Suicidality in Autism

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Who we are

- **Mental Health Autism (MHAutism)**
  - Understanding and reducing mental health problems and suicide in autism

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- **Assessment and Measurement**
- **Risk/Protective Factors**
- **Intervention / Prevention**

- Adapted tools
- Applying models of suicidality
- Autism specific risk factors
- Implications
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.
Mental Health in Autism

• Majority of autistic adults (79%) meet criteria for at least 1 mental health condition (Lever and Guerts, 2016)

• A significant risk factor for suicide in the general population (Kasper et al. 1996; Baraclough et al. 1974)

What about suicide in autism?
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 LD, and depression are risk factors (Hirvikoski et al. 2015)
Growing number of ‘counting’ studies

Not enough about Why
Overview

Assessment and Measurement
Adapted tools

Risk/Protective Factors
Applying models of suicidality
Autism specific risk factors

Intervention / Prevention
Implications
Assessment and Measurement
Challenge of Measurement in Autism

• **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 autism 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 adapted tools
• Stage 4: Establish prevalence of suicidality in autistic adults in the UK
Adaptation: Stage 1 - 2

- No validated suicidality assessment tools used in autism, or validated for this group
- Suicide Behaviours Questionnaire Revised (SBQ-R) brief 4-item candidate tool selected
- Four focus groups with variety of stakeholders (autistic adults, service providers, clinicians)
  - How clear are the questions, how important are the questions, are any important questions missing?
- 2 x 15 cognitive interviews with autistic adults
  - Tell me what you are reading and thinking about as you work through the questionnaire
- Next step – online survey to feedback on candidate tool
Adaption Stage 2

- **Difficulties with language** - break up questions, fewer options
- **Difficulties with memory and time** – diary/calendar?
- **Literal interpretation** – exactly how many thoughts, accidentally overdosing without intent to end life, “What is a plan … you always have a plan …”
- **Insensitive language** – “commit suicide”, “kill yourself”
- **Purpose of the assessment** – “Why are these cells blue?”
- **Rapport and trust** – “What will happen to me?”
Risk / Protective Factors
- Study 1: Exploration of autistic traits and the Interpersonal Psychological Theory
- Study 2: Co-designed suicidality survey with the autism community
- Study 3: Preliminary findings from first Psychological Autopsy study of suicide in autism
Interpersonal Psychological Theory of Suicide (IPTS)

Desire to die

- Thwarted Belongingness
  * (I am alone)

- Perceived Burdensomeness
  * (I am a burden)

- Social difficulties
- Social exclusion
- Unemployment

Autistic Traits


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
Participatory Research

• 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 and/or suicidality
  • Develop a survey to capture these areas
Themes identified from the focus groups

• Isolation – social and non-social
• Lack of belonging in an autism unfriendly world – thoughts of ‘leaving’
  • Lack of opportunities – employment, education etc.
• Social and communication difficulties, and tendency to mask these – mental health problems, difficulties accessing help
• Lack of autism friendly services
• Late diagnosis, misdiagnosis, diagnostic overshadowing
  • Lack of post diagnostic support
• Not supporting autistic people to have a positive identity – strengths as well as weaknesses – lack of resilience
Results

- 168 autistic adults (67 male, 101 female), and 108 control females, aged 20-60 years old

- Autism group mean SBQ-R (10.31) significantly higher than the recommended cut off for psychiatric populations (>=8); 69.8% at or above this cut off

- Significantly higher SBQ-R in autistic than control females (10.61 vs 6.27) (controlling for age, education, occupational status, living arrangements, co-morbid developmental and mental health conditions)

- Autism group - history of NSSI, at least one mental health condition, unemployment, and camouflaging associated with significantly higher SBQ-R
Psychological Autopsy

- Preliminary results from first stage of a Psychological Autopsy study aiming to:
  - establish whether definite/possible autism diagnoses are over-represented amongst people who died by suicide in the UK
  - compare the characteristics of those with and without autism who have died by suicide in the UK
  - Involve analysis of coroners inquests and interviews with friends and family of the person who died
  - Results could identify targets to prevent suicide in autism
Psychological Autopsy

- Coroners records for the period 2014-2015 recording a suicide, open, drug/alcohol or narrative conclusion were analysed for:
  - Evidence of autism (diagnosed and un-diagnosed)
  - Inter-rater reliability was >80% for evidence of autism

<table>
<thead>
<tr>
<th>Evidence of autism?</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definite Diagnosis</td>
<td>Clinical diagnosis of autism noted in the inquest.</td>
</tr>
<tr>
<td>Strong Evidence</td>
<td>Possible diagnosis noted, <em>and</em> clear indicators in &gt;=2 areas: 1) Social/Communication difficulties; 2) Narrow interests; 3) Routines; 4) Sensory difficulties; 5) Special educational needs in childhood.</td>
</tr>
<tr>
<td>Possible Diagnosis</td>
<td>Clear indicators in &gt;=2 areas (as above), but not noted in record.</td>
</tr>
<tr>
<td>No Evidence</td>
<td>No clear indicators of autism in record.</td>
</tr>
</tbody>
</table>
• 219 coroners inquest records were assessed, 150 which were ruled a likely suicide according to ICD-10 criteria.
• 11% had evidence of autism, significantly higher than the general population rate (1%)
Implications for Intervention / Prevention
Overall Summary

- Suicidality in autism significantly higher than psychiatric groups
  - 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-morbid mental health conditions
- Suicidality in autism beyond co-morbidities:
  - One new potential autism specific risk factor - camouflaging
Implications

- Timely diagnosis of autism, and post diagnostic support.
- Identifying and supporting ‘the lost generation’ of autistic adults.
- Promoting inclusion, independence and autonomy of autistic people:
  - access to education and employment, positive identity and esteem, resilience – sense of belonging.
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