The Other 25%: Autistic Girls and Women

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Disclaimer

• I have small amounts of stock in pharmaceutical companies: ABT, ABBV, NVS, NVO, JNJ, GSK
• I will not be speaking about any commercial products
• If off-label information is presented, I will identify this
Objectives

• This lecture should heighten awareness of the females on the autism spectrum who may be undiagnosed due to differences in presentation from males on the spectrum
• This lecture should increase the clinical knowledge about how autism in females may color sexual development, courtship, marriage and parent-hood.
• The lecture will address those females who are severely autistic and will differentiate those who were previously diagnosed with Asperger Disorder.
DSM-5 Autism

• A. Deficits in social communication and interaction: understanding social-emotional reciprocity, using non-verbal communication, and difficulty maintaining relationships

• B. Repetitive and restrictive patterns of behavior, interests or activities

• Includes stereotypies, insistence on sameness and inflexibility, restricted and fixated interests of great intensity, sensory issues
Severity, DSM-5

• Depends on degree of communication difficulties and degree of restricted, repetitive patterns of behavior
• SYMPTOMS MAY BE MASKED UNTIL LATER IN LIFE, BUT MUST BE PRESENT DURING EARLY DEVELOPMENT
• Differentiate from those with just a social pragmatic communication disorder
• Differentiate from intellectual deficits or global developmental delay
Interesting Numbers

- In general population, males 4.3:1
- 1.95:1 males to females in those with intellectual disability
- These numbers may not be accurate since females may camouflage their difficulties and may be undetected due to their ability to disguise their symptoms

Genetics Drive the Disorder

• The severe symptoms with communication and restricted, repetitive behaviors are almost all determined by genetics\textsuperscript{1}, unlike 2011 study that declared that the environment was responsible to a significant degree\textsuperscript{2}

\textsuperscript{2} Hallmayer, J., et al, \textit{Archives of Genl Psychiatry}, Nov 2011, 68(11)1095-1102
Epigenetic Differences in Identical Twins

- In identical twins, if one has autism, the other will only 70% of the time
- DNA methylation differences in the twin with autism

Lower Functioning Autistic Women and Girls

• More likely to have severe problems than males \(^1\)

• Can be associated with genetic disorders like tuberous sclerosis, fragile X and epilepsy

• Both genetic and epigenetic influences: identical twins with different degrees of autism or one with and one without defining symptoms

Focusing on Higher Functioning Women With Autism

• Much harder to diagnose
• Have less challenging behavior than males
• Fewer special interests
• Can be diagnosed with structured interviews and examinations such as ADOS\textsuperscript{1} or ADI-Rev.\textsuperscript{2}

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Female Genetic Differences

• Greater number of copy number variants in those females with the diagnosis, compared to the males (45% vs. 30% for males)\(^1\)

• Likely Gene-Disrupting mutations for females (LGD) significantly overlap the targets in males of lower intelligence quotients.\(^1\)

MRI Differences in Females with Autism vs Normal Brains

- Decrease in grey matter density bilat. In temporal lobes, orbito-frontal cortex (med. and lat.) rt. med. occip. Lobe and lt frontal lobe
- Smaller white matter density in ant. temporal lobe and pons
- Increase in density in association and projection fibers of frontal, parietal, post. temp. lobe, and occipital lobes
- Increase in commisural fibers of c. callosum and ant. cerebellum

Toddlers With Autism

- Amygdala size larger in autistic toddlers vs normal age mates
- Size positively correlated with severity of symptoms in social and communication skills
- Girls had a more robust size difference than boys
Genetic Architecture in ASD’s

• Hundreds of genes involved
• 107 autosomal genes incur de-novo loss-of-function mutations in over 5% of autistic subjects

• Many encode proteins for synaptic formation, transcriptional regulation, and chromatin-remodeling pathways.

Similar Abnormalities in Both Genders

- Males and females with autism studied by Craig, C et al, showed a negative correlation between decreased grey matter in the rt. limbic system and qualitative abnormalities in reciprocal interaction.

