

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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No relationships to disclose



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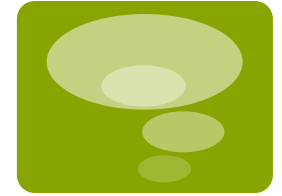
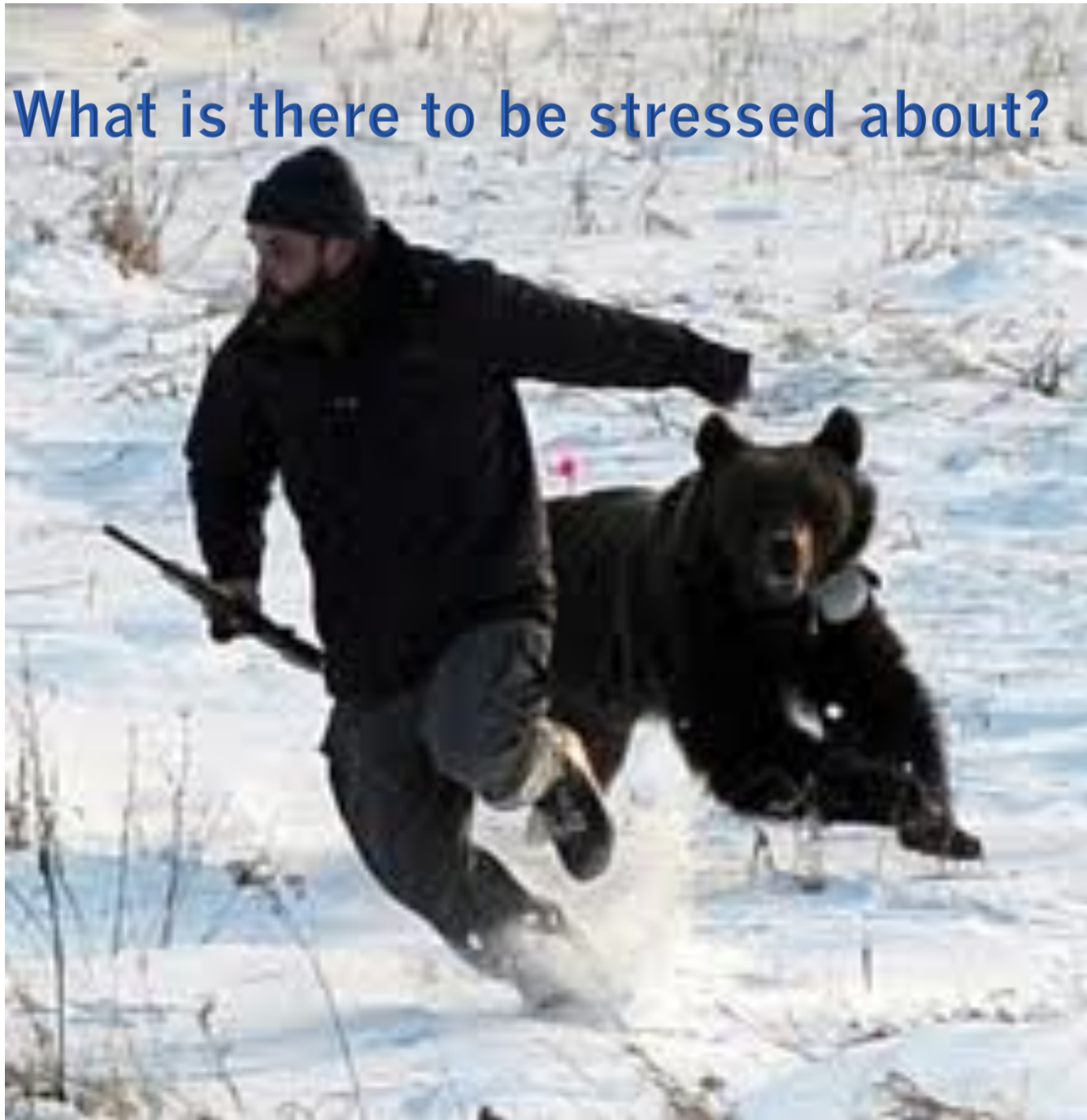
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- Participants in our MBSR programs
- The Help Group



Stress and Stress Theory



What is there to be stressed about?



What is there to be stressed about nowadays?

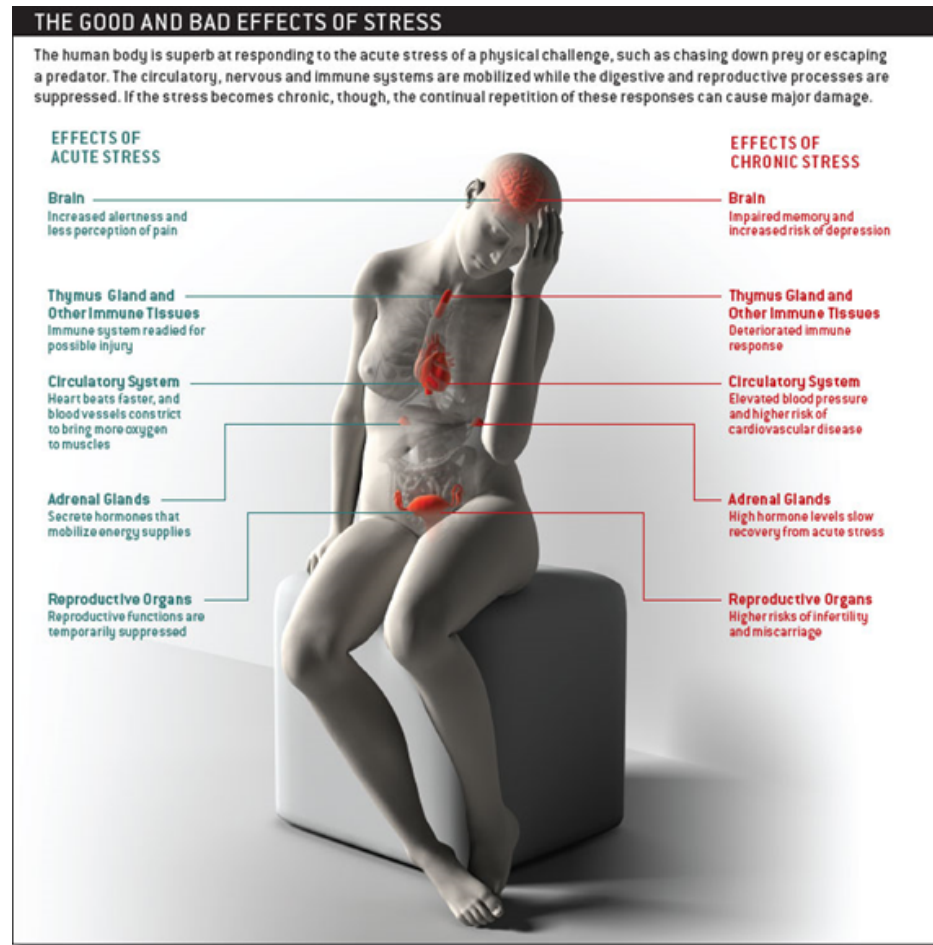


Is stress a crisis?



