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Trajectories of Emotional Well-Being in Mothers of Adolescents and Adults with Autism

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Abstract

Raising an adolescent or adult child with a developmental disability confers exceptional caregiving challenges on parents. We examined trajectories of two indicators of emotional well-being (depressive symptoms and anxiety) in a sample of primarily Caucasian mothers ($N = 379$; $M_{\text{age}} = 51.22$ years at Time 1) of adolescent and adult children with an autism spectrum disorder (ASD; $M_{\text{age}} = 21.91$ years at Time 1, 73.2% male). We also investigated within-person associations of child context time-varying covariates (autism symptoms, behavior problems, residential status) and maternal context time-varying covariates (social support network size and stressful family events) with the trajectories of emotional well-being. Data were collected on 5 occasions across a 10-year period. Average patterns of stable (depressive symptoms) and improved (anxiety) emotional well-being were evident and well-being trajectories were sensitive to fluctuations in both child and maternal context variables. On occasions when behavior problems were higher, depressive symptoms and anxiety were higher. On occasions after which the grown child moved out of the family home, anxiety was lower. Anxiety was higher on occasions when social support networks were smaller and when more stressful life events were experienced. These results have implications for midlife and aging families of children with an ASD and those who provide services to these families.

Keywords

maternal well-being; depressive symptoms; anxiety; autism spectrum disorders; longitudinal

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Raising an adolescent or adult child with a developmental disability can be stressful and confers exceptional caregiving challenges on parents. Much research has focused on stress associated with having a young child with a developmental disability, but less research has focused on how *adult* children with developmental disabilities affect the well-being of parents in midlife and old age (Ryff, Singer, & Seltzer, 2002). What is known about the well-being of parents of adult children with developmental disabilities comes from a relatively small literature characterized by cross-sectional and short-term longitudinal studies. We expand the depth of this knowledge by examining how changes in the functioning of adolescent and adult children and changes in maternal context variables covary with trajectories of depressive symptoms and anxiety across a 10-year period in a sample of mothers of adolescent and adult children with an autism spectrum disorder (ASD).

Caring for an individual with an ASD can be stressful due to the challenging nature of the core symptoms of autism, which include impairments in communication, impairments in reciprocal social interaction, and the presence of restricted and repetitive behaviors and interests (American Psychiatric Association, 2000). Individuals with an ASD also experience deficits in adaptive behavior (e.g., getting dressed, taking public transit) that contribute to maternal stress (Bishop, Richler, Cain, Lord, & Floyd, 2007; Tomanik, Harris, & Hawkins, 2004).

Stressful parenting associated with caring for a child with an ASD persists across the life course. Parents of young children with an ASD (ages 4 to 17 years) report more difficulty caring for their child and more frustration with their child's behavior compared to parents of children with other developmental disabilities, children with health care needs without developmental disabilities, and children without any special needs (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Mothers of grown children (adolescents and adults) with an ASD continue to have lives characterized by elevated stress and compromised well-being compared to other parents, including parents of individuals with other developmental disabilities (e.g., Down syndrome; Abbeduto et al., 2004). For example, Smith and colleagues (2010) found that mothers of an adolescent or adult with an ASD spent more time caring for their grown children and doing household chores, spent fewer hours engaged in leisure activities, and experienced stress (e.g., arguments, stress at home, stress at work) on more days than mothers of typically developing adolescent and adult children. Two recent meta-analyses showed that, compared to community samples, mothers of children with a developmental disability, including ASD, were at higher risk for depressive symptoms and clinical depression (Bailey, Golden, Roberts, & Ford, 2007; Singer, 2006). In both studies, depressive symptoms were more pronounced in mothers whose child was diagnosed with an ASD compared to mothers whose child had another developmental disability or whose child showed numerous behavior problems associated with autism.

Although mothers of individuals with an ASD are at higher risk for poor emotional well-being compared to other parents, age-group comparisons in cross-sectional studies of parents of individuals with a variety of developmental disabilities (including ASD) suggest that upswings may occur over time (e.g., Magana & Smith, 2006). In a recent meta-analysis of cross-sectional research (Singer, 2006) rates of depression were higher for mothers of younger compared to older children with a developmental disability. Likewise, Ha, Hong, Seltzer, and Greenberg (2008) found that differences in negative affect, somatic complaints, and psychological well-being between parents of typically developing children (the majority of whom were adolescents or adults) and parents of children with a developmental disability or mental illness were smaller in a cohort of older parents compared to a cohort of younger parents. In addition to age differences, they found that longer duration of care among parents of a child with a disability was associated with better well-being. Results from a short-term longitudinal study accord with these cross-sectional findings. Lounds, Seltzer, Greenberg,

and Shattuck (2007) showed that, on average, anxiety declined across a 1.5 year period for mothers of an adolescent or young adult child with an ASD (ages 13 to 22 years).

