the laboratory (see Fig. 4).

Cardiac autonomic function and heart rate variability analysis

Several human studies provide clear and convincing evidence that chronic life stress contributes significantly to the pathogenesis and progression of cardiac disorders (Albus, 2010). Putative underlying mechanisms may include a disruption of the sympatho-vagal balance, through an increase in sympathetic activity and/or a decrease in vagal tone. Therefore, measuring cardiac autonomic activity in parents of children with ASD is of fundamental importance for a better understanding of the impact of parenting stress on cardiac autonomic function.

In this study, heart rate variability analysis is performed on ECG signals in order to obtain information about sympathetic and parasympathetic influences on cardiac activity. ECG signals are recorded by the BT16 Plus system (F. Marazza Hardware & Software, Monza, Italy) with a bipolar derivation. Respiratory activity is also recorded via this system by means of a piezoelectric waist. ECG signals are amplified, digitally converted and transmitted to a laptop using Bluetooth technology. ECG analysis is carried out off line by means of Chart 5.0 software (AD Instrument, Australia, Sydney).

Normal heart rate is characterized by beat-to-beat variability over a wide range which are described and quantified by the analysis of heart rate variability (HRV). A high variability in heart rate is considered as a sign of a good adaptability, whereas lower variability is often a marker of abnormal and insufficient adaptability of the autonomic nervous system, implying the probable presence of a psychological malfunction (Pumprla, Howorka, Groves, Chester, & Nolan, 2002). The principle mechanism that determines heart rate variations is the autonomic nervous system (ANS). Therefore, HRV analysis provides, in a non-invasive way, information about cardiac autonomic modulation (Cardiology, 1996). In normal conditions, the two branches of the ANS are in dynamic balance. However, the activity of the sympathetic and parasympathetic components can be rapidly modulated in response to changes in the environmental demands. When these modifications lead to a static imbalance, the organism become vulnerable to pathology. Actually, the autonomic imbalance, in which one branch of the ANS predominates over the other, is associated with a lack of dynamic flexibility and health (Thayer, 2009). Many evidences suggest that the autonomic imbalance, in which typically the sympathetic system is hyperactive and the parasympathetic system is hypoactive, is associated with different pathological conditions (Thayer & Sternberg, 2009). Since the sympathetic system is associated with energy mobilization, the condition in which this branch predominates is characterized by excessive energy demands that ultimately cannot be met. Therefore, autonomic imbalance may increase morbidity and mortality in many conditions and diseases. Normally, the heart is under tonic inhibitory control by parasympathetic activity. As the parasympathetic system is associated with vegetative and

restorative functions, resting cardiac autonomic balance favors energy conservation. In addition, heart rate is characterized by beat-to-beat variability over a wide range, which is principally due to vagal influence. Therefore, autonomic imbalance in which the activity of the sympathetic branch predominates, is associated with a reduction in HRV. Low HRV has been shown to be associated with increased risk of all-cause mortality. Thus, changes in the HRV pattern offers an early and sensitive indicator of compromised health (Decker et al., 2010).

Analysis of HRV was first used in clinical practice almost 50 years ago. The first application of HRV dates back to 1965 when Hon and Lee (Hon & Lee, 1965) noted that the reduction of HRV preceded fetal distress, in particular hypoxia, before any appreciable change occurred in heart rate itself. Then, in the late 1970s the reduction of HRV was first correlated with increased mortality and arrhythmic events in survivors of myocardial infarction (Wolf, Varigos, Hunt, & Sloman, 1978). The clinical importance of HRV became appreciated in the late 1980s, when it was confirmed that HRV was a strong and independent predictor of mortality after an acute myocardial infarction (Kleiger, Miller, Bigger, & Moss, 1987). More recently, HRV analysis has been increasingly used to assess autonomic dysfunction in different pathological conditions. The first step for the analysis of HRV is obtaining high quality ECG under stationary conditions. The ECG signals are analogue/digital converted for computer processing and, in order to have a good time resolution, a sampling rate of at least 250 Hz for human ECG signals is recommended. Heart rate variability is quantified by analysis of variations of the intervals between consecutive normal heart beats. The usual definition of a heart beat interval is the time between consecutive R wave peaks. The time-course of the R-R interval is called tachogram and further quantitative analysis of this curve allows to obtain the HRV parameters (Fig. 2). Advances in computer technology have allowed sequential R-R intervals to be measured accurately and recorded in real time. It is crucial that before processing, these signals are corrected for ectopic and missed beats. Common methods to quantify HRV include time domain and frequency domain analysis (Cardiology, 1996).

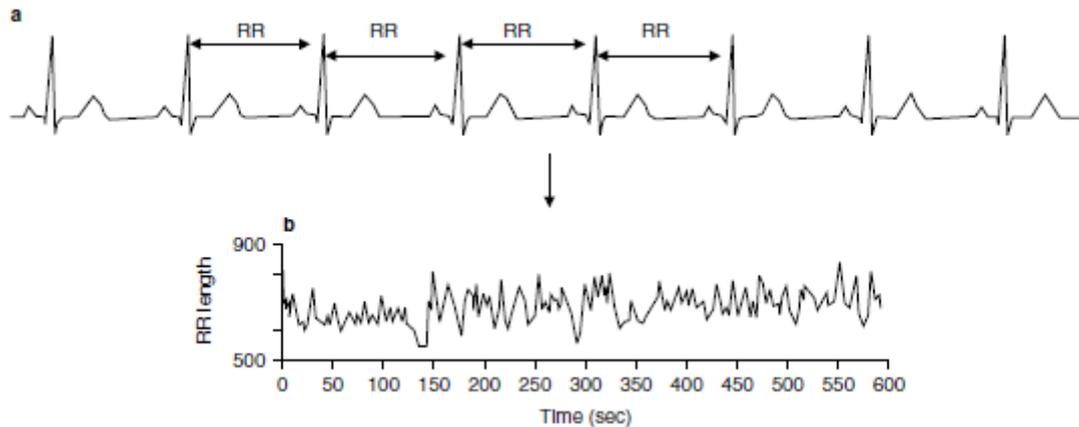


Fig. 2: Calculation of consecutive RR intervals (a) on the ECG, results in the tachogram (b) from (Aubert, Seps, & Beckers, 2003)

Time domain indexes of HRV

The time domain parameters, which represent the simplest methods to perform HRV analysis, are calculated with mathematically simple methods to measure the amount of variability present in a specific time period in a continuous ECG signal.

