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Daily Experiences Among Mothers of Adolescents and Adults with Autism Spectrum Disorder

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Abstract

In the present study, 96 co-residing mothers of adolescents and adults with an autism spectrum disorder (ASD) participated in an 8-day diary study and reported on their daily experiences. In comparison with a nationally representative sample of mothers of children without disabilities, mothers of adolescent and adult children with ASD spent significantly more time providing childcare and doing chores, and less time in leisure activities. Fatigue, arguments, avoided arguments, and stressful events were also more common among mothers of individuals with ASD. However, mothers of individuals with ASD reported similar levels of positive interactions and volunteerism as the comparison group. Daily experiences were subsequently related to well-being in both groups. These findings highlight the need for family support services.

Keywords

Daily experiences; Stress; Maternal well-being; Adolescents and adults with ASD

Introduction

Raising a child with an autism spectrum disorder (ASD) is a profoundly stressful experience (Duarte et al. 2005; Montes and Halterman 2006). Parents of children with ASD report greater negative impact of having a child with a disability and poorer well-being in comparison to parents of children with other developmental disorders such as Down syndrome, fragile X syndrome, cerebral palsy, and undifferentiated developmental disability (Abbeduto et al. 2004; Blacher and McIntyre 2006; Eisenhower et al. 2005). In the current study, we employed

a standardized daily diary methodology to elucidate the mechanisms associated with poor parental well-being in parents of children with ASD. Previous studies have relied primarily on global measures of parental stress and well-being. Unlike global measures, daily accounts of parenting may provide a more nuanced view of the “lived experience” of raising a child with ASD and shed light on the particular factors that make this experience unique.

Daily Experiences and Well-being

Daily stresses are important predictors of individual and family functioning (Crnic and Greenberg 1990; DeLongis et al. 1988). Accordingly, daily diary methods are increasingly being applied to the study of stress, coping, and well-being. There are several benefits to utilizing daily diary research designs. Daily studies allow for an examination of both between- and within-individual variation by describing a typical person's daily experiences as well as the within-person processes associated with those experiences (Almeida 2005; Bolger et al. 2003). As such, daily diary studies are useful for understanding the concurrent and cumulative impact of daily experiences, such as the associations between a stressor on a given day and reports of subjective well-being on the same and subsequent day(s). Daily diary methods also allow for linking behaviors of one individual in the family system with the experiences of other family members. Additionally, a research design which utilizes daily measurement intervals reduces error associated with retrospective reporting.

Daily diary studies have been employed to examine a variety of day-to-day experiences of individuals and families, such as the association of work stress (Repetti and Wood 1997) and marital tension (Almeida et al. 1999) with parent–child interactions. Similarly, daily diary methods have been utilized to assess the impact of caring for an aging parent, showing that caregivers experience greater psychological distress on caregiving days (Savla et al. 2008). However, very few studies have investigated the daily experiences of parents of children with disabilities. Seltzer et al. (2009) studied parents of a heterogeneous group of children with developmental disorders and mental health problems using a daily diary design with data drawn from the National Survey of Midlife in the US (MIDUS; Brim et al. 2004). Findings indicated that parents of a son or daughter with a disability had higher levels of stress and more negative affect compared to parents of children without disabilities. Interestingly, no differences were found in terms of daily time use or experiences of positive events. However, for parents of children with disabilities, time spent with the child was associated with higher negative affect in contrast to comparison parents for whom time spent with child was unrelated to negative affect (Seltzer et al. 2009).

In another recent study of daily experience of families with a son or daughter with various disabilities, Brandon (2007) investigated the time use of working mothers using data from the Australian Time Use survey. Of mothers who worked a typical work week, raising a child with a disability was associated with less time spent in leisure activities, but more time spent in socializing activities, perhaps reflecting the need of families of individuals with disabilities to stay strongly connected to their social support networks. Mothers with a child who had a disability also reported less time for personal care in comparison to mothers of children without disabilities (Brandon 2007). Finally, in a recent investigation of social support and parental mood, parents of school-aged children with ASD were interviewed biweekly for a 3 month period; results indicated that daily received support was predictive of daily mood (Pottie et al. 2009). Notably, this study did examine daily processes relative to families of children without disabilities and did not include families of adolescents or adults. The present study extends this previous research by exploring not only the between-group differences in daily experiences for mothers with a son or daughter with ASD compared with mothers of children without disabilities, but also the within-group associations of daily experiences with maternal well-being.

Present Study

The present study had three primary aims. First, we compared mothers of a son or daughter with ASD to mothers of children without disabilities on four outcomes reflecting daily psychological, physical, and economic well-being: (a) negative affect, (b) positive affect, (c) fatigue, and (d) work intrusions. Second, we examined differences in the daily experiences of both groups of mothers in terms of their (a) time use, (b) stressful events, (c) positive events, and (d) giving and receiving emotional support. Third, we evaluated the impact of daily time use, stressful events, positive events, giving and receiving support, and parenting a child with ASD (vs. parenting non-disabled children) on maternal well-being using multilevel modeling.

Similar to prior studies using global measures of functioning, we hypothesized that mothers of adolescents and adults with ASD would have higher levels of negative affect and fatigue, would be more likely to have work intrusions, and have lower levels of positive affect than mothers of children without disabilities. Based on Brandon's (2007) research on time use among working mothers of children with developmental disabilities, we anticipated that mothers of a son or daughter with ASD would have different profiles of time use in comparison to mothers of children without disabilities, particularly in reference to leisure activities. We also hypothesized that mothers of children with ASD would experience a higher number of daily stressful events than the comparison group, given that mothers of children with ASD consistently report higher levels of stress than other groups in studies using global measures of stress. In contrast, we expected that mothers in both groups would report comparable levels of positive events, similar to the findings of Seltzer et al. (2009). Additionally, we hypothesized that a higher number of stressful events, a lower number of positive events, and more time in childcare activities on a given day would be associated with poorer maternal well-being for both mothers of children with ASD and mothers of non-disabled children.

