University of Trento,

Department of Psychology and Cognitive Science

Doctoral course in Psychological Sciences and Education

Rovereto, Italy

Parents of Children with Autism Spectrum Disorders: Well-being of Parents, and Emotional & Physiological Responses to Infant Crying

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A Thesis

Submitted to the Department of Psychology and Cognitive Science

For the Degree

Doctor of Philosophy (Ph.D.)

2015

Supervisor: Professor Paola Venuti

CONTENTS

Acknowledgement

I would like to dedicate this thesis to my mother and father, Nurgül and Abbas Öztürk and to my sister, Pınar Öztürk. I thank them for supporting me emotionally and mentally, and for all their love and encouragement.

I would like to express my special appreciation and thanks to my Ph.D. advisor, Professor Paola Venuti, for supporting me during these three years. I am grateful for her insightful comments and encouragement. She was always very supportive and caring, not only in regard to my academic progress, but also about many other issues that I was involved with besides my Ph.D. study. I am also thankful for the excellent example she has provided as a successful psychologist.

I owe my deepest gratitude to FBK Team, especially to the Head of the Research Unit, Cesare Furlanello and Ph.D. students, Andrea Bizzego and Nastaran Mohammed Rad, and a bachelor student, Alessandro Battisti, for their technical support and availability.

Moreover, I would like to thank to Professor Cheryl Dissanayake for supporting me to conduct my second study within the OTARC in Australia. Her advices on my research as well as on my career have been priceless. Furthermore, I would like to thank Dr. Giacomo Vivanti for encouraging my research and for allowing me to grow as a research scientist.

I am indebted to past and current members of the ODF Lab. My colleagues were always really helpful and made my Ph.D. more enjoyable. Special thanks to Mauro and

his family for all their support and for standing beside me during my 5 years in Italy. Lastly, I would like to express my thanks to Teresa for her support and for always being there through good times and bad.

Thesis Summary

Autism Spectrum Disorder (ASD) is characterized by difficulties in social communication and restricted, repetitive patterns of behavior and interests (American Psychiatric Association, 2013). These key characteristics of autism each create a number of difficulties for individuals with autism and also their parents. It is well established that parenting a child with ASD is stressful, impacting on mental health and overall quality of life (Baker-Ericzn, Brookman-Frazee, & Stahmer, 2005; Davis & Carter, 2008; Eisenhower, Baker, & Blacher, 2005; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013). However, there are some doubts or gaps in the literature of parenting children with ASD which we addressed in this thesis.

Two main goals of this thesis were: a) examining well-being of parents of children with ASD, b) focusing on the parents' responses to cries of infants with ASD and typical development, considering two types of responses: emotional and physiological. Therefore, this thesis is composed of two parts. The first part in which we aimed to examine well-being of parents of children with ASD has been divided into two sections. The first one dealt with similarities and differences between mothers and fathers in terms of parenting stress, parental mental health and attitude (Chapter 2). Results indicated that mothers of children with ASD reported higher level of depression than fathers and considerable percentages of both mothers and fathers had scores above the clinical cut-points of stress showing that they experience clinically significant levels of parenting stress. Moreover, in terms of parental attitude, mothers engaged with their children in more social exchange than fathers do.

The final chapter in Part 1 (Chapter 3) evaluated whether maternal well-being and sense of competence are affected by the outcomes of children receiving intervention. The results suggested that child and family factors, including mothers' age, were linked to maternal well-being. However treatment-related changes in children's communication, and parenting satisfaction contributed to well-being above and beyond other factors. A mediation analysis indicated that mothers whose children make treatment gains in communication skills experience a reduction in their level of negative well-being as a consequence of increased parental sense of competence with regards to parenting satisfaction.

The second part of the thesis aimed to evaluate emotional and physiological responses of parents of children with ASD during infant crying. This part begins by laying out the theoretical dimensions of the research, and then proceeds as follows: a) the first experiment was concerned with the preparation and validation the cry episodes as unpleasant acoustic stimuli (Chapter 4); b) the second one examined emotional and physiological responses of non-parents adults while listening of infant crying (Chapter 5); c) the last experiment focused on parents of children with ASD and parents of typically developing children, examining their emotional and physiological responses during the listening of crying of children with ASD and of typically developing (TD) children (Chapter 6).

Findings from Chapter 4 indicated that all cry episodes, regardless of the types (e.g., cries of children with ASD or cries of typically developing children) were perceived as unpleasant by non-parents adults. The following study in Chapter 5 showed that cries of children with ASD (ASD cry) were reported more stressed, aroused and less pleasant compare to cries of typically developing children (TD cry) by non-parents adults; however, similar pattern was not seen in the physiological responses of listeners. Results

from the final experiment (Chapter 6) showed that parents of children with ASD and parents of TD children were not differentiated in their self-reports of stress, arousal and valence levels for ASD cry and TD cry. However, their physiological responses showed that parents of children with ASD have higher heart rate than parents of TD children during ASD cry and TD cry. Moreover, the analysis on the comparisons between ASD cry and TD cry suggested both parents perceived ASD cry more stressful, aroused and less pleasant, but physiological responses of parents of children with ASD did not show the differences between ASD cry and TD cry.

The overall structure of the thesis takes the form of seven chapters, including a general introduction (Chapter 1). The importance of those findings for future theoretical and clinical work is considered in detail in the end of related chapters and in the general discussion chapter (Chapter 7).

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Chapter 1: General Introduction

"Each day more than three-quarters of a million adults around the world experience the joys and heartaches, the challenges and rewards, of becoming new parents."

(Bornstein, 2002, p. 4)

1.1. Parenting

In a given year, approximately 143.3 million new babies are born in the worldwide (*Population Reference Bureau*, 2000) and considerable amount of adults experience the transition to becoming a parent which represents an important life change. Becoming a parent has been described as a major life transition, as well as a major life crisis, a time of crucial psychological and social adjustment (McCourt, 2006). It is a tremendous and novel experience in which parents face; however being a new parent can be really difficult, stressful and challenging in life, too. According to a recent nation-wide survey by *Zero-to-Three* -the National Center for Infants, Toddlers, and Families- parents of young children face a variety of challenges in today's world; temper tantrums (34%) and crying and controlling emotions (15%) top the list of childrearing challenges that parents identify (Zero to Three, 2009). From the day-to-day responsibilities to the larger pressures that affect many families, parents of young children face a variety of challenges in today's world.

Parenting is a care and nurturing of offspring between conception and independence, and extends through the respective lifespans such that parents parent

infants, toddlers, children in middle childhood and adolescents. Parental caregiving plays influential parts in children mental health because it regulates the majority of child-environment interactions and helps to shape children's adaptation (Bornstein, 2013). Newborn parenting is where the responsibilities of parenthood begins and a period which highly attended to by parents. In fact, parenting an infant is a "24/7" job, whether by the parent herself or himself or by a surrogate caregiver who is on call, that is because the human infant is totally dependent on parents for survival (Bornstein, 2002). Next, parenting toddlers, which is referred the age period bridging between infancy and early childhood, has its own portraits. Parental support, guidance, and structure help the child navigate the toddler period (Edwards & Liu, 2002). After this period, parents of children between ages of 5 and 12 years, namely middle childhood years, face challenges arising from both maturational changes in children and from socially imposed factors; and their parenting affect not only the current well-being of children, but carry significant implications for later life (Collins, Madsen, & Susman-Stillman, 2002). Then, the child's transformation from middle school into adolescence introduces new issues and concerns into family functioning that brings a new equilibrium in the parent-child relationship (Steinberg & Silk, 2002). Taken together, in all stages of development, parents face various challenging situations as well as children face. It seems that there is a bilateral influence between parents and child: the dynamic in the child development affects parenting, and also are influenced by parenting. All these changes during the development, in turn, affect the ways in which parents treat the child.

"And all my mother came into mine eyes

And gave me up to tears."

(Shakespeare, 1599, Act IV, scene 6, line 32)

Additionally, mothering and fathering individually remain subjects to focus. Mothers have been considered as children's primary caregivers traditionally and cross-culturally, and their parenting is most consistently associated with child outcomes (Barnard & Solchany, 2002; Bornstein & Cote, 2004; Bornstein, 2002). Mothers take important role in their children's life. Winnicott (1990, p. 49) described the mothering role as a "holding environment" for any age of children which is very demanding undertaking. Mothers provide what the child's needs naturally, such as nurturing and protection. Brody (1956, p. 377) described the importance of mothers in who everybody becomes as an individual "The genesis of motherliness is to be sought primarily in the quality of the child's attachment to her own mother in the first years of life. In that period the mother actively provides many passive satisfactions to the child, and is perceived as having the power to grant or withhold all of the pleasures that the child can imagine to be crucial. As the child grows capable of activity in her own right, she imitates the activity she is most familiar with, that of her mother." Moreover, Bowlby (1953, p. 11) highlighted that the mothering was also necessary for children's later ability to successfully mother their own children.

Fathers are as important as mothers in children's development (Parke & Buriel, 2006; Parke, 2002) and primarily helpers (Bornstein, 2013). In the past three decades, fathers' involvement in caregiving has become increasingly significant (Parke, 2002). However, Parke (2002) mentioned that mothers and fathers differ in their degree of responsibility for management of family tasks; from their children's infancy through middle childhood, mothers are more likely to assume the managerial role than fathers. In the *Zero-to-Three* survey, it has been reported that fathers' experience of parenting differs from that of mothers. As an example, fathers and mothers have different perceptions of

what they find challenging. Twice as many mothers as fathers identify temper tantrums as a top challenge, and twice as many fathers as mothers identify sleep and bedtime issues as a top challenge (Zero to Three, 2009). Another example, men are three times more likely (21%) than their female (7%) counterparts to turn to their partner for parenting information. However, as Parke (2002) suggested, it would be the fact that fathers participate less than mothers in caregiving but spend a great percentage of the time with their infants in play. Therefore, it would be expected to consider fathers as competent caregivers in spite of their limited involvement.

1.2. Parenting a child diagnosed with Autism Spectrum Disorder (ASD)

> *"I already had my standard-issue explanation, so well-rehearsed it's a verbal tic. "Carl has autism." Three short words must suffice to explain a tome of weird behaviors and limitations. It's short words must suffice to explain a tome of weird behaviors and limitations. It's shorten for Carly-is-different-she-acts-in-odd-ways-she-loves-taking-off-her-clothes-especially-if-what-she-is-wearing-has-a-spot-of-water-on-it-she-likes-repetitive-motion-like-that-of-the-swing-she-doesn't-speak."*
>
> (Fleischmann & Fleischmann, 2012, p. 5)

Besides all experiences both parents faced during child-rearing, parents of a child diagnosed with a disability are presented with a unique set of challenges associated with providing additional care for their children. Families of a child diagnosed with a disability experience more instability and dysfunction than families of a child typically developing

(Watson, Hayes, & Radford-Paz, 2011). Most of the time, they have additional responsibilities of providing care for their children. For example, parents of children with ASD deal impairments in social communication, restricted and repetitive behaviors that are two of the key diagnostic traits of ASD (American Psychiatric Association, 2013). As ASD is increasingly being recognized as one of the most common childhood disorders, a considerable literature has grown up around the theme of parenting a child with ASD, in particular parents' well-being (Baker-Ericzn et al., 2005; Davis & Carter, 2008; Eisenhower et al., 2005; Hastings, 2003; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; McStay et al., 2013; McStay, Trembath, & Dissanayake, 2014; Moes, Koegel, Schreibman, & Loos, 1992; Sharpley, Bitsika, & Efremidis, 1997; Tehee, Honan, & Hevey, 2009). Therefore, it is valuable to pause and take stock of the current studies on ASD.

ASD is a complex neurodevelopmental disorder do not only affect the diagnosed people throughout their life, but also their parents who play salient and influential roles in child development (Karst & Van Hecke, 2012). In the Diagnostic and Statistical Manual of Mental Disorders—Fifth Edition (DSM-5; American Psychiatric Association, 2013), ASD is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of ASD requires the presence of restricted, repetitive patterns of behavior, interests, or activities. Moreover, hyper- or hypo-activity sensory input is now a diagnostic criterion for ASD (American Psychiatric Association, 2013). Two systematic literature reviews on epidemiology of surveys of autistic disorder and pervasive developmental disorders worldwide, provide the median of prevalence estimates of

autism spectrum disorders that is 62/10,000, making ASD one of the most frequently observed childhood neurodevelopmental disorders (Elsabbagh et al., 2012; Fombonne, 2009).

Taking into account these core challenges and the comorbid conditions that often accompany ASDs, rearing a child with those developmental difficulties is an important and unique challenge for both mothers and fathers. These parents face challenges (e.g., challenges in communicating, social isolation, difficulties in self-care, difficult behaviors, and lack of community understanding) placing them at risk for high levels of parenting stress and other negative physiological outcomes (Montes & Halterman, 2007).

1.3. Summary

There is still much to be learned about those parents. Therefore, this thesis was designed to explore several aspects of parenting a child with ASD. One of the main aims of this thesis (Part 1) is to focus on well-being of parents of children with ASD, examining the differences between mothers and fathers (Chapter 2) and whether treatment-related changes in children with ASD affect parental well-being (Chapter 3). The second focus of this thesis (Part 2) will be to look at the parents' perceptions of infants' cries, in particular the responses of parents of children with ASD to cry of infant with ASD. It is worth to note that, details of parenting a child with ASD and well-being of parents will be explained in the introduction section of Chapter 2&3 and in the beginning of Part 2.

Part 1: Parents' Well-being

This part of the thesis attempts to examine well-being of parents of children with ASD, considering two aspects: a) the similarities and differences between mothers and fathers of children with ASD in terms of parenting stress (the magnitude of stress in the parent-child system), parental mental health (psychological problems) and parental attitude (the way how parents behave to their children); b) the extent to which treatment-related changes in children with ASD and other non-treatment-related factors affect changes in maternal well-being from pre-intervention to post intervention.

Chapter 2: Parenting dimensions in mothers and fathers of children with Autism Spectrum Disorders[1]

Chapter Plan: This chapter provides the study that has been performed to draw a comprehensive profile of both mothers and fathers who have children with ASD addressing all the important domains of parenting. Our goal is to determine whether mothers and fathers are different in terms of parenting stress, parental mental health and parental attitude (behavior). The hypothesis put forward was that mothers and fathers would differentiate in terms of these parenting dimensions.

2.1. Introduction

2.1.1. Parenting Stress

In the last decade many studies have tended to focus on parenting stress in the family of children with ASD (Baker-Ericzn et al., 2005; Davis & Carter, 2008; Eisenhower et al., 2005; Hastings, 2003; Hoffman et al., 2009; Moes et al., 1992; Sharpley et al., 1997; Tehee et al., 2009). One of the major area of interest within this field is the comparisons between mothers of children with ASD and all other mother groups defined by children's syndromes. Eisenhower and colleaugues (2005) found that mothers' reports of negative impact differed significantly by syndrome group at child age 3, with mothers in the autism group reporting higher negative impact than typically

[1]Ozturk, Y., Riccadonna, S., & Venuti, P. (2014). Parenting dimensions in mothers and fathers of children with Autism Spectrum Disorders. Research in Autism Spectrum Disorders, 8(10), 1295–1306.

developing, undifferentiated developmental delay and Down syndrome groups (Eisenhower et al., 2005). This finding is consistent with the studies which found higher level of stress in mothers of children with ASD compared to mothers of developmentally delayed children (Estes, Munson, Dawson, & Koehler, 2009) and mothers of typically developing children (Hoffman et al., 2009). In a more recent study, mother of children with ASD scored higher on stress than mothers of children with Down syndrome and mixed etiology intellectual disabilities (Griffith, Hastings, Nash, & Hill, 2010). From the brief overview of the literature provided above it is clear that there is an agreement between the studies regarding the fact that mothers of children with ASD are more stressed than various mother groups defined by children's syndromes.

The question naturally arises, do fathers of children with autism experience stress as mothers do reviewed above?

There is a little discussion about fathers of children with ASD, even though they are important as mothers in children's development (Flippin & Crais, 2011; Parke, 2002). Even though it has been reported that fathers of children with ASD, as well as mothers, were found to have elevated stress compared to those of typically developing children (Baker-Ericzn et al., 2005; Rao & Beidel, 2009), there is no general agreement in whether one of parents of children with ASD experience higher level of stress than other. Literature has emerged that offers contradictory findings about this issue. Tehee and colleaugues (2009) found that mothers were more stressed and more involved when compared with fathers of 3- to 18-year-old individuals with ASDs. Moes and colleagues (1992) reported similar results, suggesting that stress may be related to the differing responsibility assigned to child rearing for each parent. However, in both studies, they compared the stress profiles in a very small sample size: in 23 mothers and 19 fathers

(Tehee et al., 2009) and in 18 mothers and 12 fathers of children with autism (Moes et al., 1992).

On the other hand, some studies reported the similarities between stress levels of mothers and fathers of children with ASD. As stated in previous studies (Baker-Ericzn et al., 2005; Davis & Carter, 2008), both mothers and fathers of children with ASD reported significantly elevated levels of both child and parent related stress. Moreover, Hastings (2003) found that mothers and fathers did not differ in their levels of stress. Similar debate stands in the researches which focused on the comparisons between mothers and fathers of children with other disabilities or without disabilities (Baker, 1994; Beckman, 1991; Deater-Deckard, 2008; Perry, Sarlo-McGarvey, & Factor, 1992; Theule, Wiener, Tannock, & Jenkins, 2010). For example, in a meta-analysis study on parents of children with attention-deficit/hyperactivity disorder (Theule et al., 2010), it has been reported this debate in which one review concluded that fathers of children with ADHD experience less parenting stress (McCleary, 2002), whereas another concluded that there were no significant differences between mothers and fathers (Johnston & Mash, 2001). As concluded Pisula (2011), it is clear that we still know very little about the gender differences in parental stress mothers and fathers experience. However, there is no doubt that bringing up a child with autism is also a challenge to fathers.

2.1.2. Parent Mental Health

In addition, parents' mental health is another important and well-known domains of parenting. As example, depression among mothers of young children is increasingly recognized as a common and devastating public health problem affecting not only women but also the children in their care, with an estimated 1 in 10 children experiencing a

depressed mother in any given year (Ertel, Rich-Edwards, & Koenen, 2011). Mental health has been shown to have effects on parenting, such that higher levels of current maternal depression symptoms were associated with less positive and more negative maternal behaviors including lower levels of laughter, praise and support of their children's efforts, fewer constructive and useful suggestions during the task, and more negative affect, criticism, and controlling behavior (see Foster, Garber, & Durlak, 2008). Compared to non-depressed woman, depressed mothers have been found to be more negative with their children (Foster et al., 2008; Jacob & Johnson, 1997). Depressed mothers are less engaging, less vocal and less skillful at getting and keeping their children's attention than do non-depressed mothers (Sameroff, Seifer, & Barocas, 1983).

Regarding to parenting a child with ASD, a recent systematic literature review highlighted that raising a child with an ASD appears to contribute to a general decrease in parental well-being (Karst & Van Hecke, 2012). It has been shown that parents of children with autism display a variety of psychological symptoms including depression and anxiety (Daniels et al., 2008; Davis & Carter, 2008). For example, Davis & Carter (2008) reported 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. Moreover, Bitsika and Sharpley (2004) reported that half of the parents in their study were severely anxious and nearly two thirds were clinically depressed. Findings on the prevalence of anxiety problems however are mixed, with rates ranging from 15.6% to 50% (Bitsika & Sharpley, 2004; Kuusikko-Gauffin et al., 2013; Mazefsky, Folstein, & Lainhart, 2008).

In terms of comparison between parents who are differentiated due to their children's conditions, several studies have demonstrated that parents of children with autism have more mental health problems than the parents of children with Down

syndrome and fragile X syndrome (Abbeduto et al., 2004), intellectual disability (Olsson & Hwang, 2001), developmental delay without autism (Estes et al., 2009), mental retardation (Weiss, 2002) and typically developing children (Gau et al., 2012; Kuusikko-Gauffin et al., 2013; Weiss, 2002). For example, Kuusikko-Gauffin et al. (2013), using the Social Phobia and Anxiety Inventory (SPAI; Turner, Beidel, & Dancu, 2004) found that both parents of children with autism had higher total scores compared with parents of TD children. Gau et al. (2012) conducted a study in Chinese family with children with autism and found that mothers and fathers of children with autism had more psychopathology than parents of typically developing children. From looking at the overall those studies, it is clear that raising a child with ASD can be an overwhelming experience for parents (Karst & Van Hecke, 2012).

However, similar to parenting stress, there is no agreement also in the existence of similarities or differences in the level of various psychopathologies between mothers and fathers of children with ASD. Some studies reported that mothers have higher levels of depression (Davis & Carter, 2008; Hastings et al., 2005; Olsson & Hwang, 2001) than fathers. Hastings (2003) found that mothers and fathers of children with autism did not differ in their depression levels, but mothers reported more anxiety than fathers. Moreover, Ou, Cha and Wang (2010), using the Symptom Checklist (SCL-90; Derogatis & Lazarus, 1994), found that mothers of children with autism presented higher interpersonal sensitivity, anxiety and psychotic symptoms that fathers. From the brief overview of the studies provided above it is clear that there is an agreement between studies regarding the fact that parents of children with autism have more stress and mental health problems than the parents of TD children and parents of children with other developmental disabilities. However, results of studies compared mothers and fathers of children with autism have been much less consistent.

