BUILDING RESILIENCY & MITIGATING PARENTAL BURNOUT

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I have no conflicts of interest to disclose.
LEARNING OBJECTIVES

1. Understand risk and protective factors for parental burnout

2. Describe differences in burnout and resilience between mothers and fathers of autistic children

3. Identify tools and recommendations for parents who are currently struggling with burnout
PRESENTATION OVERVIEW

- Current Literature & Screening Measures
- Dissertation Findings
- Treatment & Assessment Considerations
- Examples of Parent/Provider Collaboration
- Questions & Discussion
Most parents experience stress related to their parenting role
  - Short-term and no prolonged impact on life

Parental burnout defined as "a prolonged response to chronic and overwhelming parental stress"
  - Rates reported between 8 – 36% of parents
  - Extends beyond stress and has a significant impact on life
  - The Balance Between Risks and Resources Theory

(Roskam et al., 2018; Séjourné et al., 2018; Mikolajczak et al., 2019 p. 1319)
DIMENSIONS OF PARENTAL BURNOUT

- Emotional Exhaustion related to Parenting
- Emotional Distancing
- Loss of Parental Accomplishment

(Roskam et al., 2018)
POTENTIAL RISK FACTORS

A child with a disability or chronic illness

Sociodemographics

Conditions of COVID-19

(Lindstrom et al., 2011; Blanchard et al., 2006; Mikołajczak et al., 2018; Le Vigouroux & Scola, 2018)
POTENTIAL CONSEQUENCES

Parents
- Increases in addictive behaviors
- Sleep disorders
- Escape ideation
- Suicidal ideation

Couples
- Conflicts
- Adultery

Children
- Neglect
- Violence

(Mikolajczak, Brianda, et al., 2018; Mikolajczak et al., 2019)
- **Mothers**
  - Higher average level of exhaustion and emotional distancing compared to fathers
  - Women were seen to burnout when their imbalance between their risk factors and demands was negative
  - More suicidal and escape ideation

- **Fathers**
  - Men were found to burnout earlier, even before their resources were not yet outweighed by demands
  - Greater parental neglect

(Roskam et al., 2017; Roskam & Mikolajczack, 2020)
Mothers who have felt pressure to be perfect experienced:

- Increased prevention focus
- Increased behavioral regulation
- Intent to increase involvement and improve the well-being of their children actually may lead to unintentional negative impacts on the child and family
  - Increased child depressive symptoms and lower life satisfaction in children
  - Decreased father involvement and fewer opportunities for fathers to invest in childcare-related tasks

(Meeussen & Van Laar, 2018; Repetti et al., 2002; Sutherland, 2010)
- Very minimal research
- Varghese and Venkatesan (2013) compared mothers of children with ASD and mothers of children who are hearing impaired
  - Mothers of children with ASD:
    - Reported significantly higher burnout
    - With greater symptom severity reported more severe burnout
    - Suffered from both psychological and physical burnout whereas mothers of children who are hearing impaired largely suffered psychological burnout
### Parental Burnout Assessment (PBA)

**Exhaustion in parental role**
- **EX1** I feel completely run down by my role as a parent
- **EX2** I have the sense that I’m really worn out as a parent
- **EX3** I’m so tired out by my role as a parent that sleeping doesn’t seem like enough
- **EX4** When I get up in the morning and have to face another day with my child(ren), I feel exhausted before I’ve even started
- **EX5** I find it exhausting just thinking of everything I have to do for my child(ren)
- **EX6** I have zero energy for looking after my child(ren)
- **EX7** My role as a parent uses up all my resources
- **EX8** I sometimes have the impression that I’m looking after my child(ren) on autopilot
- **EX9** I’m in survival mode in my role as a parent

**Contrast in parental self**
- **CO1** I don’t think I’m the good father/mother that I used to be to my child(ren)
- **CO2** I tell myself that I’m no longer the parent I used to be
- **CO3** I’m ashamed of the parent that I’ve become
- **CO4** I’m no longer proud of myself as a parent
- **CO5** I have the impression that I’m not myself any more when I’m interacting with my child(ren)
- **CO6** I feel as though I’ve lost my direction as a dad/mum

**Feelings of being fed up**
- **FU1** I can’t stand my role as father/mother any more
- **FU2** I can’t take being a parent any more
- **FU3** I feel like I can’t take any more as a parent
- **FU4** I feel like I can’t cope as a parent
- **FU5** I don’t enjoy being with my child(ren)

