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Reducing the Impact of Mental Health Comorbidity in Autism: A Frank Discussion

Darren Hedley
La Trobe University

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Reducing the Impact of Mental Health Comorbidity in Autism: A Frank Discussion

Abstract
Presentation given at the Autism in Malaysia Symposium, July 13 & 14, 2018.

Keywords
autism, employment, DXC Technology, Dandelion Employment Program

Comments

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Reducing the Impact of Mental Health Comorbidity in Autism: A Frank Discussion

Autism in Malaysia Symposium
13 & 14 July, 2018
Disclosure
DH and the associated research presented today is funded by DXC Technology and the Australian Government Department of Human Services and Department of Defence.
Social comparison processes and depressive symptoms in children and adolescents with Asperger syndrome

**Social relationships theory of poor mental health & wellbeing in autism**

**Alternative focus on cognitive psychological mechanisms underpinning mood disorders**

- **Barnhill & Smith-Myles, 2001;** attributional style in adolescents, attributed depressive symptoms to “cognitive errors” and “perception of having limited control over negative life events”

**Assumptions of social contribution to mental health and wellbeing**

- Adolescence is associated with “social and emotional challenges” (Howlin, 2003)
- Young people with autism may be overwhelmed by sophisticated social demands (Howlin, 2003)
- Therefore are at increased risk of negative social experiences (e.g., bullying)
- Leading them to withdraw from the social world (Howlin, 2003; Tantam, 2000)
- Vulnerability to mood disorders & depression (Attwood, 2003)
We adopted a psycho-social approach based on social comparison theory to understand depression in autism (Festinger, 1954)

- Associations between social comparison & depression documented in the literature in TD (Allan & Gilbert, 1995; Cole & Carpentieri, 1990)
- Depressive symptoms associated with “one's perceived self-other disparity” (Furnham & Brewin, 1988)
- “One of the central features of depression is a negative or undesirable feeling of difference or deviance from others” (Furnham & Brewin, 1988, p.196)

We posited “social comparison and awareness of being different” may be exacerbated in adolescents w/ autism

Negative social encounters may serve as reminder of differences from peers

- Attwood, 1998 - “Desire to be like others, without all the skills to be successful, may be a common cause of depression in autism”
- Hare, 1997 - in people with autism without intellectual disability, “increasing awareness of differences may lead to increasing levels of distress”
- Butzer & Konstantares, 2003 - higher depressive symptoms associated with parents reports of awareness of disability
- Tantum, 2000 - “Growing awareness of how others view oneself can lead to increased distress as individuals with autism become older
- Administered the Social Comparison Scale (SCS; Allan & Gilbert, 1995) & Children’s Depression Inventory (CDI; Kovacs, 1992) to 36 adolescents with autism (10-16 years)

- 9/36 (25%) were in the above average – very much above average on CDI (1 reported suicidal thoughts)

Table 3  Interpretation of CDI standardized (T) scores using Kovacs’ guidelines

<table>
<thead>
<tr>
<th>T-score</th>
<th>Guideline</th>
<th>Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;70</td>
<td>Very much above average</td>
<td>1</td>
<td>2.8</td>
</tr>
<tr>
<td>66–70</td>
<td>Much above average</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>61–65</td>
<td>Above average</td>
<td>8</td>
<td>22.2</td>
</tr>
<tr>
<td>56–60</td>
<td>Slightly above average</td>
<td>5</td>
<td>13.9</td>
</tr>
<tr>
<td>45–55</td>
<td>Average</td>
<td>13</td>
<td>36.1</td>
</tr>
<tr>
<td>40–44</td>
<td>Slightly below average</td>
<td>4</td>
<td>11.1</td>
</tr>
<tr>
<td>35–39</td>
<td>Below average</td>
<td>5</td>
<td>13.9</td>
</tr>
<tr>
<td>30–34</td>
<td>Much below average</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>&lt;30</td>
<td>Very much below average</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
• SCS and CDI significantly correlated, $r = 0.52$, $p = .001$

• Perceived Group Membership ("When I am with other people I generally feel different/same") emerged as independent significant predictor of depressive symptoms on CDI ($p = .002$), explaining 31% of variance in scores

