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Marsha Mailick Seltzer, David M. Almeida, Jan S. Greenberg, Jyoti Savla, Robert S. Stawski, Jinkuk Hong and Julie Lounds Taylor

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Psychosocial and Biological Markers of Daily Lives of Midlife Parents of Children with Disabilities*

MARSHA MAILICK SELTZER
University of Wisconsin–Madison

DAVID M. ALMEIDA
Pennsylvania State University

JAN S. GREENBERG
University of Wisconsin–Madison

JYOTI SAVLA
Virginia Polytechnic Institute and State University

ROBERT S. STAWSKI
Pennsylvania State University

JINKUK HONG
University of Wisconsin–Madison

JULIE LOUNDS TAYLOR
Vanderbilt University

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*Using daily telephone interviews, 82 midlife parents (mean age = 57.4) of children with disabilities (mean age = 29.9) were compared with a closely matched sample of unaffected parents (*N *= 82) to elucidate the daily experience of nonnormative parenting. In addition, salivary cortisol samples were obtained to examine whether parents of children with disabilities had dysregulated diurnal rhythms and the extent to which the amount of time spent with children was associated with divergent patterns of cortisol expression. We found that parents of children with disabilities had similar patterns of daily time use and similar likelihood of positive daily events as the comparison group, but they had elevated levels of stress, negative affect, and physical symptoms, all reported on a daily basis. In addition, their diurnal rhythm of cortisol expression differed significantly from the comparison group, a pattern that was strongest for parents of children with disabilities on days when they spent more time with their children.*

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When parents reach midlife, they look back on their accomplishments and life challenges (Han and Moen 1999). By this time, it is becoming clear whether their children have lived up to their potential and successfully negotiated the transition to adulthood. However, some children have limited success in life, experience social difficulties, or remain dependent on parents. Whereas the first scenario is the one that all parents hope for and experience most often, the latter occurs as a result of life disruptions experienced by children, including disability.

We have found that parenting a child with a disability has deleterious effects on parents' health and psychological well-being during midlife (Seltzer et al. 2001). Parents of children with disabilities face a range of stressors associated with their children's behavior problems, including stigma, cost of care, and having to negotiate a fragmented service system, but personal and social buffers can reduce the negative effects of stress (Cook et al. 1992; Glidden, Billings, and Jobe 2006). Parents of children with disabilities experience both acute intense stress and long-term chronic strain persisting over many decades. Most past research has focused on the long-term effects of nonnormative parenting, bringing a global perspective to the investigation of the stress process and assessing functioning over a period of years or decades (Floyd and Gallagher 1997; Glidden et al. 2006).

In contrast, in this study we focus on the acute stressors that such parents experience, bringing a daily life perspective to the study of caregiving stress. We assess the extent to which features of day-to-day experiences (such as time use, frequency and severity of stressors, mood, and physical symptoms) differ between midlife parents who have a child with a developmental or mental health problem and those whose children are healthy and nondisabled. We also examine divergent patterns in stress physiology by assessing differences between parents of children with disabilities and parents of typical children with respect to diurnal rhythms of salivary cortisol.

THEORY AND EVIDENCE

Biological Effects of Stress

Although parent caregivers have been shown to have elevated levels of mental and physical health problems, the biological mechanisms by which caregiving takes its toll remain relatively unexplored for this population. Previous research has focused largely on self-reported health and stressors (Seltzer et al. 2001). Results are commonly qualified by discussions of possible response biases and questions concerning the validity of self-reported health measures. Thus, questions remain regarding the direct relation between daily caregiving and physiological functioning. The study of biomarkers thus has the potential to add to our understanding of daily stress by corroborating and validating self-report measures. Biomarkers also give insight into the mechanisms by which stress takes a toll on health and well-being. To date, the only research that has used biomarkers to study parenting a child with a disability was conducted by Epel and colleagues (2004). They reported that life stress is associated with accelerated telomere shortening, reflecting cellular aging. Longer duration of caregiving was associated with greater telomere shortening, controlling for maternal age.

Other pathways between stress and physical and mental health problems have been demonstrated in past research, including disruption of the hypothalamic-pituitary-adrenocortical (HPA) axis. Cortisol is a biological marker of activity of the HPA axis, which plays a vital role in linking stress exposure to health problems (McEwen 1998). However, this pathway has not been examined in parents of children with disabilities.

The present study examines diurnal patterns in salivary cortisol in midlife parents (mean age = 57) of adolescent and adult children (mean age = 29) with disabilities, and how this pattern is affected by daily stressors. Cortisol typically peaks shortly after waking in the morning and then gradually declines throughout the rest of the day. Diurnal cortisol provides a window into individuals' chronobiology (Keenan, Licinio, and Veldhuis 2001). The early morning and evening levels of cortisol reflect daily engagement and disengagement of the brain with peripheral physiology, and hence the external environment. Failure to deactivate the HPA axis in the evening may indicate difficulty in disengaging from external demands, leading to inhibition of restoration and recovery processes (Sapolsky, Krey, and McEwen 1986).

Short-term increases in cortisol are thought to reflect a "normal" physiological response to stressor exposure (Sapolsky et al. 1986).

