An examination of the behavioural features associated with PDA using a semi-structured interview

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Abstract

"Pathological Demand Avoidance" (PDA) is a term increasingly used in the UK to describe children, many with an autism spectrum diagnosis, who obsessively resist ordinary demands and requests. Children with PDA show a range of difficult behaviours: poor awareness of social hierarchy; "social manipulation" (e.g. distraction, excuses), aggressive outbursts, and outrageous behaviour, apparently to subvert demands. Despite much clinical interest, PDA has received scarcely any research attention. Here we report descriptive features of 14 children aged 8-15 years who fit the PDA pattern, and in whom IQ and autistic symptomatology is well-documented. We conducted qualitative analysis on data from a semi-structured interview based on the PDA items within the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002; *Journal of Child Psychology and Psychiatry*, 43:307-325). Key behavioural traits, illustrative examples, and emergent themes are reported. Paradoxically, examples suggest social insight sufficient to use targeted social manipulation, but a lack of awareness of social hierarchy (e.g., own/others' age or status), and no concern for own reputation. Obsessive controlling behaviour towards others was also reported. Findings illustrate the extreme difficulties presented by this group; highlighting the imperative to understand better the neurocognitive basis of an apparently uneven socio-cognitive profile.

Keywords

Introduction

Pathological Demand Avoidance (PDA) is a term increasingly used by practitioners in the UK, coined to describe children said to resemble those with autism, but who displayed a striking inability to comply with everyday demands and requests (Newson et al., 2003). Newson's description of PDA includes a tendency to resort to "socially manipulative" behaviour, including subtle avoidance strategies and outrageous embarrassing acts, and an obsessive need for control, resorting to violence if thwarted. Further features were

poor awareness of their place in the social hierarchy, with many perceiving themselves as adults, while behaving in ways more typical of a younger child; and superficial social skill, but poor peer acceptance due to their need for control and insistence that everything is on their terms (Newson, et al., 2003).

Newson's description of PDA has gathered a considerable weight of interest from parents and clinicians, reflected in several over-subscribed conferences in the UK in recent years, organised by the National Autistic Society, and inclusion of guidelines on PDA in Autism Education Trust guidelines (Christie, 2007). Due to the absence of a robust evidence base, PDA has not entered the diagnostic manuals, and the concept remains controversial. There is discussion about whether PDA is a syndrome, or describes behaviour seen in a range of disorders. Its relationship with autism has also been debated. Some have argued that PDA is simply a relabeling of high-functioning autism/Asperger syndrome, or a more female-typical presentation of Autism Spectrum Disorder (ASD) (Gould and Ashton-Smith, 2011). However, several aspects of Newson's description of PDA do not fit easily within our current concept of ASD. First, unlike those with ASD, children with PDA are reported to respond poorly to routine and predictability, instead preferring spontaneity and humour. Second, a pre-occupation with role-play and fantasy is described as characteristic of PDA, but pretend-play is typically absent or delayed in ASD (Frith, 1991; Leslie, 1987). Third, descriptions of autism do not include frequent and varied manipulation of others' mental and emotional states, as reported in PDA. Last, Newson et al. (2003) reported a balanced gender distribution, in contrast to the 4:1 over-representation of males with ASD (Fombonne, 2003).

Despite the interest and debate concerning PDA, there are only two published peer-reviewed research papers on the topic (Newson et al., 2003; O'Nions et al., in press). Newson and colleagues' seminal case series described the features of PDA outlined above, but lacked standardised measures of IQ, and systematic consideration of autistic traits. Clearly, more research is needed. As a starting point, it is important to know whether children exhibiting PDA features meet ASD criteria, and whether behavioural problems stem from developmental delays or intellectual impairment. The aim of this study was to systematically explore behavioural features of children with average-range IQ who fit the PDA pattern, using qualitative analysis of data from a semi-structured interview. The interview was based on items from the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002), which, unlike other standardised diagnostic instruments, includes items tapping PDA features. We also report scores on the Autism Diagnostic

Observation Schedule (ADOS; Lord, et al., 2000) a 'gold-standard' diagnostic measure of ASD, to provide a more complete picture of PDA in the context of current debates about its relation to ASD.

Methods

Participants

Participants were N=14 parents of children who had received the PDA label from professionals, or whose behaviour fit the profile described by Newson et al., (2003). Their children ranged from 8.3 – 15.3 years (mean = 11.1; SD = 2.37), with parents of 6 boys and 8 girls included. Parents were recruited from the community via parent conferences, web groups, school contacts and educational psychologists. They formed a subset of a larger group whose children had taken part in a research-study involving cognitive and behavioural assessments.

