2024-08-08

Chronic Stress and Well-Being: Testing Mindfulness as a Proposed Method to Decrease Stress in Parents of Children with Autism Spectrum Disorder

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A dissertation submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

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ABSTRACT

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Parenting is a demanding role that encompasses many responsibilities and challenges. When a child is diagnosed with autism spectrum disorder, there are additional demands on the parent's time, energy, and financial resources, which likely leads to increased levels of chronic stress for parents. This dissertation examines the differences in chronic stress levels between parents who have children with autism and parents who do not, using hair cortisol concentration (HCC) as a benchmark. This dissertation also explores reducing parental stress by introducing a mindfulness intervention. Participants (n = 68) were recruited and divided into two groups: Parents of children who have autism spectrum disorder (ASD) and parents of neurotypical (NT) children. It was hypothesized that parents of ASD children would have higher stress levels than parents of NT children, that parents who participate in the intervention would have a reduction in stress, and that parents of ASD children would benefit more from the intervention compared to parents of NT children. The intervention consisted of an online, self-compassion-based mindfulness course that was introduced to parents. To examine the course's effectiveness in reducing stress for parents who completed (or at least began) the course, baseline, pre-, and post-mindfulness data were collected using self-report questionnaires and hair cortisol concentration levels. Questionnaire data demonstrated higher levels of stress in parents of children with autism as compared to parents of neurotypical children. However, the mindfulness course did not demonstrate effective stress reduction for parents in every self-report measure, though cortisol

levels did decrease for both groups following the intervention. Evidence suggests that the course was effective in increasing feelings of self-compassion and increasing perception of flourishing, Additionally, cortisol levels decreased significantly in parents after participating in the mindfulness course. By investigating stress in parents of children with autism and exploring mindfulness as a possible resource for stress reduction, this dissertation contributes to the broader discourse on family well-being and mental health. It is my hope that insights garnered from this research will inform the development of supportive frameworks that empower families, foster resilience, and ultimately enhance the quality of life for children with autism and their parents.

Keywords: autism spectrum disorder, mindfulness, chronic stress, daily hassles, hair cortisol, parenting, family, well-being

ACKNOWLEDGEMENTS

Pursuing a doctorate is a profound and immense privilege, as it has allowed me to immerse myself in my chosen field and contribute to the advancement of knowledge. I am incredibly fortunate to have had access to valuable resources, including academic guidance, research facilities, and financial support, which have allowed me to explore complex questions with creativity and curiosity. I am deeply grateful for the chance to pursue my passions and to be part of a community dedicated to discovery and progress.

I am very grateful to my committee, Drs. Terisa Gabrielsen, Sam Hardy, and Sandra Sephton, and I thank them deeply for their commitment and patience with me throughout this process. I would also like to thank my committee chair, Dr. Becky Lundwall. Her guidance throughout this journey has pushed me to develop resilience and has expanded my capacity for growth and self-reliance. I am very thankful to the several undergraduate researchers in our lab who have participated in this project and whose diligence and dedication have kept this project moving forward. Very special thanks to Dr. Jared Warren, who has graciously shared his fantastic mindfulness program with our lab and our participants, and to Dr. Johnny Chaston, who has donated a great deal of his time, effort, and equipment to assist in the scientific understanding and analysis of cortisol and microbiota as they are used in this project.

Thank you to my family and friends whose encouragement and advocacy have bolstered my success and achievement. Finally, I am endlessly grateful to my husband, Hayden, and our son, Asher, for their love and support. Hayden, your tireless comfort, and patient reassurance have accompanied me through my undergraduate and graduate pursuits, and I would never have made it without you by my side. Asher, you uplift me every minute of every day, and I can’t imagine this journey without you. Thank you both so very, very much.

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ACRONYMS

ASD: Autism Spectrum Disorder

FQOL: Family Quality of Life

HCC: Hair Cortisol Concentration

NT: Neurotypical

NSCQ: Neff Self-Compassion Questionnaire (modified)

PDH: Parenting Daily Hassles

PSI: Parenting Stress Index

SURF: Survey on Flourishing

Chronic Stress and Well-Being: Testing Mindfulness as a Method of Stress Reduction in Parents of Children with Autism Spectrum Disorder

Autism spectrum disorder[1] (ASD) is a developmental condition often identified in early childhood, which may initially present with delays or differences in achieving developmental milestones, such as the use of functional language or early social skills (Maenner et al., 2023). While the manifestation of traits is diverse, autism may be generally characterized by differences in socialization and communication with their neurotypical (NT) peers and family members (American Psychiatric Association, 2022; Happé & Frith, 2020; Lord & Jones, 2012), and restricted and repetitive patterns of behavior and interests (American Psychiatric Association, 2022; Chandler et al., 2016). The behavioral, communicative, and learning abilities of ASD vary greatly—no two individuals exhibit exactly the same expression of autistic traits, hence the term *spectrum.* Each person with autism has a distinct set of strengths and challenges—some individuals may require significant support in their daily lives, while others need less support.

Depending on the level of support needed, autistic children may rely much more heavily on their parents to take care of their daily needs compared to NT children of the same age (Dumas et al., 1991; Hayes & Watson, 2013). Additionally, parents of autistic children may experience other added stressors that go beyond daily needs, such as increased financial strain due to therapy, the time demands of clinical visits and evaluations, and the need for accessibility devices (Krakovich et al., 2016). There is also evidence to suggest that some parents of children with autism may face significant social stigma and lack of social support, which can also exacerbate stress levels (Gul et al., 2016; Papp et al., 2020; Phetrasuwan & Shandor Miles,

[1] Although autism is considered a disorder in the DSM-5-TR, I acknowledge that many of those who are diagnosed, and many parents of children who are diagnosed, prefer language that better incorporates their strengths and capabilities, such as “autism spectrum condition” or “on the spectrum.”

2009). These daily and chronic stressors can have a great impact on a parent's ability to provide care for their child(ren), as well as their ability to maintain their own mental health, relationships, and well-being (Bonis, 2016; Dabrowska & Pisula, 2010; Dunn et al., 2001; Krakovich et al., 2016). All of these factors can combine to place significant pressure on parents, suggesting the importance of finding ways to support their well-being.

Experiencing chronic high levels of stress can be very harmful to an individual due to the continuous wear and tear on the psychological and physiological systems that manage the stress response (Epel et al., 2018). Compared to parents of NT children and the parents of children with other developmental disabilities (non-ASD), research has found that parents of autistic children, especially mothers, experience more stress throughout the entire process of raising a child (Bonis, 2016; Dunn et al., 2001; Foody et al., 2015).

To cultivate the highest levels of well-being for the autistic child and their parents, it is crucial to understand the roots of stress within the household (i.e., daily hassles and stressors). A thorough examination of the chronic and daily stressors that parents of children with autism may experience is necessary to develop insight into the parameters and contexts in which feelings of stress most often occur and investigate measurement techniques to help identify compatible, meaningful interventions for parents and their children (Armstrong et al., 2005; Moes & Frea, 2002). When parents have children on the autism spectrum, developing ways to help parents manage their stress levels appropriately will likely positively contribute to familial functioning, affect lifelong outcomes in autistic children, and may improve the quality of life in both parents and children (Falk et al., 2014; Harper et al., 2013; Hayes & Watson, 2013).

Parenting

Becoming a parent is invigorating and joyful for many adults, mingled with a deepening

sense of love, connection, and fulfillment. However, the abrupt transformation can be overwhelming for some parents, who may feel frustrated at the loss of their old life or worried about doing a good job as a parent. This may be partly due to an abrupt change in schedule and personal roles, and there are many new responsibilities and challenges to consider (Dyer, 1963; LeMasters, 1957). Raising children adds an entirely new dimension to life that can cause significant stress and disruption, (Alpert et al., 1983; Deater-Deckard, 1998; Linville et al., 2010).

For some parents, there may be additional circumstances to adjust to. Recent estimates from the Centers for Disease Control and Prevention (2022) estimate that about 1 in 6 children in the United States have at least one developmental disability (Cogswell, 2022). Developmental disabilities often co-occur, and many children with these diagnoses may have more physical health-related needs than typically developing children. As mentioned previously, depending on the nature of their child's disability, parents may need to dedicate considerable time and effort to providing adequate care, pursuing childcare, and seeking developmental support (Bourke-Taylor et al., 2010). Data also indicates inequity in the usage of and access to medication and therapeutic services across sociodemographic subgroups and other underrepresented populations, with more at-risk sociodemographic groups often having less access to resources (Aylward et al., 2021; Mazurek et al., 2014; McManus et al., 2011). Strategies that help improve early identification and access to services for all families deserve further investigation and may help reduce some of these additional stressors for parents raising a child with a disability.

Parents who are raising a child with autism may face even more challenges beyond those of parents of children with other disabilities. While all individuals and their circumstances are unique, research has demonstrated that parents of autistic children experience higher stress levels

due to their child's autism diagnosis (e.g., Dabrowska & Pisula, 2010; Griffith et al., 2010; Watson et al., 2013). Even the most patient of parents may find it difficult to maintain their well-being in the face of day-to-day challenges and compounded stressors that may be brought on by difficult behavior that their child may exhibit. These feelings of overwhelm and distress are likely due to many things, including social stigmas and difficulties in receiving intervention services, as previously mentioned, but may also include hardships related to confronting quandaries that require unusual and innovative solutions. Many parents may at times feel unsure of how to address difficult child-rearing situations (Crnic & Ross, 2017), but the combination of unique behavioral challenges, societal stigma, and the need for specialized interventions can make the parenting journey particularly demanding and emotionally taxing for parents of children with autism, underscoring the need for comprehensive support and resources tailored to their specific needs.

Parents who are raising a child with autism may also experience higher rates of depression (Eisenhower et al., 2005; Hamlyn-Wright et al., 2007; Hayes & Watson, 2013), heightened intensity in their perception of daily hassles (Almand, 2002; Pfeiffer et al., 2017; Quintero & McIntyre, 2010; Tanner, 2017), and lower overall well-being (Blacher & McIntyre, 2006; Hayes & Watson, 2013) when compared to control groups. The relationship between stress and depression has been extensively studied, revealing that prolonged exposure to stress can precipitate depressive episodes by affecting various biological, psychological, and social factors (Bitsika et al., 2013; Bitsika & Sharpley, 2004; Ingersoll & Hambrick, 2011).

Stress-related depression is not solely a consequence of biological changes but also involves significant psychological components. Cognitive theories of depression suggest that stress can trigger negative thought patterns and cognitive distortions, which in turn exacerbate

depressive symptoms (Beck, 2008). Social factors, such as lack of support and interpersonal conflicts, further compound the effects of stress, creating a feedback loop that perpetuates depressive states (Kendler et al., 2000). The interaction of these biological, psychological, and social dimensions underscores the complexity of stress-related depression.

Heightened levels of unpredictability, particularly in the context of parenting, can significantly escalate parental stress and contribute to the development of depressive symptoms. Parents who frequently face a high concentration of unpredictability in their lives may engage in non-preferred parenting behavior, possibly resulting in distress for the child, the parent, or both (Hastings & Beck, 2004). However, it is very important to note that parental stress, unpredictability, and changes in behavior may arise for many reasons that are not at all caused by their child's diagnosis (Hayes & Watson, 2013). Parents likely need support that reduces their stress.

While there may be many individuals and families who relate to experiences of parenting difficulties, when discussing parents of children with autism specifically, it is important to consider the wide variability of the autism spectrum, both in behavior and neurodevelopment. It is possible that higher rates of overall stress in parents of a child with autism compared to levels of stress in parents of children with other disabilities may be associated with the ASD-specific phenotype (Hayes & Watson, 2013; Ingersoll & Hambrick, 2011). Many factors have been shown to contribute to the diversity in the phenotype, including genetic disparity and the environment in which the child is raised (Wozniak et al., 2017). In some cases, these phenotypic differences may impede or inhibit the abilities of parent and child to communicate effectively, which may augment feelings of stress (Hill et al., 2019; Lord et al., 2020).

Some parents have additionally reported experiencing difficulties in managing their

child's restricted or repetitive behaviors, which is a core symptom of ASD (American Psychiatric Association, 2022; Costa et al., 2017; Davis & Carter, 2008; Ingersoll & Hambrick, 2011). Other studies have indicated that the child's severity of ASD symptoms (e.g., Batool & Khurshid, 2015; Bonis, 2016; Falk et al., 2014; Ingersoll & Hambrick, 2011) and levels of intellectual functioning (Eisenhower et al., 2005; Hastings et al., 2005; Hayes & Watson, 2013) may also be significant contributors to stress or mental health concerns in parents.

Various reports contain similarities among the parenting experience of raising an autistic child, including feelings of judgment and isolation (Broady et al., 2017; Byrne, 2013; Coleman & Karraker, 1998; Green, 2007; Schnabel et al., 2020). Recent findings indicate an accumulative nature to parental stress, perhaps including any and all combinations of emotional, functional, and behavioral experiences (Picardi et al., 2018). In other words, parents raising a child with autism will likely encounter stressors or challenges due to factors beyond their day-to-day parenting responsibilities, including pervasive social and systemic issues (e.g., lack of access to resources, limits on family opportunities, financial constraints), the co-occurrence of which can cause severe levels of stress in parents (Karst & Van Hecke, 2012; Rivard et al., 2014; Sanders & Morgan, 1997).