However, individual differences as well as variation in the nature of stressors may influence the magnitude of such responses, leading to exaggerated (hyper) or diminished (hypo) responsiveness. The impact of variation in cortisol stress reactivity is thought to cumulate over time, in response to repeated or chronic stressor exposure, leading to persistent high or low levels of circulating cortisol (which in turn can influence multiple aspects of physiological functioning). Hyper and hyporesponsive cortisol stress reactivity are symptomatic of poor physical health, generally interpreted as wear-and-tear on the HPA-axis (Kiecolt-Glaser et al. 1986; Segerstrom and Miller 2004). The measurement of daily cortisol rhythms may provide the best window into cortisol physiology, providing information about overall levels and fluctuations in cortisol levels across the day, and the association of these characteristics of cortisol with exposure to stressful experiences and individual/contextual factors. Studying cortisol expression in parents of children with disabilities offers an exciting opportunity to examine how daily life experiences influence daily physiology and associations with indicators of health and well-being.

Research has shown that acute stressors are associated with elevations in cortisol levels at waking and 30 minutes after waking as compared to individuals who do not experience stress. For example, caregivers of family members with dementia have a more pronounced elevation in daytime level of cortisol than the norm (Bauer et al. 2000; Cacioppo et al. 2000; De Vugt et al. 2005). However, a different pattern of cortisol dysregulation is evident in other examples of chronic stress. Hypoactivity of the HPA axis has been documented in chronic unemployment, bereavement, environmental disasters, chronic fatigue syndrome, and fibromyalgia (Baum, Schaeffer, and Lake 1985; Demitrack et al. 1991; Griep, Boersma, and de Kloet 1993; Jacobs et al. 1987; Ockenfels et al. 1995; Scott and Dinan 1998). Pruessner, Hellhammer, and Kirschbaum (1999) found that teachers scoring high on burnout showed lower overall cortisol secretion. Of particular relevance to the present study, Adam and Gunnar (2001) found that mothers who worked more hours and had more children at home had lower morning cortisol values and a less pronounced decline in cortisol levels across the day than mothers working fewer hours and having fewer children. One purpose of the present study is to examine the extent and specific pattern of cortisol dysregulation in parents of children with disabilities as compared with closely matched control parents.

Daily versus Global Indicators of Stress, Health, and Psychological Well-being

Global measures of physical and mental health problems in parents of children with disabilities provide valuable insight about the long-term toll taken by non-normative parenting. Examination of global outcomes indicates that such parents have divergent patterns of social participation, employment, health, and psychological functioning (Avison et al. 1993; Seltzer et al. 2001). However, little is known about their daily lives and whether the stress of enacting this caregiving role can be linked directly with daily measures of health and psychological well-being. There is an emerging literature on daily stressors in the general population, suggesting that sources of interpersonal stress, such as conflict with a spouse, work-family conflict, arguments with friends and family, and the like, take a toll on health and well-being (Almeida 2005; Serido, Almeida, and Wethington 2004).

We hypothesize that spending more time with a child with a disability will be experienced as stressful due to the greater demands for care and supervision that such children present, as well as their behavior problems and behavioral unpredictability (Abbeduto et al. 2004; Floyd and Gallagher 1997). Our design permits us to assess if parents of children with disabilities report greater psychological distress and display greater dysregulation of the diurnal rhythm of cortisol on days when they spend more time with their children. Thus, a second purpose of the present article is to determine the extent to which daily measures of time use are associated with daily measures of physical symptoms, psychological health, and dysregulation of the HPA axis. This analysis builds on a recent study by Adam and colleagues (2006) showing the association between daily fluctuations in affective states and daily fluctuations in diurnal cortisol rhythm. We extend these analyses by assessing if daily variation in the amount of time spent in a stressful role is associated with daily variation in both affective states and diurnal cortisol rhythm. Thus, the present article seeks to establish a more direct link between daily stressors and HPA axis dysregulation.

RESEARCH QUESTIONS

We address three research questions. First, we ask whether midlife parents of children with disabilities differ from their counterparts whose children have no disabilities with respect to the amount of time they spend daily with their children, on routine chores, at work, and on leisure activities; the type and frequency of stressors they experience on a daily basis; and their experience of positive daily events. In addition, we ask whether they differ in their levels of positive affect, negative affect, and physical health symptoms. We hypothesize that, due to the special needs of their son or daughter with the disability, these parents will spend more time with their children and less time on leisure activities and work, but will not differ from the comparison group with respect to time spent on chores. We further predict that parents of children with disabilities will experience more stressors and fewer positive events on a daily basis. We also hypothesize that parents of children with disabilities will have higher levels of negative affect, lower levels of positive affect, and more physical health symptoms than their counterparts whose children do not have disabilities.

Second, we focus on the diurnal rhythms of salivary cortisol by fitting individual growth curves based on four daily samples on four consecutive days for each participant, using multilevel modeling. We hypothesize that parents of children with disabilities will evidence a pattern of cortisol dysregulation, with a steeper morning rise but a less pronounced decline than parents in the comparison group, suggesting less of a deactivation of the HPA axis.

Third, we examine whether parents of children with disabilities differ from the comparison group in the association between the amount of time spent with children during the day and positive affect, negative affect, physical symptoms, and cortisol dysregulation. We hypothesize that, due to the stress of responding to the needs of the son or daughter with the disability, the more time parents of children with disabilities spend with their child on a given day, the lower the degree of positive affect, and the greater the degree of negative affect, physical symptoms, and cortisol dysregulation. We predict that these effects will be significantly less pronounced in the comparison group.