- Similar brain regions were affected in both sexes.

- Women, however had an excess of white matter in the cerebellum.

- Craig, C. et al, ibid, 2007
DISCO Interview

• Diagnostic Interview for Social and Communication Disorders
• Useful in the interview of patients in adolescent and adult years

• Billstedt, E, et al, J Child Psychology and Psychiatry, 48(11), NOV. 2007, 1102-10
Not All Diagnosed Early

• Some patients on the autism spectrum, especially women, may be missed in the younger ages
• Some may not be diagnosed until adulthood and diagnosis made in reviewing a puzzling history\(^1\)
• Some may be diagnosed when a child in the family is diagnosed, and family members interviewed

\(^1\) Kim, C. *Nerdy, Shy, and Socially Inappropriate*, Jessica Kingsley Publ Co, 2014
Males Vs. Females With ASD

• In high-functioning patients on autism spectrum, females had more lifetime sensory symptoms
• Females had fewer socio-communication difficulties
• Females had more self-reported autistic traits

• Because of better superficially socio-communication ability in adult females, may be under-recognized and often receive diagnosis later in their lives than males

Females Have Higher Social Skills

- 101 10-16 year olds interviewed with a Friendship Questionnaire\(^1\)
- 25 in each group: females with autism, females with typical development; males with autism and those with typical development
- Females in both autistic and typical groups scored higher than males with the same diagnosis
- Autistic males and females scored lower than typically developing peers

Boys and Girls Differ

• Autistic boys may be more hyperactive than the girls.¹
• Girls may be more passive and collect information about people rather than things.¹
• May share interests with typical girls: horses, literature, animals, but intensity and depth of interest much greater.¹
• May be very controlling with typical peers.¹

¹ Gould, S, Ibid, GAP (Good Autism Practice), 12, 1, 2011
Different Trajectories

- Attwood, in 2007, stated that girls on the autism spectrum were more likely to model and imitate social actions than boys, resulting in missed diagnoses.

- More immature socially, girls tended to be “mothered” by other girls in social play.

- Girls may worry more than boys about fitting in and may worry about this.

- Many of the boys of their age and diagnosis have no friends; women, however, may have one special friend, and the patient may appear shy and reticent compared to many of their peers.

- They may tend to be with a group of peers, leading teachers to miss their diagnosis since they are not readily identified as being loners.


Theories Only

• Perhaps different mechanisms involved with males and females

• Females may be less vulnerable due to innately protective mechanisms

• Males and females might have equal risk genetically, but other factors may allow females to better compensate for these risks

• Is this an extreme of the male brain? Females with ASD may be more “male-like”

• 1 Schwarz, E. et al, Sex-specific serum biomarker patterns in adults with Asperger’s syndrome, Mol Psychiatry. doi: 10.1038/mp2010

• 2 Skuse, DH, X-linked genes and mental functioning, Human Molec Genetics 14 Spec No 1: R27-32, 2005

• 3 Skuse, DH, Rethinking the nature of genetic vulnerability to autistic spectrum disorders, Trends Genet 23: 387-95, 2007

Currently Diagnosis of ASD Behavioral

- Greater unusual visual responses, stereotypy and less appropriate play in males\textsuperscript{1}
- Better superficial and communication skills in females
These may lead to underdiagnosis of females.

Hartley and Sikora\textsuperscript{2} tested 157 boys and 42 girls between 1.5 yrs. and 3.9 yrs, and showed the same as above, but in addition, girls had more anxious and depressed symptoms and more sleep problems. Some studies failed to show differences between the sexes. So much variation in patients on the spectrum, no definitive differences when all of the investigations of children are evaluated overall.