Stress

The human body is designed to experience and react to stress and, for many people, can effectively regulate the physical response. However, this stress response can become problematic if it is consistently required to operate without reprieve. The duration of a stressor can be just as influential as the individual's interpretation of a situation (Epel et al., 2018). Daily events or daily hassles are stressors, often considered to be minor, which are encountered daily or nearly every day (Epel et al., 2018; McGonagle & Kessler, 1990). For parents, these often include

helping their children with chores, homework, getting dressed, or preparing and executing mealtime (Mikolajczak et al., 2018). For many parents of children with autism, these daily hassles are not as minor as they might be for parents of NT children (Ogston et al., 2011). Even without the extra time and effort that might be necessary to assist one's autistic child in these daily activities, there is often a great deal of additional mental labor associated with raising a child with autism, including preparation for action, decision-making, and future-related worries. (Dardas & Ahmad, 2015; Higgins et al., 2022; Ogston et al., 2011). These daily feats are not one-off experiences, nor are they always short-term investments (e.g., "*Soon he'll be done with the terrible twos*").

Chronic stressors are demands that are present for more extended periods, such as being a caregiver to an individual with a disability or chronic illness, being unemployed, living in a dangerous neighborhood, or experiencing consistent financial strain (Epel et al., 2018; McGonagle & Kessler, 1990). By their nature, living with chronic stressors nearly always leads to an accumulation (both in number and intensity) of daily demands, compared to people who experience fewer pressing obligations. It is possible that due to the perpetual impact of these stressors, especially if it seems there will be little or no relief, over time, they may deplete one's emotional or cognitive resources much more quickly (Harper et al., 2013; Hastings et al., 2005). These extended stressors put individuals at greater risk for more severe life events and increase their likelihood of reporting greater perceived stress at any given moment (Epel et al., 2018).

Additionally, individuals who grapple with prolonged levels of stress may experience considerable adverse effects. High levels of stress have also been found to contribute to a weakened immune system and a possible increased risk of cancer (Reiche et al., 2004). They can depress and impair the functioning of the cardiovascular system, which can cause an elevated

risk of myocardial infarction (Raikkonen et al., 1996). Sustained chronic stress has also been linked to increased rates of mental illness, including depression, Alzheimer's disease, post-traumatic stress disorder, and anxiety (see Marin et al., 2011 for a review).

Appraisal and Coping

One's interpretation or appraisal of an encountered stressor can affect one's response (Lazarus & Folkman, 1984), and is influenced by individual history and environmental experience, making it subject to variability (Epel et al., 2018). In Shakespeare's *Hamlet,* he observes, "There is nothing either good or bad, but thinking makes it so" (*Hamlet,* Act II, Scene 2, Line 259). In examining stressors, it is important to acknowledge the influence of perception on experiences. The appraisal and subsequent coping mechanism (maladaptive or otherwise) used in response to a stressful situation demonstrates how similar stressors may affect people in different ways (i.e., situations themselves are not associated with maladaptive stress; instead, one's perception of the situation is what determines the positive or negative impact; Epel et al., 2018; Sapolsky, 2015).

For some parents, adapting to their child's autism diagnosis may be a process of distress or pain, sometimes comparable to feelings of grief, as it may challenge their hopes and expectations for their child (Poslawsky et al., 2014). The diagnostic experience can be difficult for many reasons, and depending on how the parent is able to evaluate their moment-by-moment experiences, it can change their future reactions and adaptations (Milshtein et al., 2010). Through a combination of coping mechanisms and personal history, parents who adopt a negative appraisal surrounding their child's diagnosis may find themselves avoiding adaptation or inappropriately casting blame on themselves or others (Poslawsky et al., 2014).

The coping process engages when an individual perceives that the demands of their environment have overwhelmed their available resources, which experience triggers a response

to regulate their mind and body. This process ultimately serves two essential functions: to manage or change that which is causing distress and to regulate the emotional response which occurs as a result (Lazarus & Folkman, 1984, 1987). However, if the coping mechanism selected to manage distress is maladaptive to the situation or is not enough to regulate the response to the demands of the environment, stress still occurs (Hayes & Watson, 2013; Lazarus & Folkman, 1984, 1987).

One's method of coping is not innate nor stagnant; it can be as variable as the sources of stress themselves over the lifetime. Indeed, this denotes an element of control that may be applied to shape one's appraisal and subsequent coping strategy as stressors are encountered. Exploring the factors that influence coping strategies may help researchers better understand how individuals manage stress and how these mechanisms may evolve. Furthermore, identifying specific triggers that lead to changes in coping mechanisms can help tailor interventions more effectively. Understanding these distinctions offers researchers a potential method to study how appraisals may be modifiable and may provide targets for adaptable, individualized intervention (Epel et al., 2018

Using Mindfulness to Decrease Stress

In its most common form, mindfulness is the practice of putting intention and thought into awareness of one's cognition, body, and actions (e.g., Pang & Ruch, 2019; Reive, 2019). The concept of mindfulness is primarily rooted in ancient Buddhism, but the fundamental theology shares a nexus with other philosophical traditions, both historic and modern (Brown et al., 2007a). Although there is an ongoing discussion concerning what specific components of thought-work encompass mindfulness, here we consider mindfulness to include components of self-kindness, common humanity, and awareness of the present moment (Warren, 2020; Neff,

2023). Dedicated practice of this type has been shown to have beneficial effects on emotional well-being (Dorjee, 2010).

Practicing mindfulness has been shown to help individuals decrease levels of stress, increase levels of satisfaction, and report higher levels of quality of life, when controlling for socioeconomic status and gender (see Brown et al., 2007b for a review). Most parents, especially those with young children, are actively engaged in the undertakings of parenthood and household management (Taaffe Young et al., 1998) and are, at a minimum, very busy, if not chronically stressed (Mikolajczak et al., 2018). Mindfulness is a realistic solution to stress reduction due to the relative flexibility of time and location of practice. Additionally, mindfulness is a cost-effective method to manage feelings of stress and anxiety—potentially reducing the need for more expensive healthcare treatments (Klatt et al., 2009). Mindfulness encourages the development of one's state of mind to focus attention on moment-to-moment awareness and unconditional acceptance while encapsulating one's internal resources that may be used to reevaluate feelings of stress or overwhelm (i.e., coping skills; Creswell, 2017; Klatt et al., 2009; Reive, 2019).

Self-Compassion

Self-compassion is considered to be an element of mindfulness and positive psychology (Barnard et al., 2011; Dorjee, 2010). The discourse involving the composition of self-compassion as a concept has included three central elements posed by Kristin Neff of the University of Texas at Austin: Self-kindness, common humanity, and mindfulness (Neff, 2023). These topics have also been called the "Building Blocks of Self-Compassion" (Warren, 2020). This suggests that self-kindness is the opposite of self-judgment—that we should be patient and tolerant of our imperfections rather than critical or cold-hearted. Evidence also

suggests that the conceptualization of mindfulness as a multidimensional paradigm may help individuals better understand the components of mindfulness and find more ease in application (Baer et al., 2019; Baer et al., 2006).

Self-compassion is a relatable principle that may encompass many facets of mindfulness and can target specific aspects of stress (Dunkley et al., 2003; Neely et al., 2009; Pang & Ruch, 2019). Self-compassion is often defined as mindful awareness of one's thoughts and emotions and being fully present in that experience (Barnard et al., 2011). Previous literature has demonstrated that some parents or families affected by autism may experience self-blame, guilt, shame, or doubt, often most apparent in mothers (Altiere & von Kluge, 2009b; Dababnah & Parish, 2013; Martins et al., 2015). Developing an awareness of the realities and benefits of self-compassion and putting them into practice may help counter these thoughts and feelings. Self-compassion involves acknowledging the shared human experience—recognizing that one is not alone in feelings of disappointment or failure. Practicing self-compassion may help individuals recognize the intrinsic value they hold, without feeling pressure to prove their worth to themselves or others (Neff & Faso, 2015).

Using Self-Report Questionnaires

Due to the subjective nature of perceived stress and the multiple areas of impact that stress can have on the body, it is important to have both psychological and physiological measures to construct a more well-rounded conceptualization of the experience of stress (Roberts et al., 2020). The use of a biomarker in comparison to reports of perceived stress will help measure changes between pre- and post-intervention, as it may serve as a general baseline to provide structure to the subjective reports (Matousek et al., 2010, 2011; Roberts et al., 2020).

Additionally, the use of self-report questionnaires to measure stress can help researchers

understand several things about an individual's experience, including their interpretation or appraisal of daily living situations or overall family quality of life (Ingersoll & Hambrick, 2011). They may also help evaluate one's available coping mechanisms based on introspective evaluation (Troy & Mauss, 2011), and perhaps even specific stressors causing disruption (Epel et al., 2018). Measures of perceived stress or perceived well-being cannot wholly capture an individual's emotional and cognitive experiences, but they can be a helpful place to start (Achterberg et al., 2021; Costa et al., 2017; Rivard et al., 2014; Shepherd, 2018). Because it is less common to use both self-report measures and biomarkers in one study, this study is valuable and will help inform future studies. Understanding the stress factors experienced by parents of children with autism and developing effective interventions are crucial steps toward improving familial well-being and long-term outcomes for individuals with autism.

Using Hair Cortisol Concentration

Using hair cortisol concentration (HCC) as a method of measuring stress has been gaining traction in the last decade due, at least in part, to the relative ease of collection and longevity of storage, compared to saliva or other measurement methods (Bates et al., 2017; Heimbürge et al., 2019; Manenschijn et al., 2011; Meyer & Novak, 2012; Staufenbiel et al., 2013). HCC is a less invasive method with exciting implications for the field due to the unique method through which cortisol is stored in the hair, expanding possibilities of chronic stress measurement (Heimbürge et al., 2019; Lee et al., 2015; Russell et al., 2012; Staufenbiel et al., 2013; Zoccola & Dickerson, 2012). During growth, cortisol is incorporated into the hair shaft continuously, making it possible to access information about the state of the hypothalamic-pituitary-adrenal axis during the previous weeks and months (Flom et al., 2017; Heimbürge et al., 2019; Meyer et al., 2014; Meyer & Novak, 2012). It can often be difficult to predict or

"catch" moments of stress in the present moment, making a backward-investigation analysis helpful.

As described by Kirschbaum et al. in 2009, HCC analysis produces a "retrospective calendar" of stressful events (p. 33; Russell et al., 2012). While there are biases associated with HCC analysis (e.g., difficulty in distinguishing between different stressor categories, possible cross-reactivity with other steroids found in the hair; Bautista et al., 2019; Kalliokoski et al., 2019; Stalder et al., 2017), the confounds associated with salivary cortisol analysis seem to be much more numerous and more difficult to control compared to HCC (Clements, 2013). HCC has also very recently been found to indicate a relationship between perceived distress and coping mechanisms among participant groups of different HCC measurement levels (Ling et al., 2020).

Historically, salivary cortisol has been one of the most commonly used measures for stress, and while it does have great benefits, it is generally better suited to measure immediate circulating levels of cortisol (most often caused by acute stressors; Epel et al., 2018; Kamin & Kertes, 2017). Salivary cortisol can also be used as a measure of chronic stress, though it may not be the most effective measurement, as it would likely involve giving more than one sample per day, which may be taxing for the researcher and the participant (Clements, 2013; Kirschbaum & Hellhammer, 1989). Cortisol measurement by saliva can only capture one moment in time, measuring the extra levels of cortisol triggered by a stressor, which are superimposed atop normal diurnal levels (Kamin & Kertes, 2017). Diurnal cortisol release is a variable process and can fluctuate in the extreme from person to person due to time differences in the development of the hypothalamic-pituitary-adrenal axis, sleep, temperament, diet, and a near infinite amount of differing gene-environment interactions (Clements, 2013; Flom et al., 2017; Joëls et al., 2012;

Kirschbaum & Hellhammer, 1989).

Diurnal cortisol refers to the pattern of cortisol secretion in the body that tends to follow a regular daily cycle. Typically, cortisol levels peak shortly after waking in the morning and gradually decline throughout the day, reaching their lowest point late in the evening (Kirschbaum et al., 2009; Kirschbaum & Hellhammer, 1989). Diurnal cortisol tests are often used to graph an individual's cortisol levels over a period of time (often in a 12 or 24-hour cycle; Edwards et al., 2001; Smyth et al., 1997). Some studies have indicated the use of the diurnal cortisol cycle to be a useful, objective measure of stress when compared to self-report measures (Dykens & Lambert, 2013; Raffington et al., 2018; Roberts et al., 2020), but others have not found significant results (Lipschitz et al., 2013; Seltzer et al., 2010). Though hair cortisol cannot measure the diurnal cycle in this way, using hair cortisol as a specific measure of chronic stress may help give a better view of stress over time, which may be more directly related to perceptions of stress (especially as most questionnaires ask participants to think about the stress levels they have experienced over the past weeks or months; Baer et al., 2019). Therefore, it will be beneficial to have a foundational understanding of how HCC compares to self-report.

There are still unanswered questions regarding the use of HCC as a biomarker of stress, such as the possible variability of cortisol levels along the shaft of hair (Russell et al., 2012), and factors such as ethnicity and age (Dettenborn et al., 2012; Stalder et al., 2017). However, several studies have established support for the use of HCC as an indicator of cortisol levels over preceding months, including findings of overall validity, (Manenschijn et al., 2011; Stalder et al., 2017), and test-retest reliability (Short et al., 2016; Stalder et al., 2012). Provided that we can trust HCC to give us an "accurate" understanding (admittedly, it is difficult to know for sure, but perhaps we can have sufficient confidence in its scientific acceptance) of chronic stress levels,

we can use this data to better understand the levels of stress that people are experiencing. Because HCC is more difficult to get and test (though it is arguably less difficult than salivary cortisol), reliably understanding how it compares to self-report measures (which are easier to obtain and test) might increase our understanding of people's stress levels and lead to more effective interventions and treatment.