These results indicate that although emotional well-being is compromised among mothers of individuals with an ASD, mothers may adjust to their non-normative parenting roles with experience. Adjustment to caregiving challenges among mothers of adolescents and adults with an ASD may reflect, in part, normative age-related changes in perspectives that benefit emotional well-being. In the general population, improvements in emotional well-being across adulthood have been documented in both cross-sectional and longitudinal research (e.g., Jorm et al., 2005; Kasen, Cohen, Chen, & Castille, 2003). In the Strengths and Vulnerability Integration theory, Charles and Piazza (2009) propose that improvements in emotional well-being across adulthood result from a maturing of emotion regulation strategies. A lifetime of accumulated experiences and an acknowledgement that time left to live is limited can change how people think about and react to stressful situations in such a way that less negative affect is experienced with age. For example, older adults see less utility in worrying about problems and as a result older adults worry less than younger adults (Basevitz, Pushkar, Chaikelson, Conway, & Dalton, 2008). Likewise, among midlife parents of children with developmental disabilities emotional well-being is enhanced for those who use accommodative coping strategies such as flexible goal adjustment (Seltzer, Greenberg, Floyd, & Hong, 2004).

Although improvement and positive adjustment over time may characterize average emotional well-being trajectories, one must take into account the contexts that influence emotional experiences to fully understand patterns of change in emotional well-being over the life course (Charles & Piazza, 2009). Across the lifespan potential exists within individuals for different levels of functioning, depending, in part, on changes in the salient contexts with which they interact (Lerner, 1998). The life course concept of *linked lives* maintains that the developmental trajectories of partners in salient relationships are mutually influential: changes in the life trajectory of one member often lead to changes in the life trajectory of the partner (Elder, Johnson, & Crosnoe, 2003).

The parent-child relationship provides an example of linked lives: parenting and parental well-being affect child development and characteristics of the child likewise affect parenting and parental well-being (Pettit & Arsiwalla, 2008; Uhlenberg & Mueller, 2003). In the general population, parents often worry about the problems that their adult children experience (e.g., financial problems, health problems); this worry has the potential to negatively impact parental emotional well-being (Greenfield & Marks, 2006; Hay, Fingerma, & Lefkowitz, 2008; Pillemer & Suito, 1991). As another example, among adult children with developmental disabilities, autism symptoms and behavior problems are negatively associated with parental well-being (Abbeduto et al., 2004; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Longitudinal research has shown that, on average, autism symptoms and behavior problems decrease across adulthood (Shattuck et al., 2007), and decreases in behavior problems predict subsequent declines in maternal anxiety (Lounds et al., 2007). Having an adolescent or adult child with an ASD move out of the family home is also associated with improvements in maternal well-being (Krauss, Seltzer, & Jacobson, 2005; Greenberg, Seltzer, Krauss, & Kim, 1997; Seltzer, Greenberg, Krauss, & Hong, 1997). Thus, changes in the severity of autism symptoms and behavior problems over time and change in the residential status of a grown child with an ASD may account for some of the improvements in emotional well-being observed in mothers of adults with an ASD, in addition to normative improvements in emotional well-being.

The linked lives of parents and their adult children are embedded within the general family context and the family is one of several institutions embedded within the broader life course

that can impact maternal well-being (Uhlenberg & Mueller, 2003). Thus, focusing exclusively on child context variables in relation to maternal well-being overlooks other aspects of mothers' lives (i.e., other contexts to which their lives are linked) that might also impact well-being across adulthood and that may affect a mother's ability to care for a grown child with special needs. Large bodies of research show that, in the general population, having more social support (e.g., Bierman, Fazio, & Milkie, 2006; Cohen, 2004) and experiencing fewer stressful life events (e.g., Hammen, 2005; Lucas, 2007; Schneiderman, Ironson, & Siegel, 2005) are related to improved well-being. A review of the literature on social support in mothers of children with autism showed that access to formal and informal social supports is related to better outcomes for these mothers (Boyd, 2002), and among mothers of adult children with intellectual disability, having large social support networks was associated with lower levels of depressive symptoms (Greenberg et al., 1997). To our knowledge, no research has explored the association of negative life events on the well-being of mothers of children with autism.

The Current Study

The literature reviewed above indicates that despite facing exceptional caregiving challenges across midlife and old age, emotional well-being among mothers of individuals with an ASD likely improves. However, this conclusion is inferred from cross-sectional studies of mean-level differences among age cohorts and from longitudinal studies limited by short time intervals and few waves of measurement that restrict tests of intraindividual change over time. Furthermore, most of the studies reviewed only assessed global negative affect, combining depressive symptoms and anxious affect into one factor, or assessed depressive symptoms alone. Although depressive symptoms and anxiety are correlated, symptoms specific to depression (e.g., lack of positive affect) and to anxiety (e.g., heightened arousal) distinguish the syndromes (Clark & Watson, 1991). Furthermore, latent class analysis of longitudinal data has identified distinct subgroups of individuals who exhibit different patterns of anxiety and depressive symptoms over time (Olino, Klein, Lewinsohn, Rhode, & Seeley, 2009) and other longitudinal research has shown that anxiety is less stable than depression over time (Merikangas et al., 2003). If, for example, less stability in anxiety trajectories reflects heightened sensitivity to changing contexts, understanding factors associated with distinct emotional well-being trajectories may have important implications for interventions aimed at supporting mothers caring for grown children with an ASD.

