

Social Support and Well-being at Mid-Life Among Mothers of Adolescents and Adults with Autism Spectrum Disorders

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Abstract The present study investigated the impact of social support on the psychological well-being of mothers of adolescents and adults with ASD ($n = 269$). Quantity of support (number of social network members) as well as valence of support (positive support and negative support) were assessed using a modified version of the “convoy model” developed by Antonucci and Akiyama (1987). Having a larger social network was associated with improvements in maternal well-being over an 18-month period. Higher levels of negative support as well as increases in negative support over the study period were associated with increases in depressive symptoms and negative affect and decreases in positive affect. Social support predicted changes in well-being above and beyond the impact of child behavior problems. Implications for clinical practice are discussed.

Keywords Social support · Mothers · Well-being · Adolescence · Adulthood

Introduction

The risks to psychological well-being for parents of children with autism spectrum disorders (ASDs) are well-documented. Mothers of children with ASD often have elevated levels of depression (Carter et al. 2009; Ingersoll and Hambrick 2011) and report lower levels of well-being than mothers of children with other types of developmental disabilities (Abbeduto et al. 2004; Eisenhower et al. 2005).

Daily mood of mothers of children with ASD also has been found to be more negative than mothers of children without disabilities (Smith et al. 2010). The majority of studies examining contributors to poor psychological well-being among mothers of children with ASD have focused on factors related to the child with ASD. For example, child-related factors such as autism symptoms (Ekas and Whitman 2010), adaptive behavior (Green and Carter 2011), and intellectual disability status (Blacher et al. 2005) have been linked with parental well-being in past studies. Most notably, child behavior problems consistently have been indicated as a strong predictor of stress for parents across studies of children of various ages (Abbeduto et al. 2004; Hastings et al. 2005; Herring et al. 2006; Lounds et al. 2007). However, psychosocial factors such as social support also may contribute to parental well-being across the life course. The present study investigated the impact of social support on the well-being of mothers of adolescent and adult children with ASD.

Social Support for Families of Children with ASD

Social support has long been recognized as an important component in stress process and a predictor of psychological well-being (Cohen and Wills 1985; Pearlin 1989). Given the associations between social support and various aspects of health and well-being in the general population (Merz and Huxhold 2010; Umberson and Montez 2010), researchers have begun to investigate the impact of social support on well-being among parents of children with disabilities, including autism. In studies of parents of children with ASD, higher levels of social support have been associated with lower levels of negative impact (Bishop et al. 2007), psychological distress (Bromley et al.

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2004), negative mood (Pottie et al. 2009), and depressive symptoms (Benson and Karlof 2009; Ekas et al. 2010; Weiss 2002). Conversely, recent work has found that parents who experience a higher level of social support also report a higher level of positive mood (Ekas et al. 2010; Pottie et al. 2009). However, most of the past research examining social support among parents of children with ASD has focused on families during the childhood years and has used cross-sectional designs with small sample sizes, thus leaving questions regarding the nature of these relationships for families later in life.

Social Support Across the Lifespan

Although little attention has been given in the empirical literature to the role of social support for parents of adolescents and adults with ASD, social support may be a particularly critical resource for families during these points in the life course. Importantly, many parents are primary caregivers for their children well into adulthood and this prolonged caregiving period may coincide with additional challenges associated with their own aging. Further, there is often a significant reduction in the number of formal services available to families of individuals with ASD following the transition out of high school (Shattuck et al. 2011), potentially making informal sources of support all the more important for parental well-being during the adolescent and adult years. Of the few studies that have examined social support for parents of children with ASD later in life, the findings are somewhat mixed. Barker et al. (2010) recently explored trajectories of well-being in mothers of adolescents and adults with ASD over a 10-year period using data partially overlapping with the present investigation, and found that on occasions when mothers reported a larger social network size, they also reported lower levels of anxiety and depressive symptoms. However, this study examined only network size (which was defined as the total number of individuals in a mother's personal network), not the quality of the support, and did not include indicators of positive well-being.