Parents invited to complete the interview were those with whom we were in direct contact (as opposed to participants recruited via schools), whose children displayed particularly high levels of PDA relevant behaviours. Interviews included here are the 14 examples most resembling Newson's descriptions of PDA. Based on the interview data, all children were deemed to exhibit (1) Obsessive resistance to demands, sometimes resorting to violence; (2) Frequent and varied use of social manipulation (though two parents felt this wasn't "devious"); (3) Controlling behaviour to others; (4) Intense emotional lability; (5) Poor social awareness and (6) A tendency to externalise blame. Appendix 5-1 illustrates the characteristics of this sample, including diagnoses, educational placements, IQ and ADOS scores.

To the best of our knowledge, none of the children had experienced unusually difficult or abusive backgrounds, though several had had traumatic educational experiences/family difficulties subsequent to their severe behavioural problems. None had been born severely premature or had been in care, although one accessed part-time care as respite.

Given that participants described here also took part in a cognitive-experimental study, IQ scores and scores from an assessment based on the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) are available. These are reported in Appendix 5-1, to give some indication of the extent to which the present sample would meet standard observational criteria for ASD. All participants included in this study had an IQ >70.

Procedure

Parents completed an in-depth, semi-structured interview, over the phone (N=4), in person (N=1) or in an electronic format (N=9). The interview was developed by E O'Nions and F Happé, based on items measuring PDA characteristics from DISCO (Wing et al., 2002), and unpublished interview items by E. Newson (full interview included in Supplementary Table 2). Parents completed the interview by commenting on how applicable the behaviours were to their child and providing examples of relevant incidents.

Analysis

A general inductive approach (Thomas, 2006) was used to analyse the data. Four manuscripts were initially coded by two researchers (E. O'Nions and E. Quinlan), using open coding to highlight salient features. Preliminary codes formed the coding structure for further manuscripts. Codes were then grouped into categories based on relatedness, and groups were reorganized until they formed coherent themes. Themes were further developed subject to discussion between researchers and were refined to create 11 major and 60 sub-themes. A third researcher (H. Tulip) grouped all response data into these initial themes. These were collapsed to 8 main and 18 sub-themes that subsumed the data. Validity was further established through asking a subset of parents who had taken part to read the manuscript, to ensure the data had been accurately represented (N=4).

Ethical approval

The study was approved by the King's College London Psychiatry, Nursing and Midwifery ethical review board. All participants gave informed consent to participate in the study. All results are anonymised, with specific identifying details omitted.

Results

The results of the analysis are organised on the basis of the identified codes, with illustrative examples taken from the interviews. Examples are sampled from all participants, however identifiers linking multiple examples to a particular child are omitted to protect anonymity. Results from items covering difficulties with peers are presented elsewhere (Rose-Morgan et al., in prep). In considering the themes and examples below the reader is reminded that these refer to children aged 8-15 years with IQ in the average range.

1. Developmental history

The majority of children were remembered as placid, easy babies up until around 18 months (e.g. "He was like a little bird, just opening his mouth to be fed"). They were often difficult to engage, content to watch other children play rather than joining in. Others were clingy, difficult, and demanding from the start. One would scale stair gates and climb out of cots as an infant. Some were slower than their siblings to reach developmental milestones, but none was acutely delayed, and several were precocious. Most parents reported that speech was slower to develop than for siblings; though speech had developed by 2 ½ for all but 3 children, with all 14 speaking by 3½ years. Once they had started to speak, several began talking in sentences very rapidly.

2. Avoidance of demands and requests

<u>Emergence of avoidance</u>

The majority of parents reported that their child's extreme stubbornness and refusal to comply had emerged in early childhood. This was often evident at nursery: (e.g. "She would kick dinner ladies, teachers and other children. When she went ballistic, all of the other children had to be taken out to protect them"). Some were dominant and overbearing from an early age, responding to attempts to impose limits with outrage (e.g. "X tried to tell the other children and adults how to behave. She was violent and aggressive – one time pushing a child down some stairs because they were in her way and lashing out at staff").

