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CHAPTER

11 The Lifelong Health Effects of Parenting a Child With Developmental or Mental Health Problems €

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Abstract

Parenting a child with developmental or mental health problems is a lifelong process with unique challenges and adjustments. Parents of children with these conditions often experience chronic stress and an elevated risk of mental and physical health problems and cognitive decline in later life, although profiles of resilience have been noted. This chapter reviews Midlife in the United States (MIDUS) studies that have examined the lifelong effects of parenting children with developmental or mental health problems. MIDUS research has found that midlife and older parents of children with these conditions have poorer physical and mental health profiles and poorer cognitive functioning in later life than counterparts whose children do not have such conditions, and that mental and physical health disparities increase as parents age. Possible mechanisms underlying these differences have been examined in studies utilizing the multidisciplinary data of MIDUS, which include a variety of psychosocial, cognitive, and biological assessments.

Keywords: parenting, developmental problems, mental health problems, parents, children, MIDUS, physical health, mental health, cognitive functioning

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Introduction

Approximately 56.7 million people, or 19% of the US population, had a disability in 2010 (Brault, 2012) that may require lifelong care and support. We refer to parents of individuals with disabilities as facing nonnormative parenting challenges because they need to provide care and support even after their children with disabilities have reached adulthood. Among parents who face nonnormative parenting challenges, we focus on parents caring for a child at any age, including adulthood in particular, with a developmental disability or serious mental health problem. There has been a dramatic growth in the number of parents caring for such adult children because of deinstitutionalization, increases in the life expectancy of persons with developmental disabilities, and a greater awareness of mental health problems across the life course and more positive attitudes toward seeking treatment (Mechanic & Olfson, 2016). Long-term exposure to chronic stress due to the child's disability places these parents at elevated risk of experiencing mental and physical health problems and cognitive decline, especially in older age due to the cumulative disadvantages linked to parenting children with disabilities; however, there is considerable heterogeneity in the capacity of these parents to successfully adapt to these lifelong challenges.

Background Literature on Nonnormative Parenting

Developmental disabilities and mental health problems are prevalent in the United States. A 2014 national report indicated that approximately 4.1% of adults age 18 and older had a serious mental health problem in the past year (Center for Behavioral Health Statistics and Quality, 2015); half of the cases had been diagnosed by age 14, and three quarters had been diagnosed by age 24 (Kessler, Chiu, Demler, & Walters, 2005). An analysis of nationally representative data collected by the Centers for Disease Control and Prevention from 1997 to 2008 found that over 14% of children age 3 to 17 had developmental disabilities, most of which persist throughout adulthood (Boyle et al., 2011). An analysis of data from MIDUS indicated that approximately 10% of respondents report having at least one son or daughter who had a developmental or serious mental health problem (Seltzer, Abbeduto, et al., 2009).

Parents of individuals with developmental or serious mental health problems are exposed to various challenges in multiple life domains and long-term chronic stress due to the child's conditions. They often provide ongoing support for their son or daughter throughout the life course until they no longer have the capacity to provide care. This support is important because the majority of individuals with disabilities are unmarried, and public services are fragmented and poorly funded (Bauer, Koepke, Sterzinger, & Spiessl, 2012; Seltzer, Floyd, Song, Greenberg, & Hong, 2011; Wolfe, Song, Mailick, & Greenberg, 2014). In addition, these parents must manage their children's behavior problems related to their disabilities, which is one of the most stressful challenges (Lecavalier, Leone, & Wilz, 2006), and bear emotional burdens such as the stigma and worry about the future care of their son or daughter (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). They also experience financial burdens, including both direct costs such as medical expenditures and

indirect costs such as reductions in the trajectory of parental employment and earnings due to the child's caregiving needs. This financial strain associated with caregiving is known to take a toll on the parents' well-being and health (Orsmond, Lin, & Seltzer, 2007; Parish, Seltzer, Greenberg, & Floyd, 2004; Seltzer et al., 2011). These parents also have a higher risk of divorce (Risdal & Singer, 2004) and negative spillover between family and work (Song, Mailick, & Greenberg, 2014).

As a result of cumulative stress, on average, parents of children with disabilities have an elevated risk of mental and physical health problems compared to parents of children without such conditions. These parents have poorer mental health outcomes (e.g., lower levels of happiness, self-esteem, and self-efficacy and increased depressive symptoms) and physical health outcomes (e.g., higher body mass index values, cardiovascular impairment, and musculoskeletal impairment and a greater number of physical symptoms) (Emerson, Hatton, Llewellyn, Blacker, & Graham., 2006; Olsson & Hwang, 2008; Seltzer et al., 2011; L. Smith, Seltzer, & Greenberg, 2012; Yamaki, Hsieh, & Heller, 2009). However, the severity of these physical and mental health disadvantages is dependent on contextual factors (e.g., the severity of the child's behavior problems, other stressful life events, and race/ethnicity) and psychological and social resources (e.g., coping strategies, social support) (Barker et al., 2011; Magana & Smith, 2006; Piazza, Floyd, Mailick, & Greenberg, 2014; Seltzer et al., 2004).