METHODS

The data for this analysis come from the National Study of Daily Experiences, one of the projects that comprise the National Survey of Midlife in the United States (MIDUS; Carol Ryff, principal investigator). MIDUS is a national probability sample of English-speaking, non-institutionalized adults age 25 to 74 in 1994 (MIDUS I; Brim, Ryff, and Kessler 2004). Follow-up data were collected from 2003 to 2005 (MIDUS II). At MIDUS II, all parents were asked if any of their children had a developmental or a mental health problem, and, if so, which child had the condition and the name of the diagnosis. Approximately one in ten (10.5%) responded affirmatively, of whom nearly half (46.3%) had a child with a developmental problem, about two-fifths (42.7%) had a child with a mental health problem, and the remaining 11 percent had a child with another type of neurological disability.

A subset of MIDUS II sample members was also included in the second wave of the National Study of Daily Experiences (David Almeida, principal investigator), which is the source of data for the present analyses. The second wave of the National Study of Daily Experiences, which is currently ongoing, consists of short telephone interviews at the end of each of eight consecutive days, with salivary cortisol samples obtained four times a day on days two through five. The National Study of Daily Experiences daily telephone interview includes questions about daily experiences in the past 24 hours concerning time use, number of stressors and positive events, daily measures of positive and negative affect, and daily measures of health symptoms and their severity (Almeida, Wethington, and Kessler 2002).

Sample

For this analysis, two groups were selected from the 806 MIDUS II members who had participated in the National Study of Daily Experiences second wave prior to the time of the present data analysis. The first group consisted of 82 parents of children of disabilities, and the second group consisted of a matched comparison group of equal size. Disabilities in children included attention deficit hyperactivity disorder (15.9%), bipolar disorder (12.2%), schizophrenia (9.8%), depression (7.3%), Down syndrome (6.1%), and others (48.7%). If there was more than one child with a disability in the family, we designated the oldest child with a disability as the target child for this investigation because the oldest child defines the duration of non-normative parenting.

The comparison group was drawn from MIDUS II respondents who have participated in the second wave of the National Study of Daily Experiences and have at least one living child, but no child with a disability or chronic health condition, and who never provided care to a family member. Of the 806 participants, 54 were excluded from this analysis because they were not parents, an additional 254 were excluded because they provided care to another family member (e.g., parent, spouse), and 82 had a child with a disability (the target sample). Thus, there were 416 potential matches for the 82 parents with a disabled child. We selected the 82 closest matches with respect to the following variables (in this order): parent gender, parent age, number of children in the household, child age, whether the target child lives with the parent, parent marital status, and parent educational attainment.

The 82 members of the comparison group were similar to the other potential comparison group cases with respect to virtually all background characteristics and outcome variables. The only significant difference was the number of children in the family (3.21 for the selected comparison group cases versus 2.73 for the nonselected cases). As parents of children with disabilities tend to have larger families, this difference reflects one of the matching criteria.

As shown in Table 1, the matching procedures were successful in producing highly comparable groups. They were similar in parental age, gender, race, marital status, employment status, years of education, income, and number of children. The target child averaged 29 years of age, with a wide age range (from 3 to 63). However, the vast majority of the children (87.7%) were adolescents or adults. There were more sons (60%) than daughters (40%). Whereas 41 percent of the children with disabilities lived with their parents, only 32% of the comparison group still lived in the parents' household. The analysis of the third research question focuses on the co-resident sub-samples only, in order to be confident of daily contact between parent and child.

Measures

The eight-day daily telephone interview included questions about daily experiences in the previous 24 hours concerning time use, daily stressors, positive events, mood, and physical symptoms.

Time use. Time spent with *children* was coded as the amount of time in minutes that the parent spent with children, including taking them places or doing things with them. Time spent on *routine chores* assessed the amount of time the parent spent on routine chores in the house as well as yard work. Time spent on work was coded as the amount of time spent on *activities related to business, paid work, or school,* which included time commuting and thinking about work. Finally, time on *leisure activities* included time spent relaxing, engaging in leisure activities, sleeping or taking a nap, or physical exercise. These variables were significantly skewed, and thus we log transformed them in the analysis.

Stressors. Daily stressors were assessed through the "daily inventory of stressful events" (Almeida et al. 2002). The inventory consists of questions asking whether certain

TABLE 1. Descriptive Statistics (mean with standard deviation in parentheses) of Parents of Children with Disabilities (N = 82) and Comparison-group Parents (N = 82)

Variables	Parents of children with disabilities	Comparison group
Parent's Characteristics		
Age	57.4 (13.0)	57.4 (13.1)
Gender (1 = female; 0 = male)	.59 (.50)	.59 (.50)
Race (1 = non-Hispanic white ; 0 = others)	.96 (.19)	.97 (.16)
Marital status (1 = married; 0 = not married)	.79 (.41)	.84 (.37)
Employment status (1 = employed; 0 = not employed)	.57 (.50)	.61 (.49)
Years of education	14.4 (2.65)	14.5 (2.35)
Total household income	$74,400 (49,800)	$78,300 (50,100)
Number of children	3.29 (1.91)	3.21 (1.26)
Child's Characteristics		
Age	29.3 (13.4)	29.9 (13.4)
Gender (1 = female; 0 = male)	.40 (.49)	.40 (.49)
Living with parents (1 = yes; 0 = no)	.41 (.50)	.32 (.47)

types of daily stressors had occurred in the past 24 hours: arguments, avoided arguments, work stressors, home stressors, and network stressors (defined as stressors that occurred in the life of close friends and family members), and a final question that captured other miscellaneous stressors (e.g., traffic). For each daily interview, individuals who responded affirmatively to each question received a code of 1 for the relevant stressor domain. Codes of 0 were assigned to domains where no stressors were experienced on that day. The stressors were summed to create *number of stressors* per day. Additionally, a dummy-coded variable was created to indicate if the participant experienced *any stressors* on the study day. Subjective *severity of stressors* was based on respondents' answers to questions about perceived severity of stressors and was coded from 1 (not at all stressful) to 4 (very stressful).