**Emotional distancing**
- **ED1** I do what I’m supposed to do for my child(ren), but nothing more
- **ED2** Outside the usual routines (lifts in the car, bedtime, meals), I’m no longer able to make an effort for my child(ren)
- **ED3** I’m no longer able to show my child(ren) how much I love them

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**Note.** Items are rated on a 7-point scale: never (0), a few times a year or less (1), once a month or less (2), a few times a month (3), once a week (4), a few times a week (5), every day (6).
PARENTAL RESILIENCE

Defined as “the capacity of parents to deliver competent, quality parenting to children despite adverse personal, family, and social circumstances” (Gavida-Payne et al., 2015 p. 113)

Theoretical framework involves both protective and risk factors that lead to development and maintenance of resilience

Parenting resilience largely understudied in comparison to other types of resilience
Higher levels of resilience related to lower parental stress

Overall, parents of autistic children reported moderate levels of resilience and comparable resilience to parents of neurotypical children or children with Down Syndrome

Parental resilience related to parenting style
- Stricter or harsher parenting related to lower parent resiliency scores
- More positive parenting related to higher parent resiliency scores

(Pastor-Cerezuela et al., 2016; Sinha et al., 2016)
Parenting Resilience Elements Questionnaire (PREQ)

<table>
<thead>
<tr>
<th>Items</th>
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<tbody>
<tr>
<td><strong>Knowledge of the child’s characteristics</strong></td>
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<tr>
<td>I know what my child is not good at.</td>
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<tr>
<td>I know what my child will do in the future.</td>
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<tr>
<td>I can figure out the reason behind my child’s trouble.</td>
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<td>I’m aware of my child’s traits.</td>
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<tr>
<td>I have better knowledge of children’s behavior and traits than others.</td>
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<tr>
<td>I know what my child is best suited for (e.g., school subjects, play, and jobs).</td>
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<tr>
<td><strong>Perceived social supports</strong></td>
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<td>I have someone who I can talk to about child-raising.</td>
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<td>I have someone who I can trust my child with.</td>
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<td>I’m worried about raising my child without anyone’s opinion.</td>
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<tr>
<td>There is someone who helps my child when he/she is in trouble.</td>
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<td>I have no choice but to raise my child all alone.</td>
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<td>There are people who would help my child in the future.</td>
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<td><strong>Positive perception of parenting</strong></td>
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<td>I value interactions with my child.</td>
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<td>My child makes me feel energized.</td>
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<td>I enjoy talking to and playing with my child.</td>
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<td>I can do anything for my child that he needs.</td>
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(Suzuki et al., 2015)
DISserTATION FINDINGS

PARENTAL BURNOUT IN MOTHERS AND FATHERS OF CHILDREN WITH AND WITHOUT AUTISM SPECTRUM DISORDER DURING THE COVID-19 PANDEMIC
SUMMARY OF THE PROBLEM

- **Statement of the Problem**
  - Unclear how pre-COVID-19 findings generalize to COVID situation
  - Fathers are largely absent from previous research
  - Parental burnout research has largely taken place outside of the U.S. and there are only three studies on parents of children with ASD
  - Limited literature on parental resilience in parents of children with ASD and the more specific components of parental resilience

- **Current Study**
  - Aimed to identify if and how experiences and functioning differ for mothers and fathers of TD children and mothers and fathers of children with ASD
### PARTICIPANTS

Participants \((n = 185)\)

**ASD Group \((n = 88)\)**
- 48 females, 38 males, 1 non-binary, 1 preferred not to say
- 69.3% described COVID-19 as Very Challenging
- 55.7% more intense and 60.2% more frequent behavior problems
- 57% Fluent Speech
- 77% receiving pharmacological treatment

**TD Group \((n = 97)\)**
- 55 females, 41 males, 1 preferred not to say
- 42.3% described COVID-19 as Very Challenging
- 20.6% more intense and 18.6% more frequent behavior problems

Groups comparable in race/ethnicity, marital status, child age, child gender, parent age, number of children in the home.
DIFFERENCES IN PARENTAL BURNOUT BETWEEN ASD AND TD GROUPS

