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Daily Stress and Cortisol Patterns in Midlife and Older Parents of Children With Developmental Disabilities

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Abstract

Objectives: The current study aims to investigate the association between daily stressful experiences and daily diurnal cortisol in midlife and older parents of children with developmental disabilities (DD) and a matched sample of parents of children without DD.
Methods: Analyses were employed using data from the third wave of the National Study of Daily Experiences (NSDE 3) within the Midlife in the United States (MIDUS) study, a population-based sample. The study sample included 55 parents of children with DD and 591 comparison parents who provided diurnal cortisol data.
Results: Multilevel modeling showed that parents of children with DD exhibited a less pronounced cortisol awakening response (CAR) on days when the severity of daily stressors was higher than their average level across days, a pattern that was different than in the comparison group. This finding may suggest a blunted CAR, which aligns with previous research on parents of children with DD and other groups facing chronic stress.
Discussion: The current study describes a distinct pattern of cortisol response to stressful parenting, evident in midlife and older age, reflecting the lifelong impacts of parenting children with DD.

Keywords: Aging parents, Chronic stress, Daily diary data, Lifespan effects of stressful parenting, Midlife in the United States

Parents of children with developmental disabilities (DD) often have lifelong caregiving responsibilities to support their children who have significant limitations in self-care, mobility, communication, or independence (Masefield et al., 2020; Seltzer et al., 2011). Prior studies consistently showed that these parents, who were mostly in their midlife, experienced elevated stress levels and compromised health outcomes than parents whose children did not have DD (Padden & James, 2017; Sloan et al., 2020). Because disability-related symptoms and behavioral problems often continue throughout the child's life course, the daily challenges and health risks associated with parenting children with DD may persist well into the parents' old age (Barker et al., 2014). Emerging research has noted the concept of accelerated aging, a process in which the aging process is hastened due to exposure to chronic external stressors (Epel et al., 2004). Parents of individuals with DD may be particularly susceptible to this phenomenon, as they experience prolonged, intense caregiving demands that involve cumulative physiological and psychological strain, thereby potentially accelerating age-related health declines (Mailick et al.,

2017; Song et al., 2016). However, there has been relatively less research on these parents as they approach or reach older age, which motivated the current study.

Daily Stress Process Model

In studying daily stress and its effects, the daily stress process model (Almeida, 2005; Almeida et al., 2009a) has been a useful framework, and its key advantage is its capacity to assess cortisol secretion throughout the day and measure physiological stress effects (Almeida et al., 2009a; Stawski et al., 2013). Cortisol, a key stress hormone, is produced by the hypothalamic-pituitary-adrenal (HPA) axis (Karlamangla et al., 2019; Pruessner et al., 2003). Its secretion follows a diurnal rhythm, peaking within an hour after waking, decreasing during the day, and reaching its lowest point at night (Karlamangla et al., 2013; Kudielka & Kirschbaum, 2003). In response to a physical or psychological threat, cortisol levels surge to provide the body with energy, returning to normal when the threat subsides (Almeida et al., 2020a; McEwen, 2002). However, repeated, chronic, and intensive stressful

situations can lead to prolonged cortisol release and disrupted HPA axis function (Almeida et al., 2020b; Karlamangla et al., 2019; McEwen, 2002). Specific cortisol indices such as cortisol awakening response (CAR) and diurnal cortisol decline (daily decline) reflect the diurnal rhythm of cortisol and have been used to assess cortisol regularity.

The CAR refers to a sharp increase in cortisol secretion in the first 30–45 min after waking in the morning, which pertains to mobilizing/priming bodily energy to anticipate daily activities (Almeida et al., 2009b; Clow et al., 2010). The daily decline is the difference between the peak and nadir cortisol levels, and the fast decline can make room for cortisol surges in the presence of stresses of the day ahead (Clow et al., 2010). A robust morning peak and a rapid decline after peaking indicate a healthy HPA axis function (Karlamangla et al., 2019). Consistent evidence has been found about the association between chronic stress and the diminution of the diurnal dynamic range characterized by blunted CAR or flatter daily decline (Barker et al., 2012; Karlamangla et al., 2019; Sin et al., 2017).

Parenting Stress and Daily Cortisol

Behavior problems are the most powerful challenge for parents of children and adults with DD, with these difficulties often more strongly related to parental stress than functional limitations and health problems (Masefield et al., 2020). Studies examining the daily cortisol patterns of parents of children with high caregiving demands consistently show a blunted cortisol response, indicating chronic stress exposure (Padden & James, 2017; Seltzer et al., 2010; Wong et al., 2014). The confluence of findings across these diverse studies of a blunted diurnal cortisol pattern and low levels of cortisol among parents of children with DD suggests the need to extend research on these parents as they approach or reach older age, a less studied subset of the population.