2.1.3. Parental Attitude

Lastly, it is worth to note that the way how parents behave to their children with ASD is important to consider. A number of reviews suggest that parenting behavior of mothers and fathers differ in several important ways, such as father involvement in infancy and childhood is quantitatively less than mother involvement (Barnard & Solchany, 2002; Parke, 2002). Mothers spend more time with their children, and the interactions are characterized by the mother's caregiving and managerial role, whereas fathers spend more of their time with their children in play activities. Surprisingly, few studies explored from the point of parents of children with ASD. Rodrigue, Morgan, & Geffken (1990) noted that mothers of children with autism reported less parenting competence than mothers of children with Down syndrome and mothers of developmentally normal children. A more recent research revealed that self-reported parenting behaviors in parents of children with autism were slightly lower than mean levels of self-reported parenting behaviors seen in the general population (Osborne & Reed, 2010). However, as mentioned in that study, it would not be classified in a clinical context as problematic, except one area which is parents' perception of their communication with their children was found in the problematic range for parenting behavior. This finding was expected, given that social communication difficulties is one of the definitive elements in the diagnosis of autism (American Psychiatric Association, 2013). Taken together, little is known about parenting behaviors of parents of children with ASD. Nevertheless it is essential to understand caregivers' belief in their own ability to parent their child and in their attitudes toward child rearing.

2.2. Objectives

The first aim of this chapter (Chapter 1) is to provide stress profiles of parents in our sample. The second aim is to examine similarities and differences between mothers and fathers of children with ASD, in terms of parenting stress, mental health and parental attitude. We hypothesized that mothers and fathers would differentiate in terms of these parenting dimensions.

2.3. Method

2.3.1. Participants and procedure

The participants in the present study were 99 parents (50 mothers: M age = 40.67 years, SD = 5.66; 49 fathers: M age = 44.1 years, SD = 5.72) of children with ASD and 94 of them were paired (both mother and father of a child were enrolled). The children's average age at the time of the study was 87.5 months (SD = 40.9 months). The diagnosis of children was confirmed through clinical judgment by an independent clinician based on the DSM-IV-TR criteria for Pervasive Developmental Disorders (PDD) as well as through the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord, Rutter, DiLavore, & Risi, 2003) in the Observation, Diagnosis and Education Lab at the University of Trento, Italy (27% of the sample were autistic children with high cognitive function, 36% of the sample were autistic children with low cognitive function, 25% were pervasive developmental disorder not otherwise specified, and 12% were Asperger syndrome). One of three modules was used for the children passed the cut-off points for the Autism Spectrum Disorder. The socioeconomic status (SES) of the parents was calculated with the Four-Factor Index of Social Status (Hollingshead, 1975; Rossi, 1994)

which is today the most widely adopted index of SES in psychological research (M H Bornstein, Haynes, O'Reilly, & Painter, 1996; de Falco, Esposito, Venuti, & Bornstein, 2008; Gottfried, 1985; Rossi, 1994; Venuti, de Falco, Giusti, & Bornstein, 2008; Venuti & Senese, 2007). In the present study, our sample represented a middle status in the Italian population (M = 36.42, SD = 16.5).

Parents were given four questionnaires: the Parenting Stress Index-Short Form (PSI/SF; Abidin, 1995), the Parental Style Questionnaire (PSQ; Bornstein, Tamis LeMonda, et al., 1996), the Self-Perceptions of the Parental Role (SPPR; MacPhee & Benson, 1986) and the Symptom Checklist-90-Revised (SCL-90-R; Derogatis & Lazarus, 1994). Both parents completed the questionnaires on their own (taking approximately 45 min to do so) and returned them to the researchers. Schematic representation of the measures used in this study is summarized in the *Fig. 1* below.

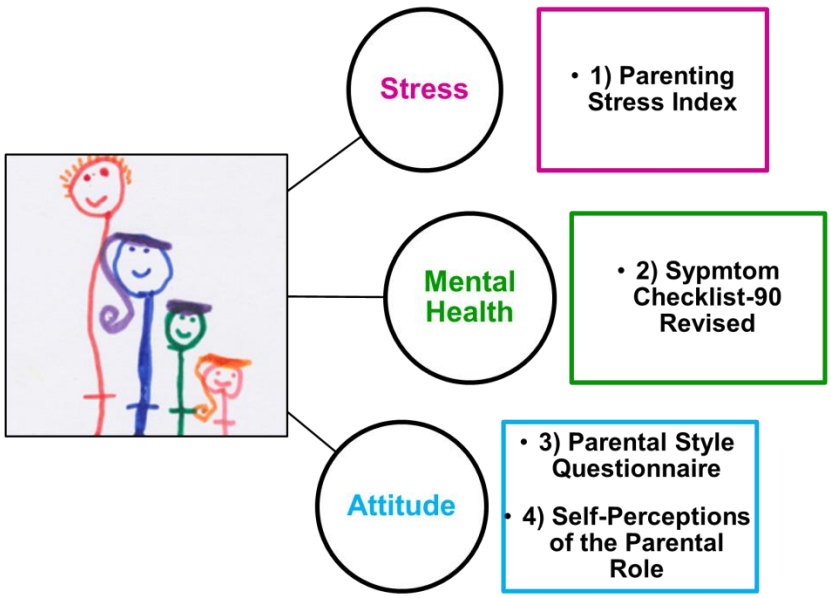

Fig. 1: Schematic representation of the measures used in this study.

2.3.2. Measures

The Parenting Stress Index-Short Form (PSI/SF; Abidin, 1995) is a self-reported measure designed to evaluate parenting stress. It consists of 36 items that parents respond to on a 5 point Likert-type scale to indicate the degree to which the participants agree with each statement, ranging from 1 (Strongly Agree) to 5 (Strongly Disagree). The PSI/SF is composed of three scales: Parental Distress (PD), Difficult Child Characteristics (DC) and Parent–Child Dysfunctional Interaction (P-CDI). The PD scale consists of items relating the distress parents experience in their roles as parents as a function of personal factors that are directly related to parenting. A sample item from the PD scale is: "Since having a child I feel that I am almost never able to do things I like to do". The DC scale measures parents' perception related to some of the basic behavioral characteristics of children that make them easy or difficult to manage, for example, "My child turned out to be more of a problem than I had expected". The P-CDI scale focuses on parents' perceptions of the interaction system between the parent and child through items such as, "Most times I feel that my child does not like me and does not want to be close to me". The PSI includes a Defensive Responding scale (DF) that indicates the degree to which the parent might be attempting to give a more positive self-image, deny stress or minimize problems in their relationship with their child. The PSI also yields a Total Stress score (TS) that is the sum of PD, P-CDI and DC to provide an indication of the total level of parental stress that an individual is experiencing in his/her role as a parent.

In general, for each scale, a score ranging between the 15th and 80th percentile is considered typical while equal or greater than the 85th percentile (the clinical cut-point) is

considered as high. A score on the DF scale equal to or more than the 10th percentile indicates high levels of defensive responding. The three scales and the total scale have shown high internal consistency (Abidin, 1995; Guarino, Blasio, D'Alessio, Camisasca, & Serantoni, 2007). In the present sample, alphas ranged from .84 to .92 for mothers across the three scales and the total scale. For fathers, alphas on these scales ranged from .81 to .91.

The Parental Style Questionnaire (PSQ; Bornstein et al., 1996) is a self-reported measure of parenting behavior. It consists of 16 items assessing three parenting style: Social Exchange (sensitivity, expressions of affection, and positive responsiveness to the child), Didactic/Material (providing stimulation and organizing an environment conducive to exploration), and Limit Setting (emphasizing rule keeping and mannerliness in the child). Parents were asked to rate the items on a 5-point Likert-type scale (from 1 hardly at all to 5 all the time) how frequently they actually engage in specific parenting behaviors. The PSQ scales have demonstrated good internal consistency and construct validity (Bornstein & Cote, 2004; Bornstein, Haynes, et al., 1996; Bornstein, Tamis LeMonda, et al., 1996; Venuti & Senese, 2007). For the present study, internal consistencies ranged from .71 to .78 for mothers, and .68 to .80 for fathers.

The Self-Perceptions of the Parental Role (SPPR; MacPhee & Benson, 1986) is a self-reported measure containing 22 items to assess the four parental self-perceptions: Competence, Satisfaction, Investment, and Role Balance. Each item has a pair of statements that describes contrasting endpoints of the dimension to minimize socially desirable responses. The parents were asked to choose the statement that describes their best and then checks "sort of true for me" or "really true for me". Possible scores range from 1 (low perceived competence, satisfaction, investment, or role balance) to 5 (high perceived competence, satisfaction, investment, or role balance). SPPR scales have shown

good internal consistency, Cronbach's alphas ranged from .72 to .80 across the scales (MacPhee & Benson, 1986; Seybold, Fritz, & Macphee, 1991). The good internal consistency was confirmed in the present study with Cronbach's alphas ranged from .75 to .78 for mothers and .72 to .77 for fathers.

The Symptom Checklist-90-Revised (SCL-90-R; Derogatis & Lazarus, 1994) is a self-reported questionnaire containing 90 items to screen for a broad range of symptoms. It consists of 9 primary symptom dimensions: Somatization (SOM), Obsessive–Compulsive (O–C), Interpersonal Sensitivity (I-S), Depression (DEP), Anxiety (ANX), Hostility (HOS), Phobic Anxiety (PHOB), Paranoid Ideation (PAR), and Psychoticism (PSY). The SCL-90 yields also a Global Severity Index (GSI) that is the mean value of all of the items. Parents were asked to answer to on a 5 point Likert-type scale, ranging from ''not at all'' (0) to ''extremely'' (4). The scales have demonstrated good internal consistency (Derogatis & Lazarus, 1994; Sarno, Preti, Prunas, & Madeddu, 2011). For the present study, the internal consistency ranged from .63 to .91 for mothers, from .62 to .81 for fathers across the scales.

2.3.3. Data analyses

First of all, we removed nine of the 99 parents (three mothers and six fathers) from the analysis, since they had high level scores on the Defensive Responding scale of the PSI/SF. We performed preliminary analyses on the remaining 90 parents (47 mothers and 43 fathers), reporting descriptive statistics of each parenting measures after incomplete cases were removed.

Then we examined all the questionnaires to determine if there are any gender differences, using only paired samples (both parents of a child). We carried out a MANOVA by considering the total scores of each questionnaires contemporarily: the TS for the PSI, the GSI for the SCL-90, and total scores for the PSQ and SPPR which were calculated by means of their scales' scores. Then (if the effect is significant) we execute the comparisons on each scale by means of paired t-tests. For the SCL-90, Wilcoxon Signed-Rank test was used due to small sample size (20 mothers and 20 fathers). Number of subjects varied among the analyses due to the incomplete data.

2.4. Results

We investigated the association between our measures on 90 parents and the corresponding demographic variables: no associations emerged between parenting measures and child age, parents' age, or family SES. Considering the first aim of this chapter, mean scores and percentages of subjects in clinically significant range among mothers and fathers on the PSI/SF are presented in *Table 1*. Forty-nine percent of the mothers and fifty-one percent of fathers reported parenting stress scores that were in the clinically significant range, as indexed by the total score on the PSI. The most stressful area for mothers and fathers relates to the basic behavioral characteristics of children that make them easy or difficult to manage; roughly, three-quarter of mothers (72%) and 63% of fathers reported clinically significant scores on the Difficult Child scale. Moreover, 47% of mothers and 53% fathers reported clinically elevated scores in the Parent-Child Dysfunctional Interaction scale. Relatively less percent of parents (26% of mothers and 23% of fathers) reported clinically significant scores on the Parenting Distress scale.

Additionally, we reported the mean scores for the PSQ, the SPPR and the SCL-90-R in *Table 2* and *Table 3*.

Results from the MANOVA demonstrated a significant multivariate effect of gender on the outcome variables (the total scores of PSI, PSQ, SPPR, and SCL-90), $F(4,48) = 2.58$, $p < .05$; Wilk's $\Lambda = 0.82$, partial $\eta^2 = .17$. Separate comparisons on each scale revealed significant differences between mothers and fathers in the Social Exchange scale of the PSQ, $t(31) = 3.46$, $p = .002$ (see *Fig. 2*): mothers reported higher score than fathers in this scale. Moreover, a statistically significant difference emerged in the Depression scale of the SCL-90-R, $T(19) = 135$, $p = .03$ (see *Fig. 3*): mothers reported higher level of depression than fathers. It is worth noting that no gender differences were found in the PSI/SF and the SPPR.

Table 1: Mean scores (with Standard Deviation) and percentages of subjects in clinical range on the Parenting Stress Index-Short Form (PSI/SF) on 90 samples (47 mothers and 43 fathers). Percentages of subjects in the clinical range for each scale of PSI/SF were determined using normative guidelines provided in the PSI/SF Manual.

	Mean *(SD)*			%Clinical Range		
	Mothers	Fathers	Total	Mothers	Fathers	Total
PD	55.0 (27.3)	54.2 (26.6)	54.6 (26.8)	26	23	24
DC	81.6 (20.7)	79.5 (23.6)	80.6 (22.0)	72	63	68
P-CDI	75.9 (20.6)	77.7 (21.3)	76.7 (20.8)	47	53	50
TS	74.9 (21.8)	74.2 (24.2)	74.6 (22.8)	49	51	50

Notes: PD: Parental Distress, DC: Difficult Child Characteristics, P-CDI: Parent–Child Dysfunctional Interaction, TS: Total Stress.

Table 2: Mean scores (with Standard Deviation) on the Parental Style Questionnaire and the Self-Perception of the Parental Role on 75 samples (39 mothers and 36 fathers).

	Mean *(SD)*		
	Mother	Father	Total
Social Exchange	4.11 (0.44)	3.76 (0.44)	3.94 (0.47)
Didactic/Material	3.48 (0.54)	3.29 (0.36)	3.39 (0.47)
Limit Setting	4.20 (0.59)	4.00 (0.64)	4.10 (0.62)
Competence	2.64 (0.50)	2.52 (0.41)	2.58 (0.46)
Satisfaction	3.37 (0.48)	3.16 (0.64)	3.27 (0.57)
Investment	2.44 (0.34)	2.37 (0.32)	2.41 (0.33)
Role Balance	2.82 (0.55)	2.76 (0.51)	2.79 (0.53)

Notes: Social Exchange, Didactic/Material and Limit Setting are the scales of the Parental Style Questionnaire. Competence, Satisfaction, Investment and Role Balance are the scales of the Self-Perception of the Parental Role.

Table 3: Mean scores (with Standard Deviation) on the Symptom Checklist-90-Revised on 52 samples (28 mothers and 24 fathers).

	Mean *(SD)*		
	Mother	Father	Total
SOM	0.58 (0.47)	0.32 (0.23)	0.46 (0.40)
O-C	1.51 (1.86)	1.75 (3.79)	1.62 (2.89)
I-S	0.68 (0.75)	0.43 (0.46)	0.56 (0.64)
DEP	0.69 (0.60)	0.52 (0.42)	0.61 (0.53)
ANX	0.55 (0.51)	0.45 (0.44)	0.50 (0.48)
HOS	0.56 (0.68)	0.49 (0.43)	0.53 (0.57)
PHOB	0.13 (0.34)	0.11 (0.21)	0.12 (0.28)
PAR	0.70 (0.69)	0.47 (0.50)	0.59 (0.61)
PSY	0.30 (0.49)	0.21 (0.25)	0.26 (0.40)

Notes: SOM: Somatization, O-C: Obsessive-Compulsive, I-S: Interpersonal Sensitivity, DEP: Depression, ANX: Anxiety, HOS: Hostility, PHOB: Phobic Anxiety, PAR: Paranoid Ideation, PSY: Psychoticism.

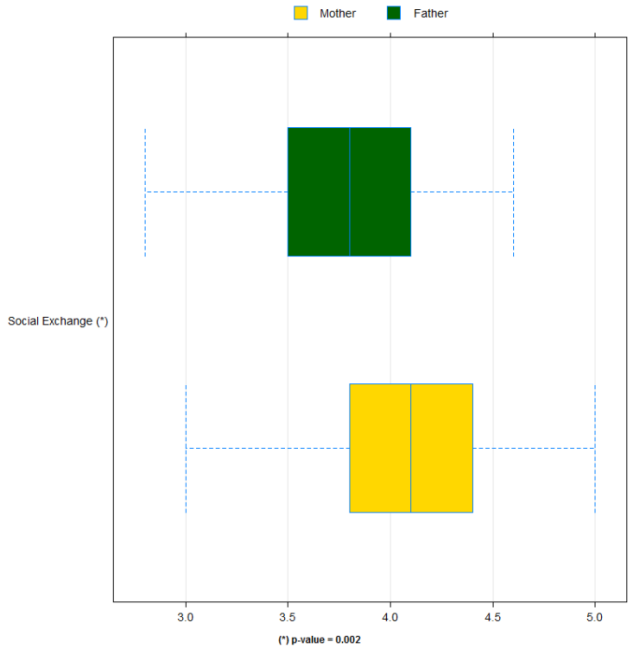

Fig. 2: Boxplots of the scores of the Social Exchange scale of the Parenting Style Questionnaire grouped by mothers (gold) and fathers (dark green). An asterisk highlights the scale having statistically significant difference by gender.

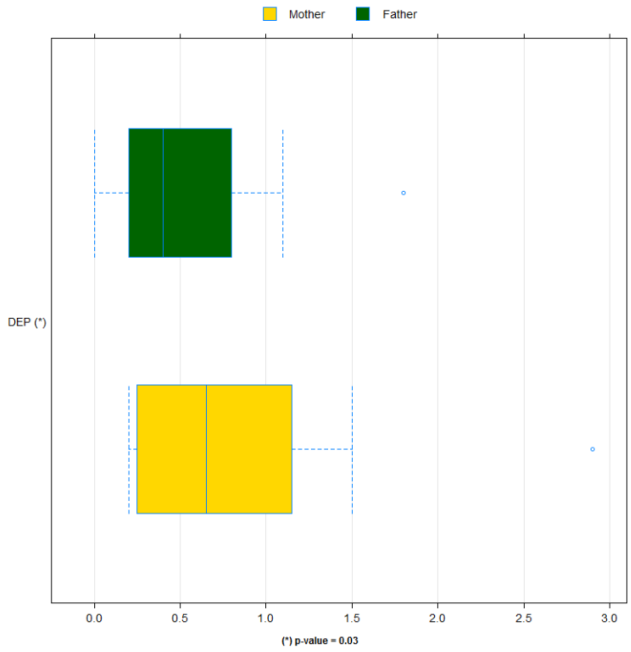

Fig. 3: Boxplots of the scores of the Depression scale in the Symptom Checklist-90-Revised grouped by mothers (gold) and fathers (dark green). An asterisk highlights the scale having statistically significant difference by gender. DEP: Depression.

2.5. Discussion

The purpose of this study was to examine the profiles of both parents of children with ASD addressing three important domains of parenting. Specifically, we aimed to determine whether mothers and fathers differ in terms of parenting stress, mental health and parental attitude. Our results highlighted both similarities and differences between mothers and fathers of children with ASD. We found differences among parents in terms of their scores on measures of attitude and mental health; the results are partially consistent with our hypothesis. Moreover, we aimed to provide stress profiles of parents in our sample. We found that considerable percentages of mothers and fathers have scores above the clinical cut-points, showing that they experience clinically significant levels of parenting stress.

Considering the parental attitude, we found that mothers reported higher score on the Social Exchange scale of the Parental Style Questionnaire than fathers did. This scale reflects sensitivity, expressions of affection, and positive responsiveness to the child. Social exchanges are affective interpersonal dyadic interchanges (Barnard & Solchany, 2002; Kaye, 1982) that include rocking, kissing, comforting, smiling, and playful face-to-face contact (Bornstein & Cote, 2004). This result may be interpreted in light of the literature on the mother–child interaction in typical development. In a previous study, Italian mothers reported that they interacted with their young children in social as well as didactic ways (Senese, Bornstein, Haynes, Rossi, & Venuti, 2012). Our findings expand this result, by extending to mothers of children with ASD and introducing a comparison with fathers. These results further support the idea that mothers and fathers interact with and care for children in different and oftentimes complementary ways (Barnard & Solchany, 2002; Parke, 2002). It could be that, compared to fathers, mothers in our sample may take on more responsibility for the social interaction with their children than

fathers. In sum, parenting attitude of mothers and fathers differ in social behaviors to their children; mothers engage with their children in more social exchange than fathers do.

With respect to the parental mental health, in line with our hypotheses, a difference emerged from the Depression scale of the Symptom Checklist-90-Revised. This scale summarizes a wide range of accompanying symptoms of a depressive syndrome (i.e., withdrawal, loss of motivation, suicidal thinking, loss of vital energy; see Derogatis & Lazarus, 1994). In our study, specifically, mothers of children with ASD reported higher level of depression than fathers of children with ASD. In the light of the present study and from the results of previous research, it appears as the difference among parents emerged in psychopathological problems, reflecting characteristics of the depressive syndrome. This result is consistent with the previous studies (Hastings et al., 2005; Olsson & Hwang, 2001) that showed gender differences in mental health with mothers of children with ASD reporting more problems than fathers, in terms of depression. Moreover, similar results have been found among parents of young newly diagnosed children (Davis & Carter, 2008).

Why did mothers of children with ASD show higher level of depression than fathers? A possible explanation may concern the differences in responsibility assigned to parenting from each parent. As a matter of fact, historically, mothers remain the primary caregivers of their children in the vast majority of cultures around the world (Barnard & Solchany, 2002), and they more likely assume the managerial role than fathers from their children's infancy through middle childhood (Parke, 2002; Russell & Russell, 1987). Also, Winnicott (1990) described mothering as a ''holding environment'' for the child, and providing a holding environment requires that mothers have the physical and psychological resources to be on alert to the child (Barnard & Solchany, 2002). Thus, parenting is often equated with mothering (Bornstein & Sawyer, 2008). In line with these

ideas, Olsson and Hwang (2001) suggested that mothers take on a larger part of extra care and practical work that the child with disabilities requires. In our sample, it could be that, mothers of children with ASD experience more depression symptoms compared to fathers of children with ASD, due to the fact that they are more involved in caregiving activities, they take more managerial responsibilities and therefore they are more exposed to the difficulties in rearing a child with special needs (Barnard & Solchany, 2002; Crnic, Low, & Bornstein, 2002; Parke, 2002). However further studies are needed to confirm this hypothesis.