Although the existing research provides compelling evidence that parents of children with disabilities are at increased risk for adverse health outcomes, there are important limitations to this body of research. The studies have unknown generalizability because most studies recruited volunteer samples of mainly white families and focused most often on mothers. There is limited information about the impacts of nonnormative parenting on families from underrepresented minority groups or on fathers. In addition, researchers have yet to fully investigate possible biological pathways through which nonnormative parenting experiences impinge on parental health and well-being.

MIDUS for Research on Parenting Children With Developmental or Mental Health Problems

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The MIDUS study provides a unique opportunity to extend prior research because it is a nationally representative longitudinal data set that contains a broad range of psychosocial, cognitive, and biological assessments; these characteristics make MIDUS a rich data source to investigate the impacts of nonnormative parenting on mental and physical health, including possible biological pathways. In addition, the oversample of African Americans in MIDUS provides the opportunity to explore the effects of nonnormative parenting across different racial groups. MIDUS has identified fathers as well as mothers whose children have disabilities and thus provides an opportunity to examine how the associations between nonnormative parenting and health are moderated by race and gender. Further, the results of analyses using MIDUS data may be less vulnerable to selection bias because respondents were not selected based on having a child with a disability. Finally, the MIDUS data are more generalizable than most extant research as they are based on a nationally representative sample.

In MIDUS 2 and 3, the following screener question was asked of all parents about each child: "Does [child's name] have a developmental disability, such as autism, cerebral palsy, epilepsy or mental retardation, or has [he/she] ever had a long-term serious mental health problem?" Those who answered affirmatively were then asked: "What type of developmental disability or serious mental health problem does [child's name] have?" Inclusion of these questions positioned MIDUS researchers to make advances in the study of nonnormative parenting impacts.

Mental and Physical Health Outcomes

In a study that utilized MIDUS data, Ha, Hong, Seltzer, and Greenberg (2008) compared the health of parents whose children had developmental or mental health problems and a closely matched comparison group of parents who did not have children with such conditions. They found that parents of children with developmental or mental health problems experienced significantly higher levels of negative affect; marginally lower levels of overall psychological well-being (composite index of autonomy, environmental mastery, purpose in life, positive relations with others, personal growth, and self-acceptance); and significantly more physical symptoms (somatic symptoms such as pain and stiff joints) than their peers who did not have children with such conditions.

Interestingly, the health impacts of parenting children with disabilities differed by the parent's age: Younger parents of children with disabilities were more vulnerable to the detrimental effects of parenting children with disabilities than their older counterparts (they had higher levels of negative affect, lower levels of psychological well-being, and more somatic symptoms), suggesting a potentially increased adaptation to parenting stress among older parents compared to their younger counterparts.

In a separate study analyzing data from the MIDUS daily diary study, Seltzer, Almeida, et al. (2009) examined daily stress and mental and physical health symptoms among 82 parents of children with disabilities by contrasting them with 82 age- and gender-matched comparison parents whose children did not have disabilities. The findings revealed that, in addition to significantly elevated levels of daily stress (and, as described further in this chapter, abnormal profiles of the diurnal rhythm of cortisol), parents of children with developmental or mental health problems experienced higher levels of daily negative affect and a greater number of physical symptoms than comparison parents, especially on days when they spent more time with their children as compared to days they spent less time. Thus, the MIDUS daily diary data provide a unique opportunity to understand the daily experiences and associated health and well-being among parents of children with disabilities, in clear contrast to their age peers who did not face the life challenges of nonnormative parenting.

A study by Ha, Greenberg, and Seltzer (2011) utilized additional MIDUS data to examine the differences in mental and physical health between African American mothers and fathers of children with developmental or mental health problems and African American comparison parents whose children did not have disabilities, both drawn from the MIDUS Milwaukee, Wisconsin, sample. The findings indicated that African American parents of children with disabilities had a greater number of physical symptoms than comparison African American parents whose children did not have disabilities. In addition, among African American parents who had lower levels of positive interactions with family members, the adverse impacts of nonnormative parenting were more pronounced.

p. 146 A. M. Smith and Grzywacz (2014) expanded the sample of nonnormative parents beyond 4 developmental disabilities and serious mental health problems to those with special care needs, typically due to a chronic medical problem. Approximately 25% of the parents who participated in MIDUS 1 reported having at least one child with a chronic disease or disability or emotional problems within the past 12 months. A. M. Smith and Grzywacz (2014) found that parents whose children had special health care needs experienced greater increases in depressive symptoms and limitations in instrumental activities in daily living over time, consistent with previous studies showing adverse impacts of nonnormative parenting on parents' mental and physical health. However, a sense of control was a protective factor that buffered the detrimental impact of parenting children with disabilities; it was more protective for mothers than fathers.

In summary, the findings from the analyses of nationally representative MIDUS data, including mothers and fathers across a wide age range and including diverse racial groups, confirmed that parenting children with developmental or mental health problems has a detrimental effect on parents' health and well-being.

