Self Harm and Suicidality in Autism

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Mental Health Autism (MHAutism)

Understanding and reducing mental health problems and suicide in autism.
Recent research showed that the autism community use a range of terms to describe themselves:

- Autistic
- Aspie
- On the spectrum
- Person with autism

On the whole, ‘autistic person’ was most preferred by the autism community, and ‘person with autism’ was preferred by professionals.
• Self harm is any behaviour resulting in harm/injury to self, regardless of intent to end life
  • Includes non-suicidal self-injury (NSSI)

• Suicidality refers to thoughts, or behaviours relating to ending life, including death by suicide

• These difficulties have been thought about very differently in autistic compared to the general population

• Resulted in these topics being overlooked for some time …
• Self harm in autism commonly referred to as self-injurious behaviour (SIB)
  • E.g. head banging or biting

• Approximately 50% lifetime prevalence

• Significantly higher in people with intellectual disability or other conditions
• Different presentation of self harm in autistic and general populations:
  • In autistic people, associated with repetitive behaviour, and more common in childhood
  • In the general population more common in adolescence/adulthood, and tends to be different form

Resulted in autistic people being excluded from self harm research
• In the general population, self harming behaviour associated with increased risk of suicidality

• Is this the case in autistic people?

• Are autistic people experiencing SIB experiencing suicidality?

• What is the prevalence, presentation and risk/protective factors for self harm and suicidality in autistic vs. general population?
Prevalence
Suicidality in Autism

• 374 newly diagnosed adults with Asperger Syndrome; suicidal ideation 66%; suicide plans/attempts 35%, depression 31%
  • Autistic traits and depression risk factors for suicidality (Cassidy et al. 2014)

• Autistic adults significantly more likely to die by suicide than the general population
  • Being female, autism without intellectual disability, and depression are risk factors (Hirvikoski et al. 2016)
  • 11-12% of those who die by suicide in the UK have evidence of autism, most are undiagnosed (Cassidy et al. 2017)
• Only three studies available:
  
  • In 42 autistic adults attending college 50% reported NSSI compared to 17-26% in the general population (Maddox et al. 2016)
  
  • In 164 autistic adults, 65% reported NSSI significantly higher than a matched sample of autistic adults (Cassidy et al. 2018a)
  
  • In 83 autistic children, 33% had experienced NSSI based on parental report (Akram et al. 2017)
Increased prevalence of self harm and suicidality in autism

Why?
**Interpersonal Psychological Theory of Suicide (IPTS)**

- **Desire to die**
  - Thwarted Belongingness 
    - *(I am alone)*
  - Perceived Burdensomeness 
    - *(I am a burden)*

- **Autistic Traits**
  - Social difficulties
  - Social exclusion
  - Unemployment

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Results

• 163 general population young adults (18-30 years)

• Autistic traits significantly predicted Perceived Burdensomeness and Thwarted Belongingness (controlling for age, gender and depression)

**Autistic traits associated with risk of suicidality through thwarted belonging and perceived burdensomeness**
• Lack of social support in ASD increases depression and in turn suicidal ideation (Hedley et al. 2017)

• Feelings of loneliness increases depression and thoughts of self-harm (Hedley et al. 2018)
• Models and measures developed for the general population
• So we formed a steering group of 8 autistic adults who had experienced mental health difficulties and/or suicidality:
  • Identify themes which may increase or decrease risk of experiencing mental health problems, self harm and/or suicidality
  • Develop a survey to capture these areas
Research Questions

• Common risk markers which are more prevalent in autism?
  • Unemployment
  • Co-occurring psychiatric conditions

• Unique autism-specific risk markers?
  • Autism diagnosis, autistic traits
  • Are there other risk markers identified by the autistic community?

• **Mental Health in Autism (MHAutism):** Participatory research project to increase understanding of mental health, self-injury and suicidality in autism
Measures