In contrast, several had displayed passive resistance; appearing compliant but making excuses. These children often failed to raise concerns (e.g. "At nursery, she was perceived as different from the other children but this was not seen as cause for concern as she 'did fine there'"). Beyond the flexibility of early years' education, things often deteriorated, with an escalation in aggression perceived by parents as related to increasing demands for conformity. One was acutely anxious and fearful of people and his environment: ("At nursery, he cried and escaped out of garden"). Another was very rigid, which created problems when this conflicted with demands.

<u>Context of avoidance</u>

For the majority of children, everyday activities (e.g. getting dressed, leaving the house) provoked obsessive resistance. In older children, avoidance often involved restricting activities and engagement with others (e.g.

refusing to go to unfamiliar places or attend classes with peers). Tolerance for demands was described as variable, and having conformed would often result in a rebound effect (e.g. "A bad day at school where she has not reacted will result in her being ultra-controlling, short tempered, avoidant and manic in her behaviour with me"). For many, it was considered impossible to appeal to their "better nature"– compliance depended on the activity suiting their agenda, their level of anxiety/arousal, and the approach taken by the person making the request.

Several parents reported that their child was compliant at school, but avoidant and controlling at home, resorting to violence. One would comply with certain favoured individuals (e.g. "She will do some surprising things for some people yet will wreak havoc with others and be very nasty"). One parent made sure she avoided praising her daughter for certain activities to avoid "rubbing in" the fact she has complied, and another child was "verbally vile" if praised. Rewards for good behaviour were sometimes effective, though the frequently the child would renegotiate their side of the bargain.

3. Social manipulation

<u>Strategies to avoid demands</u>

The majority of the children responded to demands using a range of different avoidance strategies (e.g. "Having to get ready for school, she would hit, bite or shout at others or use more passive behaviour such as complaining that her legs ached"). These included distraction, asking questions, refusing to walk, or lying on the floor and going floppy (e.g. "I am now realising that I have been physically moving her, when she has not been compliant, for many years"). One claimed requests are "killing her", or accused the person making the request of shouting. When at nursery, another would hold his breath and fall to the floor. Another would partially comply, making a small but obvious error; or comply but makes conditions (e.g. agreeing to apologise when naughty only if her mother let her hug her first).

Many avoidance strategies were socially astute (e.g. "He is very subtle and will play on mothering instincts: he is hungry, he is tired, he doesn't feel well, he needs a drink. He is being picked on, bullied, made to do things he shouldn't do by other children"). Others "outmanoeuvred" parents to get their desired result. Several adopted babyish mannerisms, or overwhelmed people with charm (e.g. "She loves to talk to new people and will engage them in intimate conversation very quickly"), though two were said to lack the social insight for this. Parents reported that their lives revolved around circumventing avoidance (e.g. "If we want something to

happen, we have to be devious about it: distract him with his interests, give him choices, or if it is something he must do, bribe him").

Extreme behaviour in response to demands

Extreme violent behaviour in response to demands or refusals to kowtow to the child's requests were common (e.g. "She will withdraw if people are not doing what she wants. She cries, screams, runs around slams doors and runs outside to scream, if anyone looks at her she shouts abuse at them"). This also included targeted verbal aggression, (e.g. "She can have explosive episodes at bedtime which can involve hitting, kicking, trying to bite, verbal abuse e.g. 'you're fat, stupid, I hate you' etc."); and threats to hurt themselves or others. Frequently, in the context of an outburst, there were no limits to what the child would resort to (e.g. threatening to jump out of windows), so parents had no choice but to avoid triggers. One was unwilling to use sanctions, as this could have unpredictable consequences for other members of the family.

Extreme behaviour frequently resulted in difficulties at school, including suspensions and exclusions (e.g. "Though X managed quite well, if there was an incident it would be big, e.g. she would throw things"). In many cases, things had escalated to the child being barricaded away from others during a meltdown due to their level of violence. Several parents reported that rigidly disciplinarian approaches or even attempts to intimidate the child by schools had led to acute exacerbation of their difficulties. This was different from the child being made aware of the limits on what was acceptable, which two identified as helpful. Some also associated fluctuations in extreme behaviour with general pressure to conform; and in some cases the presence of perceived "allies" who could mitigate demands was perceived as helpful. One participant was thriving at a Steiner school, where she had choice in her activities and was able to learn opportunistically in a way that was driven by her interests.