The most frequently used time domain indices are listed as follows:

- Standard deviation (SD, ms) of the RR interval: it is the square root of variance and is mathematically equal to total power of spectral analysis. It reflects all the cyclic components responsible for variability in the period of recording. This index measures the state of the balance between sympathetic and parasympathetic control of heart rate; in other words, it estimates overall heart rate variability and therefore includes the contribution of both branches of the ANS to the heart rate variations. SD depends largely on the duration of the recording and, therefore, values from recordings of different duration should not be compared.
- Root mean square of successive differences between adjacent RR intervals (r-MSSD, ms): to obtain the value of this parameter each difference between successive R-R intervals is squared, summed, the result averaged and then the square root obtained. It reflects very short-term HRV measured over a much longer period of time.

- Percentage of successive interval differences larger than 50 ms for humans (pNN50, %): this index is obtained counting the number of large beat to beat changes that exceed a pre-set threshold in a recording.

Time-domain measures based on beat-to-beat intervals, like SD, are useful clinical tools for detecting abnormalities of autonomic activity, but cannot be used to quantify specific changes in sympathetic or parasympathetic activity (Pumprla et al., 2002). However, r-MSSD and pNN10-20-50 can be considered as vagal indexes because they quantify the short-term, high frequency variations of the R-R interval, which are due to the activity of the parasympathetic nervous system (Stein & Kleiger, 1999). Therefore, these indices provide sensitive and specific interchangeable measurements of parasympathetic activity, which are easy to measure in human ambulatory ECGs (Kleiger et al., 1987).

Frequency domain indexes of HRV

Spectral analysis decomposes any time-dependent fluctuating signal into its sinusoidal components and allows to detect and quantify the amount of cyclical variation present at different frequencies (Cardiology, 1996). Graphically, it is presented by plotting the amount of variation present in a recording on the vertical axis against the frequency at which it occurs on the horizontal axis. This graph is usually named power spectrum and the measure of the area under the curve at different frequencies expressed as spectral power provides a numerical measure of the amount of high and low frequency variability present in the signal. Various algorithms can be used to evaluate the oscillatory components and they are generally classified in nonparametric and parametric methods (Cardiology, 1996). The most commonly used nonparametric algorithm is fast Fourier transform (FFT), which is characterized by computational efficiency and simple implementation. FFT is usually employed with a priori selection of the number and frequency range of bands of interest. Spectral analysis of the HRV requires to be performed stationary records of at least 200-500 consecutive heart-beats. To obtain a reliable spectral estimation the analyzed ECG signal should satisfy several requirements. To attribute individual spectral components to well-defined physiological mechanisms the signal should be stable, i.e. the

mechanisms modulating the heart rate should not change during the recording. In addition, for a reliable estimation it is important to select the proper sampling rate. Ectopic beats, arrhythmic events, missing data, pauses, non-periodic R-R interval changes and noise may alter the estimation of the power spectral density of HRV. Therefore, artifacts should be preferentially removed from the signal before performing spectral analysis (Cardiology, 1996). Since the first studies on power spectral analysis of the ECG recordings (Cardiology, 1996), it appeared clear that the HRV signal contains well-defined rhythms, which correspond to specific physiological mechanisms. In a typical power spectral density curve can be observed three main frequency bands: very low frequency (VLF), low frequency (LF), high frequency (HF) (Fig. 3).

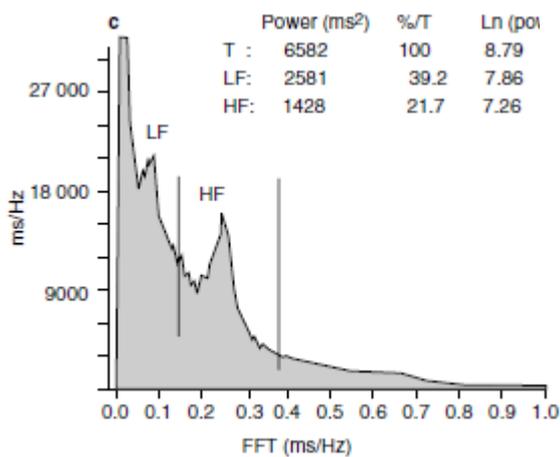


Fig. 3: example of the power spectrum of the ECG signal calculated via fast Fourier transform, from (Aubert et al., 2003). **FFT** = fast Fourier transform; **HF** = high frequency; **LF** = low frequency.

These three specific components characterize the spectral profile of many mammals, but the frequency range of each band depends on the heart rate of the specific species (Aubert et al., 1999). The amplitude of each component is assessed by its power spectral density, measured as the integral of the amplitude-frequency curve and expressed in ms^2 . VLF component (normally ranging from 0.00 Hz to 0.03 Hz in humans) contains long period rhythms and its power is due to long-term regulation mechanisms, such as thermoregulation, renin-angiotensin system, and other humoral factors (Kitney & Rompelman, 1977). The low frequency band is set in the range 0.03 Hz -

0.15 Hz for humans. Its physiological interpretation is still controversial. Actually, both sympathetic and parasympathetic contributions are considered to determine LF (Cardiology, 1996). The high frequency component is set in the range 0.15 Hz – 0.4 Hz for humans. The parasympathetic activity is considered to be responsible for HF power density. It is also associated to respiration-linked oscillation of heart rate due to the intrathoracic pressure changes and mechanical variations caused by breathing activity. The role of the vagus nerve in determining the HF band of the spectrum was confirmed after experiments with vagotomy (Cardiology, 1996) or after muscarinic receptor blockade (Cardiology, 1996). Power in the LF and HF bands can be expressed in absolute values (ms^2) or normalized units (nu). Normalized units are obtained by dividing the power of a given component by the total power from which VLF has been subtracted and multiplying by 100. The LF/HF ratio estimates the fractional distribution of power, which is taken as an indirect measure of sympathovagal balance.

Comparison between time domain and frequency domain parameters

There is a close relation between some time domain and frequency domain HRV parameters (Cardiology, 1996). The total spectral power is strongly correlated to the standard deviation of the R-R interval. Actually, both these indices measure the total amount of variability in the signal. In addition, the power of HF component of the spectrum has very strong correlation with the vagal parameters r-MSSD and pNN50. Therefore, these time and frequency domain indices can be used interchangeably. The HRV technique chosen for a particular study may depend from different factors. On the one hand, spectral analysis allows a more precise evaluation of the direction and magnitude of changes in sympathovagal balance, but it requires strict mathematical criteria for its application (Cardiology, 1996). On the other hand, time domain methods are not characterized by strict requirements of application and, therefore, are easier to apply in a variety of different experimental conditions.

PROCEDURE

All procedures were approved by local ethics committee and all participants have signed an informed consent before testing. A week before laboratory session mothers received the psychometric questionnaires and a kit for collecting salivary cortisol at home. Mothers were asked to collect salivary samples prior to laboratory assessment (two and three days before, at four time points: immediately after awaking, 30 min after awakening, before lunch and before sleeping). Immediately before and at the end of psychosocial stress test in laboratory they complete STAY for state anxiety. The protocol (see Fig. 4) consisted of the following events in fixed order: instrumentation, adaptation (20 min.), baseline rest (10 min.), psychosocial stress test (stress interview: 5 min.; mathematics test: 5 min.), post-stress recovery (30 min.).