Besides those differences, we found also some similarities between mothers and fathers in terms of their scores on measures of parenting stress. The results show that there were no significant differences between mothers' and fathers' mean scores in all aspects of parenting stress (in all scales and total score of the Parenting Stress Index-Short Form). Although these results differ from some published studies (Moes et al., 1992; Sharpley et al., 1997; Tehee et al., 2009), they are consistent with those of other studies suggesting that mothers and fathers have similar parenting stress levels (Baker-Ericzn et al., 2005; Davis & Carter, 2008; Hastings, 2003). Moreover, it is important to note that considerable percentages of mothers and fathers have scores above the clinical cut-points, showing that they experience clinically significant levels of parenting stress. Taken together, these results point out that both mothers and fathers of children with ASD have elevated parenting stress, consistent with the previous study of Davis and Carter (2008) which reported that many mothers and fathers of recently diagnosed toddlers share high levels of stress. The experience of raising a child with ASD can be stressful on individual parents, as both mothers and fathers of children with ASD have been shown to experience significant stress. In sum, our results showed that the levels of parenting stress did not really differ between mothers and fathers of children with ASD. Given the unique and

important challenges in raising a child with ASD, these results highlight the need to consider paternal stress in addition to maternal stress in the further research and also in family interventions.

Finally, a number of important limitations need to be considered in the present work. Although the measures applied in this work are widely used, they bring an issue in that the results emerge from self-reported data. More broadly, research is also needed to determine parenting domains using different methodological approaches in addition to the parents' self-reports.

In conclusion, the current study on families of children with ASD provides insights that will help researchers and clinicians to better understand the complexity of the treatment of children with ASD. Specifically, the results make noteworthy contributions to the current literature. First of all, we included fathers who are typically less considered in the literature, even though fathers are important as mothers in children's development (Parke, 2002). Second, we took into consideration several important domains of parenting: stress, attitude and mental health; whereas most studies have only been carried out with a small number of parenting domains (e.g., stress). Taken together, the current findings add to a growing body of literature on parenting and autism.

In addition, this study has clinical implications and parental practical importance. An implication of these findings is that both mothers and fathers should be taken into account but considering the differences and similarities between them in the parenting dimensions since these dimensions affect child development and have effects on parenting (Bornstein & Lansford, 2010; Bornstein, 2002; Darling & Steinberg, 1993; Foster et al., 2008; Jacob & Johnson, 1997; Senese, Bornstein, et al., 2012). Different parental style and well-being between mothers and fathers, which we found in the present

study, bring diverse parental experience, and eventually practical effects on parent–child relation. Moreover, having higher level of stress in both parents is worth to consider in the clinical implications and parental practice. Therefore, in line with our findings, specific intervention programs are needed for both parents aimed to a reduction in their stress levels with taking into account the different parental style and well-being between mothers and fathers. Furthermore, professionals might take into account a more effective father involvement in the children's life to make fathers to assist their children and also mothers. It may help to share the responsibilities in the life of their children, and decrease the experience of stress and depression. In this way professionals would be able to assist both parents comprehensively in becoming aware of important factors to focus and help them to cope efficiently with stress using suitable strategies.

Chapter 3: Treatment-related changes in children's communication impact on maternal satisfaction and well-being[2]

Chapter Plan: The previous chapter (Chapter 2) provided a profile of parents of children with ASD, highlighting similarities and differences between mothers and fathers in parenting stress, mental health and parental attitude. The following chapter (Chapter 3) will focus on different aspect of parental well-being. This study will investigate whether maternal well-being is affected by the outcomes of children receiving intervention. The aim of this study was to evaluate the extent to which treatment-related changes and other non-treatment related factors affect maternal well-being. We hypothesized that those mothers whose children undergo positive treatment-related changes will experience increased parental sense of competence and, as consequence, show reduced levels of negative well-being.

3.1. Introduction

Autism Spectrum Disorder (ASD) is characterized by difficulties in social communication and restricted, repetitive patterns of behavior and interests (American Psychiatric Association, 2013). As discussed in more detail in Chapter 2, it is well established that parenting a child with ASD is stressful, impacting on mental health and overall quality of life (Baker-Ericzn et al., 2005; Davis & Carter, 2008; Eisenhower et al., 2005; McStay et al., 2013). Compared with parents of children with other developmental

[2] Ozturk, Y., Vivanti, G., Uljarevic, M., & Dissanayake, C. Treatment-related changes in children's communication impact on maternal satisfaction and well-being. Research in Developmental Disabilities. Under review.

disabilities and those of typically developing children, parents of children with ASD are more likely to report elevated levels of parenting related stress, psychological distress, and more mental health issues, such as anxiety and depression (Eisenhower et al., 2005; Estes et al., 2009; Hoffman et al., 2009; McStay et al., 2014). For example, Bitsika and Sharpley (2004) reported that half of the parents in their study were severely anxious and nearly two thirds were clinically depressed. Findings on the prevalence of anxiety problems however are mixed, with rates ranging from 15.6% to 50% (Bitsika & Sharpley, 2004; Kuusikko-Gauffin et al., 2013; Mazefsky et al., 2008).

A number of factors negatively impact on parent well-being in this population, including the presence of severe challenging behaviors in their child with ASD, communication and social deficits, low cognitive functioning and severity of autistic symptoms (Bishop, Richler, Cain, & Lord, 2007; Hastings et al., 2005; Konstantareas & Homatidis, 1989; Lecavalier, Leone, & Wiltz, 2006; Lyons, Leon, Phelps, & Dunleavy, 2010; McStay et al., 2013, 2014; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). For example, lack of communication is a major cause of worry for parents from very early on (often before a diagnosis is made), and continues to impact quality of life and parental well-being throughout the lifespan, both directly (as difficulties in communicating can cause anxiety and confusion about the child's behavior; Marcus, Kunce, & Schopler, 2005) and indirectly (children with poor social communication skills are more vulnerable to challenging behaviors, including aggression and self-injurious behaviors; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). Indeed, it has often being suggested that communication deficits make families of these children particularly vulnerable to stress (Bebko, Konstantareas, & Springer, 1987; Bristol, 1984; Ekas & Whitman, 2010). Parents of children with ASD (Lecavalier et al., 2006) as well as those who have children

with Intellectual Disability (Hassall, Rose, & McDonald, 2005) who have better communication skills report less stress.

In addition to communication skills, the child's cognitive and adaptive behavior difficulties can also have a negative impact on parents' well-being. Indeed, child cognitive functioning has been found to be associated with maternal stress (Baker-Ericzn et al., 2005), and parents of children with ASD report that their children's cognitive problems are frustrating and stressful for them (Bebko et al., 1987). Regarding to the role of adaptive behavior issues on parental well-being, low adaptive functioning in children with autism has been found to be correlated with increased parenting stress (Hall & Graff, 2011) and high perceived negative impact (Bishop et al., 2007).

Importantly, however, the behavior of children with ASD (including communicative behavior) and cognitive functioning are subject to change with appropriate intervention (Dawson et al., 2010; Granpeesheh, Doreen Tarbox & Dixon, 2009; Koegel & Kern Koegel, 2006; Remington et al., 2007; Sallows & Graupner, 2005; Vivanti et al., 2014). Therefore it is plausible that intervention programs that target these difficulties (e.g., deficits in communication, cognitive functioning and adaptive behavior) may also impact parental well-being. A number of studies have investigated the effects of different types of parent-focused interventions for children with ASD on parents' well-being (Estes et al., 2014; Karst et al., 2014; Keen, Couzens, Muspratt, & Rodger, 2010), finding that interventions had a positive impact on parental stress. However, no research to date has investigated the extent to which treatment-related changes in children affect their parents' well-being.

Although caring for a child with disability is challenging, it has been shown that these challenges are not only possible to overcome but that the experience of having a

child with a disability may strengthen families, expand their social network and lead to increased personal growth in parents and other family members (King, Zwaigenbaum, Bates, Baxter, & Rosenbaum, 2012; Turnbull, Behr, & Tollefson, 1986). Consistent with the notion that the link between life events and psychiatric symptoms is frequently moderated by individual characteristics (Belsky & Pluess, 2009), it is plausible that certain personal characteristics of parents of children with ASD might on one hand put them at increased risk for developing stress related symptoms, and on the other, protect them despite the problems they face in their everyday lives. One such factor, the sense of competence appear important to understand parental well-being (Johnston & Mash, 1989). Two dimensions, namely perceived self-efficacy as a parent and satisfaction derived from parenting have been found to be related to well-being in parents of children with ASD (Giallo, Wood, Jellett, & Porter, 2013; Hastings & Brown, 2002). Parents of children with ASD who are less satisfied report higher levels of stress (Ozturk, Riccadonna, & Venuti, 2014). Moreover, self-efficacy was found to mediate the impact of child behavior problems on anxiety and depression in mothers of children with ASD (Hastings & Brown, 2002). Interestingly, perceived parenting competence was found to differentiate mothers of children with ASD from mothers of children with other developmentally delays and typically developing children (Rodrigue et al., 1990). Specifically, mothers of children with ASD reported lower perceived parenting competence suggesting that they may feel more uncertain about whether they possess the skills necessary to be a good parent. Therefore, parenting sense of competence (efficacy and satisfaction) might be an important factor affecting parents' well-being. Previous studies have not explored the potential role of parental sense of competence in examining change in children's symptoms as a result of intervention and parental well-being.

Taken together, a broad range of characteristics of children with ASD, including the presence of communication, cognitive and adaptive deficits, challenging behaviours and parental own characteristics, have been identified as important variables in understanding parents' well-being.

The intervention program delivered at the Victorian Autism Specific Early Learning and Care Centre (Victorian ASELCC) in Melbourne, Australia, provided an opportunity to study the impact of treatment-related changes on parents' well-being. This program, documented in Vivanti et al. (2014), involved a group of preschoolers undergoing one year of the Early Start Denver Model (ESDM) delivered in a group setting, which resulted in significant improvements across a number of behavioral domains. The ESDM is a manualized comprehensive early intervention program developed specifically for toddlers and preschoolers with ASD (Rogers & Dawson, 2010).

3.2. Objectives

In the current study, our objective was to evaluate the extent to which treatment-related changes and other non-treatment related factors affect changes in maternal well-being from pre-intervention (baseline) to post intervention (12 months later). More specifically, we aimed to explore whether treatment-related changes in children with ASD affect parental well-being and how parental sense of competence influences the effect of the treatment-related changes on parental well-being. Our working hypothesis was that those mothers whose children undergo positive treatment-related changes will experience increased parental sense of competence and, as consequence, show reduced levels of negative well-being.

3.3. Method

3.3.1. Participant

The participants comprised 43 mothers (mean age = 35.9 years; SD =4.79) of children (mean age = 38.2 months; SD = 9.8) diagnosed with ASD who were enrolled at the Victorian ASELCC in Melbourne, Australia. ASD diagnoses were confirmed through administration of the Autism Diagnostic Observation Schedule (Lord et al., 2000). Demographic characteristics of children and their families are presented in *Table 4*. The socioeconomic status (SES) of the mothers was calculated using parental education, occupation, and annual family income; a higher score indicated higher SES.

Table 4: Descriptive statistics of children, mothers and families

Demographic characteristics			%	N	Mean(SD)
Child					
	Age (month)				38.23 (9.8)
	Gender	male	88.4	38	
		female	11.6	5	
Family					
	Family Type	Single Parent	14	6	
		Natural Family	86	37	
	Number of Children	1	30.2	13	
		2	51.2	22	
		3	7.0	3	
		4	4.7	2	
Mothers					
	Age (year)				35.9 (4.79)
	Education	Completed secondary school	23.3	10	
		Tertiary Qualification	30.2	13	
		Post-graduate Degree	44.2	19	
	Occupation	On maternal leave	2.3	1	
		Student	9.3	4	
		Home carer or home duties	34.9	15	
		Self-employed	18.9	8	
		Clerical & retail services	7.0	3	
		Paraprofessional	2.3	1	
		Professional	20.9	9	
	SES				4.74 (1.47)

3.3.2. Procedure

The ADOS-G (Lord et al., 2000) and the Mullen Scales of Early Learning (MSEL; Mullen, 1995) were administered by expert clinicians at the Victorian ASELCC to assess behavioral presentation and cognition. Pre-intervention (baseline) assessments of the child were completed prior to treatment onset, and post-intervention assessments were completed 12 months later by different clinicians to avoid bias. Mothers were asked to complete a demographic information form and three questionnaires were completed at pre- and post-intervention: the Depression Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) to assess their well-being, the Parenting Sense of Competence (PSOC; Johnston & Mash, 1989) to determine their satisfaction and self-efficacy in the parenting role, and the Vineland Adaptive Behavior Scales II (VABS-2; Sparrow, Balla, & Cicchetti, 2005) to assess their children's adaptive behavior.

3.3.3. Intervention

Children received between 15 and 25 hours of group-based ESDM intervention each week for a full calendar year. Intervention was delivered by trained therapists including a speech pathologist, psychologist, occupational therapist, as well as early education and childcare staff. Treatment was delivered according to the guidelines for group implementation of the ESDM, as detailed in Rogers and Dawson (2010). The ESDM is a manualized, evidence-based intervention model, specifically designed for young children with an ASD. It uses an interdisciplinary team to teach skills that are foundational to social-cognitive development within the context of joint activity routines.

3.3.4. Measures

Depression Anxiety and Stress Scale (DASS; Lovibond & Lovibond, 1995) comprises a set of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress. The Depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The Anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The Stress scale is sensitive to levels of chronic non-specific arousal and assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient. The DASS21 was used in this study with participants asked to use 4-point severity/frequency scales ranging from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time) to rate the extent to which they have experienced each state over the past week. Scores for Depression, Anxiety and Stress are calculated by summing the scores for the relevant items. The totals for each scale were multiplied by 2 in order to be directly compared to scores from the full scales, and interpreted by reference to the normative values for the full scales. The scales have demonstrated good internal consistency (Crawford & Henry, 2003; Gloster et al., 2008; Henry & Crawford, 2005; Lovibond & Lovibond, 1995). A total DASS score was calculated to give a composite measure of mother's mental well-being.

The Parenting Sense of Competence (PSOC; Johnston & Mash, 1989) is a 17-item self-report questionnaire designed to measure parents' satisfaction with parenting and their self-efficacy in the parenting role. Items are rated on a 6-point Likert scale ranging from 1 (strongly agree) to 6 (strongly disagree). The Satisfaction subscale reflects

parenting frustration, anxiety, and motivation, while Efficacy assesses capability, problem-solving ability, and competence. High scores represent high degrees of satisfaction and efficacy with the parenting role. Acceptable levels of internal consistency have been reported for the PSOC in a number of studies (Gilmore & Cuskelly, 2009; Johnston & Mash, 1989; Rogers & Matthews, 2004).

The Vineland Adaptive Behavior Scales II (VABS-2; Sparrow, Balla, & Cicchetti, 2005) is the most widely used instrument to assess parents' perceptions of their child's everyday adaptive functioning. Domains covered by the VABS-2 in the present study include Communication, Daily Living Skills, and Socialization. The items of the VABS-2 were rated on a 3-point Likert scale (from 2 = usually to 0 = never) with higher scores indicating greater adaptive ability. Age-equivalent scores are calculated for each domain. Previous studies have found the VABS-2 to demonstrate good psychometric properties (Hall & Graff, 2011; Sparrow et al., 2005).

The Mullen Scales of Early Learning (MSEL; Mullen, 1995) is a standardized measure of early development, yielding standardized T Scores and age equivalent (AE) scores on the following subscales: Visual Reception, Fine Motor, Receptive Language, and Expressive Language. Since the standard T scores on the MSEL have a floor of 20, and many participants had scores at this floor level, verbal and non-verbal developmental quotient scores (DQ: AE scores/chronological age x 100) were created from the subscale age equivalent scores for use as outcome measures reflecting the developmental level of child (Anderson, Liang, & Lord, 2014; Rogers et al., 2012). Verbal DQ was created by combining the Expressive and the Receptive Language subscale scores, whereas non-verbal DQ was created by combining the Visual Reception and the Fine Motor subscale scores. Good internal consistency has been reported by Mullen (1995).

The Autism Diagnostic Observation Schedule (ADOS-G; Lord et al., 2000) is a standardized diagnostic observational instrument that quantifies autism symptoms in social reciprocity, communication, play and repetitive behaviors (Lord et al., 2000). On the basis of language development level, five children were administered the ADOS Module 2 (phrase speech) and all the remaining children were administered the ADOS Module 1. The ADOS calibrated severity score algorithms (SA; Gotham, Risi, Pickles, & Lord, 2007), which allow for comparison of autism severity across participants tested with different ADOS modules, were utilized. Good internal consistency has been reported by Lord et al., 2000).

3.3.5. Data Analysis

A total score encompassing Depression, Anxiety, Stress scales of the DASS was calculated as a measure of negative aspects of maternal well-being. Initial descriptive analyses examined assumptions of normality for each variable of interest. As all variables were normally distributed, the study hypotheses were tested via parametric analyses.

We performed paired dependent t-tests to ascertain change in mental Well-being between pre-intervention (T1) and post intervention (T2). Then, Pearson's Product-Moment Correlation coefficients were computed to assess the relationships between mothers' well-being at T1 (baseline) and the following variables: VABS communication, daily living and social skills, MSEL verbal and non-verbal DQ, ADOS calibrated SA, mothers' age, SES, number of children, and PSOC satisfaction and efficacy levels at T1.

Next, we explored which putative predictors (change in VABS communication, daily living and social skills, change in MSEL verbal and non-verbal DQ, change in

ADOS calibrated SA, mothers' age, SES, number of children, change in mothers' satisfaction and efficacy levels) were associated with parents' well-being at T2 by performing Pearson's Product-Moment Correlation analyses. Hierarchical multiple regression analyses were performed next with the predictors which were significant in the previous step to test the contribution of each to T2 well-being (controlling for T1 well-being). The order in which the variables were entered into the regression was based upon the strength of the correlations from the previous analysis.

Finally, mediation analysis was performed using PROCESS (Hayes, 2012), a computational tool for mediation, moderation, and mediated moderation models of observed effects that runs under SPSS (Statistical Package for Social Science software, version 21.0). Our model postulates an indirect path from children's treatment-related changes to mothers' well-being, through parental sense of competence. The Bootstrap Confidence Intervals as an inferential test for indirect effects in mediation analysis was used. Non-significant relations in models are indicated by confidence intervals overlapping with zero; effect sizes are indicated by R^2 values.

3.4. Results

Table 5 presents means and standard deviations for the outcome variables at pre-intervention (T1) and post intervention (T2). No significant change was found for maternal Well-being from T1 (M = 11.0, SD = 6.3) to T2 (M = 11.0, SD = 7.8); $t(42)$ = .02, p = .98. At Time 1, the only significant correlation was between Well-being and Satisfaction, r = - .57, p < .001.

Table 5: Mean scores at pre-intervention (T1) and post intervention (T2)

Variables		Mean *(SD)* T1	T2
Mothers			
	Well-being	11.02 (6.26)	11.00 (7.77)
	Satisfaction	20.63 (7.84)	17.58 (4.94)
	Efficacy	26.07 (6.79)	27.07 (6.52)
Children			
	VABS Communication	19.13 (13.04)	26.72 (14.86)
	VABS Daily Living Skills	25.19 (12.84)	33.15 (14.75)
	VABS Social Skills	16.87 (11.00)	22.80 (12.04)
	MSEL Verbal DQ	57.39 (30.56)	88.77 (45.79)
	MSEL Non-verbal DQ	66.28 (25.48)	98.21 (41.57)
	ADOS Calibrated SA	14.11 (4.65)	12.41 (5.08)

Note. VABS = Vineland Adaptive Behavior Scales; MSEL = Mullen Scales of Early Learning; DQ = developmental quotient ; ADOS = Autism Diagnostic Observation Schedule; SA = severtiy algorithm; T1 = pre-treatment; T2 = post-treatment; SD = standard deviation

Well-being at T2 was negatively correlated with Change in Satisfaction (r = - .50, p = .001), with Change in VABS Communication (r = - .41, p = .008), change in VABS Daily Living Skills (r = - .39, p = .01), Change in VABS Social Skills (r = - .37, p = .02), and mothers' age (r = - .38, p = .02). None of the other variables, including the MSEL scores, were significantly associated to mother's Well-being. These significant predictors were entered into the hierarchical regression to test the contribution of each to Well-being at T2, taking into account Well-being at T1. We found that only Change in VABS Communication and Change in PSOC Satisfaction significantly contributed to the variance of Well-being at T2 once Well-being at T1 and other relevant predictors were controlled for (See *Table 7*).Our working hypothesis proposed that children's treatment-

related changes would predict maternal negative well-being, with a mediating influence of parental sense of competence. Considering the regression results, we chose Change in VABS Communication as a casual variable, Well-being at T2 as a manipulated variable, and Satisfaction at T2 as a mediator in the mediation analysis; this model is graphically presented in *Fig. 4*. We predicted that there would be an indirect effect from Change in VABS Communication to maternal Well-being at T2 through maternal Satisfaction at T2. As predicted, we did find the significant indirect effect from Change in VABS Communication to Negative Well-being at T2 through Satisfaction at T2 (*B* = -.13,: LL = -.23, LU = -.02) (*Table 7*), however there was no direct effect from Change in VABS Communication to Negative Well-being at T2 (*B* = -.12, *p* = .12) (see *Fig. 4*).