- **Suicide Behaviours Questionnaire – Revised (SBQ-R):** Psychiatric cut off 8/18
- **Non-Suicidal Self-Injury Assessment Tool (NSSI-AT):** Categorised presence/absence of lifetime NSSI
- **Autism Spectrum Quotient (AQ)**
- **Unmet support needs:** number of areas actually receive support – number of areas ideally liked
- ‘Camouflaging’ autism in an attempt to fit in in social situations: presence/absence and score (sum of areas, frequency and amount)
<table>
<thead>
<tr>
<th>Variables</th>
<th>Gen Pop (N=169)</th>
<th>Autism (N=164)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD) / %</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>31.95% male</td>
<td>39.63% male</td>
</tr>
<tr>
<td>Age (years)</td>
<td>40.72 (10.87)</td>
<td>39.93 (11.03)</td>
</tr>
<tr>
<td>AQ score</td>
<td>19.87 (7.87)</td>
<td>36.42 (8.03)</td>
</tr>
<tr>
<td>Employed</td>
<td>79.9%</td>
<td>49.4%</td>
</tr>
<tr>
<td>Satisfaction with living arrangements</td>
<td>78.44 (23.16)</td>
<td>68.47 (26.67)</td>
</tr>
<tr>
<td>Depression</td>
<td>45%</td>
<td>79.9%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>36.1%</td>
<td>71.3%</td>
</tr>
<tr>
<td>≥1 Dev Cond</td>
<td>1.8%</td>
<td>22.6%</td>
</tr>
<tr>
<td>Unmet support</td>
<td>1.56 (1.6)</td>
<td>3.29 (2.33)</td>
</tr>
<tr>
<td>Age autism diagnosed</td>
<td>-</td>
<td>34.86 (13.03)</td>
</tr>
<tr>
<td>Lifetime Camouflage</td>
<td>-</td>
<td>90.2%</td>
</tr>
<tr>
<td>Camouflage Score</td>
<td>-</td>
<td>13.99 (3.88)</td>
</tr>
</tbody>
</table>
## Results

<table>
<thead>
<tr>
<th>Variables</th>
<th>Gen Pop (N=169)</th>
<th>Autism (N=164)</th>
<th>Effect Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>SBQ-R</td>
<td>6.72 (3.32)</td>
<td>10.4 (3.98)</td>
<td>$d = 1$</td>
</tr>
<tr>
<td>≥psychiatric cut off</td>
<td>33.7%</td>
<td>72%</td>
<td>OR 5.04</td>
</tr>
<tr>
<td>Suicide attempt</td>
<td>8.3%</td>
<td>38.4%</td>
<td>OR 6.91</td>
</tr>
<tr>
<td>NSSI</td>
<td>29.8%</td>
<td>65.8%</td>
<td>OR 4.55</td>
</tr>
</tbody>
</table>

$d = $ Cohen’s $d$

OR = Odds Ratio
Analyses

• Regressions statistically controlled for range of demographics and diagnoses:
  • Age, sex, satisfaction with living arrangements, employment status, developmental conditions, depression, anxiety

• Separate models explored whether each of the following predictors explained significant additional variance in suicidality / NSSI:
  • autism diagnosis, autistic traits (in gen pop), age of autism diagnosis, ‘camouflaging’, and unmet support needs
• Separate hierarchical regressions explored additional contribution of each predictor variable to the outcome variable suicidality (SBQ-R scores):
  1. Autism diagnosis (4.5%)
  2. Autistic traits in the gen pop (3.2%)

• Autism group:
  1. ‘Camouflaging’ (3.5%)
  2. Unmet support needs (3.1%)
  3. NSSI (4%)
  4. Age of diagnosis did not explain significant additional variance in SBQ-R
Predictors of NSSI

- Logistic regressions used to calculate ORs adjusted for demographics and co-occurring diagnoses:
  - Autism diagnosis OR 3.99 (95% CI 2.27-7.03)
  - Camouflaging OR 8.75 (95% CI 2.23-34.47)

- Unmet support needs, autistic traits, and age of autism diagnosis were not independent predictors
• Results confirm high rates of suicidality and NSSI in Autism, above psychiatric samples (Cassidy et al. 2014)

• Autism diagnosis / autistic traits are independent risk markers for suicidality (diagnosis only for NSSI)
  • Consistent with recent research (Chen et al. 2017)

• Unmet support needs predict suicidality
• ‘Camouflaging’ an autism specific risk marker for suicidality and NSSI
Implications

- Routine screening for suicidality in Autism
  - Validated suicidality assessment tools needed for this group (Cassidy et al. 2018a)
  - Important to explore distinction between suicidality and NSSI in autism
- Appropriate support more important than diagnosis per se, but both difficult to obtain (Jones et al. 2014; Crane et al. 2016)
- Acceptance of autistic people in society needed (Cage et al. 2018; Pelton and Cassidy 2017; Milton and Sims, 2016)
Assessment and Measurement
• **Alexythymia:** under/over reporting of suicidality?

• **Theory of Mind, literal interpretation:** over reporting of suicidal feelings?

• **Overlapping behaviours?** E.g. social withdrawal, sleep problems ...