\textsuperscript{1} Lord,C et al, Sex Differences in Autism, J Autism Dev Dis, 12: 317-30, 1982
\textsuperscript{2} Hartley and Sikora, Sex Diff in Autism Spectrum Disorder, J Autism and Dev Disorder, doi:10, 1007/s10803-009-0810-8
Obtaining Adequate Histories

• To judge adult patients, for possible ASD, include direct interview and observation
• Add hx of childhood behaviors
• Self-reports—very revealing in those who camouflage well
• Old testing
• Exploring female’s coping mechanisms in their social lives
  • Meng-C L, ibid., p. 8
Comparison of Adults with ASD (normal intelligence)\(^1\)

**Females with ASD**
- As children, no diff. from males
- Less autistic behavior in adults than males
- Cognitively about same
- Same amt of comorbid depression, anxiety, OCD

**Males with ASD**
- As children, no diff. from females
- More autistic behavior than females
- Cognitively about same
- Same amt of comorbid depression, anxiety, OCD

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“Camouflaging Autism”, Differing Trajectories

• Females on the autism spectrum may be better at consciously learning a social script to act more typical
  
• May learn how to use reciprocal conversation, gestures, gaze and socially appropriate affect
  
• Allows them to “fly under the radar,” compared to males on the spectrum
  
• Some learned to imitate the actions of popular peers – their dress, mannerisms, etc. in exquisite detail
  
• The stress of this role-playing can be exhausting

• Attwood, T, Complete Guide to Asperger’s Syndrome, Jessica Kingsley Publ Co., 2007
Special Interest May Differ

• Less eccentric and less odd interests than males \(^1\)
• May have fewer stereotyped activities \(^2\)
• May be missed by standard interviews

Increased Sensory Issues in Females

• DSM 5 now includes sensory issues as one of the key symptoms: “unusual sensory behaviors”¹
• May include over- and under-sensitivity to sensory stimuli
• Self-reporting may be better in picking this up than structured interviews which may not have sufficient no. of items assessing the sensory behaviors
• It may be that” women show fewer but perceive more autistic features than males”²

² Meng-C L, *ibid,* p. 7
Sensory Problems

- Hypersensitive females may find that handshakes, hugging and touch used in sex can hurt
- Refusal to touch interpreted by others as rejection
- Making close friends understand what is and is not tolerable for the person can be useful

1 Steward, R., ibid, p. 28
Sensory Problems...cont’d

• Hyposensitivity may lead to painful sexual interaction and may require a gentler reciprocation to the partner in order to avoid injury or soreness

• Some autistic people are very upset with change in routine, causing a fear of unknown

• Steward, R., ibid, p 30
Challenging Times for Females

- Early childhood
- Grade school
- Adolescence
- College, vocational training
- Dating, courtship, marriage
- Parenthood
- Vocational years
Pubertal Challenges

• Change, even small transitions are difficult for both males and females on the spectrum
• Puberty is a time of many changes: body changes, sexual feelings, new expectations regarding behavior
• Many rely on computer to give information: may lead to pornographic depictions “become the tutor”
• Understanding the subtleties of peer interaction continues to be a problem: girls may model themselves after a particular popular girl in order to fit in
• The naivete of these teens may lead to difficulties with peers, adults and relationships with boys

Low Functioning Autism, Sexual Challenges in Women

- Dealing with menses
- Teaching hygiene—wearing liner daily to get used to sensory aspect of wearing menstrual pads
- Considering implants or hormonal control to eliminate periods or minimize them
- Preventing pregnancy: low functioning patients may be victimized and sexually assaulted despite best intentions by family
- Understanding premenstrual behavioral exacerbations and be prepared to treat for this
Teaching Appropriate Sexual Behavior

- Masturbatory behavior is normal in all levels of autism in women
- Appropriate time, place and safety should be taught
- Internet sites may give exaggerated or false information
Very Vulnerable

- Unable to know how to respond to teasing about romantic feelings or behaviors
- Inability to read the dishonorable intentions of another
- Unsure of courting rituals and conduct
- May decide to be celibate and spend time with technology as a substitute friend
- Often later in social and emotional development than peers: can be highly intelligent but significantly behind in other areas

Executive Function Difficulties

• According to Attwood, people on the autism spectrum “live in the now,” “not looking at what the future consequences might be.”

