Eating Disorders & Autism
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Autism & Co-occurring Conditions
National Autistic Society
Leeds, January 2019
Clinical diagnoses - DSM 5

- Clinically significant & restrictive eating problems
  - Lifespan perspective
- Includes ARFID, Pica, Rumination Disorder & OSFED (Other Specified Feeding & Eating Disorder)
  - Atypical Anorexia Nervosa - no significant weight loss
  - Binge Eating Disorder/Bulimia Nervosa - of low frequency and/or limited duration
  - Purging Disorder - to influence weight or shape but not binge eating
  - Night Eating Syndrome - eating after awakening from sleep/excessive eating in the evening

Prevalence

• 62% of parents of toddlers report a feeding concern (Reau et al., 1996)
• 13 - 80% of children with developmental problems have a feeding disorder (Schreck et al., 2004)
• 89% of autistic children have fussy/picky eating (Ledford & Gast, 2006)
• Elevated ASD traits in found in eating disorder populations (Huke et al., 2013)
Presentation

• Extremely limited range
  – 5-10 highly specific foods
Presentation

• Sensory hypersensitivity
  – Look, feel, smell & taste
  – Noise = overload

• Appetite issues
  – ‘interoception’

• Gastroenterology issues
  – Constipation, allergies/intolerances
Presentation

- Neophobia – fear of new/unfamiliar food(s)
- Anxiety at mealtimes
- Routines & rituals – ‘desire for sameness’
- Contamination & rejection
- Disgust
Avoidant & Restrictive Food Intake Disorder

A. Eating or feeding disturbance (including but not limited to apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; or concern about aversive consequences of eating) as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one or more of the following:
   1. Significant weight loss (or failure to gain weight or faltering growth in children)
   2. Significant nutritional deficiency
   3. Dependence on enteral feeding
   4. Marked interference with psychosocial functioning

B. There is no evidence that lack of available food or an associated culturally sanctioned practice is sufficient to account alone for the disorder.

C. The eating disturbance does not occur exclusively during the course of Anorexia Nervosa or Bulimia Nervosa, and there is no evidence of a disturbance in the way of which one's body weight or shape is experienced.

D. If the eating disturbance occurs in the context of a medical condition or another mental disorder, it is sufficiently severe to warrant independent clinical attention.

Co-morbidity

• ARFID exists in both typical and atypical development

• More prevalent in ASD
  – Sensory hypersensitivity
  – Anxiety (‘neophobia’)  
  – Appetite differences
  – Cognitive rigidity

Pomoni, Harris & Blissett. In Preparation
Positives & negatives?

• To be included in ICD-11 (WHO, 2018)
  – Much wider scope & usage than DSM 5
  – However, unlikely to be in wide usage until 2022
• **Not** included in NICE guidelines for eating disorders
  – Very few services/supports
  – Under recognised & marginalised
• Prevalence currently unknown
  – No standard assessment tool(s) currently

Positives & negatives?

• ARFID a standardised label
  – No guidelines as to how it should be applied
• Inclusion agenda
  – Reassures, dispels myths, highlights significance
• Dividing line between ARFID & ‘typical’ or other eating disorders not easy to define
  – May be underweight/typical weight

Moving to adulthood

• ARFID children do not ‘grow out of it’ = ARFID adults
• Persistent, similarities:
  – Rejecting particular tastes or textures
  – Disliking mixed foods or food touching
  – Concerns about the availability of foods at social occasions
• Motivation +++ = greater chance of making changes
• More responsibility/independence in the choice, preparation and cooking of preferred foods
• Likely to still be debilitating & socially stigmatising
Presentation

- Extreme restriction leading to weight loss
  - Deliberate/consequential
- Anorexia Nervosa (APA, 2013)
  - Body weight significantly lower than the normal range
  - Fear of gaining weight
  - Undue influence of weight and shape on self-evaluation
  - Predominantly affects females – estimated ratio of 10:1

Differential diagnosis

**ARFID**
- Male
- Younger
- Underweight
- Anxiety/PDD/learning
- Texture issues
- Fears of vomiting/choking

**Eating disorder(s)**
- Female
- Older
- Underweight
- Mood disorder(s)
- Body image distortion
- Fear of weight gain


Differential diagnosis

**ARFID**
- Apparent lack of interest in eating or food
- Avoidance based on sensory characteristics
- Concern about aversive consequences of eating
- Significant weight loss/nutritional deficiency
- Marked interference with psychosocial functioning
- No disturbance in how body weight/shape is experienced

**Anorexia Nervosa**
- Restriction of energy intake
- Significantly low body weight
- Intense fear of gaining weight/fat
- Disturbance in how body weight/shape is experienced
- Undue influence of body weight/shape on self-evaluation
- Lack of recognition of seriousness of low body weight
- Restricting Type – no recurrent episodes of binge eating/purging behaviour
Differential diagnosis