In the current study we address these limitations by assessing two indicators of emotional well-being (depressive symptoms and anxiety) in a sample of mothers of an adolescent or adult with an ASD. Emotional well-being, child context (autism symptoms, behavior problems, whether the adult child lives in the family home), and maternal context (social support and stressful family life events) variables were measured on 5 occasions over a 10-year period, allowing for the examination of within-person covariation among the variables across this caregiving period. Our research questions were: (1) What are the average patterns of within-person change in depressive symptoms and anxiety in mothers of an adolescent or adult with an ASD, and how do these patterns differ for older mothers compared to younger mothers; and (2) What child and maternal context variables account for variation in these trajectories and how do they differ for older mothers compared to younger mothers?

Given the results of cross-sectional and short-term longitudinal studies that showed improved emotional well-being among older caregivers (Ha et al., 2008; Lounds et al., 2007; Magana & Smith, 2006), and that emotional well-being tends to improve with age in the general population (Charles & Piazza, 2009), it was expected that anxiety and depressive symptoms would improve, on average, across the 10-year caregiving period and that older

mothers would begin the study with lower levels of anxiety and fewer depressive symptoms compared to younger mothers.

It was also expected that the presence of fewer autism symptoms and behavior problems and the event of an adolescent or adult child moving out of the family home would be associated with gains in emotional well-being. Likewise, it was expected that having larger social support networks and experiencing fewer stressful events within the immediate family would be associated with positive shifts in emotional well-being trajectories. Finally, it was expected that maternal age would moderate the associations of child and maternal context variables with emotional well-being outcomes such that the associations of child context and maternal context variables would be stronger for younger mothers compared to older mothers. That is, younger mothers would be more sensitive to fluctuations in child and maternal context variables than older mothers.

Method

Procedure

As part of an ongoing longitudinal study data were collected from families of adolescents and adults with an ASD ($N = 406$ adolescents and adults with an ASD). Families were included in the study if the son or daughter with an ASD was 10 years of age or older at the start of the study in 1998, had received an ASD diagnosis (Autistic Disorder, Asperger Disorder, or Pervasive Developmental Disorder [PDD-NOS]) from an educational or health professional, and had a researcher-administered Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) profile consistent with this diagnosis. Half of the families lived in Wisconsin ($n = 202$) and half in Massachusetts ($n = 204$). Identical recruitment and data-collection methods were used at both sites. The families were recruited through service agencies, schools, and clinics. Five waves of data have thus far been collected: four waves collected every 18 months from 1998 to 2003, spanning a 4.5 year period, and a fifth wave collected in 2008, 10 years after the initial wave of data collection. In most families, mothers were the primary caregivers for the children with an ASD, and they provided data through self-administered questionnaires and in-home interviews that typically lasted 2 to 3 hours.

Participants

Data collected from 379 mothers who participated at Time 1 were used in the current study. The original sample included the families of 27 other individuals with an ASD who were excluded for a variety of reasons. At Time 1, 11 mothers completed questionnaires and interviews for two or three children with an ASD. One child was randomly selected from each family as the target child and their data were used in the current analyses. Data from two mothers who did not report their age at any wave of data collection and data from other caregivers (e.g., fathers) in 14 families were also excluded. At Time 1, mothers were, on average, 51.22 years of age ($SD = 10.52$, range 32.31 to 81.86 years). Nearly all were Caucasian (93.1%; 2.1% African American, 1.6% Hispanic, 0.5% American Indian, 1.6% Asian or Pacific Islander; 1.1% race/ethnicity not reported) and most were married at Time 1 (78.1%). Most (72.8%) had completed at least some college education and 65.7% were employed. The median household income was between \$45,000 and \$49,000 at Time 1, but a range in household income was represented (from less than \$10,000 to more than \$70,000). Languages spoken at home were not assessed.

The adolescents and young adults with an ASD averaged 21.91 years of age ($SD = 9.40$, range = 10.1 through 52.1 years) at Time 1. Most (73.2%) were male. Nearly all (94.6%) met the ADI-R (Lord et al., 1994) lifetime criteria for a diagnosis of Autistic Disorder. Case-

by-case review of the other sample members (5.4%) determined that their ADI-R profile was consistent with their ASD (i.e., PDD-NOS or Asperger's Disorder). Approximately 73.4% of the individuals with an ASD were verbal, as indicated by daily functional use of at least three-word phrases. Over two-thirds (69.8%) had an intellectual disability (i.e., mental retardation). These characteristics are consistent with the epidemiology of ASD (Bryson & Smith, 1998; Fombonne, 2003).

Of the 379 mothers whose Time 1 data were included in the present analyses, data were available for 334 (88.1%) at Time 2, 301 (79.4%) at Time 3, 291 (76.8%) at T4, and 234 (61.7%) at Time 5. Mothers who remained in the study at Time 5 were compared on all of the study variables as well as indicators of socioeconomic status to those who dropped out of the study or those who died (or whose child died) at each of the prior waves of measurement. Mothers who remained in the study had more years of education, higher household income at Time 1, younger children and were slightly younger themselves, and had larger social support networks compared to mothers who did not participate at T5.

Measures

Maternal Emotional Well-Being Outcome Measures—The 20-item Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) measured depressive symptoms at all 5 times of measurement. Mothers indicated on how many days in the past week 20 symptoms of depression were experienced on a scale ranging from 0 (*never*) to 3 (5 to 7 days). Total scores can range from 0 to 60. Higher scores reflect having experienced more depressive symptoms in the previous week. Coefficient alphas ranged from .91 to .93 across the 5 waves of measurement.

