Mindfulness-Based Stress Reduction for Parents and Caregivers of Children with Special Needs

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Presenter Disclosures

Alicia Bazzano, M.D., Ph.D.

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- The Help Group
Stress and Stress Theory
What is there to be stressed about?
What is there to be stressed about nowadays?
Is stress a crisis?
Good Stress and Bad Stress

What is stress? Who came up with stress anyway?

- “the non-specific response of the body to any demand for change” (1936)
- a physical, chemical, or emotional factor that causes bodily or mental tension
- a state resulting from a stress; especially one of bodily or mental tension resulting from factors that tend to alter an equilibrium

Hans Selye MD PhD (1907-1982)
Generalized Adaptation Syndrome: Stress Theory

Generalized Adaptation Syndrome (Seyles)

"General Adaptation Syndrome" by David G. Myers - Exploring Psychology 7th ed. (Worth) page 398. Licensed under CC BY 3.0 via Commons
Transactional Stress Theory: Stress and Appraisal

The Double ABCX Theory: Stress, Resources, Coping and Adaptation


https://theprodigalpastor.wordpress.com/2013/03/17/coping-skills/
There are More Stressors in caring for children with special needs

- Isolation
- Child behaviors are difficult to address
- Increased time and effort
- Socioeconomic demands
How stress affects caregiver and child behavior

- **Caregivers who are stressed...**
  - find it more difficult to offer praise, nurturance and the structure that children need.
  - are more likely to use harsh discipline

- **Children whose caregivers are stressed...**
  - have more challenging behaviors

Hastings and Remington, 1994; Lawson and Brien, 1994; Rose et al., 1998; Hastings et al 2006
For Parents and Caregivers, these Stressors MAY Result in…

- Grieving
- Depression
- Anxiety
- Insomnia
- Blunted cortisol responses
- Poorer physical and mental health

It’s Not Stress That Kills Us
It is our reaction to it

Hans Selye
Resilience and Stress

Generalized Adaptation Syndrome (Selyes)

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Parenting and Caregiving and Stress Interventions

A – Respite, payment of co-pays, obtaining Medi-cal/SSI, etc
B, C – Behavior therapy
D – Respite
E, F – ?
G – Support Groups
H, I, J, K – ?
Stress Management Interventions for Parents and Caregivers

- Support groups
- Parenting psychoeducation
- Respite
- Behavioral parent training
- Cognitive behavior therapy
- Mindfulness-based stress reduction
Mindfulness-Based Stress Reduction
Been on Autopilot lately?
Mindfulness

- “Moment-by-moment awareness”
- “A systematic approach to developing new kinds of control and wisdom in our lives, based on our inner capacities for
  - Relaxation
  - Paying attention
  - Awareness
  - Insight”

Jon Kabat-Zinn
Origins of Mindfulness Based Stress Reduction
Mindfulness-Based Stress Reduction

- Structured, evidence-based programs focused on
  - Nonjudgmental interpretation of events
  - Acceptance of the present situation
  - Empowerment

- 8-week group program
  - Meditation practices (breathing, body scan, loving-kindness; day retreat)
  - Gentle stretching exercises
  - Discussion ("awareness of how to get unstuck")
  - Daily informal practice (mindful eating, walking)

Jon Kabat-Zinn
Mindfulness-Based Stress Reduction

- Example class
  - Theme: “There is more right with you than wrong with you”
  - Practices: awareness of positive self, moment by moment awareness of eating and breathing, guided body-scan meditation
  - Homework: CD-guided body scan meditation, eating one meal mindfully

- Benefits occur from changes in perception
  - Acceptance of present situation
  - Stressful situation is not totality of person
Attitudes of mindfulness

- Non-judging
- Patience
- Beginner’s mind
- Trust

- Non-striving
- Acceptance
- Letting go
MBSR Components: Yoga

- Reminding and Re-bodying
- Universal—gentle, full-body conditioning
- Strength, balance, flexibility, energy
- Honor what your body is telling you by erring on the side of being conservative.
MBSR Components: Formal Practice

Sitting Meditation
Body Scan
Walking Meditation
Loving-kindness
Mindfulness: Informal Practice Opportunities

- Showering
- Walking
- Eating
- Drinking
- Washing dishes
Reacting!

- “Between stimulus and response there is a space. In that space is our power to choose our response. In our response lies our growth and our freedom.”

Viktor Frankl
Mindfulness: Informal Practice Opportunities

- Stop
- Take a breath
- Observe
- Proceed
This being human is a guest house. Every morning a new arrival.

A joy, a depression, a meanness, some momentary awareness comes as an unexpected visitor.

Welcome and entertain them all! Even if they’re a crowd of sorrows, who violently sweep your house empty of its furniture, still, treat each guest honorably. He may be clearing you out for some new delight.

