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Autism and eating disorders in girls and women (and some boys and men)

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- University of Glasgow and University of Edinburgh, and Yorkhill Hospital (Scotland)
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AUTISM AND ESSENCE (neurodevelopmental/psychiatric disorders)

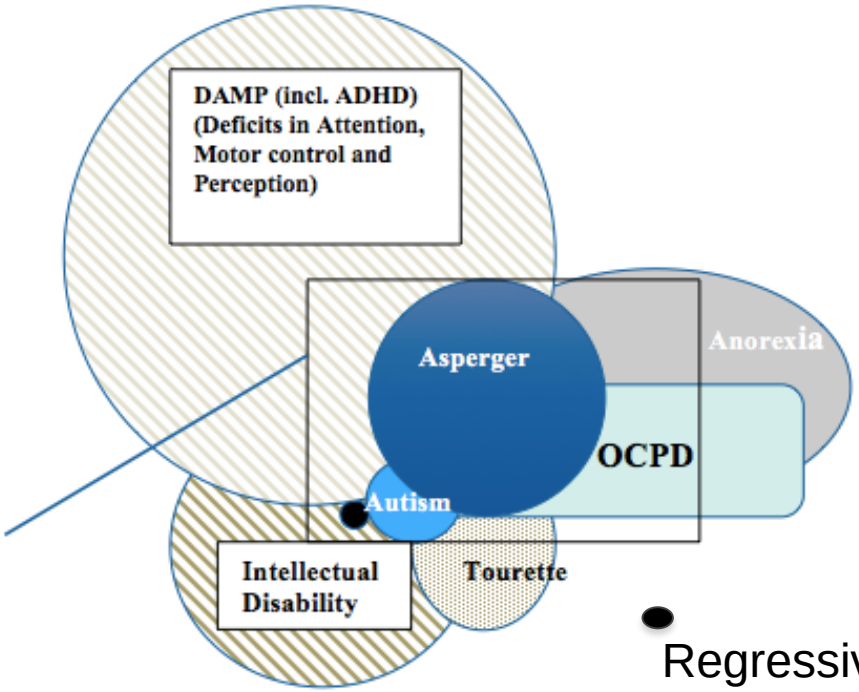
- **ESSENCE - Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations**
  - **ASD** (Autism Spectrum Disorder) with or without **regression** 1.2% (10-20% **regression**)
  - **ADHD** with or without **ODD/CD** (Oppositional Defiant Disorder/Conduct Disorder) 5-7%
  - **SLI** (Language disorder inlcuding antecedents of dyslexia) 5%
  - **DCD** (Developmental Coordination Disorder) 5%
  - **IDD (**Intellectual Disability/Intellectual Developmental Disorder) 2%
  - **TD/TS/OCD** (Tic disorders/Tourette syndrome/OCD) 1%
  - **RAD** (Reactive Attachment Disorder/Disinhibited Social Engagement Disorder) 0.5-1.5%
  - **(BPS** (Behavioural Phenotype Syndromes, including FAS and VAS) 2%)
  - **(EP/NEUROMUSC** (Epilepsy syndromes and other neurological/neuromuscular disorders (HC, CP, Sturge-Weber, Duchenne, myotonic dystrophy, neurometabolic): **Landau-Kleffner Syndrome**, CSWS, FS+, FS? 0.6%)
  - **(PANS** (Pediatric Acute-onset Neuropsychiatric Syndrome)? 0.1%)
  - **Predictors of *academic failure*, other school adjustment problems, social exclusion, *substance use*, psychiatric disorder, eating disorders including anorexia, bulimia and obesity, accidents, *empathy problems*, antisocial lifestyle and *criminality* later in life, persistent autistic features "only", early death (through accidents, criminality, substance abuse and physical health problems)**

What are the "symptoms" of ESSENCE?