Methods

Participants

Participants were drawn from two longitudinal datasets, the study on Adolescents and Adults with Autism (AAA) and the National Survey of Midlife in the US (MIDUS). Mothers of individuals with ASD were participants in an ongoing, multi-wave, longitudinal study of 406 families of adolescents and adults with an ASD (the AAA study; Seltzer et al. 2003; Shattuck et al. 2007) who were recruited via agencies, schools, diagnostic clinics, and media announcements. At entry into the AAA study, families met three criteria: (a) the family included a child 10 years of age or older; (b) the child had received a diagnosis of ASD from a medical, psychological, or educational professional, as reported by mothers; and (c) scores on the research-administered Autism Diagnostic Interview-Revised (ADI-R; Lord et al. 1994; Rutter et al. 2003) were consistent with the parental report of an ASD. An additional criterion for participation in the Daily Diary Study was that the son or daughter with ASD lived at home with the mother. When the AAA study began in 1998, fully 264 of the individuals with ASD lived with their families and 142 lived away from home. An increasing proportion of individuals moved away from the family home at each subsequent point of data collection, such that by the time of the Daily Diary Study (2006), only 136 individuals with ASD remained co-resident with their parents.

Of the 136 families who were potential participants in the Daily Dairy Study, 6 could not be reached, and 34 families declined participation in this component of the AAA study. Thus, participants in the present set of analyses consisted of a sub-sample of 96 mothers who were co-residing with their son or daughter with ASD at the time of data collection and who completed measures of daily experiences. Families who participated in the Daily Diary Study were not significantly different from families who declined in terms of maternal age, income,

marital status, and health, and the child's age, gender, and behavior problems. The adolescents and adults with ASD in the sub-sample used for the present study ranged in age from 17 to 53 years of age ($M = 24.78$ years, $SD = 7.28$). The majority of the sample was male (77%), and 57% had a comorbid diagnosis of mental retardation. Notably, this is a study of parenting adolescent and adult children with ASD.

A comparison sample of 230 mothers of co-residing adolescent and adult children *without disabilities* was drawn from the National Study of Daily Experience (NSDE), one of the projects in the National Survey of Midlife in the United States (MIDUS). MIDUS is a nationally representative study of English-speaking, non-institutionalized adults who were aged 25–74 in 1994 (MIDUS I; Brim et al. 2004; Gruenewald et al. 2008). Data used in the present study were collected from 2003 to 2005 as part of a second wave of data collection (MIDUS II). There were 1,265 individuals who participated in the second wave of the daily diary interview (NSDE II) during the MIDUS II data collection. For our comparison sample, we excluded 558 cases where the respondent was male (as the AAA study consisted only of mothers) and 66 cases where the respondent was female and had a child with a developmental disability or mental health condition. Additionally, 421 female respondents in NSDE II were excluded because they did not have any children living in their home, resulting in a comparison group of 230 mothers of co-residing children without disabilities.

The two groups of mothers were similar in terms of ethnicity, income level, marital status, and number of children (see Table 1). However, both mothers and children in the AAA sample were significantly older than those in the comparison sample: $F(1, 324) = 28.09, p < .001$, and, $F(1, 324) = 4.76, p < .05$, respectively. Mothers in the AAA sample also had higher educational attainment, $F(1, 324) = 11.31, p < .01$, than mothers in the comparison sample. Subsequently, maternal age and education level were controlled in all analyses. Given the high correlation between maternal and child age ($r = .79, p < .001$), only maternal age was included as a covariate. Marital status (married vs. not married) was also included as a covariate due to the strong association between marital status and well-being (Williams 2003).

It is important to note that, consistent with ASD prevalence rates, the majority of the children in the AAA sample were male (77%). Since the MIDUS study was not originally designed as an investigation focusing particularly on parenting, mothers in the MIDUS sample did not designate a target child, precluding controlling for child gender in the current analyses. However, we were able to calculate the proportion of female children within each MIDUS family who were co-residing with their mothers. As expected, in the comparison sample, the proportion of female children was 49%.

Procedure

For the Daily Diary Study, respondents were interviewed by telephone each evening for a period of 8 days. The daily telephone interview, which lasted ~15–25 min, included questions about daily experiences in the previous 24 h. Questions focused on time use, daily stressors, positive events, mood, and physical symptoms. Interviews for both groups were conducted by the Survey Research Center at The Pennsylvania State University. This ensured that the procedures for interviewing mothers in the AAA and NSDE studies were identical. Specifically, mothers in both groups were asked the same set of questions each day at the same time of day, with the starting day of the week being randomized for all study participants. The interviewers at the Survey Research Center were highly trained with experience administering the daily diary protocol in a variety of populations.

Measures

Positive and Negative Affect—Positive and negative emotions were measured using an adapted version of the Non-Specific Psychological Distress and Positive Emotions Scale (Kessler et al. 2002; Mroczek and Kolarz 1998). Each day, respondents indicated how frequently they felt each emotion over the past 24 h on a 5-point scale from “none of the time” to “all of the time”. The positive affect scale was created from 6 items assessing enthusiasm, alertness, and vitality on a 5-point scale; each item was summed, resulting in possible range of 6–30, with higher scores reflecting higher levels of positive affect. The negative affect scale was comprised of 6 items measuring anxiety and depression; items were summed to create a possible score of 6–30, with higher scores indicating greater negative affect. Cronbach's alphas for the positive affect scale, averaged across days, were .91 for mothers in the AAA sample and .90 for mothers in the comparison sample. Cronbach's alphas for the negative affect scale, averaged across days, were .75 for mothers in the AAA sample and .60 for mothers in the comparison sample.