Relying on the daily stress approach, the current study examines the physiological effects of parenting children and adults with DD. It is built upon the work of Seltzer et al. (2009), which examined cortisol diurnal patterns and other daily outcomes among a selected sample of primarily midlife parents of children with psychiatric or developmental disorders, using data from the second wave of NSDE. Our study specifically examines parents of children with DD. This focus on parenting children with DD is crucial because it encompasses distinct caregiving challenges and needs, particularly in areas such as functional skills, communication, and sociobehavioral development, which can lead to unique implications for parental expectations and responsibilities (Song et al., 2017). Building on this context, this study draws data from the third wave of NSDE. Our study participants primarily included midlife and young-old adults, with some extending into older age.

We tested the following hypotheses:

Hypothesis 1: Parents of children with DD will show a more blunted CAR and a flatter daily decline compared to their comparison parents.

Hypothesis 2: On stressor days or days with high stressor severity, parents will show a more blunted CAR and a flatter daily decline compared to stressor-free days or days with low stressor severity, and this association will be particularly pronounced in parents of children with DD.

Method

Data Source

The data for the study were obtained from the third wave of the National Study of Daily Experiences (NSDE), a daily diary project of the Midlife in the United States study (MIDUS; https://midus.wisc.edu/). During 2017–2019, 1,236 respondents completed brief telephone interviews, during which they were asked about the events they experienced throughout the previous 24 hrs over eight consecutive evenings: 75.5% of the respondents completed all eight interview days, 88.8% completed at least seven interview days, and 93.3% completed at least six interview days. In total, the data set is comprised of 9,301 days out of a possible 9,888 ($n = 1,236 * 8$ days), yielding a completion rate of 94.0%. Furthermore, on days two through five, NSDE 3 respondents were invited to provide four saliva samples per day that were later assayed for cortisol. Saliva was collected immediately upon waking, 30 min after waking, before lunch, and before bed.

Participants

Participants in the daily diary study were a subset of the participants in the overall MIDUS surveys. Starting with participant reports from the MIDUS 2 and 3 surveys, we first identified parents reporting that their children had DD. There were 153 respondents whose children have conditions of autism spectrum disorder, cerebral palsy, Down syndrome, intellectual/developmental disorder, learning disability, attention-deficit/hyperactivity disorder, or epilepsy/seizure disorder. Next, we selected a comparison parent group who (a) did not report any children with a developmental disability or long-term serious mental health problems in the MIDUS 2 and MIDUS 3 surveys, and (b) had not given personal care for one month or more to a family member or friend because of a physical or mental condition, illness, or disability in the past 12 months, which yielded a total of 2,157 comparison parents. Of these parents, 55 parents of children with DD and 591 comparison parents participated in the NSDE 3 survey and provided their saliva samples for up to four days, resulting in 2,560 usable daily data, which constituted the data analyzed for the present study. There was no difference between the two parent groups in providing saliva samples during the study period.

Measures

Daily stressors

Daily stressors were assessed through the Daily Inventory of Stressful Events (DISE; Almeida et al., 2002). The instrument contains seven questions for identifying whether stressful events occurred (*no* = 0, *yes* = 1) within the past 24 hrs in various life domains that include (a) having had an argument or disagreement with someone; (b) almost having had an argument or disagreement but having avoided it; (c) having had a stressful event happen at work or school; (d) having had a stressful event happen at home; (e) experiencing race, gender, or age discrimination; (f) having had something bad happen to a relative or close friend; and (g) having had anything else bad or stressful happen. We created a binary daily stressor variable summarizing across the seven categories that indicated whether (= 1) or not (= 0) any daily stressor had occurred on the day of the interview. To assess respondents' overall exposure to stressors, we created a person-level stressor exposure variable by calculating the proportion of study days that any stressors had occurred.

Daily stressor severity

Participants were asked to rate the subjective severity of each stressor (i.e., "How stressful was this for you?") they experienced, rated only on days when a stressor was experienced. Stressor severity was rated on a 4-point scale ranging from 0 (*not at all stressful*) to 3 (*very stressful*). On days with multiple stressors, the severity score was averaged.

Cortisol

Measures of salivary cortisol include CAR and daily decline from the peak. CAR was calculated for each respondent for each day by subtracting wake values from the 30-min postwaking values. Daily decline was calculated by subtracting the bedtime values from the 30-min postwaking values. We cleaned the cortisol samples following the guidance of Stawski et al. (2013).