- **Major childhood onset symptoms either lasting more than 6 months or of extremely abrupt onset from one or more of the following domains are the markers of developmental disorder/ESSENCE; the symptoms lead to concern and "specialist" consultation**
  - **General development – delayed mental development**
  - **Motor coordination – delayed gross or fine motor development**
  - **Perception/Sensory – hyper- or hyposensitive to sensory stimuli**
  - **Communication/Language – delayed speech, few or no gestures**
  - **Activity/Impulsivity – too active or too passive**
  - **Attention – inattention, not listening, "not hearing", distracted**
  - **Social interaction/Reciprocity – little interest in (most) adults, children, play**
  - **Behaviour including stereotypic, insistence on sameness, tics, and OCD**
  - **Mood swings/emotional dysregulation – inability to control temper**
  - **Sleep – disrupted sleep-wake cycle, sleep onset problems, night waking problems**
  - **Feeding – food fads, selective or consistent food refusal, for instance as in the disorder now named ARFID**

- Gillberg 2010, revised Gillberg 2013, Karjalainen et al 2017

Emanuel Miller Memorial Lecture 1991
Christopher Gillberg JCPP 1992



Disorders of empathy

Regressive/disintegrative cases

Early symptoms of ASD (<5 years)

- **Motor control problems first year of life ("serious" face, relatively little smiling (but social smile can be elicited), strange movements from back to front, compartmentalised motor development, limpness, partial hypotonia) 50-100%**
- **Sensory-perceptual abnormalities/unusual preferences in 90-100%**
- **Behaviour problems (including insistence on sameness) in 90-100%**
- **Repetitive movements in 80-100%**
- **Language problems/pragmatic problems/strange voice in 90-100%**
- **No/little reaction to own name 30-100%**
- **No or limited initiation of joint attention (=> major social interaction problems), no pointing to attract attention 80-100%**
- **Hyperactivity and impulsivity (often extreme) in 40-50%**
- **Hypoactivity in 10-25%**
- **Sleep problems in 40%**
- **Food fads and other feeding problems in 50%, ARFID in 25%?**
- **Delayed general development in 20%**
- **Major mood swings in 10%**
- **One or several of the above could be presenting complaint (n.b. except for joint attention deficits, these symptoms are also the symptoms of other ESSENCE)**
  - Coleman and Gillberg 2012, Allely et al 2013, Höglund-Carlsson et al 2013, Barnevik-Olsson et al 2013, 2014, Hatakenaka et al 2016, Höglund-Carlsson et al 2016, Allely et al 2017

ARFID (Avoidant/Restrictive Food Intake Disorder)

Diagnostic Criteria for ARFID (Based on the DSM-V)

1. **An eating or feeding disturbance (e.g., apparent lack of interest in eating or food; avoidance based on the sensory characteristics of food; 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:**

- Significant weight loss (or failure to achieve expected weight gain or faltering growth in children).
- Significant nutritional deficiency.
- Dependence on enteral feeding or oral nutritional supplements.
- Marked interference with psychosocial functioning.

2. The disturbance is not better explained by lack of available food or by an associated culturally sanctioned practice.
3. 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 in which one's body weight or shape is experienced [body image].
4. The eating disturbance is not attributable to a concurrent medical condition or not better explained by another mental disorder. When the eating disturbance occurs in the context of another condition or disorder, the severity of the eating disturbance exceeds that routinely associated with the condition or disorder and warrants additional clinical attention
   – Coleman and Gillberg 1985, 2012, Lucarelli et al 2017

Girls and women

- **IT IS LIKELY THAT ADOLESCENT AND ADULT FEMALES (AND SOME MALES) WHO HAVE HAD ASD AND/OR OTHER DISORDER/PROBLEM CONSTELLATION SUBSUMED UNDER THE ESSENCE UMBRELLA ALL THEIR LIVES ARE OFTEN MISDIAGNOSED AS SUFFERING FROM (ONLY):**
  - **"DEPRESSION",**
  - **"EATING DISORDER"**
  - **"ANXIETY"**
  - **"SOCIAL PROBLEMS; FAMILY PROBLEMS; RISK MOTHER"**
  - **"BORDERLINE/OTHER PERSONALITY DISORDER/SELF-HARM"**
  - **"CHRONIC FATIGUE, CHRONIC PAIN"**

  AND THAT THEY HAVE BECOME INVOLVED WITH SOCIAL SERVICES, BECAUSE OF DOCUMENTED OR SUSPECTED MALTREATMENT
  - Kopp et al 2010, Wentz et al 2016, Dinckler et al 2017

Letter to British Journal of Psychiatry 1983 C Gillberg

1982, **140**, 174–80) that the GHQ is "unsuitable as a screening instrument for mental illness in the community" therefore deserves close scrutiny.

