An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and their developmental histories

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Editorial comment

This paper is in two parts. The first part analyses the scores on Module 3 of the ADOS-2 of 136 children diagnosed with autism following an autism diagnostic assessment at a specialist multidisciplinary clinic. From all the information collected during the assessment, it was concluded that 65 (47 per cent) of the children in this sample had both autism and a Pathological Demand Avoidant (PDA) profile. The authors therefore compared scores on Module 3 of the ADOS-2 of the two groups. They concluded that these scores successfully differentiated children with autism only, from those with autism with a PDA profile. The ADOS-2, Module 3 may therefore be a useful assessment tool for qualified clinicians to use as part of their diagnostic formulation. The authors acknowledge that this does not constitute evidence that autism with a PDA profile is a discrete autism subgroup or that similar types of behaviours to those observed in the PDA profile are never observed in other groups of children, as this study only included children diagnosed with autism.

The second part of the study analysed the developmental histories of a slightly larger sample of 161 children, randomly selected from 351 children assessed. The authors sought to identify differences in the histories of children in three specific groups (children with autism; autism with the PDA profile; children with attachment difficulties) with a specific focus upon the reported features of the PDA profile. These findings showed that there were significant differences between those with autism with the PDA profile and the other two groups and they discuss the implications of this for practice and further research.

Part One: Exploring the PDA profile using data from ADOS-2

Introduction

This study analysed data from the assessments conducted within a diagnostic clinic. The first author is a Consultant Clinical Psychologist and is part of a multidisciplinary assessment team. Children were referred either by their parents or via local Clinical Commissioning Groups, from a wide geographical area, usually because of long waiting lists for assessment in their local area. Some of the children were referred for a second opinion and some were referred because it was felt they might meet the criteria for autism with the PDA profile (PDA). The clinic is well known for its interest and knowledge on PDA and so it is likely that more children with this type of profile are referred than in other autism diagnostic services. A number of the children were adopted and were referred as they were displaying unusual or challenging behaviours that could indicate they may be autistic.

The concept of 'pathological', or extreme, demand avoidance has caused huge, and often emotively argued, differences of opinion over the last few years. The controversy regarding both the name of the profile and its classification, is acknowledged by the authors and their work is intended to add to our understanding of children who are said to have this profile. For ease of reporting, the term PDA is used throughout this paper.

Over a two year period, a total of 351 assessments were carried out. With parental permission, all the data generated were entered into a database. All diagnostic conclusions were made prior to the data being entered on the database and their analysis for this study. Clinical experience is cited within the NICE (National Institute of Care and Clinical Excellence) guidelines (CG 142) as forming a major part of any diagnostic decision. From this initial sample of 351 children, 136 children who had completed all elements of Module 3 of the ADOS-2 (Autism Diagnostic Observation Schedule) were selected for further analysis. All of the team had many years' experience and agreed that, clinically, the 65 children diagnosed with autism using DSM 5 criteria

with the PDA profile had interacted differently with clinicians. These differences are described later in the paper. Consequently, the team examined whether ADOS scores differed between the groups to identify whether those classified as having the PDA profile were different in their social interaction and communication compared to those who were not identified as having the PDA profile.

The history of PDA

The concept of PDA was first discussed in the 1980s by Elizabeth Newson (Newson, 1983) when assessing children for autism. At that time, diagnosis of autism was made using DSM III criteria (or the ICD-9 in European countries). Although there was agreement that autism was a valid diagnostic category, there was considerable controversy about how it should be defined. In DSM III, autism and related disorders were grouped under the heading of 'Pervasive Developmental Disorders' (PDD) and an 'atypical' category was also included. The criteria determined that the onset of features of autism needed to be evident before the child reached 30 months of age. Social impairments, language deviance and 'unusual behaviour' that included rigid and repetitive behaviour also needed to be apparent. Newson initially argued that the group of children she assessed fitted some, but not all, of the criteria for autism. She felt that PDA should be viewed as a separate (but related) condition, or 'syndrome' within the broader category of Pervasive Developmental Disorders. By the time the Newson et al (2003) paper was published, the DSM III had been replaced by the DSM IV.

Over the years, and following the publication of the DSM 5, the diagnostic criteria for Autism Spectrum Disorder has changed to reflect the growing understanding of the breadth and dimensional nature of autism and it is likely that many of the original cohort of children assessed by Newson and her team would today meet the diagnostic criteria for Autism Spectrum Disorder using DSM 5.

In recent years, PDA has been more widely acknowledged as a behaviour profile seen in some children with autism. (O'Nions, Viding and Greven, 2014). However, there remains considerable controversy regarding its specificity. A paper by Green et al (2018) highlighted the challenges faced by clinicians when families present

for assessment who feel that this behaviour profile fits their child. They concluded that there was insufficient evidence to support classifying PDA as a separate profile, although they did acknowledge that there is a group of children who do present with extreme demand avoidant behaviour.

Features of the PDA profile

Descriptively, the key characteristics of PDA are an obsessive resistance to everyday demands and requests, use of socially manipulative or outrageous behaviour to avoid demands; sudden changes in mood apparently associated with a need to control and 'surface sociability'; reflected in social peculiarity, difficulties with peers and lack of social constraint (Newson et al, 2003).

Attempts have been made to develop screening tools to identify the types of behaviour observed in children with PDA. O'Nions (2014, 2016) and her colleagues developed the Extreme Demand Avoidance Questionnaire (EDA-Q). This is a 26 item questionnaire that has been found to have good reliability and validity (O'Nions, Christie, Gould, Viding and Happe, 2014). The Diagnostic Interview for Social and Communication Disorders (DISCO), (Wing et al, 2002) has also been updated to include questions that explore extreme demand avoidance. One limitation of these tools, however, is that they rely predominantly upon parent/carer report, rather than direct observation of the child.

