



# Acceptance or Despair? Maternal Adjustment to Having a Child Diagnosed with Autism

Nikko S. Da Paz<sup>1</sup> · Bryna Siegel<sup>2</sup> · Michael A. Coccia<sup>1</sup> · Elissa S. Epel<sup>1</sup>

© Springer Science+Business Media, LLC, part of Springer Nature 2018

## Abstract

Psychological adjustment to having one's child diagnosed with an autism spectrum disorder has important implications for a parent's mental health. In a longitudinal study, we examined the association between maternal adjustment to the diagnosis and measures of distress and well-being in 90 mothers of children with autism (baseline and 18 months). We used a novel 30-item scale "Adjustment to the Diagnosis of Autism." Factor analysis identified three dimensions of adjustment: acceptance, self-blame, and despair. Acceptance appeared to be a protective response, as it was associated with lower depressive symptoms, cross-sectionally and over time. Conversely, caregivers with increasing levels of self-blame and despair about the diagnosis over 18 months had worsening of mental health and satisfaction with life during this period.

**Keywords** Autism spectrum disorders · Caregivers · Stress · Adaptive adjustment · Depression

## Introduction

Caregivers of children diagnosed with an autism spectrum disorder (ASD) tend to have higher depression and worse immune function, and report greater stress-related somatic complaints than parents caring for typically developing children (De Andrés-García et al. 2012). Moreover, stress levels appear to be even more elevated for parents of children with ASD compared to parents of children with other types of clinical or medical disorders (Barroso et al. 2017). Yet there is tremendous variation, where some parents show psychological resilience, defined as heightened well-being and diminished psychological distress (Lloyd and Hastings 2009). This healthy adaptation might be explained by the caregiver's ability to move past the initial reaction of receiving the diagnosis and advancing toward an attitude of acceptance or resolution (Sheeran et al. 1997). Previous

research examining parental responses to a child's diagnosis of chronic illness or disability (e.g. cerebral palsy or epilepsy) indicated that parents did better when they embraced an attitude of acceptance toward their child's diagnosis. Specifically, parents reported less stress and more marital satisfaction (Sheeran et al. 1997), better psychological adjustment and more perceived social support (Lord et al. 2008) than parents who had not resolved their emotions regarding the diagnosis. Despite evidence that parental adjustment to a child's diagnosis plays an important role in psychological well-being, little research has examined parent reactions to a diagnosis in the context of an autism spectrum disorder. The limited previous literature measured adjustment with a semi-structured interview which provided only a categorical assessment of adjustment (e.g. resolved vs. unresolved) (Pianta and Marvin 1992). However, adjustment is a complex phenomenon that reflects different intensities of responses on several dimensions that can be best assessed with a more sensitive continuous scale rather than as a dichotomous outcome (Lazarus et al. 1980).

In the current research, we take a novel approach toward measuring maternal caregiver responses to having a child with ASD and the impact of these responses on psychological outcomes. We hypothesize that adaptive adjustment (eventual acceptance) to an ASD diagnosis would serve as a resilience factor, thereby, it should be inversely associated with distress and positively associated with psychological

✉ Nikko S. Da Paz  
nikko.dapaz@ucsf.edu

Elissa S. Epel  
elissa.epel@ucsf.edu

<sup>1</sup> Center for Health and Community, University of California, San Francisco, 3333 California Street, San Francisco, CA 94118, USA

<sup>2</sup> Autism Center of Northern California, San Francisco, CA, USA

well-being. In contrast, we hypothesize that mothers who have predominantly negative cognitions about their child's ASD, such as feeling desperation and blaming oneself, are experiencing maladaptive adaptation especially if those feelings do not diminish over time. Thus, we aim to assess whether different dimensions of adaptive or maladaptive adaptation predict trajectories of mental health over time. Given the high risk of mental disorders (Davis and Carter 2008) and poor physical health for parental caregivers (Lovell et al. 2012), it is important to identify and measure profiles of adaptation to parenting a child with ASD that may buffer against depression and its associated physical consequences. Such insights might then inform best practices for much needed parental mental health interventions.

## Methods

### Participants

The current sample was drawn from the Stress, Aging, and Emotions study (SAGE), a larger prospective study on chronic caregiving stress and cellular aging. SAGE included two groups of mothers who were: (1) raising a child with ASD ( $n=92$ ) and (2) raising a neurotypical child ( $n=91$ ). At the time of data collection, an ASD diagnosis was classified using DSM-IV criteria (American Psychiatric Association 1994). Diagnosis verification of ASD was based solely on parent report. A total of 183 women were recruited from schools, child development centers, and a local University Autism Treatment Center. Recruitment methods for all locations included local parenting publications, social media, mass mailings, and public postings. Participants were also included if they met criteria for current major depressive disorder or were taking antidepressants, which can be common among caregivers of children with a disability (Hayes and Watson 2013). Exclusion criteria included major chronic diseases (e.g., diabetes, cardiovascular, autoimmune, history of stroke, brain injury, cancer, endocrine disorders) and/or regular use of steroid prescription medications. Participants meeting criteria for current posttraumatic stress, bipolar, or eating disorders were also excluded.

