Emotional health in autistic adults: Research updates toward building better supports

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Research Program:
Identifying pathways to depressed mood in autism to inform targeted treatment development
Overview of this presentation

Background on depression in autism:
  • Prevalence & Impact
  • Presentation & Assessment

Causes & Contributors
  • Research updates from our lab

Treatment overview

Putting this all together: Next steps
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Depression is common in autism

- Autistic community ~4x more likely to experience depression (Hudson et al., 2019 meta-analysis)

Higher lifetime depression rates among autistic participants associated with:

- **Increasing age** (40.2% adult samples vs 7.7% in < 18 years old)
- **Average to above average IQ** (52.8% vs 12.2% when mean IQ is below average)
- **Structured interviews to assess dep** (28.5% vs 6.7% for other assessment methods)
- **Self-report** (48.6% vs 14.4% via caregiver report)
Impact of depression in context of autism

• Depression causes (or adds to) impairments in many areas:
  • Social skills, motivated social engagement
  • Adaptive behavior (daily living skills, communication)
  • Quality of Life, independence
  • Challenging behaviors and coping skills

• Depression in Aut also associated with systemic burden and other areas of risk:
  • greater use of service and meds
  • increased burden on caregivers
  • Suicidality
  • Heightened physical (e.g., gastrointestinal problems, seizures), emotional (e.g., anxiety), and behavioral (e.g., aggression, inattention) comorbidities

• Implications for autism interventions

See Pezzimenti, Han, Vasa, & Gotham, 2019 for references
The community is calling for this to be addressed...

• Mental health is commonly listed by autistic adult samples or groups as among their top research and clinical priorities

(HRSA-funded AASET working group, 2018 conference; Gotham, Marvin, Taylor et al., 2014)
“Traditional” features of depression seem to be common in autistic people…

- Sadness, crying
- Loss of interest and pleasure in activities
- Social withdrawal, general lack of motivation
- Sleeping and eating problems
- Decreased self-care
- Negative cognitions (failure, hopelessness, self-criticism)
- Thoughts about death

Some depressive symptoms may be more specific to autism…

- Changes in restricted interests
  - Markedly greater or lesser intensity
  - Change to morbid focus
  - Increase in repetitive or ritualistic behaviors
- Irritability
- Increased aggression and/or self-injury
- Regressions or decline in self-care

Is there an autism-specific presentation of depression? (1 of 2)

Overall, presentation of depression in autism looks more similar than different

- See Table 1 from Pezzimenti, Han, Vasa, Gotham, 2019, for summary of traditional and atypical symptoms of depression in ASD, with references;
- See also Table 1 from Magnuson & Constantino, 2012, for similar but distinct description.
Is there an autism-specific presentation of depression? (2 of 2)

- Qualitative analyses of depressive experience in autistic adults
  - N=21 aut+dep participants
  - Structured Clinical Interview for DSM Disorders (SCID-5)

- Prototypical:
  - Loss of motivation; withdrawal from life (86%)
  - Suicidal ideation (86%)
  - Rumination, perseverative thinking (52%)

- Atypical:
  - Unconventional metaphors or difficulty describing emotional experiences
  - Significantly increased or decreased interaction with hobbies and interests

- Risk Factors
  - Transition to adulthood
  - Social difficulties
  - Self-identity/acceptance of ASD
Validating a common depression symptom scale in autistic adults

• Beck Depression Inventory–II (BDI-II) in ~n=900 SPARK participants (aut) and ~n=900 community controls (non-aut):
  • Autistic and non-autistic adults answer questions in comparable ways, allowing for valid score comparisons

• Autism-specific normative scores and depression screening cutoff developed for clinical and research use

• Free online score calculator at https://asdmeasures.shinyapps.io/bdi_score
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Common pathways between Depression and Autism?

