Girls and women on the autism spectrum

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Plan of the talk

• Autism – an evolving construct
• The female autism phenotype
• Autism and eating difficulties
• Towards evidence-based practice for helping autistic people with eating disorders
What’s in a name?

Person first – ‘a person with autism’

V

Identity first – ‘an autistic person’

Martin: ‘I’m an autistic person, but a person with OCD and generalised anxiety disorder’
Which terms should be used to describe autism? Perspectives from the UK autism community

Lorcan Kenny¹, Caroline Hattersley²,³, Bonnie Molins², Carole Buckley⁴, Carol Povey² and Elizabeth Pellicano¹,⁵
The birth of autism

Leo Kanner (1894-1981)

Donald
“happiest when left alone, almost never cried to go with his mother...wandered about smiling, making stereotyped movements with his fingers...spun with great pleasure anything he could seize upon to spin....Words to him had a specifically literal, inflexible meaning....When taken into a room, he completely disregarded the people and instantly went for objects”
Kanner (1943)

“Since 1938, there have come to our attention a number of children whose condition differs so markedly...from anything reported so far, that each case merits...a detailed consideration of its fascinating peculiarities.”

1. “Inborn autistic disturbances of affective contact’
2. “Powerful desire for...sameness”
Autism(s)

- Repetitive and restricted interests and behaviours
- Social reciprocity and social communication
Autism: the 20\textsuperscript{th} century view

A \textbf{rare and severe} neurodevelopmental disorder, \textbf{usually associated with intellectual disability and delayed language development}, and \textbf{categorically distinct} from normal development and from other disorders.
Myth 1 – autism is rare

Under current diagnostic conventions, autism occurs in:
• 1-2% of children (Baird et al., 2006; Centers for Disease Control, 2014)
• 1-2% of adults (Brugha et al., 2016)

Myth 2 – most people with autism have intellectual disability

50-70% of people diagnosed with autism have an IQ in the normal range, and fluent language

Centers for Disease Control, 2014; Loomes et al., 2017
Myth 3 – autism is just about having difficulties

- Social relating
- Social communication
- Inflexibility
- Sensory processing

- Open-mindedness
- Pattern detection
- Expertise
- Detail-focused processing
Myth 4: autism is a categorical disorder
Myth 4: autism is a categorical disorder
Autism: the 20\textsuperscript{th} century view

A rare and severe neurodevelopmental disorder, usually associated with intellectual disability and delayed language development, and categorically distinct from normal development and from other disorders.
Autism: the new consensus

A relatively common, neurodevelopmental condition, usually associated with normal-range IQ, that represents a form of natural human variation, bringing both challenges and strengths.
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The diagnostic bias against girls and women on the autism spectrum

Autistic girls and women are less likely to get an autism assessment...

(Loomes et al., 2017)

...and if they do, they receive this later on average than equivalent males

(Giarelli et al., 2009)
The diagnostic bias against girls and women on the autism spectrum

And even when they do receive an assessment they are less likely to meet current diagnostic criteria, compared to males with equivalent levels of autistic traits

(Dworzynski et al. 2012; Russell et al., 2011)
Why is there a diagnostic bias against autistic females?

Thanks to Tania Marshall
DSM-5 account of ASD (p.57) “girls without intellectual impairment or language delay may go unrecognized, perhaps because of subtler manifestation of social and communication difficulties”
The female autism phenotype
Social motivation

On average, autistic girls and women are more interested in the social world

Hiller et al., 2014; Head et al., 2014
The female autism phenotype
Special interests

\[
\int_0^{\sqrt{2}} x \sqrt{1 + (2x)^2} \, dx = \frac{2\pi}{8} \int_0^{\sqrt{2}} (1 + 4x^2)^{1/2} (8x) \left[ \frac{\pi (1 + 4x^2)^{1/2}}{2\sqrt{3}} \right] \]

Images:
- Minecraft
- Justin Bieber
- Jane Austen
- Train station
- Toy store
- Wolf
The female autism phenotype

Camouflaging

“Putting on my best normal”
Hull et al., 2017

“Masking encompasses the aspects of camouflaging that focus on hiding one’s ASC characteristics and developing different personas or characters to use during social situations”

“Compensation developing explicit strategies to meet the social and communication gaps resulting from an individual’s ASC Body language”

Reflecting: Wing (1981); Gillberg, 1991; Mandy et al., 2012; Lai et al., 2016; Livingston et al., 2017; Dean et al., 2016; National Autistic Society ‘Autism in Pink’ project.
Camouflage
Who camouflages?

