Chronic Parenting Stress in Mothers of Adolescents and Adults with Autism: Vulnerability and Resilience

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Introduction

Caring for a child with an autism spectrum disorder (ASD) is stressful. The challenging nature of the core symptoms of autism, the child's behavior problems, deficits in adaptive behavior, and comorbid physical and mental health problems all contribute to maternal stress (Bishop et al. 2007; Kring et al. 2008, 2010; Schieve et al. 2007; Tomanik et al. 2004). Because autism symptoms and associated problems persist across the child's life course, stressful parenting associated with caring for a child with ASD also persists. Despite the fact that parenting stress continues across the life course, relatively little research has focused on the experiences of parents of *adolescent and adult* children with autism (Ryff et al. 2002).

Research that has been conducted on parental well-being shows that mothers of grown children with an ASD continue to have lives characterized by elevated stress and compromised well-being compared with other parents, including parents of individuals with other developmental disabilities (Abbeduto et al. 2004). Indeed, by virtue of the lifelong nature of the parenting role, mothers of grown children with ASD experience a chronic parenting stress trajectory that contributes, on average, to poor physical and mental health outcomes. Individual chronic parenting stress trajectories, like other developmental trajectories, result from dynamic

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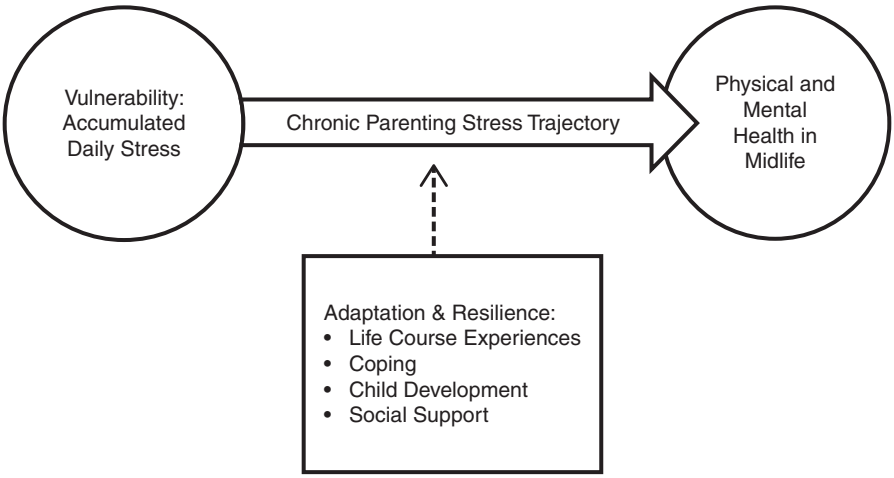

Fig. 1 Chronic parenting stress trajectory model. This figure depicts the factors that contribute to the formation of the chronic parenting stress trajectory and the factors that alter its impact on the well-being of mothers of adolescents and adults with ASD

person-context interactions (cf. Lerner 1998). Although the chronic parenting stress trajectory can be characterized, on average, as one of vulnerability, resilience – positive adjustment over time in the face of exceptional stress (cf. Masten 2001) – is also possible depending on person-context interactions over time. In this chapter, the relatively small but growing literature on the experiences of mothers of adolescents and adults with autism is reviewed with the goal of characterizing the chronic parenting stress trajectory, discussing it in relation to vulnerability for poor physical and mental health in midlife and identifying factors that promote resilience (see Fig. 1).