**Psychological**
- Loneliness, social isolation
- High trait anxiety
- Emotion dysregulation
- Poor coping skills
- Elevated cognitive attributions associated with depression

**Genetic/Biological**
- High familial aggregation of Dep in ASD
- EEG resting frontal asymmetry
- Cognitive perseveration
- Decreased amygdala inhibition by PFC
- Anomalous reward circuitry functioning
- Role of serotonin?
- Neural inflammation/microglial dysregulation

**Social Context**
- Bullying
- Lack of societal understanding / acceptance
- Poor prospects for independence and goal achievement (vocational, educational, residential, romantic)

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1. Bolton, Pickles, Murphy, & Rutter, 1998; DeLong, 2004; Mazefsky et al., 2010
2. Frick, Williams, & Pittenger, 2013
3. Burnette et al., 2011
5. Dichter, Damiano, & Allen, 2012
Looking for treatment targets: *Repetitive Thinking*

- Repetitive negative thinking (rumination) predicts or maintains depression, anxiety, suicidality, and other negative health outcomes in general population (Nolen-Hoeksema, 1991, 2000; Thomsen et al., 2004; Watkins, 2008; Miranda & Nolen-Hoeksema, 2007)

- Restricted, repetitive *behavior* (RRB) is a core symptom domain of ASD but repetitive *thinking* understudied in autism
Is RepT associated with depression? Yes and No.

- Same SPARK sample (N=762, aged 18-45)
- In SEM, controlling for neuroticism & current life stress:
  - mediated path significant
  - direct (unmediated path) n.s.

That means,
- There was a positive indirect effect of RepT on dep sx through Brooding (ab=0.11, 95% CI [0.01, 0.21]).
  - General RepT pos assoc with Brooding (a=0.18, 95% CI [0.11, 0.26])
  - ...and Brooding pos assoc with BDI-II scores (b=0.62, 95% CI [0.14, 1.09]).
  - But there was a (slight) negative direct effect of general RepT on dep sx! (c' = -0.09, 95% CI[-0.17, -0.01])

That is, to the extent that general repetitive thinking did not lead to brooding, it had a protective effect.
...and certain forms of positive RepT indeed seem adaptive

In same SPARK adult sample, **better quality of life** was associated with:

- **Solution-oriented repetitive thinking**, $\beta = 0.28$, $t(731) = 7.457$, $p < 0.001$
- **Savoring**, $\beta = 0.07$, $t(731) = 4.797$, $p < 0.001$
- **Engaging in strong interests socially**, $\beta = 0.2$, $t(731) = 2.963$, $p < 0.01$

*Rowan undergraduates Chris Pellegrino and Trey Scull*
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Treatment
Common depression treatments hold promise for adapting to the autistic community

• **Cognitive Behavioral Therapy (CBT)**
  - Highly effective in general population when delivered well
  - Kerns et al., 2016: Adaptations for using CBT for depression in autism
  - Challenges in Aut: maintaining/generalizing; not applicable to minimally verbal people

• **Behavioral Activation (BA)**
  - Particularly helpful in those with low motivation or social withdrawal, or adults with minimally structured days

• **Mindfulness-Based Therapy**
  - Relies on less insight, more observation/identification

• **Acceptance and Commitment Therapy (ACT)**

• **Pharmacological**
Cognitive Behavioral Therapy

• Cognitive Behavioral Therapy (CBT) is based on the idea that how we feel and what we do are directly related to our thoughts (e.g., attributions, interpretations)

• Focuses on relationship between

• CBT successfully modified for anxiety in children/adolescents with ASD (Sukholodsky et al., 2013 meta-analysis; Chalfant et al., 2006; Sofronoff et al., 2005; Wood et al., 2009; White et al., 2013); heading this way for depression (Kern et al., 2016)

• One resource for finding CBT therapists in your area:  http://www.academyofct.org/ (then select “Find a Therapist”)