危機
危機

Good Stress and Bad Stress

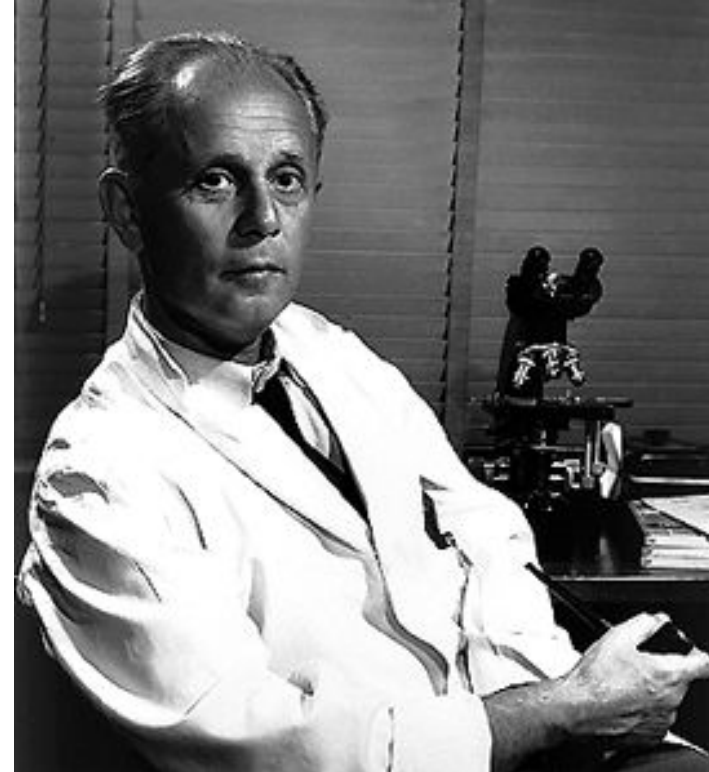


From Sapolsky, "Sick of Poverty", *Scientific American* 293: 92-99 (2005)

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

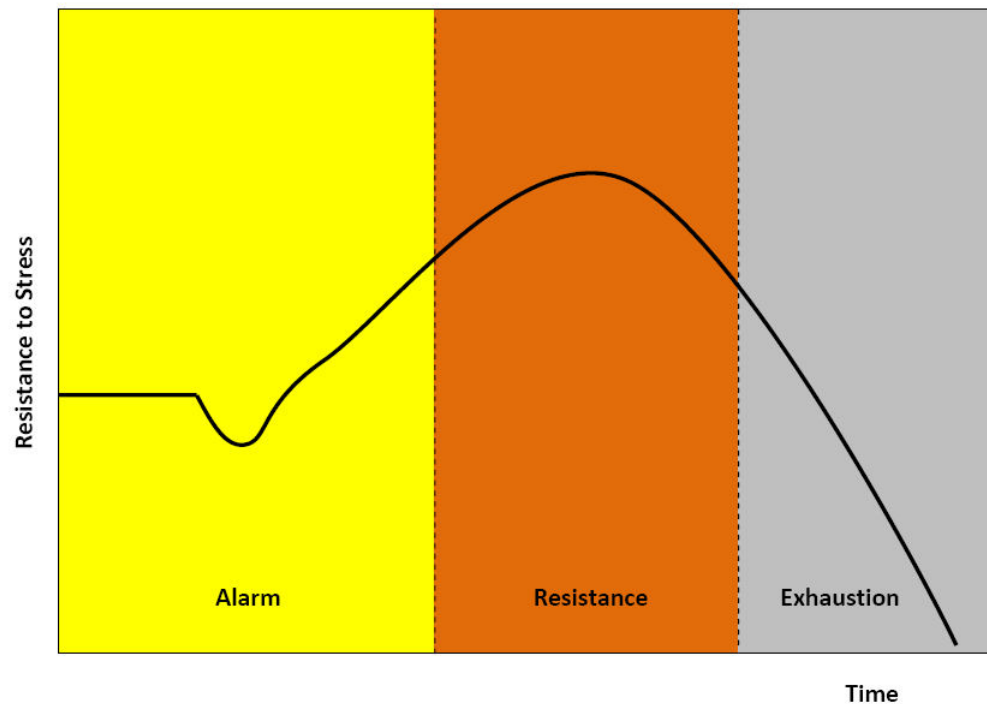


Hans Selye MD PhD
(1907-1982)

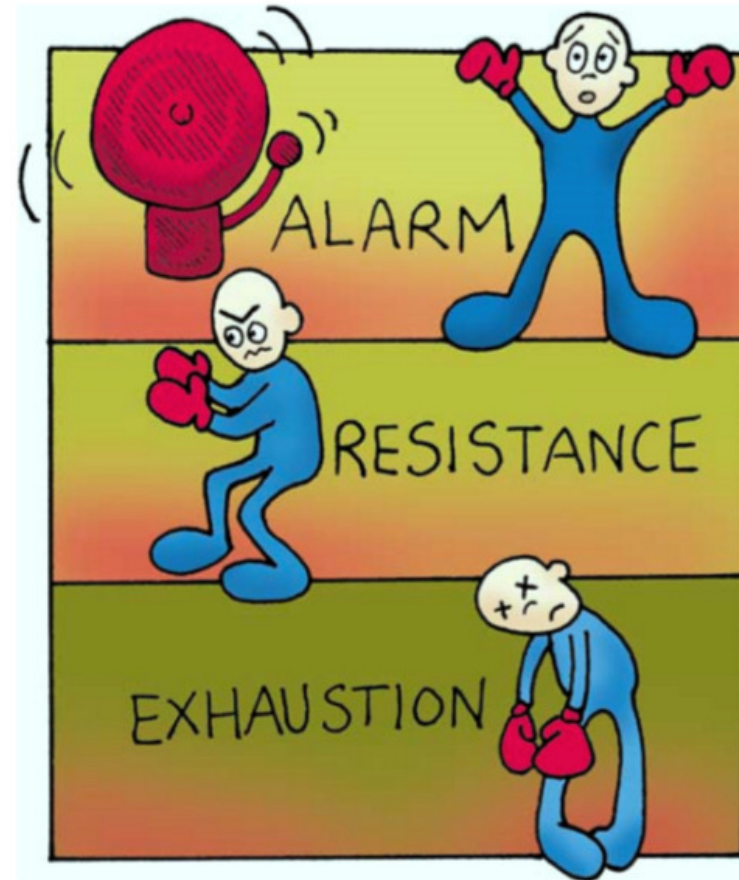
Generalized Adaptation Syndrome: Stress Theory