The Daily Lives of Mothers of Adolescents and Adults with Autism

To begin the discussion of the chronic parenting stress trajectory, research describing the daily lives of mothers of adolescents and adults with ASD will be presented. Accumulation of day-to-day stressful experiences over many years forms the chronic parenting stress trajectory. Data collected from 96 mothers co-residing with their adolescent or adult child with ASD demonstrates this (Smith et al. 2010). These mothers are part of an ongoing longitudinal project, the Adolescents and Adults with Autism Study, that has been following over 400 mothers of adolescents and adults with ASD for over a decade (Barker et al. 2010). The subsample of mothers completed 20-min telephone interviews for 8 consecutive days. Each evening, mothers reported on time use, daily stressors, and mood during the previous 24 h. Their responses were compared to those of mothers of typically

developing children drawn from a nationally representative sample who completed the same 8-day daily diary protocol. Mothers of adolescents and adults with ASD spent more hours caring for children (4.9 vs. 3.1 h/day), doing chores (2.35 vs. 1.63 h/day), and engaged less in leisure activity (2.03 vs. 2.54 h/day) compared with mothers of similarly aged children without disabilities. Across the 8-day period, mothers of adolescents and adults with ASD experienced a variety of stressors (arguments, avoided arguments, stress at work, stress at home, network stress) on a greater number of days, experienced more days with at least one stressor (5.2 vs. 3.4 days), and more days with multiple stressors (2.2 vs..88 days). Further, mothers of adolescents and adults with ASD were nearly 3 times as likely to experience a stressful event during the 8-day period compared to mothers of children without disabilities.

As a probable consequence of their busy and stressful lives, mothers of adolescents and adults with ASD were also more likely than mothers of similarly aged children without disabilities to experience work intrusions (1.8 vs..6 days), and they experienced fatigue on more days (4 vs. 2 days). In fact, 19 % of mothers of adolescents and adults with ASD reported experiencing fatigue on all 8 days compared with only 3 % of comparison mothers. Mothers of adolescents and adults with ASD also had lower levels of positive affect and higher levels of negative affect, on average, across days, compared with the mothers of typically developing children, and were more likely to give emotional support (4.2 vs. 2.8 days) and receive emotional support (2.7 vs. 1.4 days). In other daily diary studies of mothers of younger children and adolescents with ASD, daily child-related stress has been shown to be associated with same-day elevated negative affect (Ekas and Whitman 2011; Pottie et al. 2009; Pottie and Ingram 2008).

Together, results of daily diary studies show that mothers of children with ASD, including grown children, lead intense lives related to the direct care of their children. Over time, the high level of day-to-day caregiving demands that persists throughout childhood and into adulthood accumulates to form a chronic parenting stress trajectory.

Chronic Parenting Stress and Physical Health

Prolonged caregiving stress, like that experienced by mothers of adolescents and adults with autism, increases risk for health problems, and women caregivers are especially at risk for poor global health (Vitaliano et al. 2003). In a Canadian population-based cross-sectional study, parents of children and adolescents with neurodevelopmental and behavioral problems, including children with autism, had poorer self-rated health and reported more physical health symptoms than parents of typically developing children (Lach et al. 2009). A recent analysis of prospective data collected over a 49-year period from a cohort of over 1,000 high school graduates in the United States showed that individuals who became parents of children with an intellectual or developmental disability, including autism, had greater risk for cardiovascular disorder in their early 50s and greater risk for poor

health-related quality of life, musculoskeletal problems, and limitations in activity of daily living in their early old age (mid 60s), compared with parents of typically developing children (Seltzer et al. 2012). That is, the chronic parenting stress trajectory contributed to earlier development of cardiovascular disorder and greater risk for other physical diseases in old age. A recent analysis of daily health symptoms data showed that mothers of adolescents and adults with ASD experience more symptoms of health problems than comparison mothers (e.g., pain symptoms such as headache, backache, joint pain; gastrointestinal symptoms such as nausea, diarrhea, and constipation; and menstrual-related symptoms including hot flashes; Smith et al. 2011).