Another study from our research group recently examined daily well-being of mothers of adolescents and adults with ASD using a daily diary methodology (Smith et al. 2010). After controlling for other salient predictors such as child behavior problems, Smith and colleagues did not find significant associations between receiving emotional support and daily affect. This unexpected finding highlights the need to investigate the valence of support exchanges. As Rook (1984, 2001) has noted, receiving social support may come at a cost, as social exchanges can be both positive (e.g., receiving emotional support) and negative (e.g., involving embarrassment, conflict). Both types of

support, as well as changes in support over time, can have significant consequences for individual well-being. For instance, in a study of recently-widowed women, both higher levels of positive support (measured by feeling loved and having people to listen to worries) and lower levels of negative support (measured by having people who are demanding or critical) were associated with fewer depressive symptoms 18 months later; further, decreases in positive support over the same time frame likewise were associated with more depressive symptoms, highlighting how both forms of support exchanges may uniquely contribute to well-being for individuals undergoing stressful life events (Ha 2010). Similarly, Ingersoll-Dayton and colleagues have shown that the association between negative exchanges and negative affect may be particularly strong among individuals who have experienced a high level of life stress (Ingersoll-Dayton et al. 1997). These studies underscore the importance of considering the valence of social exchanges (e.g., experiences of both positive and negative support) for parents of children with ASD, a group known to have high levels of chronic stress at multiple points in the life course. The present study extends this work by examining both level and change in network size, positive support, and negative support for mothers of adolescents and adults with ASD.

Present Study

The current study had two specific aims: (1) to examine whether quantity of social support relates to change in maternal well-being over an 18-month period, and (2) to examine whether valence of social support relates to changes in maternal well-being over this time frame, investigating positive and negative support separately. To address limitations of past studies, we explored three separate components of social support, namely *quantity* of support as defined by the number of individuals in the social support network, and *valence* of support, as measured by both the average positive support from network members and the average negative support from network members. Also, in line with suggestions to study both positive and negative outcomes for families of children with disabilities (Blacher et al. 2005; Hastings et al. 2002), the present study investigated three indicators of maternal well-being: depressive symptoms, positive affect, and negative affect. Due to age-related differences in both social exchanges and well-being across the life course (Akiyama et al. 2003; Windsor and Anstey 2010), we controlled for maternal age in all analyses. Marital status likewise was entered as a control variable as it may influence both social support (August and Sorokin 2010) and well-being (Dush and Amato 2005; Stack and Eshleman

1998). Similarly, we also controlled for child behavior problems and intellectual disability status given past work indicating child-related factors as important predictors of maternal well-being.

The present study had three primary hypotheses. First, consistent with past research on parents of adolescents and adults with ASD (Barker et al. 2010) we hypothesized that having more social support network members at the initial time point of the present analysis as well as experiencing increases in the size of the social network during the subsequent 18-month period would be associated with declining levels of depressive symptoms and negative affect and increasing levels of positive affect over time. Second, based on the literature on positive support and parental well-being for parents of children with ASD (Benson and Karlof 2009; Ekas et al. 2010), we hypothesized that a higher level of positive support at the initial time point and increases in positive support over the next 18 months would be associated with declining levels of depressive symptoms and negative affect, and an increasing level of positive affect in our sample of mothers of adolescent and adults with ASD over the study period. Third, given Pottie et al. (2009)'s finding of a relationship between daily unsupportive interactions and poorer well-being in parents of children with ASD, we hypothesized that a higher level of negative support as well as increases in negative support would be related to poorer outcomes over time on each of our well-being indicators.

Method

Participants

Participants were drawn from an ongoing longitudinal study of 406 families of adolescents and adults with an autism spectrum disorder. Families in Wisconsin ($n = 202$) and Massachusetts ($n = 204$) were recruited via agencies, schools, diagnostic clinics, and media announcements. Identical recruitment procedures were used in both states, with informational packets being distributed to families inviting them to participate in the research. Data from the second and third waves of the study (Time 2, conducted in 2000–2001, and Time 3, conducted 18 months later in 2002–2003) were utilized in the present analysis. Time 2 was the first point in the present research when questions regarding negative social support were administered, and they were measured again at Time 3. No other negative support data are available in this study, so we focused the present analyses on Time 2 and Time 3.