Any research into the PDA profile is also hampered by the diverse ways in which autism is diagnosed. There is no, one standardised, or universally accepted, assessment for autism in the United Kingdom. NICE produced guidelines (CG, 128, NICE, 2017) that recommend a structured multidisciplinary approach to diagnosis. The NICE guidelines also recommend the use of certain 'gold standard' tools to support assessment. However, this approach is not used consistently and the variety of ways in which autism is assessed, present a challenge to clinicians and researchers alike. The ADOS is a diagnostic assessment tool used by clinicians where clinicians observe and rate the child's response to a series of structured interactions. It therefore adds to the information given by others.

Presentation of the children during assessment

Over the course of assessing children with 'demand avoidant behaviour', the clinicians have needed to develop a range of strategies to engage them (eg from administering assessments in tents, or under tables, delivering assessments to toys or teddies, or with the children pretending to be superheroes or animals) and direct requests have been avoided.

Clinicians also learned to manage a range of elaborate and inventive excuses, as follows:

"I'm afraid that's not how the world works"

"I can't possibly; I'm Mr Platypus and platypus' don't talk"

"My nose is running so I can't do it"

"I'm a bit tired now, maybe we should stop"

"This is boring"

"They aren't allowed in here so I can't until they leave"

While such excuses did, at times feel comical, it was always important to remember these were children whose anxiety appeared to be driving their need to be avoidant. Other avoidance tactics included asking the clinician repetitive questions, or offering large amounts of information relating to prescribed interests or previous experiences to an intense degree, in an apparent attempt to distract or delay the delivery of tasks or activities.

Some children resorted to physical avoidance tactics such as knocking items off the table or throwing objects, or physically removing themselves or the assessment materials from the room. At times, although rarely, children threatened the clinician with physical violence, or responded with hostility. Some threatened to inflict physical pain upon themselves to communicate they did not wish to continue. This was usually their final avoidance strategy, having exhausted all other means.

On many occasions, it was necessary for the clinician to relinquish any attempt to present as an authoritative professional. For example, an 8 year old said:

> "You can stop talking now", with a particular favourite being along the lines of: "How about I deliver the assessment to you instead?".

Clinicians noted many ways in which these children attempted to regain control. These included deciding upon the way in which the clinician 'was allowed' to deliver any requests (eg with the door open; facing away from them; putting on a French accent; using a superhero figure), or instructing them to complete certain activities/tasks of their choosing (eg writing cards to their family members, or drawing pictures for their peers) before they would agree to follow a request. Children also tried to control where people could sit, when people could talk and what people could say.

Autism Diagnostic Observation Scale (ADOS-2) (Lord et al, 2008)

The ADOS-G (Lord et al 2000) and the ADOS, Second Edition (ADOS-2) (Lord et al, 2008) is one of the most widely used instruments and is considered a 'gold standard' assessment tool (Kamp-Becker et al, 2018). It is a standardised assessment that explores communication, social interaction, play and imagination through the use of semi-structured activities. While it was initially felt that measures used to assess and diagnose autism had limited discriminatory and differential ability, recent research highlights how the ADOS-2 can be useful in differentiating what has become known as the 'female' profile of autism (Bargiela, Steward and Mandy, 2016). Both the ADOS-G and the ADOS-2 have demonstrated that it can be used to distinguish autism from other disorders (Gotham et al, 2007) including specific language disorders (Noterdaeme et al, 2002), developmental delay (Gray, Tonge and Sweeney, 2008), intellectual disabilities (Sappok et al, 2013), schizophrenia, psychopathy, and antisocial personality disorder (Bastiaansen et al, 2011). Studies have also found the ADOS-G and subsequently, the ADOS-2 can accurately classify autism, even in individuals with several protective factors such as a strong support system, high intelligence, more subtle autistic symptoms and comorbid psychiatric disorders (Kan et al, 2008; Tomanik et al, 2007; Wing and Potter, 2002).

Another strength of the ADOS-2 lies in the fact that its administration and coding is standardised (Lord et al, 2012). In addition, its psychometric properties have been well studied and it has been found to be a largely reliable and valid instrument (Papanikolaou et al 2009). In a number of previous investigations, the ADOS-2 has also been shown to have excellent inter-rater reliability, internal consistency, sensitivity/specificity and good predictive validity (De Bildt et al, 2009, Oosterling et al, 2010).

Aims of Study One

A bi-directional hypothesis was considered when examining the ADOS-2 scores. It was hypothesised that the 'superficial sociability' in children with a PDA profile and autism would result in differences on measures of social reciprocity when compared to the children with autism without the PDA profile. However, the difficulties often found in administering the assessment to the first group might have an impact on their scores in the opposite direction. The aim of the analysis was therefore to add to the body of knowledge and to contribute to the ongoing debate about the aetiology of the PDA profile and its link to autism.

The participants

The study was approved by the Psychiatry, Nursing and Midwifery College Ethics Review Board, at King's College, London. The 136 children were selected from a total sample of 351 children assessed over a two year period. All of the 136 children had completed every element of the ADOS-2, Module Three and had scored above the clinical cut off for Autism Spectrum Disorder. The remainder of the 351 children assessed had either completed a different module of the ADOS-2, had failed to complete the whole assessment, or had not received a diagnosis of autism and so were not included. Out of the total sample (N=351), 139 children received a diagnosis of ASD, 109 had a diagnosis of PDA and ASD and 103 had a diagnosis of 'other' which included children with attachment difficulties, learning difficulties/disabilities, language disorders and trauma presentations.

