Suicide and self-injury in autism: What we know and still need to learn about risk and management

STAR Conference 2023
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I work with so many amazing people...
That they do not fit on one slide!

THANK YOU:

- All individuals and families who participate in our studies
- Local autism groups
- All staff and colleagues
**Outline**

I. Autism and...
- mental health
- suicidality
  - Prevalence
  - Differences
  - Risk factors
- self-harm
  - Defining terms
  - Prevalence
  - NSSI as a risk marker
  - Ties to other constructs

II. Assessment and management
- Do’s and don’ts
- Warning signs
- Function of behavior
- Safety planning tips

**A note about content**

- National Suicide Prevention Lifeline: 988 (call or text)
- Crisis text line: text PA to 741741
Person with autism vs. Autistic vs. On the spectrum

- Just ask!

**Neurodiversity**

- Natural variation in our neurology
- Difference is not deficit, not a disease to be cured

**A note on language**

Bottema-Boettla et al. 2021; Keating et al., 2022

- Just ask!

**Neurodiversity**

- Natural variation in our neurology
- Difference is not deficit, not a disease to be cured

**Affirming Language Guidelines**

The ASD SIG aims to be a safe space for all members to communicate and collaborate, inclusive of neurotype. The guidelines below center autistic perspectives regarding strengths-based language that is accepting of differences.

<table>
<thead>
<tr>
<th>Instead of This...</th>
<th>Try This!</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Spectrum/Disorder, ASD</td>
<td>Autism, autistic (the term “disorder” is exclusively medicalized and reinforces negative stereotypes that autism is wrong or needs to be cured)</td>
</tr>
<tr>
<td>Person-first language (e.g., “person with autism” or “person with ASD”)</td>
<td>Identify first-language (e.g., “autistic person”), on the autism spectrum, formally identified as autistic</td>
</tr>
<tr>
<td>High-functioning, high-functioning severity or support needs</td>
<td>Describe specific strengths and needs, acknowledge support needs likely vary across elements (e.g., requires substantial support to participate in unstructured recreational activities, but minimal support to complete academic work)</td>
</tr>
<tr>
<td>“Adult” or autism on ASD</td>
<td>Increased likelihood/reduce of functioning autistic</td>
</tr>
<tr>
<td>Autism symptoms and impairments</td>
<td>Specific autistic characteristics, features, traits, or experiences</td>
</tr>
<tr>
<td>Treatments</td>
<td>Support, services, educational strategies (when applicable)</td>
</tr>
<tr>
<td>Cure/recovery/normal outcome</td>
<td>Focus on quality-of-life outcomes that pertain to what autistic people want for themselves</td>
</tr>
<tr>
<td>Mild/moderate/severe language difficulties/social communication difficulties</td>
<td>Specify the language difficulties or differences, specific characteristics of autistic communication</td>
</tr>
<tr>
<td>Poor empathy, monologues, speaks off in tangents</td>
<td>Uses longer conversational turns and initiates, characteristic of autistic communication style and sharing information and connecting with others</td>
</tr>
<tr>
<td>Blunt, abrupt, rude</td>
<td>A direct communicator, uses language efficiently</td>
</tr>
<tr>
<td>High-functioning autism, severe autism severity of autism</td>
<td>Level 1/2/3</td>
</tr>
<tr>
<td>Description of individual characteristics (e.g., without intellectual disability or language impairment) or specific support needs (see above)</td>
<td></td>
</tr>
<tr>
<td>Deficit/Weaknesses</td>
<td>Area of challenge, difficulty, difference</td>
</tr>
<tr>
<td>Fix it!</td>
<td>Uses neutral/social expressions</td>
</tr>
<tr>
<td>Permanently fixed or control</td>
<td>Prefers to use reduced level of eye contact eyes move around the room when speaking</td>
</tr>
<tr>
<td>Restricted/Special interests</td>
<td>Focused, intense, or passionate interests, Area of interest/expertise</td>
</tr>
<tr>
<td>Stereotypic behaviors</td>
<td>Repetitive body movements or actions as a form of self-regulation and communication</td>
</tr>
<tr>
<td>Ablut and distressed, on their own agenda, on their own way</td>
<td>Demonstrates a nonverbal thinking style characterized of neurotypical children, hypersensitive to intense and difficulties shifting attention to less interesting activities, difficulty of preference for body language and posture</td>
</tr>
<tr>
<td>Challenging behavior/behavior that is unacceptable</td>
<td>Meltdowns (behavior uncontrolled tantrums, throwing items, moment, more specific description of the behavior (e.g., self-harm or aggressive behavior)</td>
</tr>
</tbody>
</table>
Autism characteristics