Life stress takes a toll on physical health via an individual's *physiological* functioning, the impact of which can be indexed by dysregulation in the hypothalamic-pituitary-adrenal (HPA) axis (McEwen 1998). Cortisol is the primary marker of HPA functioning. Individuals chronically exposed to stressors have been found to have reduced cortisol activity across the day and blunted cortisol response or transient decrease in cortisol secretion following a stressor (Gunnar and Vazquez 2001; Miller et al. 2007). This pattern of hypocortisolism is theorized to result from a history of prolonged exposure to stress and downregulation of the HPA system (Fries et al. 2005). Hypocortisolism has been found in parents of children with cancer (Miller et al. 2002), in maltreated children on high-conflict days at nursery school (Hart et al. 1995), in women with fibromyalgia (Wigenfeld et al. 2008), and in adults experiencing work overload (Dahlgren et al. 2004).

A series of recent studies has demonstrated that parents of adolescents and adults with developmental disabilities, including ASD, exhibit hypocortisolism in response to child-related stress and also in response to general life stress unrelated to caregiving. In the first study connecting child-related stress to HPA functioning, Seltzer et al. (Seltzer et al. 2009) reported that parents of individuals with disabilities had significantly flatter decline in cortisol levels across the day than comparison parents, particularly following days when parents spent more time with their child. In the second study using the same daily cortisol protocol, mothers co-residing with their adolescent or adult with ASD had reduced cortisol levels throughout the day relative to a comparison group of mothers drawn from a nationally representative sample (Seltzer et al. 2010). Hypocortisolism was more pronounced in a subset of mothers of adolescents and adults with ASD whose child had elevated behavior problems. Specifically, within-group analyses showed that on days following child behavior problems, mothers of adolescents and adults with a history of clinically significant behavior problems showed flatter morning rise in cortisol compared with mothers whose adolescent or adult's history of behavior problems was lower. A third study extended this paradigm to mothers of adolescents and adults with fragile X syndrome (FXS), the leading inherited cause of ASD (Hartley et al. 2011b). Again, a blunted cortisol response was found following days when child behavior problems were elevated.

In two additional studies, the same pattern of hypocortisolism was found in response to stress unrelated to child functioning. Wong et al. (2012) found that mothers of adolescents and adults with ASD who experienced more negative life

events over the previous year showed flatter increases in morning cortisol on days following a stressful experiences compared with mothers who had not experienced a negative life event in the previous year. Likewise, in a subset of mothers of adolescents and adults with FXS, hypocortisolism was associated with having experienced an above-average number of life events in the previous year (Seltzer et al. 2011).

Together these results demonstrate the importance of considering the effects of chronic parenting stress in interaction with current experiences, both child-related and other life stressors. Furthermore, they highlight the fact that there is variation from the average trajectory depending on both the history of child problems, current child-related problems, current life stressors, and their interaction at a particular point in time.

Chronic Parenting Stress and Mental Health

The chronic parenting stress trajectory also contributes to mental health problems in mothers of adolescents and adults with ASD. Two separate meta-analyses have shown that, compared with community samples, mothers of children with a developmental disability are at elevated risk for depressive symptoms and clinical depression. Specifically, reviewing the results of 18 studies, Singer (2006) found small to moderate effect sizes for elevated depressive symptoms in mothers of children with developmental disabilities compared with mothers of children without disabilities. Respectively, 29 % compared to 19 % met the clinical cutoff for depression. Rates were higher for mothers of younger compared to older children and for mothers of children with ASD compared with mothers of children with other developmental disabilities. Likewise, after reviewing 42 studies, Bailey et al. (2007) concluded that mothers of children with a developmental disability were at greater risk for experiencing both elevated depressive symptoms and clinical depression compared with mothers of typically developing children. Their analyses also showed that depressive symptoms were more pronounced in mothers whose child was diagnosed with ASD or whose child showed elevated behavior problems compared with mothers whose child had another developmental disability. Comparing mothers of adolescents and adults with ASD to similarly aged mothers of adolescents and adults with FXS or Down syndrome, mothers of children with ASD reported higher depressive symptoms which in turn were related to elevated autism symptoms and behavior problems (Abbeduto et al. 2004). Likewise, in a sample of mothers in midlife (ages 35–70 years) who had an adult child with an intellectual disability, Eisenhower and Blacher (2006) found that behavior problems were associated with both elevated depressive symptoms and poorer self-rated health.