The Current Project

The intent of this project was to investigate methods of measuring chronic stress in parents of children with autism and to consider the use of mindfulness as an intervention to reduce stress by increasing parental coping skills through self-compassion. Additionally, I hoped to contribute to the testing of a possible supportive intervention for parents and their children and add to the body of literature to assist practitioners in recommending effective care. By identifying measurement techniques and proposing an intervention, this research aims to provide a foundation for the design and implementation of support programs that address the diverse needs of parents, thereby fostering more successful familial functioning.

Hypothesis 1. The current study aims to validate findings from previous literature that parents who have children with autism experience more stress than parents of NT children as indicated by self-report measures and cortisol levels. Significant differences in cortisol levels between the two groups are anticipated, although it is possible that the subjective experiences of stress may not align with physiological responses.

Hypothesis 2. Parents participating in the mindfulness program will experience decreased stress, as demonstrated by biological measurements (cortisol levels by HCC) and self-report measures.

Hypothesis 3. Based on cortisol results and self-report data, parents of children with autism will show a greater reduction in stress following the mindfulness intervention, with at least one

standard deviation difference, compared to the parents of NT children. Significant differences in HCC levels are expected to align with significant changes in self-reported stress scores.

The outcomes of this research could lead to more effective and tailored support services, directly improving the quality of life for these families. By filling the existing research gap, this study aims to provide valuable insights and practical recommendations that can inform support programs, ultimately fostering a more inclusive and supportive environment for families raising children with autism. Furthermore, the study's findings may inspire further research, creating a ripple effect that advances our understanding and support of autism on a broader scale.

Method

Participants

This study was approved by the Institutional Review Board (IRB) and Brigham Young University (BYU). All participants were given an informed consent document that detailed the procedures for themselves and their children through all phases of the study and specified that they could withdraw themselves or their children from the study at any time. Participants were recruited using flyers shared with autism support groups throughout Utah, especially in Utah County. Flyers were also shared on Facebook and posted in groups specifically for parents of children with autism, with permission (e.g., *Utah Autism Support, Autism Awareness*).

The principal investigator gave interviews on a local television news station and in a local newspaper to share the details of the study and the contact information for the research lab, encouraging those eligible or interested to contact us. Additionally, flyers were given to elementary school principals in the Provo school district (with permission from the district's IRB) and distributed to local businesses, including doctors' offices, after-school programs, and grocery stores. Participants were also encouraged to refer friends and neighbors who may be

interested if they felt comfortable doing so. Flyers were also distributed around the BYU campus to recruit additional participants for the last two-thirds of the study, as we found our numbers to be less than we had hoped.

Procedure

This study was conducted as a branch of a more extensive study examining gut microbiota as an early predictor of ASD traits (See Appendix A for more details). The study population and overall timeline for the current project were designed with the overarching study in mind, but the integrity and rigor of this study were maintained independently. This study consisted of three phases (see Figure 1), each spanning at least eight weeks. The three-phase design was used to simplify data collection, as participants were simultaneously participating in both the current study and the more extensive gut microbiota study (See Appendix A for more details). The first participant was enrolled on October 25, 2021, and the final participant completed data collection on June 16th, 2024. The recruitment goals of this study required rolling enrollment, which resulted in all three phases being active simultaneously as participants proceeded. Once the final participant completed a phase, that phase was locked, and no more data was collected for that phase.

Participants were divided into two groups: (1) Parents of ASD children (parent age m = 33.6 years sd = 6.69 years; 100% female): Parents of children who have (at least) one child with ASD (either formally diagnosed or provider-suspected) and also have an infant (who would participate in the microbiota arm of this study), and (2) Parents of NT children (parent age m = 28.7 years, sd = 6.85 years; 100% female): Parents of infants without any first-, second-, or third-degree relatives with autism. Parents in the NT children group did not necessarily have to have another child besides their infant. Infants participating in the microbiota arm of this study were

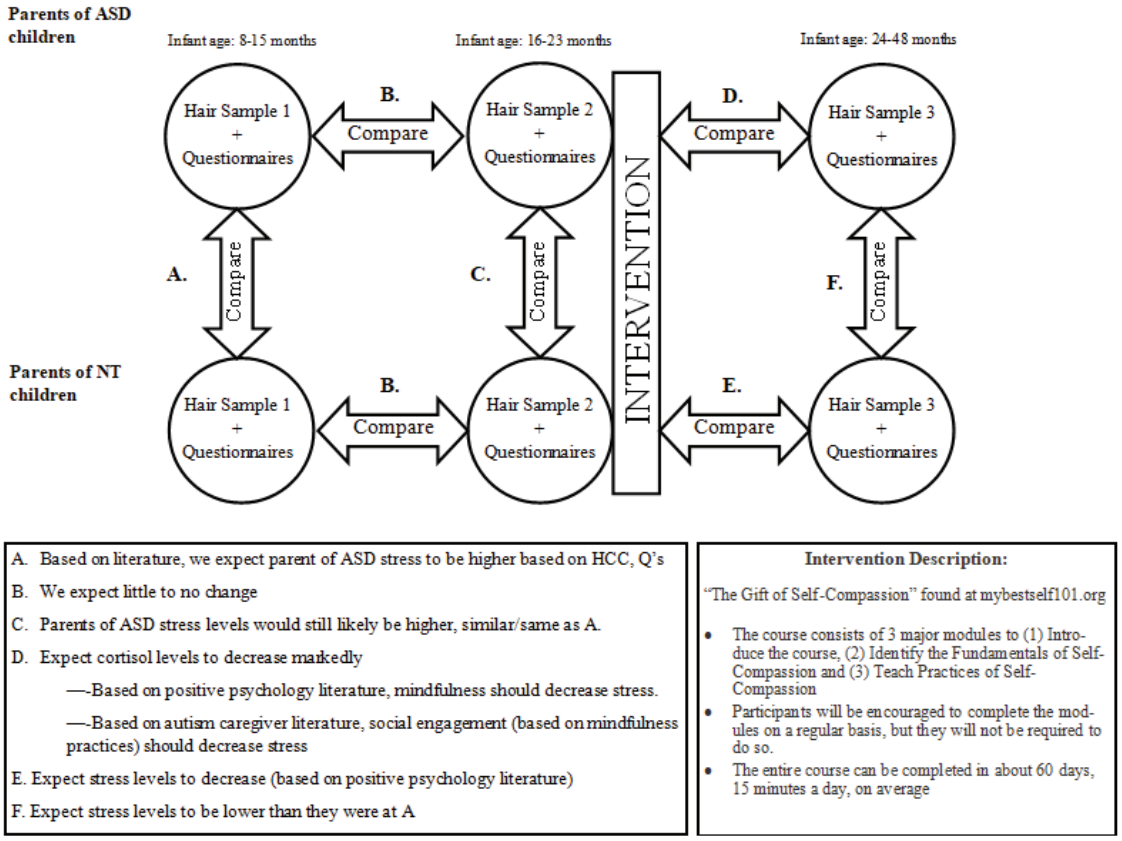
age and sex-matched between groups to appropriately compare the infants in the ASD group (age *m* = 11.12 months, *sd* = 1.91; 47.06% female) with the infants in the NT group (age *m* = 11.61 months, *sd* = 1.97; 44.7% female). Additional participant information is listed on page 28.

Although controlling for family size or the number of children would likely have enhanced the generalizability and validity of the study, implementing these restrictions would have impeded participant recruitment, which was already challenging. Of those parents in the NT children group who did have an older child, none of the older siblings had any diagnosed neurological disorders. However, the infants and parents were not excluded if a sibling had a mild physical health condition (such as a mild heart murmur or mild vision problems).

Though the present study only involved parents of children with or without autism, the initial qualification for each of the three phases in the present study was determined by the age of the infants involved in the more expansive gut microbiota study. In Phase 1, infants were 8-15 months; in Phase 2, infants were 16-23 months; and in Phase 3, infants were 24-48 months. The maximum infant age for the current project was expanded from 31 months to allow for increased recruitment. It is important to note that the expanded age range should not significantly affect parental stress, as no significant difference in parental stress has been found with children in the Phase 3 age range. (Enea & Rusu, 2020; Estes et al., 2014; Lin et al., 2021).

Figure 1

A diagram of the current project, including participant groups and phases



Phases

Phase 1

Parents provided a small hair sample (about the diameter of a pencil eraser) from the nape of the neck. The hair was cut as close as possible to the scalp without causing injury to the participant. The sample was then taped to a piece of cardstock marked to indicate which end of the hair was nearest the scalp, wrapped in a clean piece of aluminum foil, marked with the participant's ID and date of collection, and stored until the time of chemical analysis. Either parent was permitted to give a hair sample, though in every case, it was the mother who gave the

sample. Additionally, the same parent needed to provide the hair sample at each phase. The parent who gave the hair sample also filled out a brief questionnaire to be considered in the analysis of the HCC, including the type and frequency of hair products used, hours per day hair is exposed to direct sunlight, and occurrences of hair dying, bleaching, or perming. These were collected to control for confounds; however, several studies indicate no significant difference in HCC between these factors (Gonzalez et al., 2019; Gray et al., 2018; Schepers et al., 2019). During this phase, parents also completed a basic Demographics Questionnaire, the Parenting Daily Hassles Questionnaire (PDH; Crnic & Greenberg, 1990), The Survey on Flourishing (SURF; Linford & Warren, 2020), the Family Quality of Life Questionnaire (FQOL; Beach Center on Disabilities, 2006), and the Neff Self-Compassion Questionnaire-Modified (NSCQ; Linford & Warren, 2020; Neff, 2003). All questionnaires were taken by the parents online.

Phase 2

Procedures here are identical to procedures in Phase 1, with the absence of the demographics questionnaire, the addition of the Parenting Stress Index Short Form (PSI-4-SF; Abidin, 1997; Abidin, 2012) questionnaire, and the addition of the mindfulness intervention, *The Gift of Self-Compassion* (Linford & Warren, 2020). Parents were encouraged to participate for at least 5-10 minutes per day for about eight weeks, as guided by the online program and an accompanying workbook (see Appendix B). Research assistants were assigned to text participants (with their permission) every 7-10 days to offer support, answer questions, and provide help and encouragement when needed. The texts were based on a script to maintain as much consistency between participants as possible. Some parents expressed difficulty finding time to use a computer to access the online program in areas free from distractions, and, in these cases, research assistants directed parents to guided practice audio clips. These clips are found on

Kristin Neff's website, www.self-compassion.org (see Appendix C for details).

Phase 3

The procedures for this phase are identical to Phase 1, with the addition of a brief follow-up survey to obtain general feedback about the mindfulness program (e.g., whether parents enjoyed it, found it convenient, found it helpful). Additionally, parents completed the PSI as they had during phase 2 to collect post-test data.

Processing Hair Samples

For hair sample collection, simple kits included a small pair of scissors, several pieces of cardstock (marked with "TOP" in black marker at one end), several sheets of clean aluminum foil, and a dispenser of regular clear tape. It was determined that the process of cleaning the hair would be enough to rid the sample of potential microbes that could confound the cortisol analysis (Gonzalez et al., 2019; Meyer et al., 2014; Ouellet-Morin et al., 2016) therefore, sterile instruments were not necessary. However, research assistants were instructed to wear disposable gloves and to disinfect the scissors with rubbing alcohol between each participant.

Hair sample analysis for this study is based on the methods outlined in the study conducted by Meyer and his colleagues (2014). Samples for this study were processed and analyzed at BYU with the help of Johnny Chaston in his lab in the Plant and Wildlife Sciences department. Analysis procedures were standardized to ensure more accurate measurements of cortisol levels. The procedure is summarized as follows:

1. Weighing: Each hair sample was carefully removed from the foil and paper on which it had been stored. Hair longer than 3 cm from the root end is cut away and returned to the foil until it can be properly disposed of following analysis. Hair was weighed using an analytical balance scale. Approximately 15 mg of hair (within 5 mg difference) was placed

into a pre-weighed microcentrifuge tube, reinforced to withstand bead beating.

   a. Note: 60 mg is ideal, but it is more important to find a standard weight that all the samples can reach and adjust accordingly. The current study found a standard weight of 15mg, which was used throughout our sample testing. However, we found it to be incredibly difficult to change the weight by small amounts due to how difficult the hair was to work with, which accounts for the variation in weight. A 5 mg variation in weight was not expected to significantly affect results (Orta et al., 2018).

2. Washing: After the 3 cm of hair (representing the previous 3 months of cortisol deposits; Kirschbaum et al., 2009) was weighed, each sample was placed into a 15 ml centrifuge tube, and 5 ml of high-performance liquid chromatography-grade isopropanol was added to each tube. The tubes were then inverted on a rotator for 3 minutes to mix the solution thoroughly. The isopropanol was then carefully discarded without disturbing the hair sample.
3. Drying: The sample tubes were left uncapped in a secure, clean location for 2-3 days to ensure complete evaporation of any remaining isopropanol.
4. Sample Grinding: The vial was reweighed to obtain the most accurate sample weight. Three 3.2 mm steel beads were added to each vial, and the hair samples were ground using a bead beater for at least 2 minutes (note: very fine hair often takes several more minutes before it is sufficiently pulverized). Cortisol extraction should be performed in the same vial to eliminate the need for a sample transfer.
5. Cortisol Extraction: 1.5 ml of high-performance liquid chromatography-grade methanol was then added to the tube containing the powdered sample. The tube was capped and

incubated at room temperature for 18-24 hours with constant inversion. After incubation, the tubes were centrifuged at 10,000 rpm for 5 minutes to configure the hair sample into a pellet. 1.0 ml of the supernatant was transferred to a clean 1.5-tube, without disturbing the pellet.