Table 6: Summary of hierarchical regression analysis for variables predicting Well-being at T2

	Well-being T2																	
	Step 1			Step 2			Step 3			Step 4			Step 5			Step 6		
Predictor variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Well-being T1	.52	.16	.49**	.64	.13	.61***	.68	.13	.65 ***	.68	.13	.65***	.69	.13	.66***	.69	.13	.65***
Change in Satisfaction				-.43	.10	-.52***	-.27	.11	**-.35***	-.27	.11	-.35*	-.29	.11	-.37*	-.28	.12	-.36*
Change in VABS communication							-.24	.09	**-.37 ****	-.24	.12	-.38*	-.24	.12	-.37*	-.23	.12	-.37
Change in VABS daily living skills										.004	.08	.007	-.004	.08	-.008	.02	.11	.04
Mothers' Age													.15	.23	.08	.13	.24	.07
Change in VABS social skills																-.05	.13	-.07
R^2	.42			.52			.62			.62			.62			.63		
F change	10.52**			18.6***			**7.9****			.002			.43			.12		

Note. B = Unstandardized regression coefficient; SE B = Standard errors of the regression coefficient; β = Standardized coefficient; F = F value; R^2 = Squared multiple correlation coefficient; SES = socioeconomic status; VABS = Vineland Adaptive Behavior Scales; T1 = pre-treatment; T2 = post-treatment

* p < .05. ** p < .01. *** p < .001.

Table 7: Direct and indirect effects from mediation analysis between Change in VABS Communication and Well-being at T2

Variables			Direct and indirect effects								
Dependent	Predictor		Direct effect					Indirect effects through Satisfaction at T2			
		R^2	B	se	LL	UL	*p*	B	se	LL	UL
Change in VABS Communication	Well-being at T2	.50	-.12	.07	-.26	.03	.12	-.13	.05	-.23	-.02

Note. 95% confidence interval (*LL* lower limit, *UL* upper limit); B = regression coefficent ; R^2 = total regression coefficient (from standard regression statistics); se = standard error

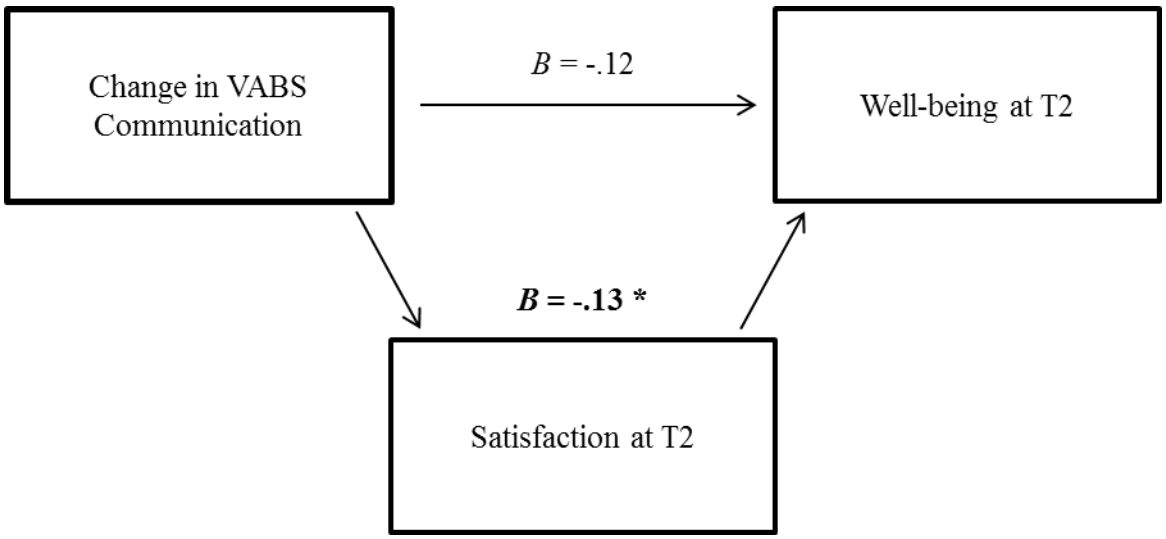

Fig. 4: Significant indirect path between Change in VABS Communication and Well-being at T2 through Satisfaction at T2

3.5. Discussion

The aim in this study was to determine whether treatment-related changes in children with ASD contribute to changes in maternal well-being from pre-intervention to post-intervention and how parental sense of competence influences the effect of treatment-related changes on maternal well-being. Analyses suggest that different child and family factors, including mother's age, were linked to maternal well-being. However, treatment-related changes in children's communication skills and changes in mothers satisfaction contributed to variance in maternal well-being at post-treatment above and beyond each of these other factors. In addition to this main focus, the mediation analysis suggested that changes in children's communication lead to increased parenting satisfaction levels which in turn lead to increased well-being (as reflected in reduced self-reported Depression, Anxiety and Stress).

The hypothesis that those mothers whose children undergo positive treatment-related changes will experience a reduction in their level of negative well-being, as a consequence of increased parental sense of competence, was supported with regards to change in communication skills as assessed through the VABS. These findings are consistent with those from previous studies indicating the influence of communication deficits on maternal well-being (Bebko et al., 1987; Bristol, 1984; Hassall et al., 2005; Lecavalier et al., 2006), and extend current knowledge by showing that improvements in communication level are linked to improvements in maternal satisfaction and in parental well-being. Furthermore, our results are in line with the findings by Hastings and Brown (2002) that parental sense of competence mediate the impact of child behaviour problems on maternal well-being in mothers of children with ASD. This might result from the fact

that mothers may question their own parenting competence because their child with ASD does not respond to them in a manner expected and/or hoped for (Hastings & Brown, 2002; Rodrigue et al., 1990). In fact, in another study, nearly all parents (over 90%) commented that they were sometimes unable to deal with their children's behavioural difficulties and were consequentially stretched beyond their abilities, feeling angry and frustrated, inadequate, depressed, isolated and lonely (Bitsika & Sharpley, 2004). Therefore, it is plausible that improvement in their child's communication would lead to an increase satisfaction with their parenting role, which in turn decreases the parents' negative emotional states of stress, anxiety and depression.

We did not find an association between changes in cognitive abilities (as measured through the MSEL verbal and non-verbal DQ) and parental satisfaction or wellbeing. This is surprising, given that a number of studies have reported an association between child cognitive functioning and maternal stress (Baker-Ericzn et al., 2005; Bebko et al., 1987). Importantly, however, the VABS evaluates child behavior as observed by parents in an everyday life context, whereas the MSEL evaluates the child's cognitive functioning as assessed in a structured setting. It is plausible that mothers are more affected by the improvement in their child's adaptive and functional use of communicative behavior in everyday life (e.g., the ability to request to go to the toilet, or the ability to follow instructions) than cognitive abilities as measured via formal testing (e.g. the ability to label objects "on demand"). Thus those mothers whose children undergo positive treatment-related changes in everyday communication skills experience less negative well-being at post-treatment compared to pre-treatment.

These results highlight the importance of communication skills in the child's and parents' life. Communication difficulties are a major cause of worry for parents and clearly impact parental well-being. Parents of children with ASD often feel that they are

unable to communicate and interact with their child and are unsure of how to do so. The consequence of communication impairments in autism can result in the parent and child failing to establish a communicative "meshing" (Aldred, Green, & Adams, 2004). Moreover, difficulties in communicating can cause anxiety and confusion in parents about their child's behavior. At the same time, communication skills can be one of the most noticeable changes following treatment; indeed several studies have reported improvements in communication outcomes as a consequence of treatment (Granpeesheh, Doreen Tarbox & Dixon, 2009; Koegel & Kern Koegel, 2006; Remington et al., 2007; Rogers & Wallace, 2011; Sallows & Graupner, 2005; Vivanti et al., 2014). It is plausible, therefore, that seeing positive changes in functional communication (for example the use of language to communicate in a child who was previously non-verbal) has a critical positive impact in the sense of competence and well-being of parents. These changes impact on parents more than increases in cognition, including changes in receptive and expressive language, as measured via standardized tests. Such improvements in daily communication might mitigate mothers' anxiety and confusion about their children's behavior and may also serve to reduce challenging behaviors, including aggression and self-injurious behaviors which are distressing and worrying for parents. While the current findings are consistent with this notion, future research is needed to determine the mechanisms through which improvements in communication affect maternal satisfaction and well-being.

This study has a number of strengths, including the focus on both treatment-related changes and family characteristics, such as SES, number of children, mothers' age and maternal sense of competence on maternal well-being. However, some relevant limitations must be noted. These include the lack of a control group, which does not allow us to determine whether the current findings are specific to treatment responses to the

ESDM. Furthermore, our focus was on the well-being of mothers of children with ASD, and the finding cannot be generalized to fathers – a research area that is often neglected even though fathers are as important as mothers in children's development (McStay et al., 2014; Ozturk et al., 2014; Parke, 2002).

3.6. Conclusions

The findings from the current study showed that treatment-related changes in everyday communication in the child as perceived by mothers, and parental satisfaction contributed to well-being in mothers post-treatment above and beyond other child and family factors. Moreover, the mediation analysis suggested that these changes in children's communication lead to increased satisfaction levels in mothers which in turn lead to a decrease negative well-being. The findings suggest that mothers are positively affected by observing improvements in their child's communication skills in everyday life contexts.

Part 2: Emotional and physiological responses of parents of children with ASD during the listening of infant cry

As described in the thesis statement and in Chapter 1, one of the main goal of this thesis is to examine the emotional responses and physiological reactivity of parents of children with autism spectrum disorder (ASD) while listening to infant crying, in particular cry of children with ASD. We planned to carry on three experiments. We will attempt to answer this following research question in the end of Chapter 6: How do parents of children with ASD perceive cry of children with ASD compare to cry of typically developing (TD) children?

In order to fully understand this concept, the Part 2 first begins with an Introduction that gives an overview of the previous studies and presents findings in the literature, focusing on the key theme that how adults perceive cry of infants. As we mentioned above, we carried on three experiments to answer the main research question of this thesis. Therefore, the remaining sections (Chapter 4, 5 & 6) will stand to explain these three experiments.

Introduction

What is cry?

Crying represents the first communicative channel infants can use in order to express their needs (Esposito & Venuti, 2009b). It is a biological siren, alerting the

caregiving environment about the needs and wants of the infant and motivating the listener to respond (Zeskind & Lester, 2001, p. 149). Therefore, it can be considered as a transaction between the baby and the caregiver (Maldonado-Durán & Sauceda-Garcia, 2008).

Most parents are readily able to distinguish the basic cry from the pain cry (Corwin, Lester, & Golub, 1996; Irwin, 2003; Rothgänger, 2003). They pay attention to the sound (particularly evaluating the intensity and the height of the pitch), observe the facial expression of the child, and take the environmental situation into account such as the time for baby's nap (Esposito & Venuti, 2009b). Caregivers are alerted to attend to the cries and, most likely, act to help alleviate the infant's distress by nursing and caring (Lin & McFatter, 2012).

However, some infants are better communicators than others, whereas other infants are not (Corwin et al., 1996). What happens when parents cannot adequately understand cry of their children? These kind of differences in how infants cry, result in parents saying that some infants are more readable than others or parents who say that they cannot tell what the infant needs or want (Corwin et al., 1996). It seems that the main problem is the difficulty in understanding the causes of crying episodes. In the end, if this "siren" does not work properly (either because the cry acoustic signal may be poor or atypical, or because the caretaker may have atypical reaction to the cry), it can create a bias in the child/caretaker relationship (Esposito & Venuti, 2008). The caregiver fails to recognize the child's needs, and these results in adequate feedback to the child (Esposito & Venuti, 2009b).

Crying in typical and atypical development

Findings from the literature support the idea that adults perceive cry of infants with atypical development (in our case ASD) differently compare to cry of typically developing (TD) infants (Esposito & Venuti, 2008, 2009a, 2010b; Venuti et al., 2012). Esposito and Venuti (2008) investigated how the crying of children with autism, as opposed to TD children was perceived. It has been found that adults felt mainly uneasiness and negative states while listening to an ASD crying episodes; more positive mental states felt during the listening of crying episodes belonged to TD children. Researchers concluded that adults' reactions to autistic crying were qualitatively different from non-autistic children and this difference is an additional cause of difficulty in sharing feelings and developing intersubjective processes. Another study with observational methods and analysis of retrospective home videos investigated qualitatively different maternal reactions to the crying of infants later diagnosed with autism compare to cries of typically developing infants and those with developmental delays (Esposito & Venuti, 2009a). In particular, mothers of children with autism used more verbal soothing, whereas other mothers used tactile or vestibular stimulation to soothe their children during episodes of crying. It was concluded that parents whose children have been diagnosed with autism probably had difficulty decoding the emotional signals of their children and they could not understand the meaning of the crying episodes; therefore they did not know how to react. A cross-cultural study confirmed the previous studies highlighting that Italians and Japanese alike perceive cries of children with autism as more distress and distressing than cries of typically developing children (Esposito, Nakazawa, Venuti, & Bornstein, 2012).

Differences have been emerged also in the studies with different methodologies. In a fMRI study using whole brain analysis in adults, Venuti et al. (2012) found that cries

of infants with autism, compared to those of typically developing infants, elicited increased activity in brain regions associated with emotional processing, suggesting that ASD cry may elicit more negative feelings and may be perceived as more arousing compare to cries of typically developing infants. A recent study on the components of the autonomic nervous system in males respond to typical and atypical infant vocalization showed that both fathers and non-fathers had greater negative responses (increased Galvanic Skin Responses) and more emotional arousal mediated by sympathetic activation while listening cries of children with ASD (Esposito, Valenzi, Islam, & Bornstein, 2015). Moreover, fathers were calmer and acted more promptly than non-fathers while listening to while listening to infant cries. Researchers concluded that perhaps because the fathers had more experience in caring for crying infants.

As we can see from the studies reviewed above, many studies examined responses of adults (non-parents and/or parents) to infant crying and highlighted differences between responses to ASD cry and TD cry. A question naturally arises, what affect adults judgements of infant cry, in particular cry of an infant with ASD?

The answer can lie on the studies from a growing literature on assessing the vocal production of children with ASD. Children with ASD, even before receiving a formal diagnosis, express atypical patterns of distress vocalization (Esposito et al., 2012; Esposito, Nakazawa, Venuti, & Bornstein, 2013; Esposito, Venuti, & Bornstein, 2011; Esposito & Venuti, 2009a, 2010a; Oller et al., 2010; Sheinkopf, Iverson, Rinaldi, & Lester, 2012), such as higher fundamental frequency (f0), shorter inter-bout pauses, fewer utterances. For example, Sheinkopf and colleagues (2012) carried on a study examined differences in acoustic characteristics of infants cries in a sample of babies at risk for autism and a low-risk comparison group. They found that 6-month-old infants at risk for ASD produced cries with higher and more variable f0 than low-risk infants. In addition,

at-risk infants later classified with ASD at 36 month had higher f0 values than those who were not later classified with ASD. A recent study examined the acoustic characteristics of cries of toddlers at high risk of ASD and found that they produce cries that had among the highest f0 and shortest durations (Esposito, Del Carmen Rostagno, Venuti, Haltigan, & Messinger, 2014). Another recent study confirmed the previous study and also highlighted the importance of the duration of pauses (Esposito, Nakazawa, Venuti, & Bornstein, 2014). Additionally, some studies have also reported different factors, such as attitudes of listeners, mediate the response to infant cry (Del Vecchio, Walter, & O'Leary, 2009; Lin & McFatter, 2012).

In summary, findings from the studies have been highlighted that episodes of crying in children with ASD have different acoustic properties and listeners perceived this type of cry episodes as unexpected and more negative than those of TD children.

The question now arises of how adults perceive cry of children with ASD physiologically. Since many studies with different methodologies proposed (Esposito & Venuti, 2008, 2009a, 2010b; Venuti et al., 2012), cry of children with ASD is perceived differently compare to cry of TD children (such that more stressful, unexpected and negative), does the same pattern exist in the physiological responses of listeners? To answer this question, non-invasive indices of stress-related indices of heart rate variability (HRV) and heart rate (HR) were examined. Heart rate variability (HRV) measured by power spectral analysis provides markers of autonomic nervous system activity which is of critical importance in the beat-to-beat regulation of the Heart Rate (HR) (Camm et al., 1996). HRV has become a widely used tool in many research fields (Acharya, Joseph, Kannathal, Lim, & Suri, 2006). To this line, we aimed to measure physiological aspects of listeners' responses (HR and HRV) as well as the subjective responses.

Objectives

Most of the literature in this field has focused on either non-parents' or parents' responses to infant crying, and mostly based on their self-reports. Here, we explored physiological responses in addition to behavioral responses in parents of children with ASD and parents of typically developing children to typical distress vocalizations and atypical distress vocalizations (in our case TD cry and ASD cry). As we mentioned in the beginning of Part 2, we carried on three experiments which will be explained in the remaining sections as follows:

1st experiment: The study in which we focused on stimuli preparation and validation processes will be explained in the Chapter 4. In particular, it focuses on the characterization of cry in a dimensional emotion-space with the valence axes. It was necessary to evaluate the cry episodes which were prepared for this thesis and validate them as a proper stimulus to use in the following experiments.

2nd experiment: The study that aimed to examine the emotional and physiological responses of non-parents adults while listening to infant crying will be described in Chapter 5. This study was designed to explore the main interest of this thesis in non-clinical sample before examining parents of children with ASD.

3rd experiment: Finally, the last experiment that focused the main aim of Part 2 on parents of children with ASD will be explained in the Chapter 6. It explored the emotional and physiological responses of parents of children with ASD and compare with parents of typically developing children during the listening of crying of children with ASD and typically developing children.

It is worth to note that the hypothesis of each experiment will be explained in the relative chapters.

Chapter 4: Cry in the dimensional emotion-space

Chapter plan: The key aspect of this study is to validate the cry episodes as proper stimuli. Therefore, we aim to evaluate the position of cry, which were prepared for this project, in a dimensional emotion-space with the axes valence. Our working hypothesis was that all cry episodes would fall into the unpleasant area (low level of valence) in the dimensional emotion-space.

Additionally, we aim compare the responses reported by our participants to those obtained from other samples from previous study (Bradley & Lang, 2007) to verify the generalizability of the obtained ratings. We expect that between valence and arousal scores in present and previous ratings would highly associated.

4.1. Method

4.1.1. Participants

Forty-five healthy adults (23 males: *M* age = 25.4 years, *SD* = 3.3; 22 females: *M* age = 24.1 years, *SD* = 2.5) were recruited through a database of volunteers available at the University of Trento, Italy. Adult non-parents were selected as participants in the present study; therefore we could exclude any bias or expertise in listening to cries of typical or atypical children and judging them in terms of their valence and arousal levels.

4.1.2. Acoustic stimuli

Four types of cry episodes were extracted from home videos of infants who belong to one of four groups: toddler later diagnosed with ASD are younger than 24 months (named ASD baby in the present study), aged matched typically developing toddler (named TD baby), toddler diagnosed with ASD are ages between 36-52 months (named ASD child), aged matched typically developing toddler (named TD child). All home videos were collected by the Observation, Diagnosis and Education Lab (ODF Lab) at the University of Trento. The diagnosis of toddlers was confirmed based on the DSM-IV-R criteria, confirmed by the Autism Diagnostic Observation Schedule (ADOS-G; Lord et al., 2000).

The cry episodes were experimentally manipulated employing the open source Audacity software (version 2.0.2) for audio editing to produce 10 separate audio files for four groups. Then they were digitized and analyzed using the Praat acoustic analysis software (Boersma & Weenink, 2001). In the present study, we obtained the fundamental frequency (f0) of each cry episodes to obtain the acoustic features. A long-term average spectrum (LTAS) was employed to provide spectral information for each cry episodes. LTAS is used to discriminate cry characteristics of different categories of children (Lin & Green, 2007). The First Spectral Peak (FSP) was obtained by identifying the value of the first amplitude peak of the LTAS output. FSP (in Hz) is an estimate of the average f0 of the episode of crying (Lin & Green, 2007). The FSPs of cry episodes used in the present study were for ASD (M = 485.07, SD = 57.73) and TD (M = 445.37, SD = 57.53), a significant difference, t(38) = 2.18, p = .03. Furthermore, all acoustic files were edited to normalize them for volume and duration (6 seconds) and to remove all background noise.

To describe a dimensional space defined (see *Fig. 5* for a graphical representation of this space), we used one hundred and fifty-nine sounds taken from the International Affective Sound Digitized Sounds (IADS-2; Bradley & Lang, 2007). The IADS-2 was developed to provide a set of normative emotional stimuli for experimental investigations of emotion. This system was created with three goals in mind: better experimental control of emotional stimuli, increasing the ability of cross-study comparisons of results, and increased ability to directly replicate studies (Bradley & Lang, 2007; Stevenson & James, 2008). The IADS-2 has been characterized by two main dimensions that generally include one bipolar or two unipolar dimensions that represent positivity and negativity, and have been labeled as valence or pleasure. Also usually included is a dimension that captured intensity, arousal, or energy level (Stevenson & James, 2008). Eventually, the IADS has been used successfully with characterizations of valence and arousal (Stevenson & James, 2008).