• This can result in problems with organization, planning, flexibility in solving problems, and with a one track mind and determination in acquiring information or obtaining a goal.

Sexual Information

• Very important to provide accurate and timely information about sexual matters to autistic individuals to prevent turning to peers or the internet for information

• Understanding of appropriate touch and mutual agreement about intimacy should be taught by parents and caregivers

Being Safe

• The physician or therapist can help autistic women understand sexual safety

• Helping patient understand sexual harassment, assault, rape, sexual boundaries

• Teaching patients to understand flirting behaviors

• Instructing girls and women about suggestive dressing, posturing, conversations to avoid being interpreted as having sexual intent

Intimacy Continuum

• Often adolescents and young adults may not understand the gradual continuum of intimacy
• If they rely on internet sources, the early and subtle steps toward intimacy are often overlooked, and the steps that are needed early in the relationship are skipped
• What is legal at what age must be discussed

Navigating Courtship Rituals

- Learning signs of courtship: physical touching, complimenting, looking into eyes for prolonged period, moving closer, kissing on the cheek
- Knowing how to discourage flirting: moving away, turning away

1 Steward, R, ibid, Jessica Kingsley Publ, 2014, pp 103-5
Internet Misrepresentation

- Pornographic sites give misinformation: sex games, physical pain and exaggerated sexual behaviors
- Relying on the internet may make person have unrealistic idea of appropriate sexual practices
Parental Monitoring

• Often Asperger patients are experts in computers—important to have safeguards in place to prevent logging into illegal sites

• Families and friends need to safeguard their credit card information to prevent unwarranted spending

• Both of these measures need to be explained to the adolescent to avoid dangers in illegal sites and dangers to finances

Common Difficulties—Literal Language

• Misinterpretation of language: Example: “would you like to sleep with me?” might be interpreted as wanting to share a bed for non-sexual reasons

• Difficulty understanding voice intonation and body language—eye contact, facial expressions, hand gestures and body movements

Like Males, Lack of Social Chit-Chat

• May not be able to keep up with peers and their social chatter
• Girls have better imaginative play than boys on the spectrum

• Rich imaginations, may escape into fiction with subjects like fairies and witches and imaginary friends
• May have a rich solitary imaginary world
• Almost like they have a script and are socially in control
• May continue with doll play into adulthood, remaining socially immature
• Difficulty using imagination in social context

• 3 Gould, J, ibid, GAP, 2010
Difficulty With Theory of Mind

• Difficulty imagining what it would be like to be someone else
• Imagining how another feels
• Imagining intent
• Imagining point of view and perspective
• Sometimes physiologic cues can give signals to autistic person warning of danger when theory of mind does not serve well

1 Steward, R, ibid, Jessica Kingsley Publ Co, 2014, p. 23
Preventing Manipulation—Counseling Thoughts

• Make a script if it is difficult to say no
• Have advocate say no for you
• Make list of positive and negative things about maintaining friendship with the person

• Imagine what things you can do with the friend that you will miss and imagine how you could do these things without that person
• Loneliness is frightening but being hurt is worse
• Friends come and go, people drift in and out of friendships

• Steward, R Ibid, pp49-50, 2014
Understanding Relationships

• Casual sexual relationships vs. romantic relationships may be hard to discern
• Understanding intimacy and understanding that having sex may not necessarily indicate sharing feelings
• Discerning the difference between feeling lust and love
• Understanding casual sexual relationships
• Learning how to decide whether to have sex or not

Staying Out of Abusive Relationships

- Autistic women often are loyal to an abuser, may not know how to prevent abuse or how to leave an abusive relationship.\(^1\)
- Red flags: partner wants to control the other person’s money
- The other person is verbally abusive—if asked to stop, the person will not
- Partner forces you to do things you do not want and threatens to leave you or kick you out if you don’t.
- Partner won’t give you time alone.
- Isolates you from friends and family.
- Partner hurts you
- Partner makes horrible derogatory remarks about you
- Partner is excessively jealous
- Partner humiliates other person

\(^1\) Steward, R., ibid, Jessica Kingsley Publ, 2014, pp. 134-5
When Is It A Date?