Families met three initial inclusion criteria: (a) the family had a son or daughter 10 years of age or older; (b) the child had received a diagnosis on the autism

spectrum from a medical, psychological, or educational professional, as reported by parents; and (c) administration of the Autism Diagnostic Interview-Revised (Lord et al. 1994) confirmed the parental report of an ASD. Of the 406 individuals in the sample, 384 (94.6%) met all criteria for Autistic Disorder on the ADI-R (qualitative impairments in communication and language; qualitative impairments in reciprocal social interaction; repetitive, restrictive, and stereotyped behaviors; and onset of symptoms prior to 36 months). The remaining 22 individuals (5.4% of the sample) demonstrated a pattern of impairments on the ADI-R consistent with their diagnosis of Asperger's Disorder or Pervasive Developmental Disorder-Not Otherwise Specified, and thus were also included in the sample.

Of the original sample of 406, 14 families were excluded from the present analysis because the father was the primary respondent; 92 families were excluded because the mother had died, declined participation, or could not be located at Time 2 or Time 3; and 31 cases were excluded due to missing data on the measures of interest at Time 2 or Time 3. This resulted in a sample of 269 mothers of adolescents and adults with ASD for the present analysis.

The mothers included in the subsample used for the present study ranged in age from 33 to 83 at Time 2 ($M = 52.35$, $SD = 10.55$). Most mothers were married (78.1%) and nearly all had completed high school (98.1%). Approximately 21% of mothers were high school graduates, 43% had some college or BA degree, and 34% had some post-bachelors education or graduate degree. Over two-thirds of mothers were employed either part- or full-time (69.1%). The median annual household income was \$50,000–\$59,000 in 2000–2001. The majority of participants were White, with 5% persons of color.

The adolescents and adults with ASD in the subsample used for the present study ranged in age from 11 to 50 years of age at Time 2 ($M = 23.15$ years, $SD = 9.82$). Consistent with the higher prevalence of autism among males compared with females (American Psychiatric Association, 2000), the majority of the sample was male (74.7%). Sixty-eight percent of the sample had a comorbid diagnosis of intellectual disability. At Time 2, 62.4% of adolescents and adults were co-residing with their mothers; by Time 3, 59.9% of the sample was co-residing.

Measures

The three measures of social support were assessed by a modified version of the “convoy model” developed by Antonucci and Akiyama (1987). Mothers were first asked to list up to 10 persons in their network who were important to them. Then they indicated whether each individual listed provided them with the following six types of positive support (each coded as yes = 1 or no = 0): someone

in whom they could confide; a source of reassurance when feeling uncertain; someone to talk with when upset, nervous, or depressed; someone who made them feel respected; someone who would provide care if the respondent was ill; and someone the respondent could talk about her health. In addition to these 6 questions about the receipt of positive support from each member of their social network, we added four items based on the work of Finch et al. (1989) and Rook (1984) to measure the extent to which the respondents were recipients of negative support from members of their social network. For each person in the social network, mothers were asked to indicate whether or not (yes = 1 or no = 0) the network member criticized the mother's involvement in her child's life; blamed her for her child's problems; made excessive demands on the mother; or made the mother feel uncomfortable.

The *network size* was a count of the number of persons listed in the network (possible range from 0 to 10). Average *positive support* was obtained by summing the availability of the six types of positive support from all members in the network and then dividing that value by the total number of network members, resulting in a possible range of scores from 0 to 6. Average *negative support* was calculated by summing the four types of negative support across all of the members in the network and then dividing that value by the total number of network members, resulting in a possible range of scores from 0 to 4. All three measures of social support were measured at Time 2 and Time 3. Change in each type of social support was measured by subtracting T2 from T3.

Center for Epidemiological Studies-Depression Scale (CES-D)

Maternal depressive symptomatology was measured at Time 2 and Time 3 using the CES-D (Radloff 1977), a 20 item self-report scale of depressive symptoms. Respondents rated the frequency of depressive symptoms in the past week on a 4-point scale ranging from 0 (*rarely*) to 3 (*most of the time*). A score of 16 or higher indicates a risk for clinical depression. The CES-D had a Cronbach's alpha reliability of .91 at Time 2 and .92 at Time 3.

Profile of Mood States (POMS)

Maternal well-being was also assessed at Time 2 and Time 3 using the POMS (McNair et al. 1971). The POMS measures the frequency of affective symptoms during the previous week on a scale of 0 (*not at all*) to 4 (*extremely*). Three POMS subscales measuring *positive affect* (vigor, friendliness, and elation) were averaged to create an overall positive affect score, with higher scores reflecting more positive well-being. Four POMS subscales measuring

negative affect (anxiety, anger, fatigue, and confusion) were averaged to create an overall negative affect score, with higher scores reflecting more negative well-being.