### Procedures

The SAGE study was approved by the Institutional Review Board (IRB). All participants provided written, informed consent using IRB approved procedures. Participants completed a battery of socio-demographic, psychological, and health questionnaires at baseline and 18-month follow-up either using paper/pencil forms or online with REDCap, a secure web-based data collection platform. Sociodemographic questions included age, self-identified race/

ethnicity, highest level of education, and household income (see Table 1). It took an average of 45 min to complete the full battery of questionnaires during clinic visits. As an incentive, participants were compensated \$75 at each clinic assessment visit (baseline and 18-month). Relevant scales used in the current investigation were measures of caregiver self-reported psychological distress and well-being.

## Outcome Measures

### Adjustment to the Diagnosis

We administered a novel 30-item self-report questionnaire, adjustment to the diagnosis of autism (ADA) to measure caregiver adjustment to parenting a child diagnosed with ASD. The ADA was developed by co-author, Bryna Siegel, and based on clinical observations from 30 years of experience with families of children with ASD. Caregivers were asked to rate the degree to which they agree or disagree with statements regarding their child's autism diagnosis (e.g. "Since my child's diagnosis, I can't take pleasure in other things as much." or "Dealing with my child's autism will make me a better person."). Responses are provided on a 4-point Likert scale ranging from 1 (*Don't agree at all*) to 4 (*very strongly agree*). The questionnaire demonstrated high internal-consistency reliability with Cronbach's Alpha ( $\alpha=0.74$  at baseline and 0.78 at 18 months). Total scores are calculated by summing then averaging across items.

### Autism Severity

To measure autism severity, we administered the 15-item Childhood Autism Rating Scale (CARS) (Schopler et al. 1980), a diagnostic tool widely used to identify children

**Table 1** Participant sociodemographic characteristics

Variable	Maternal caregivers ( $n=90$ )
Mean age ( <i>SD</i> )	42.3 (5.7)
Race (%)	
Asian	12.0
Black or African American	4.0
White	84.0
Education (% college degree or higher)	81.1
Household income (%)	
< \$49,000	10.0
\$50,000–\$99,000	22.6
\$100,000–\$149,000	24.7
\$150,000–\$199,000	15.7
> \$200,000	27.0

on the autism spectrum. Caregivers were instructed to rate the severity of their child's autism symptoms across several domains (e.g., relating to people, emotional response, and verbal communication). Responses range from 1 (*appropriate—within normal limits for his/her age*) to 4 (*severely abnormal*). Within the current sample, the scale demonstrated high internal-consistency reliability with baseline  $\alpha = 0.94$ . Because evidence in autism research suggests a strong correlation between parent-reported stress and autism severity (Boyd 2002), this variable served as a covariate for predictive analyses.

### Caregiving Burden

The burden of caring for a child with ASD was assessed with the 20-item Caregiving Burden Scale (CGBS) (Gottlieb 1988). First, caregivers were asked to indicate the presence of a stressor by responding with level of agreement for several statements about their daily lives (e.g. “Your caregiving activities interfere with the things you want to accomplish in your life.”) with responses rated on a scale of 1 (*strongly disagree*) to 4 (*strongly agree*), (5 = *not applicable*). Next, they were instructed to rate their feelings of burden and distress regarding the statement (e.g. “How much does this bother you?”) with responses provided on a 5-point Likert scale ranging from 1 (*not at all bothered*) to 5 (*very bothered*). The higher the total score, the higher the caregiver's perception of stress relative to the exposures associated with caring for the impaired child. The scale demonstrated high internal-consistency reliability with  $\alpha = 0.85$  at both, baseline and at 18-month assessment.

### Depressive Symptoms

We measured depressive symptomology with the inventory of depressive symptoms (IDS) (Rush et al. 1986), a comprehensive 30-item questionnaire that assesses severity of depressive symptoms. Responses are provided in several categorical formats specific to the question. For example, when asked about “feeling sad,” participant response choices range from 0 (*I do not feel sad*) to 3 (*I feel sad nearly all of the time*). Total scores are obtained by computing the mean of all items. The IDS demonstrated high internal-consistency reliability with  $\alpha = 0.82$  at baseline and 0.88 at 18-month assessment.

### Parental Stress

Stress associated with parenting was assessed with the 18-item self-report Parental Stress Scale (PSS) (Berry and Jones 1995). Mothers were asked to rate the degree to which they agree or disagree with statements representative of both positive and negative aspects of parenting [e.g. “I am happy

in my role as a parent.” or “The major source of stress in my life is my child(ren).”]. Responses are measured on a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). A total PSS score is calculated by reverse-coding positive items, then summing all items. A higher score indicates greater perceived parenting stress. The PSS demonstrated strong internal-consistency reliability with  $\alpha = 0.87$  at baseline and 0.89 at 18-month assessment.

