



DEPRESSION, SUICIDE AND AUTISM

What do we know and what do we *need* to know?

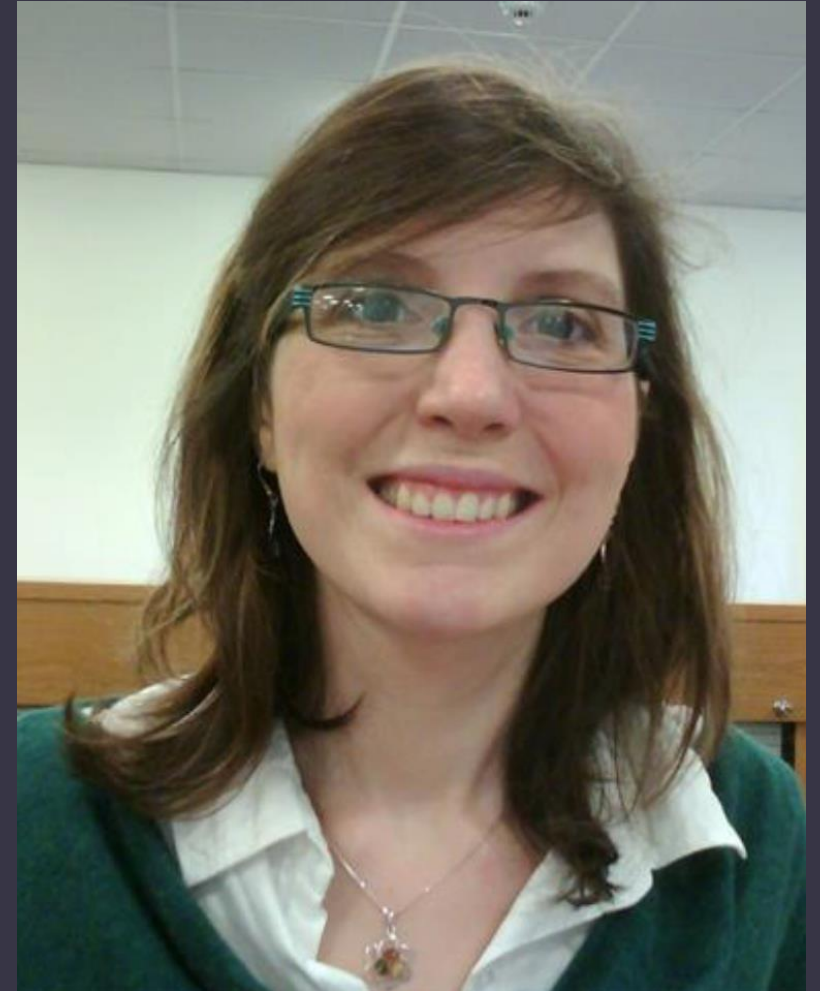
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*Research focus in
autism:
mental health, self-injury,
suicide, ageing, sex
differences, female
presentation, late
diagnosis.*



A note about my talk...

... there's a lot we still don't know about mental health and suicidality in autistic people, chiefly **how best to help**.

I wish I could give you these clear guidelines today.

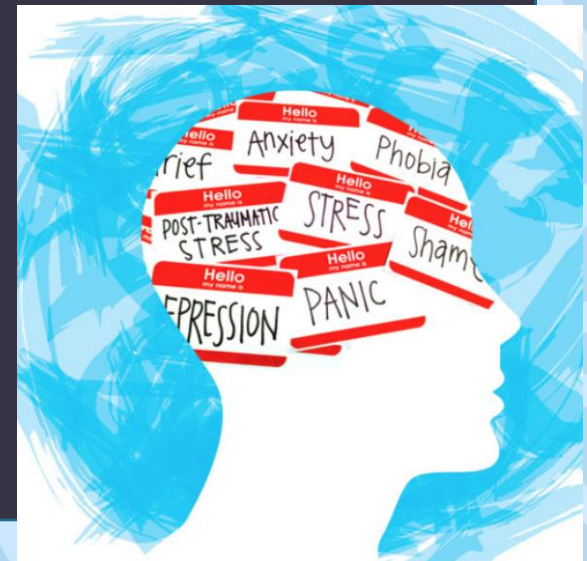
As such, my goal is to tell you what we know, currently – which will highlight where we need to go.

A second note about my talk...

... the autistic spectrum is hugely diverse, but I'm going to stick to autistic **adults, without intellectual disability**.