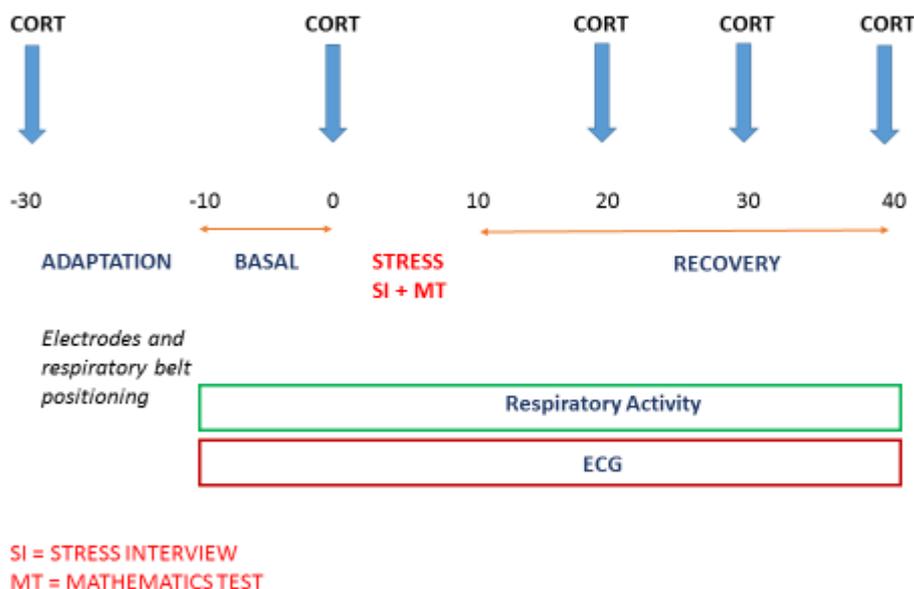


Fig. 4 Timeline of the experimental protocol applied in this study.

Statistical analysis

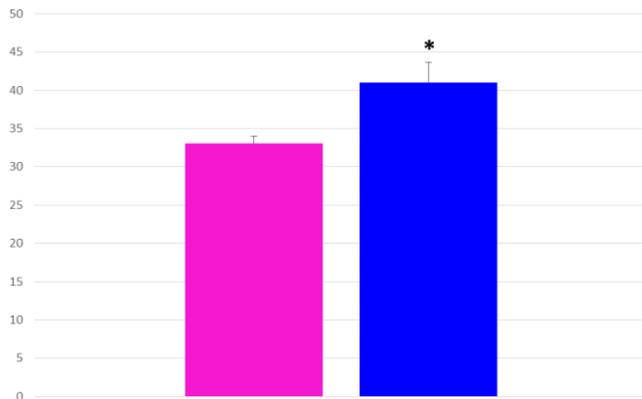
All statistics were performed using SPSS 22 software package (SPSS Inc., Chicago, IL, USA). Two-way ANOVAs for repeated measures, with “group” as between-subject factor (two levels: MCTD and MCASD), were applied for: (i) HR and HRV data during the Trier Social Stress Test (within-subject factor “time”: ten time points); (ii) cortisol data during the Trier Social Stress Test (within-subject factor “time”: five time points); (iii) daily rhythm of cortisol (within-subject factor “time”: four time points). Follow-up analyses were conducted using Student's “t”-tests, with a Bonferroni correction for multiple comparisons. A priori Student's “t”-tests, after controlling for homogeneity of the variance via a Levene test, were performed for comparisons between MCTD and MCASD on psychometric data. Relevant regression between psychometric parameters were computed. Data are expressed as mean \pm SEM. Statistical significance for all tests was set at $p < 0.05$.

RESULTS

Mean group scores for mothers of children with autism spectrum disorders and mothers of children with typical development are reported below in this order: first, scores for anxiety levels, personality D, coping strategies, parenting stress and other psychometric variables. Secondly, we present results for heart rate, heart rate variability, cortisol data during the Trier Social Stress test, daily rhythm of salivary cortisol and at the end findings about relation between psychological and physiological measures.

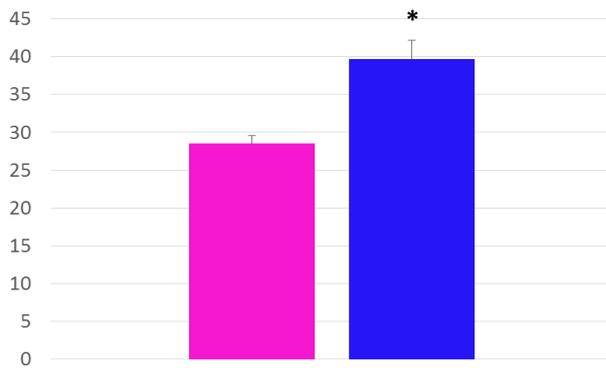
ANXIETY

STAI Y-1 pre Stress Test



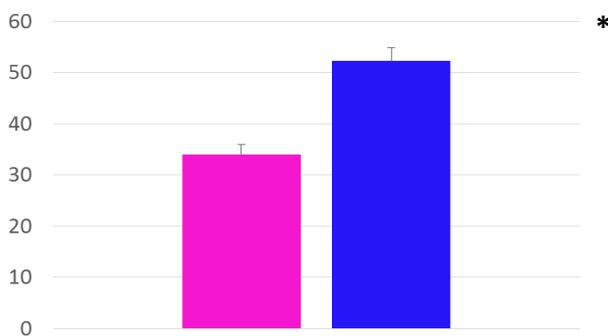
- Mothers of Children Typically Developing (MCTD)
- Mothers of Children with Autism Spectrum Disorders (MCASD)

STAI Y-1 post Stress Test



- Mothers of Children Typically Developing (MCTD)
- Mothers of Children with Autism Spectrum Disorders (MCASD)

STAI Y-2



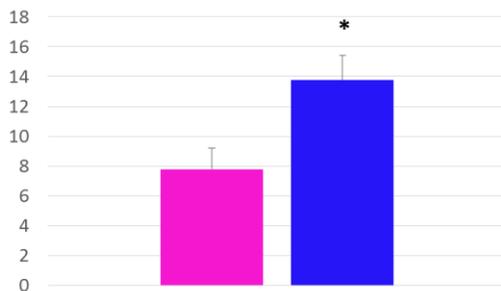
- Mothers of Children Typically Developing (MCTD)
- Mothers of Children with Autism Spectrum Disorders (MCASD)

With respect to anxiety levels there are significant differences between two groups. MCASD report higher state-anxiety levels during pre-Stress Test in laboratory than MCTD ($t = 3.30; p < 0.05$). Similarly, state-anxiety levels are higher in MCASD than MCTD during post-Stress test ($t = 4.75; p < 0.05$). With respect to trait-anxiety, MCASD report higher levels of trait anxiety than MCTD ($t = -.58; p < 0.05$).