Differences in social communication and social interaction across multiple contexts, such as difficulties with:

1. social-emotional reciprocity (info-dumps)
2. nonverbal communication for social interaction (facial expressions, reduced eye contact)
3. developing, maintaining, and understanding relationships

Restricted, repetitive patterns of behavior, interests, or activities, such as:

1. stereotyped or repetitive motor movements, use of objects, or speech
2. insistence on sameness, preference for routines
3. very focused, passionate interests
4. hyper- or hypo-reactivity to sensory input

The autism spectrum is not linear

Slide from: Kelly Beck, Jessie Northrup, Elizabeth Rutenberg
Autistic strengths

- Honest
- Detail-oriented
- Rule-based
- Fair
- Creative
- Adheres to routine
- Subject experts

Autistic Challenges

- Social situations
- Sensory
- Change/Rigidity
- Perseveration/rumination
- Executive functioning
- Slow processing speed
- Alexithymia
- Sleep difficulties
Co-occurring mental health in autism

• Child/adolescent
  • 26% ADHD
  • 22% ID
  • 11%/40% anxiety disorders
  • 7%/4-37% disruptive disorders
  • 2% bipolar disorder
  • 2.7%/14-28% depression
  • 1.8%/11% OCD
  • 0.6% psychosis

• Adult
  • 28% ADHD
  • 20-30% ID
  • 20% anxiety disorders
  • 12% disruptive, impulse control, or conduct disorders
  • 5% bipolar
  • 11%/50%- depression
  • 9%/24%- OCD
  • 4% schizophrenia spectrum

Mutluer 2022- population-based meta/
White, Maddox, Mazefsky, 2019
Lai et al 2019- pooled prevalence meta

A lack of confidence

• Interviews about therapy
  • 20/22 autistic adults reported negative psychotherapy experiences
  • 43/44 community clinicians reported learning nothing about autism in their training

• Community clinicians + safety planning
  • Only 39% had safety planning experience; 21% had ever used in ASD

“They’d ask me questions, how you feel about this, how you feel about that, and the harder I thought about it, the more I couldn’t figure out what I was feeling like . . That was kind of useless.”

-autistic adult on therapy experiences

Maddox et al., 2019; Jager-Hyman et al., 2020
Autism and Suicidality

Prevalence

- Child/adolescents
  - Ideation: **10.9% - 72%**
    - Mayes et al., 2013; Ghaziuddin et al., 1995

- Adults
  - Ideation:
    - 20% online sample
    - 60% of newly diagnosed adults (vs. 17% general population)
  - Plan/attempt: **35%** (vs. 2.5% gen pop)
  - Deaths: **0.17%** (vs. 0.11% in gen pop)
    - Hedley et al., 2017; Cassidy et al., 2014; Kirby et al., 2019
**Risk factors: What’s the same**

- Co-occurring psychiatric conditions
- Lack of social support
- Social isolation
- Unmet support needs
- Victimization/ trauma
- Impulsivity
- Difficulty with decision making, finding adaptive coping
- Difficulties with executive functioning
- Self-injury

**Risk factors: What’s different**

<table>
<thead>
<tr>
<th>Autistic burnout</th>
<th>Camouflaging/ masking</th>
<th>Female</th>
<th>Late diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Intense sense of exhaustion</td>
<td>• Acting ‘not autistic’</td>
<td>• Mixed findings;  but autistic females were at particular risk in Utah study</td>
<td>• May be tied to female, masking</td>
</tr>
<tr>
<td>• Loss of skills</td>
<td>• Trying to act like everyone else</td>
<td>• Links to loneliness, depression, and anxiety</td>
<td></td>
</tr>
<tr>
<td>• Tied to emotional outbursts</td>
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</tbody>
</table>