It is noteworthy that there are some inconsistent findings regarding the association between nonnormative parenting, parental age, and mental and physical health outcomes. Ha et al. (2008) found that older parents of children with disabilities were less adversely affected by the challenges of nonnormative parenting than younger parents with respect to outcome measures of affect, psychological well-being, and somatic symptoms, while A. M. Smith and Grzywacz (2014) found increases in depressive symptoms and a decline in instrumental activities of daily living over time among the parents of children with special health care needs. These differences may be due to differences in the sample selection criteria, the use of different outcome measures, or differences in the research design of the two studies (i.e., Ha et al.'s 2008 analysis was cross-sectional, whereas A. M. Smith and Grzywacz 2014 study followed the same people over time). Future longitudinal studies that track changes in the mental health of parents over multiple waves of the MIDUS would help clarify the pattern of the lifelong influence of nonnormative parenting on parents' mental health.

Cognition

Cognitive function is known to be affected by chronic stress and mental and physical health problems (Elderkin-Thompson, Moody, Knowlton, Hellemann, & Kumar, 2011; Karlamangla et al., 2014; Spiro & Brady, 2011). However, cognitive functioning of parents of children with disabilities has rarely been the focus of research. One exception is a study by Song, Mailick, Greenberg, Ryff, & Lachman (2016) comparing episodic memory and executive functioning in parents whose children had developmental disabilities to an age- and gender-matched comparison parents whose children did not have such conditions. The data analyzed were from the MIDUS cognitive battery, BTACT (Brief Test of Adult Cognition by Telephone; Lachman, Agrigoroael, Tun, & Weaver, 2014). BTACT is the first instrument to reliably and validly assess cognitive aging via a phone interview (Lachman et al., 2014). Consistent with previous studies (e.g., Hofer & Alwin, 2008), Song, Mailick, Greenberg, Ryff, & Lachman(2016) found that older parents had lower cognition scores than younger parents in general. Further, the findings indicated that age-related differences in episodic memory were more pronounced among mothers of children with disabilities who experienced higher levels of parenting stress. The findings suggest that providing lifelong care to a child with disabilities may place older mothers at risk for accelerated cognitive aging, especially when parenting stress is high.

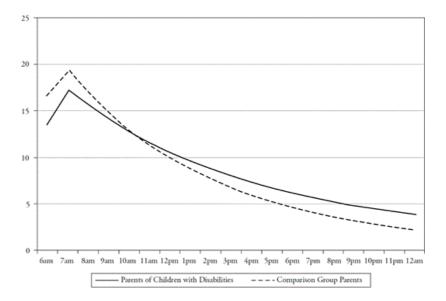
Biological Risk Factors

Health disparities between parents of children with disabilities and comparison parents may be due to elevated biological risk factors due to the stress of nonnormative parenting. In this section, we review how dysregulations of the hypothalamic-pituitary-adrenal (HPA) axis and elevated allostatic load are linked to the experience of nonnormative parenting.

HPA Axis Dysregulation

The HPA axis is an important system in physiological homeostasis. One manifestation of dysfunction is hypocortisolism, defined as insufficient cortisol production and a flattened daytime cortisol pattern that is often associated with exposure to chronic stressors (Edwards, Heyman, & Swidan, 2011). Cortisol usually peaks shortly after awakening in the morning and then declines through the rest of the day. The pattern of cortisol levels during the day, referred to as diurnal cortisol, provides useful information about bodily reactions to stress. In general, whereas acute stressors are associated with elevated cortisol (i.e., hyperactivity) (Sapolsky, Krey, & McEwen, 1986), chronic stressors have been reported as a cause of hypoactivity of the HPA axis, which has been linked to negative physical \$\frac{1}{2}\$ health outcomes (Edwards et al., 2011; Heim, Ehlert, & Hellhammer, 2000).

Figure 11.1



Diurnal rhythm of cortisol in parents of children with disabilities and comparison group parents.

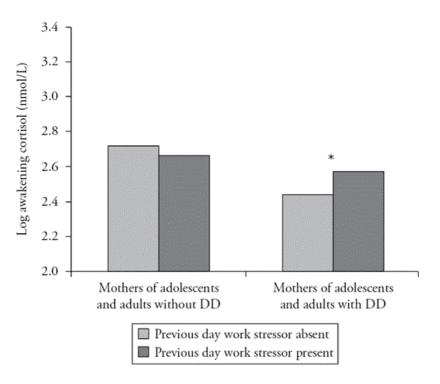
Reprinted from Seltzer, M. M., Abbeduto, L., Greenberg, J. S., Almeida, D. M., Hong, J., & Witt, W. (2009). Biomarkers in the study of families of children with developmental disabilities. *International Review of Research in Mental Retardation*, *37*, 213–249, with permission from Elsevier.

As part of the MIDUS daily diary study, saliva samples were collected over a consecutive 4-day period four times a day. These data allowed for the analysis of diurnal cortisol patterns of parents of children with disabilities as a window into physiological stress responses (Seltzer, Abbeduto, et al., 2009). The results showed that midlife and older parents of children with disabilities had a significantly flatter (less healthy) daily decline in cortisol level than their peers whose children did not have disabilities (Seltzer et al., 2009; Figure 11.1), and the pattern was particularly strong on days when these parents spent more time with their children. A related study focused on parents whose children had a serious mental illness (bipolar disorder, schizophrenia, and major depression) in the combined sample of the daily diary study in MIDUS 2 and Wisconsin Longitudinal Study and found a similar pattern (Barker, Greenberg, Seltzer, & Almeida, 2012); parents whose adult children had serious mental health problems experienced a flatter decline in diurnal cortisol levels relative to the comparison group parents.