6. Solvent Evaporation and Sample Reconstitution: The methanol was evaporated using a vacuum evaporator (to dispose of the methanol safely). The dried extract was reconstituted in an appropriate volume of the enzyme-linked immunosorbent assay buffer (assay dilutant) according to the manufacturer's instructions. The sample was immediately assayed, though it is also possible for samples to be frozen at -20° C for later analysis.

Materials

The Gift of Self-Compassion is an online curriculum that includes an easy-to-navigate, three-module program containing instructional videos, guided meditation, written resources, and specific, interactive mindfulness practices. Developed and currently operated by Jared Warren (Linford & Warren, 2020) at BYU, this program emphasizes what self-compassion looks like within an individual, evaluating how they talk to themselves and noticing when difficult moments or maladaptive emotions or thoughts occur throughout the day. The experience is unique for each person, and it aims to help expand their emotional and mental capacity and develop and apply specific coping skills that work for them. Throughout the course, Warren emphasizes common humanity, expressing the importance of remembering that struggling is part of the human experience—that individuals are not alone in their pain or suffering, encouraging individuals to embrace everyday experiences of shared circumstances. Warren stresses the foundational significance of mindfulness, explaining that, at its core, it is simply having an awareness of the present moment.

The Gift of Self-Compassion, has experienced previous success with other groups of participants in similar studies conducted by the program's creator, Jared Warren. Warren and his students have found that participants who use the online program experience significant improvements in their self-compassion and their well-being, with moderate to large effect sizes, compared to participants who did not participate in the course (Linford, 2022; Warren et al., 2022). However, it is worth noting that the usefulness of this program has not been explicitly studied in groups of parents, including parents of children with autism.

This program requires parents to use a computer to log on to www.mybestself101.com and, using the accompanying workbook (see Appendix B), move through the three main modules: Course Introduction, The Fundamentals of Self-Compassion, and The Practice of Self-Compassion. Parents are allowed to move through each part of each module at their own pace, though they are encouraged to set daily or weekly goals for time spent in the course. Though establishing a daily routine of mindfulness is not necessary for success (i.e., decrease feelings of stress or negativity; Berghoff et al., 2017; Clarke & Draper, 2020; Ribeiro et al., 2018), daily practice may improve practice *quality*, which often leads to more success overall (Goldberg et al., 2020; Laurie & Blandford, 2016). The course is designed to be picked up at a time convenient to users, with each section of the three modules being as concise as possible. It contains a combination of brief, on-page literature, short videos, and exercises (which cooperate with the workbook) to provide psychoeducation and training in self-compassion.

The Salimetrics ER HS Salivary Cortisol Kit (Item#: 1-3002-5) was used to process cortisol levels. Though this kit was specifically marketed for use in salivary cortisol samples, previous research has demonstrated that when properly prepared (based on the steps outlined above by Meyer and colleagues), it can accurately be used to measure samples of hair cortisol

as well (Meyer et al., 2014).

Measures

Demographics Questionnaire. A basic online questionnaire that asked participants to report demographic information, including race, ethnicity, age, general physical and mental health, number of children, and annual household income. This measure gathered information about the parents themselves and some information on their infant.

Family Quality of Life (FQOL). A 25-item questionnaire that uses satisfaction as the primary response format, anchored in a 1-5 Likert scale, where 1 = *very dissatisfied*, 3 = *neither satisfied nor dissatisfied*, and 5= *very satisfied.* The 25 items are categorized into five domains: *Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being,* and *Disability-Related Support.* Internal consistency ratings for importance within each subscale were $a = .94$ and $a = .88$ for satisfaction ratings, respectively. The FQOL Scale is a commonly used measure intended to assess the perceptions of familial satisfaction of families of children with disabilities ages birth through 21 years old (Hoffman et al., 2009). This study used this scale to record perceived stress as measured through perceptions of quality of life. Based on Hypothesis 2, it is possible that scores for this measure will increase over time as self-compassion increases.

Parenting Daily Hassles Scale (PDH). This measure contains 20 items based on the frequency and hassle level (low to high) of ordinary events that parents may experience daily. Example items include “the kids won’t listen or do what they are asked without being nagged” and “Having to change your plans because of unprecedented child needs.” Responses are first indicated by the frequency of the event on a 4-point scale from “Rarely” to “Constantly”, then responses are indicated by the hassle level the parent experiences from that item on a 5-point

scale (1 = low, 5 = high). Internal consistency reliabilities of the PDH scale have been reported (alpha = 0.87; *N* = 74; Crnic & Booth, 1991; Crnic & Greenberg, 1990). Based on Hypothesis 2, it is expected that over time, scores for this measure will decrease as self-compassion increases.

The Neff Self-Compassion Questionnaire (NSCQ). A scale modified by Warren and his student (Linford & Warren, 2020), based on the Self-Compassion Scale developed by Neff (2003). Neff's original scale contains 26 items, and Warren's modified scale contains 12 items. It uses a 5-point Likert scale that assesses one's trait of self-compassion by self-report. Preliminary psychometric analyses for this Self-Compassion measure indicated good internal consistency (α = .91) and significant correlation with the Neff Self-Compassion Scale total score (*r* = .85). Based on Hypothesis 2, it is expected that over time, scores for this measure will increase as self-compassion increases.

The Survey on Flourishing (SURF). A measure developed at Brigham Young University by Warren and his student (Linford & Warren, 2020), for use in the online program, *The Gift of Self-Compassion*. While self-compassion is an internal attitude towards oneself, flourishing represents an overall state of thriving and optimal functioning across various life domains. This measure is intended to assess that overall state. It is a 19-item 5-point Likert scale self-report measure to assess various facets of well-being, including satisfaction, affective experience, eudaimonia, meaning, and purpose. An internal consistency estimate for the SURF measure was high (α = .95). Several other groups of researchers, including Butler & Kern (2016), Seligman (2011), Diener and colleagues (1985), and Watson and colleagues (1988) have found that scores on SURF correlated positively with other measures of well-being. This includes the PERMA (positive emotion, engagement, relationships, meaning, and accomplishment) profiler (*r* = .79; Butler & Kern, 2016; Seligman, 2011), the Satisfaction with Life Scale (*r* = .75; Diener et al.,

1985), and the Positive Affect subscale of PANAS (r = .69) and correlated negatively with the negative affect subscale of PANAS (r = -.58; Watson et al., 1988). While these individual measures contain important aspects of flourishing, the SURF effectively combines those facets to focus on flourishing. Based on Hypothesis 2, it is expected that combined scores for this measure will increase as self-compassion increases over time.

The Parenting Stress Index Short Form (PSI-4-SF). An abbreviated version of the full-length Parenting Stress Index-4 (Abidin, 1997; Abidin, 2012). It has 36 items, which are divided into three domains: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child, which combine to form a Total Stress Scale. This is a standard measure used to evaluate the parenting system occurring in the home and helps to identify problem areas in the child's or the parent's behavior. Internal consistency estimates for the total stress measure (a composite of subscales) were high (a = .91; Abidin, 2012; Barroso et al., 2016). Based on Hypothesis 2, it is expected that over time, scores for this measure will decrease as self-compassion increases. Additionally, this measure is likely to combine with the FQOL questionnaire to examine feelings of perceived stress overall, as opposed to the other measures (PDH, NSCQ, SURF), which are intended to measure more specific aspects of stress (daily hassles) or specific feelings which may be contraindicative of stress (self-compassion and flourishing).

Hair Cortisol. Cortisol was measured using an enzyme-linked immunosorbent assay, which involves adding samples to a plate where cortisol competes with a labeled version for antibody binding sites. The resulting color change is measured as optical density, inversely indicating cortisol levels. A standard curve is created using known cortisol concentrations, plotting optical density values to derive a regression equation. The optical density values of hair samples are compared to this curve to determine cortisol concentrations. Cortisol levels were then

compared to each self-report measure across three phases (see Figure 3).

Design and Statistics for Data Analysis

To address the research hypotheses, this study's statistical analysis used a combination of independent *t*-tests, paired *t*-tests, and repeated measures ANOVA. Independent *t*-tests were used to compare baseline stress levels between parents of ASD children and parents of NT children in Phase 1. This initial analysis was used to assess any differences in self-report measures and cortisol levels between the groups before the intervention. Group status represented the independent variable, with individual scores (per measure) and cortisol levels representing the dependent variable. According to Hypothesis 1, stress levels were expected to be higher in the parents of ASD children group than in the parents of NT children group, which the independent *t*-tests investigated.

To assess the effectiveness of the mindfulness intervention, paired *t*-tests were conducted on all five self-report measures and on cortisol levels from Phase 2 to Phase 3. This analysis evaluated changes in stress levels within each group by comparing the pre-intervention (Phase 2) and post-intervention (Phase 3) scores. According to Hypothesis 2, parental stress was expected to decrease after the intervention, and the paired *t*-tests were used to determine the impact of the intervention on stress reduction. A Bonferroni correction was not used due to the small sample size (Armstrong, 2014; Leon, 2004).

Finally, a repeated measures ANOVA was used to assess the interaction effects of time (phase) and group (parents of ASD vs. parents of NT) on parental stress levels. This analysis focused on the results of Phases 2 and 3 to investigate whether the changes in stress levels before and after the intervention differed significantly between the two groups. According to Hypothesis 3, parents of ASD children were expected to experience a more significant reduction in stress than

parents of NT children following the intervention.

Results

Participants

In total, 68 participants contributed data to this study; 30 parents of ASD children (parent age *m* = 33.6 years *sd* = 6.69 years; 100% female) and 38 parents of NT children (parent age *m* = 28.7 years, *sd* = 6.85 years; 100% female). Due to the rolling enrollment style of this project and in an effort to maintain recruitment goals, some participants (33%) were permitted to join the study beginning in Phase 2 instead of Phase 1. Of the parents who joined the study when it began in Phase 1, the average age of their infant (who participated in the gut microbiota study) was 11 months, and of the parents who joined in Phase 2, the average age of their infant was 23 months. This difference in the child's age range is unlikely to significantly affect parental stress levels (Enea & Rusu, 2020; Estes et al., 2014; Lin et al., 2021). Unfortunately, not all parents were able to complete every item, and completion rates varied for each measure and phase, with some measures seeing fewer completions as the study progressed (see Table 2). Overall, both groups contributed the most data during Phase 2, compared to Phases 1 and 3. It should be noted that the measure for parental stress (PSI) was not given to participants in Phase 1 due to its late addition to the study, which certainly contributed to the discrepancies, and attrition may account for the lower completion rate in Phase 3. Despite the variation in completion rates, 24 parents of ASD children and 32 parents of NT children contributed data in at least two of the three time points, which is necessary for the longitudinal design.

Hypothesis 1

Independent *t*-tests were conducted to determine initial (Phase 1) differences in mean questionnaire scores and cortisol levels (DV) between groups (IV). According to Hypothesis 1,

the stress levels of parents of ASD children (n = 30) were expected to be higher than those of parents of NT children (n = 38)The results indicated a significant difference in daily hassles (PDH) between groups, with parents of ASD children reporting a higher level of stress than parents of NT children ($p < 0.01$, Cohen's d = -1.44, a large effect size). Additionally, parents of NT children reported a significantly higher quality of life (FQOL) compared to parents of ASD children ($p = 0.01$, Cohen's $d = 0.87$). However, no significant differences were found between groups for self-compassion (NSCQ), flourishing (SURF), or cortisol levels. See Table 1 for more details.

Table 1

Comparison of measure means between groups at Phase 1, using independent t-tests

	ASD Sibs *M (SD)*	*n*	NT *M (SD)*	*n*	*dfs*	*p* value	Cohen's *d*
Phase 1							
NSCQ	52.44 (9.45)	25	53.70 (10.99)	27	50	0.66	0.12
SURF	95.96 (18.75)	27	103.54 (15.68)	28	53	0.12	0.44
PDH	**105.52 (21.48)**	**23**	**78.74 (15.25)**	**23**	**44**	**< 0.01**	**-1.44**
FQOL	**92.71 (16.4)**	**21**	**104.8 (11.54)**	**25**	**44**	**0.01**	**0.87**
HCC	0.83 (0.25)	19	0.75 (0.25)	20	37	0.3	-0.31

Note. Significant values are bolded

Hypothesis 2

Paired *t*-tests were conducted to compare the means of questionnaire scores and cortisol levels (DV) between Phases 2 and 3 (IV) for all parents who participated in the mindfulness intervention (n = 52; see Table 2). According to Hypothesis 2, it was expected that parents who participated in the mindfulness program would have lower stress levels after the intervention. The results showed significant differences in scores measuring self-compassion (NSCQ; p = 0.01) and flourishing (SURF; $p = 0.03$), indicating improvement in these areas post-intervention. Additionally, cortisol levels between Phases 2 and 3 showed a significant decrease (p = 0.03).

However, there were no significant differences in scores measuring daily hassles (PDH; p = 0.22), or parental stress (PSI; p = 0.12) between these phases. See Table 3 for more details. A chi-squared test was conducted to examine the relationship between group and participation in the mindfulness intervention, but the results were not significant; $X^2(1, N = 68) = 2.87$, $p = 0.09$.