Cassidy et al., 2018; Hedley et al., 2017, 2018; Kirby et al., 2019; Kõlves et al., 2021; Raymaker et al., 2020

Cassidy et al., 2014; Cassidy et al., 2018; Kirby et al., 2019; Raymaker et al., 2020
Assessment issues

• Screening questionnaire in adults: 2/4 of items interpreted differently
  • Telling others about SI – less frequently
  • Attempt one day—more frequently
• Our own experience: 1 in 5 of 12-22 year olds
  • Sick and not eating
  • Not eating healthily
  • Repetitive behaviors
  • Ideation comments when upset

Cassidy et al., 2020; Conner et al., 2020

What we're doing: Autism Center of Excellence

300 people, age 18-65, through all of study (200 autistic; up to 50% with suicidality)

700 adults in online-only sample

17
**Project 1: Self-Report**

- Objective: To develop and validate a self-report questionnaire (the “Autism Suicidality Inventory;” ASI) that captures a continuum of suicide risk in autistic adults
- Neurotypical suicide measures do not work the same way with autistic individuals
- We need to be able to do more than just determine if safety precautions are needed –
  - Continuum of risk – “Propensity for Suicide”
  - Better support research
  - Prevention and support
  - Monitor change in treatment

### Conceptual Model for ASI Items

<table>
<thead>
<tr>
<th>Domain</th>
<th>Subdomain</th>
<th>Facet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Propensity for Suicidality</td>
<td>Negative Valence</td>
<td>Irritability, Low tolerance for negative emotion, Perseverative negative thoughts, Hopelessness, Intolerance of uncertainty and change, Perceived victimization, Loss of motivationally significant activities</td>
</tr>
<tr>
<td></td>
<td>Positive Valence</td>
<td>Low motivation, Anhedonia, Emotional numbing, Diminished future orientation, Low fear of death, Agitation/mania</td>
</tr>
<tr>
<td></td>
<td>Cognitive Systems</td>
<td>Negative urgency; Impulsivity/risky behavior, Poor emotion regulation; poor problem-solving under stress, Black/white thinking, Poor information processing, integration, and generalization, Low emotional self-awareness, Difficulty identifying and communicating the need for help</td>
</tr>
<tr>
<td></td>
<td>Social Processes</td>
<td>Unmet desire for social connection, Limited social support, Sensitivity to social circumstances (e.g., rejection sensitivity, becoming overwhelmed by social interactions), Lack of group identification (thwarted belongingness), Experience of stigma, Widening gap between self and peer group, Low self-compassion/acceptance; Masking of own personality, Burdensomeness</td>
</tr>
<tr>
<td></td>
<td>Arousal and Regulatory Systems</td>
<td>Reactions to over-stimulation/sensory aversion (intolerable, need to escape), Pain tolerance, Chronic pain, Low interoceptive accuracy (out of touch with one's own body), Dissociation, Poor or atypical sleep</td>
</tr>
</tbody>
</table>
Self-Harm in Autistic Individuals

Self-harm, self-injurious behavior, and Nonsuicidal self-injury

• Self-harm
  • “Self-poisoning or self-injury, irrespective of the intent” (Ourgin et al., 2012)
    • Self-harm with suicidal intent
    • Nonsuicidal self-harm
    • Self-harm with unclear intent

• Self-injurious behavior
  • “A class of behaviors, often highly repetitive and rhythmic, that result in physical harm to the individual displaying the behavior” (Fee & Matson, 1992; Weiss, 2009)

• Nonsuicidal self-injury (NSSI)
  • “Deliberate, self-directed damage of body tissue without suicidal intent and for purposes not socially or culturally sanctioned.” (Klonsky et al., 2014)
**SIB vs. NSSI**

- NSSI in the general population
  - Common topographies include cutting, carving and burning
- Considered distinct from the repetitive and rhythmic self-injurious behaviors typically seen in those with developmental disorders
  - Common topographies include head banging and self-hitting
- The purpose of NSSI has commonly been linked to emotion regulation
- Interpersonal/Social Functions of NSSI
  - Peer Bonding, Revenge, Interpersonal Influence
- Intrapersonal Functions of NSSI
  - Affect regulation, anti-suicide, anti-disassociation

