Suicide and autism
Overview

• The data on mortality in autism
• New research directions in suicide
• What we know about suicide and autism
• Relevant research questions
• Policy, information and awareness
About autism

- Lifelong neurodevelopmental condition with difficulties in social and communication skills, repetitive behaviours, narrow circumscribed interests, and sensory difficulties (APA, 2013).

- Affects 1% of the population (700,000 in the UK). Most are adults and many remain undiagnosed (Lai and Baron-Cohen, 2015).


- Mental health in autism research is the top priority (James Lind Alliance and Autistica, 2015).
About Autistica

• The UK’s leading autism research charity

• We want to give everyone affected by autism the chance of a long, happy, healthy life

• Our research strategy is driven by the views of the autism community
Data on mortality

• The largest ever autism mortality study (ASD n = 27,122; matched controls n = 2,672,185) was recently published, finding increased risk of early death in autism, OR:2.56 (2.38-2.76) (Hirvikoski et al., 2015).

• Autistic and learning disability (LD) at highest risk (OR: 5.78).

• In autistic people with no LD, risk of death is also elevated (OR: 2.18).

• Suicide is a leading cause (OR:9.40).

• 70% of children have a MH problem. 80% of adults report having had one.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Total n ASD</th>
<th>Risk ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mouridsen</td>
<td>Denmark</td>
<td>341</td>
<td>1.9 (1.3-2.8)</td>
</tr>
<tr>
<td>Pickett</td>
<td>USA</td>
<td>13111</td>
<td>2.5</td>
</tr>
<tr>
<td>Gillberg</td>
<td>Sweden</td>
<td>120</td>
<td>5.6 (2.5-10.5)</td>
</tr>
<tr>
<td>Bilder</td>
<td>USA</td>
<td>305</td>
<td>9.9 (5.7-17.2)</td>
</tr>
<tr>
<td>Schendel</td>
<td>Denmark</td>
<td>20,492</td>
<td>2.0 (1.4-3.0)</td>
</tr>
</tbody>
</table>

Data from other studies on mortality
We cannot tackle this enormous challenge alone.

Autistica has committed to raise awareness of this shocking situation, first in the UK and Europe and now internationally.

Our report in March 2016 aimed to:

• Raise awareness of the hidden mortality crisis
• Increase other funders’ investment in research
• Ensure services actively reduce premature death
• Make recommendations for action by politicians
Autistica’s scientific response

We aim to raise and leverage £10m in five years to fund new research into epilepsy, suicide and the other major causes of death for autistic people.
Autistica’s scientific response

Why?
Scoping research need

Suicide
Risk factors, prevention strategies
Stakeholder meeting to develop specific research strategy
Psychological autopsies, network, small grants aimed towards prevention

The solution
Potential research

The result
Autistic people will live longer, happier, healthier lives.
Assessing Mental Health and Suicide Risk in Autism

Dr Sarah Cassidy
Overview

• What do we know about suicide in autism?
• Challenges with assessment
• How can current tools be adapted for people with autism?
Who are we?

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

• **High rates of comorbidity with mood and anxiety disorders:**

  • Depression present in 30 – 50% of adults with autism (e.g. Cassidy et al. 2014; Lugnegård et al. 2011; Hofvander et al. 2009; Sterling et al. 2008), and 30% of children (e.g. Strang et al. 2012).

  • Anxiety present in ~50% of adults (e.g. Lugnegård et al. 2011; Hofvander et al. 2009), and ~40% of children (e.g. Strang et al. 2012; van Steensel et al. 2011).