Table 2

Sample sizes (*n*) *for both groups by phase and measure*

	Parents of ASD *n*			Parents of NT *n*		
Phases	1	2	3	1	2	3
Measures						
NSCQ	25	24	19	27	37	27
SURF	27	23	20	28	36	27
PDH	23	22	20	23	35	29
FQOL	21	21	19	25	34	28
PSI	n.d.	23	19	n.d.	26	25
HCC	19	26	20	20	31	26

Note. Parents of ASD total n = 30, and parents of NT total n = 38.
n.d. indicates no data was collected. PSI was not given to participants during Phase 1 due to the late addition of the PSI (Phase 1 had already ended for most participants).

Table 3

Comparison of measure means between Phases 2 and 3 using paired t-tests

	Mean	SD	*p* value
P3-P2			
NSCQ3	56.12	12.34	
NSCQ2	52.17	11.06	
diff	**3.93**	**10.08**	**0.01**
SURF3	100.79	15.15	
SURF2	96.28	20.38	
diff	**4.51**	**13.2**	**0.03**
PDH3	88.93	17.23	
PDH2	91.18	17.79	
diff	-2.25	12.06	0.22
FQOL3	102.28	10.64	
FQOL2	100.81	12.13	
diff	1.47	9.16	0.3
PSI3	80.23	23.56	
PSI2	83.78	24.65	
diff	-3.55	14.13	0.12
HCC3	0.66	0.14	
HCC2	0.73	0.19	
diff	**-0.07**	**0.21**	**0.03**

Note. The participant scores reported here for Phases 2 and 3 only include those who participated in the mindfulness intervention.
Significant values are bolded.

Hypothesis 3

A repeated measures ANOVA was conducted for each DV to investigate the interaction effect of phase and group on the reduction of parental stress after the intervention (i.e., between Phases 2 and 3). According to Hypothesis 3, it was expected that parents of ASD children would show a more significant reduction in stress levels following the intervention than parents of NT children. Results of the ANOVA revealed the group and phase main effects (though these are redundant to the independent and paired *t*-tests above; see Table 4 and Figure 2). The interaction effect was not significant at an alpha level of 0.05, suggesting that the change in stress levels following the intervention did not significantly differ between the groups. In other words, although parents of ASD children reported higher stress levels on some cortisol and stress questionnaire measures and although cortisol levels decreased following the intervention, the magnitude of stress reduction was similar for both parents of ASD children and parents of NT children.

Table 4

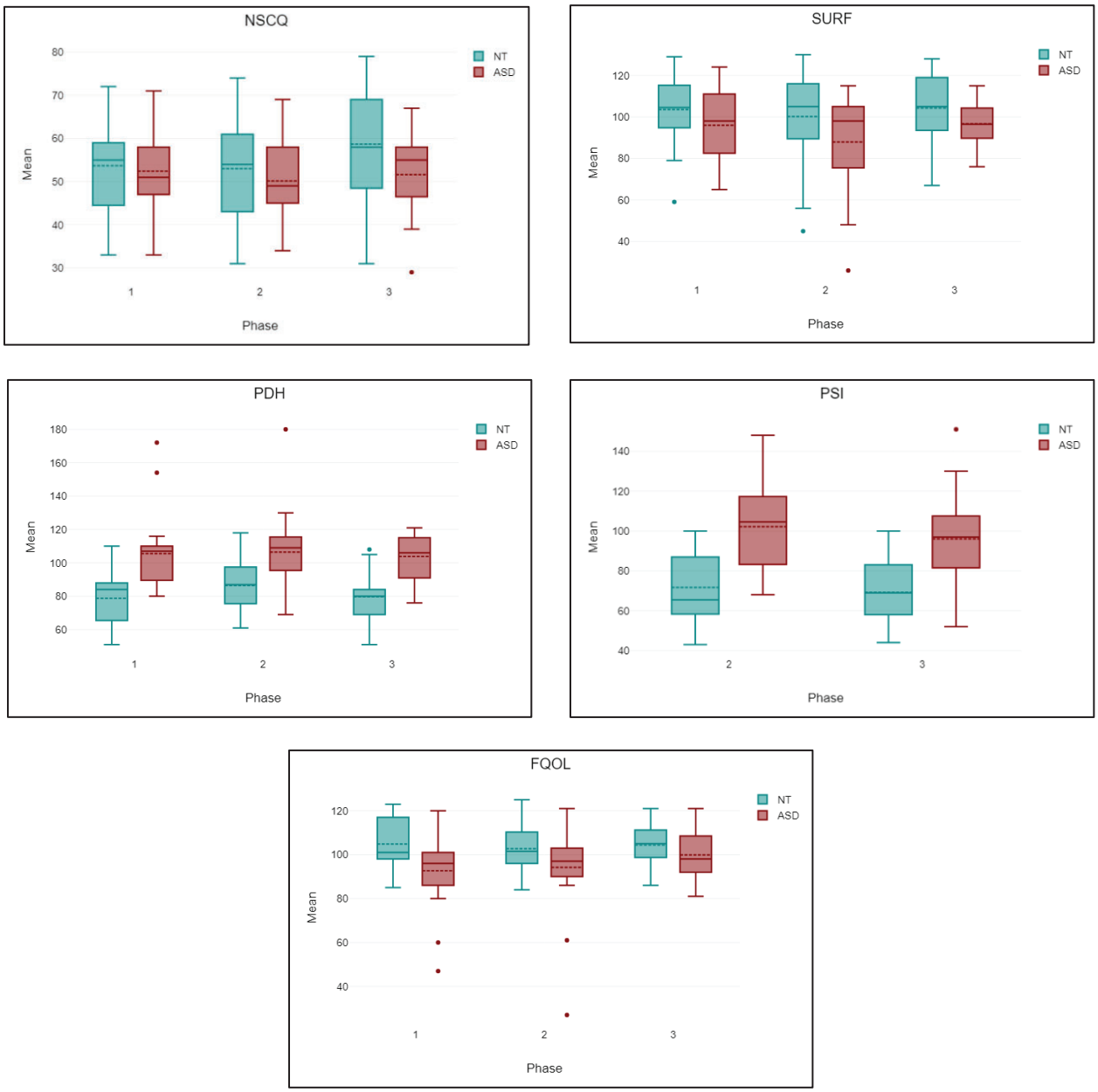
Repeated measures ANOVA for self-report and cortisol measures

Source	SS	*df*	*F*	*p*-value
NSCQ				
Group	916.93	1	4.89	0.03
Phase	260.51	1	5.08	0.03
Group x Phase	33.34	1	0.65	0.42
Residual	2101.05	41		
SURF				
Group	4115.27	1	7.54	0.01
Phase	497.45	1	5.62	0.02
Group x Phase	23.73	1	0.27	0.61
Residual	3628.8	41		
PDH				
Group	12745.37	1	29.49	< 0.01
Phase	57.43	1	0.81	0.37
Group x Phase	141.06	1	1.99	0.17
Residual	2984.06	42		
FQOL				
Group	2035.11	1	6.96	0.01
Phase	38.44	1	0.9	0.35
Group x Phase	2.07	1	0.05	0.83
Residual	1760.28	41		
PSI				
Group	18547.22	1	30.18	< 0.01
Phase	300.83	1	3	0.09
Group x Phase	80.03	1	0.8	0.38
Residual	3810.92	38		
Cortisol				
Group	0.05	1	1.3	0.05
Phase	0.44	2	6.58	0.03
Group x Phase	0.16	2	2.4	0.1
Residual	2.23	66		

Note. The participant scores reported here, for Phases 2 and 3, only include those who participated in the mindfulness intervention

Figure 2.

Comparison of questionnaire means between parents of ASD children and parents of NT children over three phases, using ANOVA.



Note. The participant scores reported here, for all three phases, only include those who participated in the mindfulness intervention

Mindfulness

Parents who completed the response survey about their participation in Neff-based mindfulness (n = 46) reported engaging in mindfulness practices for an average of 18 days, with an average daily practice of 10 minutes. The course was designed to span approximately 30 days, and participants were given at least eight weeks to complete it, allowing them to move at their own pace. Among those who completed the survey, 38 people provided positive feedback, often regarding the course's usefulness in improving their thought processes and offering strategies to manage difficult situations. However, 31 people also provided negative feedback, primarily noting that the course was time-consuming and required a computer.

Discussion

This study sought to understand stress levels among parents who have children with ASD and parents who have NT children. Hypothesis 1 stated that parents of children with autism experience more stress than parents of NT children. Findings from Phase 1 partially support this hypothesis, indicating that compared to parents of NT children, parents of ASD children reported higher stress levels on the PDH scale, suggesting that the daily hassles they experience occur more frequently and are perceived as being more highly distressing. Though not significantly different, the raw cortisol levels may indicate higher levels of stress in parents of ASD children compared to parents of NT children. However, further research would be necessary to determine a true conclusion. The significant differences in the PDH scores between parents of ASD children and parents of NT children align with other literature, which suggests that some autistic children may depend more heavily on their parents to meet their daily needs, which may also be more intense or prolonged than NT children of the same chronological age (Enea & Rusu, 2020; Hayes & Watson, 2013; Ogston et al., 2011).

Parents under constant stress without adequate relief can experience a depletion of their emotional and cognitive resources. The perpetual nature of these stressors leaves little room for recovery, further hindering parents' ability to cope effectively with daily challenges, creating a vicious cycle of stress and diminished well-being (Epel et al., 2018; Hayes & Watson, 2013). The implications of these findings suggest that the heightened PDH scores observed in our study reflect the challenges faced by parents of children with autism. It is important to note, however, that there were parents of ASD children who were involved in this study who reported that they did not feel that they were more stressed than parents of NT children.

On the other hand, parents of ASD children rated their quality of life as significantly lower than parents of NT children on the FQOL questionnaire This questionnaire asks several questions about available support in different contexts and questions regarding a cohesive family system. The significant difference in FQOL scores found in this study could suggest a difference in the perceived support available to families with autistic children or feelings of familial cohesion. This does not mean that families with autistic children never experience support or cohesion, but most research has demonstrated that there are families with autistic children who may lack social support and may experience limits in some familial opportunities (Karst & Van Hecke, 2012; Rivard et al., 2014; Sanders & Morgan, 1997).

The lack of significant findings for the difference in HCC levels between parents of ASD children and parents of NT children may be due to several factors, such as a lack of necessary sensitivity in the measurement. It is also possible that the small sample size of groups in this study affected the results. However, it could be that there simply is no difference to be found. Some literature in this area has reported consistent results (Gidlow et al., 2016; Szep et al., 2021; Weckesser et al., 2019), and others have reported inconsistent results (Russell et al., 2012; Wells

et al., 2014) with the current findings. More research is needed to clarify these findings.

Scores measuring self-compassion (NSCQ) and flourishing (SURF) increased from Phase 2 to Phase 3, partially supporting Hypothesis 2, which states that parents participating in the mindfulness program will experience decreased stress. While neither the NSCQ nor the SURF were direct measures of stress, their role in reflecting broader enhancements in mental health and well-being roughly supports the hypothesis that participants likely experienced decreased stress levels following the intervention. These results also support research that mindfulness practices can significantly benefit well-being (Dorjee, 2010; Neff, 2023; Neff & Faso, 2015; Warren, 2020). However, there was no significant difference in PDH or PSI scores from Phase 2 to Phase 3, which implies that the intervention may not have been impactful enough to see results in this area, or it may indicate the need for a different intervention more targeted to supporting parents in their daily hassles or both (Harper et al., 2013) Additionally, this could also indicate a lack of necessary sensitivity in the measurement. Because this mindfulness intervention was not targeted specifically toward reducing daily hassles, it is not surprising to see a lack of results in this area. However, it may lend credence to the need for more specific interventions, such as practical assistance, as broad and remote mindfulness programs may not be as beneficial (Althoff et al., 2019; Ji & Shim, 2020; Razani et al., 2018). Interestingly, there were significant differences in cortisol levels from Phase 2 to Phase 3, which supports Hypothesis 2. This significant decrease in cortisol indicates that the intervention may have had a beneficial effect on physiological stress, even if it did not benefit subjective stress. This dichotomy between subjective and physiological measures emphasizes the complexity and multifaceted nature of stress.

These findings imply that while parents may not have perceived a reduction in their daily hassles or overall stress levels, their bodies exhibited a physiological response indicative of

reduced stress. This discrepancy highlights an important consideration in stress research: the subjective experience of stress does not always align with physiological indicators. Previous studies have shown similar inconsistencies, where subjective measures of stress do not correspond with biomarkers like cortisol (Gidlow et al., 2016, Ling et al., 2020).

This divergence raises intriguing questions about the mechanisms through which interventions exert their effects. It is possible that the mindfulness practices employed in the intervention were effective in reducing physiological stress responses, even if participants did not consciously perceive a reduction in their stress levels. This aligns with the notion that mindfulness can influence the body's stress regulation systems directly, potentially bypassing conscious appraisal processes (Smith et al., 2017).

We did not find support for Hypothesis 3. This hypothesis predicted that parents of children with autism would benefit more significantly from the mindfulness intervention than parents of NT children. The absence of significant interaction effects suggests that the intervention's impact did not vary significantly between the two groups. This finding warrants a closer examination of the intervention's design and its applicability to the unique challenges faced by parents of children with autism, as it suggests that interventions might need to be tailored more specifically to address their distinct stressors. These parents may benefit more from interventions that are specifically designed to help them manage the unique behavioral, communicative, and social difficulties associated with autism.