The anxiety subscale of the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1981) measured maternal anxiety at each of the 5 waves of measurement. This subscale measures the frequency of nine anxiety symptoms experienced over the previous week, including feeling tense, shaky, or on edge, on a scale ranging from 0 (*not at all*) to 4 (*extremely*). Total scores range from 0 to 36; higher scores indicate having experienced more anxiety in the previous week. Coefficient alphas ranged from .89 to .91 across the 5 waves of measurement.

Years of Caregiving—Years of caregiving was quantified in two ways. To assess within-person change in emotional well-being outcomes across the 10-year period years of caregiving was coded as “time in years” at Level 1 (Time 1 = 0; Time 2 = 1.5; Time 3 = 3; Time 4 = 4.5; Time 5 = 10). To account for between-persons differences in years of caregiving prior to the study period, as well as potential differences due to normative age-related changes in well-being, maternal age at Time 1 was included in the models at Level 2. Child age and maternal age were highly correlated ($r = .89$). Thus, maternal age was a reasonable indication of the length of time spent caring for the child. The use of maternal age also accounted for potential differences due to normative age-related changes in emotional well-being.

Child Context Time-Varying Predictors—The ADI-R (Lord et al., 1994) measured current autism symptoms at all 5 times of measurement. Thirty-three items from the diagnostic algorithm appropriate for adolescents and adults were administered in interviews with mothers. Ratings of current functioning were made at each time of measurement by interviewers who had participated in an approved ADI-R training program. Inter-rater agreement between the interviewers and two supervising psychologists experienced in the diagnosis of autism and in the use of the ADI-R averaged 89% at Time 1, and the average Kappa was .81. Past research has demonstrated the test–retest reliability, diagnostic validity,

convergent validity, and specificity and sensitivity of the items used in the ADI-R diagnostic algorithm (Hill et al., 2001; Lord et al., 1997). Each ADI-R item was scored on the following scale: 0 (*no abnormality*), 1 (*possible abnormality*), 2 (*definite autistic-type abnormality*), 3 (*severe autistic-type abnormality*). Following the recommendations of Lord et al. (1994), scores of 3 were recoded as 2. A summary score was calculated, with higher scores indicating greater severity of impairments in communication, social reciprocity, and repetitive behaviors/stereotyped interest displayed by the individual with an ASD. Verbal items were excluded from the summary score so that non-verbal participants would not be excluded from the study due to missing data. Coefficient alpha values ranged from .82 to .87 across the 5 waves of measurement.

Mothers completed the Behavior Problems subscale of the Scales of Independent Behaviors-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) at each of the 5 times of measurement. Mothers indicated whether their son or daughter displayed each of eight behaviors over the previous 6 months: hurtful to self, unusual or repetitive, withdrawn or inattentive, socially offensive, uncooperative, hurtful to others, disruptive, and destructive of property. Mothers who indicated that their child displayed a given behavior then rated the frequency from 1 (*less than once a month*) to 5 (*1 more times/hour*) and the severity from 1 (*not serious*) to 5 (*extremely serious*) of the behavior. Standardized algorithms (Bruininks et al., 1996) translate the frequency and severity ratings into a general summary score. Higher scores indicate more severe maladaptive behaviors. Reliability and validity of this measure have been established by Bruininks et al. (1996).

At each time of measurement mothers indicated where their adolescent or adult child lived. When the son or daughter lived at home a code of 0 (co-residing) was assigned. When the child lived away from the family home (e.g., group home, independent living, etc.) a code of 1 (living away from the family home) was assigned. This coding strategy allowed for examination of the effects of change in living arrangement, from living at home to living away from home, on the maternal well-being outcome variables.

Maternal Context Time-Varying Predictors—The social support scale used in the current study was derived from an adapted version of the convoy model of social networks (Antonucci & Akiyama, 1987). At each of the 5 waves of measurement participants were asked to list up to 10 people in their personal network with whom they felt a special bond and with whom they exchanged support. Participants were told that these individuals could include a spouse, parent, child, friend, or any other person close and important to them. The total number of persons listed by each participant was used as an indicator of social support network size, with larger networks reflecting greater access to social support. Network size is one aspect of social support that previous research, including research with mothers in particular, has shown to be associated with lower stress and greater well-being (Balaji et al., 2007; Charles & Carstensen, 2009).

At each of the 5 waves of measurement, the 20-item Life Stress Scale of the Parenting Stress Index (Abidin, 1986) was used to measure the number of stressful events experienced by mothers or someone in their immediate family during the previous 12 months. A wide range of stressful events were inquired about including marriage (e.g., separation, marriage), finances (e.g., went deeply into debt), work changes (e.g., promotion, began a new job), pregnancy, death of a friend or family member, household moves, and alcohol or drug problems. Items were scored dichotomously, 0 (event not experienced) and 1 (self or immediate family member experienced this event), and summed. Higher total scores reflect having experienced a greater number of stressful life events within the family network in the previous year. Life events checklists are commonly used as inventories of events that

contribute to stress and compromise well-being and have been shown to be valid and reliable for this purpose (e.g., Miller, 1996; Shaw, Dimsdale, & Patterson, 2008).