Fatigue and Work—Mothers also were asked about symptoms of fatigue and changes to their work schedules each day. Specifically, mothers responded “yes” (coded as 1) or “no” (coded as 0) to whether they had experienced fatigue and/or whether they had cut-back on normal work activities, referred to as work intrusions, during the last 24 h. We then calculated two variables to reflect the proportion of days during the 8-day study period in which mothers experienced the symptom of fatigue and had work intrusions.

Time Use—During each daily interview, mothers were asked how many hours and minutes they spent on activities during the past 24 h. Specifically, mothers reported the amount of time that they spent: (a) sleeping, (b) caring for their children, (c) performing routine chores, (d) doing business, paid work, or in school, including commuting and thinking about work, (e) in leisure activities, (f) watching TV, and (g) in vigorous physical activity. For each activity, the average number of hours spent per day across the 8 days was calculated.

Stressful Events—As part of the Daily Diary Study, daily stressors were assessed through the Daily Inventory of Stressful Events (Almeida et al. 2002). The inventory consists of a series of seven questions asking whether certain types of daily stressors occurred in the past 24 h. The questions examine daily experiences in five domains: arguments, avoided arguments, work stressors, home stressors, and network stressors (defined as stressors that occurred in the lives of close friends and family members). Work, home, and network stressors were net of arguments and avoided arguments that occurred in those contexts. For each daily interview, individuals who responded affirmatively received a code of 1 for the relevant stressor domain. Codes of 0 were assigned to domains where no stressors were experienced on that day. For each stressor domain, the proportion of days in which the stressor was experienced during the 8-day study period was calculated. Additionally, a dummy coded variable was created to reflect if the participant experienced *any stressors* (arguments, avoided arguments, stress at work, stress at home, and network stress) on each study day.

Positive Events—Mothers reported on the positive events that occurred in the previous 24 h by responding yes or no to the following questions: (a) “Did you have an interaction with someone that most people would consider particularly positive since this time yesterday”, (b) “Since this time yesterday, did you spend any time doing formal volunteer work”, and (c) “Since this time yesterday, did anything happen to a close friend or relative that turned out to be particularly positive for you?” For each domain (positive interactions, volunteer work, and positive network event), codes of 1 were given for the presence of an event and codes of 0 were given when the event was not experienced on that day. We then calculated the proportion of days in which each positive event was experienced during the course of the 8 days.

Giving and Receiving Emotional Support—Mothers reported on giving and receiving emotional support that was not part of their job. For these questions, responses of “yes” were coded as 1 and responses of “no” were coded as 0. We then calculated the proportion of days in which mothers gave emotional support and received emotional support.

Data Analysis Plan

First, we compared mothers of a son or daughter with ASD to mothers of children without disabilities on outcomes of interest: positive affect, negative affect, fatigue, and work intrusions. Second, we examined differences between mothers of individuals with ASD and mothers of individuals without disabilities with respect to time use. We compared the number of hours per day mothers in the ASD sample spent in activities (sleeping, childcare, chores, work/school, leisure, watching TV, and vigorous physical activity) to the number of hours spent in the same activities by mothers in the comparison sample. Third, the experiences of multiple types of daily events (stressful events, positive events, and giving and receiving support) were evaluated in mothers from the ASD sample and the comparison sample. For all comparisons, separate analyses of covariance (ANCOVA) were conducted, with maternal age, education level, and marital status included as covariates.

Finally, using multilevel modeling, we evaluated time use, the number of daily stressors, positive events, giving and receiving support, and group status (ASD vs. comparison) as predictors of daily maternal outcomes (positive affect and negative affect). In these models, maternal age, education level, marital status, and number of children were included as covariates.

Results

Positive and Negative Affect

As shown in Table 2, mothers of adolescents and adults with ASD reported significantly lower levels of positive affect averaged across days than the comparison sample. Mothers with a son or daughter with ASD also reported significantly higher levels of negative affect averaged across days relative to mothers without a child with a disability.

Fatigue and Work Intrusions

Also presented in Table 2, mothers who had a son or daughter with ASD reported significantly more days when they felt fatigued and more days with work intrusions across the 8-day period than did comparison mothers. They experienced fatigue on 50% of days during the 8-day study, twice the number of days as the comparison group. Additionally, not shown in Table 2, was the finding that fully 19% of mothers of adolescent and adult children with ASD reported fatigue on all 8 days whereas only 3% of comparison mothers reported experiencing fatigue everyday. It is also noteworthy that mothers of individuals with ASD reported having work intrusions on 22% of days in contrast with 8% of days for comparison mothers.

Time Use

As shown in Table 3, mothers of adolescent and adult children with ASD spent significantly more time caring for their children and doing household chores than did mothers of children without disabilities, and as anticipated, significantly less time in leisure activities. Of particular interest, mothers of adolescents and adults with ASD reported spending, on average, almost 5 h per day in childcare activities as compared to just over 3 h per day for mothers of children without disabilities. Mothers of a son or daughter with ASD spent nearly one additional hour per day doing chores and had 1 h less time each day for leisure activities than comparison mothers. There were no significant differences between the two groups on time spent sleeping,

watching TV, or engaging in vigorous physical activity. Interestingly, although mothers in the ASD group reported work intrusions on a greater proportion of days than comparison mothers, the average number of hours spent each day doing business, paid work, or school activities did not differ between the groups. This finding suggested that although mothers of adolescents and adults with ASD reported having work intrusions on a given day, the overall time they spent engaging in work and school activities (including commuting and thinking about work) across the 8-day period was equivalent to comparison mothers.