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CBT modifications in Autism

- **Psychoeducation** to increase the individual’s understanding of the depression diagnosis as a descriptor for maladaptive emotional symptoms (e.g., prolonged sadness), physical symptoms (e.g., fatigue, aberrant sleep patterns), and social consequences (e.g., social withdrawal and isolation), which helps to identify core skills for symptom improvement

- **Hands-on interactive** activities (e.g., role-playing, games)

- **Visual** analogue scales (e.g., fear thermometer)

- **Technology** (e.g., using phone applications to monitor daily mood)

- **Parent and family involvement**

- **Group therapy** to foster a community of social support and accountability, and to help the adolescent or young adult transition from family-centered support to peer support

- Additional per Gloria Han, in prep: Incorporate special interests in therapy
  - To build engagement and rapport (“You teach me, I teach you”)
  - Strategies for content delivery (e.g., exposures, rewards, coping tools pertaining to interests)

- (Kerns et al., 2016)
What if one's own context is truly depressing?

- No magic answer
- Consider the framework of **Acceptance and Commitment Therapy (ACT)**

Instead of struggling against distress, clients are guided to accept that some negative feelings are **appropriate responses to certain situations**, and yet that this appropriate distress should **not prevent them from moving forward in their lives**.

From there, goal is to accept personal / situational hardships and commit to making necessary changes in behavior to move forward despite these hardships.
Focus on *prevention* of mood problems

- Healthy living, structured time
- Try to build social opportunity/engagement
- Incorporate special interests rather than suppressing

- Create an emotion regulation “toolbox”
- Support network: (tempered) vigilance in noticing behavioral changes
Physical

- Get outside (if you can safely)
  - Take walks, bike rides
  - Sit out to read a book or have a snack
- Get moving every day
  - Have WiFi? YouTube options (e.g., “Little Sports” channel for ~10 minute, simple animated workouts)
- Got meds? Take them!
- Eat
  - If possible: regularly, in moderation, with healthy choices
- Sleep
  Sleep hygiene:
  [https://www.helpguide.org/articles/sleep/getting-better-sleep.htm](https://www.helpguide.org/articles/sleep/getting-better-sleep.htm)
Social

◦ Create opportunities
  ◦ Face-to-face
    ◦ Schedule meaningful time with the people within your home (e.g., Family Game Night)
    ◦ Socially distanced get-togethers
  ◦ Online
    ◦ Schedule FaceTime, Zoom, Google hangout calls
    ◦ Start WhatsApp chats, Discord server with family and friends
    ◦ Get to know new people through shared interests
      - Facebook, Tumblr, Twitter, Instagram, etc.
      - Hiki: autism friendship/dating site (www.hikiapp.com)

◦ Keep your relationships healthy
  ◦ Say positive things
  ◦ Truly listen
  ◦ Disagree respectfully
  ◦ Not working? Take a break.

Good article on recognizing and maintaining friendship:
https://www.helpguide.org/articles/relationships-communication/making-good-friends.htm
Mastery
- Develop skills
  - Cook a new dish, practice a new instrument, learn about interests
  - Can lead to feeling more creative
- Accomplish things
  - Check off on a to-do list
  - Can improve how we feel about ourselves

Fun
- Enjoy for the sake of enjoying
  - What brings you pleasure?
  - Hobbies, games, TV, movies, music
- Create a list of options
  - Keep track and add as you think of more
  - Choose what sounds most fun for that moment
Service

- **Contribute**
  - Thoughtful ways to give back to others
  - Help someone out or do something nice for someone

- **Small actions count!**
  - Donating money / saving a life is not the only way to help!
  - We can help family members or those we live with
    - Do laundry
    - Clean a room
    - Surprise someone with a note/card
    - Prepare a meal or snack
Digging a little deeper in these unusual times...

