Measuring Mental Health and Related Factors in Autistic People: State of the Science, Implications, and Future Directions

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Disclosures

• I have no disclosures
Identity first language (i.e., autistic person) will be used throughout this presentation to align with recent research findings identifying a preference for person first language among many stakeholders and with published recommendations to avoid ableist language in autism research.
1) Describe at least one reason why accurate measurement of mental health and related factors is important for research and clinical work with autistic individuals.

2) Identify and define qualities of a “good” questionnaire.

3) Describe at least one way researchers and clinicians can work to improve measurement among autistic people.
Background on Autism & Mental Health
What are the diagnostic criteria for Autism Spectrum Disorder (ASD)?

**Social communication**

- Social-emotional reciprocity
- Nonverbal communicative behaviors
- Interpersonal relationships

**Restricted, repetitive patterns of behavior, interests, or activities**

- Stereotyped or repetitive motor movements, use of objects, or speech
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior
- Highly restricted, fixated interests that are abnormal in intensity or focus
- Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment
What does existing research tell us about mental health in autistic people?

- **Social context**
  - Loneliness, rejection due to social communication difference neurotypical-majority society
  - Emotion dysregulation
  - Neurobiological difference

- **Emotion dysregulation**

- **Neurobiological differences**

- **Autistic Youth and Adults**

- **High Rates of Mental Health Conditions**
  - Depression
  - Anxiety
  - Suicidality
  - (ADHD)

- **Quality of Life**
- **Adaptive Functioning**
- **Objective Outcomes (Employment & Independent Living)**

- **Impact**

- **Good Measurement**

(Conner et al., 2020; Farley et al., 2009; Hollocks et al., 2018; Lawson et al., 2020; Schiltz et al., 2021)
Focus on Measurement
Measurement: What role does measurement play in autism research on mental health?

- Identifying prevalence of co-occurring conditions
- Exploring how co-occurring mental health conditions emerge over time
- Examining patterns of co-occurring conditions (who is most at risk)
- Evaluating efficacy of treatment
Measurement: What role does measurement play in clinical practice with autistic people?

**Assessment**
- Differential diagnosis and diagnostic clarity
- Guiding recommendations

**Therapy**
- Identifying treatment targets
- Monitoring treatment progress & outcomes
Measurement Methods: What tools do we have?

- Questionnaires
  - Self-Report
  - Caregiver/Other Report
- Interviews
  - Structured
  - Semi-structured
  - Unstructured
- Observation
Measurement: What makes a good measure?

- Measures what it is supposed to (Validity)
- Works generally the same each time we use it (Reliability)
- Tells us when there is change (Sensitivity)

Strong Psychometric Properties
Measurement: What makes a good measure?

Validity

It measures what it is supposed to

- Does it measure the construct we want to measure? (Construct)
  - Associations with related/unrelated constructs (Convergent & Divergent)
  - Multiple aspects of construct and how these are related to each other (Structural; Dimensionality)

- Coverage of construct (Content)
Measurement: What makes a good measure?

Validitiy

It measures what it is supposed to

Does it work the same for:
• all autistic as well as non-autistic people
• across various intersecting identities and characteristics or are there systematic differences? (Differential Item Functioning/Measurement Invariance Testing)
Measurement: What makes a good measure?

It works consistently

- Does it give a similar result over time (test-retest)?
- Do people respond similarly across the items within the measure (internal)?
Measurement: What makes a good measure?

- It detects change

  Does it tell us when something has changed, either over time or across intervention?
What are some barriers that exist to accurate measurement among autistic people?

**Any-Reporter**
- Most measures were developed and normed with the general population.
- Autism-related experiences may not be captured by existing tools.

**Self-Report**
- Common difficulty identifying internal states in autism (alexithymia).
- Range of verbal/cognitive abilities in autism.

**Other-Report**
- Reliance on observable behaviors by caregivers and other reporters.
- Misinterpretation of autism symptom as those of a different condition or vice versa (diagnostic overshadowing or overlap).