### Perceived Stress

The caregiver's perception of general stress was evaluated with the 10-item self-report Perceived Stress Scale (PSS-10) (Cohen and Williamson 1988), which uses a 5-point Likert response scale ranging from 0 (*never*) to 4 (*very often*). Participants were asked how often they have felt a certain way in the last month (e.g. “How often have you felt nervous or stressed?”). Total stress score is calculated by summing all items, with a higher score indicating greater perceived stress. The PSS-10 demonstrated high internal-consistency reliability with  $\alpha = 0.87$  at both, baseline and at 18-month assessment.

### Psychological Well-Being Scale: Purpose in Life and Self-Acceptance Subscales

We assessed purpose in life and self-acceptance utilizing two 9-item subscales from the Psychological Well-Being Scale (Ryff 1989). Participants were asked to rate their degree of agreement with self-reflective statements (e.g. “I sometimes feel as if I've done all there is to do in life.”). Responses are scored on a 6-point Likert scale ranging from 1 (*strongly disagree*) to 6 (*strongly agree*). Total purpose scores are calculated by reverse-coding negative items, then summing all items. A higher score indicates greater purpose and meaning to life. A total self-acceptance score is calculated by summing all items, with higher scores indicating a positive attitude and acceptance of oneself. Both subscales demonstrated high internal-consistency reliability at baseline and 18 months with purpose in life  $\alpha = 0.78$  and 0.79 and self-acceptance  $\alpha = 0.92$  and 0.91, respectively.

### Relationship Satisfaction

We assessed marital satisfaction with the 14-item Relationship Satisfaction Questionnaire (RSQ) (Burns and Sayers 1992). Each item assesses a different aspect of the participant's romantic relationship (e.g. “communication and openness,” “intimacy and closeness,” and “raising of children”). Mothers were asked to rate their degree of satisfaction with each item on a 6-point Likert scale ranging from 1 (very dissatisfied) to 6 (very satisfied). Total scores are calculated as the mean of all 14 items, with higher scores indicating

greater relationship satisfaction. The scale demonstrated high internal-consistency reliability with  $\alpha=0.92$  at both, baseline and 18 months.

### Satisfaction with Life

We measured life satisfaction using the 5-item Satisfaction with Life Scale (Diener et al. 1985). Caregivers were asked to rate their agreement with five descriptive statements about their lives (e.g. “In most ways my life is close to ideal.”). Responses were measured on a 7-point Likert scale with responses ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Total scores are calculated as the mean of all 5 items with higher scores indicating greater satisfaction with life. The scale demonstrated high internal-consistency reliability with  $\alpha=0.92$  at both, baseline and 18 months.

### Statistical Analysis

#### Exploratory Factor Analysis for Scale Development

We conducted a factor analysis to identify constructs illustrative of adaptive adjustment to a child’s ASD diagnosis. Principal components analysis was performed using direct oblimin rotations with Kaiser normalization to allow for correlations between the extracted components. For descriptive purposes, we also assessed the percentage of parents who responded with a mean score of 3 (*agree somewhat*) or higher to calculate the percentage of positive endorsement per response.

#### Correlational Analyses at Baseline

We performed bivariate Pearson correlations to determine cross-sectional relationships between parent adjustment to a diagnosis of ASD and study outcome measures at baseline.

#### Multiple Regression Analyses for Longitudinal Relations

We performed regression analyses to determine whether change in ADA dimensions predicted change in psychological outcomes over an 18-month period. Before conducting these analyses, we computed change scores for target outcomes and predictor variables. Change scores were calculated as values at the 18-month assessment minus baseline values. We conducted multiple regressions, covarying severity of the child’s ASD diagnosis, and examined baseline adjustment. In the final models, we included both scores at baseline and change scores (of the predictors) to examine which measure was a stronger predictor of change for each outcome over time. All analyses were conducted using SPSS, Version 24 (SPSS Inc., 2016).

### Post-hoc Analyses: Duration of Caregiving

We considered that it was possible that duration of caregiving from the time of diagnosis to baseline assessment might play a role in parental adjustment. Therefore, we performed bivariate Pearson correlations and multiple regression analyses to examine adjustment in relation to duration of caregiving.

## Results

### Factor Analysis

This exploratory analysis identified three dimensions, acceptance (e.g. “I have a greater acceptance of my child’s autism than I used to”), self-blame (e.g. “There are things I did that make me worry that I contributed to my child’s difficulties”), and despair (e.g. “I worry my child won’t get any better”). Adaptive adjustment is operationalized as high levels of diagnosis acceptance, and low levels of self-blame and despair.

The Bartlett’s test of sphericity was significant [ $\chi^2(435) = 1417.63, p < .01$ ]. As shown in Table 2, the three-factor solution, which explained a cumulative 32.47% of the variance, identified three dimensions with primary loadings that ranged from 0.30 to 0.75. Only one item (“I wish we lived in a time or place where parents were expected to leave children like this in a home or hospital”) was eliminated because it failed to meet a minimum factor loading criteria of 0.30 or above. This item did not contribute meaningful information to the three dimensions of acceptance ( $\alpha=0.40$ ), self-blame ( $\alpha=0.70$ ), and despair ( $\alpha=0.79$ ).

