Using the Science of Behavior to Teach Compassionate Skills for Working with Families

Mary Jane Weiss, Ph.D., BCBA-D, LABA
Endicott College
Cambridge Center for Behavioral Studies
Annual Autism Conference
April, 2019
Santa Barbara, CA
With thanks to

Cambridge Center
My mentors, colleagues, supervisees, and students
  • Especially Sandra Harris
  • Especially Samantha Russo
  • Especially Nancy Marchese

The families of people with autism who have let me into their lives
To members of my research lab

Audrey Gifford
Joe Cihon
Nancy Marchese
Hayley Neimy
Gabi Morgan
Ksenia Kratchenko
Karen Rose
Melanie Giles

• Nick Orlando
• Roxanne Gayle
• Kristin Bowman
• Kimberly Marshall
• Colleen Suzio
• Allison Conneally
• Jessica Rohrer
• Lisa Tereshko
• Lisa Rader
Who do we focus on?

Why?

- Behavioral excesses
- Skill deficits
- Window of opportunity
- Potential outcomes
But impact is beyond the child

Children live in families

- Parents
- Siblings
- Grandparents and extended family
Broadening the conversation
Stress

What makes something stressful?

- Duration
- Intensity
- Ambiguity
- Rarity
What makes people experience the negative effects of stress?

• Nature of stressor
• Daily hassles
• Low levels of social support
Which dimensions/kinds of social support are helpful?

- Perceived availability
- Avenue for emotional expression
- Formal supports
- Knowing others in a similar situation
Attitudinal/Cognitive variables that facilitate coping

• Control
  • Belief that events can be influenced

• Commitment
  • Purpose, mission

• A “can do” attitude
  • Events are challenges
How can we facilitate coping?

- Teach instrumental coping strategies
- Foster palliative coping strategies
- Encourage commitment to advocacy
- Reduce isolation and facilitate connections
- Be available for support
- Prevent burnout
Parent Training

Successful in teaching skills and in reducing stress.

Questions:

• What is the best way to train parents?
• Why is parental non-adherence to treatments so commonly voiced as a concern among professionals?
Allen and Warczak (2000) outline a variety of factors that impact parental non-adherence to treatment protocols (poor treatment integrity).

These concepts apply to professionals as well.

The authors pointed to four broad categories of reasons for non-adherence to intervention plans:

- Practitioners do not account for relevant EOs (MOs)
- Practitioners do not account for stimulus generalization
- Practitioners do not account for response acquisition
- Practitioners do not account for consequent events
Strategies for Maintaining Skills

• How do you maintain trained skills?

• Skills are most likely to be maintained in settings where consultation, training, and feedback are provided on an ongoing basis (Noell et al., 2000).
How Do You Determine if Training Worked?

• The effectiveness of training strategies can be evaluated in four main content areas.
  • Can parents perform a behavior?
  • Does training result in improvements in the behavior of the clients (Kuhn et al., 2003)?
  • Generalization
  • Maintenance
Other Thoughts on Parent Training

Do we find ourselves evaluating parents?
- How well do we take the perspective of parents?
- How well do we understand the stressors unique to the home?
Implications

Given all we have said, what should we prioritize in working with parents of people with ASD’s?

• What are their priorities
• What will work in their lives?
• What supports have we put in place?
• How do we perceive a lack of success?
What does it mean to be a family member of a person with ASD?

Having a different kind of life
Coping with powerful negative emotions at times
Becoming strong, compassionate, tolerant
What can we learn?

Every family has a story
To be a parent or a sibling of a person with ASD is not a chosen role

- Yet people find strength, inspiration, meaning, and happiness
Positive effects of being a family member of a person with ASD

- Increased tolerance and compassion
- Strength
- See positive in adverse circumstances
- Less judgmental
- Open to diversity
- Patient
- Sense of mission in helping others
Final thoughts on family experience

The stress inherent in having a family member with autism is severe, ambiguous, and unique.

Families are helped by

- Support
  - Perceived availability
  - Knowing others in similar situations
- Skills
  - Behavioral skills training
  - Builds sense of control
  - Individualized and collaborative targets
- Advocacy and Involvement
- COMPASSION
How do we interface in this? What is our role?

Perceived availability
Support and understanding
COMPASSION
First step: Define compassion

COMPASSION IS PASSION WITH A HEART.