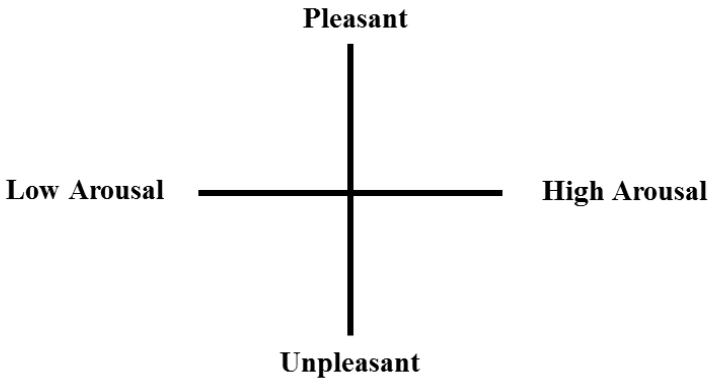

Fig. 5: Graphical representation of a two-dimensional space defined by valence and arousal

4.1.3. Measures

Self-Assessment Manikin (SAM; Bradley & Lang, 1994, 2007) is a scale that assess valence, arousal, and dominance as dimensions describing emotion. SAM ranges from a smiling, happy figure to a frowning, unhappy figure when representing the pleasure dimension, and ranges from an excited, wide-eyed figure to a relaxed, sleepy figure for the arousal dimension (*Fig. 6*). Additionally, the dominance dimension, which was not used in the present study, represents changes in control with changes in the size of SAM: a large figure indicates maximum control in the situation. It is worth to note that SAM scale was adapted according to the needs of this study (avoiding the dominance scale and adding small circles under & between the figures). The adapted version of the 9-point SAM scales is provided in *Fig. 7.*

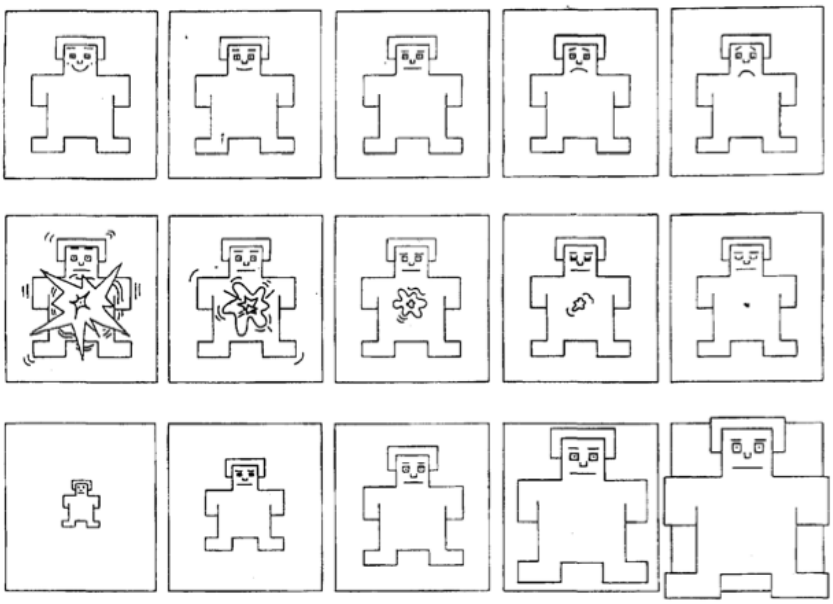

Fig. 6: Self-Assessment Manikin (SAM) system prepared by Bradley and Lang (1994) to rate the affective dimensions of valence (top panel), arousal (middle panel), and dominance (bottom panel).

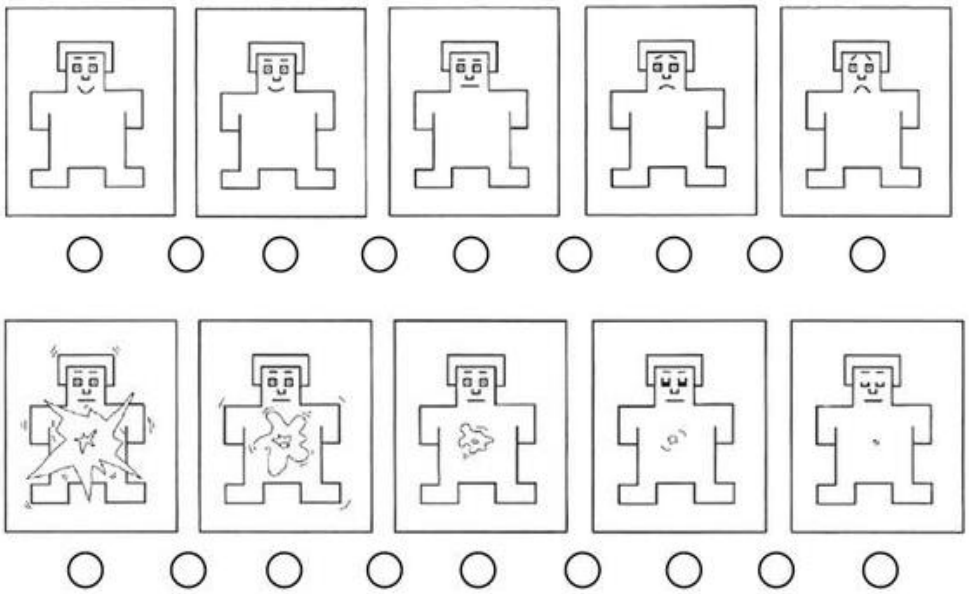

Fig. 7: The adapted version of the 9-point SAM scales used in the present study.

4.1.4. Procedure

Experimental events were controlled by an appropriate developed software (written in C-sharp). A total of 199 sessions (one sound per session) were presented randomly to the participants using a personal computer and speakers. Each session contains four phases: pre-sound resting (2s), sound (6s; a random order for each subject), resting (2s) and rating SAM (see *Fig. 8* for a graphical representation). During sound presentation an image of speaker, whereas during the rating phase SAM scales were displayed on the computer screen. Participants were instructed to listen and then rate each sound as they felt while they heard the sound. During rating phase, any of the circles under the figures in each scale, or between two figures, which results in a 9-point rating scale for each dimension could been chosen. Subjects were free (without restricted time

period) during rating phase in order to allow ample time for subjects to make two SAM ratings (Valence and Arousal) without causing stress due to an expectation of a quick response. After each 50 sounds, subjects were allowed to have a break and then continue the experiment when they would feel comfortable. Experiment lasted approximately one hour. Participants were familiarized with SAM rating procedure during the training session that appeared before the experimental session. Volume of the device was kept at the same level for all subjects.

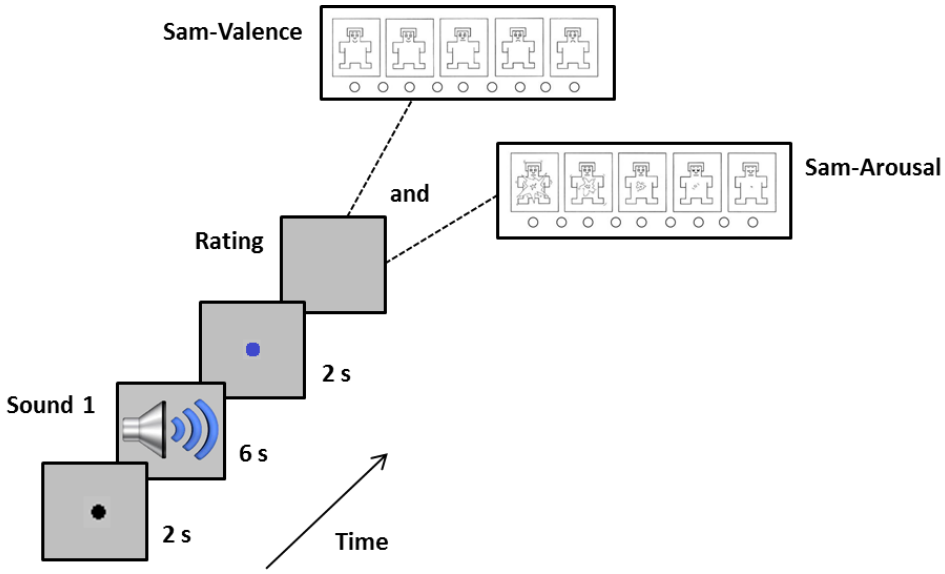

Fig. 8: Graphical representation of 4 phases.

4.2. Results

First of all, the ranges of the SAM rating were reversed to improve understandability (e.g., 9 indicate pleasant for valence, arousing for arousal dimensions,

whereas 1 indicates unpleasant for valence and calm for arousal). Then, we performed descriptive statistics and found that all cry groups (ASD baby, TD baby, ASD child and TD child) appeared to have good internal consistency to measure both valence and arousal. Cronbach's alpha coefficients are presented in *Table 8*. Additionally, mean and standard deviations of each cry episodes are displayed in *Table 9*.

Table 8: Descriptive statistics and internal consistency (Cronbach's alpha coefficients) of all cry groups

Cry groups	Valence			Arousal		
	Mean	*SD*	α	Mean	*SD*	α
ASD baby	3.49	0.91	0.87	5.04	0.26	0.95
TD baby	3.03	0.94	0.86	5.40	0.26	0.96
ASD child	3.67	0.99	0.91	4.71	0.26	0.95
TD child	3.38	0.82	0.88	4.82	0.26	0.96

Note. SD = standard deviation; α = Cronbach alpha coefficient

4.2.1. Cry in the two-dimensional space

As mentioned in the beginning of Chapter 4, our working hypothesis was that all cry episodes would fall into the unpleasant area in the dimensional emotion space. To determine whether all cry episodes were considered as unpleasant by our participants, the first step was to identify two thresholds to use for establishing three areas: Pleasant, Neutral and Unpleasant. It is worth to note that these two thresholds were defined using 33^{rd} and 66^{th} percentile of the distribution of valence scores of the IADS sounds. The area above to the 66^{th} percentile of the distribution (Mean= 5.41) was identified as *Pleasant*, whereas the area below the 33^{rd} percentile of the distribution (Mean= 4.22) was

considered as *Unpleasant*. Finally, the area between these two thresholds was identified as *Neutral* area.

After the identification of three areas, we found that all cry sounds fall into the unpleasant area (see *Fig. 9* & *Fig. 10*).

4.2.2. Correlations Between Valence and Arousal in Present and Previous Ratings

The use of the SAM in the current study allows us to directly compare the responses reported by our participants to those obtained from other samples. To verify the generalizability of the obtained ratings, we compared our ratings of young adults with available ratings of young adults from previous study (Bradley & Lang, 2007). The issue of replicability is addressed by the correlation analysis with ratings that we obtained (our data sets) and those reported by Bradley & Lang (2007). Correlations between the ratings from the two data sets were uniformly high and significant for each rating dimension; Valence: $R = .92$, Arousal: $R = .76$, all $p < .001$, two tailed. Moreover, the valence and arousal ratings reported by Bradley & Lang (2007) are predicted by the respective ratings obtained in the present study (for Valence: adjusted $R^2 = .84$, $p < .001$; for Arousal: adjusted $R^2 = .59$, $p < .001$).

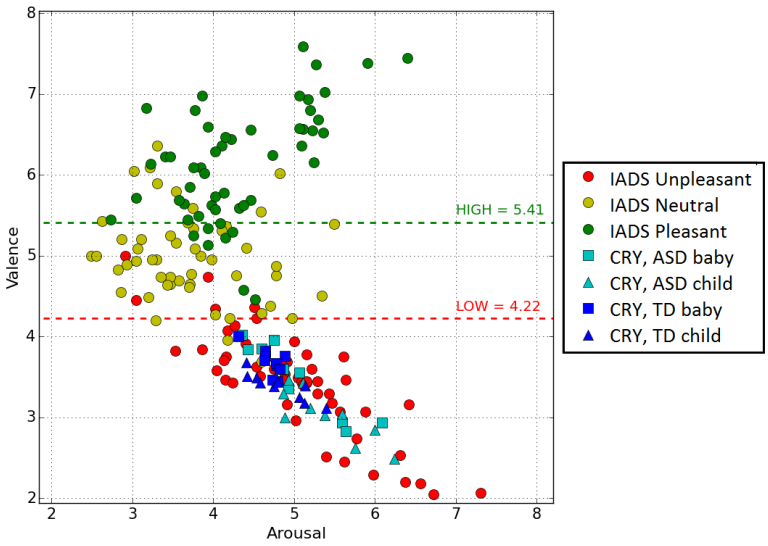

Fig. 9: Two dimensional emotional space with the axes of valence and arousal. All data points stand for the ratings that were obtained in the present study. Green and red lines show two thresholds which were identified for establishing three areas: Pleasant, Neutral and Unpleasant.

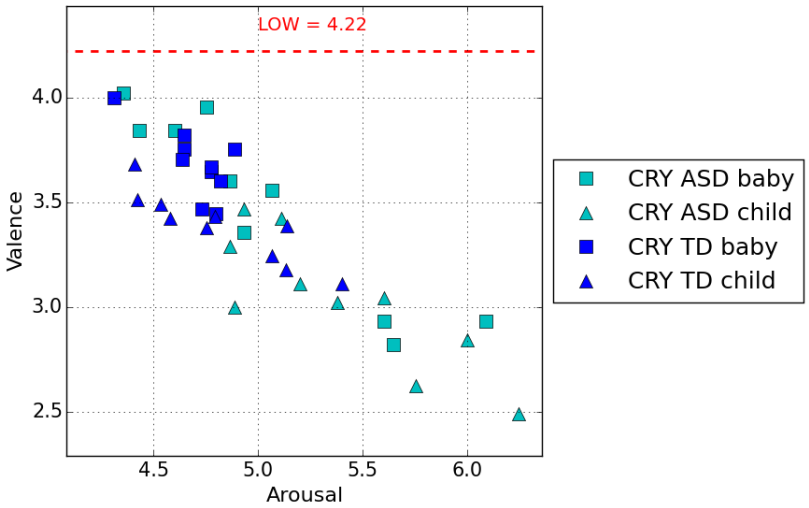

Fig. 10: The Unpleasant area of the dimensional emotional space.

Table 9: Mean and standard deviations of each cry sound for all subjects

Cry	Sound No.	Pleasure		Arousal		Cry	Sound No.	Pleasure		Arousal	
		Mean	SD	Mean	SD			Mean	SD	Mean	SD
	50	4.02	1.47	4.36	2.21		70	3.64	1.57	4.78	2.15
	51	3.84	1.46	4.43	2.3		71	4	1.58	4.31	1.94
	52	3.96	1.33	4.76	1.91		72	3.44	1.37	4.8	2.07
	53	3.84	1.33	4.6	2.04		73	3.82	1.57	4.64	2.14
ASD	54	2.93	1.1	5.6	2.08	ASD	74	3.76	1.86	4.89	2.14
baby	55	2.82	1.17	5.64	2.3	child	75	3.76	1.28	4.64	1.94
	56	3.56	1.62	5.07	2.04		76	3.67	1.64	4.78	2.04
	57	3.36	1.13	4.93	2.14		77	3.7	1.37	4.64	2.05
	58	2.93	1.5	6.09	2.13		78	3.47	1.16	4.73	2.04
	59	3.6	1.23	4.87	2.08		79	3.6	1.51	4.82	1.96
	60	3.02	1.39	5.38	2.04		80	3.24	1.13	5.07	2.29
	61	3.04	1.4	5.6	2.38		81	3.68	1.23	4.41	2.15
	62	3.47	1.42	4.93	2.03		82	3.49	1.18	4.53	2.07
	63	2.84	1.33	6	1.77		83	3.11	1.25	5.4	2.03
TD	64	2.62	1.19	5.76	2.15	TD	84	3.39	1.35	5.14	2.17
baby	65	3.42	1.16	5.11	2.01	child	85	3.18	1.05	5.13	2.15
	66	3.11	1.19	5.2	1.89		86	3.38	1.19	4.76	2.31
	67	3.29	1.18	4.87	2.18		87	3.42	1.22	4.58	1.96
	68	2.49	1.25	6.24	2.11		88	3.43	1.15	4.8	2.04
	69	3	1.08	4.89	1.97		89	3.51	1.24	4.42	2.24

4.3. Discussion

The aim of this study was to evaluate the position of cry in the dimensional emotion space. Our working hypothesis that all cry episodes would fall into the unpleasant area was supported. In fact, analyses suggest that all of them, regardless of the types (e.g., ASD child or TD child cry) were perceived as unpleasant. This finding is in accord with other studies on infant cries. It has been reported that infant cries have both infant and caretaker in a state of strong sympathetic nervous system activation which is commonly described as the "fight or flight" response (LaGasse, Neal, & Lester, 2005). Indeed, crying has been considered as a siren, alerting the adults about the infants' need

and motivating the listener to respond (Zeskind & Lester, 2001). At that point, adults try to interpret the infants' cry and translate that interpretation into appropriate behavior (Corwin et al., 1996). Our results may be explained by the fact that regardless of cry types (i.e., ASD or TD cry) all cry episodes evoke an unpleasant emotional state in adults and interpret them as unpleasant, unhappy and unsatisfied.

Additionally, we aimed compare the responses reported by our participants to those obtained from other samples from previous study (Bradley & Lang, 2007). We confirmed our hypothesis verifying the generalizability of the obtained ratings by comparing the responses reported by our participants to those reported by Bradley & Lang (2007).

In summary, we focused on adults' perception of different types of cry episodes and characterized in a dimensional emotion-space. All cry episodes, regardless of the types, fall into the unpleasant area, therefore we consider them as proper stimuli for the following two experiments. Moreover, this current study provides insight that help researchers to better understand how adults perceive infant cry and produce further studies on cry perception.

Chapter 5: Non-parents' emotional and physiological responses to infant crying

Chapter plan: This chapter focuses on emotional responses (stress, arousal, and valence) and physiological reactivity (heart rate and heart rate indices) of non-parents while listening to infant crying episodes which were validated as unpleasant stimuli in the Chapter 5. Since the main goal of second part of the thesis (exploring both behavioral and physiological responses of parents of children with ASD) has not been examined in the literature before, it was decided to carry on an experiment, first of all, on non-parent adults. We expected that cry of children with ASD would been considered more stressed, aroused and less pleasant compare to cry of TD children and to see similar patterns in the participants' physiological reactivity (such as higher HR). The chapter begins by laying out the methods of this experiment and goes on the results which have been obtained from non-parent adults. Finally, it ends with an discussion of the findings in which limitations we faced and how we handled with them will be explained.

5.1. Methods

5.1.1. Participants

The sample, in this experiment, comprised 40 non-parent adults (20 female: M age = 27.3 years, SD = 3.4 ; 20 male: M age = 28.4 years, SD = 6.1), recruited though a database of volunteers available at the University of Trento, Italy.

5.1.2. Acoustic Stimuli

The stimuli have already been described in Chapter 4 and for this reason they will only be listed here. Briefly, the acoustic stimuli were four types of cry episodes: toddler later diagnosed with ASD are younger than 24 months (ASD baby), aged matched typically developing toddler (TD baby), toddler diagnosed with ASD are ages between 36-52 months (ASD child), aged matched typically developing toddler (TD child). All cry episodes (10 separate audio files for each group) were examined and validated as proper stimuli (in other words, as unpleasant stimuli) in the previous experiment (Chapter 4). A graphical representation of cry groups is presented in *Fig. 11*.

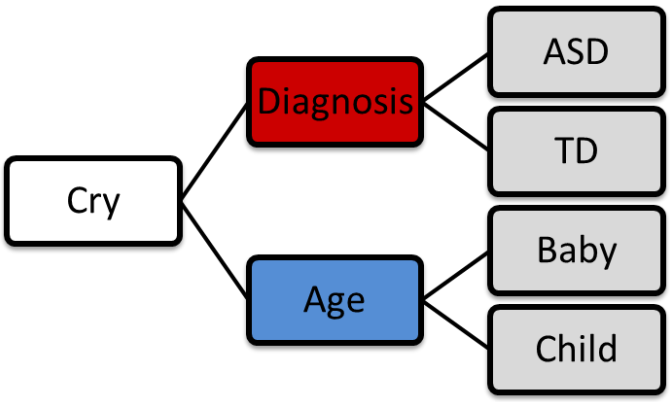

Fig. 11: Graphical representation of cry groups: ASD baby, TD baby, ASD child and TD child.

5.1.3. Procedure: Stimuli presentation and response measurements

Experiment contains 24 sessions (6 repetition x 4 cry groups) and each session consists of three phases: sound (30s), rating (28s), rest (30s). Each sound phase represents

one of the cry groups. To make 30 seconds of sound phase, 5 cry episodes from the same group (for example, 5 ASD baby cry episodes) were presented consecutively, taking into account the fact that all cry sounds appeared to have good internal consistency to measure both valence and arousal in the previous experiment (see the section 4.2. and *Table 8*). A graphical representation of a session is presented in *Fig. 12*.

The rating phase consists of 9-point Likert-scales: Stress (Non-stressed - Stressed), Valence (Unpleasant - Pleasant), Arousal (Calm - Excited), Nature of sounds (Negative - Positive). Briefly, a Likert-scale is a summated scale commonly used for the assessment of survey responds attitudes (Likert, 1932).

The following phase is the rest phase which does not contain any task. In sum, participants were asked to listen to the sound phase (5 consecutive sounds) which were presented using a personal computer and speaker, then rate (rating phase) that phase as they felt while they heard and finally have a rest (rest phase).

- *Heart Rate Variability*

Hear rate (HR) and Time-and frequency-domain hear rate variability (HRV) were analyzed from data acquired using Empatica E3 is a wrist-wearable wireless multisensor device (Garbarino, Lai, Bender, Picard, & Tognetti, 2014). The physiological data have been recorded during whole experimental session; however, only the sound phase has been considered in the analysis.