Generalized Adaptation Syndrome (Seyles)



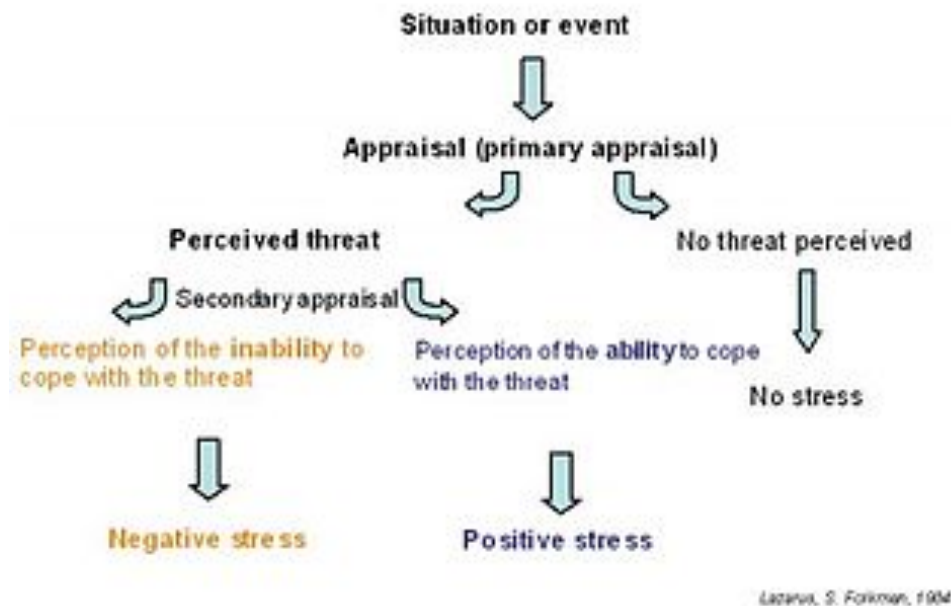
"General Adaptation Syndrome" by David G. Myers - Exploring Psychology 7th ed. (Worth)
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Three reactions or stages of stress

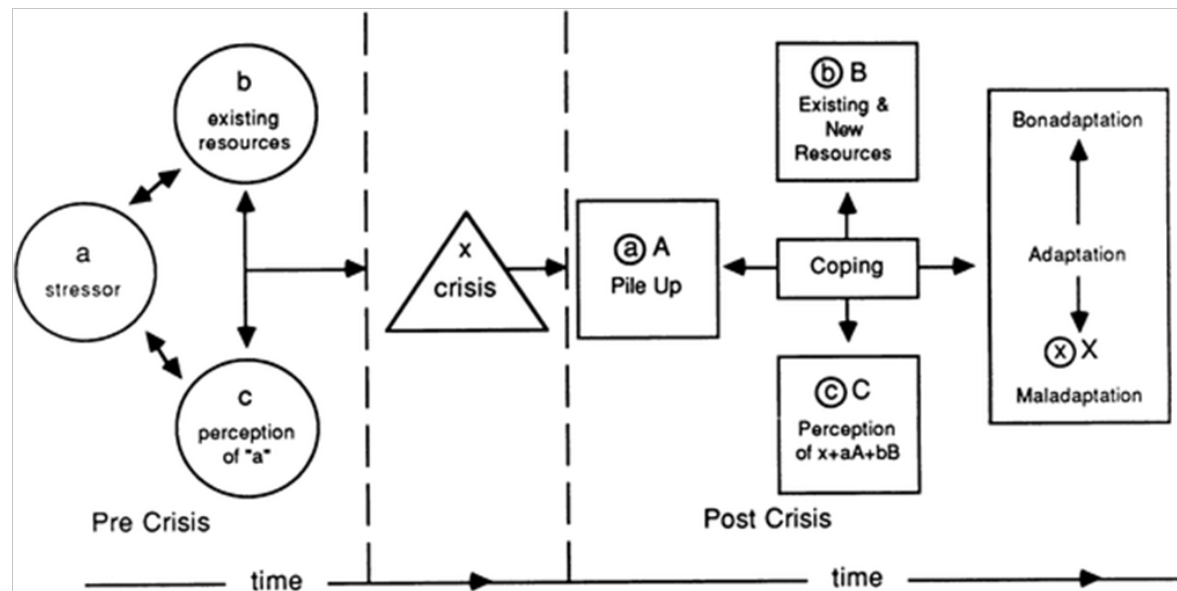
From www.thenursingblog.com

Transactional Stress Theory: Stress and Appraisal



Lazarus, R. S. and Folkman, S. (1987), Transactional theory and research on emotions and coping. *Eur. J. Pers.*, 1: 141–169. doi: 10.1002/per.2410010304