The major criticisms of the conclusion of Benjamin *et al* come under two headings. First, their study was of a small biased sample, and second, they only examined the validity of the 60 item GHQ.

The first feature, that of the biased sample, is an important one because it restricts the appropriateness of generalizing the findings of Benjamin *et al*. There is agreement on the need to revalidate the GHQ when used in different settings or in populations with different characteristics. So at best their conclusion has to be confined to GHQ use on women aged 40–49 who are still able to pass through a 'natural' menopause. To make any more general statement on the validity of the GHQ is bad science. Such general conclusions can only be reached from a consideration of many validation studies of the GHQ, most of which support its continuing use. Specifically, with non-consulting samples the GHQ provides a high validity research tool.

Some versions of the GHQ are demonstrably better and this differential validity is overlooked by Benjamin *et al*, who only consider the GHQ-60. And why "invent" a new 15 item version without assessing the merits of already validated shorter versions with their chosen sample, namely the GHQ-30, GHQ-20, GHQ-12 and GHQ-28? A recently completed study (Banks, 1983) has shown how the validity of the GHQ-30, GHQ-28 and GHQ-12 vary considerably within the same sample. In particular, attention should be drawn to the 28 item GHQ which had a sensitivity of 100 per cent, a specificity of 84.5 and overall misclassification rate of 15 per cent using a cutting score of 5/6.

It is important that clinicians and research workers receive a fair account of the GHQ, and that they understand it is composed of a family of instruments with much better psychometric, screening and validation properties than Benjamin *et al* would have us believe.

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Reference

BANKS, M. H. (1983) Validation of the General Health Questionnaire in a young community sample. *Psychological Medicine*, in press.

ARE AUTISM AND ANOREXIA NERVOSA RELATED?

DEAR SIR,

I have recently come across 3 cases of males with infantile autism who had female first-cousins with anorexia nervosa. In 2 of these cases the cousins were on the maternal side of the family. I would like to draw readers' attention to this observation and ask if any have noticed a correlation between the rare syndromes of autism and anorexia nervosa.

Two further points are worth mentioning in this context. First, there is now some evidence for a 'biochemical subgroup' of autism showing a particular chromatographic profile with regard to urinary excretion of substances giving absorbancy at 280 nm (Gillberg *et al*, 1982). This chromatographic pattern is now referred to as 'pattern A'. 'Pattern A' is not seen in normal children, but sometimes in childhood psychosis cases other than infantile autism. Also, it has been found in cases with anorexia nervosa (Trygstad *et al*, 1980). This latter point is of particular interest with regard to a hypothesis linking autism and anorexia nervosa. Second, the obsessive insistence on sameness seen in autistic children, is sometimes a striking phenomenon in anorexia nervosa too. Also, anorectic patients quite often show aloofness and problems of social relationships. Is there a possibility that a common biochemical disturbance may interact with other factors (brain damage, starvation, cultural factors) to cause autism in young boys and anorexia nervosa in prepubertal girls?

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References

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TRYGSTAD, O. E., REICHELT, K. L., FOSS, I., EDMINSON, P. D., SAELID, G., BREMER, J., HOLE, K., ORBECK, H., JOHANSEN, J. H., BØLER, J. B., TITLESTAD, K. & OPSTAD, P. K. (1980) Patterns of peptides and protein-associated peptide complexes in psychiatric disorders. *British Journal of Psychiatry*, **136**, 59–72.

FAMILY HISTORY STUDY OF ANOREXIA NERVOSA AND BULIMIA

DEAR SIR,

We regret to report that a number of numerical errors appeared in Table II in our recent article "Family History Study of Anorexia Nervosa and Bulimia" (*Journal*, February 1983, **142**, 133–8). The corrected table is published below.

