

Congenital Heart Disease and Autism

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Aims for session

- Provide a brief overview of Autism
- Evidence base exploring links between CHD and Autism
- Consider Autism in the context of acute health services
- Think about how we can support such patients, and their families, in our teams

Autism

Around 700,000 people in the UK have a diagnosis of autism (BMA, 2020).

One in 100 children have a diagnosis of autism (BMA, 2020).

The proportion of males to females diagnosed with autism varies across studies but consistently shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1 (NICE, 2020).

- It is likely that this gender divide is due to an increase in 'masking' skills among females (NICE, 2020) and potential unconscious gender bias at diagnostic assessment (Dworzynski et al. 2012).

Lifelong neurodevelopmental disorder. Cause is unknown however evidence to suggest a combination of genetic and environmental factors contribute to the development of autism.

Diagnostic Criteria for Autism

DSM 5

Social emotional reciprocity:

- Unusual social approach, difficulties with reciprocal conversation, perseveration on own interests in topics of conversation, unintentionally blunt

Non-verbal communication:

- Poorly integrated verbal and non verbal communication, unusual or reduced gestures and facial expressions, reduced eye contact

Friendships & Relationships:

- Difficulty in understanding and maintaining relationships, difficulty in adjusting behaviours to various social contexts, difficulties in sharing play or accepting other's contribution to play narratives, lack of interest in peers

DSM 5 Continued

Stereotyped/ repetitive motor movements:

- Idiosyncratic speech, echolalia, lining up toys/objects, motor movements

Routines and rigidities:

- Insistence on sameness, inflexibility/distress at changes in routines, difficulties with transitions, rigid thinking patterns, routines or rituals

Highly fixated interests

Sensory sensitivities

Evidence base

- Sigmon et al., (2019) analysed the data of 35,040 children (Autism n = 8760; Control n = 26,280)
 - Higher prevalence of children with CHD in the autism group compared to the control group.
 - Compared with controls, those with autism were also more likely to have a genetic syndrome, preterm birth, neonatal epilepsy, birth asphyxia, low birth weight, maternal gestational diabetes, and younger maternal age at birth.
 - increased risk associated with atrial septal defects, ventricular septal defects and HLHS (including when analysis was adjusted for covariates).

Evidence base continued

- Some evidence to suggest higher rates of 'possible' autism in children with Congenital Heart Conditions (Jaworski et al. 2017)
 - Screened 195 Children with CHD for autism
 - When adjusted accordingly, found a prevalence of 'possible' autism at 3.2%

Evidence base continued..

- Davidson et al., (2015) compared the data of 58 HLHS and 44 non-HLHS patients with single ventricle physiology (over the ages of 10).
 - Autism and ADHD were reported more frequently in HLHS patients (12%) compared with non HLHS patients with single ventricle physiology (0%)
 - Those undergoing early cardiac surgery with cardiopulmonary bypass are thought to be at increased risk
 - Suggested that a combination of an already vulnerable and perhaps subtly different brain may be further injured during the sensitive neonatal period in the course of necessary operative interventions

Autism in a hospital setting

Considerations:

- Increased social demands, new/unfamiliar clinicians, number of people in atrium, difficulties with social communication in appointments, other people's understanding, focus on certain topics
- Change to a routine, unfamiliar environments, rigid thinking styles, changes to surgery dates
- Sensory overload: noises; brightness; visual stimuli; smells; being touched; physical sensations of treatments

How can we as a team offer support?

Preparation is key!

- Visual aids (e.g. leaflets) with accurate, up to date photographs of the waiting and clinical areas can help people with autism prepare for an appointment/ward stay.
- Consider a step by step visual guide of the environment if possible.
- Opportunity to use technology to support (virtual tours, video links on our webpages etc).
- Asking about a person with autism's interests early in an appointment/when meeting on the ward can help to break the ice.
- If sensory aids are used to help the person with autism (ear defenders, tactile sensory objects etc) then encourage these to be brought to the appointment/ward.

Support continued...

- Encourage children, teenagers and adults to consider writing down questions before an appointment. If communication continues to be challenging then offer to read their questions
- Be aware that non verbal communication may not be fully integrated with verbal communication, meaning it can be difficult to infer how a person with autism may be feeling.
- In addition, it can be challenging for some people with autism to infer and/or express their feelings or needs.
 - It can be helpful to 'check in' with how someone is feeling. If they are struggling to express feelings verbally then encourage them to write it down or draw it.
 - It can be helpful to double check your inferences with the person with autism
 - Consider encouraging soothing activities such as (if possible) accessing a space with minimal sensory activity, creating a soothing playlist, encouraging access to journal writing, drawing, and mindful colouring.
 - Consider encouraging the creation of a sensory box/pack

Support Continued...

- It can be challenging for some people with autism to interpret hypothetical information
 - Consider asking the person with autism to repeat back what they have been told to ensure understanding
 - Try to use clear language and avoid idioms. Be aware that information can be taken literally
 - Be aware that a change in plan will cause distress, it can be helpful to outline from the outset that a plan may need to change and to give a clear reason as to why and what will happen in this eventuality

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Thank you
Any questions?