Few studies of parents of children with ASD of any age have examined trajectories of depressive symptoms over time. Carter et al. (2009) showed that depressive symptoms were stable across a 2-year period in mothers of young children with ASD and that parenting efficacy predicted change in symptoms over time; decreases in parenting efficacy predicted increases in depressive symptoms.

In a large sample of mothers of adolescents and adults with ASD, Barker et al. (2010) showed that on average across a 10-year period, depressive symptoms were stable. However, as in the Carter et al. study, Barker et al. found significant interindividual variability in the intraindividual trajectories. Depressive symptoms increased for mothers who were the average age, whose child exhibited average levels of autism symptoms and behavior problems across the 10-year period, whose child remained at home during that time, and mothers who experienced average-sized social support networks and the average number of stressful life events over the course of the 10-year period. Furthermore, on occasions when mothers reported an increase in depressive symptoms, they also reported an increase in behavior problems. This association was stronger for younger compared with older mothers in the sample.

These longitudinal results correspond with cross-sectional results showing that across the chronic parenting, stress trajectory mothers of younger and older children with autism are at risk for depressive disorders. And, as with the result on hypocortisolism, they highlight the fact that there is variation from the average trajectory depending on parenting and other life experiences.

Adaptation to the Chronic Parenting Stress Trajectory

Although the chronic parenting stress trajectory and associated poor physical and mental health outcomes result from the accumulation of daily stress associated with caring for a child with ASD across his or her life course, it is also clear from this discussion that variation from the average trajectory is possible. That is, potential exists within individuals across the lifespan for different levels of functioning, depending, in part, on changes in important life contexts (cf. Lerner 1998).

Results from cross-sectional studies show that parents of children with developmental disabilities tend to adapt to their nonnormative parenting role with time. Using cross-sectional data from a nationally representative sample in the United States, Ha et al. (2008) compared parents of a child with a developmental disability or mental health problem to parents of typically developing children and found that differences in well-being narrowed with increasing age of parents. Differences in negative affect, somatic complaints, and psychological well-being that favored parents of typically developing children over parents of children with a developmental disability were greater in younger versus older cohorts of parents. Furthermore, they found that longer durations of care among parents of a child with a disability were associated with adaptation and improvements in well-being, net of parental age. Similarly, comparing midlife (ages 40–54 years) and older (older than 54 years) mothers co-residing with a child with a developmental disability to a matched sample of mothers without caregiving responsibilities, Magaña and Smith (2006) found that depressive symptoms were elevated for the younger cohort of mothers caring for an adult child with a developmental disability relative to mothers not caring for an adult child. This was not the case for the older cohort. Older mothers caring for an adult child with a developmental disability did not

differ on depressive symptoms compared with older mothers not caring for a child with a developmental disability. Likewise, as already discussed, in Singer's meta-analysis (2006) rates of clinical depression were higher for mothers of younger compared with older children. Furthermore, the association of behavior problems with depressive symptoms in the Barker et al. (2010) study was stronger for younger versus older mothers. These results indicate that although health is compromised among mothers of individuals with ASD relative to mothers of children without disabilities, some mothers may adjust to their nonnormative parenting roles with experience.

Adjustment to caregiving challenges among mothers of adolescents and adults with an ASD may reflect, in part, normative age-related changes in coping that benefit emotional well-being. Coping strategies regulate stress and emotion (Lazarus 1999). In the general population, improvements in emotional well-being across adulthood have been documented in both cross-sectional and longitudinal research (Jorm et al. 2005; Kasen et al. 2003). In the Strengths and Vulnerability Integration Theory, Charles and Piazza (2009) propose that improvements in emotional well-being across adulthood result from a maturing of emotion regulation strategies. A lifetime of accumulated experiences and an acknowledgement that time left to live is limited can change how people think about and react to stressful situations in such a way that less negative affect is experienced with age.