In addition, the last paragraph of the methods

AUTISM IN ANOREXIA NERVOSA

- **10-50% of all with anorexia meet criteria for autism, most of these have never been recognized as having autism before the onset of the eating disorder**
- **The cognitive profiles are similar in anorexia and autism**
- **Outcome in anorexia is considerably worse in the subgroup with autism (however, usually, the intervention in this subgroup has not taken autism into account)**
- **Regional cerebral blood flow not restored 7 years after weight restoration in anorexia (particularly in the group with autism)**
  - Gillberg 1983, Gillberg and Råstam 1992, Gillberg IC et al 1995, Råstam et al 2001, Råstam et al 2003, Wentz et al 2005, Treasure 2013, Wentz et al 2009, Nielsen et al 2015, Westwood et al 2017

ADHD IN EATING DISORDERS

- **Consistent evidence that impulsivity symptoms of ADHD are associated with bulimia and overeating**
- **In one study of severe bulimia/anorexia, 17% had ADHD, most of these had not been recognized/diagnosed before the onset of the eating disorder**
- **In another study, 35-37% of individuals with bulimia or purging behaviours scored above clinical cut-off for ADHD**
- **In an early study, 40% of children with severe obesity scored above cut-off for ADHD**
- **In a later study of children with obesity 18% had a clinical diagnosis of ADHD (and parents scored very high on ADHD screening)**
  - Wentz et al 2005, Fernell et al 2008, Kaisari et al 2017, Svedlund et al 2017, Cortese and Tessari 2017, Wentz et al 2017

EATING DISORDERS AND UNUSUAL EATING BEHAVIOURS IN ESSENCE (AUTISM AND/OR ADHD)

- **Severely abnormal eating behaviours common in autism from the first or second year of life**
- **ARFID probably common in autism**
- **Children with DCD (often comorbid with ADHD) are more often overweight; children with ADHD but not DCD tend not to be overweight**
- **Premorbid high BMI predicts bulimic behaviours in those who develop anorexia**
  - Coleman and Gillberg 2012, Karjalainen et al 2016, Goulardins et al 2016, Lucarelli et al 2017, Lantz et al 2017

Why are females with autism (and other ESSENCE) missed?

- **In Swedish studies, only those girls with a phenotype consistent with severe autism in boys are diagnosed before age 3-4 years (a time when most boys with any type or severity of autism are now diagnosed in Sweden)**
- **Specialists still think about autism (and other ESSENCE) as "male disorders"**
- **Many girls who are later recognized as having autism have shown PDA-type behaviours and feeding problems in the first few years of life**
- **Many girls have insistence on sameness around social themes or food at a time when boys are more fixated on things that people believe to be typical of autism**
- **When girls have early problems, anixety and depression is what doctors and psychologists "look for", in boys it is autism and ADHD**
- **Girls with autism have at least as poor outcomes as boys (even in cases that from the beginning appear to be mild)**
- **Girls in the general population are less (gross) motorically active, more (superficially?) social and earlier in their social language development than boys**
- **However, individual variation is considerable, even within gender**

  Fernell et al 2010, Nygren et al 2012, Westman-Andersson et al 2013, Kantzer et al 2013, Christov-Moore et al 2014, Kopp et al 2017

How should we plan for best recognition and intervention in AUTISM AND OTHERE ESSENCE IN FEMALES (NOT JUST MALES)?

- **Think about autism and ADHD (and DCD and Tourette and other ESSENCE) in all young girls presenting with emotional, behavioural, cognitive, learning or coordination problems**
- **Think about autism in all girls presenting with severe eating problems, and of ADHD in those with bulimic behaviours (and early high BMI)**
- **Be aware that the "obvious phenotype" might not be so obvious**
- We need to recognize **all** the problems - **not just "the autism"**, "the ADHD", "the DCD", "the Tourette syndrome", "the IDD", "the SLI" OR THE EATING DISORDER and **all** interventions **must** be **individually** tailored **THROUGHOUT THE LIFESPAN**
- Parent "training" and education plan perhaps most important of all ("understanding the condition"), but parent ESSENCE problem needs to be taken into account (!)
- "Comorbidities" are the rule and need to treated