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Research Paper

Contributors to well-being and stress in parents of children with autism spectrum disorder

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ABSTRACT

Background: Parents of children with autism spectrum disorder (ASD) present more well-being and stress problems than parents of typically developing (TD) children. However not all parents present these problems. These problems can be due to a dynamic interaction between environmental antecedents, person antecedents, and mediating processes. Understanding how these factors separately contribute to explain parents' well-being and stress can have implications for intervention programs. The aim of this study was to explain parents' subjective well-being and physiological stress by considering whether they had a child with ASD or not and their child's negativity (environmental antecedents), their perception of their child's problems (person antecedents), and their use of reappraisal (mediating processes).

Method: Thirty-seven parents of children with ASD and 41 parents of TD children reported their subjective well-being and their physiological stress was assessed. Additionally, children's negativity was observed, parents rated their perception of their child's problems (autistic traits, emotion regulation ability, and lability/negativity), and parents reported their use of reappraisal.

Results: Compared to parents of TD children, parents of children with ASD reported having lower subjective well-being and had increased physiological stress. Parents' perceptions of children's lability/negativity and parents' use of reappraisal were better predictors of parents' subjective well-being than ASD and parents' perceptions of children's lability/negativity contributed to parents' physiological stress as much as ASD.

Conclusions: Prevention and intervention programs targeting parental well-being and stress will benefit from working with parents at the level of perceptual constructs and reappraisal ability.

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1. Introduction

Parents of children with autism spectrum disorder (ASD) are at a greater risk of increased stress and mental health problems than parents of typically developing (TD) children (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). ASD can, in fact, be one of the most demanding disorders in terms of threats to parents' well-being and mental health (Seltzer, Krauss, Orsmond, & Vestal, 2001). It has been repeatedly shown that parents of children with ASD report more stress and present more depressive symptomatology than parents of TD children (Duarte, Bordin, Yazigi, & Mooney, 2005; Lee, 2009)

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and parents of children with other disorders (Abbeduto et al., 2004; Dumas, Wolf, Fisman, & Culligan, 1991). They also report more anxiety (Bitsika & Sharpley, 2004; Lee, 2009), more mental health problems (Montes & Halterman, 2007), and decreased well-being (Nikmat, Ahmad, Oon, & Razali, 2008). However, even though families of children with ASD face serious difficulties (Dumas et al., 1991), not all concerned parents show problems with well-being and stress.

Past research has characterized the experience of parenting a child with ASD as stressful and as presenting a threat to parents' well-being (e.g. Seltzer et al., 2001). Past research has also described coping strategies used by these parents (e.g. Pottie & Ingram, 2008). However, to our knowledge, no studies have sought to understand how the different factors that have been recognized for years as predictors of stress (e.g. Lazarus & Folkman, 1984) can explain well-being and stress in parents of children with ASD. Identifying these processes in parents of children with ASD can offer outlets to intervene with these parents to improve their well-being and decrease their stress. Therefore, the aim of the present study was to explain why faced with the same life-event (i.e. having a child diagnosed with ASD) some parents present decreased well-being and stress while others do not.

The transactional model of stress and coping theory, proposed by Lazarus and Folkman (1984), defines stress as an emotional response to a situation or an event, that is important for the individual, and that is perceived as exceeding the individual's resources (Lazarus & Folkman, 1984). This model is based on the cognitive-relational theory of stress (Lazarus & Folkman, 1987) which conceptualizes stress as resulting from a recursive dynamic interaction between environmental antecedents such as a life-event or daily hassles (e.g. demands, constraints and resources, ambiguity, and imminence of a situation), person antecedents (e.g. goal hierarchies, attributions, and belief systems), and mediating processes (e.g. appraisal and coping). The interaction between these three aspects can be reflected in immediate and long-term effects such as the individual's subjective well-being, social functioning, stress, and somatic health. Using this model, differences on well-being and stress of parents of children with ASD could be understood as resulting from a dynamic contribution of (a) environmental antecedents such as the fact of having a child diagnosed with ASD and the child's negativity, (b) person antecedents such as parents' attributions and belief systems regarding their child, and (c) mediating processes such as parents' capacity to cognitively reappraise (see Fig. 1).

(a) Environmental Antecedents

Some of the environmental antecedents that can contribute to decreased well-being and increased stress in parents of children with ASD can be related to the life event of having a child diagnosed with ASD and to the daily hassles this represents. Parents need to adapt to new expectations regarding their child's future (Brogan & Knussen, 2003). Parents are also challenged by factors that are related to dealing with a chronic disorder (i.e. repeating strains) and they often describe themselves as being isolated and having to fight all the way (Woodgate, Ateah, & Secco, 2008). Furthermore, the fact that their children have normal appearances, which do not signal any disorder, but often present disruptive and sometimes antisocial behaviors, can lead to stigmatization and lack of understanding from others (Gray, 1993, 2002).