(Kinnaird et al., 2019; Kerns et al., 2015; Nicolaidis et al., 2020; )
Creating Accessible Survey Instruments for Use with Autistic Adults and People with Intellectual Disability: Lessons Learned and Recommendations

Christina Nicolaidis, MD, MPH,1–4 Dora M. Raymaker, PhD,1,3,4 Katherine E. McDonald, PhD,3,5 Emily M. Lund, PhD, CRC,4,6 Sandra Leotti, PhD,1,4,7 Steven K. Kapp, PhD,3,8 Marsha Katz, MS ED,4,9 Leanne M. Beers, PhD,4 Clarissa Kripke, MD,3,10 Joelle Maslak, BA,3 Morrigan Hunter, MA,3 and Kelly Y. Zhen1,3
### Examples of Identified Issues & Recommendations (Nicolaidis et al., 2020)

<table>
<thead>
<tr>
<th>Issue</th>
<th>Recommendation</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complicated or confusing terms or phrases</td>
<td>substitute language or use hotlink</td>
<td>lonely → the feeling of being alone when you do not want to be alone</td>
</tr>
<tr>
<td>Likert scales with imprecise or vague response options</td>
<td>use graphics and/or percentages</td>
<td><img src="image" alt="Likert Scale" /></td>
</tr>
<tr>
<td>Anxiety around answering accurately</td>
<td>reminder to give best guess &amp; comment boxes</td>
<td>please give your best guess from the provided answers</td>
</tr>
<tr>
<td>Inability to fully capture construct</td>
<td>add items as necessary</td>
<td>items about sensory sensitivities or communication skills</td>
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Examples of measures that have been developed/adapted for autistic people

<table>
<thead>
<tr>
<th>Measure</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion Dysregulation Inventory</td>
<td>• Caregiver-report of youth</td>
</tr>
<tr>
<td></td>
<td>• Used PROMIS guidelines</td>
</tr>
<tr>
<td></td>
<td>(Mazefsky et al., 2018)</td>
</tr>
<tr>
<td>World Health Organization Quality of Life–Brief Version with autism spectrum QoL Supplement</td>
<td>• Adults self-report</td>
</tr>
<tr>
<td></td>
<td>• Developed autism-specific quality of life (ASQoL) questions to add to WHOQoL-BREF</td>
</tr>
<tr>
<td></td>
<td>• ASQoL may underestimate QoL in autistic women</td>
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<td></td>
<td>(Rodgers et al., 2016)</td>
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</tbody>
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Set of guidelines developed by an NIH Roadmap Initiative with leading experts in the field

Key PROMIS Steps:
- define target concept and make a model; get feedback on model
- develop item pool based on existing measure and new items
- see how people interpret/respond to items using cognitive interviews
- perform pilot testing followed by larger scale testing using IRT

(McConachie et al., 2018; Williams et al., 2021; Rodgers et al., 2016)
Examples of measures that have been developed/adapted for autistic people

**Parent-Rated Anxiety Scale for ASD (PRAS-ASD)**
(Scahill et al., 2019)

- Parent-report of youth
- Developed using focus groups and IRT

**Anxiety Scale for Children with Autism Spectrum Disorder (ASC-ASD)**
(Rodgers et al., 2016)

- Parent- and self-report of youth
- Adapted from: Revised Child Anxiety and Depression Scale
- Re-worded items, new items
Examples of measures that have been evaluated/tested among autistic people

<table>
<thead>
<tr>
<th>Measure</th>
<th>Self-report measure</th>
<th>Measurement invariance &amp; cognitive interviews</th>
<th>Rigorous testing</th>
<th>Caregiver report of a measure</th>
<th>Caregivers respond to some items differently depending on their child’s autism features, IQ, and age</th>
<th>Self-report measure for adolescents to adults</th>
<th>Overall, performs well, with some modifications (e.g., some items loading on different factors)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suicidal Behaviour Questionnaire-R</td>
<td>measure of suicidality for adults</td>
<td>indicate need for adaptations</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Beck Depression Inventory II</td>
<td>measure of depression for adults</td>
<td></td>
<td>Rigorous testing indicates this is a good measure for autistic adults</td>
<td></td>
<td>(Williams et al., 2020)</td>
<td></td>
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<tr>
<td>Screen for Anxiety Related Disorders</td>
<td>Caregiver report of a measure for children</td>
<td></td>
<td>Caregivers respond to some items differently depending on their child’s autism features, IQ, and age</td>
<td></td>
<td>(Schiltz et al., 2021)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulties with Emotion Regulation Scale</td>
<td>Self-report measure for adolescents to adults</td>
<td></td>
<td>Overall, performs well, with some modifications (e.g., some items loading on different factors)</td>
<td></td>
<td>(McVey, Schiltz, et al., 2021)</td>
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Social Anxiety Scale for Adolescents