Positive events. In a similar manner to that for stressful events, parents reported positive events that occurred in the previous 24 hours using five questions: a particularly positive interaction with somebody, a positive interaction at work or volunteering, a positive event at home, reporting that a positive event occurred for a close friend or relative, or anything else that was particularly positive. The positive events were summed to create *number of positive events* per day. Additionally, a dummy-coded variable was created to reflect if the participant experienced *any positive events* on the study day.

Mood. Negative and positive emotions were measured each day using an adapted inventory of 20 emotions from the "nonspecific psychological distress and positive emotions scale" (Kessler et al. 2002). The negative affect scale (10 items) measured anxiety, hostility, and depression. The positive affect scale (10 items) measured enthusiasm, alertness, and vitality. Each day, respondents indicated how frequently they felt each emotion over the past 24 hours on a five-point scale from "none of the time" (coded 0) to "all of the time" (4). Averaging reliability analyses conducted on each diary day, the mean Cronbach's alpha for negative and positive affect were .94 and .93, respectively.

Physical symptoms. Symptoms were assessed each day using an adapted version of the Larsen and Kasimatis (1991) symptom checklist. We omitted items that overlapped with the psychological distress scale (e.g., "urge to cry"). This version is a checklist that combines the occurrence and severity of 19 physical symptoms including aches (headaches, backaches, and muscle soreness), gastrointestinal symptoms (poor appetite, nausea/upset stomach, constipation/diarrhea), and upper respiratory symptoms (sore throat, runny nose), as well as an open-ended item. Each day the respondents indicated if they experienced each symptom and the degree of severity on a 10-point scale from "very mild" (coded 1) to "very severe."

Salivary cortisol. Salivary cortisol samples were collected four times on each of four days in the second wave of the National Study of Daily Experiences. Respondents received a "home saliva collection kit" one week prior to their initial phone call. Saliva was obtained using the Sarstedt salivette collection devices. Sixteen numbered and color-coded salivettes were included in the collection kit, each containing a small absorbent wad, about 3/4 of an inch long, as well as a detailed instruction sheet. In addition to written instructions, telephone interviewers reviewed the collection procedures and answered any questions. Respondents provided 4 saliva samples per day on days two through five of the eight-day period to be assayed for cortisol: one sample upon awakening, one 30 minutes after getting out of bed, one before lunch, and one at bed time. Data on the exact time respondents provided each saliva sample were obtained from the nightly telephone interviews and on a paper-pencil log sent with the collection kit. In addition, approximately 25 percent of the respondents received a "smart box" to store their salivettes. These boxes contain a computer chip that secretly records the time respondents open and close the box. The correlations between self-reported times and the times obtained from the "smart box" range from .75 for the evening occasion to .95 for the morning.

Measures of salivary cortisol include three parameters of diurnal rhythm: morning rise, daily decline, and acceleration of daily decline. *Morning rise* is an indicator of how high an individual's cortisol rises, measured by the difference between cortisol at awakening and at 30 minutes after awakening. *Daily decline* refers to the slope from the typically highest point in the day, measured at 30 minutes after awakening, through the collection before bed. The *acceleration of daily decline* was calculated as the quadratic form of daily decline.

TABLE 2. Mean Comparisons between Parents of Children with Disabilities (N = 82) and Comparison-group Parents (N = 82) on Type and Severity of Stressors, Moods, and Symptoms

	Parents of children with disabilities		Comparison group		
Variables	M	SD	M	SD	t-test
Time Use					
Time spent with children (logged)	1.33	1.75	1.27	1.90	.23
Time spent on routine chore (logged)	3.13	1.45	2.82	1.44	1.37
Time spent on work (logged)	2.59	1.98	2.55	2.19	.13
Time spent on leisure activities (logged)	4.20	1.16	4.27	1.08	–.35
Stressors					
Arguments	.13	.15	.08	.12	2.36*
Avoided Arguments	.18	.17	.13	.13	2.21*
Number of Stressors	.74	.64	.52	.42	2.60**
Days with any Stressors	.50	.26	.40	.25	2.49**
Work Stressors	.07	.10	.08	.14	–.57
Home Stressors	.13	.14	.09	.11	2.30*
Network Stressors	.02	.07	.01	.03	1.28
Severity of Stressors	2.51	1.32	2.09	1.00	2.27*
Positive Events					
Number of Positive Events	1.09	.66	1.04	.63	.49
Days with any Positive Event	.69	.28	.69	.26	–.13
Affect					
Negative Affect	.20	.18	.14	.15	2.17*
Positive Affect	2.57	.73	2.78	.66	–1.88†
Symptoms					
Number of Symptoms	2.20	2.11	1.55	1.28	2.38*
Any Symptoms	.74	.30	.65	.35	1.69
Severity of Health Symptoms	7.53	9.09	5.59	5.42	1.66

Note: † $p = .06$; * $p < .05$; ** $p < .01$.