### Associations at Baseline

#### Outcomes in Relation to ADA Dimensions

As shown in Table 3 of baseline correlations, ASD severity was positively associated with Acceptance ( $r = .25; p = .02$ ) and Despair ( $r = .29; p = .01$ ) but not Self Blame. Acceptance was related to lower depressive symptoms ( $r = -.34; p < .001$ ) and perceived stress ( $r = -.27; p = .01$ ) but was not related to well-being measures. Self-blame responses were positively related to caregiving burden ( $r = .25; p = .02$ ) and parental stress ( $r = .25; p = .02$ ) and inversely related to satisfaction with life ( $r = -.31; p < .001$ ) and self-acceptance ( $r = -.29; p = .02$ ). Despair about the diagnosis was significantly related to all indices of distress and well-being, as shown in Table 3.

**Table 2** Three-factor solution and item loadings for the adjustment to the Diagnosis of Autism Scale

Items	Factors		
	1	2	3
<b>Factor 1: despair</b>			
My child's autism will always cast a shadow on our family	<b>0.75</b>	0.00	0.08
When I think about my child's difficulties, I ask myself, "Why me?"	<b>0.71</b>	-0.03	-0.04
I am surprised how much time I spend thinking, "Why did I have a child with autism?"	<b>0.64</b>	0.15	-0.07
I worry my child won't get any better	<b>0.57</b>	0.09	0.04
Siblings serve as a reminder of what is wrong with my child with autism	<b>0.56</b>	0.07	0.13
I avoid situations where others might think my child is different	<b>0.56</b>	-0.20	-0.16
Since my child's diagnosis, I can't take pleasure in other things as much	<b>0.54</b>	0.15	0.16
A parent never really gets over a diagnosis of autism in their child	<b>0.52</b>	0.24	0.10
I worry my child might get worse	<b>0.49</b>	0.28	0.10
I worry that my marriage/relationship will not survive the stress of my child's autism	<b>0.41</b>	-0.11	-0.16
The system should take the lead in helping my child improve	<b>0.34</b>	0.06	-0.03
I sometimes imagine what it would be like to leave my whole family behind and walk out on all the difficulties I face	<b>0.30</b>	-0.24	-0.23
<b>Factor 2: Self-blame</b>			
I wish we lived in a time or place where parents were expected to leave children like this in a home or hospital	0.17	0.04	0.01
I still need more information about exactly what is wrong with my child	0.06	<b>0.62</b>	-0.14
I imagine going back in time and re-doing the things I might have done to have caused my child's difficulties	0.15	<b>0.61</b>	0.09
There are things I did that make me worry that I contributed to my child's difficulties	0.10	<b>0.60</b>	0.08
I should have anticipated the risk factors that may have contributed to my child's autism	0.18	<b>0.52</b>	0.16
I believe that the magic bullet to cure my child's autism is out there	-0.07	<b>0.52</b>	0.02
I (will) feel better as my child gets better	0.12	<b>0.52</b>	-0.09
There are times I get the feeling that everything I have been told about my child's condition is wrong	0.08	<b>0.51</b>	-0.02
I am convinced that my child will overcome his/her autism	-0.42	<b>0.48</b>	-0.20
I feel angry when I think about the diagnosis	0.40	<b>0.41</b>	-0.03
After my child's first diagnosis, I wanted more opinions to be sure the diagnosis was right	0.01	<b>0.31</b>	-0.14
<b>Factor 3: Acceptance</b>			
My child's diagnosis of autism feels more real to me than it used to	0.26	-0.02	<b>0.63</b>
I have a greater acceptance of my child's autism than I used to	0.05	-0.18	<b>0.62</b>
My child's diagnosis has brought my spouse/partner and me closer together in some ways	0.10	0.07	<b>0.60</b>
Dealing with my child's autism will make me a better person	-0.27	0.20	<b>0.47</b>
Deep down, I feel my child will develop the same way, with or without special help	0.30	-0.07	<b>-0.39</b>
It's good for other people to be exposed to a child acting very autistic	-0.23	-0.10	<b>0.38</b>
At this point, I don't think about my child's long-term future	-0.06	0.15	<b>-0.36</b>

Extraction method: principal component analysis

Rotation Method: Oblimin with Kaiser Normalization. Eigenvalue > 1

Bold font = significant factor loadings > 0.30

## Prospective Associations

### Baseline Scores as Predictors

When baseline ADA was in the same model as change in ADA over time, the baseline scores were not predictive of change in outcome over time. There was one exception: Despair at baseline predicted worsening in depression and self-acceptance at 18 months. There were only small correlations between ADA baseline scores and change in ADA

over 18 months (ranging from  $r = .18$  to  $.21$ ) and thus, there were no major issues of collinearity.