The age, gender and diagnostic classification of the participants are given in *Table 1.*

Table 1: Age and gender of the participants for Study One by diagnostic classification (n=136)

	ASD		ASD and PDA		TOTAL	
	n=71		n= 65		n=136	
Item	n	%*	n	%	n	%
Age (y)						
<5	1	1	4	3	5	4
6-10	49	36	52	38	101	74
11-16	20	15	8	6	28	21
17+	0	0	2	1	2	1
Gender						
Female	26	19	31	23	57	42
Male	45	33	34	25	79	58

*Note: percentage figures rounded up

Procedure

Information from a number of screening documents was gathered in advance of the assessment. These included the Children's Communication Checklist Version 2 (CCC2) (Bishop, 1998, revised 2003), the Sensory Profile 2 (Dean, Dunn and Little, 2016) and the EDA-Q (Extreme Demand Avoidance Questionnaire, O'Nions et al, 2014). All the assessments were carried out over a two year period in the same clinic, using the same assessment tools by the same team of clinicians. All assessments followed the NICE guidelines for the Assessment and Diagnosis of Autism Spectrum Disorder in under 19's (CG 128, NICE, 2017).

Each assessment involved a Clinical Psychologist, a Speech and Language Therapist and an Assistant Psychologist, with the Clinical Psychologist obtaining a thorough developmental history and the other team members carrying out other standardised and observational assessments (eg cognitive assessment and the ADOS-2). Additional information was also obtained and considered, from third party sources (eg school staff). The ADOS-2 was administered by clinicians who had completed a recognised course in using and interpreting the ADOS-2. After each assessment, a team discussion took place and a diagnosis or alternative formulation was fed back to the child's parents/carers at the end of the day. No one assessment tool was used in isolation to inform the diagnostic decision making process.

Identification of children with autism with a PDA profile

Every child in the study was assessed primarily for Autism Spectrum Disorder. Features of the PDA profile were explored during the developmental history based upon the presence of specific behaviours as reported in the original checklist devised by Elizabeth Newson (revised in 2002); the EDA-Q (O'Nions et al, 2014) and the questions included in the DISCO 11th Revision (Gillberg et al, 2015). Examination of the current literature combined with the extensive clinical knowledge of the assessment team, led to the development of the following informal algorithm which was also used to explore whether a child met the criteria for the PDA profile. These were recorded as part of the child's developmental history, as follows:

- demand avoidance had been present since early infancy and presented across contexts and time

- features of demand avoidance were noted in the child during the assessment process

- avoidance was pervasive and often seemed illogical or perverse (eg the child may be unable to eat when hungry)

- avoidance was not limited to a specific activity (or activities) or activities in a specific context (eg school)

The ADOS-2 assessment and scoring

The ADOS-2 includes five modules and the clinician selects the most appropriate module based on the age of the child or young person in conjunction with their language level. All participants in the study were

administered the ADOS-2 Module Three. This contains a variety of tasks including joint interactive play, telling a story from a book, conversation and reporting, and a series of questions that examine the young person's understanding of their emotions and the emotions of others, as well as their perception of everyday social relationships. For Module Three the cut off algorithm score, where further consideration of ASD is suggested, is a score greater than '6'.

Each item within the ADOS-2 is assigned a score of '0' (indicating no difficulties), '1' (indicating mild difficulties), '2' (indicating more significant difficulties) or '3' (indicating marked or substantial difficulties). These items are categorised into five main areas:

- language and communication
- reciprocal social interaction
- imagination
- stereotyped behaviours and restricted interests
- other abnormal behaviours

Scores obtained in these five areas are then converted to algorithm scores covering the following areas:

- Communication (reporting of events, conversation, gestures)
- Reciprocal social interaction (unusual eye contact, facial expressions directed to examiner, shared enjoyment in interaction, quality of social overtures, quality of social response, amount of reciprocal social interaction, overall quality of rapport); and
- Restricted and repetitive behaviour (stereotyped/idiosyncratic use of words or phrases, unusual interest in play material/person, hand and finger and other complex mannerisms, excessive interest in unusual or highly specific topics/objects or repetitive behaviours)

Ratings of 3 indicate communication or interaction difficulties which are particularly severe or which interfere with the assessment. The algorithm converts assigned

ratings of 3 to algorithm ratings of 2 in an attempt to avoid disproportionately weighting any single item in the algorithm classification and for reliability in analysis (Lord, Rutter, DiLavore, Risi, Gotham and Bishop, 2012). The overall algorithm score is then converted into a comparison score which outlines the level of autism related behaviour noted during the assessment. This ranges from 'minimal – no evidence' through to 'high'. The current study examined differences in the overall algorithm scores. The children's total scores on the ADOS-2 Module 3 were compared to see whether there was a difference between the two groups.

When a child obtains a score of 2, the description of a child's difficulties in a particular area is very different to the description attached to a score of 3. For example, Item B9 entitled *'Quality of Social Response'* gives the following description of the type of interaction which is given a score of 2:

> *"Odd, stereotyped responses, or responses that are restricted in range or inappropriate to the context."*

For a score of 3, the description is:

> *"Minimal or no response to the examiner's attempts to engage the participant."*

The study therefore also examined the number of threes children scored on the ADOS-2 to explore whether there was a significant qualitative difference in the presentation of children diagnosed with autism with the PDA profile compared to those with autism only.

Analyses conducted

Research question 1

Was there a statistically significant difference in ADOS-2 Module Three total algorithm scores obtained by children diagnosed with autism with a PDA profile compared to those with autism without the PDA profile?