Daily hassles related to having a child with ASD can also be reflected at the level of the child's negativity and the difficult behaviors they often present. Children with ASD have more emotional and conduct problems compared to TD children (Pouw, Rieffe, Oosterveld, Huskens, & Stockmann, 2013; Rieffe, Camodeca, Pouw, Lange, & Stockmann, 2012; Russell & Sofronoff, 2005; Samson et al., 2014) as well as compared to children with other disorders (Bradley, Summers, Wood, & Bryson, 2004; Brereton, Tonge, & Einfeld, 2006; Eisenhower, Baker, & Blacher, 2005; Green, Gilchrist, Burton, & Cox, 2000). These difficult behaviors are also present in children with ASD who do not have intellectual disability (Pearson et al., 2006; Totsika et al., 2011).

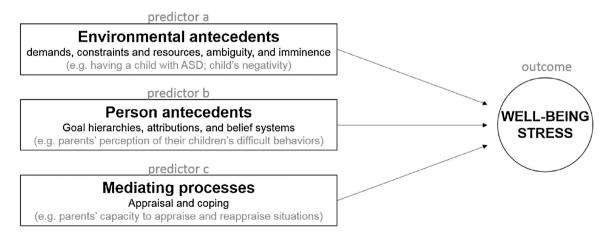


Fig. 1. Adaptation of the transactional model of stress and coping theory (Lazarus and Folkman, 1984) to explain well-being and stress in parents of children with ASD.

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(b) Person Antecedents

According to the transactional model of stress and coping theory (Lazarus & Folkman, 1984), another factor that can determine stress is related to how individuals construct a meaning about the situation, the attributions they create, and their belief systems. Parents of children with ASD often describe these as being difficult, with frequent and long-lasting tantrums, easily frustrated, inattentive, and withdrawn or depressed. Through research it has been found that emotional and behavioral problems in children with ASD play a role in parents' well-being and mental health. It has been reported that observed and parental perceptions of regulatory problems and difficult behaviors in children with ASD are related to parents' increased stress (Davis & Carter, 2008; McStay et al., 2013). Furthermore, parental perceptions of emotional and behavioral problems in children with ASD contribute significantly more to the explanation of parents' well-being and mental health than children's ASD diagnosis (Herring et al., 2006). This relation may be due to the additional burden children's emotional and behavioral difficulties represent for parents (Lecavalier, Leone, & Wiltz, 2006). Another possible explanation holds that children who are unhappy and have emotional or behavioral problems may lead parents to question their parenting skills because they feel responsible (McStay et al., 2013).

(c) Mediating Processes

Finally, specific appraisals and coping styles can play a significant role in determining parents' well-being and stress. Parents of children with ASD who use escape, avoidance (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings et al., 2005), or blaming (Pottie & Ingram, 2008) as coping styles show more negative well-being and mental health outcomes. Parents who use distraction, problem solving, and reappraisal report more positive well-being and mental health outcomes (Dunn et al., 2001; Pottie & Ingram, 2008; Sivberg, 2002). Particularly, reappraisal has been suggested as a strong protective factor against adverse life events (Troy & Mauss, 2011). This type of emotion regulation strategy involves re-evaluating events with respect to their personal meaning (Lazarus, 1999). How parents appraise and reappraise specific situations will thus essentially determine their impact.

In this line of reasoning, the way parents of children with ASD evaluate the different challenges they face may potentially determine their well-being and stress. Several studies showed that specific emotion regulation strategies in parents of children with ASD are linked to better well-being and mental health outcomes (Dunn et al., 2001; Pottie & Ingram, 2008; Sivberg, 2002). However, it is not clear if parents of children with ASD, compared to parents of TD children, differ in the use of such specific strategies, such as reappraisal. In one study, it was found that parents of children with ASD used more self-control than parents of TD children but groups did not differ in reappraisal as an emotion regulation strategy (Sivberg, 2002). In a group of studies evaluating parents' emotion regulation strategies during parent-child interactions it was found that parents of children with ASD used less strategies that facilitate emotion regulation such as cognitive reappraisal and emotional reframing, than parents of TD children (Hirschler-Guttenberg, Golan, Ostfeld-Etzion, & Feldman, 2015). However, mothers of children with ASD, compared to mothers of TD children, reported using more effortful control strategies, such as inhibitory and attentional control (Hirschler-Guttenberg, Feldman, Ostfeld-Etzion, Laor, & Golan, 2015), and used more simple regulation facilitation strategies, such as providing physical comfort to their child, but did not differ in comparatively complex regulation facilitation strategies, such as cognitive reframing and emotional reflection (Ostfeld-Etzion, Golan, Hirschler-Guttenberg, Zagoory-Sharon, & Feldman, 2015).

The aim of this study is to analyze how different factors that are related to having a child with ASD interact and can determine parents' well-being and stress. Understanding these processes can be informative in explaining why some parents of children with ASD experience stress while others do not. The present study is based on 30 years of research that conceptualize stress as a function of a recursive, dynamic interaction between the individual and the environment (Lazarus & Folkman, 1984). Based on the transactional model of stress and coping theory (Lazarus & Folkman, 1984) we hypothesize that well-being and stress of parents will be a product of (a) environmental antecedents, (b) person antecedents, and (c) mediating processes (see Fig. 1). We expect therefore that parents of children with ASD, compared to parents of TD children, will have reduced well-being and increased stress (Fig. 1, outcome). However, because not all parents of children with ASD