Autistic people camouflage more than non-autistic people (Hull et al., 2018)

There is substantial variability amongst autistic people in how much they camouflage (Lai et al., 2016; Livingston et al., 2018; Hull et al., in prep)

• Autism trait severity (Hull et al., in prep)
• IQ (Livingston et al., 2018)
• Executive function (Livingston et al., 2018)
Sex/gender and camouflaging

Do autistic females camouflage more than autistic males?
- Yes! But this is only a medium/large sized effect ($d = 0.6 - 1.0$)
- This finding fits with other methods of measuring camouflaging (Ratto et al., 2017; Dean et al., 2016; Lai et al., 2016)
Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals.
Why do people camouflage?

- “Camouflaging helps to survive in school and college and it is important for keeping jobs” F27
- “I want to avoid the bullying mostly” F48
- “It enables me to be with other people in a way that is relatively comfortable for me and for them” F56
Fig. 1 Thematic map of the three stages (motivations, camouflaging, and consequences) of the camouflaging process. Themes are indicated by rectangles; subthemes by ovals.
What are the consequences of camouflaging?

- “It’s exhausting! I feel the need to seek solitude so I can ‘be myself’ and not have to think about how I am perceived by others.” O30
- “I went for so long without being diagnosed because they didn’t know that I could pretend to be normal!” F20
- “People need to learn how to drop the camouflage when in situations such as medical assessments or dealing with support professionals” F28
- “I feel as though I’ve lost track of who I really am, and that my actual self is floating somewhere above me like a balloon” F22
Costs of camouflaging

Good social skills despite poor theory of mind: exploring compensation in autism spectrum disorder

Lucy Anne Livingston,¹ Emma Colvert,¹ the Social Relationships Study Team, Patrick Bolton,² and Francesca Happé¹

¹Social, Genetic and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology and Neuroscience, King’s College London, London; ²Department of Child and Adolescent Psychiatry, Institute of Psychiatry, Psychology and Neuroscience, King’s College London, London, UK

Higher camouflaging is associated with higher anxiety
 Costs of camouflaging

↑ Q-CAT scores are associated with:
• ↑ Depression (as measured by PHQ-9)
• ↑ Generalised anxiety (as measured by the GAD-7)
• ↑ Social Anxiety (as measured by the LSAS)

(controlling for autism trait severity)
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The female autism phenotype
Co-occurring emotional and behavioural difficulties

Mandy et al., 2012; Westwood et al., 2017; Huke et al., 2013
Anorexia Nervosa

• Diagnosed when a person becomes significantly underweight due to restricted eating, reflecting an intense fear of putting on weight and a distorted body image (APA, 2013)
• Onset typically in adolescence and early adulthood
• Affects over 10 females to 1 male
• High rates of mortality
AN and ASC

Prof Christopher Gillberg (1985)

For review of the Gothenburg studies, see Huke et al., 2013

<table>
<thead>
<tr>
<th>Study</th>
<th>Prevalence rate of autism spectrum disorders (%)</th>
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<tbody>
<tr>
<td>Råstam (1992)</td>
<td>8</td>
</tr>
<tr>
<td>Gillberg et al. (1995)</td>
<td>37</td>
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<tr>
<td>Wentz Nilsson et al. (1998)</td>
<td>31</td>
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<td>Wentz Nilsson et al. (1999)</td>
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<td>Råstam et al. (2003), Study 1</td>
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<td>Wentz et al. (2005)</td>
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<td>Anckarsäter et al. (2011)</td>
<td>28</td>
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NB. It must be noted that the comorbid disorders are also included in the analysis of Gillberg et al. (1995) (cluster C personality disorder).
But we need to be cautious...

The Minnesota Starvation Experiment (Keys et al., 1950)
The link between autism and AN

Use of gold standard measures (e.g., Westwood, Mandy Tchanturia, 2017)

Use of historical report (Vagni et al., 2016)

Findings in recovered samples (e.g., Ancarsäter et al., 2011)

20 to 30% of women with AN are autistic
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Care implications

• Women with AN in the context of autism:
  – Usually their autism is unrecognised
  – Experience the worst outcomes amongst AN patients (Wentz et al., 2009)
  – Benefit the least from current interventions (Tchanturia et al., 2016; Stewart et al., 2016)
  – Are not acknowledged, let alone accommodated, by current AN / ED guidelines (Kinnaird, Norton, Tchanturia et al., 2017)
Recently funded us to investigate AN in autistic women, to help inform improvements to care.

We have two main aims:
1. Practical – how can ED services become more autism friendly?
2. Theoretical – what causes and maintains ED in autistic people?

Phase 1 – qualitative study with autistic women, parents and professionals

Phase 2 – quantitative study, testing ideas generated in Phase 2
This talk included consideration of social camouflaging in autism.

Our group have recently developed a self-report measure of social camouflaging in teens and adults, called the Questionnaire of Camouflaging Autistic Traits (Q-CAT)

The Q-CAT is free to use.

If you would like a copy, please email Dr Will Mandy

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