Research question 2

Was there a statistically significant difference in the number of scores of 3 obtained in the ADOS-2 Module Three by individuals with autism with a PDA profile compared to those with autism without a PDA profile?

Table 2: Cross-tabulation showing ratings of 0, 1, 2, 3, for each group on the 29 items across the 5 areas of the ADOS 2

	A1	A2	A3	A4	A5	A6	A7	A8	A9	B1	B2	B3	B4	B5	B6	B7	B8	B9	B10	B11	C1	D1	D2	D3	D4	D5	E1	E2	E3
ASD																													
0	36	9	64	41	8	3	4	0	9	3	0	0	12	1	2	1	5	3	2	4	6	66	69	70	61	71	39	62	15
1	34	57	7	28	36	17	21	18	37	68	34	5	34	28	13	32	31	54	29	35	20	4	2	1	8	0	23	6	52
2	1	5	0	2	27	18	36	46	14	0	37	1	16	42	25	21	23	14	40	31	38	0	0	0	1	0	8	2	4
3	0	0	0	0	0	33	10	7	11	0	0	0	9	0	30	17	12	0	0	1	7	1	0	0	1	0	1	1	0
PDA																													
0	35	3	63	45	27	2	0	0	5	3	0	0	5	5	0	0	3	0	0	0	2	63	64	64	62	63	31	43	9
1	29	55	2	16	23	11	10	5	30	62	16	3	26	16	7	17	14	39	6	10	13	1	0	1	1	2	26	14	42
2	0	7	0	3	35	8	26	42	6	0	48	4	17	44	14	18	18	15	51	32	29	0	1	0	1	0	8	5	14
3	1	0	0	1	0	44	29	18	24	0	1	0	17	0	41	30	29	11	8	23	21	1	0	0	1	0	0	3	0

*Note B3 includes a score of 8 hence missing counts

An independent samples t-test was used post-hoc to test these two questions.

Results

For the first research question, an independent samples t-test revealed that children with autism and PDA had statistically significantly higher total scores on the ADOS-2 (M=17.68, SD=2.42) when compared to those children with a diagnosis of autism without a PDA profile (M=15.52, SD=3.56), t (124.11) = -4.159, p<0.001.

Table 3: The number of scales within the ADOS given a rating of 3 for both groups

Number of 3's	Group		
	ASD only	ASD with the PDA profile	Total
0	12	2	14
1	23	10	33
2	15	7	22
3	8	10	18
4	4	6	10
5	6	11	17
6	3	0	3
7	0	6	6
8	0	3	3
9	0	5	5
10	0	2	2
11	0	0	0
12	0	2	2
13	0	0	0
14	0	0	0
15	0	1	1

Table 4: Total scores on the ADOS items by group

Total score	Group		
	ASD only	ASD with the PDA profile	Total
6	1	0	1
7	2	0	2
8	0	0	0
9	1	0	1
10	2	0	2
11	4	0	4
12	5	4	9
13	4	0	4
14	9	2	11
15	4	4	8
16	4	11	15
17	8	6	14
18	11	9	20
19	9	14	23
20	2	3	5
21	0	1	1
22	0	0	0
23	0	0	0
24	0	1	1

For the second research question, an independent samples t-test revealed that children with autism and PDA obtained a statistically significantly higher number of scores of 3 on the ADOS-2 (M=4.66, SD=3.29) when compared to those with a diagnosis of ASD without PDA (M=1.99, SD=1.68), t (93.35) = -5.900, p<0.001.

Discussion

Results obtained from these analyses, confirmed that there was a qualitative difference in social communication and interaction when working with children with autism, when compared to those with autism who also have a PDA profile. All of the 136 children met the diagnostic criteria for ASD, using the DSM 5. They all experienced significant difficulties in social reciprocity, social relationships and displayed rigid and inflexible thinking. All reported a need for routine, whether self-imposed routines or routine behaviours others expected them to carry out. These difficulties had been apparent since an early age, although it is well documented (Bargiela, Steward and Mandy, 2016) that females, in particular, often display fewer signs of autism until the social and academic demands exceed their ability to manage them, often between the ages of 8 and 12 years.

On the face of it, the results appear counter-intuitive, given that the ADOS-2 measures social interaction and social reciprocity. In the work by Newson et al (2003), one of the criteria for the PDA profile was 'superficial or surface sociability', so it might have been expected that a child with autism with PDA would be more likely to score a higher number of zeros (indicating less difficulty). Interestingly, this was not the case. In fact, the study indicated that the autism with PDA group had a higher number of scores of 3 across all areas. When examining the narratives provided to aid the scoring for each question, it was noted that the interaction of the children with autism was more often judged as being 'slightly unusual' or 'inappropriate', thus scoring a 1 or a 2, whereas the children in the autism with PDA group were more likely to be given a score of 3 on these same questions, on the basis that, for example, there was 'little social chit chat or give and take', or 'the participant shows minimal regard for the examiner' or 'the session was markedly uncomfortable' with the child showing 'little or no expressed pleasure' in the interaction.

The children with a diagnosis of autism tended to be described as 'quirky' or 'slightly inappropriate'. During the ADOS-2 assessment, the children with autism only, frequently went off topic to talk about their own special interests. However, if the examiner followed their train of thought and/or accommodated the 'quirkiness' or occasional inappropriate overture, it was perfectly

possible to establish a reasonable conversation and a good rapport. The interaction was, therefore, unusual but not difficult to manage or sustain.