Table 1 Sample characteristics: Means (M), standard deviations (SD), ranges, sample size, Pearson's chi square values (χ^2) , t-values, and significance levels (p) for age and gender differences between parents of children with ASD and parents of TD children and their children. Mann-Whitney values (U), standardized test statistic (z), and significance levels (p) for parents' education and income levels.

| | ASD M (SD, range) n = 37 | TD M (SD, range) n = 41 | Statistics (ASD/TD) |
|---------------|--------------------------------|-------------------------------|--------------------------------------|
| Parents | | | |
| Mother/Father | 31/6 | 36/5 | $\chi^2(1) = 0.26$, $p = 0.61$ |
| Age | 41.29 (4.88, 33-53) | 39.12 (4.77, 26-49) | t(74) = 1.95, p = 0.06 |
| Education | | | U = 741.50, $z = 0.91$, $p = 0.37$ |
| Income | | | U = 616.50, $z = -0.70$, $p = 0.48$ |
| Children | | | |
| Male/Female | 32/5 | 32/9 | $\chi^2(1) = 0.94$, $p = 0.33$ |
| Age | 9.07 (2.60, 3-13) | 8.42 (2.20, 4–13) | t(76) = 1.20, p = 0.23 |

ASD autism spectrum disorder, TD typically developing.

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experience decreased well-being and stress, we hypothesize that children's negativity (Fig. 1, predictor a), parents' belief systems regarding their children's difficult behaviors (Fig. 1, predictor b) and parents' capacity to reappraise (Fig. 1, predictor c) will be more determinant of parents' well-being and stress than ASD diagnosis.

2. Methods

2.1. Participants

A convenience sample of 37 parents of children previously diagnosed with ASD, 1 (i.e. 31 mothers 2 6 fathers) and 41 parents of TD children (i.e. 36 mothers, 5 fathers) participated in the study with their children (Table 1). Parents were aged between 26 and 53 years old and their children were aged between 3 and 13 years old. Children with ASD were diagnosed by a pediatrician or by a multi-disciplinary team of professionals working with children with ASD. Children had been previously diagnosed with: (a) the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), (b) the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999), or (c) the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1986), according to criteria provided by the DSM-IV (American Psychiatric Association, 1994) and the DSM-IV-TR (American Psychiatric Association, 2000). Participants in this study were part of a larger study on emotional reactivity and emotion regulation.

2.2. Procedure

Invitations to participate in the study were sent to parents of children with ASD through specific institutions and to parents of TD children through primary schools. Prior to contact with parents, the study was reviewed and approved by the university's ethics review panel. Parents and, when possible, children read and signed informed consent forms for participation and data collection. The study consisted of a single visit. During the visit, parents were requested to fill out a demographics questionnaire, a questionnaire on their subjective well-being, and a questionnaire on their use of reappraisal. Moreover, parents completed questionnaires about their children's autistic traits, their children's lability/negativity, and their children's emotion regulation ability. Once questionnaires were completed an electrocardiogram (ECG) measurement of parents took place at rest for approximately five minutes. After that, children's negativity was observed during a frustration eliciting situation.

2.3. Measures

2.3.1. Indicators of parents' well-being and stress

2.3.1.1. Parents' well-being. The Difficulties in Emotion Regulation Scale (DERS; Gratz & Roemer, 2004) is a 36-item self-report questionnaire that assesses different aspects of emotion regulation difficulties such as impulse control difficulties (e.g. "When I am upset, I feel out of control") and lack of emotional awareness (e.g. "I am attentive to my feelings"). This questionnaire was used as a subjective indicator of parents' well-being because of the close relationship between emotional ability and well-being (Martins, Ramalho, & Morin, 2010; Schutte, Malouff, Thorsteinsson, & Rooke, 2007). Parents were asked to rate the degree to which they agreed to statements concerning themselves on a 5-point scale ranging from "almost never" to "almost always". Ratings of the 36 items were added to obtain a composite score indicating subjective well-being. A higher score reflects lower subjective well-being. A French translation (Dan-Glauser & Scherer, 2013) of the questionnaire was used and the items were translated and back-translated into German by two independent native speakers who were also fluent in English. Inconsistencies in translation were discussed and resolved. Internal consistencies for French and German versions, computed on the basis of the sample described here, proved to be satisfactory. Cronbach's alpha was α = 0.92 for the French and α = 0.89 for the German version.

2.3.1.2. Parents' stress. Individual differences in heart rate variability (HRV) constitute an objective indicator of the brain's ability to organize emotional responses through the autonomous nervous system (Appelhans & Luecken, 2006). High resting HRV is thought to indicate readiness to respond to environmental demands and a positive relationship has been found between high resting HRV and increased emotion regulation capacity (Porges, 2007). Therefore, HRV indexes important organism functions associated with adaptability and health and represents a marker of stress and health (Thayer, Åhs, Fredrikson, Sollers, & Wager, 2012). HRV can be observed through the periodic changes that occur in consecutive R wave to R

¹ Among the 37 children diagnosed with ASD 20 were diagnosed with ASD with cognitive impairments (3 female) and 17 were diagnosed with ASD without cognitive impairments (2 female). Analyses comparing children with ASD with and without cognitive impairments revealed that the two groups of children did not differ in any of the reported variables: Autistic traits [t(33) = 0.45, p = 0.66], Lability/negativity [t(25) = 0.98, p = 0.34], and Emotion regulation [t(35) = 0.82, p = 0.42]. Additionally, parents of children with ASD with and without cognitive impairments did not differ on any of the reported variables: Reappraisal [t(35) = 0.58, p = 0.56], DERS [t(35) = 0.66, p = 0.51], and HRV [t(24) = 1.06, p = 0.30]. For this reason, and for parsimony, we have grouped the two sub-groups of children with ASD into one group and analyzed it as one.