### Change Scores as Predictors

Changes in ADA predicted changes in outcomes, as shown in Table 4. Maternal improvement in Acceptance over time was significantly associated with reductions in depressive symptomatology ( $\beta = -0.30$ ;  $p = .05$ ). Reductions in Self-blame over time were strongly associated with increases in satisfaction with life ( $\beta = -0.30$ ;  $p = .04$ ). Reductions in

**Table 3** Correlations between ADA Subscales and Study Outcomes

Measure (r/p)	1	2	3	4	5	6	7	8	9	10	11	12
1. Autism severity	1											
ADA subscales												
2. Acceptance	.248**	1										
3. Self-blame	.167	-.016	1									
4. Despair	.294*	-.154	.463**	1								
5. Caregiving burden	.365**	-0.048	.211*	.517**	1							
6. Depression	.146	-.337**	.134	.263*	.456**	1						
7. Parental stress	.266*	-.029	.237*	.506**	.551**	.324**	1					
8. Perceived stress	.135	-.272*	.181	.237*	.487**	.657**	.432**	1				
Psychological pathology												
9. Purpose in life	.011	.149	-.080	-.232*	-.340**	-.318**	-.420**	-.376**	1			
10. Relationship satisfaction	.049	.094	-.090	-.235*	-.255*	-.369**	-.220*	-.437**	.420**	1		
11. Satisfaction with life	-.210	.152	-.313**	-.418**	-.520**	-.499**	-.503**	-.585**	.490**	.625**	1	
12. Self-acceptance	-.172	.168	-.286*	-.433**	-.391**	-.536**	-.511**	-.617**	.412**	.468**	.638**	1
Psychological well-being												
9. Purpose in life	.011	.149	-.080	-.232*	-.340**	-.318**	-.420**	-.376**	1			
10. Relationship satisfaction	.049	.094	-.090	-.235*	-.255*	-.369**	-.220*	-.437**	.420**	1		
11. Satisfaction with life	-.210	.152	-.313**	-.418**	-.520**	-.499**	-.503**	-.585**	.490**	.625**	1	
12. Self-acceptance	-.172	.168	-.286*	-.433**	-.391**	-.536**	-.511**	-.617**	.412**	.468**	.638**	1

ADA adjustment to the diagnosis of autism

\*  $p \leq .05$ ; \*\*  $p \leq .01$

Despair over time were associated with improvements in caregiving burden ( $\beta = 0.39$ ;  $p < .001$ ), parental stress ( $\beta = 0.47$ ;  $p < .001$ ) and satisfaction with life ( $\beta = -0.42$ ;  $p < .001$ ).

### Post-hoc Analyses: Duration of Caregiving

We examined duration of caregiving extensively and did not find significant associations or predictive abilities with any of the ADA scales.

## Discussion

Parenting a child diagnosed with autism is a major life challenge that requires ongoing coping skills. Attitudes toward the child's diagnosis can naturally be very negative at first, and require tremendous adaptation to adjust. It often creates elevated psychological distress that can last

for years as the parent copes with the child's condition and often tries multiple treatments. Although this study was observational and cannot test causal relations, our results suggest that adaptive adjustment to the diagnosis can have potentially protective effects on well-being over time.

We examined adjustment as a complex system of attitudes and beliefs held by the parent. We identified three dimensions of adjustment, acceptance, self-blame, and despair, that predicted significant relationships with both distress and well-being measures over an 18-month period. We were especially interested whether initial acceptance of the diagnosis and changes in acceptance over time might serve as a resiliency factor, preventing depression and promoting well-being. Indeed, at study entry, mothers' report of high levels of acceptance was associated with less psychological distress, specifically, less depression and perceived stress. More importantly, increased

**Table 4** Results of multiple regression analysis of change in ADA domain scores in relation to change in psychological outcomes

Change in outcome <sup>a</sup>	Step predictors	Self-blame				Despair					
		$R^2$ (adj)	F	$\beta$	p	Step predictors	$R^2$ (adj)	F	$\beta$	p	
Psychological distress	Caring Burden	Overall model	.07	4.86	.03	1	Overall model	.07	4.86	.03	.03
		ASD severity <sup>b</sup>			0.29	.03	ASD severity			0.29	.03
	Depression	Overall model	.04	1.85	.15	2	Overall model	.14	3.90	.01	2
		ASD severity			0.26	.07	ASD severity			0.22	.09
		Acceptance at BL			0.13	.42	Self-blame at BL			0.27	.04
		Change in acceptance			0.11	.47	Change in Self-blame			0.24	.07
Parental Stress	Depression	Overall model	.01	1.35	.25	1	Overall model	.01	1.35	.25	1
		ASD severity			0.16	.25	ASD severity			0.16	.25
	Stress	Overall model	.20	5.12	.00	2	Overall model	-.03	0.54	.66	2
		ASD severity			0.04	.76	ASD severity			0.16	.29
		Acceptance at BL			0.25	.11	Self-blame at BL			-0.05	.72
		Change in acceptance			-0.30	.05	Change in self-blame			0.05	.72
Perceived Stress	Parental	Overall model	-.02	0.04	.85	1	Overall model	-.02	0.38	.85	1
		ASD severity			0.03	.85	ASD severity			0.03	.85
	Stress	Overall model	-.06	0.09	.97	2	Overall model	.01	1.20	.32	2
		ASD severity			0.02	.91	ASD severity			0.01	.92
		Acceptance at BL			0.03	.85	Self-blame at BL			-0.16	.26
		Change in acceptance			-0.05	.77	Change in self-blame			0.18	.22
Stress	Overall model	-.00	0.92	.34	1	Overall model	-.00	0.92	.34	1	
	ASD severity			0.13	.34	asd severity			0.13	.34	
Stress	Overall model	.00	1.05	.38	2	Overall model	-.03	0.45	.72	2	
	ASD severity					Overall model					