A study by Wong, Mailick, Greenberg, Hong, and Coe (2014) also found that mothers of children with disabilities had lower levels of cortisol than comparison mothers on average, but that experiencing work stressors during the previous day significantly increased the level of awakening cortisol the next morning among the mothers of children with developmental disabilities. This reaction to previous day work stress was not found among the comparison group mothers. This finding indicates that mothers of children with developmental disabilities may be more vulnerable to cortisol dysregulation in the presence of additional stressors (Figure 11.2). The results are consistent with studies of post-traumatic stress disorder, where average cortisol levels are lower than normal, but cortisol increases more than average in the face of additional stressors (e.g., Bremner et al., 2003).

hypotension) (Edwards et al., 2011; Heim et al., 2000), hypocortisolism and HPA axis dysregulation may be one possible pathway by which nonnormative parenting stress leads to poorer physical and mental health.

Figure 11.2



Log awakening cortisol level by parent status and perceived day work stressor. DD = developmental disabilities. * p < .05.

Reprinted from Wong, J. D., Mailick, M. R., Greenberg, J. S., Hong, J., & Coe, C. L. (2014). Daily work stress and awakening cortisol in mothers of individuals with autism spectrum disorders or Fragile X syndrome. *Family Relations*, *63*(1), 135–147.

Allostatic Load

Allostatic load is an indicator of the cumulative dysregulation of multiple physiological systems. It is known to be sensitive to chronic exposure to life challenges and stresses, which eventually increases susceptibility to disease (Juster, McEwen, & Lupien, 2010). Using MIDUS Biomarker data, Song, Mailick, Ryff, Coe, Greenberg, & Hong (2014) created a composite index of allostatic load based on multiple biomarkers and examined whether parents of children with a developmental problems were at risk of elevated allostatic load, relative to control parents. The analysis compared 38 MIDUS parents of children with developmental problems and 38 age- and gender-matched comparison parents from MIDUS who did not have children with disabilities. The two groups did not differ in level of allostatic load. However, for mothers and fathers of children with developmental problems, those who had lower levels of positive affect had elevated allostatic load, whereas no such association was evident for parents in the comparison group. This pattern is consistent with previous studies showing health protective effects of positive psychological well-being (see Boehm & Kubzansky, 2012, for a review) and more salient health benefits of positive psychological resources among more than less disadvantaged individuals (e.g., Morozink, Friedman, Coe, & Ryff, 2010). The benefits of positive affect for parents of children with disabilities in the Song, Mailick, Ryff, Coe, Greenberg, & Hong (2014) study remained significant after controlling for the potential influence of negative affect, showing the protective effects of positive affect, independent of negative affect. The findings point to the importance of positive affect as a protective factor among parents facing this nonnormative challenge.

Given the significant positive association between allostatic load and the risk of mental and physical health problems and mortality (e.g., Goldman et al., 2006; Juster et al., 2010), it is likely that elevated allostatic load in the absence of positive affect increases the risk of parents of children with disabilities to mental and physical health problems. Testing these predictions with additional waves of MIDUS data is an important future objective.

In summary, studies using the MIDUS data have found evidence that parents of children with disabilities exhibit physiological dysfunction and increased cumulative physiological risks, and that \$\(\) such patterns are heightened by specific psychosocial factors. HPA axis dysregulation (measured by hypocortisolism) was found to be particularly evident on days when parents of children with disabilities spent more time with their children. Higher allostatic load was manifested particularly by parents of children with disabilities who had low levels of positive affect. These are important but nuanced patterns that may be possible mechanisms leading to mental and physical health disadvantages associated with nonnormative parenting. Future MIDUS studies that take advantage of longitudinal data sets to examine the associations between nonnormative parenting, physiological dysregulation markers, and health outcomes may improve the understanding of the biological mechanisms that lead to the adverse health impacts of nonnormative parenting.

Parents of Children With Autism Spectrum Disorders and Fragile X Syndrome: Using MIDUS as a Normative Comparison Group

The MIDUS data have also been used to form normative comparison groups for other studies examining the long-term impact of caregiving on parents of children with specific diagnoses. For example, L. Smith et al. (2012) examined the daily health conditions of mothers whose adolescent or adult children had autism spectrum disorders (ASDs), mothers whose adolescent or adult children had fragile X syndrome (FXS), and a matched comparison group of MIDUS mothers whose children did not have any disabilities. An analysis of health symptoms during the previous 24 hours revealed that mothers of children with ASD or FXS had a significantly greater number of physical health problems than MIDUS comparison mothers who had only unaffected children; the former group reported more days with headaches, backaches, muscle soreness, fatigue, and hot flashes than comparison mothers.

In addition, MIDUS has been utilized as a comparison group in studies that examined possible physiological pathways between nonnormative parenting and physical health outcomes. Studies comparing mothers of adolescents or adults with ASD or FXS and a matched comparison group of MIDUS mothers whose children did not have disabilities showed that mothers of adolescents and adults with ASD or FXS had significantly lower levels of cortisol throughout the day than comparison mothers (Seltzer et al., 2010; Wong et al., 2014).