Compassion without action is just observation.
Definition of Compassion

Merriam Webster

sympathetic consciousness of others' distress together with a desire to alleviate it

it refers to both an understanding of another’s pain and the desire to somehow mitigate that pain
Dictionary definition

Related words on Dictionary.com
Mercy, Empathy, Tenderness, Sorrow, Benevolence, Humanity, Sympathy, Kindness, Grace, Compunction, Lenity, Heart, Yearning, Clemency, Softness, Consideration, Condolence, Charity, Commiseration, Humaneness

Com·pas·sion [kuhm-pash-uhn]
noun : a feeling of deep sorrow for another who is stricken by misfortune, accompanied by a strong desire to alleviate the suffering.
The absence of compassion

Mercilessness
Indifference
Who needs compassion?

People in pain
People who are suffering
People in need of assistance

How can I help?
People met with compassion feel

Validated
Understood
Supported
Helped
Relevance to ABA intervention for ASD

OUTCOMES
FAMILY FUNCTIONING
PR
Ethical mandate and responsibility
Humane care
Part two: What are the skills?

OPERATIONAL DEFINITION, Please
Importance of teaching empathy skills: Lessons from the medical community

Linked to patient satisfaction, adherence, comprehension, and perception of a good interpersonal relationship with provider

Leads to improved health status of patients (Beckman & Frankel, 1984; Bendapudi et al, 2006)

Reduces malpractice risk (Levison et al, 1997)
Scope of problem in medical community

Only 21% emotional responding to patient emotional content (Levison et al)
Easter and Berach : 70% of opportunities missed in first visit oncology meetings

Other issues
• Interrupting
• Failing to allow patients to convey concern
Bonvicini et al 2009

Looked at three kinds of opportunities
Statements of Progress
Challenge
Emotion
Types of Patient Communication Opportunities

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Empathic opportunity rules of the empathic communication coding system (ECCS).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 1—emotional feeling statement</strong></td>
<td>An emotional feeling statement is one where the patient describes him or herself feeling an emotion. This emotion should be one that is being felt at the present time. The emotional statement may be related to a physical problem (“My knee really hurts and I’m worried that it might be bone cancer.”), a psychosocial concern (“I am scared that I am going to be laid off from my job” and may be either negative as in the above examples or positive (“I am so proud of myself for quitting smoking.”))</td>
</tr>
<tr>
<td><strong>Category 2—progress statement</strong></td>
<td>A progress statement is an explicit statement that the patient makes about a positive development in physical condition that has improved quality of life, a positive development in the patient’s life, or a recent, very positive, life-changing event. Examples include, “By following that diet, I’ve gotten my weight down pretty good,” “I just have to take it easy on my back.”</td>
</tr>
<tr>
<td><strong>Category 3—challenge statement</strong></td>
<td>A challenge statement is an explicit statement that the patient makes about the negative effect a physical or psychosocial problem is having on the patient’s quality of life, or a recent, devastating, life-changing event. Examples include, “My arm hurts so bad, I can’t do my work very well,” “My husband and I decided that we are going to get divorced.”</td>
</tr>
</tbody>
</table>

## Coded Response Categories

**Table 2**

Empathic communication coding system (ECCS) of physician responses.

<table>
<thead>
<tr>
<th>Level and name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 6—shared feeling or experience</td>
<td>A response should be categorized in this level if the physician makes an explicit statement that he or she either shares the patient's emotion or has had a similar experience, challenge, or progress.</td>
</tr>
<tr>
<td>Level 5—confirmation</td>
<td>Responses in this level convey to the patient that the expressed emotional feeling, progress or challenge is legitimate. This can be done in several different ways depending on the empathic opportunity. For example, this type of response may be a congratulatory remark, an acknowledgment that the challenge the person is experiencing is difficult, or a statement legitimizing the patient's emotion. Also, by making a statement that others have experienced this same emotion, progress or challenge, the physician is providing confirmation. A physician's statement that he or she understands a patient's emotion also fits in this category.</td>
</tr>
<tr>
<td>Level 4—acknowledgement of patient statement with pursuit</td>
<td>This level is characterized by the physician's acknowledgment of something that the patient has either said explicitly or that the physician has inferred from the patient's statement. Often the response is a restatement of what the patient has said. In addition, the physician pursues the topic with the patient by asking the patient a question, clearly elaborating on a point the patient has raised, or trying to comfort the patient.</td>
</tr>
<tr>
<td>Level 3—acknowledge of patient statement without pursuit</td>
<td>This level is also characterized by the physician's acknowledgment of something that the patient has either said explicitly or that the physician has inferred from the patient's statement. However, level 3 is distinct from level 4 because the physician does not pursue the topic with the patient.</td>
</tr>
<tr>
<td>Level 2—implicit recognition of patient perspective</td>
<td>This level contains responses that do not explicitly recognize the central issue in the empathic opportunity, but focus on a peripheral aspect of the statement. These statements tend to be more content-based, or focused on the biomedical issue, not dealing directly with the progress, challenge or emotion. These may also include questions or advice.</td>
</tr>
<tr>
<td>Level 1—perfunctory recognition of patient perspective</td>
<td>This level is characterized by a physician's automatic, scripted-type response (back-channeling cues) to a patient's statement. These are minimal responses that do not truly acknowledge that the patient has been heard.</td>
</tr>
<tr>
<td>Level 0—denial of patient perspective</td>
<td>This response is characterized by the physician either ignoring the patient's empathic opportunity or by making a disconfirming statement.</td>
</tr>
</tbody>
</table>

## Overall Ratings in 3 categories

*Table 3*  
Physician-expressed empathy: global rating scale measures of physician-expressed empathy from Kemp-White dataset [40].