In MCASD, there are not within group differences between state-anxiety during pre- and post-Stress Test: that is, anxiety levels do not significantly decrease after laboratory session ($t = 0.35$; $p = 0.71$). In fact, MCASD maintain high levels of anxiety after testing. On the contrary, in MCTD, anxiety levels significantly decrease during post Stress Test session compared to the pre-stress test level ($t = -3.35$; $p \leq 0.05$).

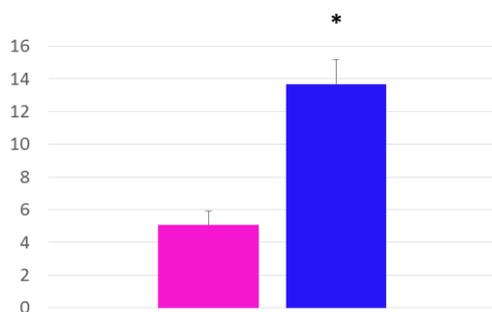
TYPE D PERSONALITY

NEGATIVE AFFECTIVITY



- Mothers of Children Typically Developing (MCTD)
- Mothers of Children with Autism Spectrum Disorders (MCASD)

SOCIAL INHIBITION

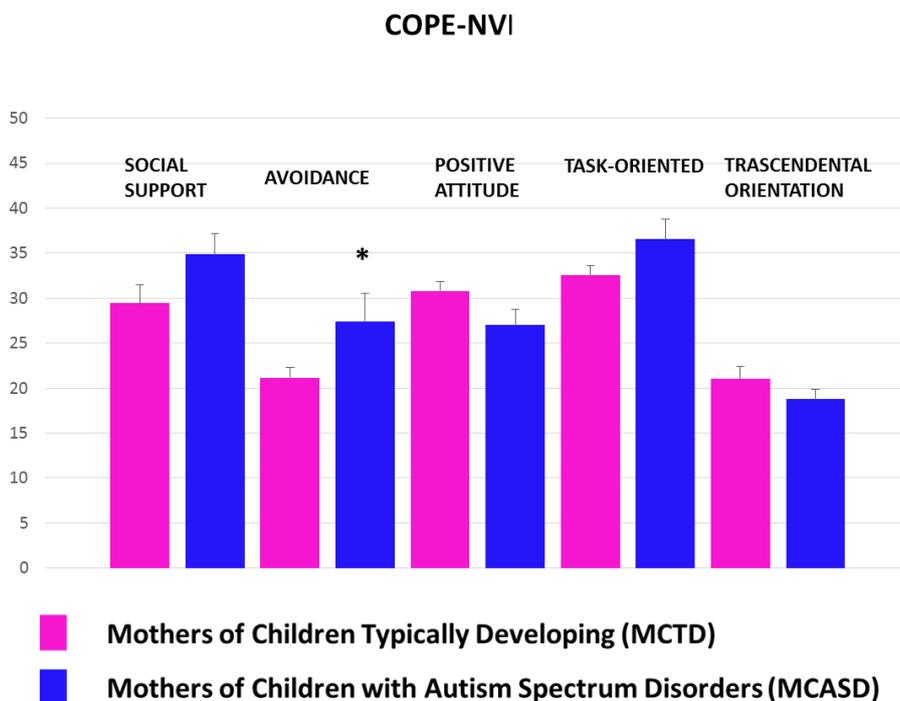


- Mothers of Children Typically Developing (MCTD)
- Mothers of Children with Autism Spectrum Disorders (MCASD)

We found interesting results about Type D Personality. In fact, MCASD had significantly higher scores in both “Negative Affectivity” ($t = 2.74$; $p < 0.05$) and “Social Inhibition” ($t = 5.33$; $p < 0.05$) scales than MCTD. Importantly, seven out of nine MCASD mothers were classified as having Type D Personality (scores in both scales ≥ 10).

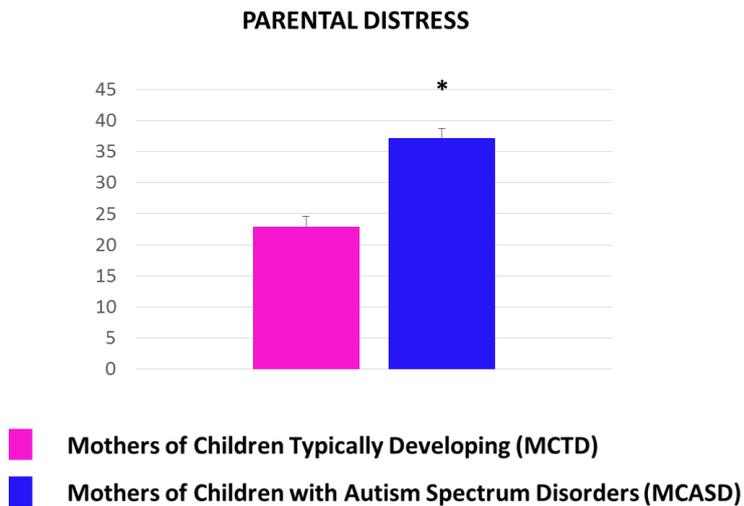
Respect to these results, a simple linear regression was calculated to predict “Negative Affectivity” based on “Trait-Anxiety” in group of mothers of children with Autism Spectrum Disorder. A significant regression equation was found ($F_{(1;7)} = 36,05$; $p < 0.001$), with an R^2 of 0,84. Trait Anxiety, in fact, was a significant predictor explaining 84% of Negative Affectivity variance. In group of mothers of Typically Developing Children we found also a significant regression equation ($F(1, 12) = 18,05$; $p < 0.001$), with an R^2 of 0,60. In this last case, Anxiety was a significant predictor, but explaining a different proportion of variance (60%).

COPING STRATEGIES



MCASD reported significantly higher scores in “avoidance” than MCTD ($t = 2.19; p < 0.05$). The two groups did not show any significant differences for the others coping strategies investigated. However, results show a pronounced preference for “social support” and “task-oriented” coping strategies for mothers of children with ASD.

PARENTING STRESS



As expected, MCASD reported higher levels of stress than controls ($t = 5,89; p < 0.05$). This is in agreement with literature data (Estes et al., 2009; Griffith, Hastings, Nash, & Hill, 2010), and supports the concept that the impact of a child with a disability on the family is a stressful condition and leads to high levels of stress and psychological burden on parents.

Mean differences for others variables are reported in Table 4.