You will see a lot of them: approximately half the autistic population do *not* have an intellectual disability (NAS).

You will see a lot of them: psychiatric issues in ASC are almost universal.

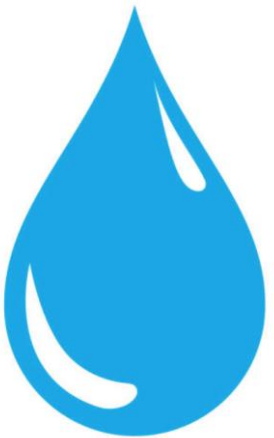


When it comes to depression...

... prevalence is 3-4 times higher in autistic adults (Hudson et al, 2019).

Who is most at risk? Autistic people who:

- Have a higher IQ, better cognitive ability and less social impairment; possibly more aware of their difficulties?
(Greater recognition of differences from others, and low self-esteem, are associated with depression in autism! [Hedley & Young, 2006; Gotham et al, 2014])
- Caucasian? *(likely this is a problem with studies – we need to be aware)*
- Males and females may be more vulnerable at different times; males in adolescence, females in later life. *But symptoms increase at a faster rate in teenage girls! (Gotham et al, 2015)*
- Older autistic people are more vulnerable?

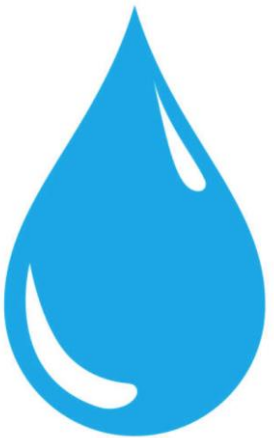


... but could depression be more common than we think?

Are the measurement tools we have fit for purpose?

... we don't know (Hudson et al, 2019).

- Only the properties of the Beck Depression Inventory (II) have been tested in autism – and found wanting (Cassidy et al, 2018).
- Some of the items overlap with autistic features – e.g. trouble sleeping, moving or talking slowly, flat affect. How can you separate them out?
- Literal interpretations (“feeling down”)
- Alexithymia - does not have the language to describe emotions.



What does depression *look* like in autism?

- Changes in sleeping patterns
- Apparent worsening of autistic symptoms: more socially withdrawn, more inflexible, worse concentration, more agitated/aggressive.
- Regression in self-care abilities
- *Less likely* to express feelings of sadness, hopelessness, low self-esteem, worthlessness, excessive guilt, or suicidal ideation



Bitsika &
Sharpley, 2015;
Cassidy et al,
2018;
Chandrasekhar &
Sikich, 2015

What does depression *look* like in autism?

- Loss of pleasure/interest in normally enjoyed activities, *anhedonia*, may be the most robust feature, rather than low mood. For e.g.: no longer interested in special interest. This is important when diagnosing autistic people, as criteria that are needed to meet cut-offs on our measurement tools may not be right for autism.
- Be mindful of biopsychosocial transition times – these will be especially challenging (e.g. puberty, menopause).



*Bitsika &
Sharpley, 2015;
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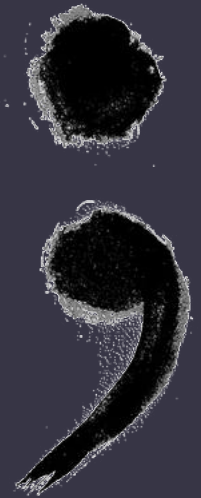
The statistics for suicide in autism:

Up to 66% of adults report suicide ideation, up to 35% report attempts (Hedley & Uljarevic, 2018)

9 times more likely to end their own lives (Autistica, 2016)

We're not sure which figure is correct... but autistic people are at much higher risk of suicide.

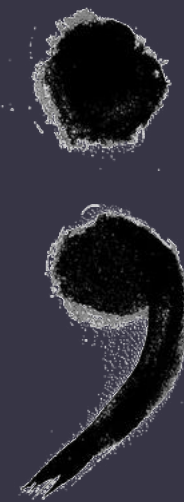
Hedley & Uljarevic, 2018; Kirby et al, 2019; Cassidy et al, 2018; Autistica, 2016;



Suicide is most likely...