• **Unique aspects of suicidality in Autism:** Reduced cognitive flexibility …

Involve autistic community in development of Qs …
Adapting Tools

- Stage 1: Systematic review of measurement tools to assess suicidality in adults with/without autism diagnosis
- Stage 2: Focus groups, cognitive interviews and survey to inform and test adaptations
- Stage 3: Explore measurement properties of original adapted tools
- Stage 4: Establish prevalence of suicidality in autistic adults in the UK
• High rates of suicidality in autistic people (Cassidy et al. 2018a; Hirvikoski et al. 2016; Cassidy et al. 2014)

• BUT systematic review showed no suicidality assessment tool has yet been used or validated in autistic adults (Cassidy et al. 2018b)

• The Suicide Behaviours Questionnaire – Revised (SBQ-R) was identified as a promising candidate tool to adapt
Research Questions

• What is the evidence regarding the appropriateness and measurement properties of the SBQ-R in autistic adults?

• **Structural validity:** Are we measuring the same thing in autistic and the general populations?

• **Content validity:** If not, can we ascertain clues from how autistic adults interpret and respond to the SBQ-R items?
• **Mental Health in Autism (MHAutism):** Participatory research project to develop new assessment tools for autistic adults

• **Study 1:** Online survey to gather large sample of autistic and general population adults SBQ-R to compare the structure between groups

• **Study 2:** Sub-sample of autistic adults (n = 15) from the online survey complete interviews to explore interpretation of the SBQ-R
## Participants

<table>
<thead>
<tr>
<th>Variables</th>
<th>Gen Pop (N=183)</th>
<th>Autistic Pop (N=188)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD) / %</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>33.9% male</td>
<td>40.4% male</td>
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<td>Age (years)</td>
<td>40.92 (11.13)</td>
<td>39.66 (11.36)</td>
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<td>AQ score</td>
<td>19.93 (7.95)</td>
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<td>79.2%</td>
<td>48.1%</td>
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<tr>
<td>Satisfaction with living arrangements</td>
<td>78.11 (23.22)</td>
<td>69.04 (26.6)</td>
</tr>
<tr>
<td>Depression</td>
<td>47%</td>
<td>77.5%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>37.7%</td>
<td>70.6%</td>
</tr>
<tr>
<td>≥1 Dev Cond</td>
<td>1.6%</td>
<td>23.4%</td>
</tr>
<tr>
<td>Unmet support</td>
<td>1.59 (1.56)</td>
<td>3.34 (2.4)</td>
</tr>
<tr>
<td>Age autism diagnosed</td>
<td>-</td>
<td>34.36 (13.34)</td>
</tr>
</tbody>
</table>
Measurement Invariance Analysis: does a tool capture a construct in the same way between groups?

<table>
<thead>
<tr>
<th>Invariance Level</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Configural Invariance</td>
<td>• Do the same items measure the same construct across groups?</td>
</tr>
<tr>
<td>Metric Invariance</td>
<td>• Do groups attribute the same meaning to the questions?</td>
</tr>
<tr>
<td>Scalar Invariance</td>
<td>• Are scores equivalent between groups?</td>
</tr>
<tr>
<td>Strict Invariance</td>
<td>• Are the factor variances/error equivalent across groups?</td>
</tr>
</tbody>
</table>

SBQ-R Hypothesised Structure

1. Lifetime experience of suicidal ideation and/or attempt.
2. Frequency of suicidal ideation over the past twelve months.
3. Threat of a suicide attempt – communication of suicide intent to others.
4. Self-reported likelihood of suicidal behavior in the future.

**SBQ-R Hypothesised Structure**

1. Lifetime experience of suicidal ideation and/or attempt.
2. Frequency of suicidal ideation over the past twelve months.
3. Threat of a suicide attempt – communication of suicide intent to others.
4. Self-reported likelihood of suicidal behavior in the future.
• Evidence for good overall model fit in autistic and general population

• BUT no evidence for metric invariance between the groups

• Source of metric invariance is item 4 (trend for item 3)
## Study 1: Results MI

<table>
<thead>
<tr>
<th>SBQ-R Item</th>
<th>Autism Group</th>
<th>Gen Pop Group</th>
<th>Item Comparisons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Factor Loading</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>1. Lifetime suicidality</td>
<td>3.03 (.93)</td>
<td>.862</td>
<td>2.2 (.95)</td>
</tr>
<tr>
<td>2. Frequency of suicidal ideation in past year</td>
<td>2.95 (1.64)</td>
<td>.805</td>
<td>2.04 (1.44)</td>
</tr>
<tr>
<td>3. Threat of suicide attempt</td>
<td>1.75 (.86)</td>
<td>.785</td>
<td>1.28 (.61)</td>
</tr>
<tr>
<td>4. Self reported likelihood of suicidal behaviour in the future</td>
<td>2.54 (1.68)</td>
<td>.689</td>
<td>1.43 (1.32)</td>
</tr>
</tbody>
</table>
Suggests that autistic adults are not attributing the same meaning to item 4: likelihood of suicidal behaviour in the future
Study 2: Cognitive Interviews

• How are the items of the SBQ-R interpreted by autistic adults?