The dark thought, the shame, the malice, meet them at the door laughing, and invite them in.

Be grateful for whoever comes, because each has been sent as a guide from beyond.
The Evidence on MBSR

MBSR in Action
MBSR Participants

Target: parents or primary caregivers of community-dwelling children with developmental disability

Recruitment: newsletters, parent support groups & flyers

Incentives: free classes ($500 value), CD players, food, respite, on-site childcare, taxi vouchers
Intervention: MBSR for Parents and Caregivers

- Program adaptations
  - Shortened class sessions and daily practice
  - Half-day silent retreat
  - Multiple, concurrent class days (day and night)
  - Parent/caregiver discussion topics
    - “acceptance of child’s developmental disability”
    - “mourning loss of idealized child”
    - “feeling compassion for self as caregiver”
  - Bi-lingual materials (Spanish & English) and simultaneous in-class Spanish translation
Evaluation of the Adapted MBSR Program

- Pre/post test and 2 month follow-up

- Mindfulness Measure: Mindfulness Awareness Attention Scale

- Stress Measures: Perceived Stress Scale-10 Item, Parental Stress Scale

- Psychological health: Scale of Psychological Well-Being, Self-Compassion Scale

- Physical health: single item perceived health
MBSR Program Evaluation

- Mindful Awareness Attention Scale
  - “It seems I am ‘running on automatic,’ without much awareness of what I’m doing.”
  - “I find myself preoccupied with the future or the past”

- Parental Stress Scale
  - “My child(ren) is an important source of affection for me”
  - “Having child(ren) has meant having too few choices and too little control over my life”

- Perceived Stress Scale-10 Item
  - “In the last month, how often have you found that you could not cope with all the things you had to do?”
MBSR Evaluation continued

- **Scale of Psychological Well Being**
  - “In general, I feel I am in charge of the situation in which I live”
  - “I enjoy personal and mutual conversations with family members or friends”
  - “Everyone has their weaknesses, but I seem to have more than my share”

- **Self-Compassion Scale**
  - “When I’m feeling down I tend to obsess and fixate on everything that’s wrong”
  - “When something painful happens I try to take a balanced view of the situation”
Results: Stress Reduction following MBSR

MBSR Program Decreased Parental Stress and Perceived Stress

- Parental Stress (N=59)
  - Pre-Program: 46.4
  - Post-Program: 21.9

- Perceived Stress (N=66)
  - Pre-Program: 36.3
  - Post-Program: 15.0
What did participants gain?

- “A new way of looking at life and dealing with stress. A way to calm myself down—I have been feeling much better and calmer with my son.”

- “Balance, calmness, and peace of mind for the family and the rest of my life.”

- “I found a way to be centered in the midst of the storm of my son’s many challenging behaviors, such as self-injury, aggression, and lack of communication.”
Impact of the MBSR program on parents and caregivers of children with DD

<table>
<thead>
<tr>
<th></th>
<th>Pre-Program</th>
<th>Post-Program</th>
<th>Difference</th>
<th>t (p-values)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAAS</td>
<td>3.66 (.99)</td>
<td>4.20 (0.86)</td>
<td>0.54</td>
<td>-4.54(0.001)</td>
</tr>
<tr>
<td>SCS</td>
<td>2.91 (0.71)</td>
<td>3.49 (0.65)</td>
<td>0.58</td>
<td>-8.58(0.001)</td>
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<tr>
<td>PWB</td>
<td>230.27 (31.26)</td>
<td>249.86 (38.36)</td>
<td>19.59</td>
<td>-4.92(0.001)</td>
</tr>
<tr>
<td>ParentSS&lt;sup&gt;a&lt;/sup&gt;</td>
<td>46.44 (10.19)</td>
<td>36.25 (9.42)</td>
<td>-10.18</td>
<td>8.38(0.001)</td>
</tr>
<tr>
<td>PSS10</td>
<td>21.96 (7.31)</td>
<td>15.04 (6.51)</td>
<td>-6.92</td>
<td>6.54(0.001)</td>
</tr>
</tbody>
</table>

<sup>a</sup> N = 66 except Parent Stress Scale (N=59);
What do you love about today?
Don’t Stress about Stress!
Resources

- **Local:**
  - Insight LA
  - UCLA Mindful Awareness Research Center
  - Well Baby Center
  - Center for Reflective Parenting

- **Internet/Books/Other:**
  - mbsrworkbook.com
  - vueinnovations.com/psip
  - Center of Mindfulness in Medicine, Health Care, and Society (U Mass)
  - UCSD Center for Mindfulness
  - UCSF Mindful Birthing and Parenting
  - Jonkabat-zinn.com
  - *The Mindful Child* by Susan Kaiser Greenland
  - *Mindfulness for Carers* by Cheryl Rezek
What is there to be stressed about?