**P < .001**
DIFFERENCES IN MOTHERS AND FATHERS IN TYPES OF BURNOUT

** p < .01; *** p < .001
CHILD AND SOCIODEMOGRAPHIC FACTORS AND PARENTAL BURNOUT

- Child behavior problems related to all five types of parental burnout in fathers and most types of burnout in mothers in the ASD group
- Fathers of older children reported higher levels of all five types of parental burnout and mothers of older children reported higher levels of feelings of being fed up
- Family income and education were also positively related to emotional distancing and feelings of being fed up for mothers
  - Fathers of older children with ASD who are experiencing more maladaptive behaviors are experiencing greater burnout
  - Generally, mothers of children with behavior problems are more burnout
  - Mothers who are more highly educated and more financially secure are more emotionally distanced and more fed up with their role as a parent
PARENTAL RESILIENCE

Knowledge of Child's Characteristics

- *p < .05; **p < .01

Perceived Social Supports

* p < .05; ** p < .01
Sheds light on how parents’ experiences of children with and without ASD differed during the COVID-19 pandemic

Findings highlight the importance of clinicians providing parents of children with ASD with increased knowledge and support, especially fathers

Essential for clinicians to assess parents’ level of functioning, feelings, and behaviors related to their parenting role

Despite extreme challenges, participants exhibited resilience in their parenting role and acceptance of their children
TREATMENT AND ASSESSMENT CONSIDERATIONS
Stop and Listen

Attempt to educate and include fathers

Go beyond labeling of 'non-compliance' and further understand the why
ASSESSMENT CONSIDERATIONS

Knowledge of a child's abilities, behavior, and diagnosis related to parental resilience, and therefore, father or secondary caregiver involvement can be very important.

Tailoring feedback to family (i.e., length, topics of discussion)

Priority recommendations
TIPS FOR PARENTAL EXHAUSTION

- Take breaks alone – no matter how short
- When possible, prioritize sleep over tasks
- Include kids in calming activities

(Hill, 2022)
TIPS FOR EMOTIONAL DISTANCING

- Human touch
- Include children in hobbies
- Mindfully observe children

(Hill, 2022)
TIPS FOR INADEQUACY

SELF-COMPASSION  PSYCHOLOGICAL FLEXIBILITY  INCREASING SOCIAL SUPPORT

(Hill, 2022)
EXAMPLES OF PARENT/PROVIDER COLLABORATION
Parents have shared that it can be very challenging at times to share their true emotions or struggles related to their own mental health.

“Finally someone is listening.”

“No one ever stops to ask how I am.”

- Provide space
- Openness to re-evaluation of goals
- Validation of letting things go
“This is overwhelming and I’m just so tired but I have to keep going.”

- Develop list of priorities and *one* thing that they want to change/focus on
- Permission to sit out of therapy on some days
PARENT/PROVIDER COLLABORATION

- “I’m concerned that you aren’t seeing what I see at home.”
- Including parents in goal development
- Asking if how the child presents is consistent with presentation; if not, how is it different?
- Continuously bringing our intervention work back to the parent’s goals and priorities
Parental burnout can impact any 'type' of parent but parents of children with ASD or other behavioral/emotional challenges are at higher risk.

Fathers may burnout more quickly and as clinicians we should pay special attention to father's knowledge of their child's challenges and their level of perceived social support.

Parental burnout may impact our work in both treatment and assessment.

Awareness of and slight adjustments in our clinical work when we sense parental burnout may increase positive outcomes with parents, children, and families as a whole.
COLORADO ASD PARENTING RESOURCES

- **Boulder Autism Society** – [www.autismboulder.org](http://www.autismboulder.org) – Monthly support groups and other social/educational activities
- **Autism Society Colorado** - [https://www.autismcolorado.org/support-groups](https://www.autismcolorado.org/support-groups)
- **Autism Community Store** – [www.autismcommunitystore.com/store-events](http://www.autismcommunitystore.com/store-events) – Lots of activities in addition to a wonderful store. Monthly parent and sibling support groups and have a yearly resource fair, sensory friendly haircuts, and much more!
- **The Living Spectrum** – [www.thelivingspectrum.org](http://www.thelivingspectrum.org) – Monthly support groups and a mom's and dad's group. They have a very active Facebook page and are generally a wonderful resource.
- **Denver Special Needs Dad's Empowerment group** – Richard Wygand – 561-889-5792 – richard@adadonamission.com
- **Mountain Summit Parent Perspective** - [www.mountainsummitconsulting.com](http://www.mountainsummitconsulting.com) – Monthly virtual education and parent support group for children with disabilities.
- **Parent to Parent of Colorado** - [https://www.abilityconnectioncolorado.org/p2p-co/](http://www.abilityconnectioncolorado.org/p2p-co/) – Offer different support groups.
QUESTIONS?
COMMENTS?