Coping strategies may change in ways that contribute to resilience through motivational processes (e.g., goal selection, control capacities) that regulate the life course (cf. Heckhausen et al. 2010). Among mothers of adolescents and adults with developmental disabilities, emotional well-being is enhanced when accommodative coping strategies such as flexible goal adjustment are used (Seltzer et al. 2004). In a sample of mothers of adolescents with ASD (Smith et al. 2008) and in a sample of mothers of younger children with ASD (Benson 2010), similar associations between cognitive reframing coping and higher levels of maternal well-being were found. In another caregiving context, Wrosch et al. (2011) showed that goal disengagement among individuals providing care for a family member with a mental illness protected against longitudinal increases in depressive symptoms.

In addition to normative age-related changes in maternal coping, adaptation to stress associated with caring for a child with ASD into the child's adolescence and adulthood may result from improvements in child functioning. The life course concept of *linked lives* maintains that the developmental trajectories of partners in salient relationships are mutually influential: Changes in the life trajectory of one member often affect changes in the life trajectory of the partner (Elder et al. 2003). That is, parenting and parental well-being affect child development and characteristics of the child likewise affect parenting and parental well-being (Pettit and Arsiwalla 2008). Changes in the severity of autism symptoms, behavior problems, and daily living skills over time may account for some of the improvements in well-being observed in mothers of children with developmental disabilities. On average, autism symptoms and behavior problems decrease across adulthood (Shattuck et al. 2007) and daily living skills improve (Smith et al. 2012b).

Additionally, having an adolescent or adult child with an ASD move out of the family home is also associated with improvements in maternal well-being (Krauss et al. 2005).

On the other hand, the transition to adulthood for families of adolescents with autism can be stressful and negative experiences during this transition can acerbate problems. For example, Baker et al. (2011) showed that across a 7-year period, in mothers who became increasingly critical of their child during the transition to adulthood, increased criticism led to increases in behavior problems over time. The child's transition to adulthood is a normative life course transition that is embedded in the chronic parenting stress trajectory. Transitions can contribute to stressors that may exceed the coping resources of some individuals, transitions may alter the match between individual needs and contextual resources, and developmental transitions may exacerbate ongoing risks. Risks to successful development increase as an individual's sense of balance and well-being is disrupted and increase further when multiple and simultaneous transitions are experienced (Graber and Brooks-Gunn 1996). Changes in contexts that heretofore supported the child and family, mainly school, health, and service systems, often change drastically during the transition to adulthood (Shattuck et al. 2011) and impact families during and after the transition (Hauser-Cram et al. 2009).

Recent research aimed at describing the transition to adulthood for those with ASD has shown that many young adults remain dependent on their families (Billstedt et al. 2011) and that these young people often become socially isolated (Liptak et al. 2011) spending much of their time alone (e.g., watching television, using a computer) or with their mothers (Orsmond and Kuo 2011). In a recent analysis of data from a subsample of adolescents who made the transition to adulthood during the course of an ongoing longitudinal study, it was found that daily activities varied as a function of symptomatology and functional abilities (Taylor and Seltzer 2010). Those receiving adult day services had the highest levels of autism symptoms and behavior problems and the lowest functional independence; most had an intellectual disability. Those who were attending postsecondary education or were employed in competitive employment for more than 10 h/week had the fewest symptoms and behavior problems and were more independent; most did not have ID. The young adults who participated in no or very few regular daily activities had moderate levels of autism symptoms and behavior problems. Thus, depending on the child's level of functioning and developmental trajectory and the services available for adults with ASD, this transition may perpetuate the chronic stress trajectory, increase vulnerability further, or potentially contribute to resilience and gains in well-being for mothers in midlife.