**Prevalence of SIB and NSSI**

- There is a breadth of work examining self-injurious behaviors with a strong focus on autistic people with intellectual disability
  - Prevalence ~42% (estimate includes NSSI)
  - Strong link with IQ
  - Most common topographies: hand hitting, skin picking, and hitting self against objects
  - Least common topography: self-cutting
- More recent work has examined NSSI in autistic people without intellectual disability
  - Lifetime NSSI has been reported to be
    - 50%-63.6% in autistic adults, substantially higher than the general population (~15-20%)
    - Autistic women may be more at risk
    - Most common: Severe scratching, cutting, self-biting
    - Least common: Tried to break bones
NSSI as a risk marker for suicide attempts

- In nonautistic samples, NSSI has commonly been found to be a risk marker for suicide attempts (Nock et al., 2006; Victor & Klonsky, 2014)
  - Greater NSSI frequency
  - Number of NSSI methods
  - Cutting topography

- Emerging area for autism research
  - In mainly late-diagnosed autistic samples, risk markers included
    - Greater NSSI frequency
    - Cutting topography

Potential risk markers of NSSI in autistic individuals

- Risk markers for NSSI in autistic adults (Moseley et al., 2019)
  - Greater alexithymia (e.g., difficulty understanding and identifying one’s own emotions)
  - Greater depressive symptoms
  - Greater anxiety symptoms
  - Greater sensory sensitivities (e.g., a high response to sensation due to a low neurological threshold, which manifests in distractibility and discomfort)

- Within autistic adults with a history of NSSI (Maddox et al., 2017)
  - Greater difficulty with emotion regulation was significantly related to sensation seeking functions of NSSI
Assessment and Management

What you may see

- Sensory difficulties
- Opposite emotions (seems fine, joking)
- Difficulty identifying/verbalizing emotions
- Literal thinking/understanding
- Many misunderstandings/miscommunication with others
- Difficulties with making/keeping friendships/relationships
- Feels isolated from society, disconnected
- Slower processing speed
- Perseveration- getting stuck on negative
- Echolalia (echoed speech), odd tone, pace of speech

**Do’s and Don’ts**

- Be direct, use few words
- No metaphors or idioms--- e.g., "I'm with you"
- More direct questions than emotion words- "what happened next," not "how do you feel?"
- Allow extra time to respond

- Ask about interests that they want to talk about
- Explain the purpose of distraction strategies
- More support in making a safety plan

**Things to consider**

- Presence of a risk factor vs. Change for that person's normal
  - Anxiety
  - Sleep issues
  - Self-harm
  - Presence of interest in death-related topics
  - Distress from sensory or social situations
  - Withdrawing from people
  - Big shifts in mood
  - Explosive outbursts/meltdowns/anger

Warnings signs

These warning signs are contingent upon a marked increase or change of specific experiences or behaviors that are different than usual for that individual. Often more than one warning sign would be present in an autistic individual at imminent risk of suicidal behavior.

1. Sudden or increased withdrawal
2. No words to communicate acute distress
3. Current traumatic event, reported by self or others
4. Marked increase in rate and/or severity of self harm
5. Worsening in levels of symptoms of anxiety and/or depression
6. A new focus on suicidal talk, ideation, or death-related topics that are not a special interest
7. Perseverative suicidal thoughts and ruminations
8. Seeking means or making plans for suicide or suicide rehearsal
9. Statements about no reason for living or no sense of purpose in life
10. Hopelessness


Self-harm/NSSI vs. SIB

• Can be tricky to figure out
• What's the function?
  • When/where does it happen
  • History of behavior?
• Chain analysis (DBT)
Safety planning considerations

- May need more direction
- Short, specific instructions
- Visual aids
- Be mindful of emotion recognition to id crisis
- Coping strategies that are mindful of sensory needs

Schwartzman et al 2020

- **Watch this space**: 2 current grants

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Thank you!

Any Questions?

Email me: connercm2@upmc.edu
References


References (contd)

References (contd)


References (contd)