Covariates

Based on the review of prior studies (e.g., Charles et al., 2020; Stawski et al., 2013), the models incorporated several covariates, including age, sex, race, education (1 = *no school/some grade school* to 12 = *PhD or other advanced professional degree*), coresidence with children, smoking status, medication use, self-rated health (1 = *poor* to 5 = *excellent*), employment status, number of children, and daily wakeup time.

Analytic Strategy

A multilevel modeling approach was used to analyze daily diary data and account for the nested data structure where an individual is considered a cluster (Level 2), and repeated measures across the eight days are considered variations within an individual (Level 1). This data structure enables the disaggregation of between-person and within-person effects (Curran & Bauer, 2011). The between-person association concerns cross-sectional differences between individuals. The within-person association examines the variation within an individual and the associated changes in outcomes while controlling for the effect of person-level attributes. We focused on examining within-person associations in the analysis. STATA software was used for the set of analyses. In preliminary analyses, we observed that respondents' exposure to stressors was not significantly related to the outcomes, and thus is not reported in the tables.

Results

Descriptive statistics of the sample characteristics are presented in Table 1. In the total sample of 646 parents, 55.3%

Table 1. Descriptive Characteristics of Parents of Children With and Without Developmental Disabilities

Variables	Total (*n* = 646)		Parents of children with developmental disabilities (*n* = 55)		Comparison group (*n* = 591)		Bivariate analysis
	N or mean (*SD*)	% or observed min./max.	*N* or mean (*SD*)	% or observed min./max.	*N* or mean (*SD*)	% or observed min./max.	
Gender							
Male	289	44.74%	19	34.55%	270	45.69%	−1.59
Female	357	55.26%	36	65.45%	321	54.31%	
Race							
White	553	85.60%	43	78.18%	510	86.29%	1.33
Black	53	8.20%	8	14.55%	45	7.61%	
Others	38	5.88%	4	7.27%	34	5.75%	
Age	62.28 (10.24)	43/89	58.29 (9.51)	43/83	62.65 (10.24)	43/89	−3.04**
Education	7.82 (2.40)	1/12	7.73 (2.50)	3/12	7.83 (2.39)	1/12	−0.30
Self-rated health	3.58 (0.98)	1/5	3.35 (1.04)	1/5	3.60 (0.97)	1/5	−1.87[†]
Smoker	44	6.81%	5	9.09%	39	6.60%	0.70
Medication use	198	30.65%	21	38.18%	177	29.95%	1.27
Coresided with children	257	39.78%	30	54.55%	227	38.41%	2.34*
Number of children	2.83 (1.68)	1/22	3.67 (3.29)	1/22	2.75 (1.42)	1/11	3.95***
Employment status	301	46.59%	32	58.18%	269	45.52%	1.92[†]
Any daily stressors[a]	2.91 (2.09)		3.42 (2.17)		2.87 (2.08)		1.85[†]
Stressor severity	1.75 (0.63)		1.87 (0.57)		1.73 (0.64)		1.45
Cortisol awakening response (CAR)	12.65 (15.00)		7.87 (12.32)		13.11 (15.16)		−2.37*
Daily decline (from peak)	1.35 (0.96)		1.19 (1.12)		1.37 (0.94)		−1.20

Notes: Education was coded as: 1 = no school/some grade school, 2 = junior high school, 3 = some high school, 4 = GED, 5 = graduated from high school, 6 = 1–2 years of college, 7 = 3 or more years of college, 8 = college graduation (2-year, vocational), 9 = college graduation (4–5 year), 10 = some graduate school, 11 = master's degree, 12 = PhD or other advanced professional degree. Self-rated health was coded as: 1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent.
[a]Number of days that any daily stressors had occurred.
The significance level was indicated as [†]$p < .10$. *$p < .05$. **$p < .01$. ***$p < .001$.

were mothers, 85.6% were non-Hispanic white, and 39.8% coresided with their children. On average, respondents were 62.3 years old (range = 43–89), reported 3 or more years of college ($M = 7.82$, $SD = 2.40$), and reported good health ($M = 3.58$, $SD = 0.98$). Parents of children with DD were significantly younger ($M = 58.29$, $SD = 9.51$) and rated their health less positively ($M = 3.35$, $SD = 1.04$) than their counterparts in the comparison group. On average, there was a flatter increase between waking to 30-min-postwaking (i.e., CAR) for parents of children with DD than their comparison group ($p < .05$). Figure 1 illustrates the mean levels of cortisol secretion between the two parent groups and suggests compression of the diurnal range of cortisol for parents of children with DD.