Promoting Resilience by Enhancing Social Support

The literature on the experiences of mothers of adolescents and adults with ASD shows that by virtue of the lifelong nature of their active parenting role and associated caregiving demands, these mothers are vulnerable to physical and mental health

problems. At the same time, variation around average trajectories exists, in part due to maternal and child developmental processes. That is, depending on how life course trajectories interact and are negotiated, adaptation and resilience is possible. One way to promote resilience across the chronic parenting stress trajectory is the establishment and maintenance of positive social support networks, both formal and informal. Indeed, large bodies of research show that in the general population, social support promotes physical and mental health by buffering or offsetting the negative effects of stress (Balaji et al. 2007; Cohen 2004).

A review of the literature on social support in mothers of children with ASD showed that access to formal and informal social supports are related to better outcomes for these mothers (Boyd 2002). For example, Ekas et al. (2010) showed that support from family members contributed to increases in maternal optimism that in turn predicted better outcomes (e.g., lower negative affect, fewer depressive symptoms, higher positive affect, and life satisfaction). Among mothers of adolescents and adults with ASD, having larger social support networks is associated with lower levels of depressive symptoms (Smith et al. 2012a). Additionally, over time, social support network size covaries with symptoms of anxiety such that on occasions when mothers report increases in social support networks, they report fewer symptoms of anxiety (Barker et al. 2010). On the other hand, negative support systems (e.g., having family members who are critical) increase stress and contribute to negative outcomes (Smith et al. 2012a).

As discussed in detail elsewhere (Boyd 2002; Hartley et al. 2011a), the marital relationship in particular is an important source of support for parents of children with ASD. Ekas et al. (2010) showed that partner support had a direct effect on depressive symptoms, life satisfaction, and psychological well-being in parents of children with ASD. Benson and Kersh (2011) showed cross-sectionally and longitudinally that marital quality was associated with fewer depressive symptoms for mothers of children with autism. In a longitudinal analysis of marital satisfaction across a 7-year period, maternal reports of marital satisfaction declined slightly on average among mothers of adolescents and adults with ASD, especially on occasions when behavior problems were elevated (Hartley et al. 2012). Parents of children with ASD are at greater risk of experiencing marital dissolution than parents of typically developing children, and the period of elevated risk for divorce persists many years longer for parents of children with ASD, into child's early adulthood, than for parents of typically developing children (Hartley et al. 2010). Thus, although the marital relationship is an important source of support for parents of children with autism, it too is vulnerable to the negative effects of chronic parenting stress and may require targeted intervention to prevent marital discord and dissolution.

Summary and Conclusion

In this chapter, the relatively small but growing literature on the experiences of mothers of adolescents and adults with ASD has been reviewed and integrated.

It has been demonstrated that because autism symptoms and associated problems persist across the child's life course, stressful parenting associated with caring for a child with ASD also persists and forms, over many years, a chronic parenting stress trajectory. Midlife mothers of grown children with ASD lead stressful and intense daily lives, and the accumulation of daily stressful experiences forms the chronic parenting stress trajectory. In turn, the chronic parenting stress trajectory contributes to vulnerability for physical and mental health problems in mothers of grown children with ASD during midlife because an individual's history of stressful parenting experiences leaves one vulnerable to negative physical health outcomes and mental health outcomes. Nevertheless, variation from the average chronic parenting stress trajectory that results from normative developmental processes and contexts over time contributes to adaptation and resilience for some mothers.

This review highlights the need for interventions that will support parents at all points along the chronic parenting stress trajectory. Indeed, there is evidence that interventions aimed at reducing parenting stress among parents of children with developmental disabilities are effective, at least in the short term (see Singer et al. 2007 for a review). Encouraging accommodative coping, targeting parents before and during the transition to adulthood, and supporting marital relationships would benefit mothers across the life course, which in turn would benefit entire families. Indeed, research on physical health and emotional well-being experiences of other family members, such as fathers and siblings, is in even shorter supply than that on mothers of adolescents and adults with ASD (e.g., Hartley et al. 2012; Orsmond and Seltzer 2009). With a better understanding of the experiences of families, adolescents, and adults with ASD across midlife, appropriate interventions can be developed that will serve to shift the chronic parenting stress trajectory from one characterized only by vulnerability to one dominated by resilience.