Table 4 (continued)

Change in outcome <sup>a</sup>	Step predictors	$R^2$ (adj)	F	$\beta$	p	Step predictors	$R^2$ (adj)	F	$\beta$	p	Step predictors	$R^2$ (adj)	F	$\beta$	p
Psychological well-being	ASD severity					ASD severity					ASD severity				
	Acceptance at BL	.14	9.05	0.08	.57	Self-blame at BL	.14	9.05	0.11	.43	Despair at BL	.14	9.05	0.14	.33
	Change in acceptance			-0.09	.59	Change in self-blame			0.02	.88	Change in despair			-0.27	.06
Purpose in life	Overall model	.12	3.16	-0.15	.35	Overall model	.13	3.56	0.10	.51	Overall model	.12	3.36	0.16	.25
	ASD severity					ASD severity					ASD severity				
	Acceptance at BL	.14	9.05	-0.40	.00	ASD severity	.14	9.05	-0.40	.00	ASD severity	.14	9.05	-0.40	.00
Relationship satisfaction	Overall model	.12	3.16	-0.37	.01	Overall model	.13	3.56	0.17	.23	Overall model	.12	3.36	0.14	.34
	ASD severity			-0.04	.79	ASD severity			0.10	.48	ASD severity			-0.03	.86
	Change in acceptance			0.08	.59	Self-blame at BL					Despair at BL				
Satisfaction with life	Overall model	-0.02	0.13	0.08	.72	Overall model	-0.02	0.13	0.10	.72	Overall model	-0.02	0.13	-0.03	.72
	ASD severity					ASD severity					ASD severity				
	Overall model	-0.05	0.30	-0.05	.72	Overall model	.04	1.57	-0.05	.72	Overall model	.02	1.30	-0.05	.72
Satisfaction with life	ASD severity					ASD severity					ASD severity				
	Acceptance at BL	.03	1.54	-0.03	.86	ASD severity			-0.06	.71	ASD severity			-0.03	.87
	Change in acceptance			-0.04	.85	Self-blame at BL			0.29	.06	Despair at BL			0.17	.26
Satisfaction with life	Overall model	-0.01	0.59	0.11	.54	Overall model	-0.01	0.59	-0.06	.67	Change in despair			-0.19	.23
	ASD severity					ASD severity					Overall model	-0.01	0.59		
	Overall model	.03	1.54	-0.11	.45	Overall model	.05	1.89	-0.11	.45	ASD severity	.14	3.72	-0.11	.45
Satisfaction with life	ASD severity					ASD severity					Overall model				
	Acceptance at BL	.03	1.54	-0.30	.08	Self-blame at BL			0.05	.75	ASD severity			-0.06	.65
	Change in acceptance			-0.02	.91	Change in self-blame			-0.30	.08	Despair at BL			0.07	.60
Satisfaction with life	Overall model	-0.02	0.13	0.08	.72	Overall model	-0.02	0.13	-0.30	.04	Change in despair			-0.42	.00
	ASD severity					ASD severity					Change in self-blame				
	Overall model	-0.05	0.30	-0.05	.72	Overall model	.04	1.57	-0.05	.72	Overall model	.02	1.30	-0.05	.72



**Table 4** (continued)

Change in outcome <sup>a</sup>	Step predictors	Step predictors			Step predictors			Step predictors			
		$R^2$ (adj)	F	$\beta$	p	Step predictors	$R^2$ (adj)	F	$\beta$	p	
Self-acceptance	1	Overall model	-.02	0.19	.66	1	Overall model	-.02	0.19	.66	1
		ASD severity			.07	.66	ASD severity			0.07	.66
	2	Overall model	-.01	0.78	.51	2	Overall model	-.01	0.80	.50	2
		ASD severity			0.12	.46	ASD severity			0.05	.75
Change in acceptance	2	Acceptance at BL			-.012	.53	Self-blame at BL			0.22	.15
		Change in acceptance			0.14	.41	Change in self-blame			0.06	.71

ADA Adjustment to the Diagnosis of Autism, BL baseline

Models controlling for ASD severity

<sup>a</sup>Change scores calculated as 18 month value—baseline value

<sup>b</sup>ASD severity measured with the Childhood Autism Rating Scale

\* $p \leq .05$ ; \*\* $p \leq .01$

feelings of acceptance over time correlated with reductions in depression symptomology over that same period.