Table 4. Mean and Standard Deviation for other psychometric variables

		MCASD		MCTD		t	
		Mean	Std.dev.	Mean	Std.Dev.		
EQ	tot.	46,78	5,14	51,36	6,53	1,77	
TAS20	tot.	42,56	9,18	38,86	5,17	-1,24	
QUIT	Social Orientation	2,45	0,67	4,09	0,19	8,64	*
	Inhibition to Novelty	3,08	0,73	2,96	0,70	3,87	*
	Motor Activity	4,26	0,41	3,58	0,33	-4,32	*
	Positive Emotionality	3,22	0,92	4,14	0,18	3,63	*
	Negative Emotionality	3,83	0,33	2,81	0,25	-8,32	*
	Attention	3,09	0,42	3,23	0,66	0,58	
TIPI	Extraversion	3,89	0,85	5,14	0,84	3,46	*
	Agreeableness	4,22	0,90	5,07	0,58	2,74	*
	Conscientiousness	5,94	0,58	4,71	0,75	-4,05	*
	Emotional Stability	3,50	0,50	4,25	0,87	2,33	*
	Openness to Experiences	4,06	0,52	5,64	0,71	5,69	*
* p ≤ 0.05							

We did not find any significant differences for Empathy and Alexithymia levels between the two groups. However, with respect to QUIT subscales, MCASD reported their children as being significantly less social oriented, more inhibited to novelty, with higher levels of motor activity, with lower expression of positive emotions and greater expression of negative ones compared to children typically developing. We found significant differences also in personality factors: MCASD reported higher scores on the “Conscientiousness” subscale of TIPI and significant lower scores in

“Extraversion”, “Agreeableness”, “Emotional Stability” and “Openness to Experiences” subscales compared to MCTD.

Heart rate, heart rate variability and cortisol data during the Trier Social Stress Test.

HR and HRV data during the Trier Social Stress Test are depicted in Fig. 5. Two-way ANOVA yielded a significant effect of group for HR data ($F=7.3$, $p<0.5$). Specifically, MCASD had significantly higher HR than MCTD in baseline conditions (min -5: $t=2.2$, $p<0.05$, min 0: $t=2.1$, $p=0.05$) and through the recovery period (min 15: $t=3.1$, $p<0.5$; min 20: $t=3.1$, $p<0.5$; min 25: $t=3.3$, $p<0.5$; min 30: $t=2.9$, $p<0.5$; min 35: $t=2.7$, $p<0.5$; min 40: $t=2.9$, $p<0.5$). As expected, HR accelerated in both groups during the stress protocol, with the magnitude of this acceleration being similar between the two groups. No significant differences were found for HF and LF/HF values in any of the recording periods.

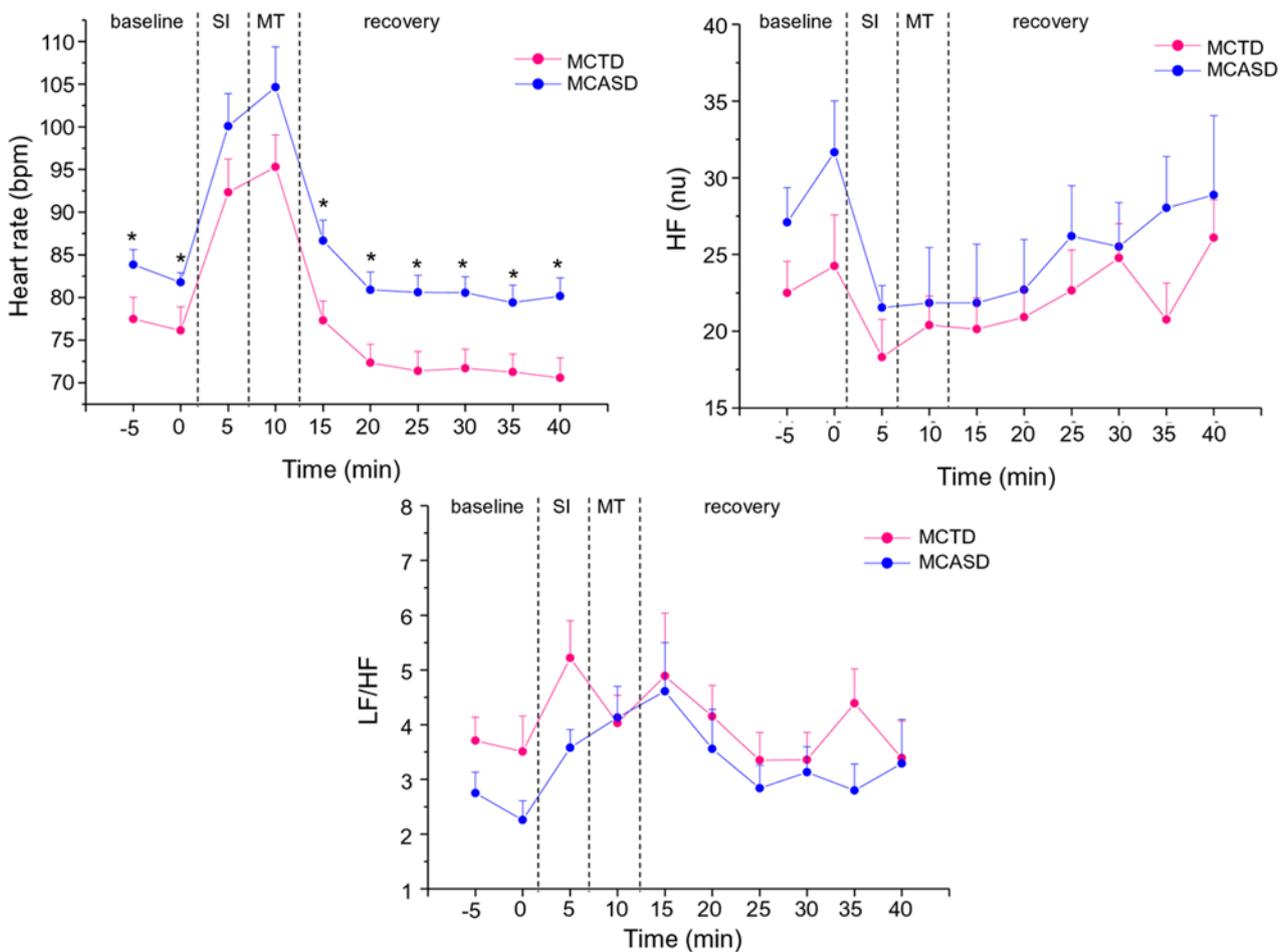


Fig. 5 Time course of changes in heart rate (top-right panel), high-frequency (HF) spectral power (top-left panel), and low-frequency (LF) to HF ratio (bottom panel) during the Trier Social Stress Test, in mothers of children typically developing (MCTD, n=9) and mothers of children with autism spectrum disorder (MCASD, n=14). Data are presented as means \pm SEM. * indicates a significant difference between the two groups ($p < 0.05$).