MIDUS also has been used as a comparison group in studying divorce among parents of children with disabilities. For example, Hartley et al. (2010) compared the risk of divorce between parents of children with ASD and a matched representative sample of MIDUS parents whose children did not have disabilities. The findings revealed that parents of children with ASD had higher rates of divorce than comparison parents. Further, this gap increased over time because the divorce rate among parents of children with ASD remained high throughout the life course, while the divorce rate among comparison parents decreased after their children moved beyond childhood (after about 8 years old) (Figure 11.3).

Overall, prior studies suggest that there are many unique advantages to using MIDUS to draw a normative comparison group. Because the survey is nationally representative and includes a wide age range of respondents as well as detailed demographic data, researchers can use stratified matching procedures to construct appropriate comparison groups. The rich multidisciplinary assessments, including daily

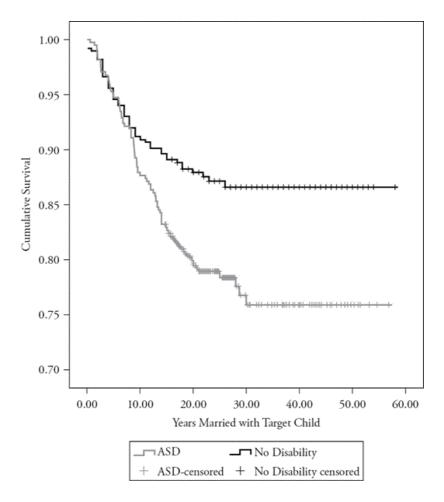
experience of stress and well-being, cognition, biological markers, and various mental and physical health measures, make it possible to investigate predictors and outcomes of significant interest.

Conclusion and Future Directions

Given the substantial prevalence of individuals with developmental or mental health problems in the United States, as well as increasing life expectancy and the high cost to society of these conditions, the impact of long-term parenting of children with disabilities on parents' mental and physical health is a significant public health issue that merits empirical analysis, including a focus on the pathways through which these parenting experiences are associated with parents' outcomes.

Empirical studies have documented the mental and physical health disadvantages among parents of children with disabilities: These parents experience higher levels of stress and greater physical and mental health problems than their peers whose children do not have disabilities. The possible pathways through which the experience of nonnormative parenting has adverse impacts on parents' mental and physical health outcomes have been explored by utilizing the unique data in MIDUS measuring a range of biological, cognitive, and psychosocial domains as well as in more specialized studies that are not population based. Overall, the findings converge. Additionally, these studies have \$\(\phi\) found biomarker profiles that indicated a greater risk for health problems among parents of children with disabilities than among their peers who do not have affected children. Parents who experienced nonnormative parenting had both HPA axis dysregulation (measured by hypocortisolism) and greater cumulative physiological dysregulations (measured by a higher level of allostatic load in the absence of positive affect). Future studies that directly examine the mediating effect of physiological dysregulation in the association between nonnormative parenting and mental and physical health outcomes with longitudinal data would help to improve the understanding of the long-term health impacts of nonnormative parenting and its possible biological mechanisms.

Figure 11.3



Survival plot for divorce in parents of children with an autism spectrum disorder (ASD) and parents of children without a disability.

Reprinted from Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449–457.

Research has shown that certain factors may lessen or amplify the negative effects of nonnormative parenting stress on mental and physical health. Psychosocial factors such as positive affect, a sense of control, coping strategies, social support, and the amount of time spent with children may buffer or amplify the adverse impacts of the stress of nonnormative parenting. It would be important to examine how biological, psychological, and social factors may interact to affect parents of children with disabilities at both the individual and family levels (e.g., genetic characteristics/vulnerability, personality, financial resources) to improve the understanding of the lifelong impacts of parenting children with disabilities.

Studies have reported that mothers and fathers of children with disabilities have different parenting experiences (e.g., Rowbotham, Carroll, & Cuskelly, 2011). However, the empirical evidence regarding the differences between mothers and fathers is limited, in part due to sampling limitations (e.g., the lack of data on both mothers and fathers in many studies). Extant studies present somewhat inconsistent findings: Some have found that mothers, relative to fathers, are more vulnerable to the adverse impacts of nonnormative parenting on health and \$\Geq\$ well-being as measured by body mass index, self-rated health, and cognition (Seltzer et al., 2011; Song, Mailick, Greenberg, Ryff, & Lachman, 2016), while others have found no gender differences in the health impacts of nonnormative parenting (Piazza et al., 2014). It is likely that gender differences depend on a variety of factors, such as the availability of parental psychological and social resources, physiological differences, and the larger family and community context. The MIDUS data

make it possible to significantly advance our understanding of differences and similarities in the experience of mothers versus fathers of children with disabilities due to the large sample who participated in the MIDUS main survey and the daily diary study, which have a very rich set of measures of biological, psychological, and social processes and outcomes.

A major unanswered question in studying parents of children with disabilities is whether their mental and physical health disadvantage is partly attributable to an unobserved genetic vulnerability. The availability in the MIDUS of data from siblings and twins of parents of children with disabilities makes the investigation of this question on unobserved genetic vulnerability possible. Analyses that compare mental and physical health outcomes between parents of children with disabilities and these parents' siblings or twins who do not have children with such conditions would provide new information about the relative proportions of mental and physical health disadvantage attributable to genetic factors versus environmental factors.