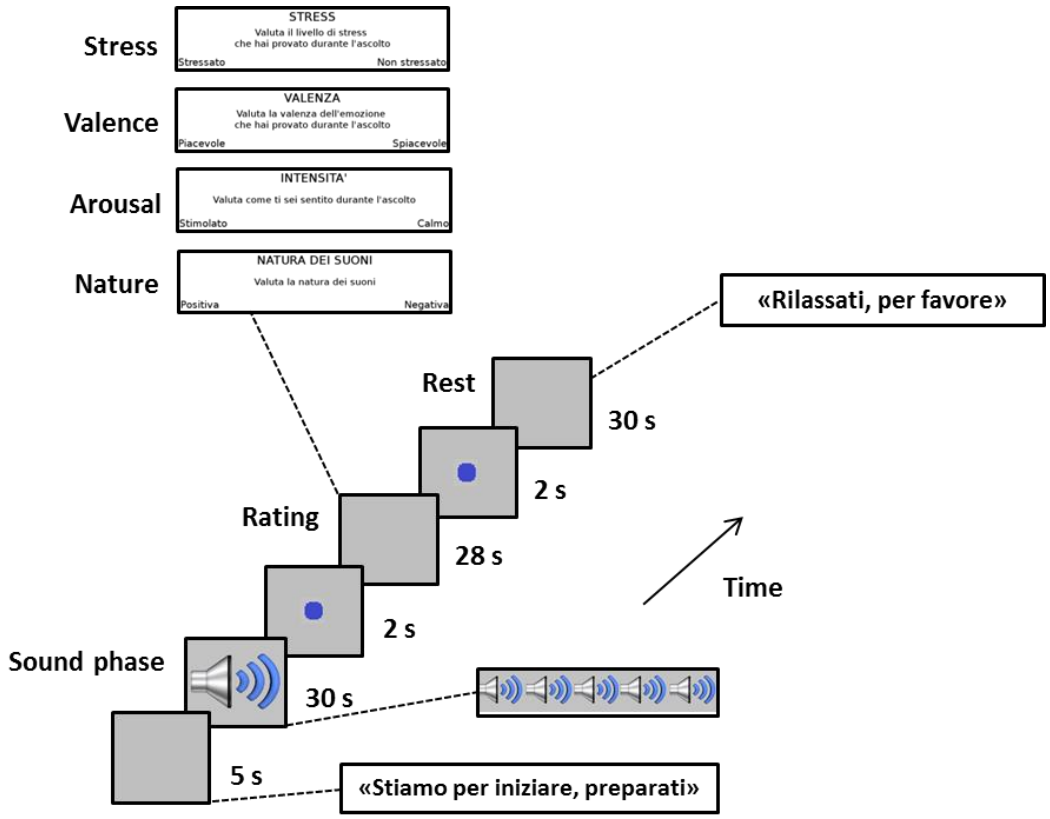

Fig. 12: A graphical representation of a session with three phases: Sound, rating, rest.

5.1.4. Analytic plan

Regarding the behavioral data analysis, first of all, the values from all the repetitions within the groups were summed to create a score for each group (for example, "ASD baby" score). The reason to choose the sum instead of the mean lies on the composition of the Likert scale used in the behavioral data collection (Likert, 1932). Then, we performed descriptive statistics and examined whether cry groups have good internal consistency to measure stress, arousal and valence.

We checked whether the normality assumption has been met. Then, we performed mixed ANOVAs with between-subjects factor consists of subjects' gender (Female vs

Male) and with within-subjects factors consist of Diagnosis (ASD vs TD) and Age (Baby vs Child).

Regarding HRV analysis, we followed these steps: The automatic beat detection (R-peaks) and abnormal beat recognition have been performed (Aboy et al., 2005). Then the signal segmentations using the portion of 1) the sound phase (30 seconds length), 2) the first sound within each sound phase (6 seconds length) have been done. Finally, HR and Time- and Frequency- domain HRV indices have been computed using pyHRV (Bizzego, Mina, Zarbo, Esposito, & Furlanello, 2014). Because the normality assumption has not been met, we performed Wilcoxon tests considering each factor individually (Female vs Male, Baby vs Child, ASD vs TD). It is worth to note that 33 subjects (16 male and 17 female) instead of 40 have been analyzed due to the technical issue during the physiological data acquisition.

5.2. Results

Descriptive statistics showed that all cry groups (ASD baby, TD baby, ASD child and TD child) appeared to have good internal consistency to measure stress, arousal and valence. Cronbach's alpha coefficients, mean and standard deviations are presented in *Table 10*.

Table 10: Descriptive statistics and internal consistency (Cronbach's alpha coefficients) of all cry groups

Cry groups	Valence			Arousal			Stress		
	Mean	*SD*	α	Mean	*SD*	α	Mean	*SD*	α
ASD baby	19.50	5.75	0.69	30.37	8.53	0.86	32.76	10.15	0.88
TD baby	25.36	7.61	0.84	26.38	7.76	0.82	26.05	9.17	0.87
ASD child	17.36	6.56	0.85	32.08	9.16	0.88	34.05	10.64	0.90
TD child	22.76	5.63	0.73	26.35	8.09	0.85	27.09	0.42	0.88

Note. SD = standard deviation; α = Cronbach alpha coefficient

Mixed ANOVAs were conducted to examine the effect of two within-subjects factors, namely diagnosis and age, and one between-subjects factor, which is subjects' gender, on the outcome variables (stress, arousal and valence). There were a statistically significant effect of diagnosis ($F(1,38)= 77.81$, $p< .001$), age ($F(1,38)= 4.58$, $p= .03$), and gender ($F(1,38)= 4.81$, $p= .03$) effects on stress. ASD cry (M= 32.92, SD= 1.56) is considered more stressed than TD cry (M= 26.08, SD= 1.35), Child cry (M= 30.21, SD= 1.43) is considered more stressed than Baby cry (M= 28.79, SD= 1.46) and Females (M= 32.59, SD= 1.99) reported more stress than Males (M= 26.41, SD= 1.99). *Fig. 13* illustrates these results.

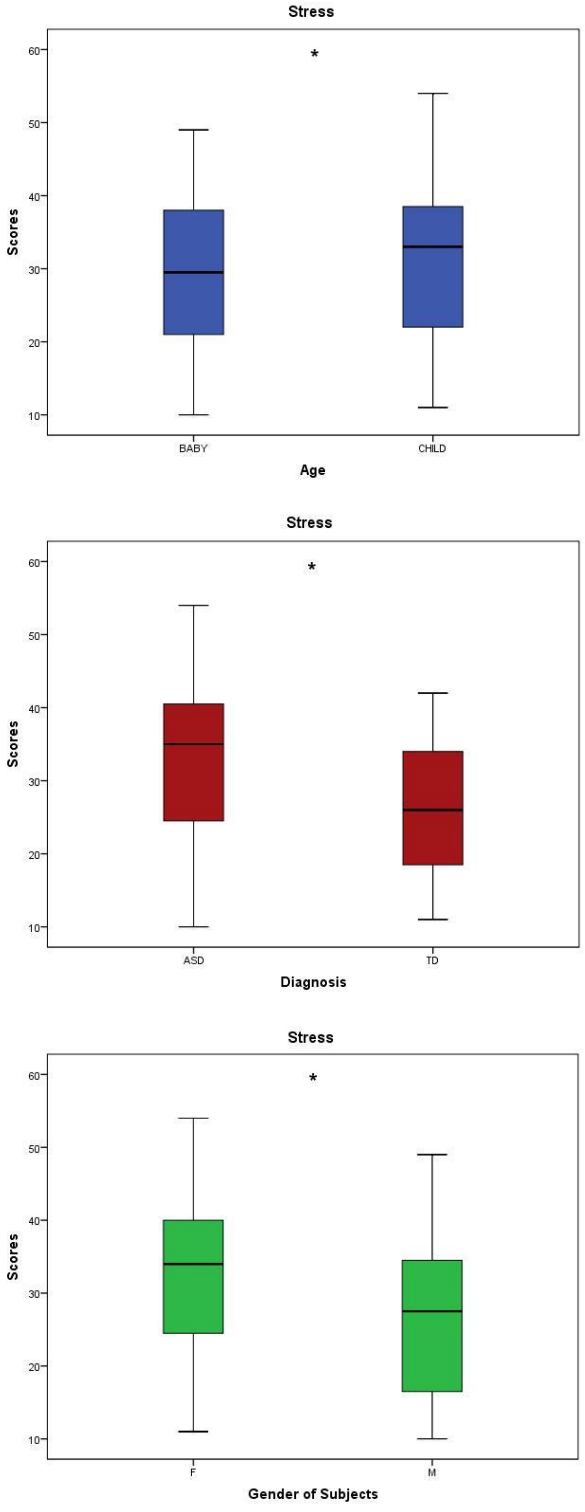

Fig. 13: Boxplots of the stress scores. An asterisk highlights the scale having statistically significant difference.

There were a statistically significant effect of diagnosis (F(1,38)= 48.62, p< .001) and gender (F(1,38)= 5.42, p= .03) effects on arousal. ASD cry (M= 31.2, SD= 1.25) is considered more aroused than TD cry (M= 26.34, SD= 1.13), and Females (M= 31.43, SD= 1.61) reported more arousal than Males (M= 26.11, SD= 1.61). *Fig. 14* illustrates these results.

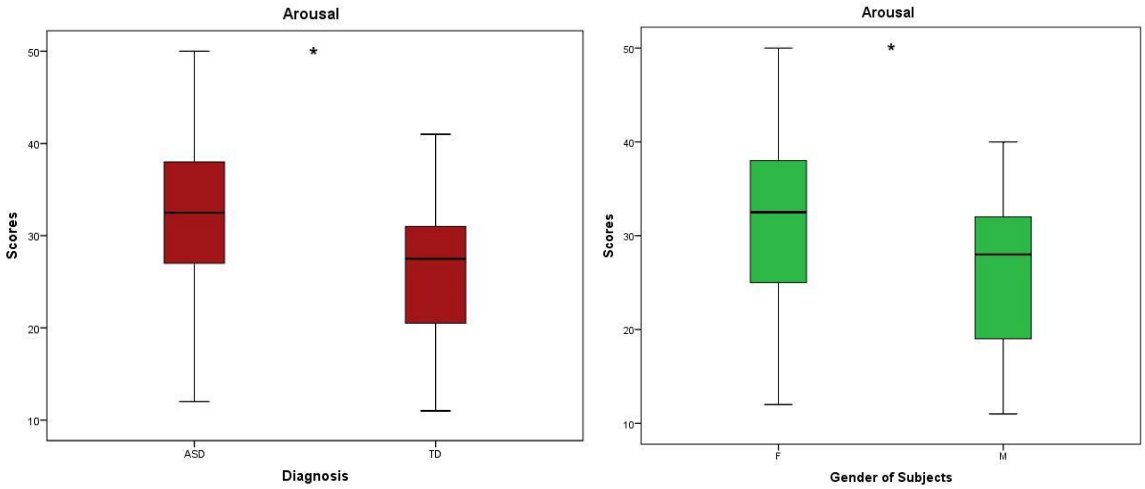

Fig. 14: Boxplots of the arousal scores. An asterisk highlights the scale having statistically significant difference.

There were a statistically significant effect of diagnosis (F(1,38)= 69.4, p< .001) and age (F(1,38)= 14.56, p< .001) effects on valence. TD cry (M= 24.0, SD= .92) is considered more valence than ASD (M= 18.35, SD= .91) cry and Baby cry (M= 22.35, SD= .95) is considered more valence than Child cry (M= 20.0, SD= .86). *Fig. 15* illustrates these results. It is worth to note that no interaction effect has been found for all three outcome variables.

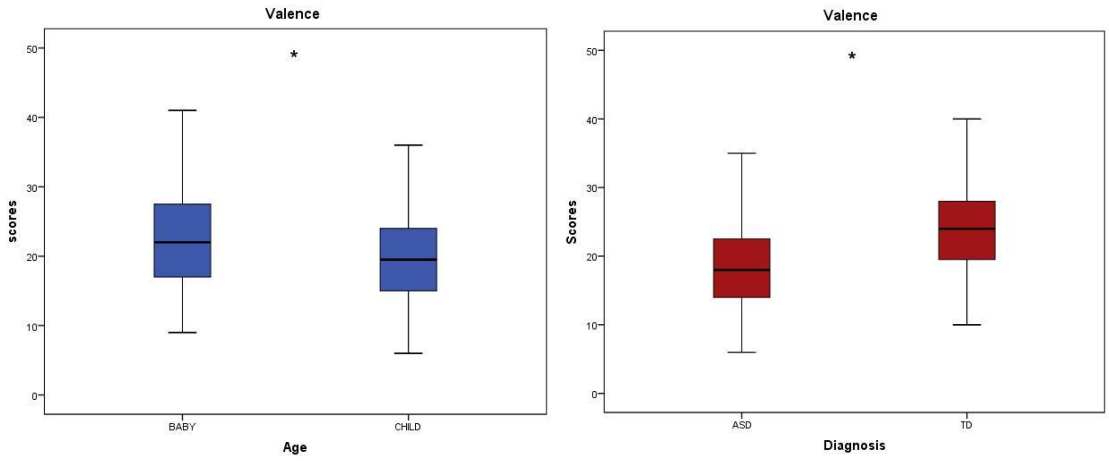

Fig. 15: Boxplots of the valence scores. An asterisk highlights the scale having statistically significant difference.

Regarding to the physiological data, first of all, we extracted hear rate and time- and frequency-domain indices from the whole sound phase (30 seconds) of each session and performed Wilcoxon tests, considering each factor individually. Unfortunately, we did not find any significant results. Then, we extracted heart rate and time-domain indices from the first cry sound (6 seconds) within each sound phase. The reason to use only time-domain indices lies on the fact that the duration of the first sound is relatively short time window for acquiring frequency domain indexes. We found significant differences in HRSD (W = 71421, p= .03), RMSSD (W = 72800, p= .01) and SDSD (W = 72176.5, p= .02) indices for gender factor. HRSD is higher in Males (Mdn = 504.57) than Females (Mdn = 462.85), RMSSD is higher in Males (Mdn = 567.14) than Females (Mdn = 515.72), and SDSD is higher in Males (Mdn = 524.57) than Females (Mdn = 500.76).

5.3. Discussion

As mentioned in the literature review, listeners perceive ASD cry as unexpected and more negative than those of TD children. In this study we explored both emotional and physiological responses in non-parents males and females to such stimuli. Specifically, we assessed their emotional responses (stress, valence and arousal), and heart dynamics (heart rate and heart rate variability) to typical (TD) and atypical (ASD) cry, and to baby and child cry. Moreover, we considered the gender differences within our sample. We hypothesized that ASD cry would been considered more stressed, aroused and less pleasant and we expected to see similar patterns in the participants' physiological reactivity (such as high HR and low HRV). We partially confirmed our hypotheses.

In summary, we found some different responses in both emotional and physiological aspects. ASD cry was reported more stressed and aroused, and less pleasant compare to TD cry. Moreover, Child cry was reported more stressed and less pleasant compare to Baby cry. Lastly, Females reported more stressed and aroused during while listening to crying than Males. In terms of heart dynamics, males were generally calmer (higher HRSD, RMSSD and SDSD) than females while listening of cries.

This result is consistent with previous studies that revealed negative patterns of behavioral responses to ASD cry (Esposito & Venuti, 2008, 2009a, 2010b; Venuti et al., 2012), and also adding an emotional (in terms of arousal and valence) and physiological (heart rate) perspectives. It seems that ASD cries are processed differently compare to TD cries even though the perceivers are not caregiver of a child. Possibly, decoding this signal of the children with ASD was difficult and listeners could not understand the meaning and reason of cry. Eventually, they reported ASD cry as more stressful, aroused

and less pleasant. However, we did not find such a difference between their physiological responses to ASD cry and TD cry. It might be happened due to the limitations of this study which will be explained in the following section ("Limitations and adjustments for the future study"). However, we found differences between females and males in their physiological reactions while listening cries. This difference emerged from 6s-single cry sound (the first sound of each session). It seems that females are more getting ready for the preparation for the activity while listening to cries and they act more promptly. This result may be interpreted as related to infant exposure; perhaps because females, in general, have more exposure to or experience in caring for crying children than males, even though they are not parents of any child.

Limitations and adjustments for the future study

A limitation of this study is that the significant results for heart rate dynamics were not emerged from the whole sound sessions where we reached the significant results in the behavioral responses of subjects. We found significant results from the physiological data within the first cry episodes of each session. Even though those cry episodes have good internal consistency to measure self-reported stress, arousal and valence responses, each cry might have different feature (i.e., acoustic features such as f0) compare to other one within the same category (i.e., cry episodes within ASD baby category). Therefore, we adjusted the experimental design of the next experiment, taking into account this limitation. Briefly, we used single sound (6s) within each session in the following experiment.

Another limitation is related to have 4 within-groups (ASD baby, TD baby, ASD child and TD child) and one between-groups (Female and Male) to compare in the

statistical analysis step. Since our main interest in the responses of parents to ASD cry versus TD cry and it would be better to avoid too many comparisons, we decided to keep only two within-groups: ASD cry and TD cry in the following experiment.

Last limitation is connected with the stimuli presentation and data collection. It might be the fact that the process during the rating section which requires thinking of their feeling could affect the physiological responses. Therefore, we decided to design the experiment dividing into two parts: the first one stands for measuring physiological reactivity and does not contain any task, whereas in the second part, behavioral responses to the cry stimuli are taken.

Chapter 6: Emotional and physiological responses to infant crying in parents of children with ASD and parents of TD children

Chapter plan: This chapter focuses on the last experiment of this thesis in which we examined the emotional (stress, arousal and valence) and physiological (Hear rate) responses of parents of children with ASD while listening to infant crying, in particular cry of children with ASD. In the end of this chapter, we answered the main question: How do parents of children with ASD perceive cry of children with ASD compare with cry of typically developing (TD) children?

We prepare all settings of this experiment, taking into account Chapter 4 for the stimuli selection and Chapter 5 for the experimental design. Then, finally, we carried on the final experiment on parents of children with ASD and also parents of TD children. We aim to investigate the differences in the emotional and physiological responses to ASD cry and TD cry between parents of children with ASD and parents of TD children. We expect that parents of TD children and parents of children with ASD would been differentiated in the behavioral responses to ASD cry, probably it may be more stressful, aroused and less unpleasant for parents of children with ASD. Moreover, parents of children with ASD would show higher HR for ASD cry compare to parents of TD children.

6.1. Methods

6.1.1. Participants

The participants comprised 30 parents (15 mothers: M age = 33.9 years, SD = 6.02; 15 fathers: M age = 38.1 years, SD = 7.15) of typically developing children (M age = 3.0 years; SD = 1.70) and 19 parents (11 mothers: M age = 40.5 years, SD = 3.78; 8 fathers: M age = 40.8 years, SD = 3.15) of children diagnosed with ASD (M age = 5.7 years; SD = 1.82). The diagnosis was confirmed through clinical judgement by an independent clinician based on the DSM-IV-TR criteria for Pervasive Developmental Disorders (PDD) as well as through the Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord, Rutter, DiLavore, & Risi, 2003) in the Observation, Diagnosis and Education Lab at the University of Trento, Italy. The socioeconomic status (SES) of the parents was calculated with the Four-Factor Index of Social Status (Hollingshead, 1975; Rossi, 1994). Our sample represented a middle status in the Italian population (Parents of children with ASD: M = 37.24, SD = 11.09 ; Parents of TD children: M = 44.05, SD = 15.08).

6.1.2. Acoustic stimuli

In the present study, we planned to have stimuli grouped by two groups: ASD cry and TD cry. 8 ASD and 7 TD cry episodes were selected from ASD and TD child groups from the previous experiments (Chapter 4&5). The reason of this adjustment has been already explained in the section 5.3.1 (titled Limitations and adjustments for the future study). A graphical representation of cry groups of this study is presented in *Fig. 16*.

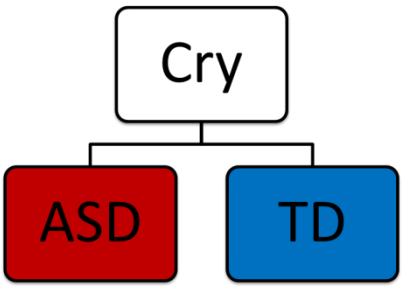

Fig. 16: A graphical representation of cry groups: ASD cry and TD cry.

Briefly, ASD cry consists of 8 cry episodes which were extracted from home videos of toddler diagnosed with ASD are ages between 36-52 months and TD cry consists of 7 cry episodes of aged matched typically developing toddler. All home videos were collected by the Observation, Diagnosis and Education Lab (ODF Lab) at the University of Trento. The diagnosis of toddlers was confirmed based on the DSM-IV-R criteria, confirmed by the Autism Diagnostic Observation Schedule (ADOS-G; Lord et al., 2000).

The cry episodes were experimentally manipulated employing the open source Audacity software (version 2.0.2) for audio editing to produce separate audio files for the groups. Then they were digitized and analyzed using the Praat acoustic analysis software (Boersma & Weenink, 2001). We obtained the fundamental frequency (f0) of each cry episodes to obtain the acoustic features. A long-term average spectrum (LTAS) was employed to provide spectral information for each cry episodes. LTAS is used to discriminate cry characteristics of different categories of children (Lin & Green, 2007). The First Spectral Peak (FSP) was obtained by identifying the value of the first amplitude

peak of the LTAS output. FSP (in Hz) is an estimate of the average f0 of the episode of crying (Lin & Green, 2007). The FSPs of cry episodes used in the present study were for ASD (M = 514.07, SD = 7.04) and TD (M = 492.73, SD = 6.93), a significant difference, $t(13) = 5.90$, $p < .001$. Furthermore, all acoustic files were edited to normalize them for volume and duration (6 seconds) and to remove all background noise.

6.1.3. Procedure: Stimuli presentation and response measurements

The experiment was structured into two parts; the first part stands for the physiological data acquisition, whereas the second one stands for the behavioral data acquisition.