Data Analytic Plan

Multilevel modeling was used to address the following aims: first, to describe trajectories of emotional well-being in mothers of adolescents and adults with an ASD across a 10-year period; second, to examine the associations of between-persons differences and within-person fluctuations in child context and maternal context variables on trajectories of emotional well-being. Data were analyzed with the hierarchical linear modeling (HLM) program (Raudenbush & Bryk, 2002). Separate models were tested for each outcome: depressive symptoms and anxiety. In the first set of models, we explored the rate of change for each outcome by testing a linear growth model, and assessing the moderating effect of maternal age on these trajectories. In the second set of models, the within-person effects of child and maternal context variables were tested controlling for between-persons differences in each variable. In all models, the between-persons effects of maternal age on initial status, rate of change, and the associations of each with-person predictor and each outcome were tested. For all analyses, continuous variables at Level 1 (within-persons) were group-mean centered and grand-mean centered at Level 2 (between-persons). One strength of the multilevel modeling approach is that all participants are included in the analysis. Cases with complete data at all points of measurement on the outcome measures are weighted more heavily, but as long as one occasion of measurement is available, the case is used in the estimation of effects. Additionally, the inclusion of observed predictors of attrition in the models (e.g., maternal age, social support) and the use of all available time points for participants reduces bias (Raudenbush & Bryk, 2002; Singer & Willett, 2003).

Results

Descriptive Statistics and Correlations

Means and standard deviations for the outcome variables and the five time-varying predictor variables are presented in Table 1. All autocorrelations for the outcome, child context, and maternal context variables were significant ($ps < .001$), and indicated moderate to high levels of stability across the study period (depressive symptoms $rs = .55$ to $.69$; anxiety $rs = .46$ to $.63$; autism symptoms $rs = .71$ to $.83$; behavior problems $rs = .52$ to $.70$; living arrangement $rs = .61$ to $.88$; social support $rs = .61$ to $.94$; stressful family life events $rs = .30$ to $.51$).

10-Year Trajectories of Change in Maternal Well-Being

Prior to data analysis, univariate distributions for both outcome variables were examined separately by wave of measurement. Anxiety score distributions were slightly positively skewed due to the presence of outliers at the positive ends of the distributions. A square root transformation was performed to correct this problem. Comparison of the multivariate distributions using raw and transformed scores for anxiety showed that use of the transformed anxiety scores better met the assumptions of multilevel modeling. For ease of interpretation all results for anxiety are presented in the original anxiety scale metric, but reported statistical significance tests are based on analyses using square root transformed anxiety scores. Raw scores were used in the depressive symptoms models.

Results of the average growth models, controlling only for maternal age, for both outcomes are presented in Table 2. Depressive symptoms did not increase or decrease in a linear pattern, on average, across the 10-year period, controlling for maternal age. Older mothers reported fewer depressive symptoms at the beginning of the study compared to younger mothers. The maternal age coefficient, $-.103$, indicates that depressive symptoms were 1.06

points lower for mothers who were 1 standard deviation (10.52) older than the mean ($-.103 * 10.52 = -1.06$). That is, depressive symptom scores for mothers who were in their mid-60s when the study began were about 2 points lower (2.11) than mothers who began the study in their early 40s.

On average, controlling for maternal age, anxiety decreased across the 10-year period. Older mothers were less anxious at the beginning of the study compared to younger mothers. The maternal age coefficient, $-.132$, indicated that anxiety scores were 1.39 units lower for mothers who were 1 standard deviation ($-.132 * 10.52 = 1.39$) older than the mean. That is, anxiety scores for mothers who were in their mid 60s when the study began were about 3 points lower (2.78) than mothers in their early 40s.

Child Context and Maternal Context Time-Varying Covariates

Next the associations of two sets of time-varying covariates, child context and maternal context variables, with the maternal emotional well-being outcome variables were tested (see Table 3). Child context variables included autism symptoms, behavior problems, and residential status. Maternal context variables included social support network size and stressful family events. At Level 1, all of the time-varying covariates were group-mean centered and entered as fixed or non-randomly varying predictors of maternal well-being. The Level 1 effects assessed the within-person associations of time-varying covariates with outcome measures at each wave of measurement. Interactions between maternal age and all time-varying covariates were tested. At Level 2, we controlled for the effects of between-persons differences in average levels of each time-varying covariate on initial status and linear rate of change for each outcome. We controlled for the between-persons effects in these models to appropriately specify the within-person time-varying effects (Hoffman & Stawski, 2009; Raudenbush & Bryk, 2002).

Depressive symptoms—When between-persons differences in average levels of child and maternal context variables were added to the growth model, having larger social support networks and experiencing fewer stressful family events on average across the 10-year period were associated with fewer depressive symptoms at Time 1 (see Table 3). Maternal age was no longer related to initial depressive symptoms. When the between-persons effects of child and maternal context variables on the linear rate of change were added to the model, depressive symptoms *increased*, on average, across the study period. Pseudo- R^2 (Raudenbush & Bryk, 2002) was calculated to determine the amount variance in depressive symptoms means (intercept) and change (time slope) accounted for by the inclusion of the between-persons effects of average levels of child and maternal context variables. The variables as a set accounted for 13.8% of the variance in initial depressive symptoms scores and 4.0% of the variance in depressive symptoms trajectories.