• 15 interviews: “tell me what you are reading and thinking about when you answer the questions”

• “Think aloud” followed by prompts informed from pilot focus groups
Study 2 Results: Cognitive Interviews

1. Have you ever thought about or attempted to kill yourself? (check one only)
   - □ 1. Never
   - □ 2. It was just a brief passing thought
   - □ 3a. I have had a plan at least once to kill myself but did not try to do it
   - □ 3b. I have had a plan at least once to kill myself and really wanted to die
   - □ 4a. I have attempted to kill myself, but did not want to die
   - □ 4b. I have attempted to kill myself, and really hoped to die

2. How often have you thought about killing yourself in the past year? (check one only)
   - □ 1. Never
   - □ 2. Rarely (1 time)
   - □ 3. Sometimes (2 times)
   - □ 4. Often (3-4 times)
   - □ 5. Very Often (5 or more times)

3. Have you ever told someone that you were going to commit suicide, or that you might do it? (check one only)
   - □ 1. No
   - □ 2a. Yes, at one time, but did not really want to die
   - □ 2b. Yes, at one time, and really wanted to die
   - □ 3a. Yes, more than once, but did not want to do it
   - □ 3b. Yes, more than once, and really wanted to do it

4. How likely is it that you will attempt suicide someday? (check one only)
   - □ 0. Never
   - □ 1. No chance at all
   - □ 2. Rather unlikely
   - □ 3. Unlikely
   - □ 4. Likely
   - □ 5. Rather likely
   - □ 6. Very likely

**Difficulty interpreting questions**

“If you have a plan, you always have a plan – ‘at least once’ is a problem
“It’s a future question and you don’t know what is going to happen in the future so it’s almost impossible to answer”

**Missing options**

“It might be a brief passing thought that has lingered for weeks but this would go under ‘once’. It’s not capturing how serious the thought was or the length of time”

**Not autism specific**

“Don’t understand why this question matters? … I am much less likely to tell someone, it’s hard enough having a normal chat”
• Results suggest that the SBQ-R is not operating in the same way in autistic vs. general population adults

• Both statistical analysis and interviews suggest that items tapping into social and abstract future thinking are particularly problematic for autistic people
• Mean scores cannot be compared between autistic and general population adults using the SBQ-R

• Items need to be adapted to better capture suicidality in the autistic community
Next steps ...

• We have adapted the SBQ-R based on feedback from the interviews

• We have obtained feedback on the adapted tool from further interviews

• We have launched an online survey to obtain further feedback on the original and adapted tools.

Follow @MHAutism for further info!
Implications for Intervention / Prevention
Overall Summary

• Self harm and suicidality in autism significantly higher than the general population
  • However, unclear whether this is under/over-estimated
• Late diagnosed / undiagnosed adults without ID appear most at risk
• Increased vulnerability to risk factors for suicidality:
  • Reduced sense of belonging, isolation
  • Difficulty accessing support and treatment
  • Unemployment, co-occurring mental health conditions
• Suicidality in autism beyond ‘co-morbidities’:
  • One new potential autism specific risk factor – ‘camouflaging’
• Timely diagnosis of autism, and post diagnostic support
• Identifying and supporting ‘the lost generation’ of autistic adults (Lai and Baron-Cohen, 2015)
• Promoting inclusion, independence and autonomy of autistic people
• Beware of the messages we are sending …
• Adapting tools to more effectively capture mental health and suicidality in autism
Thanks to …

**Coventry University:** Dr. Louise Bradley, Dr. Rebecca Shaw.

**Newcastle University:** Dr. Jacqui Rodgers, Magdalena Glod.

**University of Worcester:** Prof. Erica Bowen.

**Autism Research Centre, University of Cambridge:** Prof. Simon Baron-Cohen, Paula Smith.

**Coventry Autism Steering Group and Attendees of MHAutism stakeholder workshops**

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