Salivary cortisol levels during the Trier Social Stress Test are represented in Fig. 6. Baseline cortisol levels were similar between the two groups. As expected, stress exposure provoked a rise in cortisol levels, with the magnitude of this increment being similar between the two groups.

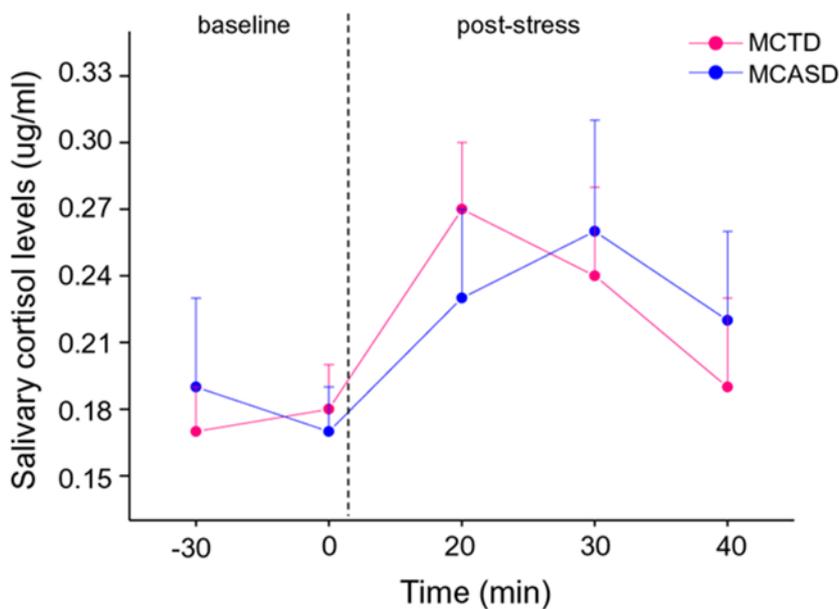


Fig. 6 Time course of changes in salivary cortisol levels during the Trier Social Stress Test, in mothers of children typically developing (MCTD, n=8) and mothers of children with autism spectrum disorder (MCASD, n=13).

Daily rhythm of salivary cortisol

The daily rhythm of salivary cortisol is depicted in Fig. 7. Two-way ANOVA yielded a significant effect of time ($F=68.1$, $p<0.05$). Cortisol levels were similar between the two groups at awakening (min 0). Cortisol awakening response (i.e., the difference between min 30 and min 0 values) was similar between the two groups. However, MCASD showed significantly higher salivary cortisol levels at lunch-time compared to MCTD ($t=2.1$, $p<0.05$). No group differences were found in bed-time cortisol levels.

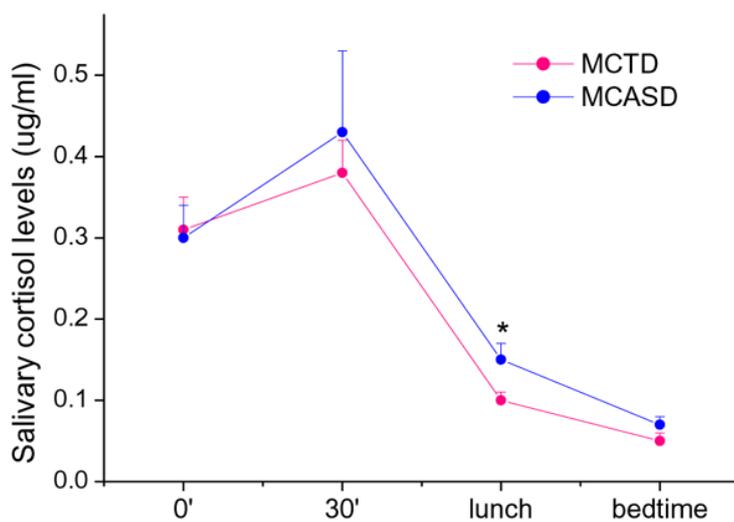


Fig. 7 Daily rhythm of salivary cortisol during the Trier Social Stress Test, in mothers of children typically developing (MCTD, $n=8$) and mothers of children with autism spectrum disorder (MCASD, $n=13$). * indicates a significant difference between the two groups ($p<0.05$).

Concerning the association between physiological and psychological variables we have not found significant relationship, we assume that the small sample size can affect the results. Further investigations are required to explore this area of great interest.

DISCUSSION

Raising a child with Autism Spectrum Disorders affects all the family system. Such a long-term care not only impacts parents' various life domains (e.g., marriage and career) and leads to caregiver stress (Hayes & Watson, 2013), but also influences service utilization and treatments effectiveness (Brannan, Heflinger, & Foster, 2003). Thus, from both the individual and social perspectives, identifying and understanding factors that are related to parenting stress is crucial for the treatment of the child, for caregivers' well-being and their entire family, and the interest of the community. Factors such as child's symptoms severity and diagnosis communication are inevitable and objective stressors for the mothers. However, individual psychological characteristics may mediate mothers' attitudes towards their children and their parenting role (Mak, Ho, & Law, 2007). Thus, this concept should be taken into account when we project parent training programs. These are, in fact, generally child-focused and designed with the aim to control child's problematic behaviors and increase their learning ability and social skills. This is essential of course, but these programs often forgive emotions and well-being of parents. Indeed, if there is a strong relationship between mother-reported stress and effectiveness of early intervention in children with ASD (Osborne et al., 2008), we should pay particular attention to the psychophysical health of mothers, who usually have the main role of caretaker. Thus, supporting families with children with autism is not solely a question of setting up an effective behavioral management program for the child, but it also requires an understanding of the emotional burden for the parent.

With respect to the psychometric measures assessed in the present study, mothers of children with Autism Spectrum Disorder reported higher levels in all anxiety domains (State and Trait) compared to controls, indicating this construct as being a distinctive feature of parenting an autistic child. In addition, these mothers maintained high anxiety levels at the end of the Trier Social Stress Test, suggesting difficulty in deactivating the anxious stress response, (which is also adaptive in a situation perceived as performing), and an excessive emotional arousal. Worrying about child rearing and management of daily activities can increase this aspect of their personality. Many of these mothers describe the future, particularly the thought of when they will