Control Variables

Maternal demographic characteristics of age (continuous) and marital status (1 = married, 0 = not married) were included as control variables. We also controlled for child characteristics including whether or not the son or daughter with ASD also had intellectual disability (1 = yes, 0 = no) and average behavior problems. Behavior problems were measured at Time 2 using the Scales of Independent Behavior-Revised (SIB-R; Bruininks et al. 1996). The SIB-R scales assess eight types of behavior problems: self-injurious behavior, unusual or repetitive behavior, withdrawn or inattentive behavior, socially offensive behavior, uncooperative behavior, hurtful to others, destructive to property, and disruptive behavior. Mothers were asked to indicate if their son or daughter with ASD had manifested each of the eight behavior problems during the previous 6 months and, if so, to rate the frequency of each behavior problem (ranging from 1 = less than once a month to 5 = one or more times an hour) and its severity (1 = not serious to 5 = extremely serious). Using standardized algorithms (Bruininks et al. 1996), frequency and severity scores were translated into a total problems score. The reliability and validity of the SIB-R has previously been shown to be excellent (Bruininks et al. 1996). Higher scores on the SIB-R reflect more severe behavior problems.

Procedures

At both Time 2 and Time 3, mothers completed self-administered questionnaires and participated in a 2- to 3-h in-home interview. Data collection for Time 2 and Time 3 occurred approximately 18 months apart. Notably, all data collectors participated in multi-day trainings every 18 months and received ongoing reliability checks every 5th interview to ensure consistency of administration across data collectors and over time.

Results

Descriptive statistics and correlations among study variables are presented in Table 1. We note that all but one mother in our sample reported having at least one person in their support network at Time 2 (range = 0–10, mean = 7.62 members). We also note that a quarter of mothers in our sample (24.9%) were above the cutoff for the risk of clinical depression on the CES-D at Time 3, the point of our outcome measure. In terms of network composition, at Time 2

Table 1 Pearson correlations, means, and standard deviations of study variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
1. T2 CES-D	1															
2. T3 CES-D	.65***	1														
3. T2 positive affect	-.68***	-.48***	1													
4. T3 positive affect	-.50***	-.64***	.71***	1												
5. T2 negative affect	.82***	.59***	-.57***	-.43***	1											
6. T3 negative affect	.64***	.82***	-.44***	-.57***	.71**	1										
7. T2 network size	-.20**	-.24***	.17**	.22***	-.19**	-.21**	1									
8. T2 positive support	.09	.13*	.01	-.06	.17**	.18**	-.06	1								
9. T2 negative support	.26***	.17**	-.14*	-.17**	.28***	.24***	-.12†	-.07	1							
10. Change network size	.05	.07	-.03	-.04	.09	.12†	-.27***	.05	.00	1						
11. Change positive support	-.15*	-.19**	.13*	.15*	-.16**	-.16*	.00	-.44***	-.03	-.18**	1					
12. Change negative support	.00	.15*	-.06	-.06	.01	.13*	-.03	.04	-.53***	-.03	-.08	1				
13. Marital status	.02	-.07	-.02	.01	.02	-.02	-.02	.11†	-.02	.00	-.11†	.03	1			
14. Maternal age	-.10	-.09	.09	.14*	-.24***	-.20**	.00	-.19**	-.03	-.03	.00	.04	-.25***	1		
15. ID Status	-.01	-.09	.08	.07	-.03	-.06	-.06	-.04	.09	.00	.01	-.10†	-.08	.21**	1	
16. Behavior problems	.21***	.15**	-.12†	-.16**	.27***	.23***	-.03	.12*	.12*	.07	-.05	-.01	.04	-.30***	.18**	1
M (SD)	12.15 (9.82)	2.28 (9.76)	15.04 (5.22)	15.22 (4.90)	8.85 (5.59)	8.60 (5.51)	7.62 (2.36)	4.20 (1.17)	0.20 (1.17)	0.20 (0.27)	0.20 (1.20)	-.13 (1.00)	.78 (.41)	52.35 (10.55)	.68 (.47)	113.18 (10.09)

† $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

mothers reported multiple types of network members including friends (91.8% of mothers), spouse (66.2% of mothers), children (60.6% of mothers), and parents (41.6% of mothers). Additionally, the amount of change in network size from T2 to T3 was small on average (mean = .20).