While acceptance appeared protective from depression, it was not associated with aspects of positive well-being. Rather, a reduction in self-blame and despair was a stronger predictor of parental adjustment and psychological resilience over time. Particularly, self-blame about the diagnosis was moderately associated with greater feelings of caregiving burden (greater distress for each aspect of parenting burden) and stress about parenting issues. As feelings of self-blame decreased over 18 months, mothers reported increased satisfaction with life. Despair about the diagnosis was the most consistent correlate of high distress and poor well-being. In contrast, reductions in despair responses over time were associated with reduced caregiving burden, paternal stress and increased satisfaction with life. Quite possibly, interventions aimed at helping shift a mother’s negative cognitions about the diagnosis might buffer against emotional distress, thereby boosting psychological resilience.

An interesting relationship was found between baseline acceptance of the diagnosis and severity of the child’s autism. One might presume that less severe ASD symptoms would make it easier for parents to embrace acceptance of the diagnosis. However, our findings indicated the exact opposite: the greater the condition severity, the greater the parent’s acceptance. Quite possibly, more subtle symptoms might increase a parent’s hope for a mainstream path, and lead them to search for answers, cures, or another diagnosis all together. When a child exhibits extreme levels of autism severity, denial of the condition and hope that the diagnosis will go away are unlikely, thus, compelling parents toward acceptance.

These findings related to the types of adaptation may have implications for interventions that aim to promote acceptance and reduce despair in maternal caregivers. There is a need to better understand distress associated with parenting a child with ASD in order to ameliorate it. Respite care and most interventions studied so far do not appear to have consistent effects on reducing psychological stress or depression (Dababnah and Parish 2016; Whitmore 2016). Social support groups are natural and accessible interventions for caregivers, and can be helpful for some (Da Paz and Wallander 2017). However, depending on types of groups, especially those not guided by a professional, there could be modeling or norms for non-acceptance and despair.

This study is limited in its ability to generalize these results to parents of diverse demographic backgrounds. First, the majority of mothers in SAGE were college-educated Caucasian women with a reported a mean income of \$100,000 or more. It will be important to study fathers’ adjustment in the future, since their experiences may be different, as they are heavily impacted but typically secondary rather than the primary caregiver. Targeting participants of

diverse demographic backgrounds might further knowledge on parental adjustment for a wider population of caregivers. In addition, there was no relation between duration of caregiving with ADA adjustment subscale scores. In this sample, the age of the child with ASD at enrollment ranged from 2 to 9 years, and it is possible that if we had a larger range, including young adults, we may have seen relationships between duration of caregiving and ADA outcomes. A further limitation is the study's reliance on self-reported measures. Future examinations of adjustment to an ASD diagnosis could be strengthened with the inclusion of stress biomarkers and other appropriate objective measures.

Given the observational nature of this study, it is possible, for example, that reductions in depression led parents to view the diagnosis as less threatening and easier to accept. Regardless of the child's condition severity, for most parents, it is an emotional challenge and developmental process to adjust to having a child with a typically lifelong condition. As such, these dimensional responses to an ASD diagnosis, as measured by the ADA, might be helpful to adapt for use in studies of other developmental disorders or disabilities.

Although the aim of this study targeted an understanding of maternal outcomes in relation to their child's diagnosis, they live within a family system and affect all other family members. It might be useful to test whether maternal mental health improvements and psychological resilience might positively influence outcomes for the child with ASD. This is important because mothers tend to take on the role of primary caregiver and consequently experience a greater burden of caregiving compared to fathers (Tehee et al. 2008). Moreover, an initial study has found that elevated maternal stress can reduce the effectiveness of early intervention treatment gains for their child with ASD (Osborne et al. 2008). Further, severity of maternal depression has significantly predicted paternal stress (Boyd 2002). Hence, future research could systematically evaluate both child outcomes and family dynamics in relation to positive gains in maternal well-being. Targeted maternal intervention might be an important objective for optimal family outcomes.

Given that increased acceptance of the child's condition is related to reductions in maternal depression, improvement in acceptance may be a helpful goal. However, limited research exists on how to increase acceptance of one's child's diagnosis. Evidence-based interventions like Mindfulness or Acceptance Commitment Therapy, for example, might be helpful for parents and caregivers of children with ASD. A systematic review suggests that mindfulness parenting interventions may reduce stress although more research is needed (Townshend et al. 2016). Intervention studies that alter narratives about the diagnosis, such as through expressive writing, may also promote better acceptance (Lovell et al. 2016). Interventions offer a more direct way to assess any causal nature of responses to the diagnosis of autism

on well-being, and thus more treatment-outcome research is necessary to evaluate the impact of related therapies and programs.

**Acknowledgments** We gratefully acknowledge the time of caregivers and families who participated in this study. We also thank Alexandra Crosswell, Julie Vaccaro, Stefanie Mayer, Rachel Radin, and Carlos Almeida for their constructive and insightful comments on this manuscript. This study was supported by the National Institute on Aging, award numbers R01 AG030424 and R24AG048024, and the Althea Foundation, San Francisco.