Stressful Events

Consistent with our hypothesis, there was a strong pattern of differences in the reporting of stressful events between mothers in the two groups (see Table 4). Mothers with a son or daughter with ASD reported having arguments on twice as many days as mothers in the comparison group (25% of days vs. 13% of days). In contrast to mothers in the comparison group, mothers of adolescent and adult children with ASD also reported more days during which there was a time they could have had an argument, but chose to not to argue (i.e., avoided arguments; 26% of days vs. 16% of days). In contrast to mothers in the comparison sample, mothers of adolescents and adults with ASD reported significantly more days in which something stressful happened at home, at work, and to a friend or relative (termed “network stress”). In fact, mothers of adolescents and adults with ASD experienced twice as many days with stress at home and among friends and family as did mothers in the comparison group.

For each day, we calculated whether or not mothers experienced at least one stressful event (argument, avoided argument, work stress, home stress, or network stress). We also calculated the number of days in which multiple stressful events were experienced. As shown in Table 4, mothers of a son or daughter with ASD experienced significantly more days with at least one stressful event than mothers in the comparison group. Similarly, mothers of individuals with ASD reported more than twice as many days with multiple stressors in comparison to mothers of children without disabilities (see Table 4).

Another way to consider the relative impact of caregiving is by computing the Odds Ratios (OR) of experiencing at least one stressful event (data not shown). Results from a logit model revealed that the OR for mothers of adolescents and adults with ASD was 2.93 times larger than the comparison group, after controlling for age, education, and marital status (data available from the first author), indicating that mothers of individuals with ASD were nearly three times as likely to experience a daily stressful event as the comparison group.

Positive Events and Exchange of Support

As shown in Table 5, consistent with our hypothesis, mothers of a son or daughter with ASD did not differ from mothers in the comparison group in terms of the percent of days during which they experienced positive interactions or did volunteer work. It was notable that mothers in both groups reported having positive interactions on a majority of the days in the daily diary study. Furthermore, mothers in the ASD sample reported significantly more days with positive events experienced by friends and relatives (termed “positive network events”) than the comparison sample (18% of days vs. 10% of days).

Finally, mothers of adolescent and adult children with ASD were significantly more likely than comparison mothers to both give emotional support (53% of days vs. 35% of days) and receive emotional support (34% of days vs. 18% of days).

Daily Time Use, Stressors, Positive Events, and Support as Predictors of Maternal Outcomes

Multilevel models using Hierarchical Linear Modeling (HLM) software (Raudenbush and Bryk 2002) were constructed to examine the effects of daily stressors and positive events on

maternal well-being. In contrast to OLS regression, where a single regression equation is estimated for the entire sample (one estimate of an intercept and one estimate of a slope), in HLM separate regression equations are estimated for each individual participant to account for dependence in repeated measures data. For illustrative purposes, the simple form of a multilevel model can be conceived of as two separate models, one a within-person model (Level 1) and the other a between-persons model (Level 2). Predictors can be added at both Level 1 and Level 2. The first level of analysis (Level 1) models data collected over repeated occasions of measurement (daily diary period) for each person. A between-persons model (Level 2) can then be estimated in which the Level 1 intercepts (averages) and slopes (effects) are treated as dependent variables regressed on person-level variables (e.g., ASD vs. comparison group variable, maternal age).

Table 6 shows the results of the multilevel models predicting parental well-being (positive affect and negative affect) using daily (Level 1; within-person) and person-level (Level 2; between-persons) variables. Daily variables included number of stressors (argument, non-argument, work stress, home stress, and network stress), number of positive events (positive interactions, volunteer work, and positive network event), time use (hours in childcare and chores and hours in leisure activities), and giving and receiving emotional support. Time in childcare and chores and time in leisure activities were chosen over other time use variables for inclusion in the multilevel models given the significant difference between the two groups in these areas.

Person-level variables included a group variable (ASD vs. comparison) and demographic characteristics (maternal age, education level, marital status, and number of children). Number of children was included as a covariate in these analyses given the potential association between number of children and time spent on childcare activities. Cross-level interactions included each of the day-level predictors by the group variables (ASD vs. comparison).

Positive Affect—As seen in the first column of Table 6, there was a significant group effect for positive affect. As we found in the ANCOVA analyses, mothers of a son or daughter with ASD reported significantly lower levels of positive affect, on average, than mothers in the comparison group. Maternal age was also a significant person-level predictor of positive affect, with older mothers reporting a higher level of positive affect.

In terms of day-level predictors, there was a significant difference in the effect of the number of stressors on positive affect between the two groups, as indicated by the significant group by stressors interaction term. As shown in Fig. 1, the impact of number of stressors on positive affect was more pronounced (i.e., a steeper declining slope) for the comparison group, whereas for mothers of adolescents and adults with ASD there was a blunted response to daily stressful events. Similarly, there was a significant interaction for receiving emotional support by group, such that a higher level of receiving support was associated with a lower level of positive affect, but this effect only held in the comparison group (see Fig. 2).