**ARFID**
- Extension of the ‘neophobic’ response
- Sensory hypersensitivity
- Visual similarity to known & accepted foods
- Usually restriction of textures
- Unlikely to be vegetables/salad
- More likely to be beige/dry carbohydrate & smooth textures
- Seen frequently in ASD

**Anorexia Nervosa**
- The need to control diet to ‘healthy’ norms
- The need to control weight
- Females with ASD more able to restrict intake?
- Rather than disinhibit & then binge (bulimia)
- Diet restricted to ‘healthy’ & low calorie foods
- Co-morbid with ASD?

Co-morbidity

• Prevalence of autism in eating disorder populations = 22.9%
  – Over representation (typically 1%)
• Similar cognitive profiles?
  – Impaired theory of mind
  – Impaired central coherence
  – Impaired set shifting
• Alexithymia
• Social withdrawal
• Repetitive/restricted behaviour(s)

Co-morbidity

• ASD traits a result of starvation? (Keys, Brozek, Henschel, Mickleson & Taylor, 1950)
  – Obsessionality/rigidity/social cognition/emotional regulation
  – Improves when eating disorder is treated

• ASD traits an ‘endophenotype’ of eating disorders?
  – Genetically connected
  – AN & ASD coexist in families (Gillberg, 1983; Berkman, Lohr, & Bulik, 2007)

Impact?

• Estimated that more than 8,000 autistic females, aged 15 to 40 have anorexia
• 5\textsuperscript{th} of women with anorexia may have autism
  – Often unrecognised/diagnosed
• Not primarily driven by desire to be thin but other factors:
  – Sensory, interoceptive, rule bound, fitting in
• Autistic women less likely to benefit from current treatments

Eating to control anxiety

• Adolescence a risky time…
• Extra anxiety
  – Social & academic pressures/puberty
• More difficult for girls?
  – Masking/fitting in
• Strategies for controlling anxiety
  – Routines & rituals
  – Controlling calories/weight – special interest?
• Weight loss + mental health issues = eating disorder and/or ASD

Presentation

• Restricting whole food groups
  – E.g. Vegetarianism, ‘healthy/clean’ eating
• Health-related problems and/or impairment in social, occupational or other areas of functioning
• ‘Orthorexia Nervosa’ (Bratman, 1997)
  – Pathological obsession with the quality (rather than quantity) of food
• Not yet recognised as an eating disorder

Orthorexia Nervosa

• No agreed diagnostic criteria, however some agreement:
  1. Obsessional preoccupation with healthy, ‘pure’ or ‘clean’ foods
  2. Rigid avoidance of ‘unhealthy’ or ‘unclean’ foods
  3. Distress at the violation of food rules
  4. Impairment to social, physical, psychological wellbeing

Orthorexia Nervosa

• A distinct eating disorder?
  – Stage in other eating disorders?
• Risk factor for developing other eating disorders?
  – Perfectionism
• Socially acceptable way of restricting?
  – Coping strategy?
• Influence of social media
  – Health & ‘wellness’

Presentation

- Pica - ‘persistent eating of non-nutritive substances’
- ‘Feeding and Eating Disorder’ (DSM V, 2013)
- Cross-cultural & life span
- More prevalent in:
  - Developing countries
  - Pregnant women
  - Adults with LD and/or autism

Pica

• Likely to be different types of pica
  – Different causal factors: LD, mental health, nutritional, environmental, sensory/physiological
• Risks – 1 episode can be life-threatening
  – Toxicity, obstructions, perforations, aspiration, social impact
• No guidelines for management
• No evidence base for interventions

Developmental risk factors in autism?

**Infancy**
- Sensory hypersensitivity
  - Refusal of lumps during weaning
- Neophobia in 2nd year
- Gastroenterology issues
  - Reflux, constipation, diarrhoea
- Appetite issues

**Childhood**
- Neophobia continues
- Anxiety at mealtimes
- Routines/rituals
- Gastroenterology issues
- Appetite issues
- Eating non-foods
- ARFID/Pica
Developmental risk factors in autism

**Adolescence**
- Anxiety +++
  - Social/academic pressures
  - Puberty
- More difficult for girls?
  - Masking/fitting in
- Routines & rituals
  - Controlling calories/weight
  - Special interest

**Adulthood**
- Continued restriction
- Weight loss + mental health = eating disorder(s)
  - In-patient/community treatment
  - ASD label
- Persistent sensory/anxiety issues
- **Chronically debilitating eating problems**
Implications for autistic females

• **More vulnerable**
  - Social & peer pressures
  - Masking/copying others
  - Special interest in food/eating
  - Later diagnosis of ASD

• **More complex**
  - May present with more than 1 eating disorder(s)
  - Less likely to present with distorted cognitions

• **More likely to lose weight?**
  - Poor health, social & educational outcomes
Response?