Key Terms

Adaptation. Positive adjustment to parenting stress with experience and maturation.

Coping. Behavioral and cognitive responses that regulate emotions associated with stress.

Chronic parenting stress trajectory. Accumulation of exceptional parenting challenges over many years.

Life course experiences. Include normative or typical life course milestones experienced by most people at the same point in the life course and nonnormative events experienced by few people at different points in the life course.

Parenting stress. Subjective experience of and response to challenges posed by parenting demands.

Resilience. Positive adjustment over time in the face of exceptional stress.

Social support. Instrumental/tangible and emotional support received from significant others in one's social network.

Vulnerability. Susceptibility to negative outcomes.

Well-being. Multidimensional construct that includes subjective and objective indicators of emotional and physical health.

Key Facts of Developmental Trajectories

- From a developmental systems perspective, developmental trajectories result from dynamic interactions between an organism and the multilevel integrated contexts in which it is embedded.
- Patterns of relationships among contextual systems produce individuals' behavior and changes in these patterns produce developmental change in the form of developmental trajectories.
- Within individuals, potential exists across the lifespan for different levels of functioning.
- Discontinuities, or changes in level of functioning from one time to another, may arise from changes in individuals or contexts or both.
- To fully describe and explain development, the person and context must be considered together.

Key Facts of Daily Diary Methodology

- Different people experience and deal with life differently and these differences can be captured by daily diary data.
- Daily diary methodologies are considered intensive repeated measures designs.
- Daily diary methodologies are often used to study the impact of daily events on physical and mental health outcomes.
- Understanding daily processes can advance theories about human development based on results from traditional cross-sectional, experimental, or longitudinal research by exploring processes within individuals as they live their lives.
- Daily diary research can help clarify relations between relatively stable factors and factors that fluctuate from day-to-day and their interaction on behavior.

Key Facts of Hypocortisolism

- Cortisol, the primary marker of hypothalamic-pituitary-adrenal axis functioning, normally peaks shortly after waking in the morning and then gradually declines throughout the rest of the day.
- When exposed to a stressful event, the hypothalamic-pituitary-adrenal axis is activated and cortisol is released from the adrenal cortex, which in turn helps the body to adapt by regulating protein synthesis and glucose, immune functioning, and mental activity.
- A temporary increase in cortisol secretion in the face of stressful situation is a normal response.

- Individuals chronically exposed to stressors often have lower overall cortisol activity across the day and may exhibit a blunted cortisol response or even transient decrease in cortisol secretion following a stressor.
- This pattern of hypocortisolism is theorized to result from a history of prolonged exposure to stress and elevated cortisol levels, which subsequently leads to downregulation of the HPA system and decreased cortisol secretion.

Summary Points

- Relatively little research has focused on the experiences of parents of *adolescent and adult* children with autism spectrum disorder.
- Because autism symptoms and associated problems persist across the child's life course, stressful parenting associated with caring for a child with autism spectrum disorder also persists.
- Midlife mothers of grown children with autism spectrum disorder lead stressful and intense daily lives, and the accumulation of daily stressful experiences over many years forms a chronic parenting stress trajectory.
- The chronic parenting stress trajectory contributes to vulnerability for physical and mental health problems in mothers of grown children with autism spectrum disorder.
- Normative life course experiences, adaptive coping, and changes in child functioning contribute to adaptation and resilience for some mothers.
- Enhancing social support, formal and informal, across the child's life course is important for promoting resilience across midlife and into old age.

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