Within individuals, of the child context variables, only child behavior problems covaried with depressive symptoms across the 10-year period (see Table 3). On occasions when behavior problems were lower depressive symptoms were also lower. Maternal age interacted with the within-person effects of child behavior problems such that the association was stronger for younger mothers compared to older mothers. None of the main effects of the maternal context variables were significant, but maternal age interacted with stressful family events. Higher levels of depressive symptoms were associated with having experienced more stressful family events in the previous year to a greater extent for younger mothers compared to older mothers. Pseudo- R^2 tests indicated that the inclusion of the child context variables accounted for an additional 3.6% of the within-person variance and the maternal context variables accounted for an additional 1% of the within-person variance in depressive symptoms scores.

Anxiety—All of the significant between-persons associations of child and maternal context variables with the anxiety intercept were in the expected directions: less anxiety at Time 1 was associated with fewer child behavior problems, larger social support networks, and experiencing fewer stressful family events on average across the 10-year period (see Table 3). Maternal age was no longer related to initial anxiety when these variables were added to the model. When the between-persons effects of child and maternal context variables on the linear rate of change were added to the model, the linear decrease in anxiety remained significant. Pseudo- R^2 tests indicated that the variables as a set accounted for 19.5% of the between-persons variance in initial anxiety scores and 3.0% of the between-persons variance in anxiety trajectories.

Within individuals, two of the child context variables covaried with anxiety over time (see Table 3). On occasions when behavior problems were lower and the adolescent or adult had moved out of the family home anxiety was lower. Both maternal context variables also covaried with anxiety. When participants' social support networks were smaller and when participants experienced more stressful family events in the previous year anxiety was elevated. Pseudo- R^2 tests indicated that the inclusion of the child context variables accounted for 3.2% of the within-person variance and the maternal context variables accounted for an additional 1.7% of the with-person variance in anxiety scores.

Follow-up Analyses

Because attrition analyses showed that Time 1 indicators of socioeconomic status and marital status were associated with continuation in the study, all models were tested controlling for the effects of maternal education and marital status (0 = always married; 1 = never married, separated, divorced, widowed during the study) on the intercept (Time 1) and linear time slope. When the effects of maternal education and marital status were controlled, the pattern of results with regard to the associations of maternal age and child and maternal context variables with each emotional well-being outcome was the same.

Discussion

The present study was the first to examine intraindividual change in emotional well-being in midlife and aging mothers of adolescents and adults with an ASD. The first goal of the study was to assess how depressive symptoms and anxiety changed across a 10-year period of caregiving in midlife and old age. We hypothesized that both aspects of emotional well-being would improve, on average, over time. Initial growth models showed that depressive symptoms did not change on average across the 10-year period, controlling for maternal age, but at the beginning of the study period older mothers reported fewer depressive symptoms than younger mothers. Controlling for maternal age, anxiety declined across the 10-year period and older mothers reported less anxiety at the beginning of the 10-year period.

The average patterns of change and age differences in emotional well-being at the beginning of the study period are indicative of resilience, i.e., positive adjustment over time in the face of exceptional stress (cf. Masten, 2001): emotional well-being improved (anxiety) or was stable (depressive symptoms) over time despite the fact that mothers of adolescents and adults with an ASD have lives characterized by elevated stress and compromised well-being compared to other parents (e.g., Abbeduto et al., 2004; Smith et al., 2009). Although parents of individuals with an ASD have lower mean-levels of well-being compared to other parents, in cross-sectional studies improvements with age in emotional well-being have also been shown in parents of individuals with other types of developmental disabilities (e.g. Ha et al., 2008). Thus, it is likely that our findings of resilience or positive adjustment to parenting challenges overtime, would also be seen in midlife and aging mothers of grown children with developmental disabilities other than ASD.

In addition to understanding average patterns of change in emotional well-being, to fully understand change in emotional well-being over time one must also take into account changes in salient contexts that impact how one feels (Charles & Piazza, 2009). To this end, the second goal of the study was to identify child context (autism symptoms, behavior problems, residential status) and maternal context (social support network size, stressful family events) variables that were associated with emotional well-being trajectories. When child and maternal context variables were included in the models, the average pattern of change in anxiety over the 10-year period remained one of decline, but counter to our hypothesis depressive symptoms actually increased over time. Furthermore, maternal age differences at the beginning of the study that showed that older mothers were less anxious and reported fewer depressive symptoms than younger mothers were no longer significant.

According to the Strengths and Vulnerability Integration theory (Charles & Piazza, 2009), improved emotional well-being associated with age-related maturation of emotion regulation processes may be muted under chronic stress conditions, including stress associated with chronic caregiving. We found evidence for this in the current study. On occasions when more behavior problems were reported anxiety and depressive symptoms were higher. The association between behavior problems and depressive symptoms was stronger for younger compared to older mothers. Behavior problems are positively related to caregiving strains (e.g., not having enough time for the self) in mothers of adolescents and adults with an ASD (Orsmond, Seltzer, Greenberg, & Krauss, 2006) and to maternal depressive symptoms in mothers of individuals with an intellectual disability (Eisenhower & Blacher, 2006). Thus, caregiving strains associated with elevated behavior problems may offset improvements with age in emotional well-being for midlife and aging mothers providing care for grown children with an ASD. It is interesting to note that autism symptoms did not covary with maternal anxiety or with depressive symptoms over and above the effect of behavior problems. Past research on child-related factors associated with elevated psychological distress among parents of children with an ASD consistently shows that behavior problems, much more so than autism symptoms, are significant sources of stress (Hastings et al. 2005; Lounds et al. 2007). Behavior problems are also significant source of stress for mothers of grown children with developmental disabilities other than ASD (e.g., down syndrome; Esbensen, Seltzer, & Krauss, 2008) and thus shifts in behavior problems are expected to similarly influence well-being trajectories of mothers of grown children with other types of developmental disabilities.