<table>
<thead>
<tr>
<th></th>
<th>SCS</th>
<th>Rank and achievement</th>
<th>Social attractiveness</th>
<th>Perceived group membership</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDI total score</td>
<td>0.52*</td>
<td>0.40</td>
<td>0.31</td>
<td>0.56*</td>
</tr>
<tr>
<td>Negative mood</td>
<td>0.41</td>
<td>0.34</td>
<td>0.18</td>
<td>0.45*</td>
</tr>
<tr>
<td>Interpersonal problems</td>
<td>0.39</td>
<td>0.08</td>
<td>0.35</td>
<td>0.34</td>
</tr>
<tr>
<td>Ineffectiveness</td>
<td>0.46*</td>
<td>0.38</td>
<td>0.30</td>
<td>0.37</td>
</tr>
<tr>
<td>Anhedonia</td>
<td>0.37</td>
<td>0.30</td>
<td>0.18</td>
<td>0.47*</td>
</tr>
<tr>
<td>Negative self-esteem</td>
<td>0.36</td>
<td>0.23</td>
<td>0.18</td>
<td>0.57*</td>
</tr>
</tbody>
</table>

*p < 0.01.
• Tentative support for hypothesis that social comparison (perceived difference from others) was important to adolescents with autism, and may play a role in depressive symptoms

• Challenges impaired Theory of Mind (ToM; thinking about what others are thinking) hypothesis and supports importance of social relationships to people on the autism spectrum

• “Understand, accept, and appreciate differences” may be important to improve mental health outcomes
Mental health & common co-morbidities in autism

- Rates of co-morbid (co-occurring) symptoms in autism vary from 4-81% depending the study
- Almost all individuals with autism will experience significant co-morbid symptoms at some time in their life
- Rates of co-morbid symptoms are significantly higher than in neurotypical development, other neurodevelopmental or neuropsychiatric diagnoses (Eaves & Ho, 2008; Hofvander et al., 2009; Leyfer et al., 2006; Simonoff et al., 2008)
• ADHD
  - Once exclusion for ASD diagnosis, now can be co-diagnosed
  - Most common early to mid-childhood, less prevalent in adulthood
  - Hofvander et al. (2009)
  - 43% met diagnostic criteria for ADHD

• OCD, schizophrenia, substance abuse less common, but should be considered

• Highest prevalence though is Anxiety, Depression, Sleep Disturbances
Anxiety

- Noted in first descriptions by Leo Kanner and Hans Asperger
- Higher presence compared to typical development or other disability groups
- Rates vary: 13-84% (van Steensel et al., 2011); likely 40-50% show clinically elevated levels of anxiety
I NEED TO GET OUT OF HERE!

HYPERVENTILATING

HEART GOIN’ CRAZY

CAN’T BREATHE

SWEATY PALMS

PANIC
Sleep problems

- 30% in the general population suffer sleep problems at some point in their lives (Roth, 2007)
- Up to 80% of people with autism (independent of age/IQ) have significant sleep disturbance
- Insomnia is most common (Baker & Richdale, 2015; Richdale & Schreck, 2009)
- Associated with behaviour problems in children
- Can affect work
- Associated with depression
- Gaming?
• Depression

- Lifetime rate of 53% in autism (Hofvander et al., 2009)

- Many people with autism report feeling lonely, isolated, and lack active and sustained friendships or social supports beyond their immediate family

- Only 5-10% in long-term romantic relationship (Eaves & Ho, 2008; Howlin et al., 2004; Jobe & White, 2007; Mazurek, 2014; Ormond et al., 2004)
Summary

• Anxiety, depression, & sleep problems often co-occur with profound negative impacts on the individual

• Underlying factors & mechanisms leading to high rates of co-morbid conditions in autism are unclear

• Hence therapeutic choices are limited, and often effectiveness in people with autism is unclear

• Support for behavioural/CBT approaches to treating anxiety, and melatonin/CBT for sleep

• Importantly, depression is a significant risk factor for suicidal behaviour, with 90% of attempted or successful suicides suffering from clinically significant depression (Baraclough et al., 1974)

Next...

• There is recent attention on autism as a risk factor for suicidal behaviour, and on the possibility that people with autism are at significant increased risk of suicide compared to other groups.

• Following a 10-15 minute group discussion/activity, we will turn to research in this area, including several of our studies from Australia.
Dying before their time: Addressing premature mortality among autistic people

Autistic adults with a learning disability are 40 times more likely to die prematurely due to a neurological condition, with epilepsy the leading cause of death.