• **Mood disorders are a significant risk factor for suicide in the general population (Kasper et al. 1996; Baraclough et al. 1974)**

What about suicide risk in autism?
Suicidality in adults with autism

**Adults with ASC at significant risk of suicide:**

- 42 adults with AS living in the community; suicidal ideation 40% suicide attempts 15% (Balfe and Tantam, 2010)
- 26 adult psychiatric patients with ASC; suicidal ideation 30.8%, 7.7% died by suicide (Raja et al. 2011)
- 74 adults with ASC + depression; suicidal attempts 24% (Takara and Kondo, 2014)
- Adults with ASC/AS make up 7.3% - 15% of suicidal populations (Kato et al. 2013; Ryden et al. 2008)

**Small non-representative samples, no comparison groups, lack of confirmed diagnosis** (Cassidy et al. 2014; Segers and Rawana, 2014)
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)
• Adults with autism 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)
Presentation of suicidality in autism

• Suicide attempts in autism tend to be more aggressive/lethal (Takara and Kondo, 2014; Kato et al. 2013; Spencer et al. 2011; Schmid, 2011; Hare, 1997)

• Role of social difficulties:
  • Peer victimisation in 38-75% of samples (Mayes et al. 2013; Mikami et al. 2009; Shtayermman, 2007; 2008; Spencer et al. 2011; Schmid, 2011; Hare, 1997)

• Co-morbidity of psychiatric problems, e.g. BPD, depression, psychosis

• Less connected to psychiatric services (Kato et al. 2013; Raja, 2014)
Summary

• Consistently high rates of depression, suicidal thoughts and behaviours in autism
  • High suicide rates (31%) – lack of identification of patients at risk?
• Unique presentation of suicidality in ASC
  • Only half of suicidal patients depressed (under-diagnosed depression in Autism?)
  • Lack of gender difference

Valid Measurement Needed …
Challenge of measurement in autism

- **Alexythymia**: under/over reporting of suicidality and depression?
- **Theory of Mind, literal interpretation**: over reporting of suicidal feelings?
- **Overlapping symptoms in ASC and depression?** E.g. social withdrawal, sleep problems …
- **Unique aspects of suicidality and depression in autism:**
  - Disinhibition, reduced cognitive flexibility …
Some possible solutions …

- **Alexythymia**: visual support to identify and label feelings
- **Theory of Mind, literal interpretation**: specific clear questions not open to interpretation
- **Overlapping symptoms in autism and depression?** Social withdrawal vs social isolation, measure behaviour change
- **Capture unique aspects of suicidality and depression in autism?** Disinhibition, reduced cognitive flexibility …

  > Involve autism community in development of Qs …
Adapting measures for autism

• We identified the most robust tools to identify depression and suicide risk in the general population and those with autism

  • Suicide Risk:
    • None have been used in research so far in those with autism
    • C-SSRS, BSS, SBQ-R – robust in general population and psychiatric samples
Thanks to …

Violence and Interpersonal Aggression Theme, Coventry University:
Prof. Erica Bowen.

Newcastle Autism Lifecourse and Ageing Program:
Dr Jacqui Rodgers, Dr Jeremy Parr, Prof. Helen McConachie and Stephen Barton

Autism Research Centre, University of Cambridge:
Prof. Simon Baron-Cohen
Influencing policymakers

We are calling for:
• Premature deaths in autism to be a national priority
• Better data collection and analysis
• Better support for autistic people (health checks, risk plans, screening, new therapies)
• More training for healthcare professionals
• More research
Awareness

Over 120 newspapers, TV and radio stations and news websites have covered the issue

We briefed the leading UK autism charities and presented our report at Autism Europe Congress 2016 and to the NIMH in the US

We continue to spread the word nationally and internationally
Information

This is new to the vast majority of the autism community

We must take care how and when we communicate the risks, be clear on what we do and don’t yet know, and be sensitive to autistic people’s needs

We have just published new information resources for individuals and families
Driving a response

Together, we should be aiming to give everyone affected by autism the chance of a long, happy, healthy life

• New collaborative studies
  • Better understanding of risk
  • Autism-appropriate interventions

• Re-examining the current service model – does it exclude or cause issues for autistic people?
Thank you.

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