• Not enough research *as yet*
• Very few specialist services for ED & autism
  – Multi-disciplinary approach
  – Knowledge of the types of eating disorders & complexities of presentation
  – Responsive, reflexive, respectful

• **UNDERSTAND AUTISM**
Intervention principles

• Understand what causes eating disorders in autism
  – Sensory, anxiety, rigidity, social-communication differences

• Manage autism
  – Settings, routines, autism-informed strategies

• Adapt & accommodate autism
  – Visual aids, specialist intervention

• Manage risks
Managing risk

- Be aware of the increased risk of eating disorders in ASD
  - ARFID/Anorexia/Bulimia, controlled eating, orthorexia, pica
- Be aware of risky times
  - Transitions, adolescence
- Be aware of risky life events
  - Bullying, problems at home/school, puberty
- Be aware of sources of support
  - GP, mental health, specialist eating disorder services
## Which professional?

<table>
<thead>
<tr>
<th>Health professional</th>
<th>Works with</th>
<th>Helps with</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Psychologist</td>
<td>Behaviour, emotional, psychological and/or mental health issues</td>
<td>Reduce anxiety, teach relaxation and manage mealtime stress</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>Gut and bowel issues, e.g. Constipation, diarrhoea, allergies/intolerances</td>
<td>Prescribe medications and conduct physical examinations</td>
</tr>
<tr>
<td>Hypnotherapist</td>
<td>Phobias, anxiety and other mental health issues</td>
<td>Teach relaxation/ visualization</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Tasks of daily living, sensory issues</td>
<td>Assess and intervene with oral-motor skills and sensory issues</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>Child health conditions</td>
<td>Monitor growth, health/development and coordinate/refer to other services</td>
</tr>
<tr>
<td>Speech and Language Therapist</td>
<td>Communication, eating and swallowing skills</td>
<td>Assess chewing and swallowing, provide sensory/desensitization programmes</td>
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ARFID - what doesn’t work?

• Strategies that decrease acceptance:
  – Pressure to eat
  – Hiding & disguising foods
  – Force feeding
  – Sitting in front of new/unaccepted foods
  – Leaving to go hungry
  – Rewarding with other foods
ARFID - what might work?

• No evidence based interventions (as yet)
• CBT, family based treatments
• Medications? SSRI’s
• Psychoeducation, empowering, graded exposure, weight restoration, anxiety management

ARFID - practice-based interventions

1. **Allow** preferred foods
2. **Reassure** – psychoeducation
3. **Schedule** – regular eating times
4. **Increase** sensory ‘tolerance’
5. **Reduce** anxiety & mealtime stress
6. **Increase** range – ‘spreading the sets’
7. **Try** new foods - taste ‘trials’/CBT

Anorexia

• NICE guidelines for:
  – Anorexia, Bulimia, Binge-eating Disorder, OSFED
  – Does not cover ARFID/Pica
• Anorexia
  – Psychoeducation, monitoring of weight/health, MDT, collaboration with relatives and/or Family Therapy, weight restoration, talking therapies e.g. CBT
• Manage co-morbid conditions, e.g. mental health
• Transition planning

Pica

1. **Manage risks**
   - **Monitoring**
     - What is ingested, where & when
   - **Environment**
     - ‘Pica safe’/restricting access
     - Meaningful alternative activities
   - **Medical checks**
     - Blood tests/scans
   - **Sensory & anxiety**
     - Safe alternatives/sensory diets
Recommendations

• Screen for autism in eating disorder services
  – Early identification & outcomes
  – Females

• Provide specialist assessment & treatments
  – Social-communication differences
  – Co-morbidities
  – Specialist services/environments

• More research
  – Study of Eating Disorders in Females (SEDAF)
    http://sedaf18.blogspot.com/
Websites

- [www.infantandtoddlerforum.org](http://www.infantandtoddlerforum.org) – The Infant & Toddler Forum – evidence-based factsheets on all aspects of feeding & eating in childhood
- [www.beateatingdisorders.org.uk](http://www.beateatingdisorders.org.uk) – UK national charity for eating disorders
- [www.scottishautism.org.uk](http://www.scottishautism.org.uk) – Scottish Autism’s ‘Right Click’ online training programme(s) which include resources for managing eating in autism
- [www.autism.org.uk](http://www.autism.org.uk) – The National Autistic Society’s online women & girls module - includes information on managing eating in autistic females
- [www.networkautism.org.uk](http://www.networkautism.org.uk) – Network Autism – articles & interviews on eating in autism