Autistic adults without a learning disability are 9 times more likely to die from suicide.

Understanding and prevention of suicide in autism

A small body of research is showing worryingly high rates of suicidality in people with autism. In a large-scale clinical study of adults newly diagnosed with Asperger’s syndrome, 66% reported that they had contemplated suicide, significantly higher than rates among the UK general population (17%) and patients with psychosis (59%); 35% had planned or attempted suicide. A large-scale population study showed that suicide is a leading cause of premature death in people with autism.

The risk factors for suicide in people with autism can be very different to those in the general population, and thus require tailored prevention strategies. Insights from suicidology are needed to synthesise priorities for future research using high-quality research methods, to further our understanding of suicide in autism and inform new evidence-based prevention strategies for this group. For example, psychological autopsy methods could be extremely valuable for exploration of the prevalence of autism in people who have died by suicide, and identification of any unique suicide prevention targets for this group.

Existing theories explaining the movement from suicidal thoughts to behaviours in the general population, and treatments for suicidality and self-harm, have yet to be considered in the context of autism. However, such theories and treatments have the potential to be successfully adapted for this group. Existing models of good practice need to be applied to the autism population.

Over the next 2 days, researchers from Coventry and Newcastle University, UK, will be running the first international suicide in autism summit, funded by Autism Speaks in association with the James Lind Alliance. We will be convening a wide range of stakeholders to develop priorities for future suicide prevention in autism research, ensure that appropriate and rigorous methods are developed and applied to achieve these aims, and develop recommendations for changes to policy and practice to reduce suicide in autism. We call on researchers, policy makers and practitioners to participate by reading and feedback on the outcomes from this meeting, which will be made available via our website.

*Sarah Cassidy, Jacqui Rodgers
sarah.cassidy@coventry.ac.uk

Additional information can be found at the Autism Speaks website.
Systematic Review of Suicide in Autism Spectrum Disorder: Current Trends and Implications

Darren Hedley¹ • Mirko Uljarevic¹²

- Review of literature last 5 years (2013-17)
- 4 systematic reviews, 13 empirical papers
- 30,663 (69.8% male) individuals with autism
  - 1 x population-based mortality study; n = 27,122
  - USA (5), Japan (3), Australia (1), Canada (1), Sweden (1), Turkey (1), UK (1)
  - 39% children/adolescents (1-18 years)
  - 61% older adolescents/adults (17-65+ years)
  - 86% IQ in higher range (>70/80), 14% lower range
Main findings

- Quality of diagnosis varied considerably between studies
  - Few studies (n = 1) used suicide specific assessment instruments, most relied on self-report, and 1x used national registry data
- Co-morbid depression/mood disorder were most common, 1 study reported ADHD (65%)
- Prevalence rates:
  - Suicidal ideation = 11-66%
  - Suicidal attempts = 1-35%
  - Mortality = 0.31% of population (0.04% in controls)
- Compared to age and gender matched controls, risk of premature death by suicide is significantly increased in people with autism who do not have a co-morbid intellectual disability (OR = 9.40, p < .001) and is the leading cause of premature death in this group (Hirvikoski et al., 2016, Premature mortality in autism spectrum disorder, BR J Psychiatry, 208, 232-8).
- Correlates/predictors of risk include: bulimia, anxiety/mood disorders, ADHD, female, psychotic symptoms, family HX, higher IQ, behaviour problems, race (black/Hispanic in US), PTSD, HX of suicidal behaviour
- Autistic traits????
Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder

Darren Hedley1 © · Mirko Uljarević1 · Mathilda Wilmot1 · Amanda Richdale1,2 · Cheryl Dissanayake1