- Both Adolescent report and Parent report

- Items:
  - 18 items related to anxiety
  - 4 filler items (e.g., my child/I likes to play sports)

- 5-point Likert scale:
  - 1 Not at all to 5 All of the time

- Three subscales:
  - Fear of Negative Evaluation (FNE) - I worry that others don’t like me
  - General Social Avoidance and Distress (SAD-G) - I am quiet when I’m with a group of people
  - Avoidance and Distress Specific to New Situations (SAD-N) - I get nervous when I meet new people

(Schiltz et al., 2021)
SAS-A has been used to examine:

• Prevalence of Social Anxiety in ASD
• Correlates of Social Anxiety in ASD
  • Neurophysiological (EEG)
  • Behavioral (Social Abilities)

(Schiltz et al., 2021)
Psychometric Assessment of SAS-A in Autism

- Adolescent-parent item-level agreement: Poor
- Factor Structure: Two-Factors
- Measurement Invariance: Lack of Evidence
- Convergent and Divergent Validity: Some Evidence

(Schiltz et al., 2021)
Recommendations & Future Directions
We know more about

- Anxiety
- Children
- Parent-report
- People without intellectual disability

We know less about

- Other constructs
- Adults
- Self-report
- People with intellectual disability

(Kim & Lecavalier, 2021)
Recommendations: Researchers

• Considerations for selecting measures for studies
  • Choose measures that have psychometric support in autism
  • Make evidenced based adaptations as necessary
  • Multi-method, multi-informant approach
Future Directions: Measurement Researchers

• Do more research on measurement!
  • Evaluating measures, and when necessary, adapting/developing measures for autism
  • Focus on areas with less evidence: adults, ID, self-report, other than anxiety
  • Involve stakeholders (e.g., focus groups, cognitive interviews, etc.)
  • Use advanced psychometric approaches (e.g., IRT)
    • Test measures for bias (both comparing autistic to non-autistic respondents as well as within autistic individuals – like IQ, gender, race)
  • An example approach is the PROMIS Method
Recommendations: Clinicians

• Considerations for selecting measures in clinical practice
  • Choose measures that have psychometric support in autism
  • Multi-method, multi-informant approach

• Considerations for administering measures in clinical practice
  • Complete questionnaires with clients/patients
  • Provide a visual of response options (e.g., see Nicolaidis et al., 2020)
  • Ask clients/patients about their experience completing the questionnaire
Future Directions: Stakeholders

• Involvement in studies helping both researchers and clinicians improve measurement
  • What things should we be measuring?
  • Which aspects of your experience aren’t captured by existing measures?
Some Takeaways!

• Good measurement is the foundation of good science and clinical practice.
• There are certain qualities of measures that we can test to ensure good measurement (including validity, reliability, and sensitivity to change)
• However there are some barriers to good measurement of mental health and related factors among autistic people
• There is a need for researchers, clinicians, and stakeholders to work together to develop, test, and utilize measures with sound psychometric properties that can ultimately help to improve quality of life among autistic people.
If you’re interested in this topic...

Colleagues and I will be leading a Special Interest Group at the International Society for Autism Research Annual Meeting!

*Improving Patient Reported Outcome Measures (PROMs) in Autism Research: Bridging the Gap Between Advanced Psychometric Techniques and Stakeholder Priorities*

Saturday May 14, 2018 7:00AM – 8:30AM
References


References