Shocking/ humiliating behaviour with intent

The majority of children behaved in ways apparently intended to shock, upset or provoke a reaction. Some parents felt this had a compulsive quality (e.g. "She gets distressed by her behaviour herself as she cannot stop it, but it does sometimes feel like it is on purpose: she uses these extreme behaviours to remind us that she is in control"). Shocking behaviour was used instrumentally by some (e.g. "If she wanted to get rid of someone visiting, she would resort to removing clothes, attacking me and the other person, trashing the house and so on until the other person left"). One identified others' weak spots and used this to verbally

attack. Extreme acts occurred in a minority, such as urinating on other people's possessions. One mimicked another boy at his school who displays sexually inappropriate actions in public. According to his mother, he enjoyed the reaction the other boy's behaviour received, so mimicked it to get the same response.

4.   Controlling behaviour towards others

The majority of children needed to be in control, becoming extremely cross if thwarted (e.g. "He sees things in black and white – his way or no way"). Many parents reported that their lives revolved around meeting the child's demands, getting nothing back in return. This was often evident in the child's tendency to interrupt and monopolise conversations, accusing others of rudeness if they objected (e.g. "He did this at a school meeting with three adults present. They kept calm and had a logical discussion, but he shouts you down and takes over"). Need for control was also evident during games (e.g. "She has to be completely in control. If it is cards she has to deal, if it's monopoly she has to be the banker"). Several had "intense reactions" to losing, insisting play continued until they won. Three children were unable to stick to swaps or trades, or took back gifts; failing to appreciate the object that had been given away wasn't theirs anymore. Two parents felt their child had no appreciation of how others feel or what they may want.

Several children displayed obsessive controlling behaviour towards a particular member of their family. For several, this involved acute jealousy over attention (e.g. "If I am on the phone she switches it off at the wall, or answers it before I do and then tells the other person that I am out or in the bath"). Several had paradoxical emotions about a favoured person (e.g. saying rude things about them, despite appearing to like them). Others needed to be centre of attention in social contexts; drawing attention to themselves with outrageous lies or clownish behaviour, mortifying their siblings.

5.   Intense emotional lability

<u>Mood changes dramatically in an instant - from happy to angry and vice versa</u>

Dramatic mood changes to very minor events were frequently reported. For many, it was rarely clear what the trigger had been. The majority have had meltdowns including violence in public (e.g. at school, in front of peers), though two mostly restricted this to private contexts. Some were described as "touchy", reacting badly to jokes, or perceiving banter as bullying. Several were said to recover rapidly from these outbursts, and one parent reported that they can sometimes be pre-empted with a well-timed joke. Other parents reported a "priming" effect: once triggered, their child's anger and anxiety re-occur very easily.

<u>Over-the-top excitability</u>

Several parents reported over-excitability when interacting in a group or anticipating festivities (e.g. Christmas), in a way that was unusual for their age. Several got carried away with games, becoming aggressive and hurting siblings, even when they appeared to be enjoying themselves. Some displayed confused emotional behaviour (e.g. appearing to enjoy hugs but simultaneously pinching or using verbal insults). Others were overbearing in the way they expressed affection (e.g. squeezing too hard when hugging).

<u>Anxiety</u>

Several children displayed phobic like fears about activities such as having a bath, going to the toilet, or even to their own pets. One felt unable to go outside in case she had a tantrum, which she couldn't control and found embarrassing. Two older children refused to leave the house or go to unknown places. A theme identified by parents was that fear of the unknown provoked aggressive or extreme outbursts.

<u>Negative self-image</u>

Several parents perceived that their child had a negative self-image (e.g. "She is never happy with her work, and has torn up her homework through frustration and the perception her work is rubbish"). In some, this had resulted in resistance to learning (e.g. "Even though X is intelligent – she refused to learn to read, and became explosive if made to try. She said that she would not do it – everyone else was better at it and she just couldn't"). Parents perceived that negative educational experiences and victimisation had damaged self-esteem (e.g. "While at school in the past, children had told X that they would be glad if she was run over by a bus. Given her more literal understanding, this was very frightening for X."). In some, dislike of praise also seemed related to low self-esteem: the child claimed it was only said to make them feel better.

6.   Poor social awareness

<u>Apparent lack of awareness of unspoken rules about conforming to social norms and obligations</u>

The majority of children failed to constrain behaviour to maintain their reputation with others; apparently unaware their behaviour was inappropriate, or unable to apply this knowledge to modulate their ongoing behaviour. Several made personal comments (e.g. "She will tell someone if she thinks that they are fat, ugly, stupid and so on, or whisper rude remarks to me right in front of them"). Some played with toys in a way more

typical of a younger child (e.g. "She (aged 11) has an obsession with a toy dog, she dresses him, talks to him, takes him to school"). Several were able to act in public how others would expect, though this was sometimes perceived to be a "persona" rather than natural behaviour.