When a grown child with a developmental disability moves out of the family home, caregiving strains are reduced and thus improvements in maternal emotional well-being would be expected (Krauss, Seltzer, & Jacobson, 2005; Seltzer, Greenberg, Krauss, & Hong, 1997). In the current study, on occasions after which the adolescent or adult with an ASD moved out of the family home maternal anxiety was indeed lower. However, change in child residential status was not associated with depressive symptoms. This pattern of reduced anxiety, but stable negative affect, following the child moving out of the family home has also been reported in the general population, and may be related to stressful parenting more broadly. In the general population, Dennerstein, Dudley, and Guthrie (2002) found that grown children moving out of the family home was associated with improvements in mood, but only for mothers who at an earlier time point were not worried about their child leaving home; negative affect was stable for mothers who previously had concerns about their child's transition to adult independence. Thus, although mothers' anxiety about the child's day-to-day activities and future care arrangements may subside when a grown child moves out of the family home, there may be a longlasting effect of stressful parenting (regardless of the source of this stress- ASD or other child problem) on negative affect. Stable maternal depressive symptoms, despite changes in child residential status, may be true for mothers experiencing a variety of types of chronic parenting stress.

Because the linked lives of parents and their adult children are embedded within the general family context (Uhlenberg & Mueller, 2003) in the current study we also examined associations of maternal context variables that might impact emotional well-being and potentially affect a mother's ability to care for a grown child with an ASD across midlife and old age. Mothers reported more anxiety on occasions when social support networks were smaller in size and when they experienced more stressful family life events. As with change in child residential status, the association between a reduction in the size of one's social support network and elevated anxiety may reflect worry about future care for the son/daughter with an ASD as options within the social network for alternative care diminish. Experiencing fewer stressful life events with the general family context likely has a more global effect on anxiety. Social support network size did not covary with depressive symptoms. Experiencing more stressful life events was related to more depressive symptoms only for younger mothers, suggesting that older mothers may be better able to cope with general life stressors (Charles & Piazza, 2009).

Although maternal context variables covaried with emotional well-being trajectories over time, the associations among these variables are likely reciprocal and cumulative in nature. That is, social support and experiencing fewer life stressors likely foster well-being and well-being in turn likely begets the maintenance of social support and successful coping (Charles & Carstensen, 2009). Between-persons differences in these variables were consistently related to initial levels of depressive symptoms and anxiety. Mothers with larger networks on average and who experienced fewer stressful family events on average across the study period were better off at the outset of the study.

The relative lack of moderation of maternal age on the within-person associations of child and maternal context variables with emotional well-being trajectories suggests that therapeutic supports, respite care, and community living options for adolescents and adults with developmental and intellectual disabilities would benefit mothers and their families across the adult lifespan. Furthermore, fostering informal social support networks and adaptive coping strategies early on in the caregiving trajectory may be effective means of promoting and maintaining maternal emotional well-being. But such benefit may not be limited to mothers of grown children with an ASD. Our findings on social support and adaptive coping are likely to be true of mid-life and aging parents more broadly, and thus parents of both normally developing children and children with other types of developmental disabilities could likewise be expected to benefit from enhancement of social support and adaptive coping. Social support and adaptive coping are consistently associated with well-being across the life course in a diverse array of population (Bridges, 2003; Cohen, 2004).

Several limitations should be taken into account when interpreting the findings of the current study. First, most of the mothers in the study were Caucasian. Thus, the sample is not representative of all families with adolescents and adults with an ASD, especially minority families. The patterns of association among the variables may be different for ethnic minority families or low SES families whose access to supports and exposure to stressors differs from non-minority or more affluent parents (Magana & Smith, 2006). Second, all variables were ascertained through maternal self-reports at each wave of measurement. Thus, associations among the variables may be inflated due to common method variance and the direction of causation cannot be determined due to the endogeneity of the variables. Additionally, we did not include a comparison group of mothers of non-disabled children to which patterns of change and absolute levels of well-being could be compared. Finally, we cannot separate cohort from simple aging effects. Research has shown that younger generations report more depressive symptoms and anxiety compared to older generations (Kasen et al., 2003; Twenge, 2000). Thus, age-group differences may reflect cohort

differences rather than differences associated with aging. Future research should also consider additional context variables (e.g., quality of the social support networks rather than just the size) as well as moderators and mediators of the associations of child and maternal context variables with maternal emotional well-being. Delineating more specific mechanisms that promote particular aspects of well-being in mothers of adolescents and adults with an ASD will further guide programs and policies aimed at supporting these mothers and their families.