Research by Weiss et al. (2012) found that parent training programs specifically designed for parents of children with ASD, focusing on behavioral management and coping strategies, were more effective in reducing parental stress than general stress reduction programs. Similarly, Keen et al. (2010) highlighted the importance of incorporating elements that address the specific

needs of autistic children, such as communication skills and social support networks, into parental support programs.

This discrepancy between subjective and physiological stress measures found in this study suggests that future research should explore interventions that combine mindfulness with other therapeutic approaches, such as cognitive-behavioral therapy, which have proven effective in addressing the specific needs of children with autism and their families (Estes et al., 2014; Blackledge & Hayes, 2006).

Furthermore, this study highlights the importance of using both subjective and objective measures to capture stress. Self-report measures like the PDH and PSI provide valuable insights into the psychological and emotional aspects of stress, while cortisol levels offer an objective biomarker of physiological stress response. The lack of significant differences in cortisol levels between NT and ASD groups at baseline, despite higher self-reported stress among parents of children with autism, suggests that subjective experiences of stress may not always align with physiological responses. This finding underscores the need for a holistic approach to understanding and addressing parental stress, which may include facilitation of familial teamwork and discussion of hardships (Smith et al., 2017).

The results also suggest that support programs need to be more carefully tailored for parents of children with autism. For instance, the use of mobile-friendly interventions rather than computer-only programs could enhance participation and effectiveness. While the mindfulness intervention showed promise in increasing self-compassion and flourishing, additional strategies are necessary to address the persistent daily hassles reported by these parents. Practical assistance and strategies to manage daily stressors are essential components of effective support programs. The increase in self-compassion and flourishing suggests that interventions focusing

on psychological well-being can have positive effects, but more comprehensive support is needed to address the full range of stressors experienced by these parents.

Limitations

Several limitations must be acknowledged. The small effect sizes observed in cortisol level changes suggest that the physiological impact of stress might be more subtle or require more sensitive measures to detect. This subtly may have limited our findings, as more pronounced changes might be necessary to observe significant effects. Though HCC has been used as a reliable measure of reporting long-term stress levels (Brianda et al., 2020; Goldberg et al., 2014; Kirschbaum et al., 2009), it is possible this may not provide a comprehensive enough picture of the physiological stress response. Future research may benefit from exploring a wider array of biomarkers to capture a more complete picture of the stress response.

Additionally, in preparing the hair samples to analyze, we found the hair samples to be difficult to work with, which affected our ability to weigh the samples with precision. Static cling often caused pieces of hair to move unexpectedly or stick to our instruments (e.g., tweezers, test tubes), which impacted our ability to add or remove very small amounts of hair when weighing the samples. This resulted in up to a 5 mg variability in weight across samples, though this was not expected to affect the results (Orta et al., 2018). Other studies have washed the samples before weighing them (Meyer et al., 2014), which likely helped mitigate this issue. Future HCC research should consider this to help minimize weight differences between hair samples.

Most notably, during this study, there was substantial inconsistency regarding completing the mindfulness course. Of the parents in this study, 23% did not participate in the course. Of those parents, 19% refused to participate in the course outright, roughly 37% attempted to

participate but found the requirements too time-consuming or strenuous, and nearly 19% decided to leave the study altogether. The remaining parents did not participate in the mindfulness course for unknown reasons. However, almost 68% of parents completed the follow-up questionnaire at the end of the study, which included an open-response section. We plan to analyze this data in a future project but do not consider it sufficient for determining why so many parents chose not to participant in mindfulness.

Unfortunately, this study had difficulty aligning the researchers' schedules (including the university calendar) with those of the participants. In addition to this, strict pacing was not made a high enough priority, which resulted in participants moving at different paces and being exposed to varying conditions over time. Though we were consistent about a minimum of eight weeks between each phase, the maximum amount of time was only constrained by the child aging out of the extended microbiota study based on phase age limits, which, in turn, peaked the parent's participation in that phase of the present study. For example, a participant may have begun Phase 1 when their child was ten months old, finished the questionnaires and hair sample for that phase within a week, and then not begun Phase 2 until their child was 22 months old, resulting in 12 months passing between Phase 1 and Phase 2, and leaving them only one month to complete Phase 2. This resulted in a non-uniform experience for participants, potentially introducing variability in the data. This heterogeneity in participant experiences complicates the analysis and interpretation of the results, as it is challenging to attribute changes solely to the study interventions without accounting for discrepancies. Future studies should consider more synchronized pacing protocol strategies to mitigate these variations and enhance the reliability of the findings.

Another limitation of this study is the lack of control regarding likely confounds of

family structure and family size. While these factors could influence the outcomes measured, restricting enrollment criteria to account for them would have significantly hindered participant recruitment. Given the challenges we already faced in enrolling a sufficient number of participants, further limiting the pool by family structure and size would have likely resulted in an unfeasibly small sample. Although statistical adjustments could have been employed to account for these confounding variables, recruitment restrictions often provide more straightforward and effective control. However, the necessity to balance practical recruitment issues with methodological rigor led to the decision to prioritize sample size over these specific controls. Future research should aim to incorporate these factors either through more extensive recruitment efforts or more sophisticated statistical techniques to ensure a comprehensive understanding of their impact on the study's findings.

Additionally, the small sample size of participants in this project affects the generalizability of the findings. It limits the potential ability to perform subgroup analyses, which could provide more nuanced insights into the effects of the mindfulness program on different demographics. Furthermore, a smaller participant pool may not adequately represent the broader population of parents with children with autism compared to parents with NT children, limiting the external validity of the study. Future research should aim to include a larger and more diverse sample to enhance the reliability and applicability of the results. By increasing the sample size, future studies can better capture the variability within the population and provide more robust evidence regarding the impacts of mindfulness programs on parental stress.

Though some qualitative data was collected using a brief follow-up questionnaire sent to participants after Phase 3, no interviews were conducted. These could have provided deeper insights into the discrepancies between self-reported stress and cortisol levels. Without this

interview data, we were unable to fully explore the contextual factors and personal experiences that contribute to the perceived stress levels of parents. Interviews could have revealed how parents interpret and articulate their stress, uncovering subtleties that quantitative measures alone cannot capture. This lack of qualitative insight limits our understanding of why some parents report high stress despite relatively low cortisol levels. Future research should include in-depth interviews to better understand individual coping strategies, support systems, and specific stressors related to parenting a child with autism. Integrating this type of qualitative data with quantitative findings would offer a more comprehensive view of parental stress, thereby enhancing the effectiveness and personalization of interventions.

Future research should consider exploring the impact of a wider variety of interventions, including those offering practical support and community resources (Eun Sun Ji & Ka Ka Shim, 2020). This could help identify the most effective strategies for supporting these parents. Additionally, investigating the role of parental self-efficacy could offer more nuanced insights into the challenges faced by parents of children with ASD and inform more targeted support programs (Coleman & Karraker, 1998; Higgins et al., 2022; Jackson & Scheines, 2005). Studies should also consider the broader family context, including the impact of parental stress on siblings and the potential benefits of family-centered interventions (Altiere & von Kluge, 2009a; Anversa Carmo et al., 2019; Greeff & van der Walt, 2010; Pfeiffer et al., 2017).This approach may help reveal more about the intricacies and components of daily stress, and help develop more effective and holistic support strategies.

If the scientific community can provide tools to support the intuitive, daily practice of self-compassion, parents may feel better equipped with adaptive coping mechanisms to combat negative self-talk or negative appraisal of daily situations. However, based on the results of this

study, it seems likely that just providing tools to apply to difficult situations may not be enough to reduce parental stress. More practical applications of stress reduction, such as providing respite care (Harper et al., 2013) or behavioral support (Weiss et al., 2012) may make a more impactful difference. The findings of the current study underscore the critical need for future research methods to investigate targeted strategies of stress reduction and the advantages of developing self-compassion. These efforts are crucial to benefit the overall well-being of parents of children with autism and positively contribute to their family's well-being.

Conclusion

This study demonstrated that parents of children with autism experience significantly higher stress levels compared to parents of NT children, especially in regards to daily hassles and reduced quality of life. Integrating a mindfulness intervention showed potential benefits in reducing physiological stress, evidenced by a significant reduction in cortisol levels. The integration of mindfulness interventions showed potential benefits in reducing physiological stress, as evidenced by significant reductions in cortisol levels and increased self-compassion and flourishing. These findings reinforce the need to develop comprehensive support systems that address the psychological and physiological aspects of parental stress.

This research revealed discrepancies between parents' physiological and self-reported stress levels, which emphasizes the importance of integrating biomarkers like hair cortisol into future research to gain a more accurate and comprehensive understanding of parental stress. By integrating hair cortisol with a more traditional methodology, this study has incorporated a dual approach of a biological measurement with a self-report measurement capturing both subjective and objective aspects of stress., paving the way for more targeted and effective interventions.

This study represents a step towards a broader understanding of parental stress in the context of autism, but it also opens avenues for future research. The combination of self-report measures and cortisol analysis represents a methodological advancement in stress research, offering a model for future studies that capture subjective experiences and objective stress markers. Even so, it is important to address the role of daily hassles on parents. A better understanding of parenting daily hassles will likely allow for the development of more effective support strategies and the exploration of increasingly accurate measurements. The intention of this research has been to add to the overall body of work on parental stress in the context of autism, and we hope that future research will continue developing comprehensive support systems that enhance the lives of parents and their children with autism.

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Appendix A

A more extensive study involving the same participants (or, more accurately, the children of the parents involved in the current study) was also conducted to examine the gut microbiota as an early predictor of autism traits. This study examined gut microbiota in three phases, occurring before, during, and after gut microbiota has been assumed to stabilize. This umbrella study required infant participants to have an older sibling with ASD. However, during the early years of the COVID-19 pandemic, autism diagnosis was significantly delayed, which affected recruitment. To help mitigate this delay, the following screeners were used to help identify suspected autism in children being considered for this study (M-CHAT-R, SCQ, ITC). Additionally, to identify autism traits in the infants (who, by the end of the study, would be between 24 and 32 months old), the ADOS-2, Mullen, and Vineland-3 were used.

The Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R):

The M-CHAT-R is completed by parents of children 16-30 months. It contains 20 questions and takes 5-10 minutes to complete. The M-CHAT has a sensitivity of 0.87, specificity of 0.99, positive predictive power of 0.80, and negative predictive power of 0.99. Discriminant function analysis indicates that the M-CHAT can correctly classify 99% of children as "have ASD" or "do not have ASD." Referral to formal evaluation is necessary for a diagnosis (Robins et al., 2014).

Social Communication Questionnaire (SCQ):

The SCQ is completed by parents of children who are 2.5 years old or older. It contains 40 items and takes approximately 15 minutes to complete. Sensitivity and specificity are high for discriminating between cases of ASD and non-ASD, (sensitivity 0.88, specificity 0.72) and between autism cases and non-autism cases (sensitivity 0.90, specificity 0.86; Chandler et al., 2007). Recent studies have also shown efficacy for ASD detection in children as young as 2

years old (Corsello et al., 2013). Use of the SCQ is an invaluable resource in the current study by providing an age-appropriate and psychometrically sound parent-report measure (Chandler et al., 2007; Rutter et al., 2003).

Infant Toddler Checklist (ITC):

The ITC is completed by the parents of children between 6 to 24 months old, including children who exhibit communication delays. It consists of 24 questions regarding typical social communication milestones meant to address possible parent concerns. The validity of the ITC for detecting communication delays with estimates of positive and negative predictive value at or higher than 70%. The ITC is able to identify cases of autism in a population sample at 93.3%, though it is unable to reliably distinguish children with autism from children with other communication delays (Wetherby et al., 2008).

Autism Diagnostic Observation Schedule-2 (ADOS-2):

The ADOS is a semi-structured, standardized assessment of communication, social interaction, play, and imagination designed for use in diagnostic evaluations of individuals referred for ASD The ADOS encompasses four modules, each with its own schedule of activities that allow examiners to observe behavior in participants of social and language levels, ranging from those with no expressive language to verbally fluent children and adults. In toddlers, the ADOS is capable of distinguishing between autism cases and non-spectrum cases (sensitivity 0.89, specificity 0.94; Gotham et al., 2006; Lord et al., 2012).

Mullen Scales of Early Learning (Mullen):

The Mullen is a developmentally integrated system that assesses language, motor, and perceptual abilities, and measures cognitive ability and motor development quickly and reliability. It should be administered to children from birth to 68 months, by a qualified administrator. It can take

anywhere from 15 minutes to 60 minutes to complete, depending on the age of the child. While the Mullen is not a definitive indicator for autism, it can be used to evaluate the strengths and challenges of the child, and may assist in the selection of services (Akshoomoff, 2006; Mullen, 1995).

The Vineland Adaptive Behavior Scales Third Edition (VABS-3, or Vineland-3):

The Vineland is a useful instrument for supporting the diagnosis of intellectual and developmental disabilities. The Interview and Parent/Caregiver Form is appropriate to administer to parents of children ages 3-21 years old. The Vineland assesses communication, daily living skills, socialization, motor skills, and maladaptive behavior (Perry & Factor, 1989; Sparrow et al., 2016).

Appendix B

Course Workbook

Welcome to the Gift of Self-Compassion Course! This workbook is designed to give you a helpful structure for progressing through the course material.

You can use this workbook to keep track of insights (you can use the space provided or the notes pages at the end), record responses to the course exercises, and keep track of any time you spend to learning about and practicing self-compassion strategies .

Please follow the instructions in this booklet carefully, as some directions may differ from the original course material

This workbook is just for you—we won't be collecting them.

Congratulations on taking this step toward a kinder and gentler relationship with yourself!