Table 6 also shows that experiencing a greater number of positive events on a given day was associated with a higher level of positive affect on that day; this effect was not different between groups (i.e., the interaction between the number of positive events and group was not significant). Hours spent in leisure activities was also a day-level predictor of positive affect, such that spending more time doing leisure activities was associated with higher positive affect in both groups of mothers. Conversely, for both groups of mothers, giving more emotional support was associated with a lower level of positive affect.

Negative Affect—As shown in the second column of Table 6, group (ASD vs. comparison) was a significant person-level predictor of negative affect. Mothers with a son or daughter with

ASD reported significantly higher levels of negative affect averaged across days relative to mothers without a child with a disability. Number of children was also a significant person-level predictor, with a higher number of children predicting a lower level of negative affect.

At the day level, as we hypothesized, the number of stressors was a significant predictor of higher negative affect. There was no significant cross-level interaction for stressors and group, suggesting that the effect of the number of stressors on negative affect was the same for the two groups. However, there were differences between the groups in the way in which giving and receiving emotional support impacted negative affect. As shown in Table 6, there was a significant cross-level interaction of giving support by group, indicating that a giving more emotional support was associated with a higher level of negative affect, but only for mothers of a son or daughter with ASD (see Fig. 3). There was also a significant interaction of receiving support by group, such that receiving more emotional support was associated with a higher level of negative affect, but this effect was only found for the comparison group (see Fig. 4).

We also examined preliminary multilevel models in which time use, stressful and positive events, and giving and receiving support were entered as predictors of fatigue and work intrusions. The patterns of findings in these models were very similar to the patterns for negative affect, although the relationships were not as strong. As such, we chose to only present the results from the affect models. Findings for the fatigue and work intrusions models are available from the first author upon request.

Discussion

The present study contributes substantially to our understanding of stress in the lives of mothers of individuals with ASD. Previous investigations have indicated that mothers of children with ASD experience significantly higher levels of stress and lower levels of psychological well-being than mothers of children without ASD (Abbeduto et al. 2004; Blacher and McIntyre 2006; Eisenhower et al. 2005). However, findings have not been informative with regard to which factors contribute to this elevated stress profile. Through careful examination of the daily experiences of mothers of adolescents and adults with ASD, the current study begins to shed light on potential explanations for the differences in well-being reported by mothers of children with ASD compared to those of typically developing children or those with non-spectrum developmental disabilities.

Consistent with prior research using global measures of maternal functioning, and supportive our hypotheses, we found significant differences between mothers of a son or daughter with ASD and mothers of children without disabilities in terms of psychological well-being. Mothers of adolescent and adult children with ASD reported higher levels of negative affect and lower levels of positive affect than comparison mothers. Additionally, mothers of a son or daughter with ASD reported feelings of fatigue on 50% of days in the 8-day study period, in contrast with only 25% of days for mothers in the comparison group. Mothers of children with autism also reported experiencing work intrusions on more days during the study period than comparison mothers.

One explanation for these large differences in well-being between mothers of a son or daughter with ASD and comparison mothers pertains to stressful daily events. Mothers of individuals with ASD reported experiencing more stressful events than mothers in the comparison sample. Arguments and avoided arguments, and stressful events at work, at home, and in the social network, were all significantly and substantially more common among mothers of individuals with ASD. In fact, mothers of adolescents and adults with ASD were three times as likely to experience at least one stressful event on a given day as the comparison group. Also striking, mothers of a son or daughter with ASD experienced more than twice as many days with multiple

stressors as did the comparison group. Subsequently, number of daily stressors was significantly related to daily negative affect in both groups of mothers. The presence of multiple daily stressors in the lives of mothers of individuals with ASD, significantly greater than in the general population, is a primary explanatory factor for differences in global measures of well-being between mothers of children with ASD and mothers of children without ASD reported in previous studies (Abbeduto et al. 2004; Blacher and McIntyre 2006; Eisenhower et al. 2005).

Another explanatory variable for these large differences in well-being between mothers of a son or daughter with ASD and comparison mothers pertains to how mothers spent their time on a daily basis. Analogous to findings from prior studies of the general population on the connection between personal well-being and the amount of time spent in leisure activities (e.g., Lampinen et al. 2006), we found that spending more time in leisure activities was associated with a higher level of positive affect. However, over the course of the 8-day study, mothers of adolescents and adults with ASD spent significantly less time in leisure activities and significantly more time providing childcare and doing chores compared to mothers of individuals without disabilities. The differences between mothers of individuals with ASD and mothers of children without disabilities on time spent in childcare activities and chores in the present study stand in contrast with Seltzer et al.' (2009) recent daily diary study of parents of children with various types of disabilities. In that study, there were no reported differences in how parents of children with disabilities used their time relative to the comparison group. Although the Seltzer et al. study included both mothers and fathers, which might have obscured time use differences, it is also possible that one of the primary differences between mothers of children with ASD and other types of disabilities is having less discretion in how they allocate their time, greater time demands placed on them by child care, and less time for leisure activities on a daily basis.

It is also noteworthy that mothers of individuals with ASD in the present study were similar to comparison mothers in other domains of time use (e.g., hours spent in work/school activities and vigorous physical activity) and in their experiences of volunteerism and positive interactions. This suggests that although mothers of adolescent and adult children with ASD spent a larger proportion of their days in caregiving activities and chores relative to comparison mothers, they compensated by reducing their own leisure activities, not by limiting participation in other family and community activities. Consistent with the suggestions of Brandon (2007), it is possible that mothers of children with ASD simply “run out” of hours in the day that could be spent on leisure activities that promote well-being. Also consistent with the results of Brandon (2007), mothers of adolescents and adults with ASD gave and received more emotional support than the comparison group, possibly reflecting their embeddedness in social support networks. However, as discussed below, exchange of social support had a different effect on mothers of adolescents and adults with ASD than the comparison group.