<table>
<thead>
<tr>
<th>Item</th>
<th>Physician-expressed empathy ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Poor</td>
</tr>
<tr>
<td>GRS-1: The physician connected with the patient as a person.</td>
<td>1</td>
</tr>
<tr>
<td>GRS-2: The physician was empathic with the patient.</td>
<td>1</td>
</tr>
<tr>
<td>GRS-3: The physician invited the patient to share their understanding, perspective, and feelings.</td>
<td>1</td>
</tr>
</tbody>
</table>
What was the training?

Six hour workshops: Didactic and Practice
  • Clinician-Patient Communication (4E’s: Engage, Educate, Empathize, Enlist)
  • Choices and Changes (Making health changes, included expression of empathy)
  • Difficult Relationships

Each workshop followed up with individual coaching session of 45 min
Each workshop followed by review of taped interaction by participant with real patient
Results and Discussion

Showed changes in pre and post
Showed 6 month follow up maintenance
What else do we know from other disciplines?
Many fields value and teach and study it

Psychology
Social Work
Counseling
Counseling/Psychology

Humanitarian psychology
Positive Psychology
Compassion Centered Counseling
Self-compassion
Compassion fatigue
Social Work

COMPASSIONATE COMPETENCE

an ethically, successful integration and transformation of knowledge, skills, attitudes, behaviors, and policies to sympathetically and consciously alleviate suffering (Swindell, 2013).
What do we know from ABA?

Several seminal articles in recent years
Focus on moving into action, beyond empathy
Gould, Tarbox, and Coyne 2017
Taylor, 2018
Operational definitions and instructional approaches developing
Parental distress reduced over time

- Realigning goals
- Self-care
- Acknowledging gains
Taylor et al 2018 define Compassionate Care

Combine perspective taking, tacting when others are suffering
Tact own personal experiences
Observe how suffering might relate to his or her own
Act intentionally to alleviate the suffering of the caregiver
Compassionate Care

Relates to RFT and ACT
Involves perspective taking
Deitc Frames
  • I-YOU

kindness
goodness
sympathy
courtesy
grace
generosity
compassion
Listening and Collaboration: Areas to Improve

- Compromising During a Disagreement
- Inquiring about Satisfaction
- Role Clarification
Empathy and Compassion: Areas to Improve

- Demonstrating caring about the entire family
- Acknowledging mistakes or treatment failures
- Being patient
- Being reassuring.
Items that may Contribute to Problems

Seems to have his or her own agenda about the direction of my child’s program
Underestimates my child’s ability
Focuses too much on my child’s challenging behavior
Failed to communicate with me
Focuses too much on my child’s deficits
Has an authoritarian demeanor rather than a collaborative one when discussing decisions about my child’s program
Is too busy to discuss things about my child’s program that are important to me
Often seems distracted during meetings
Let his or her opinions of other professions or other treatments interfere with our relationship
Interrupts me during meetings about my child
Uses too much technical language that I don’t understand
Part Three: How can we teach these skills?

- Educate about the importance
- Operationally define target skills
- Actively teach with EBP
- Expand into coursework
- Use rubrics to deliver performance based feedback
Framing with Empathy vs Anger
Self-awareness and tecting
Build self-compassion

WHAT IS SELF-COMPASSION?

- **Mindfulness**: Self-compassion involves recognizing when we’re stressed or struggling without being judgmental or over-reading.
- **Self-Kindness**: Being supportive and understanding towards ourselves when we’re having a hard time, rather than being harshly self-critical.
- **Connectedness**: Remembering that everyone makes mistakes and experiences difficulties at times; we are not alone.
Components of poor self-compassionate care

Negative self-assessment
Disproportionate focus on routine clinical error
Self-critical verbal behavior

If your compassion does not include yourself, it is incomplete.

- Jack Kornfield
Other barriers

- Stressors at work
- Stressors at home
- General burnout
- Poor coping skills
Operationally define targets


- Eye contact
- Muscles of facial expression
- Posture
- Affect
- Tone of voice
- Hearing the whole patient
- Your response.
Strategies for improving trust and rapport—reflect and avoid passing judgment, interruptions, blame, trigger words. Jargon.