As a preliminary analysis, an examination of the correlations presented in Table 1 indicated that network size was significantly associated with all three well-being outcomes; having a larger number of network members was associated with lower levels of depressive symptoms and negative affect and higher levels of positive affect. Change in network size was not significantly related to these outcomes. There was a significant positive correlation between level of positive support and depressive symptoms. However, increases in positive support were significantly associated with lower levels of depressive symptoms and negative affect and higher levels of positive affect. Level of negative support was significantly associated with depressive symptoms, negative affect, and positive affect in hypothesized directions and increases in negative support were significantly associated with higher levels of depressive symptoms and negative affect. Although marital status and intellectual disability status were not significantly correlated with any of the well-being outcomes, being older was associated with significantly higher levels of positive affect and lower levels of negative affect. Child behavior problems were also significantly associated with poorer well-being outcomes.

To address our research aims, we examined whether quantity (network size) and valence of support (positive support and negative support) at Time 2 would predict maternal well-being (depression, positive affect, and negative affect) at Time 3 (approximately 18 months later). For these analyses, we conducted a series of separate multiple regression analyses, with depression, positive affect, and negative affect at Time 3 as dependent variables. Social support variables (network size, positive support, and negative support) at Time 2 and change in social support variables from Time 2 to Time 3 were entered as unique independent variables. We also included the following covariates in all models: the Time 2 level of the relevant well-being variable (depression, positive affect, or negative affect), maternal age, maternal education level, child intellectual disability status, and child behavior problems.

Quantity of Social Support as a Predictor of Well-Being

To test our first hypothesis, we conducted three separate regression analyses with network size (Time 2 size and change in size from Time 2 to Time 3) predicting depressive symptoms, positive affect, and negative affect, respectively. These models are presented in Table 2. Each column represents a separate regression model for each well-being outcome (depressive symptoms, positive affect, or negative

Table 2 Regression models of network size predicting Time 3 well-being variables

	CES-D	POMS positive	POMS negative
T2 level of DV	.64***	.68***	.69***
Marital status	-.10*	.03	-.05
Maternal age	-.02	.06	-.02
Child ID status	-.10*	.02	-.06
Behavior problems	.03	-.06	.04
T2 network size	-.13**	.11*	-.08†
Change network size	.02	.00	.04
R2	.47***	.52***	.52***

† $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

affect). Consistent with our first hypothesis, having a larger social network at Time 2 was associated with declining levels of depressive symptoms from Time 2 to Time 3. Further, having a larger number of network members at Time 2 was associated with increasing levels of positive affect from Time 2 to Time 3. There was also a trend for network size to predict negative affect, although this was not significant at the .05 level. Change in network size from Time 2 to Time 3 was not a significant predictor in any of the models. Being married and having a child with ID was also associated with declining levels of depressive symptoms. There were no other significant covariates.

Valence of Social Support as a Predictor of Well-Being

For our second hypothesis, we conducted three separate regression analyses with positive support (both Time 2 level and Time 2 to Time 3 change) predicting depressive symptoms, positive affect, and negative affect, respectively. These models are presented in Table 3. Counter to our hypothesis, positive support was not significantly related to any of the well-being outcomes. There was a trend for increasing positive support from Time 2 to Time 3 to be associated with declining levels of depressive symptoms from Time 2 to Time 3, but this effect was not significant at the .05 level. Notably, although marital status was a significant predictor of depressive symptoms, there were no other statistically significant covariates.