² Two of the mothers of children with ASD were grand-mothers who were the legal representatives of the child since the child was an infant.

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wave (RR) intervals on ECG measurements at rest. The high frequency (HF, 0.15-0.40 Hz) component of these changes has been designated as the most reliable indicator of HRV (Porges, 2007) and lower values reflect less emotion regulation capacity and more stress. The absolute value of HF power was, therefore, chosen as unit (ms²) of HRV. To obtain HRV, an ECG measurement was realized using a Polar chest band equipped with three electrodes and an ambulatory H7 Bluetooth 4.0 heart monitor. Parents were requested to adjust the strap around their chest and to relax for five minutes. Interbeat intervals were continuously transmitted and stored via Bluetooth to the application for iOS Heart Rate Variability Logger (Altini, 2013). Interbeat intervals were recorded between successive R-waves at a sampling frequency of 1000 Hz, with a temporal resolution of 1 ms for each RR interval. ECG data were analyzed offline. Intervals' correction was performed to prevent artefacts due to ectopic beats and motion. To calculate HRV, RR intervals were first linearly interpolated, a hamming window was applied to the interpolation, and then a fast Fourier transform was performed. Cardiac data collected with the Polar monitor has been shown to be valid and reliable (Gamelin, Berthoin, & Bosquet, 2006; Nunan et al., 2009).

2.3.2. Predictors of parents' well-being and stress

According to the postulated model based on the assumptions of the transactional model of stress and coping theory, three factors can contribute to stress (see Fig. 1): (a) environmental antecedents, (b) person antecedents, and (c) mediating processes. In the following section we describe the variables used as indicators of these factors:

(a)Environmental antecedents.

The life-event component was assessed by taking diagnostic group into consideration (TD/ASD).

The *daily hassles* component was assessed by rating children's negativity during a frustration eliciting situation. This situation was adapted from the Attractive Toy Placed behind Barrier situation from the Laboratory Temperament Assessment Battery (Goldsmith & Rothbart, 1999). In this situation frustration is created by presenting toys to children and allowing them little time to play with the toys by removing them and placing them behind a transparent barrier. During the time that the toys are placed behind the barrier (frustration moments; total time = 90 s), children can see the toys but cannot easily access them. Children were videotaped during the frustration moments and their emotions (neutral, happy, sad, angry, and afraid) were coded by two independent coders in 10-s intervals. Inter-rater reliability between the two coders for 100% of the data yielded a good level of Cohen's Kappa measure of agreement [κ = 0.76 (95% CI, 0.712–0.798), p < 0.001]. The frequency of negative emotional expressions (sad, angry, and afraid) was used as an objective indicator of children's negativity.

(b)Person antecedents. Three measures of parents' perceptions of their children's problems were used as indicators of parents' attributions and belief systems related to their child.

The Autism Spectrum Quotient Questionnaire for Children (AQ-child; Auyeung, Baron-Cohen, Wheelwright, & Allison, 2008) is a 50-item parent-report questionnaire measuring children's autistic traits. The AQ-child can be used with clinical and non-clinical populations and a cut-off score of 76 has proved to have good sensitivity (95%) at identifying children diagnosed with ASD. Parents were asked to rate the degree to which they agreed to statements concerning their child on a 4-point scale ranging from "definitely agree" to "definitely disagree" (e.g. "My child prefers to do things the same way over and over again"). Ratings of the 50 items were added to obtain a composite score indicating autistic traits. A higher score in this scale reflects parents' perception of more autistic traits in their children. French (Bastien, n.d.) and German (Gundelfinger, n.d.) translations of the questionnaire were used. Internal consistencies for French and German versions, computed on the basis of the sample described here, proved to be satisfactory. Cronbach's alpha was α = 0.95 for both the French and German version. Six children from the ASD group had a score below the cut-off point of 76 (scores: 52, 65, 68, 71, 72, and 73). Even though these children showed a score below the cut-off point, all children with ASD had a governmentally recognized diagnosis of ASD established by either a psychologist or a psychiatrist which is also the basis for obtaining health insurance provisions. Therefore all children with ASD were included in the study. Only one child from the TD group had a score above the cut-off point (score: 77). Because the score was so close to the cut-off point and it falls within the expected amount of TD boys who score above this value (7%; see Auyeung et al., 2008), the child remained in the study.