RESULTS

Group Differences in Daily Experiences and Well-being

Table 2 presents the data for the first research question which examined differences between parents of children with disabilities and comparison-group parents on daily experiences and well-being. Parents of children with disabilities and comparison parents did not differ in the time they spent on a daily basis with their children, on routine chores, at work, or in pursuit of leisure activities.

However, consistent with our hypothesis, parents of children with disabilities experienced a significantly greater number of stressors and more days on which they experienced at least one stressor. On average, parents of children with disabilities reported experiencing at least one stressor on 50 percent of the study days (versus 40% for the comparison group). They also reported significantly more arguments and tense moments with others (i.e., avoided arguments) than the comparison group. The elevation in their measures of daily stressors reflected significantly more stressors at home, but they did not differ from the comparison group in the stressors they experienced at work or with their social network. They rated their stressors as significantly more severe than the comparison group.

Counter to our prediction, parents of children with disabilities experienced a similar number of positive events as the comparison group and a similar number of days in which they experienced at least one positive event. Both sets of parents experienced at least one positive event on 69 percent of the study days. However, parents of children with disabilities had significantly higher levels of negative affect and a greater number of physical symptoms than the comparison group, and marginally lower levels of positive affect, as we predicted.

Daily Rhythms of Salivary Cortisol

Next, we used multilevel modeling to assess both inter and intraindividual variation of diurnal cortisol (Adam et al. 2006). These models estimated variation in the morning rise, daily decline, and the acceleration of daily decline. The inclusion of the acceleration parameter allowed us to assess whether deactivation of the HPA system occurs closer to the end of the day, as failure to deactivate HPA by the end of the day is a marker of dysregulation.

As shown in Table 3, both groups showed a significant morning rise in cortisol level, but counter to our prediction, parents of children with disabilities and comparison parents did not significantly differ in the slope of the morning rise (.245 vs. .199, $p > .05$). Although both groups declined in cortisol level during the day, parents of children with disabilities exhibited significantly less pronounced daily decline slopes, a pattern consistent with our prediction. The linear component of the daily decline parameter was substantially less pronounced for parents of children with disabilities (44% less pronounced than for the comparison group). Furthermore, there was a significant quadratic trend in the daily decline slopes, indicating that the linear decline in cortisol abates throughout the day, and this abatement is much stronger (by 100%) for parents of children with disabilities than for the comparison parents. This pattern indicates that parents of children with disabilities are significantly less likely to deactivate the HPA axis at the end of the day than their counterparts in the comparison group, suggesting inhibition of restoration and recovery processes.

The bottom portion of Table 3 shows the variance components of the diurnal rhythm of cortisol. At the between-person level, both groups of parents exhibited significant individual differences in each of the parameters of diurnal rhythm. Furthermore, the between-person covariance suggests that individuals with a steeper morning rise had a less pronounced daily decline in cortisol. At the within-person level, there was also evidence of significant day-to-day variation in diurnal patterns of cortisol among both groups of parents.

We also examined group differences in the diurnal rhythm of cortisol, controlling for coresidence status of the child. The significant differences remained, with the magnitude of the group difference remaining virtually unchanged for either the linear (estimate = –.03,

TABLE 3. Parameter Estimates for Parents of Children with Disabilities (N = 82) and Comparison-group Parents (N = 82) for Diurnal Cortisol Rhythm

	Parents of children with disabilities		Comparison-group parents		Difference		Interpretation
Fixed Effects	Estimate	(SE)	Estimate	(SE)	Estimate	(SE)	
Morning Rise	.245	(.063)**	.199	(.069)**	–.046	(.094)	
Daily Decline (L)	–.038	(.010)**	–.068	(.010)**	–.030	(.015)*	44% flatter for parents of children with disabilities
Daily Decline (Q)	.004	(.001)**	.002	(.001)**	–.002	(.001)*	100% greater for parents of children with disabilities
Average Bedtime Cortisol Level	1.314	(.067)**	1.241	(.067)**	–.073	(.095)	
Variance Components							
Between-Person (Level 3)							
Var (Intercept)	.261**		.239**				
Var(Morning Rise)	.067†		.109**				
Var (Daily Decline (L))	.002**		.001**				
Cov (Morning Rise.Daily Decline(L))	.016**		.009**				
Within-Person Across Day (Level 2)							
Var(Intercept)	.103**		.102**				
Var(Daily Decline (L))	.001**		.001**				
Cov(Intercept. Daily Decline (L))	.007**		.008**				
Within-Person Within-Day (Level 1)							
Residual	.246**		.218**				

Note: † $p = .07$; * $p < .05$; ** $p < .01$. L = Linear; Q = Quadratic, Var = Variance, Cov = Covariance

SE = .01, $p < .05$) or the quadratic (estimate = –.002, SE = .0008, $p < .05$) components.

Time with Children and Daily Well-being

The goal of the final set of analyses was to use the amount of time parents spend with their children on a given day to predict within-person variation in diurnal pattern of cortisol and other indicators of daily well-being. Specifically, we investigated if there were within-person associations between time spent with children and negative affect, physical symptoms, and the cortisol measures among parents whose child with the disability was living in the household. Although only 34 of the 82 children with disabilities were co-resident with the parent at the time of data collection, we focused on the co-resident subgroup in this final analysis to ensure a closer association between daily contact with children and well-being; it was only in these 34 cases that we could be confident that there was daily contact between parent and the child with the disability. Since our sample of co-resident children with disabilities was small, we used a multilevel modeling approach with a time-varying covariate (time spent with children), with standard error estimates based on 1,000 bootstrap samples to obtain bias-corrected confidence intervals by repeated reestimations of the parameter estimates. To do this, we used random samples with replacement from the original panel data.