- In adults without intellectual disability
- In autistic women (more than autistic men, and much more than non-autistic women)
- In those who expend a lot of time/effort camouflaging their difficulties
- In those with unmet support needs
- In those with comorbid ADHD
- In those with additional anxiety disorders or PTSD, mood disorders, bulimia, or psychosis, or sleep disturbances
- In autistic people of ethnic/racial minorities

Hedley & Uljarevic, 2018; Kirby et al, 2019; Cassidy et al, 2018; Autistica, 2016



Self-injury is also more common

It looks more similar to self-injury in the general population than it does to the form of self-injury seen in children and adults with intellectual disability.

Some small differences are hinted at, but studies in this area are still very new – these need much more and bigger investigations.

5 most common forms of SI:
Severe scratching or pinching, cutting,
hitting objects, hitting self, biting

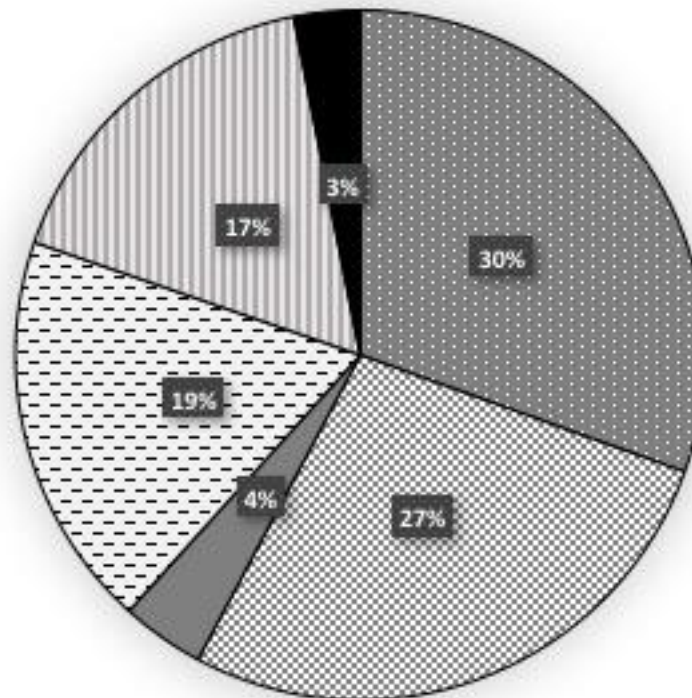
5 most common areas: arms, hands, head, wrists, face

Maddox et al, 2016; Moseley et al, 2019



Motivations for self-injury

Functions of SIB



- Affective-imbalance: low pressure (30%)
- ▣ Affective-imbalance: high pressure (27%)
- Social communication and expression (4%)
- ▣ Self-punishment and deterrence (19%)
- ▣ Sensation seeking (17%)
- Other (3%)

Attitudes towards self-injury are very different:

"It was definitely **not a conscious decision** for me, it is a **sign of how unwell I was**"

"Nobody wants to do it"

"I have **no problem with intentional hurting**.. I can either not do [the stressful thing] or cause some pain to achieve homeostatic balance"

"Of course there are different degrees of self-harm, but mine is fairly mild and has simply helped me to cope with certain situations. To me it's **almost a positive thing**"

But regardless how they feel about it:

Self-injury predicts suicide ideation (a “gateway” behaviour”) – feelings about it *don't appear to matter*.

Certain forms of self-injury were predictive of suicide ideation/attempts (cutting), but others were not (scratching/pinching, hitting self or objects).



Moseley et al, 2019; Cassidy et al, 2018

There are other variables that seem to be important...