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

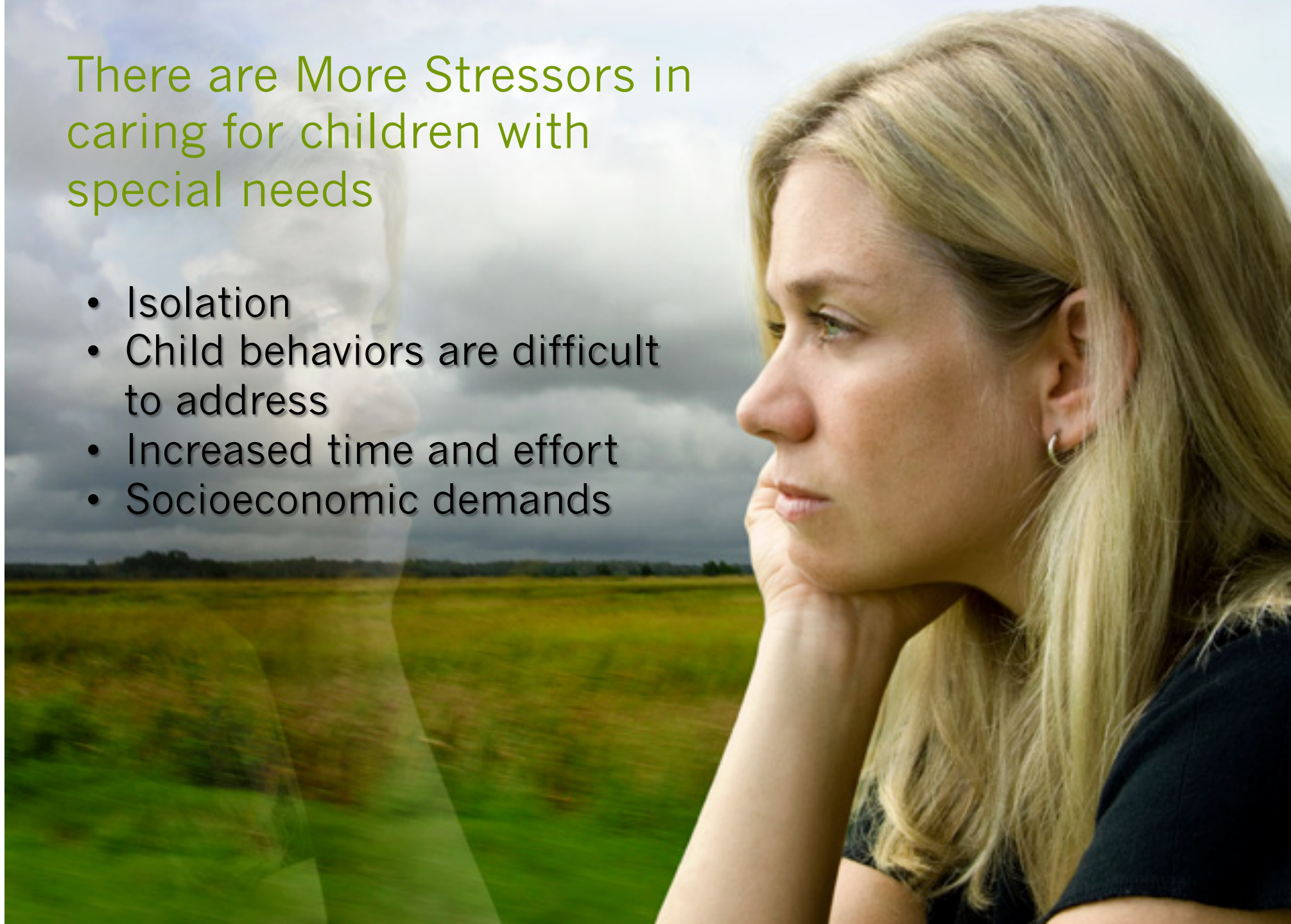


Hamilton I. McCubbin & Joan M. Patterson (1983) The Family Stress Process, Marriage & Family Review, 6:1-2, 7-37, DOI: 10.1300/J002v06n01_02

<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



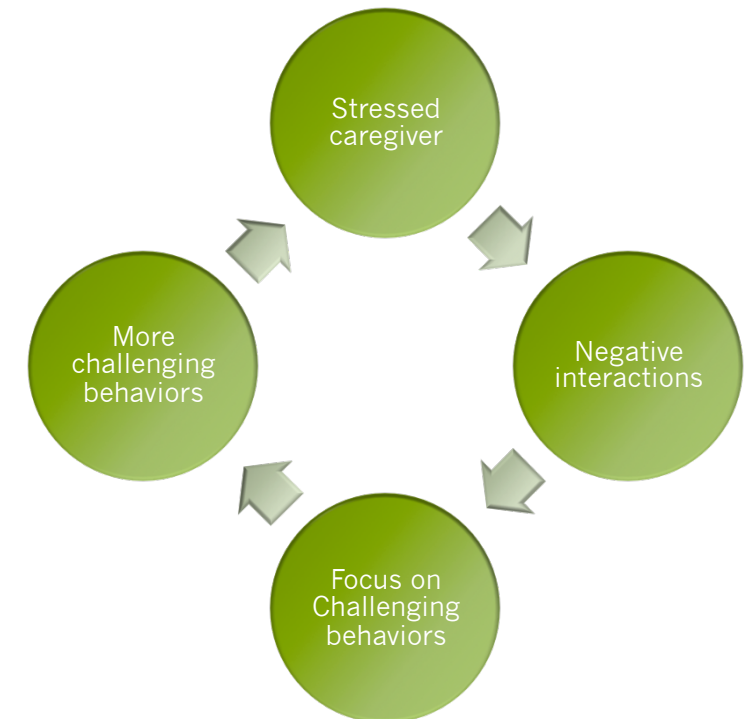
How stress affects caregiver and child behavior