• It is ok to ask, “is this a date?”
• If woman is invited to a person’s house, it is acceptable to suggest a more public place
• If response to this is negative or derogatory remarks made, don’t respond.  

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• Avoiding certain topics early in dating: health, religion, past relationships, religion, how much money you earn, sexual experiences, abuse
• Asking a neurotypical person about topics and opinions

• 1 Steward, R, ibid, 2014, p. 154
Learning To Dress Appropriately

- Being careful of how much of a person’s body to allow to show
- Avoiding wearing sexually suggestive slogans on clothes
- Avoiding see-through clothes

- At times, clothing that is suggestive may give the impression that the woman is promiscuous
- Advising women regarding appropriate posturing and facial expressions: chewing gum may hide overly expressive facial expressions

1 Steward, R, ibid, pp. 215-18, Jessica Kingsley Publ Co, 2014
Discussing Being Autistic

- May say, “sometimes I may become overwhelmed; at that time, please leave me alone.”
- Meltdowns may cause relationships to fizzle
- Declaring that one is autistic may have many reactions and may scare off others
- Avoiding being over-attached
Teaching How to Sustain Relationships

• Teach autistic woman to let partner know how she feels about them
• Using words to express how she feels
• Having a means of communication like a turnaround book left in a common place

• Change, albeit uncomfortable, may help sustain the relationship—new surroundings, new schedules, new sexual behaviors

• 1 Steward, R., ibid, pp 162-3, 2014
Teaching How to Apologize

• Not intuitive to admit responsibility when something goes wrong
• Scripting how to apologize may help autistic woman to resolve arguments and criticisms
Obsessions

- May have a subject that completely occupies her time
- Can memorize lots of facts and info about the subject
- May see solutions and creative problem solving “outside the box”

- Call these circumscribed interests rather than obsessive
- Can be a big problem if being obsessed about another person who may not feel the same for the autistic person

1 Steward, R., ibid, 329-31, Jessica Kingsley Publ Co, 2014
Early Years Less Problematic than Middle School Years

• Girls less disruptive in early school years

• As middle school approaches, Catherine Lord of U. of Michigan sees a subset, “literally dumbstruck by anxiety,” when social demands escalate

• According to Emily Bazelon, NY Times, 8-5-2007, high functioning men are more likely to marry than the women studied, but the number of women was small
Females More Likely to Have Mood Disorders

- Lainhart and Folstein at Johns Hopkins showed that despite being 1:4 patients with autism, females were half the autistic patients with mood disorders.
Making Autism Alert Card

- [www.zazzle.com](http://www.zazzle.com) has template to make a personalized alert card that explains about patient’s autism and what happens when a person is overwhelmed
- It suggests what can be done to help an autistic person in distress
- It gives contact numbers
Take Home Messages

• Autistic women may be difficult to detect, due to their ability to imitate more socially appropriate behaviors
• Some may not be diagnosed until adulthood
• The work of “playing a role” may be exhausting and lead to anxiety and meltdowns
• Women may have more sensory sensitivities than men with autism, and history taking should ask about these
More Take-Home Messages

• Genetics may determine susceptibility for autism, but epigenetics determines expression

• Autistic women with normal intelligence may marry, have families and be very productive

• Many co-morbidities exist in women with autism: especially noted are anxiety, depression, panic disorders

• You probably know a few of these people – now it makes sense understanding their autism
Women, “Research Orphans”

• Ami Klin, who directs Yale Autism Program, calls females “research orphans”
• They have rarely been included in studies of medications used for autism, and they are often culled from studies on autism
• Is the world more forgiving of boys on the spectrum with their quirky behaviors, than for girls?
• The numbers are small for this group