

PATHOLOGICAL DEMAND AVOIDANCE SYNDROME: A NECESSARY DISTINCTION WITHIN THE PERVERSIVE DEVELOPMENTAL DISORDERS
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Supporting information

THE CONTEXT OF PDA

As indicated in the above paper, PDA is seen as a specific pervasive developmental disorder, ie one part of the 'PDD family' which also includes autism and therefore the Asperger syndrome which is a special case of autism. It is useful to describe Asperger syndrome and classic autism together as forming the autistic spectrum; but in our view it is not useful to use 'autistic spectrum disorders' as synonymous with 'pervasive developmental disorders', as has become more prevalent lately in the UK. 'Pervasive developmental disorders' is the entirely satisfactory term of DSM-IV, in which each word has a relevant meaning to describe the nature of this 'family'; it is acceptable to parent groups in the United States and Canada, and it is easily understandable when explained to parents in the UK, where lately it has been increasingly used by such groups. PDA is a pervasive developmental disorder but not an autistic spectrum disorder: to describe it as such would be like describing every person in a family by the name of one of its members. It is proposed as giving 'specific' status to those children (and adults) who would earlier by default have been diagnosed as having 'pervasive developmental disorder not otherwise specified' (DSM-IV) but who are now seen to meet the evidential criteria for PDA.

It is helpful to conceptualise the pervasive developmental disorders as **clusters of symptoms** which have a tendency to occur together, ie to form **syndromes**. Classical autism and Asperger syndrome form two closely related clusters; PDA is another. There are inevitably family links between them: for instance, both show obsessive behaviour or preoccupations, although of different kinds. Preliminary enquiry also suggests genetic links (eg autistic sibs

of PDA children in perhaps 5% or more of cases). The conceptualisation of clusters within an overall family also suggests an occasional clinical picture falling between clusters in an atypical way; and this, of course, is already recognised in DSM-IV's PDD nos (1)- which itself is much more rare once we recognise PDA as an entity in itself. Some of these in-between children will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.

It is also helpful to realise that in every case of pervasive developmental disorder, the child or adult has difficulty in **coding** or **making sense of** a particular area of communicative life where we usually regard 'making sense' as biologically normal. This is not necessarily in terms of spoken language, but may be about the non-verbal ways in which we understand each other, such as **body language, personal meanings and intentions** (autism/Asperger), or **identity and obligation** (PDA).

Figure 1 in the paper sets PDA in the context of the family of pervasive developmental disorders. It offers enough information to trigger a differential recognition process for parents and for professionals in medicine, psychology and education. Obviously it needs to be enlarged upon by a much more extensive clinical description, which appears in the paper as Table 1, in the form of a list of 'defining criteria for PDA', and includes brief examples of the varied ways in which these may manifest themselves. Clearly no child will show all the behavioural examples listed, any more than all autistic children show the whole repertoire of autistic behaviours; but every child with clear-cut PDA will manifest the overall complex pattern, not merely one or two features. This is important in differentiating from Asperger or ADHD children; for instance, the objection that 'We all know an Asperger child who does this' cannot be sustained when we are referring to such a complete pattern.

DISCRIMINANT FUNCTIONS ANALYSIS

We mentioned in the paper that a discriminant functions analysis was carried out (4, 9) to test whether the proposed entity of PDA was significantly different from classic autism and Asperger syndrome, tested both separately and together. This study was based on three random samples drawn from files of children diagnosed between November 1987 and February 1996: 50 children with a clear-cut diagnosis of PDA, 20 with classic autism and 20 with Asperger syndrome. A standardised data collection form was used to collect information from the original diagnostic assessment reports, and data points were analysed using Microsoft Excel 4.0 and SPSS 4.0 packages. Inter-rater reliability testing was provided by an independent psychologist, Caroline Fleming. The comparative data presented below demonstrates the essential significant differences between PDA and the two autistic disorders that tend to be taken as paradigmatic of the pervasive developmental disorders.

The histogram (Table 1) shows comparisons of the three groups for ten variables found to be discriminant, other than demand avoidance. With hindsight, one would wish to look separately at the components of some of these variables, notably the various role play aspects of symbolic play.

Social manipulation can be seen as especially discriminant, as is excessive lability of mood. Mannerisms are much less common in PDA than in Asperger's or autism, and Asperger children use more repetitive language than PDA children, while PDA children show better catch-up speech. It is interesting that although PDA children do often show a brief period of echoing, they show less pronoun reversal than either autistic or Asperger children. While Asperger children have much more symbolic play than classically autistic children, they have significantly less than PDA children, despite a greater overall functional ability level by definition. The significant gender difference is obvious.