- Increased cholesterol and fatty acids in blood for energy production systems
- Decreased protein synthesis, intestinal movement (digestion); immune and allergic response systems
- Increased blood pressure
- Increased metabolism; e.g., faster heartbeat, faster respiration
- Localized inflammation (redness, swelling, heat, and pain)
- Faster blood clotting
- Increased production of blood sugar for energy
- Increased stomach acids
## Results: Participant Demographics

<table>
<thead>
<tr>
<th>Sample Characteristics</th>
<th>N</th>
<th>%</th>
<th>Race/Ethnicity</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td><strong>Male</strong></td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>Male</td>
<td>15</td>
<td>23</td>
<td>Caucasian</td>
<td>21</td>
<td>32</td>
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<tr>
<td>Female</td>
<td>51</td>
<td>77</td>
<td>Hispanic</td>
<td>30</td>
<td>45</td>
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<tr>
<td><strong>Race/Ethnicity</strong></td>
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<td></td>
<td><strong>African American</strong></td>
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<td>12</td>
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<tr>
<td><strong>Relationship Type</strong></td>
<td></td>
<td></td>
<td><strong>Other</strong></td>
<td>7</td>
<td>11</td>
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<tr>
<td><strong>Primary Diagnosis of Child</strong></td>
<td></td>
<td></td>
<td><strong>Completed HS or less</strong></td>
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<td>18</td>
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<tr>
<td>Autism</td>
<td>36</td>
<td>59</td>
<td>Some college</td>
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<tr>
<td>Cerebral Palsy</td>
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<td>5</td>
<td>College degree</td>
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<td>Down Syndrome</td>
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<td>3</td>
<td>Graduate school</td>
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<tr>
<td>Mental Retardation</td>
<td>13</td>
<td>21</td>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
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<tr>
<td>Other</td>
<td>7</td>
<td>11</td>
<td>&lt;$25,000</td>
<td>19</td>
<td>30</td>
</tr>
<tr>
<td><strong>Primary Language</strong></td>
<td></td>
<td></td>
<td><strong>$25,000-50,000</strong></td>
<td>16</td>
<td>25</td>
</tr>
<tr>
<td>English</td>
<td>44</td>
<td>67</td>
<td><strong>$50,001-100,000</strong></td>
<td>19</td>
<td>30</td>
</tr>
<tr>
<td>Spanish</td>
<td>22</td>
<td>33</td>
<td>&gt; $100,000</td>
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<td>14</td>
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<tr>
<td><strong>Age of Participant</strong></td>
<td></td>
<td></td>
<td><strong>Mean (SD)</strong></td>
<td>45.7</td>
<td>11.1</td>
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</table>

<table>
<thead>
<tr>
<th>Mean (SD)</th>
<th></th>
<th></th>
<th><strong>Income Level</strong></th>
<th></th>
<th></th>
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</thead>
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<tr>
<td><strong>Primary Language</strong></td>
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<td></td>
<td><strong>Income Level</strong></td>
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<td>&lt;$25,000</td>
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<td>$25,000-50,000</td>
<td>16</td>
<td>25</td>
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<td>19</td>
<td>30</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>&gt; $100,000</td>
<td>9</td>
<td>14</td>
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</tbody>
</table>
## Results: Effect of Mindfulness on Stress

Multivariate linear regression controlling for demographics (N=66)

<table>
<thead>
<tr>
<th>Dependent var: PSS-10</th>
<th>Beta (SE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>R(constant)</td>
<td>22.5 (3.7)</td>
</tr>
<tr>
<td><strong>Change in MAAS score</strong></td>
<td>- 2.9 (0.9)**</td>
</tr>
<tr>
<td>Language of Program</td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>2.8 (2.1)</td>
</tr>
<tr>
<td>Spanish</td>
<td>referent group</td>
</tr>
<tr>
<td>Age at baseline</td>
<td>-0.1 (0.1)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>-3.0 (1.9)</td>
</tr>
<tr>
<td>Female</td>
<td>referent group</td>
</tr>
<tr>
<td>Parent Education Level</td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>referent group</td>
</tr>
<tr>
<td>Some College</td>
<td>-1.6 (2.6)</td>
</tr>
<tr>
<td>College degree</td>
<td>- 5.7 (2.8)</td>
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<tr>
<td>Graduate school</td>
<td>0.1 (2.9)</td>
</tr>
<tr>
<td><strong>Adjusted R-square</strong></td>
<td>0.156</td>
</tr>
</tbody>
</table>

* = p≤.05; **= p ≤.01