Poor awareness of their own place in the social hierarchy

A key theme was the child identifying themself as having adult status (e.g. "She doesn't like me to tell her off and will sometimes tell me off back in a very disrespectful way"). Several were domineering with unfamiliar adults (e.g. one had 'told' a friend's parent that it was alright for the friend to come for tea, even when the parent had already said no). The majority were insensitive to authority (e.g. "At one school, X was talking during assembly. When the head shouted at him, he just kept on talking, even though everyone else was shocked"). Three had been physically aggressive towards their head-teacher. Although they ignored rules, several insisted other children conform (e.g. "X is quite put out if she feels that someone is misbehaving or not doing what they should be doing, when in fact X is the worst culprit").

Makes no allowance for other's age or likely level of comprehension

Just as many of the children were reported to relate to adults without regard to normal social hierarchy, the children were often said to interact with much younger children in unusual ways. Several failed to realise that younger children have less developed understanding, and had tried to converse with toddlers or babies. Many parents were reluctant to leave their child unsupervised with a younger child: if the younger child didn't do as they wished, they wouldn't make allowances (e.g. "She reduced a 4 year old to tears by screaming at him because she didn't want to play his game"). Others tolerate younger children, who comply more readily with their overbearing orders.

Insensitive to others' emotions

The majority of children were said to be unconcerned or unaware when others were hurt or upset (e.g. "She doesn't seem to be aware that she actually hurts me when she is violent, and has no ability to control herself"). Several would laugh if someone hurt themselves, or became more demanding (e.g. "If someone was feeling ill or low, it seemed to be picked up by X and taken as a signal to behave with total lack of consideration – almost deliberately done to make the person feel worse"). Another behaved in a superficially caring manner, but on her terms, insisting this took on a role-play quality. One had always displayed concern if someone was upset – appearing to like the feeling of being helpful.

7. Others always to blame / sees others as hostile

<u>Blames other people irrationally when things go wrong</u>

All parents reported their child blamed others when things go wrong, even when it was their own fault. This frequently had an irrational quality, such as blaming younger siblings or parents for their own behaviour, or using elaborate justifications to blame people for events they were unconnected to. Targets of blame were often people they disliked (e.g. "People seem to blot their copy-book in her eyes and the positive feelings that she originally had for that person quickly turn sour"). Several perceived hostile intents in others; even believing that inanimate objects had done things to hurt them "on purpose" (e.g. if a car door swung shut on them). One child had paranoid thoughts, believing others to have injured him or got into his head and changed his memories. Another often felt he had been unfairly treated, but could get over this if he negotiated a treat.

<u>Limited sense of responsibility</u>

Parents were often very concerned about the limited sense of responsibility their child displayed ("Each bout of bad behaviour was totally justifiable to X – no remorse was shown whatsoever"). The majority felt they couldn't trust their child to tell the truth – instead they would get the truth "as she sees it". One failed to appreciate why she couldn't steal. Many tried to pass on the blame for their own bad behaviour to others, or denied things even when caught red handed. Several made false accusations ("She will make things up and tell tales to get her brother into trouble, and then wants me to tell him off in front of her").

8. Excessive fantasy engagement/ideation

<u>Over-engagement in role-play</u>

Role-play was common among participants, particularly the girls. Some re-enacted scenes from films or real events ("She has memorised large chunks of the scripts and will get very angry with people when they want to change the story"). Others made up their own stories, though for some, the same roles and scenarios were always repeated. Several took it beyond the normal limits (e.g. "X sometimes acts out the role of a maid and seems to take this too far. It drives her sister nuts as she does not understand why X does it"). Some really appeared to believe their soft toys were real, attributing feelings to them or insisting they were cared for like a real child. Parents reported that toys had occasionally been "useful allies": one child complied with demands delivered through her toy far more readily than directly from her parents.

<u>Social mimicry: takes on others' roles and styles</u>

Several adopted borrowed roles and personas. For some, styles were interwoven throughout their interactions with others (e.g. "There are many instances when she takes on the mannerisms of older people, babies and TV characters (e.g. mothering younger children, adopting a charming baby role)"). Some adopted cartoon-like personas, to the extent that their parents had to block certain channels (e.g. "She will copy "girlish" roles and pose and flutter her eyes at her mother"). Favoured borrowed expressions were often those used by adults to control younger children (e.g. "Her favourite is 'NO' with pointed finger as if a parent is saying no to a toddler").