■ 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

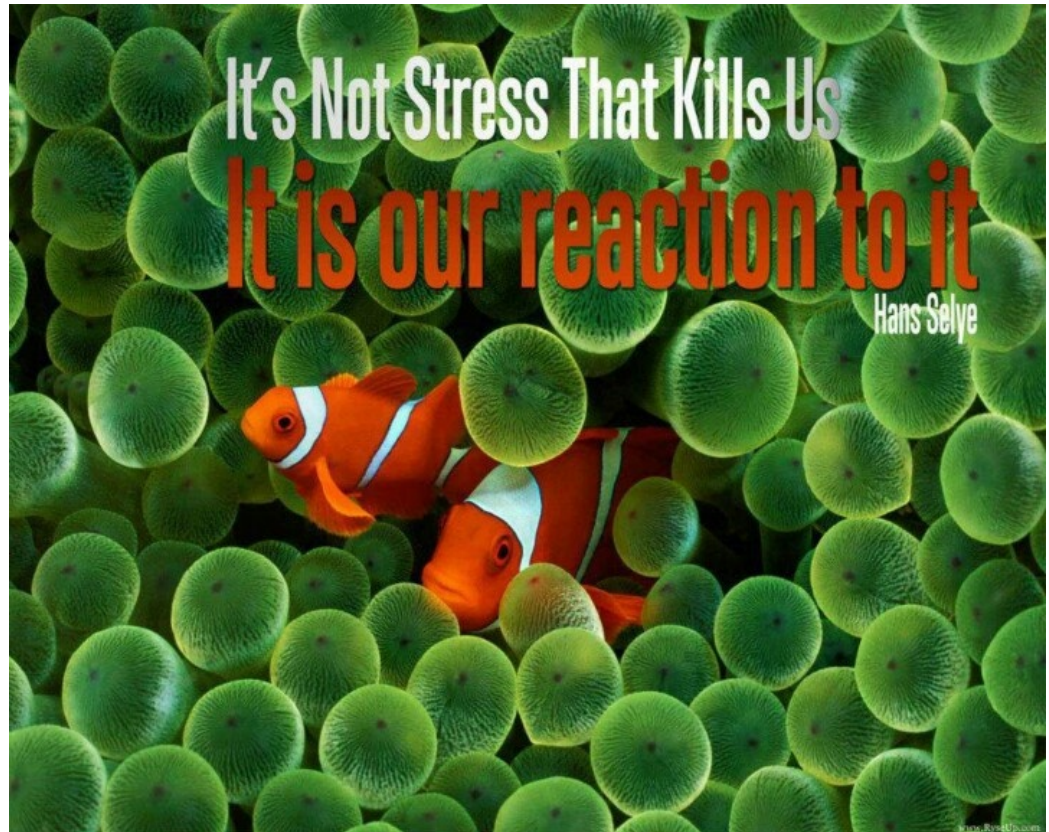


Hastings and Remington, 1994; Lawson and Brien, 1994; Rose et al., 1998; Hastings et al 2006

For Parents and Caregivers, these Stressors
MAY Result in...



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



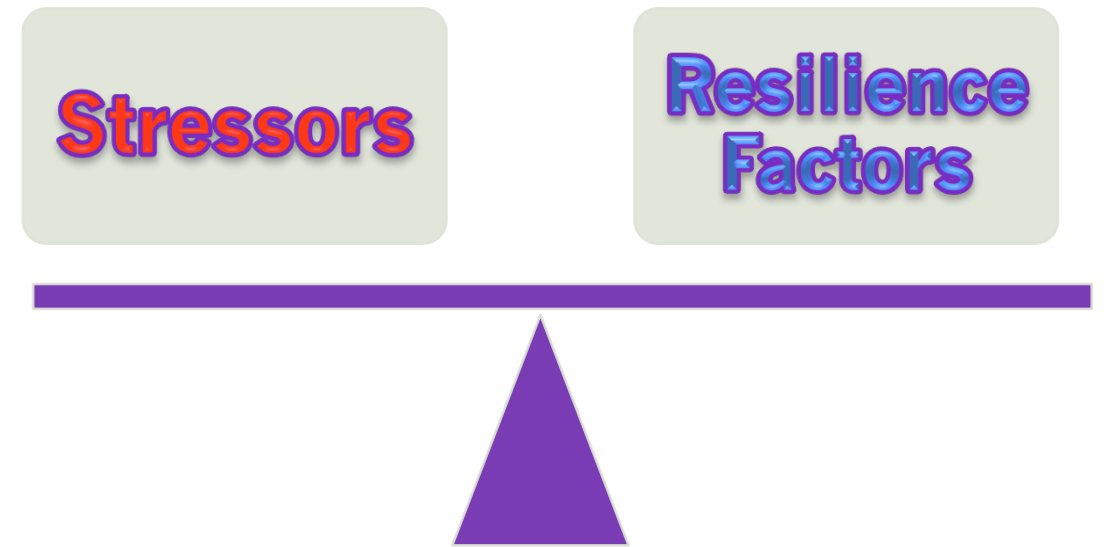
Resilience and Stress



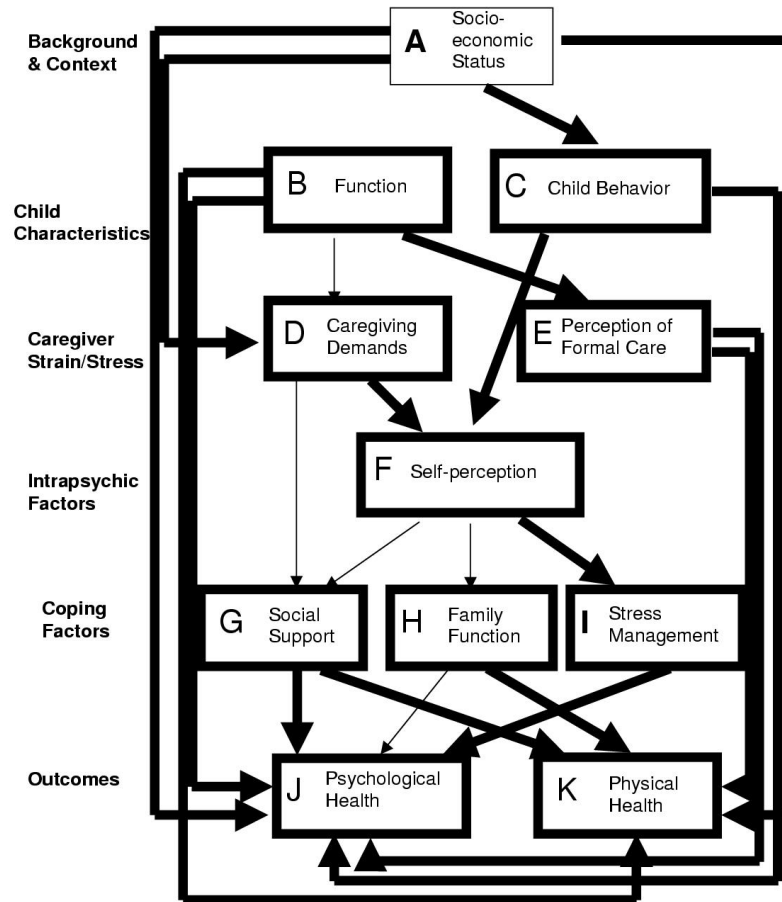
Generalized Adaptation Syndrome (Selye)



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



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 – ?