Finally, we conducted three separate regression analyses with negative support (both Time 2 level and Time 2 to Time 3 change) predicting change in depressive symptoms, positive affect, and negative affect, respectively. These models are presented in Table 4. Consistent with our third hypothesis, negative support was a significant predictor of change in depressive symptoms, positive affect, and negative affect, with a higher level of negative support associated with declining levels of well-being on each of the well-being outcomes (e.g., more depressive symptoms and

Table 3 Regression models of positive support predicting Time 3 well-being variables

	CES-D	POMS positive	POMS negative
T2 level of DV	.65***	.70***	.70***
Marital status	-.11*	.04	-.06
Maternal age	-.02	.06	-.02
Child ID status	-.09†	.01	-.06
Behavior problems	.02	-.06	.04
T2 positive support	.02	-.02	.02
Change positive support	-.10†	.05	-.05
R2	.46***	.52***	.52***

Sample size $n = 268$; case without any members in support network was excluded

† $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

Table 4 Regression models of negative support predicting Time 3 well-being variables

	CES-D	POMS positive	POMS negative
T2 level of DV	.63***	.69***	.66***
Marital status	-.09*	.02	-.05
Maternal age	-.01	.03	-.01
Child ID status	-.08†	.02	-.06
Behavior problems	.02	-.06	.04
T2 mean negative support	.14**	-.14**	.18**
Change negative support	.20***	-.09†	.20***
R2	.48***	.53***	.55***

Sample size $n = 268$; case without any members in support network was excluded

† $p < .10$, * $p < .05$, ** $p < .01$, *** $p < .001$

negative affect and less positive affect). Additionally, increases in negative support from Time 2 to Time 3 were associated with increasing levels of depressive symptoms and negative affect, and there was a trend for increases in negative support to be associated with declining levels of positive affect, but this was not significant at the .05 level. Finally, being married was associated with significantly lower levels of depressive symptoms.

Discussion

The present study investigated the impact of social support on psychological well-being of mothers of adolescents and adults with ASD. Past studies have examined associations between social support and well-being of parents during childhood (Benson and Karlof 2009; Ekas et al. 2010; Weiss 2002) and the present study extended this work by exploring these linkages later in the life course, a time

when there are relatively few formal services available to families of individuals with ASD (Shattuck et al. 2011; Taylor and Seltzer 2011). The present study also addressed gaps in past research by utilizing longitudinal data to measure the quantity and valence of social support, including both positive and negative aspects of support exchanges, over an 18-month period. Overall, our findings suggested that the *number of members* in a social network as well as the *valence of support* from those members, particularly negative forms of support, were highly predictive of psychological well-being for mid-life mothers of individuals with ASD.

Consistent with our hypothesis, we found that having a greater number of network members was associated with declining levels of depressive symptoms as well as a higher level of positive affect 18 months later, even after controlling for child-related factors (e.g., behavior problems). In essence, the findings indicated that having a larger social support network was associated with improvements in multiple aspects of maternal well-being over time. This is consistent with past work among parents of younger children with ASD (e.g., Bishop et al. 2007) and similar to previous work which has shown a relationship between network size and negative affective symptoms among mothers of individuals with ASD during mid-life (Barker et al. 2010).

In addition to exploring associations between *quantity* of support and maternal well-being, the present study investigated the impact of *valence* of support (both positive and negative) on these outcomes over an 18-month period. In fact, the most robust predictor of well-being in the present study was negative support. Even after controlling for a variety of child and maternal factors, a higher level of negative support was associated with increasing levels of depressive symptoms and negative affect as well as declining levels of positive affect. Additionally, change in negative support predicted depressive symptoms and negative affect, with increases in negative support associated with lower levels of well-being. Consistent with the work of Rook (1984) and others (Finch et al. 1989), the present study highlighted how negative aspects of social interactions and exchanges can have a detrimental impact on well-being.

In contrast with the findings for negative support, positive support was not a significant predictor of change in any of the well-being outcomes. This was an unexpected finding given past work on positive social support in samples of younger children with ASD (e.g., Ekas et al. 2010). One possibility for this lack of predictive power of positive support is that there may be a restriction of range in the positivity of network members by mid-life, as mothers likely have selected people for inclusion in their network with whom they had positive relations. However,

the strong associations found for negative support but not positive support is in line with work by Ingersoll-Dayton et al. (1997) that suggested that negative support may be particularly influential for individuals with a high level of life stress. The chronic and non-normative nature of the stress associated with caring for a child with ASD during the adolescent and adult years may contribute an increased sensitivity to negative support relative to positive support during this point in the life course. In short, negative support is not simply the absence of positive support, but something far more challenging for mothers. Taken together, the findings from the present study suggest that for mothers of adolescents and adults with ASD, having network members who are rarely critical or demanding is more beneficial than having network members who provide high levels of positive support.