The *Emotion Regulation Checklist* (ERC; Shields & Cicchetti, 1997) is a 24-item parent report questionnaire measuring children's emotional reactivity and ability to regulate emotions. Parents were asked to rate the degree to which their child exhibits specific characteristics on a 4-point scale ranging from "never" to "almost always". The ERC is composed by two subscales, the lability/negativity sub-scale and the emotion regulation sub-scale. The lability/negativity sub-scale is composed of eight items assessing emotional intensity, lability, and reactivity (e.g. "My child displays negative emotions when attempting to engage others in play"). The emotion regulation sub-scale is composed of 16 items assessing adaptive emotion regulation (e.g. "My child displays appropriate negative emotions — anger, fear, frustration, distress — in response to hostile, aggressive, or intrusive acts by peers"). The items of each sub-scale were added to obtain a lability/negativity and an emotion regulation score. A higher score in each scale reflects a greater amount of the dimension being measured: higher parent-perceived liability/negativity and higher parent-perceived emotion regulation ability in their children. The questionnaire was translated and back-translated to French and German by two independent native speakers who were also fluent in English. Inconsistencies in translation were discussed and resolved. Internal consistencies, computed on the basis of the sample described here, proved satisfactory for both translations. Cronbach's alpha was α = 0.89 for the French version and α = 0.91 for the German version.

(c) Mediating processes. The Reappraisal sub-scale of the Emotion Regulation Questionnaire (Gross & John, 2003) was used as a measure of parents' ability to reappraise situations. It is composed of 6 self-report items that assess the use of reappraisal. Parents were asked to rate the degree to which they agreed to statements concerning themselves on a 7-point

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scale ranging from "strongly disagree" to "strongly agree" (e.g. "I control my emotions by changing the way I think about the situation I'm in"). The average of the scale was computed to obtain a reappraisal score. A higher score reflects a higher use of reappraisal as an emotion regulation strategy. French (Séguin, n.d.) and German (Abler & Kessler, 2009) translations of the questionnaire were used. Internal consistencies for French and German versions, computed on the basis of the sample described here, proved to be satisfactory. Cronbach's alpha for the reappraisal sub-scale was α = 0.93 for the French and α = 0.85 for the German version.

2.4. Analysis

Independent samples t-tests were used to compare the ASD group and the TD group in parents' subjective well-being (DERS), parents' physiological stress (HRV), children's negativity, parents' perception of their children's problems, and parents' use of reappraisal. The Pearson correlation coefficient was used as a measure of effect size. An effect size of r = 0.10 reflects a small effect, r = 0.30 a medium effect, and r =0.50 a large effect.

ANCOVAs with parents' age and gender, children's age and gender, and all existing control variables (language of assessment, parents' age, parents' gender, children's age, and children's gender) entered as covariates were used to examine possible effects of these factors on observed mean differences. Partial eta squared was used as a measure of effect size. An effect size of $\eta_p^2 = 0.01$ reflects a small effect, $\eta_p^2 = 0.06$ a medium effect, and $\eta_p^2 = 0.14$ a large effect.

A hierarchical regression analysis, based on the transactional model of stress and coping theory (Lazarus & Folkman, 1984), was used to assess the contribution of different predictors to parents' well-being (DERS) and physiological stress (HRV). That way, environmental antecedents were entered on a first step (group and children's negativity), followed by person antecedents on a second step (parents' perceptions of children's autistic traits, lability/negativity, and emotion regulation), and finally mediating processes on a third step (parents' use of reappraisal).

3. Results

3.1. Group differences

Independent samples t-tests were used to compare group differences among the ASD group and the TD group in the outcome and predictor variables (Table 2). Regarding the outcome variables, it was found that parents of children with ASD, compared to parents of TD children, reported lower subjective well-being (higher DERS score) [t(64) = 2.36, p < 0.05, r = 0.28], and showed more physiological stress (lower resting HRV) [t(45) = 2.55, p < 0.05, r = 0.36]. Regarding the predictor variables, it was found that children with ASD had more negativity than TD children [t(48) = 2.69, p < 0.05, r = 0.36], and that parents of children with ASD, compared to parents of TD children, perceived more difficulties in their children in all indicators considered here: they described their children as having significantly more autistic traits [t(74) = 12.34, p < 0.001, r = 0.82], more lability/negativity [t(76) = 5.64, p < 0.001, r = 0.54], and less emotion regulation ability [t(76) = 3.68, p < 0.001, r = 0.39]. Additionally, parents of children with ASD reported using reappraisal less than parents of TD children [t(76) = 2.13, p < 0.05, t = 0.24].

ANCOVAs controlling for parents' and children's age and gender effects on parents' subjective well-being (DERS), physiological stress (HRV), and use of reappraisal revealed no significant effects on the observed group differences (Table 3). Group differences thus remained even after controlling for all control variables simultaneously (language of assessment and parents' and children's age and gender; see Table 3).