<u>Tells tall tales</u>

In keeping with excessive fantasy engagement, several talked about things that never happened as if they were real events. In one child, this was particularly evident when she needed to compete for attention. A second elaborated on real events, so his fantasies were well disguised. If challenged, he would insist his version was correct. A third often relayed bizarre stories (e.g. "Once, she told a lady at swimming that she had just come back from America where she had spent the previous year, and that she had a social worker with a mechanical leg. The lady believed her").

Discussion

The present study provides an in-depth exploration of parent-reported characteristics of children exhibiting PDA features, all of whom had an average-range IQ. Main themes were: (1) Developmental history often characterised by passivity, (2) Early emergence of avoidance of demands and requests, resorting to violent outbursts if thwarted, (3) Frequent and varied use of social manipulation, (4) Controlling behaviour towards others, (5) Intense emotional lability, (6) Poor social awareness (e.g. of age and hierarchy), (7) Blaming others and (8) Excessive fantasy engagement or ideation.

The findings provide insight into the nature and depth of difficulties characteristic of this group, and the enormous burden their families manage. Severity of impairment is evidenced by the high rate of school exclusions from mainstream and specialist settings (see Appendix 5-1). Several reports suggest that standard reinforcement-based management approaches had been tried and had failed, in one case resulting in escalation of aggressive behaviour and the subsequent breakdown of the educational placement. Several parents reported difficulties having the nature of their child's difficulties recognised by professionals as not

merely arising from inadequate discipline, despite the clearly anomalous socio-cognitive features evidenced by their unusual social behaviour.

Notably, even in autism, behaviour can sometimes appear manipulative, when in fact the child is really using a learnt behaviour (e.g. setting off the fire alarm) to achieve a concrete goal (e.g. escape a situation), with no real intent to trick, deceive or control socially. In PDA, the nature of manipulative acts, frequency and flexibility of such behaviour, and the propensity to target specific individuals appear to suggest real manipulative intent. Indeed, the pattern of social insight and social difficulty presents a real clinical puzzle. On the one hand, Machiavellian manipulation implies good social insight. Yet these children also display a striking absence of embarrassment, lack a sense of the need to conform socially, and show difficulties judging their place in the social hierarchy. This could imply that, while most children with ASD show deficits in 'theory of mind', those with PDA have problems selectively impairing other aspects of socio-cognitive processing. Alternatively, children with this profile may have ToM impairments, but use what insight they have in a much more devious manner than most children with ASD without PDA features.

Given that only cooperative families who appear to provide supportive backgrounds were sampled, these observations suggest that the PDA profile can exist without preceding adversity (e.g. abusive home environments). However, parents in this sample did identify adverse experiences resulting from peer reactions and mishandling as exacerbating influences on behavioural problems. Effective management (e.g. flexible school environments with high staffing ratios) had led to improvements in behaviour for some.

Several limitations of this study should be acknowledged. First, the aim was to illustrate the range of profiles of children showing the PDA pattern in the normal ability range. This group was selected to include the most acute cases, and avoid ambiguous profiles. As such, it is difficult to determine how representative this group is of those displaying PDA characteristics in the wider population. Second, parents who took part in the study were highly motivated and had selected in to the study, so are unrepresentative of the general population. Third, the use of a semi-structured interview as the basis for data-gathering likely influenced the traits sampled and could have led to the omission of important co-occurring features.

To conclude, these findings illustrate and contextualise the nature of difficulties in children displaying the PDA pattern, providing concrete examples and parents' perspectives on factors that shape them. These insights could inform hypotheses about possible unique socio-cognitive substrates associated with PDA in future research.

Conflict of Interest

None.