We also note that overall there were very few significant covariates in the regression models, further highlighting the importance of social support for maternal well-being. However, consistent with past studies in the general population (Dush and Amato 2005; Stack and Eshleman 1998), being married was consistently associated with declining levels of depressive symptoms. Similarly, having a child with a dual diagnosis of ASD and intellectual disability was associated with declines in depressive symptoms. Finally, although the simple correlations between behavior problems and the well-being measures were significant, the level of behavior problems was not a significant predictor in any of the regression models which controlled for prior levels of well-being. This suggests that behavior problems are a less salient predictor of change in well-being over time than social support variables.

Limitations and Future Directions

There were limitations of the present study which should be addressed in future work. First, the sample was primarily White and middle class, and, thus, findings cannot be generalized to all families who have a son or daughter with ASD. Second, although all mothers had an adolescent or adult with ASD, there was a wide range of ages for mothers in the current study. However, we included maternal age as a covariate in all models and it was not a significant predictor. Third, we did not examine instrumental sources of support provided to the mother such as exchanges of money and resources or help with physical tasks (e.g., yard work, household chores). These types of support exchanges also may influence maternal well-being, particularly during economic downturns or when mothers begin to experience declines in their own health. Accordingly, future research should investigate how instrumental support may relate to well-being in aging parents of adults

with ASD. Given that mothers of children with ASD are at increased risk for physical health problems compared to mothers of children without disabilities (Smith et al. 2011), future work also should examine possible linkages between various types of social support and physical health of parents. Finally, the present study investigated social support and well-being over an 18-month period. We know that in the general population there are normative changes in social networks across the lifespan (Antonucci and Akiyama 1987) and negative interactions, in particular, have been found to decrease with age (Akiyama et al. 2003). It will be important for future research to examine how social support may change for parents of children with ASD over a longer period of time and how these patterns of change in support may relate to parental health and well-being.

In conclusion, the present study has several important implications for clinical practice. Past studies, including studies from our own lab (e.g., Seltzer et al. 2010), have suggested that families of children with ASD would benefit from interventions that address child behavior problems, as reducing challenging behaviors likely would result in gains not only for the individual with ASD, but also for parents in terms of decreased stress and improved well-being. The present study, however, indicates that enhancing social support may be another equally-valuable (if not more valuable) avenue for promoting positive maternal well-being, at least during mid-life. Importantly, we found that quantity and valence of social support predicted changes in psychological well-being above and beyond the impact of child behavior problems. Given the rapid rise in ASD diagnoses in recent years (Gurney et al. 2003) and the current dearth of formal services available to individuals with ASD and their families during adulthood (Shattuck et al. 2011; Taylor and Seltzer 2011), new programs need to be developed to assist parents to maintain supportive social ties and to reduce exposure to negative exchanges as they continue to care for their son or daughter later in the life course. The present study specifically suggests that future interventions should take a family systems approach to help parents recognize and reduce their exposure to negative support, as having a high proportion of people who are critical or demanding in a close social network carries a significant emotional cost for mothers.

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References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Osmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*, 237–254.
- Akiyama, H., Antonucci, T., Takahashi, K., & Langfahl, E. S. (2003). Negative interactions in close relationships across the life span. *Journal of Gerontology: Psychological Sciences, 58*, 70–79.
- Antonucci, T. C., & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology, 42*, 519–527.
- August, K. J., & Sorkin, D. H. (2010). Marital status and gender differences in managing a chronic illness: The function of health-related social control. *Social Science and Medicine, 71*, 1831–1838.
- Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2010). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology, 47*, 551–561.
- Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*, 350–362.
- Bishop, S. L., Richler, J., Cain, A. C., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation, 112*, 450–461.
- Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry, 18*, 507–513.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting autistic spectrum disorders: Social support, mental health status, and satisfaction with services. *Autism, 8*, 409–423.
- Bruininks, R. H., Woodcock, R. W., Weatherman, R. F., & Hill, B. K. (1996). *Scales of independent behavior-revised*. Itasca, IL: Riverside.
- Carter, A. S., Martinez-Pedraza, F. L., & Gray, S. A. O. (2009). Stability and individual change in depressive symptoms among mothers raising young children with ASD: Maternal and child correlates. *Journal of Clinical Psychology, 65*, 1270–1280.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310–357.
- Dush, C. M. K., & Amato, P. R. (2005). Consequences of relationship status and quality for subjective well-being. *Journal of Social and Personal Relationships, 22*, 607–627.
- Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behavior problems, and maternal well-being. *Journal of Intellectual Disability Research, 49*, 657–671.
- Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274–1284.
- Ekas, N., & Whitman, T. L. (2010). Autism symptom topography and maternal socioemotional functioning. *American Journal on Intellectual and Developmental Disability, 115*, 234–249.
- Finch, J. F., Okun, M. A., Barrera, M., Jr., Zautra, A. J., & Reich, J. W. (1989). Positive and negative social ties among older adults: Measurement models and the prediction of psychological distress and well-being. *American Journal of Community Psychology, 17*, 585–605.
- Green, S. A., & Carter, A. S. (2011). Predictors and course of daily living skills development in toddlers with autism spectrum