Multilevel modeling was used to examine the group difference in the within- and between-person associations between daily stress experience and cortisol expression. Table 2 shows the within- and between-person effects of daily stressor severity on CAR and daily decline. We found statistically significant within-person effects of daily stressor severity on CAR ($b = -11.47$, $p < .05$) for parents of children with disabilities. In other words, parents of children with DD showed less pronounced CAR than the comparison group on days when stressor severity was higher than the within-person average across days. We also found marginally significant within-person effects of daily stressor severity on daily decline ($b = -0.50$, $p = .06$) for parents of children with disabilities.

Discussion

The primary objective of this study is to explore the physiological patterns of parents of children with DD as they approach or enter older adulthood. Parenting children with

DD often requires a lifelong commitment to care and support that extends well into the parent's later years. Additionally, these parents may face additional challenges in managing the aging process of their children, particularly since individuals with DD may have an increased risk of age-related conditions, such as Alzheimer's disease, among individuals with DD (Dekker et al., 2021). Research indicates that the long-term parenting of individuals with DD can adversely affect the health and well-being of parents as they age (Namkung et al., 2018). However, the current literature on aging parents of individuals with DD remains limited, emphasizing the need for further investigation into the unique challenges these parents face as they navigate older adulthood.

As reflected in the bivariate analyses, we partially supported our first hypothesis that parents of children with DD would exhibit a significantly less steep CAR compared to their comparison parents. This is illustrated in Figure 1, which shows an overall pattern of compressed diurnal dynamic range characterized by a lower CAR and smaller peak-to-nadir difference, as observed in studies of the general population (Karlamangla et al., 2022).

Support was also found for the second hypothesis that for parents of children with DD, their diurnal cortisol reactions to daily stressor severity were more suppressed than the comparison group. Specifically, there were statistically significant within-person effects of stressor severity on CAR for parents of children with DD. Additionally, there were marginally significant within-person effects of stressor severity on daily decline for parents of children with DD. These findings suggest a blunted cortisol response to stress, indicating that cortisol levels may not increase sufficiently in response to stressors (Clow et al., 2010; Seltzer et al., 2009). This aligns with existing literature on parents of children with autism spectrum disorders (ASD) and other DD, which has shown that these parents tend to have lower cortisol levels and less pronounced morning rise and daily decline compared to their comparison parents (e.g., Padden & James, 2017; Seltzer et al., 2010; Wong et al., 2014). Our result is also consistent with Seltzer et al. (2009), who studied a sample of parents of adults with DD or severe mental illness. The authors also found that these parents showed significantly less pronounced daily decline.

Taking these consistent findings into account, we concluded that the diminution of cortisol response is apparent in both midlife and older age among parents of adult children with DD. Given the established evidence between cortisol dysregulation and adverse health outcomes, such as higher allostatic load, cognitive decline, and early mortality (Adam et al., 2017; Karlamangla et al., 2022), these findings suggest that such changes in cortisol secretion and response to stress may serve as a pathway through which parenting children with DD can affect parents' health.

The current study has limitations worth noting. The first is the overrepresentation of non-Hispanic whites in the study sample (83%). Additionally, the NSDE relies on respondents to collect saliva samples and report the times collected. However, about 25% of the respondents were provided with a "smart box" for storing their salivettes (Cayuga Design, Ithaca, NY). These boxes were equipped with a computer chip that recorded the time when respondents opened and closed them, serving as an additional compliance check. The correlations between self-reported times across different collection occasions were all above 0.9 (Almeida et al., 2009b).
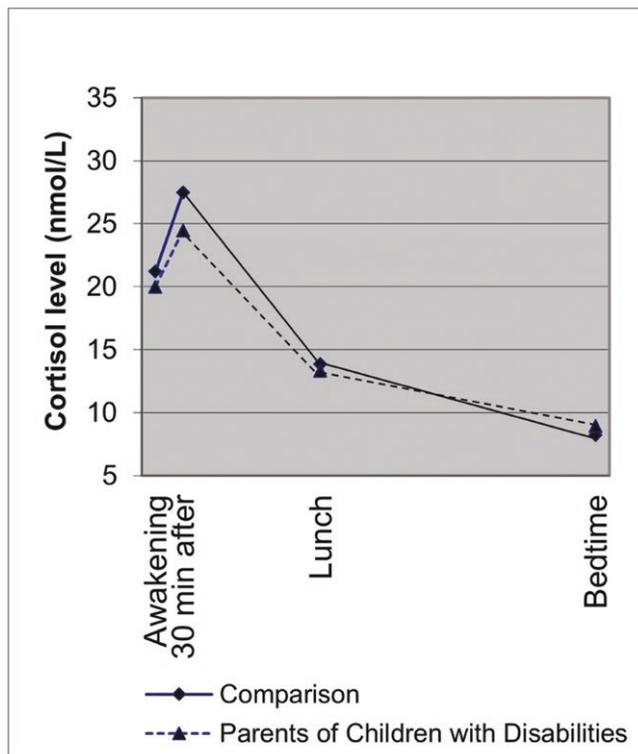