Although in both groups of mothers the number of daily stressors was associated with negative affect and the number of positive events was associated with positive affect, there were some notable differences between the groups in the prediction of well-being. For instance, for mothers in the comparison group, experiencing fewer stressors on a given day was associated with reports of higher levels of positive affect at the end of the same day. However, among mothers of individuals with ASD, the impact of number of stressors on positive affect was dampened. This suggests that whereas having stress-free days resulted in higher levels of positive affect in the comparison group, the association between daily stress and affect was blunted in mothers of individuals with ASD.

Similarly, receiving more emotional support during the day was associated with a lower level of positive affect and a higher level of negative affect for comparison mothers, but for mothers

of individuals with ASD there was no relationship between receiving support and affect. We interpret this finding for the comparison group as suggesting that emotional support is received in response to life's difficulties, which is why levels of negative affect are higher on days when more emotional support is received. Mothers of children without disabilities also may interpret receiving emotional support as a threat to their self-esteem, leading to lower well-being (Fisher et al. 1982). In contrast, mothers of a son or daughter with ASD may be accustomed to receiving emotional support from others such that the risk to self-image and well-being is less, potentially reflecting adaptation over time. Alternatively, the absence of this association in mothers of adolescents and adults with ASD, as well as the weaker association between number of stressors and positive affect, may suggest a profile of "burn out" following an average of two decades of providing care to their son or daughter with ASD, such that their levels of well-being are no longer as responsive to experiencing daily stress or receiving more emotional supports.

For mothers of children with ASD, giving more emotional support during the day was related to a higher level of negative affect, whereas this relationship was not found for mothers in the comparison group. This may indicate that mothers of adolescent and adult children with ASD, given their already low levels of emotional well-being, are more taxed by providing emotional support to others than mothers of children without disabilities. It may also be important to consider the interactional context in which mothers are giving and receiving support (Pottie et al. 2009). Given the high level of network stress experienced by mothers in the ASD group, interactions during which mothers of individuals with ASD provide support may be notably more stressful than for mothers of children without ASD. This may be particularly true if a mother has multiple individuals in her social network who likewise have children with ASD. This is an interesting avenue for future research.

Taken together, these findings point to the need for more supportive services designed for mothers of individuals with ASD. Family support services are necessary in order to afford mothers the opportunity to seek out activities for themselves. Particularly promising are support programs provided through the Medicaid Home and Community-Based Services Waiver which allow families to receive funding to act as careproviders for the family member with a disability (Heller and Schindler 2009). Some parents may not have access to or feel comfortable with traditional respite services and the ability to hire other family members or friends to help with caregiving may increase the likelihood that parents will take time for themselves. Adequate family support programs also may prevent the need for these mothers to miss work as a result of their caregiving responsibilities. Additionally, for mothers of children with ASD there may be times when adjustments to work schedules are unavoidable; as such, employment policies that promote flexible hours, working from home, and sufficient personal or family leave would also be beneficial.

Strengths and Limitations

The present study had several strengths. First, the current study extended previous investigations of stress and well-being among families of individuals with ASD by employing a daily diary methodology in order to understand day-to-day experiences of mothers, in contrast with past studies which have relied on global measures. Second, the present study used a normative comparison group, drawn from a nationally representative sample. Third, we not only examined differences between mothers of adolescent and adult children with ASD and mothers of children without disabilities in terms of time use, stressful events, and positive events, but also explored the associations between daily events and daily reports of well-being, providing a nuanced approach for understanding the distinct processes associated with elevated stress among families of children with ASD. Finally, the study's design made it possible to begin to sort out the temporal ordering of variables within and across days.

The present study, however, was not without limitations. First, the sample was limited to co-residing mothers and their adolescent and adult children. Thus, the findings are not reflective of all families with individuals with ASD. Second, the participants in the AAA study were predominately White, which limits the generalizability of the findings to more diverse groups. Finally, we did not include a comparison group of mothers of adolescents and adults with non-spectrum developmental disabilities. This will be an important next step in understanding the factors that specifically underlie the elevated stress levels of mothers of children with ASD relative to other diagnostic groups, specifically fragile X syndrome and Down syndrome.

Conclusion

The present study provides us with important insights into the daily lives of mothers of individuals with ASD. Daily data were found to be useful to examine hypotheses about why families of individuals with ASD represent such a vulnerable population, as well as to identify potential areas in which to intervene and provide support. In our study, we found that everyday experiences such as daily stressors were significantly related to maternal well-being. It is likely that these stressors accumulate over years of caregiving, potentially taking a cumulative toll on the well-being of mothers of individuals with ASD and further highlighting the need for appropriate family services.

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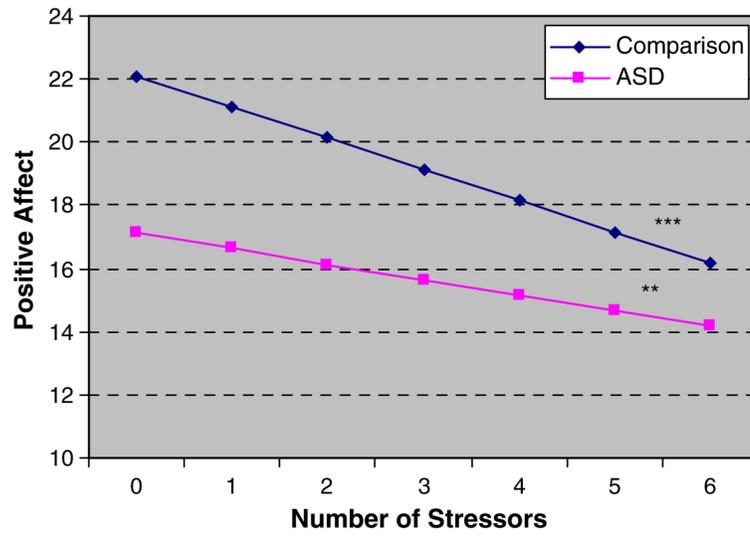