As shown in Table 4, there was a significant interaction between parental status (having a child with a disability versus unaffected children) and time spent with co-resident children with respect to parental well-being outcomes. On days when they spent more time with their children, parents of children with disabilities reported higher levels of negative affect compared to days they spent less time with their children, whereas parents in the comparison group did not evidence a difference in negative affect based on the amount of time they spent with their children (see Figure 1). Figure 2 shows that parents of children with disabilities reported *fewer* physical symptoms on days when they spent more time with their children, whereas parents in the comparison group showed the opposite pattern. Finally, parents of children with disabilities had a (marginally) less pronounced daily decline of cortisol expression on days when they spent more time with their children as compared to days they

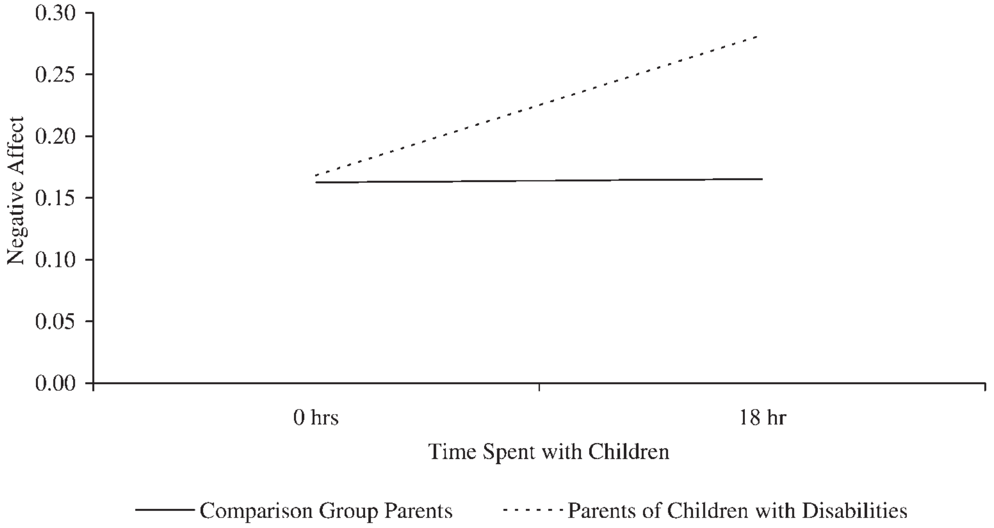
TABLE 4. Multilevel Model Parameter Estimates for Daily Variation in Time with Children Predicting Daily Well-being of Parents with Co-residing Children with (N = 34) and without (N = 26) Disabilities

	Negative Affect		Positive Affect		Physical Symptoms		Cortisol Morning Rise		Cortisol Daily Decline	
Fixed Effects	Est.	(BSE)	Est.	(BSE)	Est.	(BSE)	Est.	(BSE)	Est.	(BSE)
Intercept	.16	(.03)**	2.66	(.16)**	1.36	(.23)**	.79	(.31)**	–.16	(.03)**
Time Spent with Children (Log)	.01	(.01)	–.01	(.01)	.03	(.04)	–.05	(.06)	.00	(.01)
Parenting Status (disabilities vs control)	.01	(.04)	.06	(.19)	1.18	(.44)**	–.05	(.35)	–.03	(.04)
Time with Children × Parenting Status	.02	(.01)*	–.01	(.02)	–.10	(.05)*	–.04	(.08)	.01	(.01)†
Variance Components										
Between-Person (Level 2)	.02**		.44**		2.72**		.30**		.01	
Within-Person Across Day (Level 1)	.04**		.12**		1.44**		1.21**		.01**	

Note: † $p = .06$; * $p < .05$; ** $p < .01$. BSE = Bootstrapped Standard Error. Parenting status is coded as 0 = control and 1 = parents of children with disabilities.

Technical Note. Since Table 4 presents a multi-level model, the analysis is based on two sample sizes at each level, the number of subjects and the number of person-days (negative affect, positive affect, and physical symptoms were collected over an eight-day period and cortisol over a four-day period). Thus, for negative affect, positive affect, and physical symptoms, there were 34 parents of children with disabilities and 26 comparison-group parents, with the total number of days in the analysis being 453 (258 days in the disabilities sample and 195 days in the comparison sample). With respect to the morning rise in cortisol, because of missing data, there were 22 comparison-group parents and 28 parents of children with disabilities, representing a total of 177 days (97 parent days for parents of children with disabilities and 80 comparison-group parent days). The analysis predicting the morning decline was based on 28 parents of children with disabilities and 22 comparison-group cases, representing a total of 172 parent days (96 parent days for the disability group and 76 days in the comparison group).

FIGURE 1. **Daily Negative Affect in Parents as a Function of Time Spent with Co-residing Children with and without Disabilities**



spent less time, whereas again the opposite pattern was evident for the parents in the comparison group (see Figure 3). This finding suggests that parents of children with disabilities were less likely to deactivate the HPA axis during higher stress days than the comparison group.