Future studies of longitudinal data from representative samples with a wide age range of parents (e.g., MIDUS 2 and MIDUS 3) could provide a systematic examination of the mental health impacts of nonnormative parenting at different life stages and could clarify the pattern of long-term changes in mental health outcomes among these parents. Different diagnostic groups have different characteristics and consequently possibly different impacts on parents' lives (e.g., a mental health problem is usually diagnosed during adolescence or early adulthood, while a developmental disability is typically diagnosed during the first few years of childhood (Seltzer et al., 2004). Thus, longitudinal examinations of health changes among parents of children with different types of disabilities will also improve our understanding of nonnormative parenting impacts. In addition, because the disparities in mental and physical health between parents of children with disabilities and their peers with unaffected children may increase with age, it would be helpful to explore not only morbidity but also mortality to improve the understanding of the long-term impacts of nonnormative parenting on parents' mental and physical health.

Although much has been written about the stigma that family members of persons with disabilities experience and its relationship to poor mental and physical health outcomes (Krieger, 2014; Mak & Cheung, 2008), few studies have been in a position to explore how stigma affects the well-being of parental caregivers of persons with disabilities. The MIDUS study provides a unique opportunity to explore this very question as respondents were asked about their experience with "discrimination" and "shame/embarrassment" which are major components of the concept of stigma. In a recent study that utilized data from MIDUS 2 and 3, Song, Mailick, and Greenberg (2018) examined the associations between parenting status (having children with disabilities or not), stigma, and parents' physical health outcomes. The findings revealed that stigma mediated the link between nonnormative parenting and poorer physical health among parents; parents of children with disabilities reported higher levels of stigma, and a higher level of stigma was in turn associated with poorer physical health. Given that stigma has been linked to increased distress and caregiver burden among parents of children with disabilities (Chou, Pu, Lee, Lin, & Kröger., 2009; Green, 2004, 2007; Mak & Kwok, 2010), the MIDUS biological data provide a rare opportunity to look at the physiological mechanism by which stigma affects health outcomes for parents of children with disabilities.

Another recent study that analyzed the MIDUS 2 and 3 data sets, which were collected before and after the Great Recession that began at the end of 2007, found that parents of children with mental illness experienced a greater level of negative recession impacts following the Great Recession than their peers who did not have children with disabilities, even when prerecession financial characteristics and demographics were controlled (Song, Mailick, & Greenberg, 2018). Increased financial vulnerability among parents of children with disabilities may be another possible mechanism underlying the adverse impact of nonnormative parenting on mental and physical health of parents. Future studies exploring various psychosocial mediators of the negative impacts of nonnormative parenting would provide additional p. 152 mechanistic understanding. The multidisciplinary aspects of MIDUS would make it an 🕒 invaluable data

source to address these questions. In addition, the inclusion of various types of samples (e.g., siblings, twins, African Americans) and multiple waves of nationally representative longitudinal data provide further possibilities for future studies.

In conclusion, future research should explore modifiable risk and protective factors, as well as possible interactions among these factors, to alleviate the negative effects of stressful parenting. In addition, our analyses of MIDUS data have set the stage to help guide the development of future interventions and programs to serve the most vulnerable subgroups of parents of children with disabilities. For example, we have found that parents of children with disabilities who experienced a greater number of stressors benefited more from maintaining a state of positive affect than their counterparts with fewer stressors. Thus, interventions targeting those parents of children with disabilities who are most vulnerable could have the greatest public health impact. As a nationally representative longitudinal data set with multidisciplinary assessments, MIDUS has proven to be a valued resource that can point the way to interventions for improving the mental and physical health and well-being of parents of children with disabilities.

References

Barker, E. T., Greenberg, J. S., Seltzer, M. M., & Almeida, D. M. (2012). Daily stress and cortisol patterns in parents of adult children with a serious mental illness. *Health Psychology*, *31*(1), 130–134.

Google Scholar WorldCat

Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*, 47(2), 551–561.

Google Scholar WorldCat

Bauer, R., Koepke, F., Sterzinger, L., & Spiessl, H. (2012). Burden, rewards, and coping—The ups and downs of caregivers of people with mental illness. *The Journal of Nervous and Mental Disease*, 200(11), 928–934.

Google Scholar WorldCat

Boehm, J. K., & Kubzansky, L. D. (2012). The heart's content: The association between positive psychological well-being and cardiovascular health. *Psychological Bulletin*, *138*(4), 655–691.

Google Scholar WorldCat

Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., . . . Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, 127(6), 1034–1042.

Google Scholar WorldCat

Brault, M. (2012, July). Americans with disabilities: 2010. Washington, DC: US Census Bureau.

Google Scholar Google Preview WorldCat COPAC

Bremner, J. D., Vythilingam, M., Vermetten, E., Adil, J., Khan, S., Nazeer, A., . . . Charney, D. S. (2003). Cortisol response to a cognitive stress challenge in posttraumatic stress disorder (PTSD) related to childhood abuse. *Psychoneuroendocrinology*, *28*, 733–750.