Figure 1. Diurnal rhythm of cortisol secretion: parents of children with developmental disabilities and their comparison

Table 2. Association Between Parenting Status and Stressor Severity on CAR and Daily Decline

Variable	CAR[a]		Daily decline	
Random effects				
Intercept	25.99 (5.82)***	25.83 (5.82)***	1.33 (0.28)***	1.32 (0.28)***
Wakeup time (BP)	–0.77 (0.69)	–0.78 (0.69)	0.02 (0.03)	0.03 (0.03)
Wakeup time (WP)	–0.65 (0.65)	–0.64 (0.65)	0.07 (0.03)*	0.07 (0.03)*
Stressor severity (BP)	–2.56 (1.39)†	–2.59 (1.39)†	–0.04 (0.07)	–0.04 (0.07)
Stressor severity (WP)	–0.13 (1.83)	1.17 (1.89)	0.05 (0.08)	0.10 (0.08)
Parenting status	–0.34 (2.87)	–0.46 (2.87)	–0.18 (0.15)	–0.15 (0.15)
Parenting status * stressor severity (WP)		**–11.47 (5.54)***		**–0.50 (0.26)**†
Male	–4.10 (1.79)*	–4.04 (1.79)*	–0.07 (0.09)	–0.08 (0.09)
Black[b]	–5.99 (3.81)	–6.11 (3.82)	–0.64 (0.19)**	–0.63 (0.19)**
Other races[b]	–3.91 (3.66)	–3.83 (3.66)	–0.26 (0.19)	–0.25 (0.19)
Age	0.08 (0.10)	0.07 (0.10)	0.00 (0.00)	0.00 (0.00)
Education	0.37 (0.39)	0.37 (0.39)	0.02 (0.02)	0.02 (0.02)
Self–rated health	0.42 (0.96)	0.39 (0.96)	0.02 (0.05)	0.02 (0.05)
Smoker	12.55 (3.47)***	12.66 (3.47)***	0.24 (0.16)	0.23 (0.16)
Medication use	–1.30 (2.17)	–1.22 (2.16)	–0.13 (0.10)	–0.13 (0.10)
Coresiding with children	1.02 (1.81)	0.95 (1.81)	0.03 (0.09)	0.03 (0.09)
Number of children	–1.09 (0.52)*	–1.01 (0.53)†	–0.00 (0.03)	–0.00 (0.03)
Employment status	1.93 (1.81)	1.91 (1.81)	–0.00 (0.09)	–0.00 (0.09)
Random effect				
Variance of intercept	91.50	89.79	0.32	0.33
Variance of daily stressor severity	123.93	97.18	0.27	0.25
Covariance between intercept and daily stressor severity	–14.99	–9.51	–0.17	–0.17
Residual variance	246.94	250.24	0.31	0.31

Notes: BP = between-person; CAR = cortisol awakening response; WP = Within-person. Only included WP stressor severity as random effects. Key significant results are in bold.
[a]Cortisol awakening response.
[b]Reference category is White.
†$p < .10.$ *$p < .05.$ **$p < .01.$ ***$p < .001.$

Lastly, the current study did not assess the specific stressors associated with parenting children with DD. Relatedly, it was not possible to determine whether coresiding children included those with DD due to the format of the questions.

Despite the limitations, the current study demonstrates evidence of the blunted cortisol responses to severely appraised stressors for parents of adult children with DD. One of our strengths was using a national sample and incorporating daily diary designs that included cortisol measurements, providing a better understanding of the daily stress experiences/processes for midlife and older parents of children with DD. Further research is needed to explore the stress experiences and outcomes of older parents of children with DD as they move further into older age, in order to better understand how to support these parents. Using objective indicators of biological aging, such as epigenetic aging scores or telomere length, could further illuminate the process of accelerated aging and offer more nuanced insights into how chronic parenting stress affects the aging processes of parents of children with DD. Additionally, further research should investigate the roles of cortisol dynamics and responses as potential mechanisms that connect parenting stress to long-term health and well-being outcomes. Such directions offer promising avenues for advancing aging-related studies, allowing for a deeper understanding of the intersection of parenting, disability, and aging.

Conflict of Interest

None.

Data Availability

This study was not preregistered. Data, analytic methods, and study materials are available upon request.

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