**Author Contributions** ND conceived of the current hypotheses, performed the relevant statistical analyses, and drafted the manuscript. BS developed the novel scale and assisted with drafting the manuscript. MC participated in the design of the study and assisted with statistical analyses and interpretation of the data. EE conceived of the larger prospective study on chronic caregiving stress and cellular aging (SAGE) from which the data was extracted, coordinated its design and data collection, and helped to draft the manuscript. All authors read and approved the final manuscript.

**Funding** This study was supported by the National Institute on Aging, award numbers R01 AG030424 and R24AG048024, the Goldman Fund, and the Althea Foundation.

## Compliance with Ethical Standards

**Ethical Approval** All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. All participants provided written, informed consent using IRB approved procedures.

**Conflict of interest** All authors declare that there is no conflict of interest.

## References

- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th edn.). Washington, DC.
- Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2017). Parenting stress through the lens of different clinical groups: A systematic review and meta-analysis. *Journal of Abnormal Child Psychology*, *45*, 1–13.
- Berry, J. O., & Jones, W. H. (1995). The parental stress scale: Initial psychometric evidence. *Journal of Social and Personal Relationships*, *12*, 463–472.
- Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, *17*, 208–215.
- Burns, D., & Sayers, S. (1992). *Development and validation of a brief relationship satisfaction scale*. Philadelphia, PA: Unpublished manuscript, Department of Psychiatry, Presbyterian Medical Center of Philadelphia.
- Cohen, S., & Williamson, G. (1988). Perceived stress in a probability sample of the United States. In S. Spacapan & S. Oskamp (Eds.), *The social psychology of health: Claremont symposium on applied social psychology* (pp. 31–67). Newbury Park, CA: Sage.
- Da Paz, N. S., & Wallander, J. L. (2017). Interventions that target improvements in mental health for parents of children with autism

- spectrum disorders: A narrative review. *Clinical Psychology Review*, 51, 1–14.
- Dababnah, S., & Parish, S. L. (2016). A comprehensive literature review of randomized controlled trials for parents of young children with autism spectrum disorder. *Journal of Evidence-Informed Social Work*, 13, 277–292.
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38, 1278–1291.
- De Andrés-García, S., Moya-Albiol, L., & González-Bono, E. (2012). Salivary cortisol and immunoglobulin A: Responses to stress as predictors of health complaints reported by caregivers of offspring with autistic spectrum disorder. *Hormones and Behavior*, 62, 464–474.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment*, 49, 71–75.
- Gottlieb, B. (1988). *The dislocations scale*. Guelph, ON: Unpublished manuscript: University of Guelph
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629–642.
- Lazarus, R. S., Cohen, J. B., Folkman, S., Kanner, A., & Schaefer, C. (1980). Psychological stress and adaptation: Some unresolved issues. In H. Selye (Ed.), *Selye's guide to stress research* (Vol. 1, pp. 90–117). New York: Van Nostrand Reinhold.
- Lloyd, T., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53, 957–968.
- Lord, B., Ungerer, J., & Wastell, C. (2008). Implications of resolving the diagnosis of PKU for parents and children. *Journal of Pediatric Psychology*, 33, 855–866.
- Lovell, B., Moss, M., & Wetherell, M. A. (2012). The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD. *Psychoneuroendocrinology*, 37, 534–542.
- Lovell, B., Moss, M., & Wetherell, M. A. (2016). Assessing the feasibility and efficacy of written benefit-finding for caregivers of children with autism: A pilot study. *Journal of Family Studies*, 22, 32–42.
- Osborne, L. A., Mchugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 1092–1103.
- Pianta, R., & Marvin, R. (1992). *The reaction to diagnosis classification system*. Charlottesville, VA: Unpublished manuscript, University of Virginia.
- Rush, A. J., Giles, D. E., Schlessner, M. A., Fulton, C. L., Weissenburger, J., & Burns, C. (1986). The inventory for depressive symptomatology (IDS): Preliminary findings. *Psychiatry Research*, 18, 65–87.
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069.
- Schopler, E., Reichler, R. J., Devellis, R. F., & Daly, K. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *Journal of Autism and Developmental Disorders*, 10, 91–103.
- Sheeran, T., Marvin, R. S., & Pianta, R. (1997). Mothers' resolution of their child's diagnosis and self-reported measures of parenting stress, marital relations, and social support. *Journal of Pediatric Psychology*, 22, 197–212.
- Tehee, E., Honan, R., & Hevey, D. (2008). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22, 34–42.
- Townshend, K., Jordan, Z., Stephenson, M., & Tsey, K. (2016). The effectiveness of mindful parenting programs in promoting parents' and children's wellbeing: A systematic review. *JBIM Database of Systematic Reviews and Implementation Reports*, 14, 139–180.
- Whitmore, K. E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: An integrative review. *Journal of Pediatric Nursing*, 31, 630–652.