- We examined role of social support in suicidal ideation in autism using online survey in individuals who had applied for the Dandelion Employment Program (may or may not have been successful getting job)
  - 76 (69 male), 17-56 years (M = 25.15, SD = 7.74 years)
  - 55.3% employed part- full-time
- ISEL-12 social support (“I don’t often get invited to do things with others”)
- PHQ-9 (“In the last 2 weeks have you had thoughts that you would be better off dead, or of hurting yourself”)
- Hypothesis
  - Social support would be associated with depression and suicidal ideation directly and indirectly
• 25% in clinical range for depression on PHQ-9 (7.6% in general European population; Casey et al., 2008)
• 20% reported suicidal ideation (9.5% in general European population; Casey et al., 2008)
• 37% had a diagnosis of depressive disorder as well as autism
• 40% reported a diagnosis of an anxiety disorder
Table 2  Study variables (internal reliability, $M$, $SD$, range) and correlations ($n=76$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\alpha$</th>
<th>$M$</th>
<th>$SD$</th>
<th>Range</th>
<th>Shapiro Wilk</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. AQ-Short $^a$</td>
<td>0.810</td>
<td>76.15</td>
<td>9.88</td>
<td>54-97</td>
<td>0.98</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>2. W-ADL $^a$</td>
<td>0.769</td>
<td>30.45</td>
<td>3.62</td>
<td>20-34</td>
<td>0.86**</td>
<td>–0.019</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>3. ISEL-12 appraisal</td>
<td>0.755</td>
<td>6.79</td>
<td>2.91</td>
<td>0-12</td>
<td>0.97*</td>
<td>–0.168</td>
<td>–0.034</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>4. ISEL-12 belonging</td>
<td>0.801</td>
<td>5.41</td>
<td>3.11</td>
<td>0-11</td>
<td>0.95**</td>
<td>–0.294*</td>
<td>–0.041</td>
<td>0.518**</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>5. ISEL-12 tangible</td>
<td>0.775</td>
<td>8.03</td>
<td>3.08</td>
<td>0-12</td>
<td>0.91**</td>
<td>–0.086</td>
<td>0.018</td>
<td>0.532**</td>
<td>0.456**</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>6. Depression (PHQ-8)</td>
<td>0.836</td>
<td>6.16</td>
<td>4.98</td>
<td>0-19</td>
<td>0.93**</td>
<td>0.045</td>
<td>–0.015</td>
<td>–0.214</td>
<td>–0.144</td>
<td>–0.294*</td>
<td>–</td>
</tr>
<tr>
<td>7. Suicidal ideation (PHQ item 9)</td>
<td>–</td>
<td>0.263</td>
<td>0.619</td>
<td>0-3</td>
<td>0.48**</td>
<td>–0.061</td>
<td>–0.066</td>
<td>–0.065</td>
<td>–0.209</td>
<td>–0.158</td>
<td>0.558**</td>
</tr>
</tbody>
</table>
• Found support for the indirect model whereby tangible support (perceived availability of material support – “If I were sick, I could easily find someone to help me with my daily chores”) acted on suicidal ideation indirectly, through depression (model accounted for 31.1% of variance in suicidal ideation)

• Better perceived access to tangible support associated with reduced depression and reduced depression associated with reduced suicidal ideation
Brief Report

Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness

Darren Hedleya,*, Mirko Uljarevićb, Mathilda Wilmota, Amanda Richdalea,b, Cheryl Dissanayake1

a Olga Tennison Autism Research Centre, La Trobe University, Melbourne 3086, Victoria, Australia
b Cooperative Research Centre for Living with Autism (Autism CRC), Long Paddock, Brisbane, Queensland, Australia

• Similar sample/design to previous study
• UCLA loneliness scale (“How often do you feel part of a group of friends?”)
• Loneliness significantly associated with both depression ($r = .39, p < .01$) and ideation ($r = .34, p < .01$)
• No correlation between ASD traits (AQ), depression or ideation
Model supported where relationship between loneliness and suicidal ideation was mediated by depression, mediator (depression) accounted for 56.7% of effect.
Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder

Darren Hedley PhD | Mirko Ulijarević PhD | Kitty-Rose Foley PhD | Amanda Richdale PhD | Julian Trollor MD

1.95 (94 females; 14-80 years; $M = 36.69$, $SD = 15.57$) with autism participating in 2x national online studies