- disorders. *Journal of Autism and Developmental Disorders*. (Online ahead of print). doi:[10.1007/s10803-011-1275-0](https://doi.org/10.1007/s10803-011-1275-0).
- Gurney, J., Fritz, M., Ness, K., Sievers, P., Newschaffer, C., & Shapiro, E. (2003). Analysis of prevalence trends of autism spectrum disorder in Minnesota. *Archives of Pediatrics and Adolescent Medicine*, *157*, 622–627.
- Ha, J.-H. (2010). The effects of positive and negative support from children on widowed older adults' psychological adjustment: A longitudinal analysis. *The Gerontologist*, *4*, 471–481.
- Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *15*, 269–275.
- Hastings, R. P., Kovshoff, H., Ward, N. J., degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, *35*, 635–644.
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, *50*, 874–882.
- Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *5*, 337–344.
- Ingersoll-Dayton, B., Morgan, D., & Antonucci, T. (1997). The effects of positive and negative social exchanges on aging adults. *Journal of Gerontology: Social Sciences*, *52*, 190–199.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview—Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, *24*, 659–685.
- Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal on Mental Retardation*, *112*, 401–417.
- McNair, D., Lorr, M., & Droppleman, L. F. (1971). *Profile of mood states*. San Diego, CA: Educational and Industrial Testing Service.
- Merz, E.-M., & Huxhold, O. (2010). Wellbeing depends on social relationship characteristics: Comparing different types and providers of support to older adults. *Ageing & Society*, *30*, 843–857.
- Pearlin, L. I. (1989). The sociological study of stress. *Journal of Health and Social Behavior*, *30*, 241–256.
- Pottie, C. G., Cohen, J., & Ingram, K. M. (2009). Parenting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology*, *34*, 419–429.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, *1*, 385–401.
- Rook, K. S. (1984). The negative side of social interaction: Impact on psychological well-being. *Journal of Personality and Social Psychology*, *46*, 1097–1108.
- Rook, K. S. (2001). Emotional health and positive versus negative social exchanges: A daily diary analysis. *Applied Developmental Science*, *5*, 86–97.
- Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., et al. (2010). Maternal cortisol levels and child behavior problems in families of adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, *40*, 457–469.
- Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatric and Adolescent Medicine*, *165*, 141–146.
- Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. (2010). Daily experiences among mothers of adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, *40*, 167–178.
- Smith, L. E., Seltzer, M. M., & Greenberg, J. S. (2011). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. doi:[10.1007/s10803-011-1422-7](https://doi.org/10.1007/s10803-011-1422-7).
- Stack, S., & Eshleman, J. R. (1998). Marital status and happiness: A 17-nation study. *Journal of Marriage and the Family*, *60*, 527–536.
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, *41*, 566–574.
- Umberson, D., & Montez, J. K. (2010). Social relationship and health: A flashpoint for health policy. *Journal of Health and Social Behavior*, *51*, S54–S66. doi:[10.1177/0022146510383501](https://doi.org/10.1177/0022146510383501).
- Weiss, M. L. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, *6*, 115–130.
- Windsor, T. D., & Anstey, K. J. (2010). Age differences in psychosocial predictors of positive and negative affect: A longitudinal investigation of young, midlife, and older adults. *Psychology and Aging*, *25*, 641–652.