DISCUSSION

A considerable amount of past research has provided global assessments of the toll of parenting a child with disabilities (Glidden et al. 2006; Seltzer et al. 2001). The present study extends this research. First, we focused on the daily level, providing data about these parents' use of time, the sources of stress and positive events that comprise their days, and the daily experience of positive affect, negative affect, and physical symptoms. The comparison between parents of children with disabilities and their counterparts whose children are unaffected presents a deeper understanding of the spe-

FIGURE 2. **Daily Reported Physical Symptoms in Parents as a Function of Time Spent with Co-residing Children with and without Disabilities**

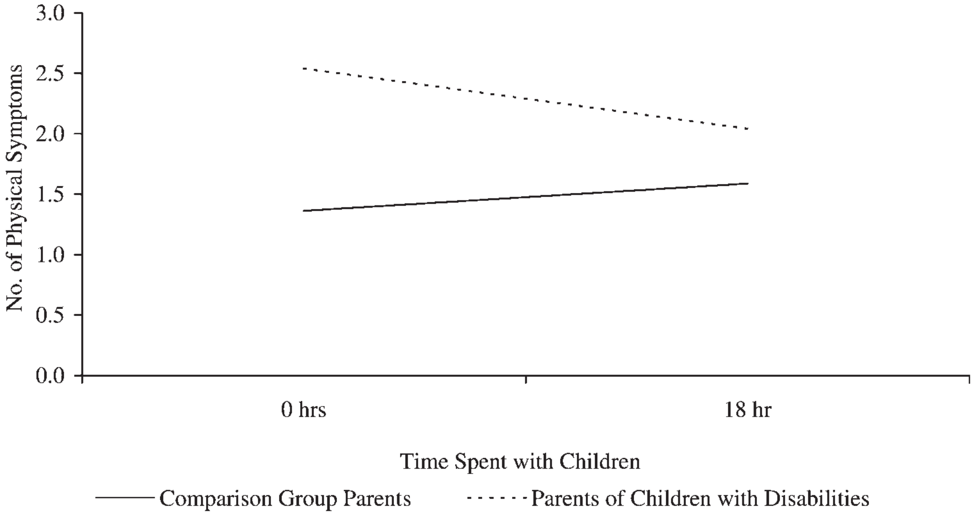
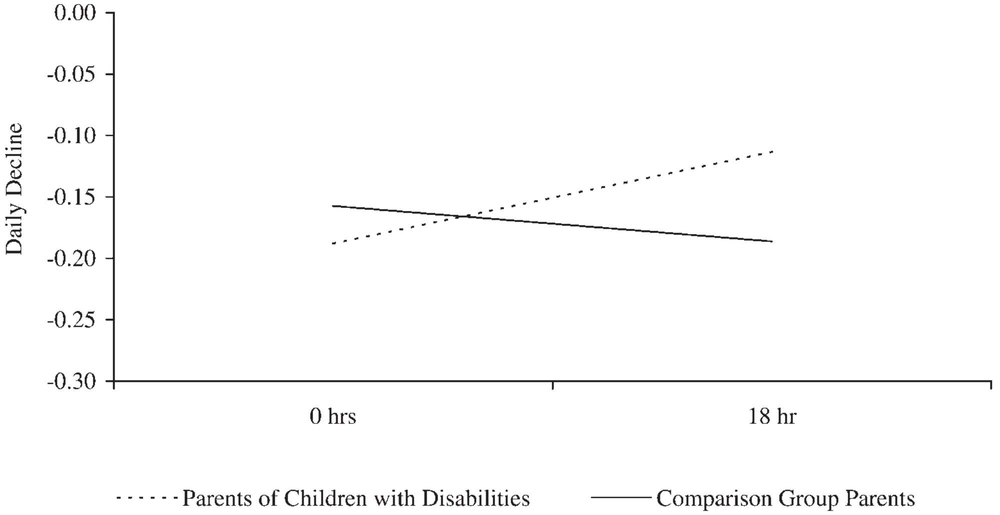


FIGURE 3. Daily Decline in Cortisol in Parents as a Function of Time Spent with Co-residing Children with and without Disabilities



cific ways that parenting a child with a disability does and does not take a toll on daily life.

Counter to our expectations, this non-normative parenting role does not dysregulate parents' patterns of time use: We found that they spent the same amount of time, on average, as the comparison group with children, doing chores, working, and enjoying leisure activities. This finding supports prior research on the amount of time spent on a daily basis by parents with their young children with developmental delays (Konstantareas, Homatidis, and Plowright 1992), which did not differ from an unaffected comparison group. Combined with our findings regarding stress and negative affect, the comparability in time use suggests that it is the qualitative aspects of daily life, rather than the schedule, that differentiates the lives of parents of children with disabilities.

Parents of children with disabilities report having (and avoiding) more arguments and experiencing more frequent and severe stressors, especially at home, than the comparison group. Similarly, they report more negative and less positive affect on a daily basis, and they experience a greater number of physical health symptoms. Although the present study focuses on the daily lives of these parents, the patterns we observed during this eight-day window accumulate over decades. The average age of the children in this study was 29 years, and the average duration since the onset of the child's disability was 18.23 years. Thus, it is not surprising that daily stress translates in the long run into chronic strain.

We collected these data from an unselected sample of parents of children with disabilities who were drawn from a national probability sample. Nearly all previous studies of the impact of parenting a child with a disability were based on self-selected samples, and thus it is possible that they overestimated or underestimated the degree of stress experienced. Much in the same way that Thoits (2005) used a national community sample to include both identified and unidentified persons with a mental illness, the present sample was not based on self-selection from caregiving support groups, service utilization, or professional referral.