not be able to provide care of their children, as one of the most anxious aspects of their life (Foster, Kozachek, Stern, & Elsea, 2010). Families of children with autism, in fact, have identified their concern about the future as a significant contributor to their experience of stress (Bayat, 2007). Some of the diagnostic criteria for Generalized Anxiety Disorder (APA, 2014) such as being easily fatigued, difficulty concentrating, muscle tension, sleep disturbance, are found in many parents of children with autism when they are asked to report their health conditions (Hastings, 2003). These symptoms, even though they not always lead to an anxiety disorder, can affect mental health and daily activities. Anxiety levels of these mothers could also negatively influence parenting beliefs and their self-efficacy. In fact, anxiety is the most salient emotion in mothers who spend a lot of time training their child, having big expectations for progress and they force themselves to find treatment resources, trying many methods, and they become highly demanding and strict. After diagnosis they do everything to see their child recover quickly, with a sense of urgency. Unfortunately, autism is characterized by slow progress and requires a lot of patience, but these mothers have low tolerance for this, being easily frustrated and so they experienced negative emotions as helplessness and disappointment. Accordingly, present findings on personality factors are somehow those expected: mothers of children with ASD had higher scores in “Negative Affectivity” and “Social Inhibition” subscales, and seven out of nine MCASD mothers were classified as having the distressed (Type D) Personality. This personality profile is an emerging risk factor for anxiety and depressive symptoms and poor health outcomes in patients with cardiovascular disease (Pedersen & Schiffer, 2011). Individuals with this personality disposition are typified by a general propensity to experience psychological distress with impact on quality of life (Pedersen & Schiffer, 2011). The results we found on Type D Personality in mothers of children with ASD as well as the significant differences in “Negative Affectivity” and “Social Inhibition” compared to controls, led us to the following considerations.

First, a little digression: parents of children with autism spectrum disorder have been the subject of studies and theories over time rather controversial: theories of Kanner (Kanner, 1951) and Bettelheim (Bettelheim & Sylvester, 1950) have created generations of guilt in parents of children

with this disease and without defined evidence. Over the years, research on family members has focused on three main areas: studies on stress related to parenting in disability (Dardas & Ahmad, 2014), work on the Broader Phenotype (Gerdtts & Bernier, 2011; Klusek, Losh, & Martin, 2014) and those on parents as therapists for their children (Farmer & Aman, 2011). When it comes to Broader Phenotype, this is defined as a constellation of linguistic, personality, cognitive and behavioral features reflecting autistic traits (often at a subclinical level) that have been detected in parents of children with ASD (Ruta, Mazzone, Mazzone, Wheelwright, & Baron-Cohen, 2012). It should be observed that the concept of autism spectrum was originally conceived as a gradient of severity in a clinical population, while in recent years it has been understood as a continuum of autistic traits in the general population (Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001). Specifically, the difficulties and the differences found in the parents of children with ASD are much milder than those of their diagnosed children, and do not fall within a clinically significant range. The results of these studies simply report several characteristics of autistic phenotype among parents of ASD children compared with controls, but these traits do not cause a functional or social deficit that warrants a clinical diagnosis (Gerdtts & Bernier, 2011). The studies in this area have focused on personality characteristics of the family along with their relational skills (Johnson, Filliter, & Murphy, 2009) and the results obtained have described these individuals as being more *anxious*, more rigid and more *inhibited* than the control groups.

Back to Type D personality: individuals included in this categorization are considered as having a tendency to express negative emotions, including depressed mood, anxiety, anger, feelings of hostility: these people have a negative view of the world and of themselves. Social inhibition is a tendency to avoid the potential dangers of social interactions, such as disapproval and lack of recognition from others. From a clinical perspective, subjects with Type D personality tend to be worried and to take a pessimistic view of life, to feel *anxious* and easily irritated, they have a tendency to not share these emotions for fear of being rejected or criticized (Denollet et al., 1996).

It seems that these characteristics are almost the same of Broader Autism Phenotype, in particular rigidity, anxiety, depressed mood and emotional inhibition. However, we did not find these

mothers as being less empathic or more alexithymic than controls, similarly to what has been reported in literature (Szatmari et al., 2008), and so far there are not data showing Type D Personality among these mothers. This is an important finding with respect to mothers' health and to the previously cited studies, about this personality profile and cardiovascular risk. In fact, considering results from HRV analysis, mothers of children with ASD reported significantly higher Heart Rate than MCTD in baseline conditions and through the recovery period. If we consider almost all the epidemiological studies that aimed to answer the question of the relationship between heart rate and all-cause or cardiovascular morbidity and mortality, they reported that a high heart rate was associated with a higher risk of all-cause mortality and cardiovascular events (Perret-Guillaume, Joly, & Benetos, 2009) and this is a crucial question for mothers health. The importance of this finding among mothers of children with ASD, in addition to the relation between Type D personality and health, is reinforced by another result: in fact, a regression analysis found trait anxiety as significant predictor of Negative Affectivity. Thus, a greater anxiety level influences emotional expression, particularly negative emotions. Therefore, we argue that the key variable for mothers of children with ASD is anxiety and emotional expression. We should take into account that often anxiety Disorders are comorbid in children with Autism Spectrum Disorder (Simonoff et al., 2008) and, as we reported in the first chapter, a mindful parenting practice, calm and emotionally controlled, decreases aggressive behaviours in children (Singh et al., 2006). Therefore, therapists could help mothers to manage anxiety and to improve parenting practices that do not create an anxious context for children.

The results on coping strategies employed by mothers of Autistic children are related to the results on anxiety. In fact, we found that, compared to controls, they scored higher in Avoidance strategies, in coping behaviors of distancing and escape. Generally speaking, avoidance coping leads to increased anxiety (Blalock, Robinson, Wetter, & Cinciripini, 2006). For example, people with panic disorder engage in avoidance coping (including not leaving their home in some cases) in order to try to avoid panic feelings. The more they try to avoid situations that might trigger panic feelings, the more likely almost every situation begins to trigger panic feelings. Therefore,

avoidance and anxiety are strictly connected. If mothers of an autistic child employed avoidance coping strategy (for example, about her emotions) and had anxious thoughts, she could feel more inadequate than a mother using a different coping strategy and with a lower anxiety level. It is not surprising that a mother of a child with ASD may find herself inadequate in dealing with the behaviors commonly exhibited by her autistic child (i.e., repetitive behaviors, withdrawal behavior and/or misbehavior), which may affect social life of a family with an ASD child (Higgins, Bailey, & Pearce, 2005), for example by reinforcing social avoidance and social inhibition out of the domestic context. In fact, parents of children with ASD often reported experiences of shame and social exclusion together with feelings of isolation from friends and family (Farrugia, 2009) that are clearly reinforced by an avoidance attitude in a vicious cycle. Many mothers perceive both negative stereotypes related to the ability of someone with ASD to be an independent adult and beliefs about autism causes and characteristics. They also reported stigma processes as an additional difficulty of raising a child with ASD (Kinnear, Link, Ballan, & Fischbach, 2015) and this play a strong role when they have to face community and social contexts, in particular in regard to anxiety and avoidance. Furthermore, the type of coping strategy used in a stressful situation could have consequences for health. In fact, an important variable of cardiovascular reactivity seems to be the individual coping strategy (Sgoifo et al., 2003). Consequently, we should consider this behavioural and cognitive aspects of parenting stress.