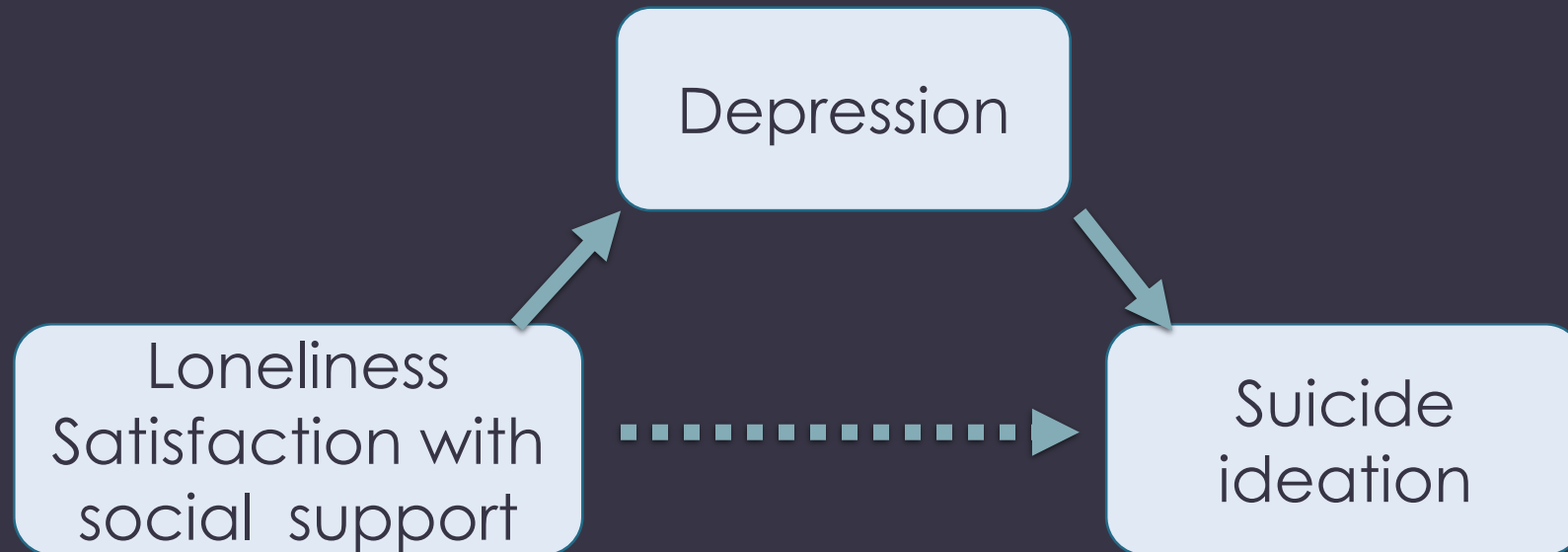
Loneliness
Satisfaction with
social support



Suicide
ideation

Hedley et al, 2018a, 2018b

There are other variables that seem to be important...



Best practice for depression in autism



NICE (general suggestions):

- Encourage involvement of supporters
- Be aware of greater likelihood of sensitivity to psychotropic drugs; start on a low dose?
- Be clear and precise: what is the nature, content, duration of an intervention? What should they expect? What should they do if ___? Check understanding.
- “Offer psychosocial interventions informed by existing NICE guidance for the specific disorder” - but they recognise that the methods of delivery must be adjusted.

NICE

National Institute for
Health and Care Excellence

Best practice for depression in autism



Research:

- Be aware or find out about baseline personality, range of emotional expressions, activities. **When diagnosed:** consider screening for mental health issues and suicidality.
- Consider triangulating self-report with other assessment techniques if possible, if an informer can be present. But be aware that parents/caregivers can under-report.
- Make sure concepts are understood, for e.g. “guilt”.
- Psychotropic drugs – commonly used, but efficacy uncertain, + side effects. See Murphy et al (2016) for recommendations.
- We lack randomized controlled trials of CBT, mindfulness – there will be problems with standard therapeutic approach if not adapted for autism.





Best practice for depression in autism

➤ Be aware...

That autistic adults may come to you with huge anxiety and low expectations of health-care and HC professionals

“People like me don’t get support” (Camm-Crosbie et al, 2019)

- Lack of funding
- Lack of autism support for adults
- Dismissed as appear to be coping, not believed or listened to
- Support given wasn’t suited to needs (e.g. prescribed number of CBT sessions on the NHS is too few to make a connection)

... but people do have good experiences, too!



Best practice for depression in autism

➤ Be aware...

That autistic adults often find it very difficult to connect with professionals in mutual understanding.

“Understand how traumatic it can be if you cannot communicate normally, cannot regulate your emotions and feel isolated or stigmatised etc. when you know that inside you are a rational and sentient being. I think that ASC is the loneliest way of being”

(Moseley et al, 2019)

Many aspects of suicide prevention start further back...

Before the damage of growing up undiagnosed, without access to support, and the impact on self-worth; or lacking support despite diagnosis;

At a societal level, doing more to address social isolation, unemployment or underemployment, and meet support needs;

To provide support post-diagnosis.

Interview with Sarah Cassidy, National Autistic Society, 2015

We don't know yet how to best treat autistic people who are suicidal, though it's a major research priority.

Thank you so much for listening.

I am happy to take questions, and to send papers/resources on request!

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