In contrast, the children in the autism with the PDA profile, often began the ADOS-2 assessment by initially demonstrating a degree of 'surface sociability'. However, as the assessment progressed, their social energy appeared to wane, and they became increasingly less motivated to engage. They were often reluctant to continue with the interaction and in some cases, disengaged completely. They employed a variety of strategies which included ignoring the examiner, attempting to distract (sometimes with intentionally shocking behaviour), refusing to participate, leaving the room, or, in some cases, becoming extremely agitated and dysregulated or 'freezing'. So, when scoring the quality of the interaction, a score of 3 was given. However, while all the clinicians were qualified and experienced in using ADOS-2, a potential limitation is that the scoring can be subjective, particularly in terms of areas such as 'rapport'.

Concluding comments

The data set used in the exploratory analysis, while not without its limitations, is unique and of value in the current debate on the PDA profile. In the study, both the children with a diagnosis of autism, and those deemed to have the PDA profile as well, all achieved scores above the diagnostic cut off for autism, but displayed different social communication and interaction styles. It was also notable that the observed interaction style was remarkably similar within the PDA profile group.

The authors are not suggesting that this is evidence for the existence of '*autism with PDA*' as a separate diagnostic category, behaviour profile or sub type of autism. This would need a larger scale, independent study. The authors fully acknowledge that as a diagnostic team, they have a known interest in the PDA profile, and so a larger percentage of their referrals is likely to be for children presenting with this type of profile than would typically be seen in other autism diagnostic assessment populations. In addition, the current study only included those children who completed Module Three of the ADOS-2 and so it is not clear whether Modules One, Two and Four would provide similar results.

However, it is suggested that the ADOS-2 might help to tease out qualitative differences in the interactive style of children with autism and those with extreme (or pathological) demand avoidance. Previous research (eg O'Nions et al, 2014; 2016) was based on parental reports and, as such, is potentially open to bias, whereas the results of the current study were based on clinical observations. In addition, it is important to note that the clinicians had to use a particular range of strategies and negotiation skills to manage the anxiety levels of the children with ASD and the PDA profile. This has implications both clinically and educationally in terms of how to support this cohort of children.

The following strategies proved effective:

- Framing demands as a challenge – parts of the assessment were presented as a challenging game with different levels that the child could progress through (it is important that they have the ability to achieve all the levels in this 'challenge') or as a challenging game played against the clinician where the child was able to compare their achievements (it was important that the child was always able to 'win')

- Framing demands as a race – providing the child with the opportunity to demonstrate their ability to achieve and win

- Using inadvertent discovery – placing objects or materials near to the child proved useful in seeing whether such objects sparked a child's interest. If so, there appeared greater likelihood of the task being completed

- The clinician pretended to be incompetent, using extreme exaggeration and dramatisation to allow the child to feel competent, and this often generated humour, encouraged engagement, and subsequently resulted in completing the task

- Directing demands to others in the room or to objects or toys also proved successful

On many occasions the clinician found that saying things like: *"Well, maybe Spiderman knows the answer to this question?"* or "*I think it's Teddy's turn to do this job"* or *"I've got so many jobs to do, my manager is not*

going to be particularly impressed with me if I don't finish them", appeared to alleviate some of the pressure on the child to comply, and also allowed the child's confidence to remain intact if indeed they were not sure how to complete the task.

Finally one of the most important elements that proved effective was simply spending time with them. Engaging in conversations on their special interests, engaging in activities they enjoyed, and taking time to build a rapport was often key. This approach enhanced engagement and trust, following which the children were much more open to completing the tasks.

Part Two: Differentiating autism and autism with PDA from attachment difficulties: an analysis of the data from the developmental histories of the children in all three groups

Introduction

In 2018, O'Nions et al outlined exemplars of behaviour that were drawn from interviews with parents who believed their children exhibited features of the PDA profile. The study involved interviews with 26 families in a community setting. A number of themes emerged. There was a strong theme of *'avoidance of everyday demands'* and 85 per cent of the sample were said to show controlling or obsessive behaviour towards a particular individual, including peers. *'Strategically disruptive'* behaviour was also reported with 77 per cent making excuses for noncompliance, 88 per cent demonstrating *'aggressive'* behaviour, making threats or engaging in *'extreme'* behaviour. Sudden, dramatic changes in mood and acting as if they had adult status and blaming others for their behaviour were also reported. However, Malik and Baird (2018) in their commentary article, felt these interviews had limited validity as the parents who were interviewed already knew about PDA and believed their children fitted the profile.

One issue that causes particular distress to parents is the assumption that demand avoidance may be due to poor or neglectful parenting practices or that there are *'attachment difficulties'*. Children who struggle with demands are often diagnosed with Oppositional Defiance Disorder (ODD) (DSM 5 313.81, F91.3, page 462). In the DSM 5 criteria for ODD, under 'associated features supporting diagnosis', it is stated that the disorder is more prevalent in families in which:

> *"childcare is disrupted by a succession of different caregivers or in families in which harsh, inconsistent or neglectful child-rearing practices are common"* (page 464).

Many children who are in the looked after or adopted population and have experienced this type of early start in life, may present at Child and Adolescent Mental Health and Paediatric services with a range of challenging behaviours including aggression, oppositional behaviour, demand avoidance/refusal to comply with adult requests and a range of sensory processing difficulties. Van der Kolk (2005) and his colleagues suggest that many of these behaviours result from, what he refers to as, 'developmental trauma' which, it is claimed, impacts upon the ability to self-regulate.