Table 2Means (*M*), standard deviations (*SD*), *t*-values, significance levels, and effect sizes (*r*) of outcome variables (subjective well-being – DERS, and physiological stress – HRV) and predictors (children's negativity, parents' perceptions of children's autistic traits, lability/negativity, and emotion regulation and parents' use of reappraisal) for the ASD group and TD group.

| | ASD M (SD) | TD M (SD) | Statistics (ASD/TD) | |
|-----------------------|------------------|-------------------|------------------------|----------|
| Outcomes | | | | |
| DERS | 82.59 (21.89) | 72.39 (15.42) | $t(64) = 2.36^{\circ}$ | r = 0.28 |
| HRV | 698.64 (1171.99) | 2097.32 (3070.21) | $t(45) = 2.55^{\circ}$ | r = 0.36 |
| Predictors | | | | |
| Children's negativity | 1.46 (2.09) | 0.46 (0.90) | $t(48) = 2.69^{\circ}$ | r = 0.36 |
| Autistic traits | 94.29 (16.46) | 51.63 (13.68) | t(74) = 12.34 | r = 0.82 |
| Lability/negativity | 37.14 (5.75) | 28.37 (7.73) | t(76) = 5.64 | r = 0.54 |
| Emotion regulation | 21.19 (3.93) | 25.07 (5.22) | t(76) = 3.68 | r = 0.39 |
| Reappraisal | 4.60 (1.34) | 5.22 (1.22) | $t(76) = 2.13^{\circ}$ | r = 0.24 |
| | | | | |

ASD autism spectrum disorder, TD typically developing, DERS Difficulties in Emotion Regulation Scale, HRV Heart Rate Variability (High Frequency, absolute units in ms²).

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p < 0.05. p < 0.001.

 $F(1,74) = 5.03^{\circ}, \ \eta_{\rm p}^2 = 0.06$

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Table 3ANCOVAs controlling for language of assessment, parents' age and gender effects, children's age and gender effects, and all effects together on group differences (ASD/TD) on subjective well-being (DERS), physiological stress (HRV), and use of reappraisal.

| differences (ASD/TD) on subjective well-being (DERS), physiological stress (HRV), and use of reappraisal. | | | | | |
|---|--|--|--|---|--|
| | Statistics (ASD/TD) | | | | |
| | Controlling for language of assessment effects | Controlling for parents' age and gender effects | Controlling for children's age and gender effects | Controlling for all effects simultaneously | |
| DERS HRV | $F(1,75) = 6.77^{\circ}, \ \eta_{\rm p}^2 = 0.08$ $F(1,69) = 5.37^{\circ}, \ \eta_{\rm p}^2 = 0.07$ | $F(1,72) = 7.44^{\circ}, \ \eta_{\rm p}^2 = 0.09$ $F(1,66) = 5.95^{\circ}, \ \eta_{\rm p}^2 = 0.08$ | $F(1,74) = 7.24^{\circ}, \ \eta_{\rm p}^2 = 0.09$ $F(1,68) = 6.31^{\circ}, \ \eta_{\rm p}^2 = 0.09$ | $F(1,69) = 8.74^{**}, \ \eta_p^2 = 0.11$ $F(1,63) = 4.71^*, \ \eta_p^2 = 0.07$ | |

ASD autism spectrum disorder, TD typically developing, DERS Difficulties in Emotion Regulation Scale, HRV Heart Rate Variability (High Frequency, absolute units in ms^2).

 $F(1,72) = 6.02^{\circ}, \ \eta_{\rm p}^2 = 0.08$

3.2. Regression of parents' well-being and stress

Reappraisal $F(1,75) = 5.24^{\circ}$, $\eta_p^2 = 0.07$

Hierarchical regression analyses were used to model parents' subjective well-being (DERS) and physiological stress (HRV) as a function of (a) environmental antecedents (group and children's negativity), (b) person antecedents (parents' perceptions of their children's autistic traits, lability/negativity, and emotion regulation), and (c) mediating processes (parents' use of reappraisal; Table 4).

In the parents' well-being (DERS) model, when group (TD/ASD) and negative emotions were entered in a first step, group was a significant predictor [t(73)=2.06, p<0.05] but the predictive model was not significant [R^2 =0.07, F(2,73)=2.82, p=0.07]. When parents' perceptions of children's problems were added to the model, parents' perceptions of children's lability/negativity significantly predicted parents' well-being above and beyond group [t(70)=2.38, p<0.05] and the model was statistically significant [R^2 =0.17, F(5,70)=2.83, p<0.05; ΔR^2 =0.10, p=0.05]. When parents' use of reappraisal was added to the model, reappraisal significantly predicted parents' well-being above and beyond group and above and beyond parents' perceptions of children's lability/negativity [t(69)=-4.60, p<0.05]. The overall model significantly predicted parents' well-being [R^2 =0.22, F(6,69)=3.15, p<0.01; ΔR^2 =0.05, p<0.05].

With respect to parents' physiological stress (HRV) model, group (TD/ASD) and negative emotions were entered in a first step; here, group showed to be a significant predictor of this criterion [t(67) = -2.25, p < 0.05] rendering the predictive model significant [$R^2 = 0.09, F(2,67) = 3.25, p < 0.05$]. When parents' perceptions of children's characteristics were added to the model, parents' perceptions of children's lability/negativity significantly predicted parents' stress [t(64) = -2.19, p < 0.05]; this predictive model was significant as well [$R^2 = 0.15, F(5,64) = 2.31, p = 0.05; \Delta R^2 = 0.06, p = 0.19$]. When parents' use of reappraisal was added to the model, reappraisal did not contribute to parents' stress [t(63) = 0.78, p = 0.44] and the overall predictive model was not significant [$R^2 = 0.16, F(6,63) = 2.01, p = 0.08; \Delta R^2 = 0.01, p = 0.44$].