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Appendix 5-1: Participant characteristics PDA interview study

ID	Age	School	Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Counts*	PDA specific Obs.	PDA traits	PDA/ unusual features
1	15.3	Excl. from MS	F	Asperger with complex presentation	89	15	0	15	11	7	18	Refused to engage; made snide comments. Extremely flat and lacking interest. Seemed passive. Refused to try many tasks.
2	11.8	MS	F	ASD, ADHD	99	10	0	10	8.5	0	8.5	Compliant but on edge. Voice extremely flat. No response to praise and little shared enjoyment. Unusual fantasy engagement
3	8.7	MS	M	ASD, PDA, ADHD, dyspraxia	96	16	2	18	5.5	5	10.5	Excuses, requests, nonsensical comments, slow compliance. Cartoon-like mannerisms. Appeared to consider answers carefully but then failed to respond.
4	8.8	Excl. from MS with 1:1	M	ASD, ODD, Anxiety, sensory	123	5	2	7	7	6	13	Mostly compliant but ignored some requests. Engaged and happy talking about own interests. Anxious at other times and became more agitated during session.
5	13.6	Excl. from ASD	M	ASD ADHD, tourettes	90	20	2	22	9.5	8	17.5	Hid face throughout, refused some tasks and all questions about friends, experiences or emotions. Became angry when asked.
6	9.9	MS	F	ASD	117	7	3	10	10	10	20	Compliant but domineering and authoritative. Adopted baby-voice and over-dramatic mannerisms. Sometimes more serious and age appropriate.
7	9.1	MS	F	ASD	139	9	1	10	4.5	6	10.5	Adopted baby voice and cute mannerisms, appeared younger and less able than she is. Procrastinated over answering questions and then responded "I don't know".

ID	Age	School	Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Counts*	PDA specific Obs.	PDA traits	PDA/ unusual features
8	8.3	MS with 1:1	F	ASD	99	15	0	15	11	10	21	Refused to engage and made snide comments, broke wind, left the session. Requests delivered by a toy were more acceptable.
9	12.1	SEBD	M	ASD, PDA	103	18	2	20	9	4	13	Extremely passive - no enjoyment or interest. Made excuses or said he didn't know the answer. Very poor engagement.
10	9.6	Steiner (excl. from PRU)	F	ASD, ADHD	100	6	4	10	9	16	25	Initially refused to participate; then agreed, but volatile and impetuous. Very domineering. Tasks had to catch her interest or she would leave. Said shocking things.
11	10.6	MS	F	Attachment disorder	78	1	0	1	11	3	14	Appeared compliant and engaged, though sometimes diverted conversation. Voice very flat and limited enjoyment.
12	13.7	ASD/ SEBD	M	ASD	80	9	4	13	6.5	13	19.5	Extremely controlling and volatile. Got too close, said shocking things, but could be polite. Complied with tasks after period of controlling conversation.
13	9.3	ASD/ SLD	F	ASD, PDA, ADHD	94	8	2	10	9	5	14	Mostly compliant. Very babyish at times, said shocking things, mimicked experimenter, distracted.
14	14.4	ASD	M	ASD	N/A	NA	NA	NA	6	NA	NA	Had a meltdown and hid under table - unable to complete testing.

Note. ADOS = Autism Diagnostic Observational Schedule; RRBI= rigid and repetitive behaviours and interests. MS = mainstream school; PRU = pupil referral unit; SEBD = specialist school for social, emotional and behavioural difficulties; MLD = specialist school for moderate learning difficulties; SLD = specialist school for severe learning difficulties; ODD= oppositional defiant disorder.

For details of measures (EDA-Q counts, PDA specific obs., PDA traits) and observational protocol/ coding, see Chapter 8.

1. Obsessively resists and avoids ordinary demands, led by need to control

How did things go when A started nursery/ school?

Does A strongly resist attempts to make him or her do things, or change his or her behaviour? What sorts of requests does A avoid?

Does everything have to be on his/ her terms? What happens if you push A to comply or accept limits?

Does A dislike praise?

2. Socially manipulative behaviour to avoid demands

Would you describe A as good at getting round others and making them do as s/he wants, or playing people off against each other?

What strategies does A use to get out of things? Are these strategies targeted at a particular person?

(e.g. Distracting (e.g. asking questions); Apologising and making excuses; Withdrawing into role play or toy play; Charm; Passively (e.g. selective mutism); Other).

3. Takes control of the conversation through repetitive questioning/ interrupting

Does A interrupt conversations to get attention or to take control? If attention is not paid to A, how does s/he react?

How does A do this? (e.g. repeatedly asking questions, make statements to provoke parents attention).

4. Lacks awareness/ is not concerned about age group or social hierarchy

Does A seem to have a sense of the "pecking order" – that adults can tell children what to do? Or does A treat everyone the same, seeing no difference between himself and adults/ authority figures?

Does A tell other children how they should behave, but does not feel these rules apply to him/herself?

Does A see him/herself as a child?