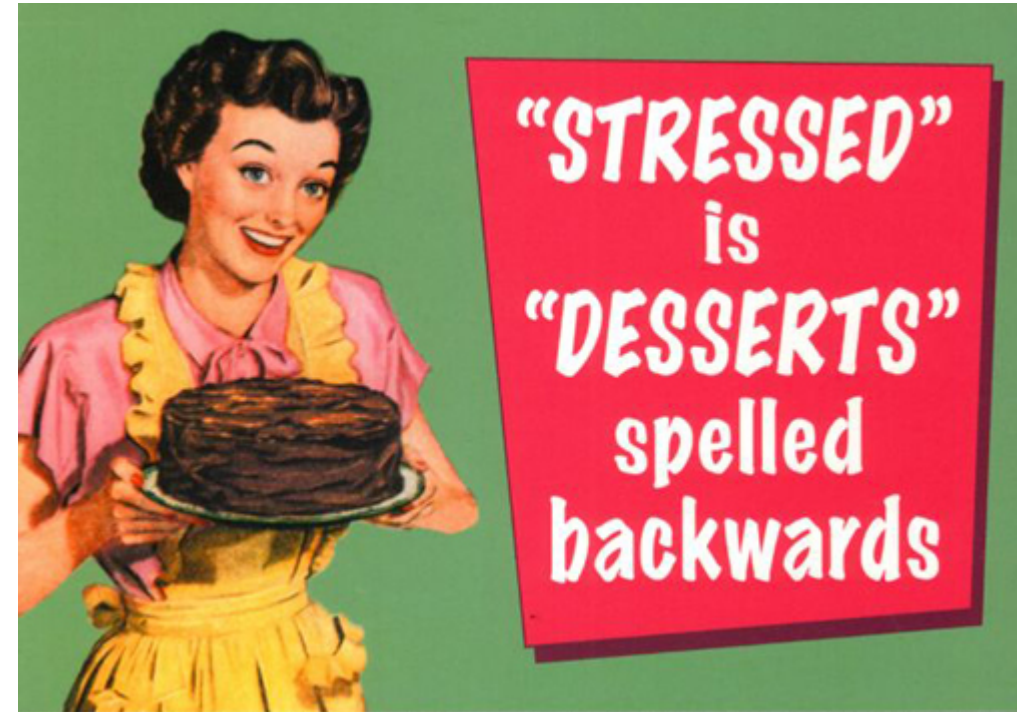
G – Support Groups

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



Feel what it's like to breathe



LOOK around



LISTEN



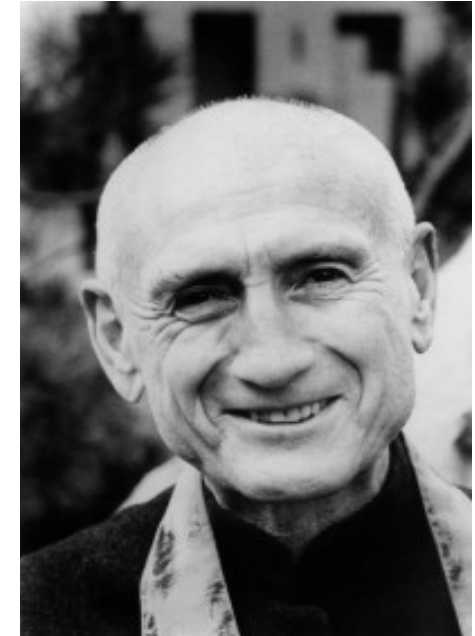
FEEL your body



Reset

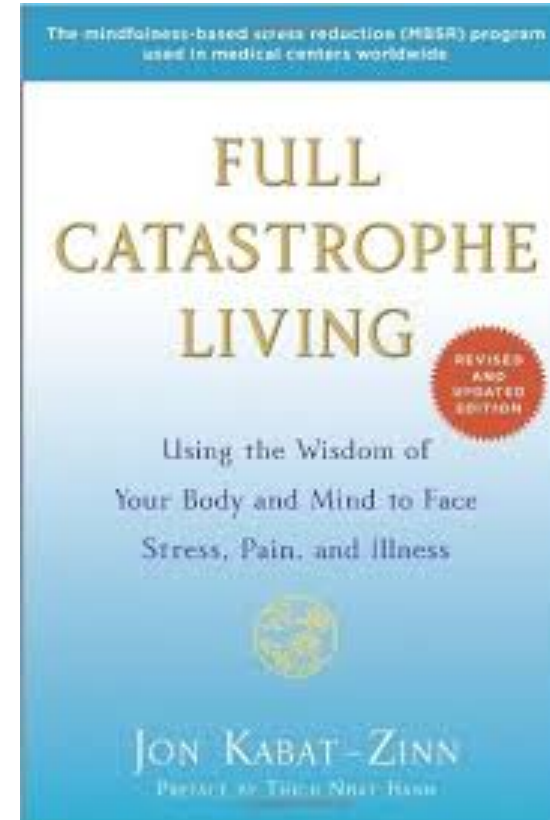
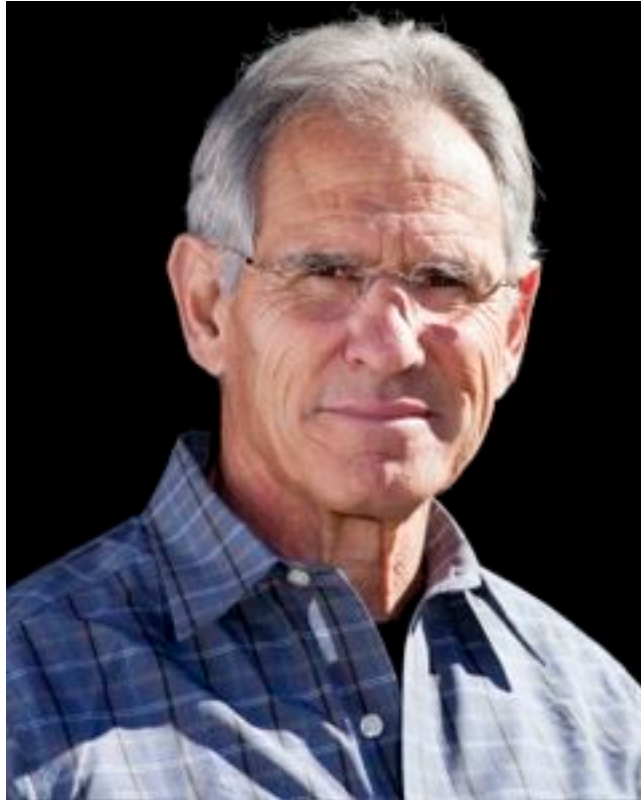
- “Moment-by-moment awareness”
- “A systematic approach to developing new kinds of control and wisdom in our lives, based on our inner capacities for
 - Relaxation
 - Paying attention
 - Awareness
 - Insight”

Jon Kabat-Zinn



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Origins of Mindfulness Based Stress Reduction



Mindfulness-Based Stress Reduction



Mind Full, or Mindful?