A limitation of this study is that the MIDUS participants have higher than average levels of socioeconomic status, and thus generalizations should be made cautiously. An additional limitation is that we were not able to analyze subgroups based on age of the child or type of disability (due to the small size of the sample) or severity of disability (the MIDUS study did not collect data on severity). Our previous research, which focused on global rather than daily processes, has shown that there are differences in the impact of non-normative parenting according to the type of disability of the child (Seltzer et al. 2001). This type of contrast should be pursued in future studies of daily stress. In addition, future studies should examine the specific aspects about the daily lives of these parents that contribute to poor outcomes, such as the perception that the child with the disability can control his or her own behavior, which has been shown to increase distress (Greenley 1986; Hooley and Campbell 2002).

Another limitation of our study is that we were unable to control for parental well-being separate from the child's disability. There is considerable evidence that first-degree relatives of persons with mental illness suffer from high rates of mental health problems of their own (Laurent et al. 2002; Wilens et al. 2007). Thus, we cannot rule out the possibility that some of these parents had poorer well-being prior to onset of their child's disability. However, in a recent study (Aschbrenner, Greenberg, and Seltzer forthcoming), we found that parents of adults with bipolar disorder had poorer well-being even after controlling for the parents' preexisting mental health problems.

One strength of this study is that we included biomarkers of stress as well as self-report measures, and the data show a converging pattern. We found that parents of children with disabilities experience significantly more stress and have dysregulated cortisol rhythms. Follow-up analysis showed that, among parents who live in the same household as the child with the disability, in contrast to the comparison group, more time spent with children is associated with more psychological distress and more dysregulated cortisol expression. Thus, the study provides strong new evidence that the stress reported by these parents leaves a biological signature.

The specific pattern of cortisol dysregulation was somewhat different than expected. Although we hypothesized that parents of children with disabilities would show a steeper morning rise than the comparison group, there was no group difference in this regard. A steeper morning rise is typical of the response to acute stress. Rather, we observed the expected differences in the daily decline parameter, with parents of children with disabilities showing a substantially less pronounced decline than the comparison group. This diurnal pattern is associated with chronic strain more than with acute stress (Adam and Gunnar 2001; Cacioppo et al. 2000), consistent with the chronic nature of these parents' caregiving responsibilities, extending over decades. Our focus on midlife parents made it possible to detect effects of chronic strain rather than acute stress which would be more likely in the early years of non-normative parenting (Ha et al. 2008).

Although we found that parenting a child with a disability was associated with a number of negative outcomes (e.g., elevated levels of stressors and negative affect, and dysregulated cortisol expression), there were other measures on which they were similar to the norm, including time spent with children, on chores, at work, and on leisure activities; stress at work and with friends and family; and the occurrence of positive events. Furthermore, on days when parents of children with disabilities spent more time with their children, even though they had elevated negative affect, they did not differ in their level of positive affect. These findings reveal the ways in which these families have normative daily lives as well as the ways in which their non-normative parenting role takes a toll on well-being.

A surprising finding was that on days when parents of children with disabilities spent more time with their children they reported *fewer* physical symptoms. Although this might be an anomalous finding, it also might suggest the reverse causal order, namely that parents spend less time with their children, and even make other arrangements for child care, on days when they are not feeling well. Such an explanation would cast these parents into the role of "psychological activists" (Thoits 1994) who head off problems as a strategy for stress reduction.

In conclusion, the present study provides a new understanding of the daily lives of midlife parents of children with disabilities, benchmarked by a normative comparison group, and it has implications for future research as well as for service delivery for parents and their children with disabilities. The findings suggest how daily stress accumulates over the months and years of parenting a child with a disability, leading to a pattern of dysregulation of cortisol that is more consistent with chronic than acute stress. The association between time spent by the parent with the child during the day and dysregulation of parental cortisol underscores the need for respite services and other sources of family support that may buffer the effects of daily stress. This study provides insight into one mechanism by which parenting a child with a disability takes a toll on parental health and psychological well-being, and it points the way for future research to determine the extent to which parenting children with different types of disabilities may lead to distinct profiles of daily stress processes.

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Marsha Mailick Seltzer is the director of the Waisman Center at the University of Wisconsin-Madison and professor in the School of Social Work. Her research examines the life course impacts of developmental disabilities on the family.

David Almeida is professor of human development and family studies at the Pennsylvania State University. His research examines the role of daily stressors in physical health and well-being.

Jan S. Greenberg is director and professor in the School of Social Work at the University of Wisconsin-Madison. His research examines the challenges faced by families of persons with severe and persistent mental illness.

Jyoti Savla is an assistant professor in the Department of Human Development and Family Studies and Center for Gerontology at the Virginia Polytechnic Institute and State University. Her research investigates everyday life stressors experienced by caregivers and older adults and their implications for health and well-being.

Robert S. Stawski is a research associate at the Pennsylvania State University Gerontology Center. His research examines links among stress, health, and cognition across the adult life-span.

Jinkuk Hong is associate researcher at the Waisman Center, University of Wisconsin-Madison. His research examines the effects of multiple roles and caregiving on the well-being of older adults.

Julie Lounds Taylor is assistant professor of pediatrics and special education at Vanderbilt University. Her research examines how individual and family characteristics interact to promote healthy development in the face of non-normative family situations.