The Coventry Grid (Moran, 2010): Differentiating autism from attachment difficulties

Clinical Psychologist, Heather Moran, first identified the challenges facing clinicians attempting to distinguish autism from 'attachment problems' (Moran, 2010) and introduced the 'Coventry Grid'. She noted similarities in the type of behavioural challenges observed in children with autism and those who were identified as having attachment difficulties. The term 'attachment problems' was used to describe the type of social, emotional and behavioural difficulties that are seen in many children and not simply those who would meet full diagnostic criteria for an Attachment Disorder.

The key features of these behavioural difficulties as outlined by Moran (2010) include demonstrating behaviour patterns that 'push' other people into responding to the child (either negatively or positively). These children have often experienced inconsistent care or have a care history that has been disrupted. Often the function of this behaviour is to 'test' the adult to see how strong the relationship actually is. These children can also be hyper vigilant, often misconstruing the intentions and actions of others. They may also struggle to maintain interpersonal boundaries and communicate in an appropriate manner. Children with this type of history will also frequently display emotional lability and may have 'meltdowns' where they become dysregulated or aggressive. They may refuse to follow adult direction and many will also experience differences in the way they process sensory information (Mubarak et al, 2017).

Challenges for clinicians

All of the above leads to huge challenges for clinicians who frequently have limited time in which to make an assessment of children who present with highly challenging and distressed behaviour. It can be especially difficult if there is no documented history of early caregiver disruption or trauma and the child has grown up in an apparently safe and nurturing environment, in the absence of caregiver mental health difficulties and often with typically developing siblings who have shared the same environment.

Aims of study two

This study aimed to further elaborate upon and clarify how demand avoidance may present in specialist clinical services, and how this might differ from the types of behaviour displayed by children who have a documented history of neglect or developmental trauma.

The participants

Data from 161 children were analysed following a multi-disciplinary diagnostic assessment for autism following NICE 2011 (updated 2017) guidelines (CG 128). The team concluded that 63 children in this sample, had autism with the PDA profile, 53 were given a diagnosis of autism and 45 children were adopted. The latter group had all been referred because they were displaying behaviour that challenged others and where autism

had been suggested as a possible explanation. The team concluded that these children did not meet the criteria for ASD and instead were given a formulation of Attachment Difficulties (AD).

Children were excluded from this study if they had either a learning disability, or a documented history of foetal alcohol or substance exposure.

Table 5: Age and gender of the children in the three groups

	PDA (n=63)	ASD (n=53)	ATTACHMENT (n=45)	TOTAL (n=161)
Gender				
Male	39	23	30	92
Female	24	30	15	69
Age group				
<5	16	11	8	35
6-10	32	22	16	70
11-16	9	15	18	52
17+	6	5	3	14

Assessment of the children's developmental histories

Comprehensive developmental histories were obtained from the parents or caregivers of all the children involved in the study. These were obtained using a semi-structured interview developed by the assessment team. It included many items that correspond with existing standardised developmental history tools, such as the DISCO and the ADI-R (Autism Diagnostic Interview – Revised, Lord, Rutter and LeCouteur, 1994). The interview proforma included open ended questions relating to the

Table 6:   Characteristics of PDA derived from the literature

Characteristics
Early passivity
Language delay
Superficial/surface sociability
Obsessively resists/avoids ordinary demands
Lability of mood
Blaming other people
Fantasising, lying, cheating and stealing
Socially shocking or outrageous behaviour
Seemingly manipulative behaviour
Repetitive questioning
Communicating through dolls/toys
Weak or limp hands
Dominating or bossy towards peers
Harassment of others
Strong fascination towards particular persons (positive or negative)
Difficulties with other people
Rapid, inexplicable changes in mood
Comfortable in role play

Note: All items have been identified in the DISCO specific list of PDA behaviours, and/or the EDAQ list of PDA behaviours, and/or Newson's original list of PDA behaviours.

following areas: pre-pregnancy issues, current family dynamics, pregnancy and birth, early infancy, language and communication, social interaction, play and imagination, rigidity/inflexibility of thought, emotional regulation, sensory difficulties, self-care, behaviour, strengths of the child, mental health of the child and educational experiences. Participants' responses were recorded verbatim by the assessing clinician and subsequently transcribed into a comprehensive report.

The 'Developmental History' sections of the children's diagnostic assessment reports were analysed using a deductive, qualitative content analysis approach. This involved four main stages: decontextualisation, recontextualisation, categorisation, and compilation. During the decontextualisation stage the researcher read and re-read each child's developmental history to become familiar with the content. This stage also involved open coding where the researcher extracted sentences and paragraphs relating to an original matrix. This matrix included specific characteristics identified in previous research which are thought to be indicative of a PDA profile (O'Nions, 2014, 2017, Newson, Le Marechal and David, 2003), see *Table 3*.

The recontextualisation phase involved reading the extracted sentences and paragraphs relevant to these characteristics alongside the developmental history texts to see whether the remaining 'unmarked' data (ie data that did not directly fit within this list) could provide any additional information, or highlight any other common characteristics.

To test inter-rater reliability, a second rater coded and categorised the transcripts of 16 randomly selected participants. There was 69 per cent agreement (11/16 total agreement).

Chi-square tests were used to investigate whether there were statistically significant differences in the frequency with which evidence for each theme within the original matrix and newly identified themes, were reported in the developmental histories. The test analysed whether the identified themes were seen statistically significantly more frequently in the autism with the PDA profile group, compared to the other two groups.