Despite these limitations the current study had several strengths. It was the first study to examine trajectories of emotional well-being in a sample of midlife and aging mothers of adolescents and adults with an ASD. It was comprehensive in several respects, including the collection of longitudinal data on multiple occasions of measurement from a large sample over a 10-year period and the measurement of two indicators of emotional well-being and multiple time-varying covariates from both child and maternal contextual domains. The results accord with those of cross-sectional studies (e.g., Abbeduto et al., 2004; Essex & Hong, 2005; Kersh et al., 2006), but move beyond the cross-sectional “snap shot” view to demonstrate how these mothers’ lives are linked to and travel together with the lives of their grown children in midlife and old age. We showed that although anxiety may decrease over time, depressive symptoms may not improve and may actually worsen for some mothers. Thus, interventions aimed at supporting midlife and aging mothers providing care to a grown child with an ASD, or other developmental or intellectual disabilities, may be optimized if anxious and depressive affect are addressed separately, taking into account the specific contexts associated with each aspect of emotional well-being.

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Table 1
Means and Standard Deviations for Outcome Variables and Time-Varying Child and Maternal Context Covariates by Wave of Measurement

Variables	Time 1		Time 2		Time 3		Time 4		Time 5	
	Mean	SD								
Outcome										
Depressive Symptoms	12.52	9.97	12.13	9.50	12.39	9.97	11.94	9.79	13.06	11.08
Anxiety	11.48	6.87	9.89	6.52	9.93	6.73	8.95	6.44	9.70	6.72
Within-Person Predictor										
Child Autism Symptoms	25.52	7.63	25.09	7.97	24.53	7.97	23.93	8.85	24.41	8.83
Child Behavior Problems	115.37	11.16	112.78	10.00	112.80	10.25	111.15	10.13	110.54	9.73
Child Lives Away from Home ^a	.35	.48	.38	.49	.40	.49	.46	.50	.56	.50
Social Support Network Size	7.19	2.42	7.59	2.39	7.46	2.83	7.61	2.69	5.29	2.69
Stressful Family Events	2.12	1.84	2.32	2.15	2.23	1.95	1.96	1.80	2.47	2.14
Total N ^b	343–379		238–334		227–307		193–274		168–219	

^a child lives away from home = 1; co-residing = 0.

^b For outcome variables.

Table 2

Multilevel Linear Growth Models of Rates of Change in Maternal Emotional Well-Being Outcome Variables and Between-Persons Effects of Maternal Age on Initial Status and Rates of Change

Variables	Depressive Symptoms (<i>N</i> = 374)		Anxiety (<i>N</i> = 375)	
	Coefficient	SE	Coefficient	SE
Initial Status Intercept Time 1 (Random)	12.287*	.45	10.693*	.30
Maternal Age	-.103*	.04	-.132*	.03
Linear Rate of Change Time Slope (Random)	.046	.06	-.172*	.04
Maternal Age	-.002	.01	.003	.00
Variance Components (<i>SD</i>)				
Intercept	58.741* (7.66)		23.683* (4.87)	
Linear Time Slope	.184* (.43)		.048* (.22)	
Level-1 Effect	34.462 (5.87)		19.452 (4.41)	

* $p < .05$.

Table 3

Multilevel Models of Within-Person Associations of Child Context, Maternal Context, and Maternal Age with Maternal Emotional Well-Being Trajectories

Variables	Depressive Symptoms (<i>N</i> = 366)		Anxiety (<i>N</i> = 366)	
	Coefficient	SE	Coefficient	SE
Initial Status Intercept at Time 1 (Random)	12.418*	.60	11.007*	.39
Maternal Age	-.038	.06	-.063	.04
Mean Autism Symptoms	.056	.05	.001	.04
Mean Behavior Problems	.109	.06	.117*	.04
Child always lives at home = 0	-.240	1.13	.513	.80
Mean Social Support Network Size	-.754*	.20	-.631*	.13
Mean Number of Stressful Family Events	1.343*	.30	.873*	.20
Linear Rate of Change Time Slope (Random)	.191*	.09	-.14*	.06
Maternal Age	-.004	.01	.004	.00
Mean Autism Symptoms	-.007	.01	-.005	.01
Mean Behavior Problems	.017	.01	.012	.01
Child always lives at home = 0	-.090	.13	-.017	.09
Mean Social Support Network Size	-.006	.03	.030	.02
Mean Number of Stressful Family Events	.033	.04	-.022	.03
Child Autism Symptoms Fixed Slope	-.002	.06	-.074	.04
Maternal Age	.000	.01	.001	.00
Child Behavior Problems Fixed Slope	.073*	.04	.074*	.02
Maternal Age	-.012*	.01	-.003	.00
Child Lives Away from Home Fixed Slope ^a	-.940	.99	-1.560*	.71
Maternal Age	.077	.06	.025	.04
Social Support Network Size Fixed Slope	-.093	.16	-.248*	.11
Maternal Age	.003	.02	.011	.01
Stressful Family Events Fixed Slope	.144	.13	.265*	.08
Maternal Age	-.025*	.01	-.011	.01
Variance Components (<i>SD</i>)				
Intercept	50.268* (7.08)		19.793* (4.45)	
Time Slope	.256* (.48)		.069 (.262)	
Level-1 Effect	32.784 (5.72)		18.692 (4.32)	

^a child lives away from home = 1; co-residing = 0.

* $p < .05$