Authoritarian demeanor (authoritative and collaborative instead).

Strategies for identifying and repairing a damaged relationship.

Recognizing that there is a problem and apologizing.

Assessing the relationship—self and other assessment.

Managing planned and unexpected difficult conversations.

Reflection and perspective taking.
Ideas from Alpine (Taylor, LeBlanc, & Nosik, 2018)

Positive social interactions
- Includes eye contact, appreciation, asks how parent is
- Avoids flat affect, negative comments about child

Empathy
- Includes open ended questions, verification of feelings
- Avoids distraction and jumping to solutions too fast

Compassion
- Includes pauses, supportive statements
- Avoids interruption and defensiveness

Collaboration
- Includes seeking parent ideas and approval, acknowledging mistakes
- Avoids judgement, jargon
Related skills with parallel desired outcomes

Teaching self-compassion via ACT to parents of children with autism (Gould et al., 2017)

Developing procedures to teach interventionists to develop rapport with children with autism (Lugo, King, Lamphere, & Paige, 2017)
Teaching these skills

Use evidence-based procedures
Embed into coursework

EMPHASIZE PARENTAL EXPERIENCE
COLLABORATION CLASS
SKILL BUILDING
• TEACH SOFT SKILLS
Embed into supervision

- Use rubrics
- Observe interactions with families
Nancy Marchese’s work on collaboration with families

<table>
<thead>
<tr>
<th>1. Asked open-ended questions (e.g., “can you tell me more about…”, “what has this been like for you?”, “is there anything else”, “are you ok with how things are going””)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Demonstrated appropriate non-verbal behaviors (e.g., nodding where appropriate, maintained soft eye contact, maintained an open-posture, was not engaged in other activities)</td>
</tr>
<tr>
<td>3. Delivered supportive statements (e.g., “I imagine that must be…”, “sound like you are…”, “that sounds very difficult”, “that’s great! I bet you’re feeling pretty good about that”)</td>
</tr>
<tr>
<td>4. Paused and gave time for caregiver to respond</td>
</tr>
<tr>
<td>5. Summarized information, asked for clarification, checked for accuracy and accepted correction (if applicable) (e.g., “let me know if I’ve gotten this right”, “tell me more about..”, “I want to make sure that I understand what you’ve said..”, “I don’t want us to go further until I’m sure I’ve gotten it right”)</td>
</tr>
<tr>
<td>6. Offered support and partnership (e.g., “I’m committed to working with you to…”)</td>
</tr>
</tbody>
</table>
## Research Lab on Collaboration Skill Devt

<table>
<thead>
<tr>
<th>Nondefensive posture and language:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arms at sides or hands on table</td>
</tr>
<tr>
<td>Hands calm in lap or on table</td>
</tr>
<tr>
<td>Smile or neutral expression on face</td>
</tr>
<tr>
<td>Sole attention on speaker (turn towards who is speaking)</td>
</tr>
<tr>
<td>Physically orient towards speaker</td>
</tr>
<tr>
<td>Calm and cool demeanor (no dramatic gestures)</td>
</tr>
<tr>
<td>Positive or neutral words</td>
</tr>
<tr>
<td>Calm tone of voice</td>
</tr>
<tr>
<td>Use names of the people</td>
</tr>
<tr>
<td>Provide pauses and opportunities</td>
</tr>
<tr>
<td>Rephrases frequently</td>
</tr>
<tr>
<td>Work on collaboration: Coding difficult conversations</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>Reflects Statements of acknowledgement of the other person’s point of view</td>
</tr>
<tr>
<td>Provides the opportunity to speak- the behavior analyst does not cut the other person off</td>
</tr>
<tr>
<td>Asks one or more specific neutral questions, preferably open ended</td>
</tr>
<tr>
<td>Validate something about the parent’s view of the learner</td>
</tr>
</tbody>
</table>
Why should we do this?

- Universal desire for respect
- Universal desire to be understood and validated
- We seek good impressions from families
- We desire better outcomes with those we serve
- We want an improved reputation for the field
Good news

This is the time
We have good sources/starts
Convergence
Consensus
Thanks for your attention!

THANK YOU FOR HAVING ME

For info and references:

mweiss@endicott.edu

---

“EVERYONE YOU WILL EVER MEET KNOWS SOMETHING YOU DON’T.”

BILL NYE

---

Love and compassion are necessities, not luxuries. Without them humanity cannot survive.

Dalai Lama

---

Be The Change
You Wish To See
In The World.

-Gandhi