Findings from the analysis of the developmental histories

From an analysis of parent/carer reports, statistically significant differences were found between the three groups for many of the features of PDA (but not all), as follows:

- superficial/surface sociability

- obsessively resists/avoids ordinary demands

- blaming other people

- socially shocking or outrageous behaviour

- manipulation

- communication through dolls/toys

- dominating or bossy towards peers

- strong fascination towards particular people

- rapid inexplicable changes in mood

- comfortable in role play

Statistically significant differences were NOT found for:

- early passivity

- language delay

- fantasising

- lying

- cheating

- stealing

- repetitive questioning

- weak or limp hands

- harassment of others

- difficulties with others and peer relationships (see *Table 3*)

Five new themes emerged, as follows:

- elaborate excuses

- sabotaging

- extreme aggression

- ineffectiveness of traditional reward and consequence based parenting strategies

- home schooling

Statistically significant differences were found for all these themes with a higher frequency within the autism and PDA group when compared to the autism and AD groups, apart from home schooling (see *Tables 4 and 5*). Home schooling was common across all three groups.

Table 7: Frequency counts, percentages, and Chi-Square statistics comparing themes and diagnoses

Theme/subtheme	PDA and ASD (n=63)		ASD (n=53)		AD (n=45)		CHI-SQUARE RESULTS	
	n	%	n	%	n	%	X	p
Early passivity (M)	31	19	26	16	10	6.8	8.10	0.02
Language delay (M)	20	12.	11	7	14	89	2.317	0.36
Superficial/surface sociability (M)	33	20	20	13	6	4	16.17	0.000*
Obsessively resists/avoids ordinary demands (M)	51	32	19	12	8	5	45.9	0.000*
Blaming other people (M)	17	11	3	2	4	3	12.10	0.002*
Fantasising, lying, cheating and stealing (M)	15	9	12	8	6	4	2.28	0.320
Socially shocking or outrageous behaviour (M)	18	11	3	2	6	4	11.35	0.003*
Seemingly manipulative behaviour (M)	22	14	2	1	2	1	26.94	0.000*
Repetitive questioning (M)	4	3	5	3	0	0	4.21	0.121
Communicating through dolls/toys (M)	6	4	0	0	0	0	9.69	0.008*
Weak or limp hands (M)	9	6	9	6	11	7	1.89	0.388
Elaborate excuses (N)	38	24	7	4	1	1	52.55	0.000*
Sabotaging(N)	39	24	6	4	0	0	60.80	0.000*
Dominating or bossy towards peers (M)	49	30	23	15	14	9	23.73	0.000*
Harassment of others (M)	10	6	1	1	3	2	7.412	0.025
Strong fascination towards particular persons (positive or negative) (M)	20	12	5	3	5	3	11.78	0.003*
Difficulties with other people and peer relationships (M)	42	26	22	14	18	12	8.73	0.013
Rapid, inexplicable changes in mood (M)	44	27	13	9	7	4	38.53	0.000*
Extreme aggression(N)	32	20	6	4	15	10	20.36	0.000*
Comfortable in role play (M)	30	19	4	3	3	2	20.75	0.000*
Traditional strategies (N)	42	26	6	4	9	6	45.03	0.000*
Home schooling (N)	16	9.9	6	3.7	8	5.0	3.792	0.150

Note: n = the number of participants for which evidence of the theme was present. *indicates significant p value following Bonferroni correction for multiple comparisons. M = theme from the literature. N = new theme identified during content analysis.

Table 8: Chi-Square statistics comparing themes reported in the three groups

Theme/Subtheme	All three groups	PDA and ASD vs ASD	PDA and ASD vs AD	ASD only vs AD
Passive early history (M)	0.017	-	-	-
Language delay (M)	0.361	-	-	-
Superficial sociability (M)	0.000*	0.229	0.000**	0.004**
Obsessively resists/avoids ordinary demands (M)	0.000*	0.000**	0.000**	0.029
Blaming other people (M)	0.002*	0.002**	0.019	0.536
Fantasising, lying, cheating and stealing (M)	0.320	-	-	-
Socially shocking or outrageous behaviour (M)	0.003*	0.001**	0.060	0.294
Manipulation (M)	0.000*	0.000**	0.000**	0.867
Repetitive questioning (M)	0.121	-	-	-
Communication through dolls/toys (M)	0.008*	0.021	0.033	-
Weak or limp hands (M)	0.388			
Elaborate excuses (N)	0.000*	0.000**	0.000**	0.048
Sabotaging (N)	0.000*	0.000**	0.000**	0.020
Dominating or bossy towards peers (M)	0.000*	0.000**	0.000**	0.228
Harassment of others (M)	0.025	-	-	-
Strong fascination towards particular persons (M)	0.003*	0.004**	0.012	0.785
Difficulties with others (M)	0.013	-	-	-
Lability of mood (M)	0.000*	0.000**	0.000**	0.192
Extreme aggression (N)	0.000*	0.000**	0.116	0.004**
Comfortable in role play (M)	0.000*	0.000**	0.000**	0.866
Traditional strategies (N)	0.000*	0.000**	0.000**	0.234
Home schooling (N)	0.150	-	-	-

Note: *indicates significant result following Bonferroni correction for multiple comparisons (p<0.0083). **indicates significant result following Bonferroni correction for multiple comparisons (p<0.0125). – indicates that further analysis was not conducted due to no identified significant difference across groups.

Discussion

This study had a mixed group of children who were all referred for an autism diagnostic assessment and, in addition, were displaying some degree of behaviour that was deemed to be unusual or challenging. Forty five of the children were adopted and had experienced known developmental disruption. In all cases, the developmental history interview was similar, with parents/carers given the opportunity to provide an account of their child's development across all areas. They were not able to answer simply 'yes or no' but instead were invited to provide multiple examples of observed behaviours.

