

# Further exploring the PDA profile – evidence from clinical cases

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# Background

- \* The concept of Pathological Demand Avoidance has provoked extensive (and often emotionally argued) discussion about what it is, is not or potentially could be
- \* There remains some controversy regarding its specificity as a 'profile', including what the criteria for identifying it should be and how best to support families and young people who present with extreme anxiety and often challenging and distressing behaviour

# Background

- \* A recent paper by Prof Jonathan Green and his colleagues (Green et al, 2018) published in the Lancet outlines his team's thinking about what PDA might be and whether there was currently sufficient good quality research evidence to clarify this
- \* They concluded that, although as clinicians, they were aware of and had observed the types of challenge experienced by some families and young people, they did not feel there was sufficient evidence to consider PDA as a separate and discrete diagnostic category, but more as a constellation of behaviours.

# Background

- \* There has also been debate about whether children and young people with PDA all meet the criteria for a diagnosis of Autism or whether extreme demand avoidance is seen in other groups
- \* ‘Critical Autism’ academics, such as Richard Woods have argued that PDA has no specificity and is better considered as a trauma response to adverse events in the environment

# Background

- \* As a team, and in conjunction with leading academics such as Liz O’Nions and Professor Francesca Happé, we began a research project three years ago in an attempt to learn more about the PDA profile.
- \* All of our data were collected as a routine part of our usual assessment process
- \* Over a two year period, we examined data from 351 children who were all assessed in the same clinic environment, by the same team, using the same process and clinical assessment tools.

# Background

- \* As we are known as a centre with a good understanding of both Autism and the PDA profile, we openly acknowledge that our sample is likely to include a greater proportion of children presenting with the PDA profile than most CAMHS teams would tend to see.

# Details of our sample

351 children and young people were assessed

\* 150 females

\* 201 males

Age range

\* 3 – 5 years            43

\* 6 – 10 years        171

\* 11 – 17 years      101

\* 17 – 19 years      35

# Assessment tools used

- \* Cognitive assessment (WPPSI IV, WISC V or WAIS IV depending upon the age of the child)
- \* The CCC2 (Children's Communication Checklist – Dorothy Bishop)
- \* The Short Sensory Profile/Adolescent Sensory Profile – Winnie Dunn
- \* The ADOS (Autism Diagnostic Observation Schedule) modules 2, 3 or 4
- \* The EDA-Q – Extreme Demand Avoidance Questionnaire – O'Nions
- \* A full developmental and family history

# Analysis of data

- \* As you can imagine, this has generated a vast amount of data for us to consider and analyse
- \* We are still in the process of looking through all of it.
- \* I will only talk about part of it today
- \* This information will be presented in 'lay-person' terms. The full details have been included in a write up for submission to academic journals.

# Study One

- \* In this study, we looked at the data gathered from the ADOS
- \* The ADOS is a structured assessment of social interaction and play and is considered one of the 'gold standard' assessments for Autism
- \* It should not be used in isolation as part of an Autism assessment and should be used alongside other tools and a good developmental history
- \* The ADOS has four different 'modules' – one, two, three and four
- \* The examiner selects the most appropriate module depending upon the age and ability of the child or young person
- \* We examined the data gathered from 136 children who were all assessed using Module Three.

# Participants

136 children in total

71 received a diagnosis of ASD

26 were girls

45 were boys

They ranged in age from 5 - 17

# Participants

- \* 65 children were diagnosed first with Autism and then found to meet the criteria for PDA
- \* 31 were girls
- \* 34 were boys
- \* They ranged in age from 5 – 17 years

# Our Criteria for PDA

- \* Examination of the current literature combined with the extensive clinical knowledge of the assessment team, led to the development of an informal algorithm which was used to determine whether a child met the criteria for the Pathological (or Extreme) Demand Avoidant profile:
- \* The child or young person displayed (or was reported to have displayed) the main features outlined in the revised Newson checklist, the NAS website, the EDA-Q and the specific questions included in the DISCO. These were recorded as part of the child's developmental history.