- 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

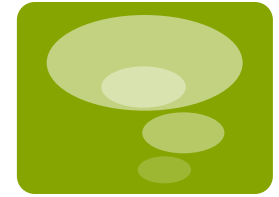
- Benefits occur from changes in perception

- 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

Gratitude for all emotions...



The Guest House by Jellaludin Rumi, translation by Coleman Barks

This being human is a guest house.
Every morning a new arrival.

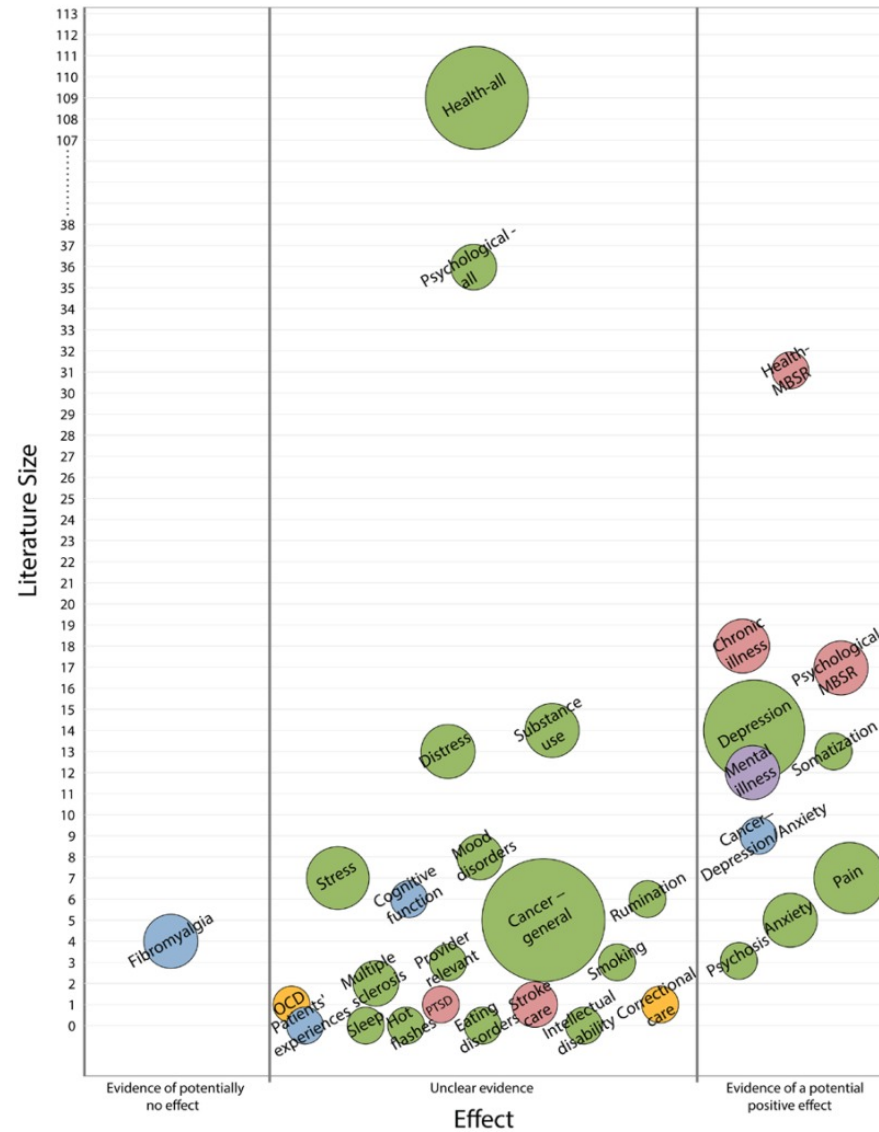
A joy, a depression, a meanness,
some momentary awareness comes
as an unexpected visitor.

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



Hempel S, Taylor SL, Marshall NJ, et al. Evidence Map of Mindfulness [Internet]. Washington (DC): Department of Veterans Affairs (US); 2014 Oct.