Following analysis of the themes generated, it was noted that certain key 'themes' emerged, some of which were similar to those reported in the original Newson studies and in the O'Nions et al (2018) study on PDA. The analyses showed that these were reported more frequently in the autism with PDA group than in both the ASD group and the Attachment Difficulties group. Parent/carers reports of a passive early history was similar in both the ASD group and the ASD with PDA group. This suggests that a degree of passivity or lack of social motivation is evident in both groups from an early age. It is difficult here to draw any firm conclusions about the Attachment Difficulties group as some of the children were not adopted until after the early developmental period and so, little information about their early presentation was available.

The findings from the current study have relevance in two distinct areas which will be discussed separately. First, a number of themes were identified that appeared to distinguish children with ASD with PDA from children with ASD alone. Perhaps most importantly from the point of view of supporting and helping these children and their families were the reports that traditional parenting and management strategies were reportedly not as effective in the ASD with PDA group.

In addition, many parents in the ASD with PDA group reported that, in their endeavour to find support for their child's difficulties, they had been referred to, and seen by, services where it had been suggested that there were either attachment difficulties, or that there were insufficient boundaries in the household. Parents reported having attended numerous parenting courses and having been advised to implement firm boundaries and reward based programmes. Almost all, without exception, reported that these had not proved effective and had, in fact, in many cases made the behaviour challenges worse. This can cause real concern to parents and affect the parent-professional dynamic.

This study showed that there were a number of areas frequently reported by the parents of the children with ASD with PDA and infrequently, if ever, by the parents of the children with AD. The children with AD were unlikely to display superficial sociability or obsessively resist everyday demands. They were also less likely to use social strategies to manipulate and get their own way; deliberately sabotage events or be bossy or dominating towards their peers. Perhaps most interestingly, given that all of the children in the AD group had experienced disruption to their early attachments, only children in the ASD with PDA group were reported to be somewhat obsessive about particular people. In most cases, this was the child's mother. This often presented as an over attachment, an unwillingness to be separated from and a need for control over her. Furthermore, a number of the caregivers in the AD group reported that they had found strategies that helped their child, whereas the overwhelming message from the ASD with PDA group was that few if any of the strategies that were offered worked, and in fact often made the child more distressed and dysregulated.

All of these findings are reported as initial findings and should be considered as speculative until they can be replicated in future, larger scale, research. However, as was found in the initial Newson study (Newson, Le Marechal and David, 2003), the behaviour and presentation reported in this study were remarkably similar, both within the ASD with PDA group and when compared to children discussed in other studies. In all cases, the demand avoidant and anxious behaviour had been present from a very early age (some parents reported that they had noted this from birth or shortly after birth).

This was distinct from children assessed as having ASD without PDA, who displayed more 'rational' demand avoidance. For these children, the developmental

history was different, with parents reporting that the demand avoidance only started in response to certain environmental stressors – often school. When the child's cognitive ability, executive function and sensory profile were examined, there was often a clearly defined reason why the child might be resisting certain activities (eg they were struggling with poor personal organisation, poor processing speed and often sensory overload in a busy, noisy classroom). This was combined with social difficulties (and often bullying), which frequently became more apparent as the child progressed through school.

In contrast, the children who presented with 'pathological' or extreme demand avoidance had displayed this behaviour consistently throughout infancy and early childhood. To an onlooker, this avoidance often appeared irrational or illogical and often involved activities that the child enjoyed. It was pervasive across all contexts and across time. The developmental histories gathered were consistent and, at times, taken from parents who were unfamiliar with the concept of the PDA profile.

Concluding comments

This study, while not claiming to provide conclusive evidence of a specific or exclusive set of behaviours associated with a PDA profile, does add to the growing body of evidence of parental reports of certain types of behaviour. The themes and sub-themes reported were generated as part of a standard assessment process by the same team, using the same tools and analysed using a deductive method. None of the behaviours in the themes were seen exclusively in children with the ASD with PDA profile, but several occurred significantly more often in this group. At the very least, it is hoped that this study will be seen as adding to our knowledge of this often distressing presentation and will lead to further, larger scale studies. Regardless of whether the PDA profile is deemed sufficiently robust to consider it as a separate, or identifiable entity, this study demonstrates the fact that there are some children with a diagnosis of ASD, whose development and presentation are significantly different from others with ASD, and who are likely to need different strategies.

When an assumption is made by a clinical team that a child's difficulties can be accounted for by attachment difficulties, the strategies that are suggested tend to focus predominantly upon the introduction of boundaries or rewards and consequences for behaviour. If the child does not have AD but instead has a PDA profile, then traditional parenting and management strategies are not likely to be effective. Work by Lucyshyn and colleagues (2015) provides a framework to understand why habitual patterns of avoidance can develop that are very resistant to change. Avoidance, and other behaviour that successfully leads to withdrawal of demands, is reinforced by the reduction in anxiety that the child experiences when this occurs.

It is hoped that the features identified in this study in the ASD with PDA group can be used in the future to develop standardised tools which will be useful to help clinicians in the difficult task of differential diagnosis.

A final area worthy of further research is what has been referred to by the authors as 'rational' demand avoidance. There is no doubt that demand avoidance is seen in many diagnostic groups as well as in typically developing children in response to certain stressors which may include their cognitive ability, executive function, sensory profile, or social difficulties. It is possible that 'rational' demand avoidance is misinterpreted as 'pathological' by some parents and some professionals. The defining feature of 'pathological' demand avoidance is that it often appears irrational or illogical and involves avoiding activities that the child enjoys. It does not, therefore, have a 'rational' or easily identifiable explanation. Future research could explore the potential confounding influence of 'rational demand avoidance' on the identification and differentiation of the PDA profile.

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