1th Part: It contains 32 sessions; 16 sessions for ASD cry and 16 sessions for TD cry. Each cry repeated two times and only one cry from the TD cry group repeated three times (this cry was chosen randomly). Each session consists of two phases: sound (6s) and rest (10s). A graphical representation of a session is presented in *Fig. 17*. Participants were asked to listen each sound which were presented using a personal computer and speaker and then have a rest without moving. There is no task in this part of the experiment. HR was recorded during only this part of the experimental session by Empatica E4 is a wrist-wearable wireless multisensor device (Garbarino et al., 2014).

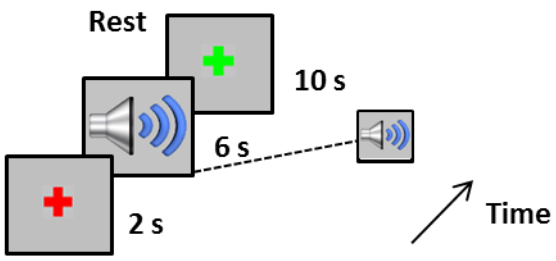

Fig. 17: A graphical representation of a session for physiological data acquisition.

2nd Part: It contains 15 sessions; each cry has its own session to get ratings. Each session consists of two phases: sound (6s) and rating (25 s : 5 scales x 5 seconds). A graphical representation of a session is presented in *Fig. 18*. Participants were asked to listen each sound and then rate that sound using 9-point Likert-scales. There were 3 rating scales to measure subjects' emotional responses to the stimuli: stress, arousal and valence. Moreover, we asked subjects to reply two additional questions about the child who was crying; they were asked to judge the level of stress child express and age of the child.

Experimental events were controlled by an appropriate developed software (written in C-sharp). After the first part, subjects were allowed to have a break and then continue the experiment when they would feel comfortable. The wristband were removed from the arm of the subject after the first part ended. Experiment lasted approximately half an hour. Participants were familiarized with rating procedure during the training session that appeared before the experimental session. Volume of the device was kept at the same level for all subjects.

Furthermore, the participants completed two questionnaires the day before the experiments done: the Parenting Stress Index-Short Form (PSI/SF; see Chapter 2 for details about this index) and the Weinstein Noise Sensitivity Scale (WNSS; Senese,

Ruotolo, Ruggiero, & Iachini, 2012). The WNSS is one of the most widely used questionnaires to measure noise sensitivity.

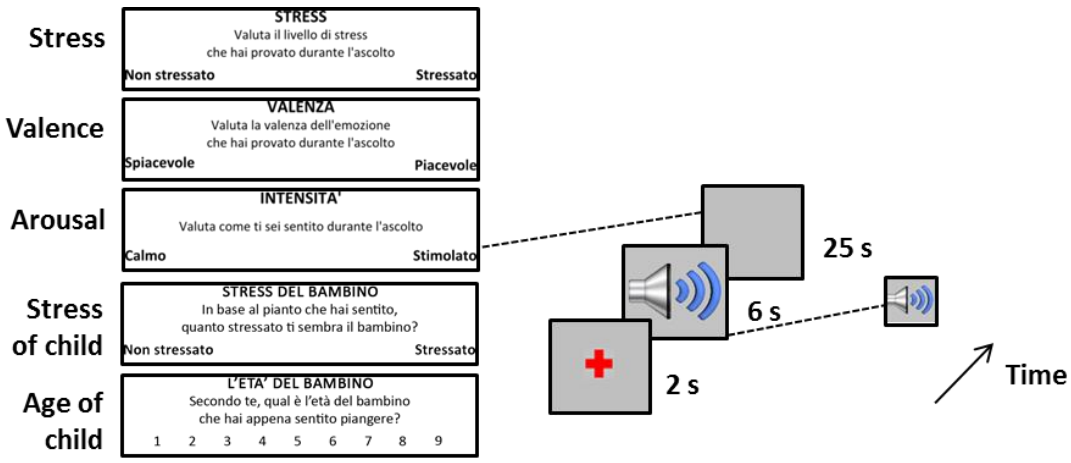

Fig. 18: A graphical representation of a session for behavioral data acquisition.

6.1.4. Analytic plan

Regarding to the behavioral data analysis, the values from the rating of sounds within the same groups (i.e., the scores for 8 ASD cry episodes within ASD cry group) were aggregated computing mean to create a score for each group (i.e., "ASD cry" score). Then, we performed Wilcoxon tests (due to the fact that normality assumption has not been met), considering the Bonferroni multiple comparison correction.

Regarding the physiological data analysis, we followed these steps: The automatic beat detection and abnormal beat recognition have been performed (Aboy et al., 2005). Then the signal segmentation using the portion of the sound phase (6 seconds length) has

been done. HR indices (HR mean, HR median, HRSD) have been computed using pyHRV (Bizzego et al., 2014). We performed quantile normalization and then, because the normality assumption has not been met, we performed Wilcoxon tests considering the Bonferroni multiple comparison correction. It is worth to note that we consider single sound and single repetition in the physiological data analysis.

6.2. Results

No associations emerged between outcome measures and parents' age, family SES, the total score from the PSI or the score from the WNSS. We reported the comparisons between the responses of Parents of children with ASD and Parents of TD children to both ASD cry and TD cry, and continued with the comparisons between the responses to ASD and to TD cry. Then, we reported the results which reflect how participants evaluated stress of children during cry.

Comparisons between Parents of children with ASD and Parents of TD children

- **Stress:** There is no difference in stress response to ASD cry between Parents of children with ASD (Mdn = 6.4) and Parents of TD children (Mdn = 5.8) ; W = 310.5, p = .61. Also, there is no difference in stress response to TD cry between Parents of children with ASD (Mdn = 4.9) and Parents of TD children (Mdn = 3.6); W = 373, p = .07 (see *Fig. 19*).

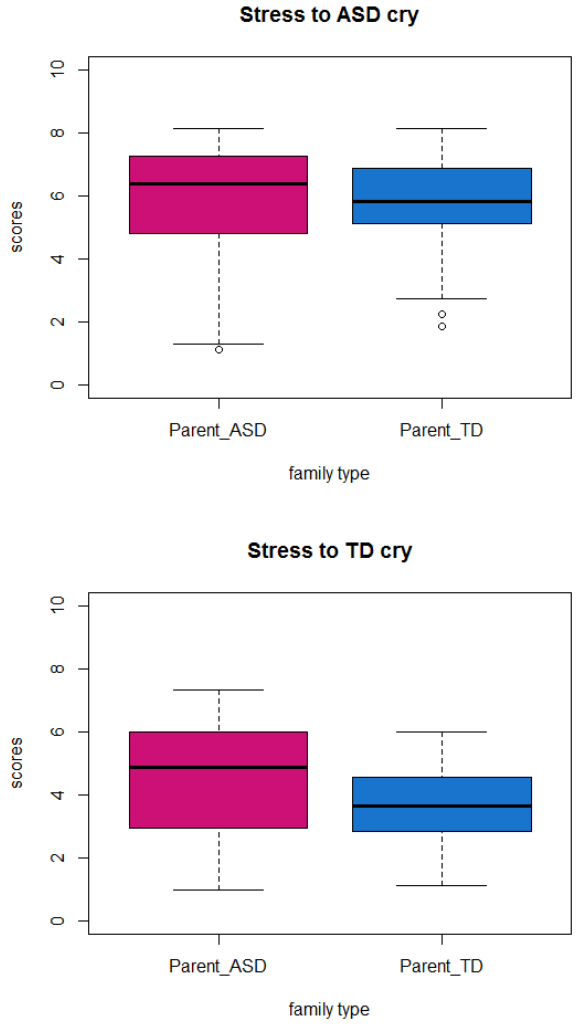

Fig. 19: Boxplots of the stress scores. Parent_ASD: Parents of children with Autism Spectrum Disorder; Parent_TD: Parents of typically developing children.

Arousal: There is no difference in arousal response to ASD cry between Parents of children with ASD (Mdn = 6.4) and Parents of TD children (Mdn = 5.3) ; W = 328.5, p = .38. Moreover, there is no difference in arousal response to ASD cry between Parents of children with ASD (Mdn = 4.3) and Parents of TD children (Mdn = 3.3); W = 355, p = .15 (see *Fig. 20*).

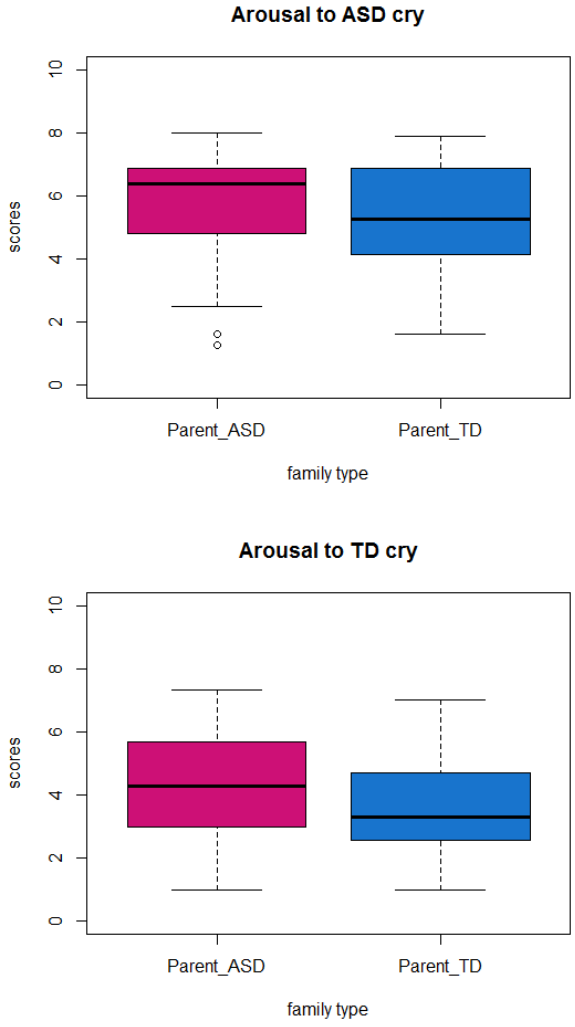

Fig. 20: Boxplots of the arousal scores. Parent_ASD: Parents of children with Autism Spectrum Disorder; Parent_TD: Parents of typically developing children.

Valence: There is no difference in valence response to ASD cry between Parents of children with ASD (Mdn = 3.1) and Parents of TD children (Mdn = 2.9) ; W = 282.5, p = .97. However, there is a statistical difference in valence response to TD cry between Parents of children with ASD and Parents of TD children; W = 174, p = .02. Parents of children with ASD (Mdn = 3.8) reported less pleasant than Parents of TD children (Mdn = 4.4) for TD cry (see *Fig. 21*). However, the results are not significant after Bonferroni correction.

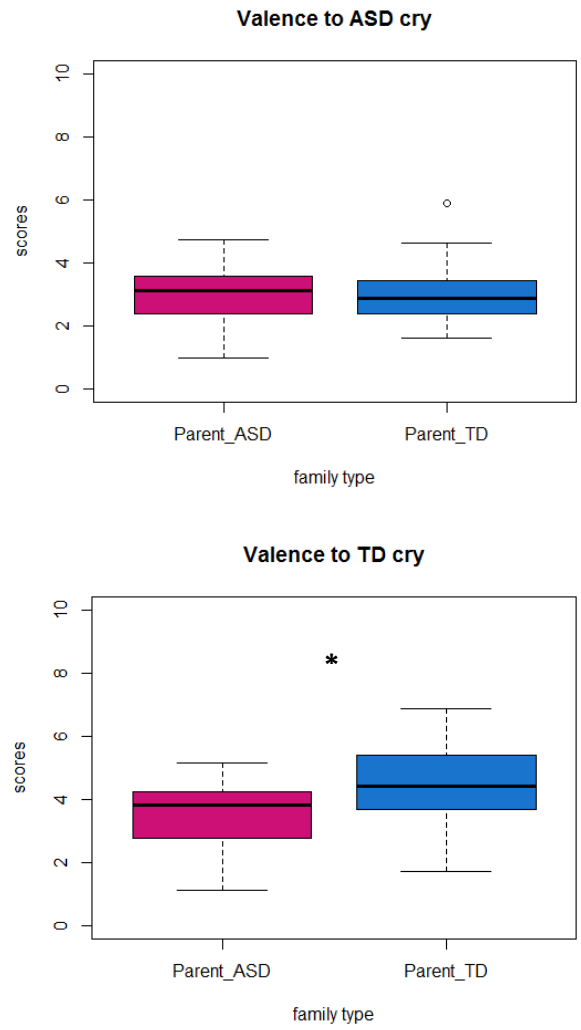

Fig. 21: Boxplots of the valence scores. An asterisk highlights the scale having statistically significant difference. Parent_ASD: Parents of children with Autism Spectrum Disorder; Parent_TD: Parents of typically developing children.

Hear Rate (HR): Regarding to the comparisons between Parents of children with ASD and Parents of TD children, there are significant differences (see *Fig. 22*): Parents of children with ASD had higher HR than Parents of TD children during ASD cry ($W = 102541$, $p < .001$) and TD cry ($W = 95866$, $p < .001$).

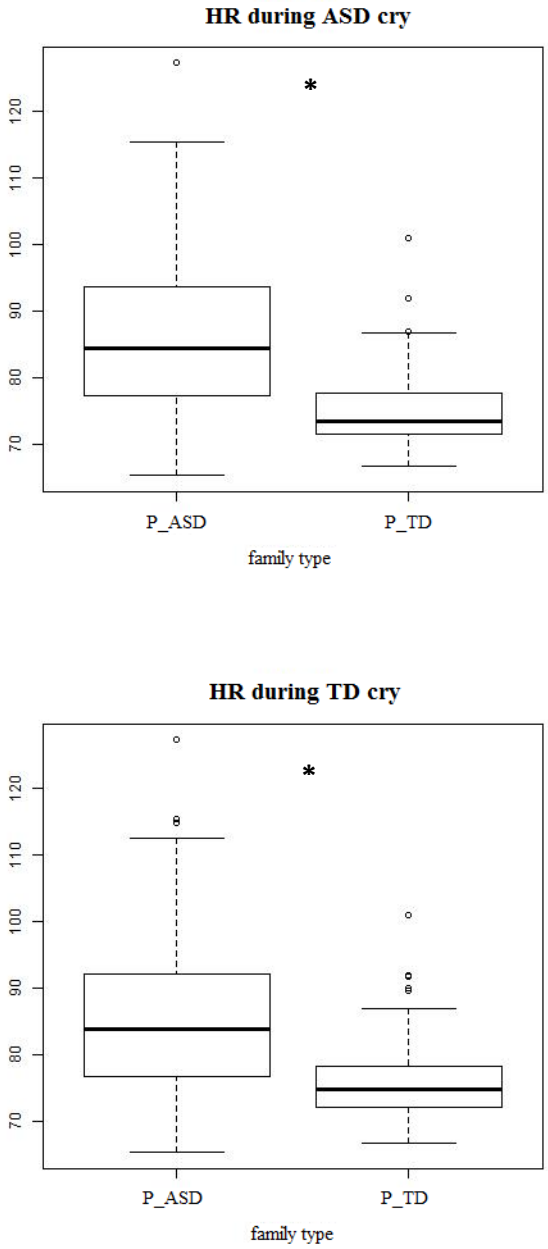

Fig. 22: Boxplots of the HR values. An asterisk highlights the scale having statistically significant difference. P_ASD: Parents of children with Autism Spectrum Disorder; P_TD: Parents of typically developing children.

Comparisons between cry sounds (ASD cry and TD cry)

Stress: There is a significant difference between self-reported stress response of Parents of children with ASD to ASD cry (Mdn = 6.4) and to TD cry (Mdn = 4.9); V = 172, p < .001. Also, Parents of TD children reported as more stressful for ASD cry (Mdn = 5.8) compare to TD cry (Mdn = 3.6); V = 465, p < .001 (see *Fig. 23*).

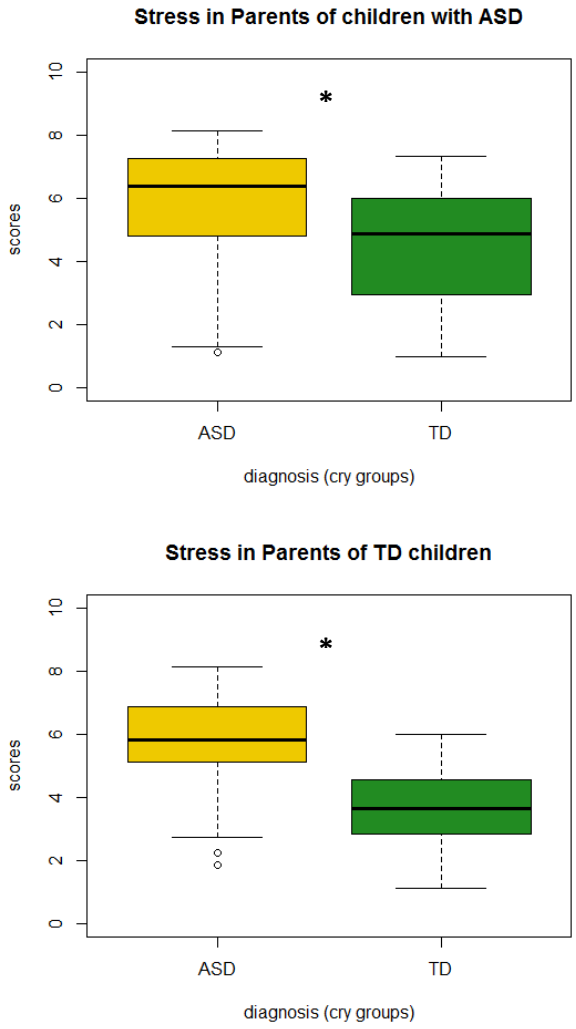

Fig. 23: Boxplots of the stress scores. An asterisk highlights the scale having statistically significant difference.

Arousal: There is a significant difference between self-reported arousal response of Parents of children with ASD to ASD cry (Mdn = 6.4) and to TD cry (Mdn = 4.3); V = 188, p < .001. Also, Parents of TD children reported as more aroused for ASD cry (Mdn = 5.3) compare to TD cry (Mdn = 3.3); V = 432, p < .001 (see *Fig. 24*).

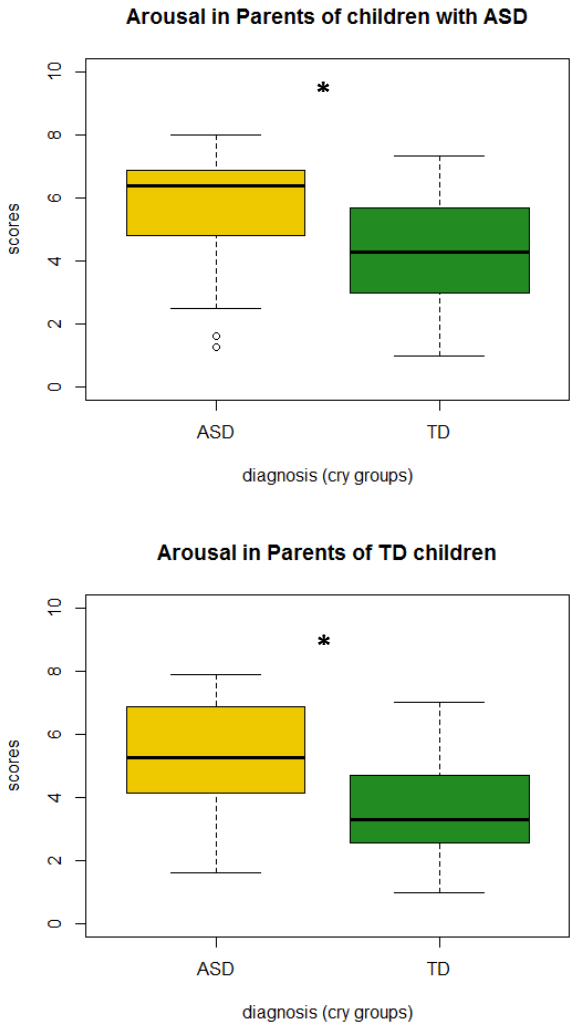

Fig. 24: Boxplots of the arousal scores. An asterisk highlights the scale having statistically significant difference.

Valence: There is a significant difference between self-reported valence response of Parents of children with ASD to ASD cry (Mdn = 3.1) and to TD cry (Mdn = 3.8); V = 7, p < .001. Moreover, Parents of TD children reported as less pleasant for ASD cry (Mdn = 2.9) compare to TD cry (Mdn = 4.4); V = 4, p < .001 (see *Fig. 25*).

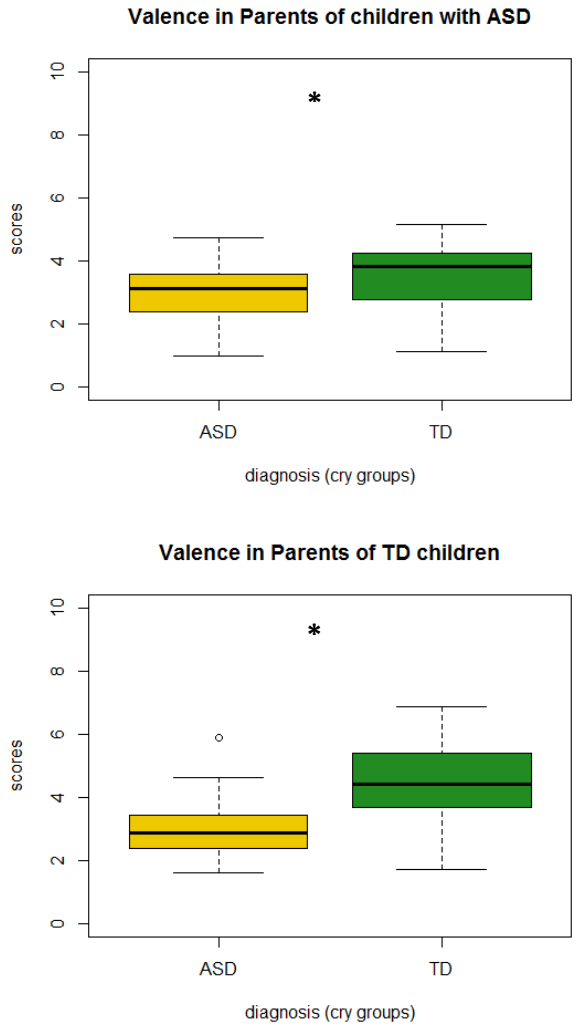

Fig. 25: Boxplots of the valence scores. An asterisk highlights the scale having statistically significant difference.