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

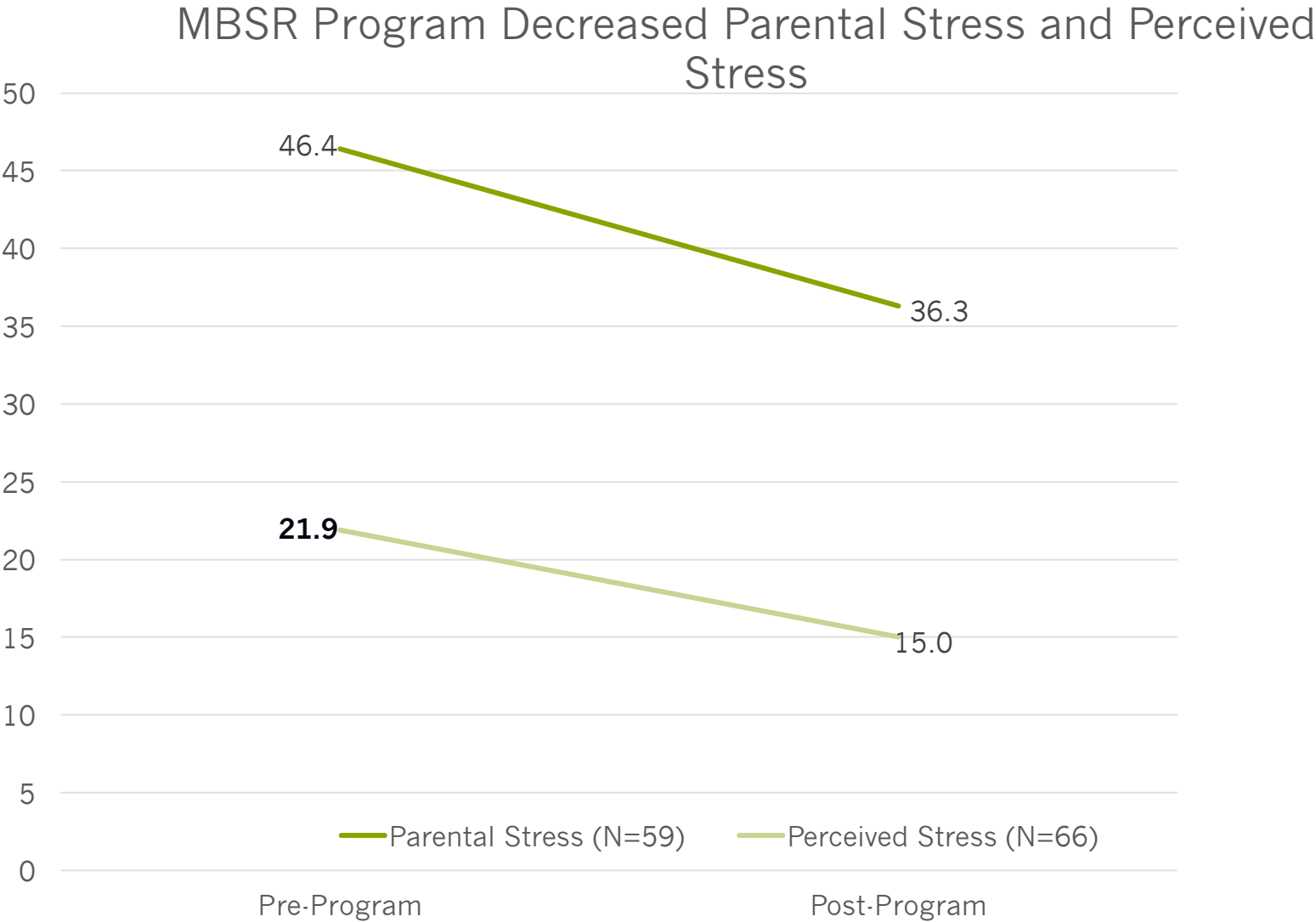
- “In general, I feel I am in charge of the situation in which I live”
- “I enjoy personal and mutual conversations with family members or friends”
- “Everyone has their weaknesses, but I seem to have more than my share”



- 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





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



	Pre-Program	Post-Program	Difference	t (p-values)
	Mean (SD)	Mean (SD)		
MAAS	3.66 (.99)	4.20 (0.86)	0.54	-4.54(0.001)
SCS	2.91 (0.71)	3.49 (0.65)	0.58	-8.58(0.001)
PWB	230.27 (31.26)	249.86 (38.36)	19.59	-4.92(0.001)
ParentSS ^a	46.44 (10.19)	36.25 (9.42)	-10.18	8.38(0.001)
PSS10	21.96 (7.31)	15.04 (6.51)	-6.92	6.54(0.001)

^a N = 66 except Parent Stress Scale (N=59);



Don't Stress about Stress!



Resources



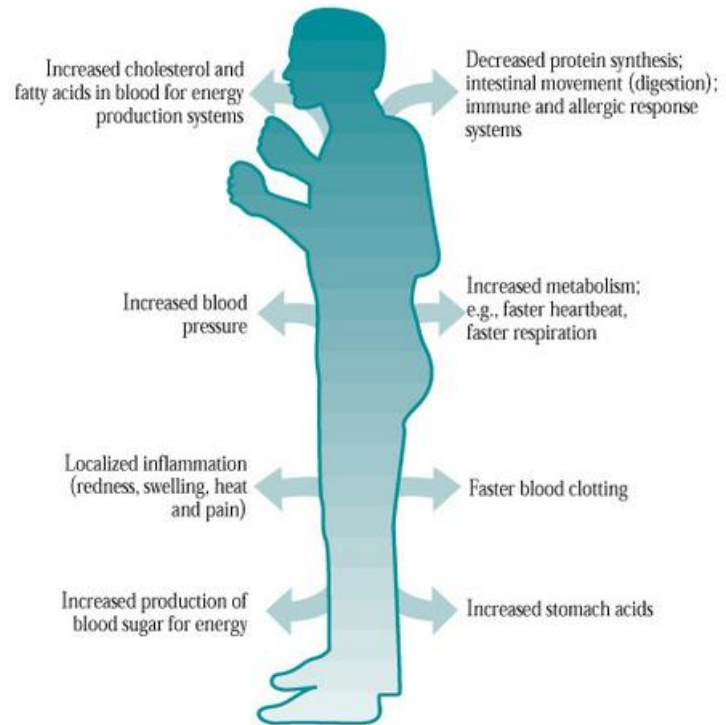
■ Local:

- 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?



Results: Participant Demographics

PARTICIPANT DEMOGRAPHICS (N = 66)						
Sample Characteristics		N	%		N	%
Gender				Race/Ethnicity		
Male	15	23		Caucasian	21	32
Female	51	77		Hispanic	30	45
Relationship Type				African American	8	12
Parent	59	89		Other	7	11
Caregiver	7	11		Education Level		
Primary Diagnosis of Child				Completed HS or less	12	18
Autism	36	59		Some college	20	30
Cerebral Palsy	3	5		College degree	17	26
Down Syndrome	2	3		Graduate school	17	26
Mental Retardation	13	21		Income Level		
Other	7	11		<\$25,000	19	30
Primary Language				\$25,000-50,000	16	25
English	44	67		\$50,001-100,000	19	30
Spanish	22	33		> \$100,000	9	14
Mean (SD)						
Age of Participant		45.7 (11.1)				

Results: Effect of Mindfulness on Stress

Multivariate linear regression controlling for demographics (N=66)

Dependent var: PSS-10

	Beta (SE)
R(constant)	22.5 (3.7)
Change in MAAS score	- 2.9 (0.9) **
Language of Program	
English	2.8 (2.1)
Spanish	referent group
Age at baseline	-0.1 (0.1)
Gender	
Male	-3.0 (1.9)
Female	referent group
Parent Education Level	
High school or less	referent group
Some College	-1.6 (2.6)
College degree	- 5.7 (2.8)
Graduate school	0.1 (2.9)
Adjusted R-square	0.156

* = $p \leq .05$; **= $p \leq .01$