Fig. 1. Effects of stressors on positive affect for ASD and comparison groups

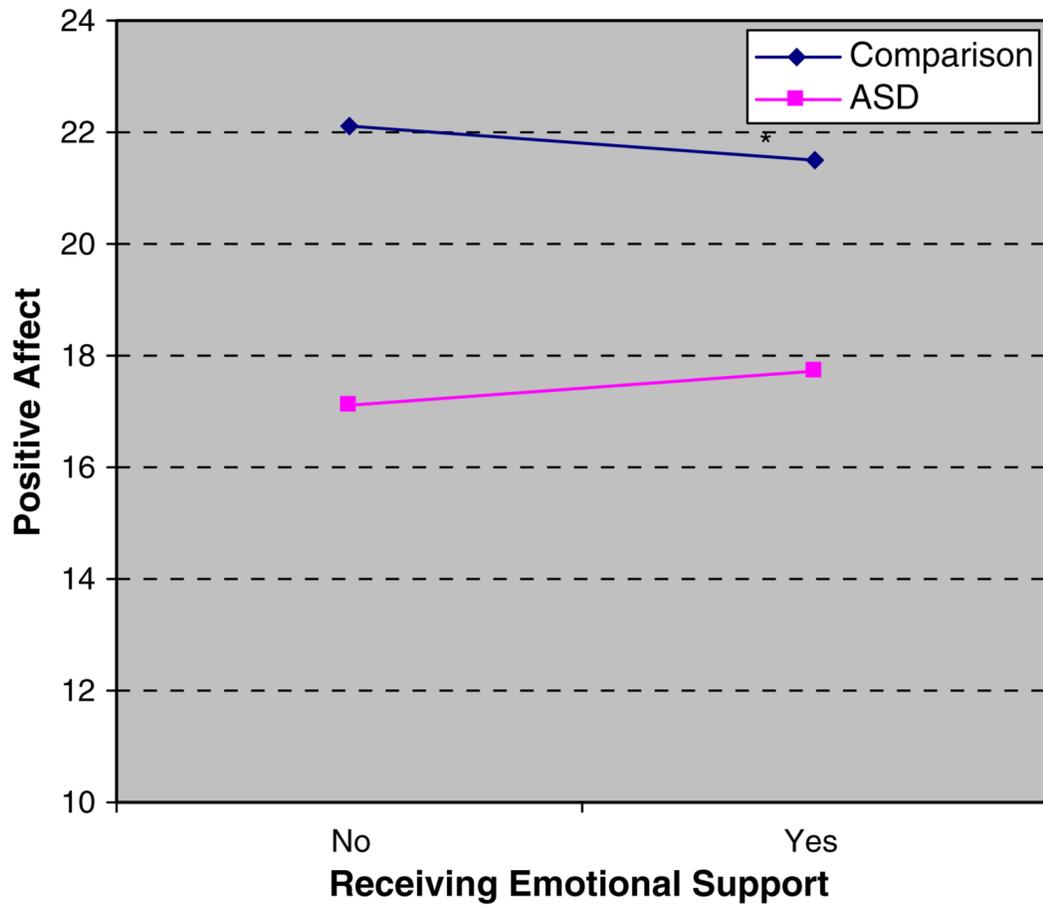


Fig. 2.
Effects of receiving emotional support on positive affect for ASD and comparison groups



Fig. 3. Effects of giving emotional support on negative affect for ASD and comparison groups

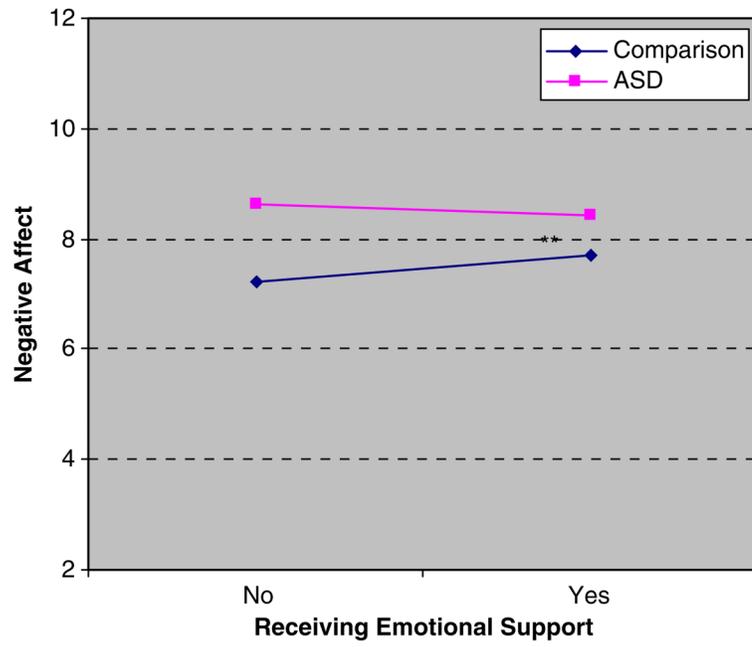


Fig. 4. Effects of receiving emotional support on negative affect for ASD and comparison groups