Previous research on psychological outcomes for parents of children with developmental disabilities has identified the nature and severity of a child's disability (Ricci & Hodapp, 2003), the child's caretaking demands (Minnes, 1988) and the child maladaptive behaviors (internalizing and externalizing problem behaviors; (Hastings, 2003)) as strong stressors. Among these, the child's maladaptive behaviour profile is most reliably linked to parent stress (Weiss et al., 2012). Mothers psychological characteristics may intensify the negative perception of their children. Indeed, results obtained from QUIT about children's temperament show that autistic children are significantly perceived as more inhibited respect to novelty, with higher motor activity and expressing more negative emotions compared with controls. They are autistic and these are

common features of this disease. However, we could suppose that anxious, rigid and pessimistic approaches may influence the way in which mothers perceived their children. Further investigation is required to clarify this issue.

Finally, how can we help mothers of children with ASD to improve their resilience and to improve their ability to handle stress, taking into account our results and an integrated approach that has as its purpose the well-being of the entire family system?

We can assume as theoretical framework the Resiliency Model of Family Stress, Adjustment and Adaptation developed by McCubbin and McCubbin (McCubbin, McCubbin, Mischler, & E., 2001). This is a strength-based model expanded from the family stress theory and that has been used in many studies of families with high levels of stress induced by changes, such as gains and losses, strains and transitions and acute and chronic illnesses. This model helps to explain individual's ability to recover from or adjust to or even triumph stressors arising from life events. Family resources are attributes that are available for the family and can be found in three domains: individual, the family unit and the community. The individual level includes cognitive resources, knowledge and skills, personality traits, physical and emotional health. Family unit resources include skills like decision making as well as conflict resolution skills. Community resources are personal support (friends and relatives) and institutional support (religious institutions and healthcare facilities). Families that show a balance of all these components can achieve positive adjustment (Troy, Connolly, & Novak, 2007). Results of our study have focused on anxiety, emotion expression, coping strategies and health of caregivers, mothers in particular, of children with ASD, at the individual level cited above and it provided information on main aspects that are critical for this group. Therapists who work with mothers have the possibility to improve emotion's regulation and emotion's expression trying to provide these mothers a space in which they can feel not only a mother, not only a mother of an autistic child, but in which they can explore their role also as a woman and/or wife. It could be argued, in fact, that only focus on the parent's role (which is common in these situations) could lead to a high level of frustration in a context with a long life disability. Many documented support programs for this parental group tend to focus on

the child, providing strategies to help the parent manage externalizing behaviours, and providing psychoeducation on autism and its behavioural and developmental implications (Keen, Reid, & Arnone, 2010). However, it may be that such support is leaving a key area of need unmet. Often, unfortunately, Public Services do not include psychotherapeutic support for the parent as a core component of their intervention programs. As reported by a mother who provided an informal feedback as part of the present study: *'Why is it always about my child? I do not always want to talk about him. Health professionals seem to forget that I exist independently from my child. I wanted to take part in this study because it was about me and not about my child.'* This sentence expresses a fundamental need. We suppose that taking care of this domain could help individual well-being but also influence the mother-child relationship and intervention efficacy. When designing a parent training program, we should consider the individual profile of mothers of children with ASD, their personality traits, their behaviours, their attitude, the way they cope with stress, to improve not only their parenting practices, but also their personal and emotional well-being which is an essential protective factor for resilient outcomes and for having hope for their future as a family.

An interdisciplinary approach, connecting psychology and biology, which was the setting for our study, allowed us to reflect on both the clinical and theoretical aspects of parenting stress by providing the tools for further investigations from a therapeutic, health and scientific point of view, in order to improve the support for these families.

In the end, we reported below a letter of a mother of a child with ASD who painfully and honestly explains how she feels as a mother of a disabled child; she clearly expresses difficulty, sadness and frustration and also...love. As therapist and researchers we should be aware of mothers feelings and we must not forget that behind the practical problems, the skills and performance, there is a person whose emotional well-being is crucial for having a healthy relationship with their child.

"Most nights, for more years than I can remember, I have had the same dream. I'm walking along the street, arm-in-arm with my beautiful, dark-haired daughter.

Her brown eyes are sparkling with joy, she's chatting 19 to the dozen, making me laugh and giggle along with her. But every morning I wake to the same chilling reality. My 34-year-old daughter, Louise, is disabled.

Her speech can be almost unintelligible even to us, she will never hold down a job, have a family or even live by herself. Louise is a scared, anxious little girl imprisoned in a woman's body. Her dream is to have 20 children and 20 cats and to marry a man who owns a curry shop, because curry is her favourite food.

Will any of it happen? Of course not. The brutal truth is that Louise's life is little more than a living death. She can never look forward to the things the rest of us can. And, forgive me for saying it, her problems are a huge burden to herself and her family. The simple truth is that Louise's handicap — and, let's not beat about the bush, a 'handicap' is exactly what it is — isn't just hard for her to bear, it has taken an intolerable toll on the rest of her family. I wouldn't wish the hell we have endured on anyone. Because for many average families such as mine, having a handicapped child is hell. You enter a black tunnel from which you never escape. But I must confess that I am tired of hearing about devoted parents who say that seeing the world through a handicapped child's eyes is a blessing.

Please forgive me for sounding so cynical, but I'm convinced that parents say this only because they need to find something positive in their difficult, if not miserable, situations. As a writer, working at home was impossible. Zombified by lack of sleep and the stress of coping with Louise, every day was pure torture. My husband came home from his job as a driver with the local council to a wife who was bouncing off the walls.

Robert and I never attended a single parent's evening, sports day or carol concert together because one of us always had to stay at home with Louise. Her behaviour also affected the other children's friendships, for who wanted to come and play when Louise was around?

We vowed we would make it up to them when Louise needed us less. What a pipe dream that was.

One challenge followed another. Because of her autism, Louise needed a life of strict routine, so we couldn't go on holiday. Our home was a wreck because Louise had no co-ordination. She broke endless music players and TVs. The effect on my marriage was also devastating. Couples split up very easily in similar circumstances, but we managed to cling to and lean on each other, too exhausted to fight.

And if that wasn't hard enough, we had to fight for every scrap of support from the State.

The grim reality of caring for a handicapped child is that you have to battle for every bit of help, while agonising constantly about the future.

Nevertheless, we loved Louise passionately, and were convinced that our efforts would bring eventual improvement.

Even so, she often pops up in my dreams as a completely normal young woman, and I wake in tears because I know that she will only ever be like that in my dreams.

I would pay any price to remove Louise's handicap. As I said, I would give my own life in exchange. That's how much I love her")(Henderson, 2012).

Limitations

Some limitations have to be considered in the present study. Firstly, further study is recommended with a larger sample size in order to generalize our results with greater certainty. Secondly, due to lack of male participants, the sample used in this study is limited to mothers of children with ASD, but it could be interesting to explore fathers profile with respect to the variables considered.

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