Google Scholar WorldCat

Center for Behavioral Health Statistics and Quality. (2015). Behavioral health trends in the United States: Results from the 2014 National Survey on Drug Use and Health (HHS Publication No. SMA 15-4927, NSDUH Series H-50). Retrieved from https://www.samhsa.gov/data/sites/default/files/NSDUH-FRR1-2014/NSDUH-FRR1-2014.htm
WorldCat

Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L. C., & Kröger, T. (2009). Effect of perceived stigmatization on the quality of life among ageing female family carers: A comparison of carers of adults with intellectual disability and carers of adults with mental illness. *Journal of Intellectual Disability Research*, 53(7), 654–664.

Google Scholar WorldCat

Edwards, L. D., Heyman, A. H., & Swidan, S. (2011). Hypocortisolism: An evidence-based review. *Integrative Medicine*, *10*(4), 30–37.

Google Scholar WorldCat

Elderkin-Thompson, V., Moody, T., Knowlton, B., Hellemann, G., & Kumar, A. (2011). Explicit and implicit memory in late-life depression. *American Journal of Geriatric Psychiatry*, 19(4), 364–373.

Google Scholar WorldCat

Emerson, E., Hatton, C., Llewellyn, G., Blacker, J., & Graham, H. (2006). Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 50, 862–873.

Google Scholar WorldCat

Goldman, N., Turra, C. M., Glei, D. A., Seplaski, C. L., Lin, Y. H., & Weinstein, M. (2006). Predicting mortality from clinical and

nonclinical biomarkers. Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 61(10), 1070-1074.

Google Scholar WorldCat

Green, S. E. (2004). The impact of stigma on maternal attitudes toward placement of children with disabilities in residential care facilities. *Social Science and Medicine*, 59(4), 799–812.

Google Scholar WorldCat

Green, S. E. (2007). We're tired, not sad: Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64. 150–163.

Google Scholar WorldCat

Ha, J.-H., Greenberg, J. S., & Seltzer, M. M. (2011). Parenting a child with a disability: The role of social support for African American parents. *Families in Society*, 92(4), 405–411.

Google Scholar WorldCat

Ha, J.-H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health problems or development disorders: Report of a national study. *Journal of Health & Social Behavior*, 49(3), 301–316.

Google Scholar WorldCat

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449–457.

Google Scholar WorldCat

Heim, C., Ehlert, U., & Hellhammer, D. H. (2000). The potential role of hypocortisolism in the pathophysiology of stress-related bodily disorders. *Psychoneuroendocrinology*, *25*, 1–35.

Google Scholar WorldCat

 $Hofer, S. \, M., \& \, Alwin, \, D. \, F. \, (2008). \, \textit{Handbook of cognitive aging: Interdisciplinary perspectives}. \, Los \, Angeles: \, Sage. \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, of \, Cognitive \, Alwin, \, D. \, F. \, (2008). \, Handbook \, Older \, Alwin, \, C. \, (2008). \, Handbook \, Alwin, \, C. \, (2008). \, Handbook \, Alwin, \, C. \, (2008). \, Handbook \, Alwin, \, C. \, (2008).$

Google Scholar Google Preview WorldCat COPAC

Juster, R. P., McEwen, B. S., & Lupien, S. J. (2010). Allostatic load biomarkers of chronic stress and impact on health and cognition. *Neuroscience and Biobehavioral Reviews*, *35*(1), 2–16.

Google Scholar WorldCat

Karlamangla, A. S., Miller-Martinez, D., Lachman, M. E., Tun, P. A., Koretz, B. K., & Seeman, T. E. (2014). Biological correlates of adult cognition: Midlife in the United States (MIDUS). *Neurobiology and Aging*, 35(2), 387–394.

Google Scholar WorldCat

Kessler, R. C., Chiu, W. T., Demler, O., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of 12-month *DSM-IV* disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry*, *62*(6), 593–602.

p. 153 Krieger, N. (2014). Discrimination and health inequalities. *International Journal of Health Services*, 44(4), 643–710. Google Scholar WorldCat

Lachman, M. E., Agrigoroael, S., Tun, P. A., & Weaver, S. L. (2014). Monitoring cognitive functioning: Psychometric properties of the Brief Test of Adult Cognition by Telephone. *Assessment*, *21*(4), 404–417.

Google Scholar WorldCat

Lecavalier, L., Leone, S., & Wilz, J. (2006). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, *50*, 172–183.

Google Scholar WorldCat

Magana, S., & Smith, M. J. (2006). Health outcomes of midlife and older Latina and black American mothers of children with

developmental disabilities. Mental Retardation, 44(3), 224-234.

Google Scholar WorldCat

Mak, W. W. S., & Cheung, R. Y. M. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, 21(6), 532–545.

Google Scholar WorldCat

Mak, W. W. S., & Kwok, Y. T. Y. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine*, 70, 2045–2051.

Google Scholar WorldCat

Mechanic, D., & Olfson, M. (2016). The relevance of the Affordable Care Act for improving mental health care. *The Annual Review of Clinical Psychology*, *12*, 515–542.

Google Scholar WorldCat

Miller, G. E., Chen, E., & Zhou, E. S. (2007). If it goes up, must it come down? Chronic stress and the hypothalamic-pituitary-adrenocortical axis in humans. *Psychological Bulletin*, 133(1), 25–45.

Google Scholar WorldCat

Morozink, J. A., Friedman, E. M., Coe, C. L., & Ryff, C. D. (2010). Socioeconomic and psychosocial predictors of interleukin-6 in the MIDUS national sample. *Health Psychology*, 29(6), 626–635.