5. Difficulties interacting with peers- bossy and domineering

Does A have friends who he/she enjoys spending time with?

How does she interact with her friends/ peers? (e.g. bossy/ controlling, play with them or using them as aids in own activities)

What do peers think of A?

6. Little shame/ embarrassment and bizarre/ embarrassing remarks in public

Does A behave in ways that other people would find embarrassing or shameful in public? (e.g. wetting him/herself, removing clothes in public, screaming through a school play)?

Does A make embarrassing personal remarks, or say bizarre things in public? (e.g. asking strangers inappropriate questions or swearing at them, commenting on others' physical peculiarities)

Is A aware this behaviour is inappropriate or babyish?

7. Sense of responsibility to others/ social obligation

Can you appeal to A's "better nature" to persuade him or her to do things?

Does A have a sense of obligation towards others (e.g. will stick to a bargain; is nice to friends who come to visit?)

Can you trust A to tell the truth?

8. Difficulties with peers and siblings

Does A frequently tease, bully, refuse to take turns, make trouble?

9. Socially shocking behaviour with deliberate intent

Does A shock other people by unexpectedly inappropriate actions, for no apparent reason? What does A do?

Does A ever threaten to hurt him/herself, or do things to hurt him/herself?

Is this behaviour impulsive, or does A do it on purpose to show s/he is in control, cause distress or get attention?

10. Blames others inappropriately/ makes false accusations

Does A blame other people when things go wrong?

Does this have an irrational and obsessional quality?

Does A accuse people of things they haven't done?

11. Behaviour towards younger children and pets

Can you rely on A always to be kind to younger children and pets?

Would you be happy to leave A alone with a younger child (e.g. let him/her babysit), knowing that s/he would be kind?

12. Emotional response to others' distress

Does A react inappropriately to others' emotions (e.g. becoming excited when someone is upset, failing to react at all?).

13. Changeable mood/ extreme emotional responses

Does A have frequent marked swings of mood for no obvious reason, or in response to minor things?

Do switches in mood lack an "emotional legacy" – changing suddenly from one mood to the next?

14. Rapid, inexplicable changes from loving to aggression

Does A slip from loving to violent or aggressive behaviour (or vice versa) for no apparent reason?

Does A seem to display affection in an aggressive way (e.g. squeezing someone too hard; digging their nails in whilst holding hands).

15. Laughs or becomes "silly" or over-excited for no reason

Does A ever laugh for no reason? Is this laughter unusual?

Does A ever seem to get "high" or extremely over-excited, and if so, what brings this on?

16. Role play/ imaginative play – lives the part, not the usual pretence

Does A act out the role of an object, animal, fictional person or real person, so that A seems to become the acted role- it is not just pretence? If not role play, imaginative play?

Are these new or embellished stories, or just copied exactly from TV or films?

Is this a major part of A's play/ unusual for someone of their age?

Is it difficult for A to come back to reality?

17. Social mimicry

Does A mimic adult mannerisms and styles from people s/he knows, computer games or tv (e.g. uses phrases adopted from teacher/parent to tell other children off)?

Uses over-animated facial expressions, possibly practising these in front of a mirror?

18. Fantasises, tells tall tales

Tells tall tales in a way that is inappropriate for their age

Does A talk about fantasies as if real?

19. Communicates indirectly (e.g. through doll, props, picture cards, puppet, toy animal, or as a persona)

Does A use a doll, puppet or object to communicate needs?

Does A seem more comfortable communicating indirectly (e.g. using picture cards instead of speaking; having adopted a role)?

20. Obsessed with a particular person, real or fictional

Is A obsessed with a person, real or fictional; or have over-intense friendships with others?

Does A behave in inappropriate ways towards this person, perhaps causing them distress? (A may display love or hatred towards this person).

21. Unusually quiet & passive in infancy; hands limp for unwelcome tasks

Was A an exceptionally good baby compared to others of the same age? Did you feel "I did not know I had a baby in the house"?

Was A very passive (e.g. reluctant to crawl; dropped objects placed in his/her hands, and did not reach for them)? Did it seem as though nothing was worth the bother for A?

Was A 'floppy' or limp as a baby?

Was A content to watch other children play - observing rather than joining in?

Did A become more actively resistant over time?

22. Language delay

Were you concerned about your child starting to talk later than others born around the same time?

Once s/he had started talking, did s/he seem to catch up very rapidly?

23. Other concerns

Do you have any other concerns about aspects of your child's behaviour not covered in this questionnaire?