- 50% part- full-time employed
- 46.5% had a Bachelor’s degree or higher

- AQ-Short
- UCLA Loneliness Scale
- Social Support Questionnaire (SSQ-6; Sarason et al., 1987)
  - Number of people they “can really count on to be dependable when you need help”
  - How satisfied are you with the support you receive
- PHQ-9
<table>
<thead>
<tr>
<th>PHQ</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity</strong></td>
<td></td>
</tr>
<tr>
<td>None-Minimal (0-4)</td>
<td>46  24.9</td>
</tr>
<tr>
<td>Mild (5-9)</td>
<td>49  26.5</td>
</tr>
<tr>
<td>Moderate (10-14)</td>
<td>47  25.4</td>
</tr>
<tr>
<td>Moderately severe (15-19)</td>
<td>29  15.7</td>
</tr>
<tr>
<td>Severe (20-24)</td>
<td>14  7.6</td>
</tr>
<tr>
<td><strong>Clinical cut-off</strong></td>
<td></td>
</tr>
<tr>
<td>Below (&lt;10)</td>
<td>95  51.4</td>
</tr>
<tr>
<td>Above (≥10)</td>
<td>90  48.6</td>
</tr>
<tr>
<td><strong>Ideation</strong></td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>119  64.3</td>
</tr>
<tr>
<td>Several days</td>
<td>46  24.9</td>
</tr>
<tr>
<td>More than half the days</td>
<td>11  5.9</td>
</tr>
<tr>
<td>Nearly every day</td>
<td>9   4.9</td>
</tr>
</tbody>
</table>

**TABLE 2** Distribution of PHQ depression symptom severity, depression cut-off (≥10), and suicidal ideation (N = 185)

\[ \text{PHQ Severity: } \text{None-Minimal (0-4)}, \text{Mild (5-9)}, \text{Moderate (10-14)}, \text{Moderately severe (15-19)}, \text{Severe (20-24)} \]

\[ \text{Clinical cut-off: } \text{Below (<10)}, \text{Above (≥10)} \]

\[ \text{Ideation: } \text{Not at all}, \text{Several days}, \text{More than half the days}, \text{Nearly every day} \]
<table>
<thead>
<tr>
<th>Variable</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
</tr>
</thead>
<tbody>
<tr>
<td>AQ-Short</td>
<td>-</td>
<td>.175</td>
<td>-.085</td>
<td>-.164</td>
<td>.246*</td>
<td>.129</td>
</tr>
<tr>
<td>ULS-8</td>
<td>.232*</td>
<td>-</td>
<td>-.457**</td>
<td>-.505**</td>
<td>.409**</td>
<td>.209*</td>
</tr>
<tr>
<td>SSQ-6N</td>
<td>-.079</td>
<td>-.294**</td>
<td>-</td>
<td>.482**</td>
<td>-.383**</td>
<td>-.304**</td>
</tr>
<tr>
<td>SSQ-6S</td>
<td>-.023</td>
<td>-.629**</td>
<td>.368*</td>
<td>-</td>
<td>-.424**</td>
<td>-.357**</td>
</tr>
<tr>
<td>Depression</td>
<td>.289**</td>
<td>.502**</td>
<td>-.248*</td>
<td>-.490**</td>
<td>-</td>
<td>.496**</td>
</tr>
<tr>
<td>Ideation</td>
<td>.06</td>
<td>.38*</td>
<td>-.181</td>
<td>-.410**</td>
<td>.608**</td>
<td>-</td>
</tr>
</tbody>
</table>

AQ-Short, Autism Spectrum Quotient-Short; ULS-8, University of California Los Angeles Loneliness Scale-Short Form; SSQ-6N, Social Support Questionnaire Number; SSQ-6S, Social Support Questionnaire Satisfaction.

*P < .05, **P < .01.
FIGURE 1 Path model
Notes: *p<.05; **p<.01; ***p<.001
Conclusions

- High risk of depression and suicidal ideation and behaviour in people on the autism spectrum
- Mortality studies indicate much higher risk (up to 9x) of general population
- Leading cause of premature death in individuals without intellectual disability
- We are interested in potential mechanisms underlying this increased risk and prevalence
- We posited, and found support for a psycho-social model of depression and suicidal ideation in autism
- Specifically, **loneliness**, access to **tangible social support**, and the **quality/satisfaction** of social support may operate as risk and protective factors for mental health outcomes, respectively, in people with autism
- **Social relationships ARE important for people with autism**
- Some, but not overwhelming support for the role of autistic traits (assessed with AQ) in mental health and wellbeing – more work needed in this area
- **It is important to increase availability of, and access to social support networks for people on the autism spectrum**
  - Employment?
Contributions & thank you to...
Thank you

latrobe.edu.au/otarc