Table 1

Sample demographics

	ASD (<i>n</i> = 96)	Comparison (<i>n</i> = 230)
Ethnicity	92% White	91% White
Maternal education	79% Some college or higher	66% Some college or higher
Household income	\$45,000–\$49,000	\$45,000–\$49,000
% Married	79	75
Maternal age	54.4 (9.05)	48.0 (10.30)
Number of children	2.6 (1.0)	2.57 (1.32)
Child age	22.4 (7.87)	19.7 (11.32)
Child gender (% female)	23	49

Table 2

Average positive and negative affect and proportion of days with fatigue and work intrusions by group with maternal age, education level, and marital status as covariates

	ASD (<i>n</i> = 96)	Comparison (<i>n</i> = 230)	<i>F</i> values
Average positive affect	17.39 (4.90)	20.83 (4.74)	36.72***
Average negative affect	8.32 (2.13)	6.81 (.92)	64.68***
Fatigue	.50 (.37)	.25 (.27)	41.52***
Work intrusions	.22 (.25)	.08 (.16)	32.43***

p < .001

Table 3

Average time use across days by group with maternal age, education level, and marital status as covariates

	ASD (<i>n</i> = 96) (h)	Comparison (<i>n</i> = 230) (h)	<i>F</i> values
Sleeping	6.98 (1.02)	7.14 (1.02)	3.47
Care of children	4.90 (3.56)	3.13 (2.96)	33.42***
Chores	2.35 (1.47)	1.63 (.99)	16.63***
Business, paid work, school	3.53 (2.97)	3.73 (2.90)	1.32
Leisure activities	2.03 (1.11)	2.54 (1.51)	15.28***
Watching TV	1.49 (1.03)	1.61 (1.14)	1.51
Vigorous physical activity	.58 (.88)	.52 (.87)	1.21

p < .001

Table 4

Proportion of days with stressful events by group with maternal age, education level, and marital status as covariates

	ASD (<i>n</i> = 96)	Comparison (<i>n</i> = 230)	<i>F</i> values
Arguments	.25 (.28)	.13 (.17)	19.60***
Avoided arguments	.26 (.21)	.16 (.15)	19.80***
Stress at work	.16 (.18)	.10 (.14)	11.34**
Stress at home	.25 (.23)	.11 (.14)	30.49***
Network stress	.11 (.14)	.05 (.08)	18.19***
At least 1 stressor day	.65 (.27)	.43 (.28)	38.04***
Multiple stressor day	.28 (.28)	.11 (.17)	34.93***

**
p < .01;

p < .001

Table 5

Proportion of days with positive events and exchange of support by group with maternal age, education level, and marital status as covariates

	ASD (<i>n</i> = 96)	Comparison (<i>n</i> = 230)	<i>F</i> values
Positive interaction	.70 (.26)	.60 (.28)	3.14
Positive network event	.18 (.19)	.10 (.15)	11.84**
Volunteer work	.12 (.23)	.09 (.16)	.04
Gave emotional support	.53 (.30)	.35 (.26)	19.63***
Received emotional support	.34 (.32)	.18 (.23)	18.67***

**
p < .01;

p < .001

Table 6

Multilevel models of daily stressors, positive events, time use, and emotional support predicting maternal well-being

	Positive affect	Negative affect
Fixed effect		
Intercept	17.12 (.69)***	8.64 (.28)***
Person-level predictors		
Group (ASD cases = 1)	-4.99 (.58)***	1.39 (.23)***
Mother's age	.06 (.02)**	-.01 (.01)
Mother's education	-.17 (.29)	.09 (.08)
Mother's marital status (married = 1)	-.04 (.58)	-.36 (.20) ⁺
Number of children	.27 (.16) ⁺	-.11 (.04)*
Day-level predictors		
# Stressors	-.49 (.16)**	.39 (.11)***
# Positive events	.33 (.11)**	.04 (.09)
Hours spent on taking care of children or chores	-.03 (.03)	.00 (.03)
Hours spent on doing leisure time activities	.28 (.08)**	-.08 (.06)
Giving emotional support	-.50 (.25)*	.70 (.20)***
Receiving emotional support	.60 (.35) ⁺	-.23 (.20)
Cross-level interaction		
# Stressors × group	.50 (.21)*	.11 (.14)
# Positive events × group	-.13 (.14)	-.05 (.10)
Hours spent on taking care of children/chores × group	.05 (.04)	-.02 (.03)
Hours spent on doing leisure time activities × group	-.16 (.10)	.12 (.07) ⁺
Giving emotional support × group	.37 (.31)	.55 (.21)*
Receiving emotional support × group	1.23 (.45)**	-.69 (.25)**
Random effect (variance component)		
Between-person intercept (level 2)	17.627 (<i>df</i> = 139) $X^2 = 3,897.8$ ***	1.934 (<i>df</i> = 160) $X^2 = 2,008.4$ ***
Between-person # stressors (level 2)	.786 (<i>df</i> = 164) $X^2 = 254.3$ ***	.450 (<i>df</i> = 164) $X^2 = 264.8$ ***
Between-person receiving emotional support (level 2)	2.315 (<i>df</i> = 164) $X^2 = 252.3$ ***	.458 (<i>df</i> = 164) $X^2 = 217.5$ **
Between-person hours spent on doing leisure time activities (level 2)	.162 (<i>df</i> = 164) $X^2 = 293.9$ ***	.070 (<i>df</i> = 164) $X^2 = 345.8$ ***
Within-person (level 1)	6.550	1.903

⁺ $p < .10$;* $p < .05$;** $p < .01$;*** $p < .001$