You may progress through the units at your own pace. We encourage you to do your best to practice the strategies you learn every day, even if it's just for a short amount of time.

Unit 1.1 Your Self-Compassion Journey Begins Here!

- ☐ Watch the introduction video
- ☐ Write your commitment below

I commit to . . . .

You should have already taken the Self-Compassion Questionnaire and the Survey on Flourishing, and you do not need to take them again unless you would like to.
You also do not need to download the other workbook provided—just use this one

- ☐ Record your scores if you would like to
- ☐ Leave a comment on the website if you would like to

Unit 1.4 About Your Instructor

- ☐ Meet your instructor (watch the video)
- ☐ Leave a comment if you would like to

Unit 1.5 How to Make the Most of this Course

- ☐ Watch the instruction video
- ☐ I am committed to this course
- ☐ I am willing to approach this as an experiment
- ☐ I will be engaged in this course

The private Facebook Group isn't applicable to this study, so don't worry about joining it
But if you would like to find a friend to help you stay committed, that's up to you!

- ☐ Leave a comment if you would like to

Unit 1.7 Quick Self-Compassion Practices

- ☐ Read the Urgent Self-Compassion Practices
- ☐ Complete the 90 second guided practice (audio)
- ☐ Read the 5-Minute Self-Compassion Practices
- ☐ Complete the 5-minute guided practice (audio)
- ☐ Leave a comment if you would like to

Unit 1.8 Self-Compassion Strategies Menu

- ☐ Read through the Self-Compassion Strategies Menu
- ☐ Bookmark that page for later use
- ☐ Leave a comment if you would like to

Unit 2.1 What is Self-Compassion?

- ☐ Watch the video explaining Self-Compassion
- ☐ Complete the supplemental reading assignment found on the link provided

Exercise:

How do I/would I treat a friend who is hurting? (phrases, nonverbal expressions, actions, etc.)

How do I treat myself when I am hurting?

- ☐ **Pick Your Practice:** Do the 5-minute practice again, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 2.2 Building Blocks of Self-Compassion (and their opposites)

- ☐ Watch the video explaining the building blocks of self-compassion
- ☐ Complete the supplemental reading assignment found on the link provided
- ☐ Leave a comment if you would like to

Exercise:

Think of a recent challenging experience where your mind was producing some self-critical thoughts. Write down the self-**critical thoughts (use quotation marks; e.g., "I'm not good enough," "I really blew it.")**.

As you recall this challenging experience, how many people do you think have ever felt the same way? How many people in the world right now may be experiencing the same emotions? Could there be people you know well who can relate to this experience? **Whatever you're experiencing, you're not alone in this. Write down some thoughts** about how this experience could actually increase your sense of connection with others.

This is a challenging experience. No need to sugar-coat it or pretend it's better than it is. **It's okay to struggle at times. Take a deep breath and observe what your mind is saying about the experience. Is there a discouraging "storyline" or familiar theme that** comes along with this experience? Go ahead and label the story or theme. See if you can **put a few words to the emotions you're experiencing. Breathe into those emotions (whatever that feels like for you), and just observe what's there with a gentle curiosity.**

Continued on next

Storylines/themes:

Emotions:

Finally, write down some phrases that would communicate kindness toward yourself. If you need to, start by thinking of what a close friend or loved one would say to show kindness toward you in this situation.

Let those phrases of kindness and encouragement sink into you; soak them up like **you're a sponge. Spend at least 15 seconds taking in those words of support, and let** them stay with you as you go about the rest of your day.

Unit 2.3 The "Magic" of Mindful Awareness

- ☐ Watch the video explaining mindful awareness
- ☐ **Complete the supplemental reading: "What is mindfulness" provided as a link**
- ☐ **Complete the supplemental reading: "Resistance and Acceptance" provided as a link**
- ☐ **Pick Your Practice:** Do the 5-minute practice, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 2.4 Misconceptions About Self-Compassion

Exercise:

Write down any concerns or misgivings you currently have about self-compassion.

- ☐ Watch the video explaining the misconceptions about self-compassion
- ☐ Complete the supplemental reading assignment found on the link provided
- ☐ Leave a comment if you would like to

Unit 2.5 Why Self-Compassion Matters

- ☐ Watch the video explaining why self-compassion matters
- ☐ Complete the supplemental reading assignment found on the link provided

Exercise:

What do you hope to get out of learning self-compassion? How could your life be different if you got better at this?

- ☐ Leave a comment if you would like to

Unit 3.1.1 Introduction to the Practice Session

- ☐ Read the welcome message
- ☐ Choose another practice or exercise from the link provided, or from the bonus exercises
- ☐ **Decide on a couple of "go-to" practices that you could do anytime, and write them here**

Unit 3.1.2 A Taste of Self-Compassion

- ☐ Complete the Brief Self-Compassion guided practice (audio)
- ☐ Leave a comment if you would like to

Unit 3.2 Compassionate Grounding

- ☐ Find a place where you can sit comfortably, with both feet on the floor
- ☐ Complete the Compassionate Grounding guided practice (audio)
- ☐ Leave a comment if you would like to

Unit 3.3 Becoming Aware of the Self-Critical Voice

- ☐ Complete the Leaves on a Stream guided practice (audio)
- ☐ Leave a comment if you would like to

Unit 3.4 Working with Challenging Emotions

- ☐ Complete the lesson, Working with Challenging Emotions
- ☐ **Practice:** Bring to mind a recent challenging experience that evoked some difficult emotions. Experiment with the techniques listed, spending at least a minute or two with each. Write down which ones you liked the most.

Exercise:

What did you notice as you practiced these experiences? Which ones would you like to **spend more time with? Are there ways you'd like to adapt or personalize these** exercises? If you think of additional ways you could practice acknowledging, allowing, and accommodating emotions, write down your ideas.

- ☐ Leave a comment if you would like to

Unit 3.5.1 Nurturing: A Supportive Touch

- ☐ Complete the lesson, Nurturing: A Supportive Touch

Exercise:

What did you notice as you practiced these physical gestures of support? Which ones would you like to continue to work with?

- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.5.2 Nurturing: Finding your Phrases

- ☐ Complete the lesson, Nurturing: Finding your Phrases

Exercise:

Reflect on what you just read. Think: What do I need? What do I long to hear to feel truly nurtured? What would make a difference in my life if I really believed it or lived it?

My favorite self-compassion phrases so far:

- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.6 A "Compassionate Benefactor"

- ☐ Complete the Compassionate Benefactor guided practice (audio)
- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.7 RAIN of Self-Compassion

- ☐ Complete the lesson, RAIN of Self-Compassion
- ☐ Complete the RAIN of Self-Compassion guided practice (audio)
- ☐ Leave a comment if you would like to

Unit 3.8 Notice and Pivot

- ☐ Complete the lesson, Notice and Pivot (Note: this unit is long—feel free to break it up)

Exercise:

Notice self-criticism

Can you think of some recent self-criticisms your mind has come up with? What are some of the most common self-critical statements your mind produces? Write them out using quotation marks (e.g., "I'm not good enough," "I'm too lazy," "I'm not smart.").

Extra noticing practice: Spend the next day or two paying careful attention to any self-criticisms your mind produces, and write them down along with the context they came up in. [For example: *Self-Criticism:* **"I'm unattractive."** *Context:* Watching a music video with attractive models/dancers].

Be ready to pivot toward self-kindness as described below. Also, notice patterns in the contexts/circumstances where self-criticisms arise. Over time, you can be aware of the circumstances that tend to elicit self-criticisms, and be prepared with self-compassionate phrases and gestures when those circumstances can't be avoided.

Continued on next

Pivot Toward Self-Kindness

No need to argue with the self-critical thought or evaluate its accuracy; simply imagine taking that energy your body and mind are devoting to self-criticism, and redirecting it into self-kindness.

Choose a few of the kind, nurturing responses that you've worked with so far and practice using them now (e.g., a favorite kind phrase toward yourself, a supportive touch), just as if a close friend or loved one were extending this kindness to you.

Take a few moments to experiment with these expressions of kindness in response to the self-criticisms you identified; keep going until you have a sense for which responses will be most helpful.

Action Plan:

Use this plan to extend kindness to yourself whenever you notice these specific self-criticisms arise: *when I notice my mind saying...*[insert self-critical thought], *I will...*[insert self-kindness response].

Great! Now be on the lookout for these self-criticisms so you can quickly pivot toward self-kindness!

Notice the impulse to self-isolate

Can you think of a time when you were facing a challenge and your impulse was to distance yourself from others? In what contexts and circumstances is this most likely to happen for you? Write down a few examples from your experience.

Continued on next

Pivot Toward Common Humanity

There are many ways to pivot toward common humanity. It can start with just the acceptance that challenges are a normal part of the human experience. Can you give yourself permission to be human? Permission to be a work in progress? It's normal to struggle at times; you're in good company!

Even though your specific circumstances and experiences are unique to you, who else can relate to how you're feeling? You're really not alone in this. Are there people in your support network you would be willing to lean on? It's okay to give yourself some "alone time" when you need it. Just consider whether or not that really is the most compassionate response in helping yourself move through this challenge.

Seeking connection when you're struggling can feel vulnerable, but are there helpful ways you can turn toward others instead of away from them? Consider the Swedish proverb: "Shared joy is a double joy; shared sorrow is half a sorrow."

Write down a few ways that you could tap into the principle of common humanity, including phrases, reminders, and actions to reinforce your connection with others.

Action Plan:

Use this plan to pivot toward common humanity: *When I'm struggling and I notice the impulse to isolate myself from others, I will...*[insert common humanity response].

Excellent! In the coming days, pay attention to impulses to distance yourself from others, so you can quickly pivot toward common humanity!

Continued on next

Notice Rumination and Over-Identification

Think about times recently when your mind has been "stuck" on an unhelpful train of thought. What was the issue and what were the thoughts that kept you stuck? Write down a few examples:

A similar process happens when we over-identify with a thought or judgement, letting **it define us (e.g., "I'm a failure", "I'm an anxious person").** Write down examples that come to mind for you:

Pivot Toward Mindfulness

Happily, most of the exercises in this course help cultivate mindfulness! Continuing to practice with any of your favorite exercises will help you more quickly notice and escape from rumination and over-identification. In particular, spend more time with the following exercises: Compassionate Grounding (3.2), Leaves on a Stream (3.3), RAIN of Self-Compassion (3.7), and Affectionate Breathing (3.13).

In a pinch, you can work with very simple practices, like taking three deep breaths, **pausing to notice physical sensation, or reflecting on something you're grateful for.**

Action Plan:

Use this plan to pivot toward mindfulness: ***When I notice I'm stuck ruminating in an unhelpful way, I will...*** [insert a favorite mindfulness exercise].

Nice work! In the coming days, pay attention to when your mind is ruminating or over-identifying with a thought or judgement, so you can quickly pivot toward mindfulness!

Unit 3.9 Active Self-Compassion

- ☐ Complete the lesson, Active Self-Compassion

Exercise:

Think about a couple of challenging areas in your life right now that may benefit from active self-compassion. For each of the four categories discussed in the lesson (*Motivation, Protection, Providing for Needs, Taking Action*), brainstorm ways that you could practice active expressions of self-compassion.

- ☐ Check out the Personal Growth module at the link provided
- ☐ Check out the Supportive Relationships module at the link provided
- ☐ Leave a comment if you would like to

Unit 3.10 Metta Practice: Fostering Connection

- ☐ Complete the SC Metta Practice guided practice (audio)
- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.11 Working with Challenging Thoughts

- ☐ Complete the lesson, Working with Challenging Thoughts

Exercise:

Write down some of the recent challenging thoughts your mind has thrown at you (e.g., **"No one cares about me," "I'm not very attractive.").**

Continued on next

Which of the techniques in the lesson helped create some healthy perspective or distance from the challenging thought? What did you notice?

Pick one of your most challenging thoughts:

- Does this thought take you toward the life you want or away from it?
- If you let this thought guide your actions, will that help you behave like the person you want to be?
- If you were to believe this thought 100%, where would it take you? Who would you be? Who would you be and how would you act if you set this thought aside?

- ☐ Leave a comment if you would like to

Unit 3.12 Self-Compassion Letter

- ☐ Complete the lesson, Self-Compassion Letter
- ☐ Carefully read the instructions in the lesson, and use the next page in this workbook or a separate notebook or journal to record your letter
- ☐ Leave a comment if you would like to

Continued on next

Unit 3.13 Affectionate Breathing

- ☐ Complete the Affectionate Breathing guided practice (audio)
- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.14 Tackling Perfectionism

- ☐ Complete the reading and exercises in the Tackling Perfectionism Mini Module

Exercise:

Which "optimalism" strategies would you like to work on? Make a plan for how you will bring these strategies into your weekly routine to soften the oppression of perfectionism.

- ☐ Leave a comment if you would like to

Unit 3.15 Self-Compassion in Relationships

- ☐ Complete the lesson, Self-Compassion in Relationships
- ☐ Complete the In for Me Out for You guided practice (audio)
- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.16 Loving Your Mess

- ☐ Complete the lesson, Loving Your Mess
- ☐ Complete the Loving Your Mess guided practice (audio)
- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.17 From Struggle to Connection

- ☐ Complete the lesson, From Struggle to Connection

Exercise:

Follow the instructions for Exercise 3.17 in the lesson

What came out of the conversation with your friend/family member/colleague? Could you relate to each others' experiences? How did it help you to hear how someone you admire has experience with self-criticism and discouragement?