Table 4Results of the hierarchical regressions used to model parents' subjective well-being (DERS) and physiological stress (HRV).

| Step and predictor | DERS | | HRV | |
|-----------------------|--------------------|------|--------------------|---------|
| | $\overline{\beta}$ | SE β | $\overline{\beta}$ | SE β |
| Step 1 | | | | |
| Group (TD/ASD) | 9.41* | 4.57 | -1320.01^{*} | 587.08 |
| Children's negativity | 1.34 | 2.42 | -168.31 | 303.11 |
| Step 2 | | | | |
| Group (TD/ASD) | 4.26 | 8.02 | -1997.37 | 1049.10 |
| Children's negativity | 1.24 | 2.43 | -53.84 | 311.10 |
| Autistic traits | -3.67 | 5.26 | 1127.04 | 709.91 |
| Lability/negativity | 7.77* | 3.27 | -935.37^{*} | 427.64 |
| Emotion regulation | -3.43 | 2.56 | 305.77 | 347.01 |
| Step 3 | | | | |
| Group (TD/ASD) | 3.90 | 7.85 | -1990.35 | 1052.36 |
| Children's negativity | 1.91 | 2.40 | -86.23 | 315.36 |
| Autistic traits | -3.80 | 5.15 | 1146.68 | 712.54 |
| Lability/negativity | 6.33 | 3.27 | -859.21 | 439.94 |
| Emotion regulation | -3.01 | 2.51 | 286.55 | 348.95 |
| Reappraisal | -4.60^{*} | 2.27 | 232.39 | 298.00 |

DERS Difficulties in Emotion Regulation Scale, HRV Heart Rate Variability (High Frequency, absolute units in ms²), TD typically developing, ASD autism spectrum disorder.

Note: Standardized coefficients are shown.

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 $F(1,69) = 7.03^{\circ}, \ \eta_{\rm p}^2 = 0.09$

p < 0.05.

p < 0.01.

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4. Discussion

The overall aim of the present study was to analyze how different factors determine parents' well-being and stress; with this we want to identify protective factors that can be used to improve well-being and prevent stress in parents of children with ASD. In order to achieve this, we analyzed parents' well-being and stress in the framework of the transactional model of stress and coping theory (Lazarus & Folkman, 1984).

4.1. Group differences

Based on that model our first hypothesis was that parents of children with ASD, compared to parents of TD children, would have reduced well-being and increased stress (Fig. 1, outcome). Additionally, we wanted to test whether children with ASD would display more negative emotions than TD children (Fig. 1, predictor a); whether parents of children with ASD, compared to parents of TD children, would perceive the behaviors of their children as more difficult (Fig. 1, predictor b); and whether they would use less reappraisal (Fig. 1, predictor c). We found that, as expected and as found in previous studies (Duarte et al., 2005; Nikmat et al., 2008; Totsika et al., 2011), parents of children with ASD report decreased well-being and increased stress compared to parents of TD children. Additionally, and in agreement with previous research (e.g. Pouw et al., 2013), children with ASD displayed more negativity than TD children. As a further consistent finding (Herring et al., 2006; McStay et al., 2013), parents of children with ASD reported that these show more difficult behaviors than parents of TD children. Finally, the few existing research on the use of reappraisal by parents of children with ASD has been so far inconclusive. In some studies it was found that parents of children with ASD, compared to parents of TD children, used less cognitive reappraisal and emotional reframing (Hirschler-Guttenberg, Feldman et al., 2015). Our results revealed that parents of children with ASD, compared to parents of TD children, use less reappraisal.

If we consider parents' emotion regulation in the framework of how children's individual differences can influence the degree to which parents react negatively to parenting situations (Eisenberg et al., 1999; Gottman et al., 1996) it becomes evident that parents of children that display an increased negativity and are poorly regulated, such as children with ASD (e.g. Samson, Hardan, Lee, Phillips, & Gross, 2015), also report more emotional problems for themselves.

In studies with TD children, it was shown that reactions of parents to their children became less negative as children aged and became more regulated (Eisenberg et al., 1999). Furthermore, parents reacted differently to sons and daughters. Mothers were more permissive of boys' aggression and fathers were more permissive of girls' aggression (Rothbart & Maccoby, 1966). However, in our study we did not find effects of children's age or gender in parents' subjective well-being, in parents' physiological stress, or in parents' use of reappraisal. It is, however, possible that parents' difficulties persist independently of children's age or gender because children with ASD have regulatory difficulties that are persistent across their development and the disorder is more prevalent among boys than girls (Mazefsky & White, 2014).

Additionally, some studies report that parents' age and gender are important factors for parental subjective stress (e.g. Duarte et al., 2005; Herring et al., 2006). However, in the present study we found that parents' age and gender did not affect group differences in subjective well-being or stress.

4.2. Predictors of parents' well-being and stress

Taking into consideration that parents of children with ASD had decreased subjective well-being and increased physiological stress than parents of TD children, the second hypothesis of this study was that children's negativity (Fig. 1, predictor a), parents' belief systems regarding their children's difficult behaviors (Fig. 1, predictor b), and parents' capacity to reappraise (Fig. 1, predictor c) would be as much, or even more, determinant of parents' well-being and stress than the diagnosis.