- Practice tolerating uncertainty
- Practice flexibility
- Practice moderation
  - Limit media consumption
  - Limit screentime (somewhat)
  - Balance mastery and fun
- Practice gratitude
Organize your experience the way you want it

- Make a schedule
- Redecorate, de-clutter
- Seek some solitude, sensory experiences

Terrific COVID-19 Toolkit by/for autistic adults:

Ask directly for social support

- “I am feeling lonely right now, I would really appreciate hearing from you.”
- Encourage people to talk about themselves.
“Like many of us, I am being productive when I can, and —perhaps most importantly— I am being kind to myself when I cannot.”


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Prepare ahead of time, then use your “menu”

**RELAXATION**
- Progressive muscle
- Visualization/imaginative
- Breathing exercises
- Repetitive action or sensory input (at appropriate time)
- Quiet activity (model building, drawing)
- Music – listening/playing
- Reading

**PHYSICAL ACTIVITY**
- Exercise – e.g., trampoline
- Sport
- Creative/destructive
- Swing

**SOCIAL TOOLS**
- Spend time with family member or friend
- Be with a pet
- Ask for help (to clarify what just happened, to give reminders of calming strategies, to help employ thinking tools)

**THINKING TOOLS**
- Put event in perspective
- Promote flexible thinking (e.g., “It might have been an accident. I should check before I get angry”)
- Social story
- What would you like to do? Desired outcome? How to get there?
Mood in the minimally verbal population

• Rather than verbal report, rely on behavioral change (particularly in areas of self-injury, aggression, irritability, tearfulness)

• Focus first on behavioral activation strategies and increasing self-help skills

• Increase social exposure

• Try alternative therapies like art, music, etc.

• We are currently piloting a nonverbal eyetracking task to index depressive symptoms in autistic adults with limited or no spoken language. Contact seahl@rowan.edu for more info!
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Depression in autism (Summary)

- **Prevalent** – rates 4x greater than general population (Hudson et al., 2019)
- **Impactful** – assoc with poorer phys/ment health, qual of life, caregiver burden, suicidality
- **Research prioritized by community** (Benevides et al., 2020)
Depression in autism  
(Summary, cont.)

• Assessment and diagnosis is challenging

• Evidence for effective treatment is limited, but adapted psychotherapies show some promise.

• We hope that focus on potential causal pathways (e.g., repetitive thinking, social motivation) may lead to improved interventions.
Next steps

• Better measures → better research
  • BDI-II seems to work in autistic adults! (Williams, Everaert, & Gotham, 2020)
  • Cassidy/Rodgers group (2021): *Autistic Depression Assessment Tool - Adult (ADAT-A)*
  • Our lab is currently validating 2 new self-report instruments in aut adults: 1 for depression, 1 for rep thinking

• “No man left behind” – focus on vulnerable subgroups
  • Gender and sexuality minorities, those with limited language and/or intellectual disability, child/adolescent populations

• “No stone left unturned” – focus on diverse potential causal contributors
  • Camouflaging, burnout, employment, romantic & other life goal fulfillment, nutrition, sleep, trauma

• “Thinking outside the box” – we need more than just clinicians/researchers working on this
  • Community involvement
  • Multidisciplinary teams, novel disciplines
“Long game” & “Fast track”: We need both now

- We need careful, thoughtful research for long-term solutions
  - That is usually slow and meticulous

- We need wide-scale social change toward acceptance and respect

AND

- We need creative, nimble “bandaids” in the meantime
  - e.g., continuing education packages on autism for clinicians who already know depression tx
  - building awareness to keep this on the radar for families and providers
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Adult participants and their families ❤️

Thank you for listening!

Questions/comments?
gotham@rowan.edu
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Please contact us if you are interested in participating in person!

We are currently recruiting for:

**Roundabout Minds Project**
- Verbally fluent adults
- aged 18-45
- with autism and/or current depression
- no history of bipolar/schizophrenia

**Tracking the Blues in Minimally Verbal Adults**
- Autistic adults with limited or no spoken language
- aged 18-45

Our lab is in Glassboro, NJ
- 20 min south of Philadelphia
- 2 hours south of New York City
- 1 h 45 min north of Baltimore

Contact: seahl@rowan.edu