- ☐ **Pick Your Practice:** Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.18 Self-Compassion and Your Body

- ☐ Complete the content and exercises in the Body Appreciation Mini Module
- ☐ Leave a comment if you would like to

Unit 3.19 Values: A Wellspring of Self-Compassion

- ☐ Complete the lesson, Values: A Wellspring of Self-Compassion
- ☐ Note: This unit is long, feel free to break it up

Exercise:

Using the next page of this workbook or a separate notebook or journal, write down the answers to the following questions:

Continued on next

- What do I want my life to be about?
- What do I want to offer the world?
- What message do I want to be attached to my existence?
- As a child, what kind of life did I dream about?
- What do I want to stand for?
- What in my life right now brings me a sense of purpose, meaning, or engagement?
- **In the times in my life when I've felt the most "alive", what was I doing?** How was I acting?
- Who do I most admire? Who inspires me? What strengths or qualities do **they have that I'd like to emulate?**

Answers:

Continued on next

Values Clarification Exercise:

Instructions:

1. Review the list of values below and circle the ones that best represent what is *most important* to you (i.e., how you want to live; what you stand for in life). Write your own if needed in the spaces provided
2. See if you can narrow down the list to the most important 6-8 core values. If necessary, compare values head-to-**head and consider which one would "win" most often for you**
3. On the following page, rank order your values as best you can starting with the most important value. Then write a behavioral description (1-2 sentences) of what it would look like for you to live in alignment with each value.

Acceptance	Excitement	Intelligence	Respect
Achievement	Fairness	Intimacy	Responsibility
Adventure	Fame	Justice	Safety
Assertiveness	Family	Kindness	Self-Acceptance
Authenticity	Fitness	Knowledge	Self-Control
Balance	Flexibility	Learning	Sensuality
Beauty	Forgiveness	Love	Service
Belonging	Freedom	Making a Difference	Sexuality
Challenge	Friendship	Mastery	Solitude
Comfort	Fun	Mindfulness	Spirituality
Commitment	Generosity	Openness	Stability
Community	Gratitude	Order	Strength
Compassion	Growth	Passion	Tolerance
Contribution	Hard Work	Patience	Trust
Courage	Harmony	Peace	Truth
Creativity	Hope	Persistence	Virtue
Cultural Heritage	Honesty	Pleasure	Wealth
Curiosity	Health	Power	Wisdom
Discipline	Humor	Protection	_____
Engagement	Independence	Quiet	_____
Environmentalism	Integrity	Relationships	_____

Continued on next

Value: Behavioral Description:

Ten Years From Now...

Imagine you are in the future, ten years from now, and you are looking back on your life as it is today. Complete these three sentences:

I spent too much time worrying **about...**

I did not spend enough time doing **things like...**

If I could go back in time, what I'd do differently is...

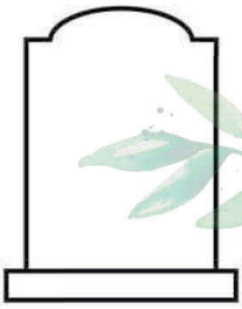
Continued on next

The Magic Wand

With the wave of a magic wand, any difficult emotions, thoughts, memories, or barriers no longer have any impact on you. What would you do with your life? How would you act differently? What would you start doing, or do more of, stop doing, or do less of? If a documentary were being filmed on your new magical life without limitations, what would we see you doing?

Your Tombstone

On the outline of the tombstone below, write your full name at the top. Below your name, write the words: **"A person who. . ."** Now let yourself imagine that you have just died, after a full life, having lived it exactly how you wanted to live. Your tombstone is being carved with a single sentence that captures what your life was about, and you have the power to choose those words. When you're ready, write the words that express the ideal version of your life.



Continued on next

Your Eulogy

Imagine your funeral, where family, friends, and others whose lives were touched by you are gathered to celebrate your life. Imagine that a masterful Eulogist has surveyed all of these people to learn about their experiences with you, and has summarized these into 3 overarching themes. What do you want these 3 themes to be? Don't worry if these don't completely describe you right now; you will have the opportunity to make them true as you live and learn in the coming years. Consider how these themes can be incorporated into your statements of core values.

Theme 1

Theme 2

Theme 3

Wrap-up

Using your notes from the above exercises, summarize in a small number of words or phrases what you consider to be your core values. As in the Values Clarification exercise, it's helpful to expand those thoughts by writing a behavioral description for what each core value can look like in your life right now. For example, I have *Courage as one of my core values, so I wrote as a behavioral description: "Doing the things that are hard but important for living with integrity, authenticity, and wholeheartedness."*

Phrases describing your core values:

- ☐ Make a goal to connect with your core values at least weekly
- ☐ Leave a comment if you would like to

Unit 3.20 Loving Who You Are

- ☐ Complete the Loving Who Your Are guided practice (audio)
- ☐ Pick Your Practice: Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.21 Create Your Own Practice

- ☐ Complete the supplemental reading assignment found on the link provided
- ☐ Complete the lesson Create Your Own Practice

Exercise:

Come up with your own brief self-compassion exercise that attends to what you need most right now. You can write it out in a script, or just use a few bullet points describing the main steps, but see if you can come up with your own exercise that pulls from any or all of the components listed.

- ☐ Leave a comment if you would like to

Unit 3.22 Self-Compassion Troubleshooting

Moving forward on your self compassion journey, what do you see as the most likely obstacle in applying these practices?

Based on what you've learned so far, what will you do to overcome the obstacle when it comes up?

- ☐ Pick Your Practice: Choose a practice from any of the previous lessons, or choose one from the Self-Compassion Strategies Menu
- ☐ Leave a comment if you would like to

Unit 3.22 Self-Compassion Troubleshooting

My 3 favorite practices when I need a quick boost (a minute or two):

My 3 favorite practices when I have a little time (5 to 15 minutes):

Longer term self-compassion and self-care practices that I will prioritize and work into my life:

- ☐ Leave a comment if you would like to

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Bonus Exercises

Unit B.1 Self-Compassion Tree Exercise

- ☐ Watch the Self-Compassion Tree Exercise video
- ☐ Complete the accompanying activity (below)

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Unit B.2 Self-Compassion Stone Exercise

- ☐ Watch the Self-Compassion Stone Exercise video
- ☐ Complete the accompanying activity (below)

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Unit B.3 Emotional Intelligence—Body Awareness Exercise

- ☐ Watch the Emotional Intelligence—Body Awareness Exercise video
- ☐ Complete the accompanying activity (below)

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Unit B.4 Self-Compassion Rose Exercise

- ☐ Watch the Self-Compassion Rose Exercise video
- ☐ Complete the accompanying activity (below)

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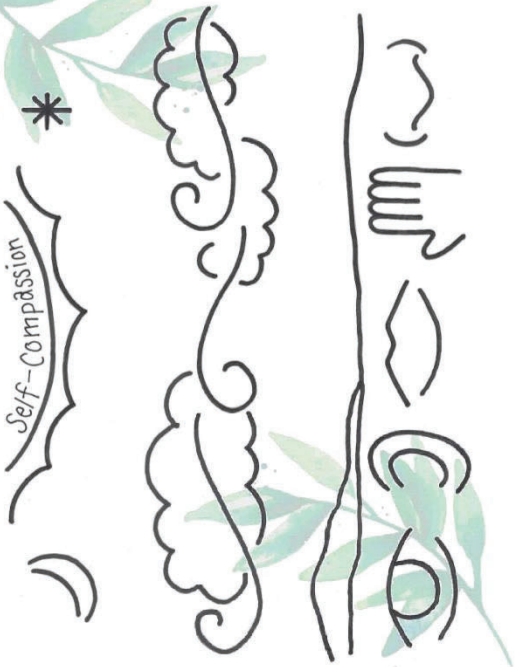
Unit B.5 Compassionate Awareness Exercise

- ☐ Watch the Compassionate Awareness Exercise video
- ☐ Complete the accompanying activity (below)



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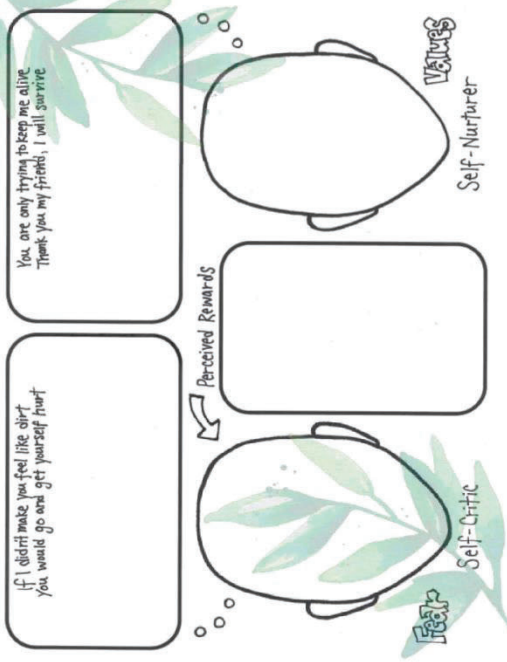
Unit B.6 Understanding the Self-Critic

- ☐ Watch the Understanding the Self-Critic video
- ☐ Complete the accompanying activity (below)



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Your Journey Continues!

Unit 4.1 Epilogue

- ☐ Pick Your Practice: Choose a practice from any of the previous lessons, the bonus exercises, or choose one from the Self-Compassion Strategies Menu
- ☐ Watch the Epilogue video
- ☐ Leave a comment if you would like to

Unit 4.2 Progress Questionnaires

You should have already taken the Self-Compassion Questionnaire and the Survey on Flourishing, and you do not need to take them again unless you would like to.

- ☐ Record your scores if you would like to
- ☐ Leave a comment if you would like to

Unit 4.3 Course Feedback + a Special Reward for You

You will be completing a separate feedback form as a part of this study, so you don't have to fill this one out unless you would like to. And feel free to choose a photo!

Unit 4.4 Become an Affiliate

- ☐ Recommend the course to someone else, if you would like to (though... they would not necessarily be a part of this particular study)
- ☐ Do something special to celebrate the huge accomplishment of completing this course!

Thank you and Congratulations!

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Notes/Insights

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Notes/Insights

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Notes/Insights

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Notes/Insights

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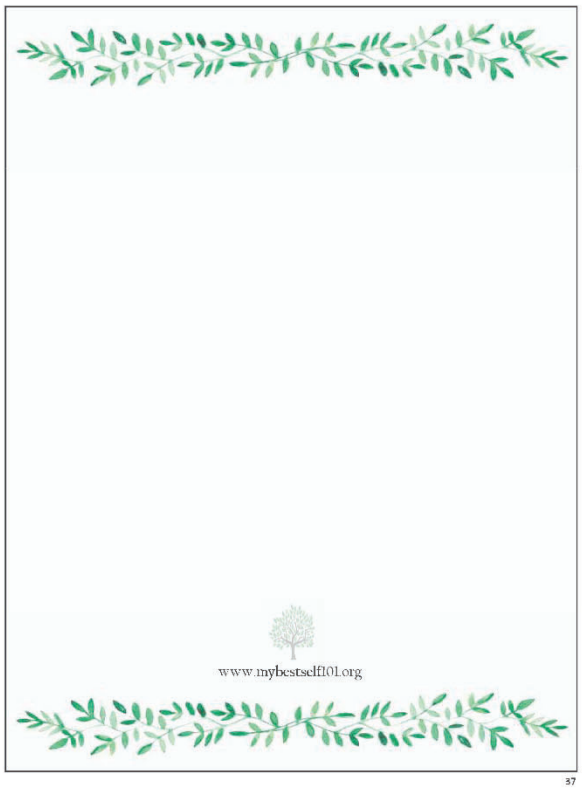

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Appendix C

The following is a transcript from the audio clip “General Self-Compassion Break” from Kristin Neff’s website, www.self-compassion.org.

This practice is called the self-compassion break, and it's something you can do anytime during the day or at night when you need a little self-compassion. So to practice this exercise, we actually need to call up a little suffering so I'd invite you to think about a situation in your life right now that is difficult for you. Maybe you're feeling stressed , or you're having a relationship problem or you're worried about something that might happen I’d invite you to think of something that is difficult but not overwhelmingly difficult especially if you're new to practicing the self-compassion break. So finding a situation and getting in touch with it what's going on what happened or what might happen who said what really bring the situation to life in your mind's eye and then I'm going to be saying a series of phrases that are designed to help us remember, the three components of self-compassion. The three components of self-compassion when we need it most. So the first phrase is this is a moment of suffering we're bringing mindful awareness to the fact that suffering is present and I'd invite you to find some language that speaks to you something like this is really hard right now or I'm really struggling we're actually turning toward our difficulty acknowledging it naming it this is a moment of suffering the second phrase is suffering is a part of life we're reminding ourselves of our common humanity suffering is a part of life and again finding language that speaks to you. It may be something like it's not abnormal to feel this way many people are going through similar situations the degree of suffering may be different the flavor of suffering may be different but suffering is a part of life part of being human. And then the third phrase is may I be kind to myself in this moment and to support bringing kindness to yourself. I'd invite you to

perhaps put your hands over your heart or some other place on your body that feels soothing and comforting. Feeling the warmth of your hands the gentle touch letting those feelings of care stream through your fingers may I be kind to myself and using any language that supports that sense of kindness, perhaps language you would use with a good friend you care about who is going through a similar situation it may be something like I'm here for you it's going to be okay I care about you. You can even try using a diminutive if that feels comfortable, oh darling I'm so sorry, or you can try calling yourself by your first name, anything that feels natural to express your deep wish that you be well and happy and free from suffering and then letting go of the practice and noticing how your body feels right now allowing any sensations to be just as they are allowing yourself to be.