With respect to their predictive weights, we found that parents' subjective well-being was better predicted by parents' perceptions of their children's lability and negativity than by the child's ASD diagnosis. However, parents' use of reappraisal was an even better predictor of parents' well-being since it reached higher predictive weight than child's diagnosis and parents' perceptions of their children's problems. We also found that parents' physiological stress was predicted as much by parents' perception of children's lability and negativity as by children's ASD diagnosis. However, parents' use of reappraisal did not contribute to parents' physiological stress. Additionally, children's negativity and parents' perceptions of children's autistic traits or children's emotion regulation ability did not contribute to the prediction of parents' subjective well-being or physiological stress.

Our results provide evidence that parents' perception of children's problems, specifically of children's lability and negativity, and how parents are able to reappraise, can be more important to parents' subjective well-being than the diagnosis of ASD. Additionally, parents' perception of children's lability and negativity can contribute as much as ASD diagnosis to parents' physiological stress. These results are in agreement with the postulated assumptions of the transactional model of stress and coping theory (Lazarus & Folkman, 1984) that stress is determined by the contribution of different factors. Namely, environmental antecedents (ASD diagnosis), person antecedents (attributions and belief systems such as parents' perception of their children's lability and negativity), and mediating processes (parents' capacity to reappraise situations).

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The present results can potentially bridge our understanding on the interaction among the triad of factors that can influence well-being and stress in parents of children with ASD and provide information to identify protective factors that could explain why some parents of children with ASD experience decreased well-being and increased stress and others do not.

4.3. Implications

The present study has several implications for intervention programs aiming at improving parents' well-being and reducing parents' stress. A first implication from our results is that how parents perceive their children's lability and negativity is related to parents' well-being and stress. Therefore, it is important to take into consideration parents' attributions and belief systems regarding their children when addressing parents' well-being and stress in interventions. Helping parents change the cognitive frame regarding their children's problems, may help to improve parents' well-being and reduce their stress.

Additionally, parents of children with ASD used less reappraisal than parents of TD children and the use of reappraisal contributed more than the ASD diagnosis and parents' perceptions of children's problems to the explanation of parents' well-being. This is in agreement with previous studies that found that reappraisal is a determinant factor in parents' well-being (Troy & Mauss, 2011). Therefore, teaching parents how to reappraise can potentially improve their well-being.

Furthermore, improving parents' capacity for emotion regulation may also be relevant when addressing children's emotional difficulties. Parents' emotional difficulties and parenting patterns influence children's emotional development (Bowlby, 1988; Eisenberg, Fabes, & Murphy, 1996). Therefore, by improving parents' cognitive reframing and use of reappraisal, it might not only have benefits for the parents but also for the children.

4.4. Limitations and outlook

The present study improves our understanding on the interaction between different factors that might contribute to the well-being and stress of parents of children with ASD. However, our study presents some limitations that need to be mentioned. In the present study parents' subjective well-being (i.e. difficulties in emotion regulation) closely overlaps with parents' use of reappraisal, which was one of our key predictors. This could explain why reappraisal was a strong predictor of parents' subjective well-being while it was not a predictor of parents' physiological stress. Even though these measures can contribute to our understanding of some aspects of well-being and stress, future studies should consider using alternative measures of well-being and mental health such as anxiety or depression.

Secondly, most of our measures are self-report measures of parents. This might have implications for the interpretation of the present results. Even though these reports have been found to be reliable and valid (Capaldi & Rothbart, 1992), they can be somewhat biased. Parents who have more emotional difficulties might see their children's interactions and behaviors differently from parents who do not have emotional difficulties. This could have led to a certain amount of variance in our results that we could not account for.

Additionally, due to the size and the socio-demographic specificities of the present sample, it should be emphasized that these results are limited in their generalizability. Factors such as the country's social security and insurance context, community support, and cultural attitudes towards disability might also play a determinant role in the well-being and stress of parents of children with ASD.

Finally, our results represent a first attempt to analyze the different relations between ASD diagnosis, daily hassles indicated by children's negativity, parents' perceptions of their children's problems, and parents' use of reappraisal in parents' well-being and stress. However, the identified factors cannot be said to cause well-being or stress in parents. Future research in different socio-economic contexts, with larger samples, and with experimental or longitudinal designs, that allow for the analysis of causal relations, are needed in order to determine the extent to which these factors can indeed influence parents' well-being and stress.

5. Conclusions

Despite some limitations, the present study shows strong implications for intervention and prevention programs addressing parents of children with ASD. Findings clearly highlight the importance of parents' evaluation and appraisals and thus underline the potential of cognitive-behavioral trainings aiming at improving parents' well-being and reducing their stress. More specifically, our results suggest that cognitive reframing of their children's problems by targeting parents' attributions and belief systems (e.g. interventions on parent-child joint engagement; Gulsrud, Jahromi, & Kasari, 2010) as well as teaching parents to use reappraisal as an emotion regulation strategy will be helpful in this respect.

Conflict of interest

The authors declare that they have no conflict of interest.

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Ethical standards

The present work was carried out in accordance with the ethical standards of the ethics review panel from the University of Luxembourg and with the Declaration of Helsinki as revised in 2000.

Informed consent

Informed consent was obtained from all participants.

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