# Our Criteria for PDA

- \* Demand avoidance had been present since early infancy and presented across contexts and time
- \* Avoidance is pervasive and often seems illogical or perverse (e.g. the child may be unable to eat whilst hungry)
- \* Avoidance is not limited to a specific activity (or activities, e.g. school) or activities in a specific context.

# Our Criteria for PDA

- \* It is important to point out that all diagnoses (not just ours) are made on the basis of professional judgement, rather than relying upon a specific number of features displayed in any particular checklist or assessment tool.
- \* Information is always gathered from a variety of sources and discussed and assimilated before a diagnosis is given

# Analysis

- \* A variety of statistical tests were carried out on our data. These are outlined in full in our write up of this study.
- \* There were significant differences between the scores obtained in the ADOS assessment for the ASD group compared to the ASD/PDA group
- \* Both groups scored above the 'cut-off' score which supports a diagnosis of Autism (we consistently achieve good inter-rater reliability between different examiners)
- \* The differences reflect qualitative differences in the way the child or young person interacted with the examiner
- \* Certain descriptions of behaviour within the ADOS assessment were able to predict the likelihood of a child receiving a diagnosis of ASD/PDA

# Findings

- \* The way in which the children interacted with the examiner during the ADOS differed.
- \* Most of the ASD/PDA group started the assessment with a degree of superficial sociability but as the assessment progressed they became less motivated to engage
- \* They employed a variety of strategies in order to avoid completing the ADOS as requested

# Findings

These strategies included (no prizes for guessing 😊)

- \* Ignoring the examiner
- \* Attempting to distract (with sometimes intentionally shocking behaviour)
- \* Refusing to participate
- \* Making it difficult for the examiner to access the assessment materials
- \* Leaving the room
- \* In some cases 'freezing' or becoming very dysregulated

# Study Two

- \* Our second study involved detailed analysis of a sample of developmental histories taken as part of our assessments
- \* In this study we were looking at differences in the presentation of three groups:
  - \* ASD
  - \* ASD/PDA
  - \* Not-ASD
- \* Diagnostic decisions were made based upon the same assessment materials and criteria as outlined in Study One

# Participants

- \* 161 developmental histories were analysed. Two raters independently checked a sample of these and achieved a high level of inter-rater agreement
  - \* They ranged from 5 – 17 years of age
  - \* 92 boys
  - \* 69 girls
  - \* ASD – 53
  - \* ASD/PDA – 63
  - \* Not ASD\* - 45
- \* All of the 'Not ASD' group were adopted children with a history of early trauma/attachment difficulties

# Analysis

- \* Our developmental histories are written in a narrative format. We invite parents to ‘tell us about’ their child at certain ages and developmental stages.
- \* Following assessment, these developmental histories were analysed using a particular qualitative technique which generated ‘themes’
- \* All of these ‘themes’ were spontaneously offered by the parents/caregivers and were not in response to particular questions
- \* These ‘themes’ were then statistically analysed by group.

# Findings

- \* A number of 'themes' were found significantly more frequently in the **ASD/PDA group** compared to the **ASD group**
- \* There were also a number of themes that were reported significantly less frequently in the **Non-ASD group** compared to the **ASD/PDA group**

# Conclusions

- \* Although we recognise the limitations of our studies, our participants were all seen by the same team, in the same location, using the same assessment process
- \* All of the children who were identified as having the PDA profile met criteria for Autism first
- \* There were significant differences in the way the children with ASD/PDA interacted with the examiners
- \* There were significant differences between the behaviour reported for the ASD/PDA children compared to both the ASD and Non-ASD children

# Conclusions

- \* We hope that this preliminary study can be seen as a starting point to further explore the PDA-ness of the PDA profile, what it is, what it is not and what it might be
- \* Since the data analysis started and the original 351 children were seen, we have assessed at least a further 200 children and we continue to observe the same patterns of behaviour and gather the same developmental histories. These children come to us from all over the world, sometimes their parents have not even heard of PDA