Google Scholar WorldCat

Olsson, M. B., & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, *52*, 1102–1113.

Google Scholar WorldCat

Orsmond, G. I., Lin, L.-Y., & Seltzer, M. M. (2007). Mothers of adolescents and adults with autism: Parenting multiple children with disabilities. *Intellectual and Developmental Disabilities*, 45(4), 257–270.

Google Scholar WorldCat

Parish, S. L., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2004). Economic implications of caregiving at midlife: Comparing parents with and without children who have developmental disabilities. *Mental Retardation*, *42*(6), 413–426.

Google Scholar WorldCat

Piazza, V. E., Floyd, F. J., Mailick, M. R., & Greenberg, J. S. (2014). Coping and psychological health of aging parents of adult children with developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, 119(2), 186–198. Google Scholar WorldCat

Risdal, D., & Singer, G. H. S. (2004). Marital adjustment in parents of children with disabilities: A historical review and meta-analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95–103.

Google Scholar WorldCat

Rowbotham, M., Carroll, A., & Cuskelly, M. (2011). Mothers' and fathers' roles in caring for an adult child with an intellectual disability. *International Journal of Development and Education*, *58*, 223–240.

Google Scholar WorldCat

Sapolsky, R. M., Krey, L. C., & McEwen, B. S. (1986). The neuroendocrinology of stress and aging: The glucocorticoid cascade hypothesis. *Endocrine Review*, 7, 284–301.

Google Scholar WorldCat

Seltzer, M. M., Abbeduto, L., Greenberg, J. S., Almeida, D. M., Hong, J., & Witt, W. (2009). Biomarkers in the study of families of children with developmental disabilities. *International Review of Research in Mental Retardation*, 37, 213–249.

Google Scholar WorldCat

Seltzer, M. M., Almeida, D. M., Greenberg, J., Savla, J., Stawski, R. S., Hong, J., & Taylor, J. L. (2009). Psychosocial and biological markers of daily lives of midlife parents of children with disabilities. *Journal of Health and Social Behavior*, 50(1), 1–15.

Google Scholar WorldCat

Seltzer, M. M., Floyd, F. J., Song, J., Greenberg, J. S., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, 116(6), 479–499.

Google Scholar WorldCat

Seltzer, M. M., Greenberg, J. S., Floyd, F. J., & Hong, J. (2004). Accommodative coping and well-being of midlife parents of children with mental health problems or developmental disabilities. *American Journal of Orthopsychiatry*, 74(2), 187–195. Google Scholar WorldCat

Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with disability. *American Journal on Mental Retardation*, *106*(3), 265–286.

Google Scholar WorldCat

Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., & Stawski, R. S. (2010). Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, *40*(4), 457–469.

Google Scholar WorldCat

Smith, A. M., & Grzywacz, J. G. (2014). Health and well-being in midlife parents of children with special health needs. *Families*, *Systems*, & *Health*, 32(3), 303–312.

Google Scholar WorldCat

Smith, L., Seltzer, M. M., & Greenberg, J. S. (2012). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 42(9), 1836–1846.

Google Scholar WorldCat

Song, J., Mailick, M. R., & Greenberg, J. S. (2014). Work and health of parents of adult children with serious mental illness. *Family Relations*, 63, 122–134.

Google Scholar WorldCat

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). The impact of the Great Recession on midlife and older parents of individuals with a mental problem or a developmental disability. *The Gerontologist*, *58*(3), 448–455.

Google Scholar WorldCat

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. Manuscript submitted for publication.

Song, J., Mailick, M. R., Greenberg, J. S., Ryff, C. D., & Lachman, M. E. (2016). Cognitive aging in parents of children with disabilities. *Journal of Gerontology. Series B: Psychological Sciences & Social Sciences*, 71(5), 821–830.

Google Scholar WorldCat

Song, J., Mailick, M. R., Ryff, C. D., Coe, C. L., Greenberg, J. S., & Hong, J. (2014). Allostatic load in parents of children with developmental disorders: Moderating influence of positive affect. *Journal of Health Psychology*, 19(2), 262–272.

Google Scholar WorldCat

Spiro, A., & Brady, C. B. (2011). Integrating health into cognitive aging: Toward a preventive cognitive neuroscience of aging. *Journal of Gerontology*, Series *B*: Psychological Sciences and Social Sciences, *66B*(S1), i17–i25.

Google Scholar WorldCat

p. 154 Wolfe, B., Song, J., Mailick, M. M., & Greenberg, J. S. (2014). Ripple effects of developmental disabilities and mental illness on nondisabled adult siblings. *Journal of Social Science and Medicine*, 108, 1–9.

Google Scholar WorldCat

Wong, J. D., Mailick, M. R., Greenberg, J. S., Hong, J., & Coe, C. L. (2014). Daily work stress and awakening cortisol in mothers of individuals with autism spectrum disorders or fragile X syndrome. *Family Relations*, 63(1), 135–147.

Google Scholar WorldCat

Yamaki, K., Hsieh, K., & Heller, T. (2009). Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. *Intellectual and Developmental Disabilities*, 47, 425–435.

Google Scholar WorldCat