- **Hear Rate (HR):** We found that Parents of TD children have higher HR during TD cry compare to ASD cry; W = 92009, p = .02. However, the results are not significant after Bonferroni correction. Interestingly, HR is not differentiate during TD cry and ASD cry in Parents of children with ASD (W = 43521, p = .47) (see *Fig. 26*).

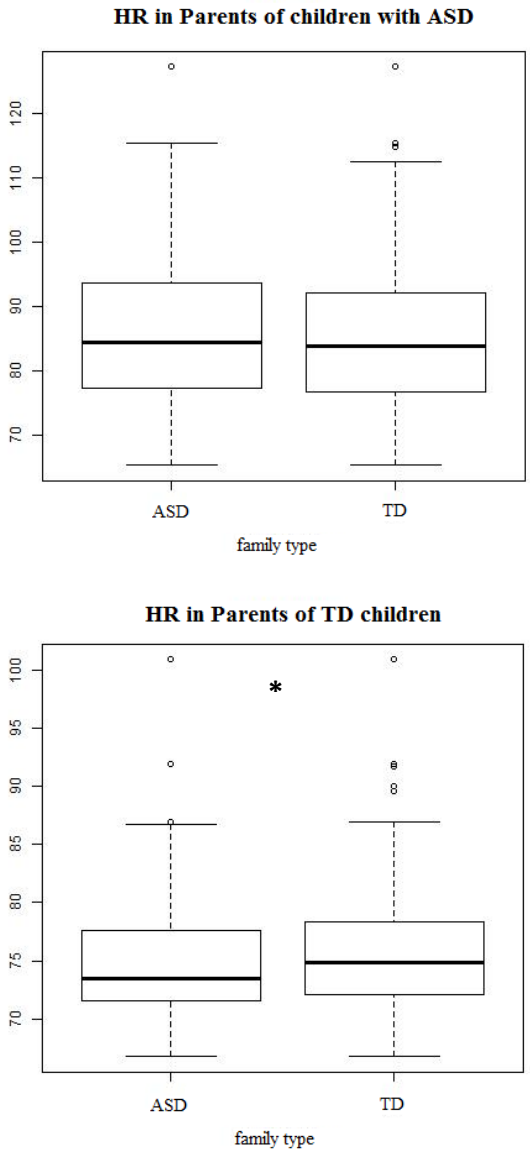

Fig. 26: Boxplots of the HR values. An asterisk highlights the scale having statistically significant difference.

Adults' judgements of the level of stress of children

A significant difference emerged between ASD and TD cries in the responses of Parents of children with ASD (V = 178, p < .001). Participants rated ASD cry (Mdn = 6.8) as expressing more stress than TD cry (Mdn = 5.1). Moreover, Parents of TD children rated ASD cry (Mdn = 5.8) as expressing more stress than TD cry (Mdn = 4); V = 406, p < .001 (see *Fig. 27*).

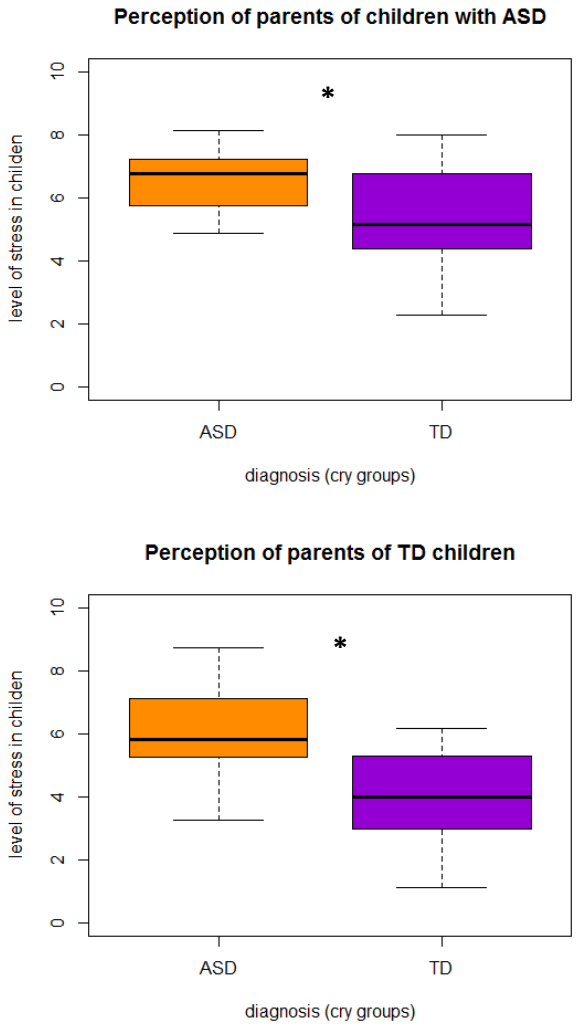

Fig. 27: Boxplots of the scores about the level of stress in children. An asterisk highlights the scale having statistically significant difference.

6.3. Discussion

This study set out to determine emotional and physiological (biological) responses of parents of children with ASD while listening to infant crying, in particular cry of children with ASD. Returning to the hypothesis/question posed at the beginning of this study, it is now possible to state that parents of children with ASD and parents of TD children are not differentiated in terms of how they perceive ASD cry and also TD cry, they reported same levels of stress, arousal and valence for both ASD cry and TD cry. Interestingly, physiological results showed that parents of children with ASD have higher heart rate than parents of TD children during both cry groups. These results will be discussed in more depth below.

It seems that parents of children with ASD felt, psychologically, as stressful as parents of TD children during both cry groups; however their physiological responses showed different pattern: parents of children with ASD showed higher heart rate compare to parents of TD children. This result might be interpreted keeping in mind this description: physiological stress is a body's method of reacting to a challenge and cry can be considered as a challenging situation. In general, cry is expressed as a biological siren, alerting the caregiver about the needs and wants of the infant and motivating the listener to respond (Zeskind & Lester, 2001, p. 149). However, if this biological siren does not work probably (in our case because of the atypical cry), the caregiver can fail to give adequate feedback to the child (Esposito & Venuti, 2008, 2009b). Parents of children with ASD, even now, have life with an autistic children with ASD cry which has been found confusing and overwhelming in the literature (Esposito et al., 2012; Esposito & Venuti, 2008, 2009a). They are exposed to this specific cry in their daily life and possibly, they have their own strategy to deal with this confusing and overwhelming situation. In our sample, parents of children with ASD showed more heart rates during both cry groups

compare to parents of TD children. It might be that biological structures of parents of children with ASD (in our case heart dynamics) are getting ready during this challenging situation in order to react/respond to cry, more than the one of parents of TD children; then they can give adequate feedback to the child (responding the child who is crying) as soon as possible.

Even though there was not any difference between parents of children with ASD and parents of TD children, both parents reported high levels of stress, arousal and low level of pleasure for ASD cry. In fact, based on the comparisons between the responses to ASD cry and TD cry within parents of children with ASD and within parents of TD children, it was found that both parents perceived ASD cry more stressed, aroused and less pleasant compare to TD cry. It might be that both parents can distinguish the differences between ASD cry and TD cry. Indeed, these 2 types of cries have different acoustic characteristics which is important on adults judgment of infant cry (Del Vecchio et al., 2009; Esposito, Del Carmen Rostagno, et al., 2014; Esposito, Nakazawa, et al., 2014; Lin & McFatter, 2012; Sheinkopf et al., 2012). However, we did not find differences between ASD cry and TD cry within the physiological responses of parents of children with ASD, but we do find a trend within the physiological responses of parents of TD children. The explanation lies on the same fact we mentioned above that parents of children with ASD, in their life, have more exposure to or experience in caring for crying children with ASD cry which is an uneasy and negative stimuli (Esposito & Venuti, 2008), and now both cry types trigger their physiological structures, not only ASD cry; so that we did not find differences between ASD cry and TD cry within the physiological responses of parents of children with ASD.

In sum, parents of children with ASD reported same levels of stress, arousal and less valence for both cry groups and showed higher heart rate, compare to parents of TD

children. However, regarding to comparisons between ASD cry and TD cry, parents of children with ASD reported higher levels of stress, arousal and valence for ASD cry, but showed same levels of heart rate, compare to TD cry. These findings highlight similarities and differences in parents' psychological and physiological responsiveness to cries of children with ASD. It may help us to understand the situation which parents of children with ASD are in and to do further researches on this topic (e.g., studies combining several methodological approaches). Moreover, regarding to the clinical implications, an intervention program for parents of children with ASD might be helpful to attend atypical crying episodes so parents can correctly interpret the signal from their children.

This study has a number of strengths, including the focus on parents of children with ASD and the method which allowed us to measure physiological responses (heart dynamics). However, some relevant limitations must be noted. These include the sample size, which does not allow us to determine whether the findings are gender-specific.

Chapter 7: General Discussion

This thesis had two main goals. The first goal was to examine well-being of parents of children with ASD, considering two aspects: 1) the differences between mothers and fathers in terms of parenting stress (the magnitude of stress in the parent–child system), parental mental health (psychological problems and symptoms of psychopathology) and parental attitude (the way how parents behave to their children); 2) the extent to which treatment-related changes in children with ASD and other non-treatment related factors affect changes in maternal well-being from pre-intervention (baseline) to post intervention (12 months later). The second goal was to examine the parents' responses to cries of infants with ASD and typical development, considering two types of responses: emotional and physiological. This final chapter will summarize the main findings of this research before considering implications and future directions.

7.1. Parents' well-being

7.1.1. Why is well-being of parents of children with ASD an important area of research in the field of autism?

Key characteristics of children with ASD each create a number of difficulties for individuals with autism and also their families, in particular their parents. Caring a child with disability is challenging and parents are greatly affected by the condition of autism. Therefore, it is worth to take into account parents in addition to children in the field of autism. Indeed, in the literature, parents of children with autism have been found to have

higher levels of stress when compared to both parents of children with other disabilities and parents of typically developing children. Understanding how parents experience these difficulties is necessary in order to design efficient support programmes for parents.

7.1.2. What were the aims and what has this programme of research achieved?

As noted throughout this thesis, it is established that decreasing in well-being is often seen in parents of children with ASD. However, there is a big debate about how mothers and fathers individually experience these difficulties. There is no general agreement in the existence of similarities or differences in the level of stress or various psychopathologies between mothers and fathers of children with ASD. Therefore, the first goal of this thesis (Chapter 2) was to examine similarities and differences between mothers and fathers in terms of how they experience parenting a child with ASD. Moreover, no research to date has investigated the extent to which treatment-related changes in children affect their parents' well-being. The second study of this thesis (Chapter 3) was conducted to examine whether treatment-related changes in children with ASD contribute to changes in maternal well-being from pre-intervention to post-intervention and how parental sense of competence influences the effect of treatment-related changes on maternal well-being.

- The findings from Chapter 2 highlighted similarities in parenting stress and differences in parental attitude and mental health between mothers and fathers of children with ASD (Ozturk et al., 2014). Mothers of children with ASD reported higher level of depression than fathers and considerable percentages of both mothers and fathers have scores above the clinical cut-points of stress, showing that they experience clinically significant levels of parenting stress. Moreover, in terms of parental attitude, mothers

reported that they engage with their children in more social exchange than fathers do. All those results showed that mothers and fathers experience parenting a child with ASD differently, however both parents have elevated parenting stress. Given the unique and importance challenges in raising a child with ASD, these results highlight the need to consider parental stress in addition to maternal stress in the family interventions.

- The results in Chapter 3 suggested that different child and family factors, including mothers' age, were linked to maternal well-being (Ozturk, Vivanti, Uljarevic, & Dissanayake, under review). However, treatment-related changes in children communication skills and changes in mothers satisfaction contributed to variance in maternal well-being at post treatment above and beyond each of these factors. The mediation analysis indicated that the changes in children's communication lead to increased satisfaction levels in mothers which in turn lead to a decrease negative well-being, as reflected in reduced self-reported Depression, Anxiety and Stress. These results highlighted the importance of communication skills in the child's and parents' life. Mothers are positively affected by observing improvements in their children's communication skills in everyday life contexts.

All of the above mentioned results represent a unique contribution of this programme of work to the literature on parenting in the field of autism, showing gender difference between mothers and fathers of children with ASD in a number of parenting dimensions and also highlighting the importance of child's communications skills in maternal satisfaction with the parenting role and maternal well-being.

7.2. Parents' responses to cries of infants with ASD and typical development (TD)

7.2.1. Why is it important to understand how parents of children with ASD response to cries of infants with ASD and with TD?

Cry is a signal which child use to express his needs/wants to his/her caregiver. It is important that parents understand this signal adequately and then respond properly. Otherwise, as Esposito and Venuti (2009b) highlighted, parents fail to recognize the child's needs, and these result in adequate feedback to the child. Understanding of the emotional and physiological responses of parents of children with ASD to infant crying is a necessary step in developing or further enhancing the specificity of interventions. As we discussed throughout this thesis, to date, physiological aspects of parents' reactions to infant crying has received considerably less attention than other aspects.

7.2.2. What were the aims and what has this programme of research achieved?

Our main aim was to explore physiological responses in addition to behavioral responses in parents of children with ASD to typical and atypical distress vocalizations that are TD cry and ASD cry. Before addressing this goal, we carried on three experiments. The first step in this process was to prepare and validate cry episodes, that has been done in Chapter 4. 20 TD and 20 ASD cry episodes were extracted from home videos and analyzed using the Praat acoustic analysis software (Boersma & Weenink, 2001). Afterwards, we defined how adults perceive all those cry sounds in terms of valence (pleasant-unpleasant). The following chapter (Chapter 5) focused on non-parents' emotional and physiological responses while listening to infant crying episodes. Finally,

the aim of Chapter 6 was the main interest of this thesis and we attempted to answered the question: How do parents of children with ASD perceive cry of children with ASD?

- The results from Chapter 4 showed that cry was considered as unpleasant by non-parent adults. All 40 cry episodes, regardless of types, fall into the unpleasant area in the emotional-space. It was important to identify those cry episodes with emotional aspects (in our case pleasant, neutral or unpleasant), which were prepared for this thesis, because then those cry episodes could be considered as unpleasant sounds in the following experiments.

- The findings from Chapter 5 supported the literature showing that listeners perceive cry of infants with ASD differently compare to cry of TD infants (Esposito & Venuti, 2008, 2009a, 2010b; Venuti et al., 2012). As it was the hypothesis, ASD cry was reported more stressed, aroused and less pleasant compare to TD cry by non-parents adults. These results highlighted the differences between emotional responses to ASD cry and TD cry, based on non-parents' self-reports. However, we did not find similar pattern in the physiological responses of listeners. Taking into account the results and also all the issues we faced, we developed our new experimental design with a couple of adjustments for the final study.

- In the final experiment (Chapter 6), the analysis found an interesting pattern on both behavioral and physiological response types. When parents of children with ASD and parents of TD children were compared, it was found that they reported similar levels of stress, arousal and valence during ASD cry and also TD cry. However, their physiological reactions showed that parents of children with ASD have higher heart rate than parents of TD children during both types of cry, meaning that parents of children with ASD, biologically, are getting more ready during cry episodes in order to respond to

the challenging situation. The hypothesis was to observe this differences also in the behavioral data. However, it seems that physiological functions were highlighting the differences between two types of parents, even though their self-reports indicated the similarities.

Additionally, the analysis on the comparisons between ASD cry and TD cry suggested that both parents perceived ASD cry more stressful, aroused and less pleasant. This result shows that parents can distinguish the difference between these two types of cry that each type has its own acoustic features (the f0 of ASD was higher than the f0 of TD, $t(13) = 5.90$, $p < .001$). Regarding to the physiological reactions, parents of TD children had higher heart rate during TD cry compare to ASD cry; it might that those parents can distinguish TD cry and ASD cry and showing more physiological reactions during a specific type of cry they use to listen and react in their daily life (TD cry). On other hand, physiological reactions of parents of children with ASD did not show this specificity to ASD cry. It seems that physiologically they perceive two types of cries with similar level.

All of above mentioned results represent a unique contribution of this programme of work to the literature on parents' emotional and physiological mechanisms of perceptions of ASD cry since, at the time of writing none of concepts have been addressed both mechanisms together in the existing literature. The findings from this part of the thesis showed that parents of children with ASD and parents of TD children have different physiological reactions to cry (both ASD and TD cry), even though their self-reports indicate similarity. This highlights the importance of measuring different aspects of parents' responses, such as physiological and behavioral responses to infant crying, in order to gain a better and deeper understanding of parents of children with ASD. It is worth to note that for the first time in the literature, both behavioral and physiological

responses of parents of children with ASD to ASD cry and TD cry were evaluated, comparing with responses of parents of TD children.

7.3. Limitations

The work of this thesis was limited by a number of factors which constrain its conclusion. These have been referred to in each chapter, and here they will be reviewed again.

The first limitation of this thesis was sample size which in particular limited the analysis on parents of children with ASD (Chapter 6). This necessarily limits the generalizability of that particular finding. Moreover, due to sample size, it was not possible to add gender effect into the analysis. However, it is important to point out that, the sample size was sufficient for performing two groups comparisons and reporting results with Bonferroni adjustments.

The second limitation include the lack of a control group in Chapter 2 and 3. For example, this limitation did not allow to determine whether the current findings from Chapter 3 were specific to treatment responses to a particular intervention program. The mediation analysis suggested that the changes in children's communication skills lead to increased satisfaction levels in mothers which in turn lead to a decrease negative well-being. However, the issue of control group limits the interpretation specifically on the ESDM intervention program. Moreover, the focus in Chapter 3 was on the well-being of mothers of children with ASD, not fathers. Therefore, the finding cannot be generalized to fathers. This detail should be taken into account when results are interpreted.

However, the results from these studies provide starting point for the future studies that will be discussed in the next section.

7.4. Implications and Future Directions

Findings from this thesis provided a wide range of parenting a child with ASD and could influence further understanding in this field. The work has contributed to existing understanding of this concept that has been investigated by this thesis.

The results from Chapter 2 have their own theoretical and clinical implications. This study provide insights that would help researchers and clinicians to better understand the situation mothers and fathers face. The findings add to a growing body of literature on parenting and autism, taking into consideration several important domains of parenting that are stress, mental health and attitude. The similarities and differences between mothers and fathers should be taken into account and specific intervention programs are needed for both parents aimed to a reduction in their stress levels. Moreover, particularly fathers involvement would be helpful both parents to cope efficiently with stress and depression. However, this thesis has not been explored coping strategies of parents of children with ASD. This is an important aspects in parenting a child with disabilities for the future research.

As already discussed in Chapter 3, such improvements in daily communication in their children would lead to an increase satisfaction with their parenting role, which in turn decreases the parents' negative emotional states of stress, anxiety and depression. These results highlight the importance of communication skills in the child's and parents' life. Therefore, it is worth to note that treatment-related changes in children do not affect

only children, mothers are positively affected by observing improvements. Future research is needed to determine the mechanisms through which specific improvement in communication affect maternal well-being.

The second part of the thesis explored the reactions of parents of children with ASD to cry, specifically to ASD cry and found that those parents and parents of TD children showed different pattern in their physiological responses to ASD cry and also to TD cry. Parents of children with ASD, biologically, are getting more ready during cry, compare to parents of TD children, in order to respond to immediately. It seems that those parents who are rearing a child with ASD, which has been accepted as a challenging situation, are more prepared to react while they hear infant cry. Moreover, parents of children with ASD can distinguish ASD cry from TD cry and it is worth to note that those two types of cry have different acoustic features too. However, those results come from their self-reports on their stress, arousal and valence levels. Their physiological responses show that their heart rates were not differentiated during ASD cry and TD cry. It seems that both cry types trigger their biological structures (heart dynamics) similarly, physiologically they cannot distinguish the difference between ASD cry and TD cry. Future work should test this argument measuring other components such as hand temperature, as it has been reported that increases in skin temperature of the right hand are associated with promptness to action (Esposito et al., 2015; Rimm-Kaufman & Kagan, 1996). Furthermore, regarding to clinical implications, these results highlight the need of intervention programs for parents of children with ASD, specifically focusing on training them to attend to ASD cry so that they can correctly interpret the cry and give adequate feedback to their children with ASD.

7.5. Conclusions

In conclusion, despite some of the limitations, the work from this thesis provided significant contributions to the literature on parenting a child with ASD. The findings added to a growing body of literature on this field. This thesis makes several noteworthy contributions: 1) it shows differences between mothers and fathers of children with ASD in terms of stress, mental health and attitude; 2) it highlights the importance of the improvement in children's communication skills on maternal satisfaction and well-being, and has significant implications for understanding of how children's outcomes have a critical positive impact in the sense of competence and well-being of mothers; c) for the first time in the literature, both behavioral and physiological responses of parents of children with ASD and parents of TD children were evaluated, comparing their responses to ASD cry with the ones to TD cry. This work, through the focus on physiological aspects of parental response, has placed important step stones towards enhancing our understanding of caregiver responses to infant crying.

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