Table 2 shows a comparison between PDA children and autistic/Asperger children together (autistic spectrum), using crosstabs data plus data from the discriminant functions analysis; these differences are all highly significant, p being less than or equal to 0.001 in all cases.

TABLE 1

Histogram comparing the three groups for ten variables found to be discriminant

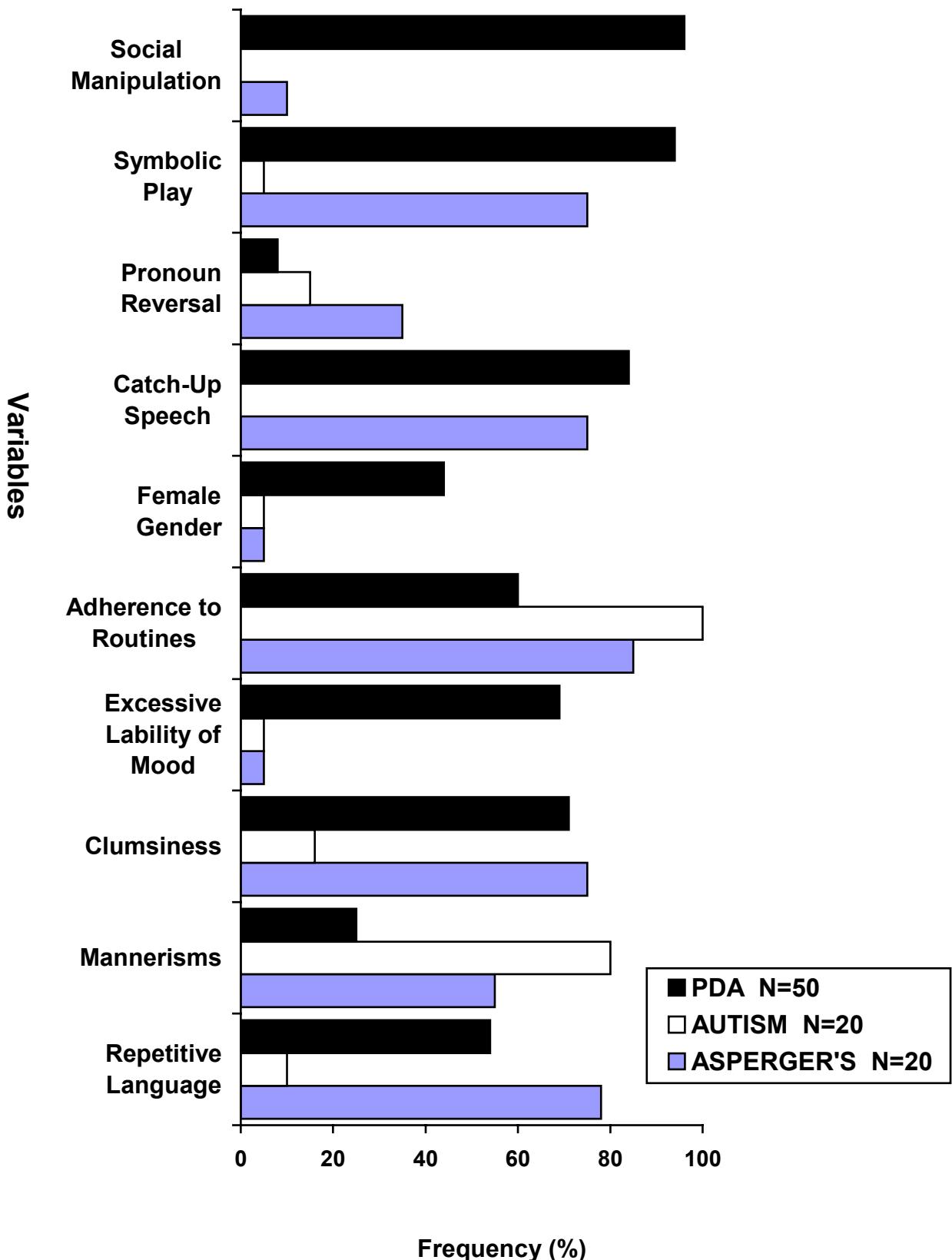


TABLE 2

COMPARING PDA CHILDREN WITH AUTISTIC/ASPERGER CHILDREN TOGETHER

(using crosstabs data plus data from discriminant functions analysis; p less than or equal to 0.001 in all cases)

PDA children are LESS likely:

-to have caused anxiety to parents before 18 months of age
-to show stereotypical motor mannerisms
-to show (or have shown) non-social echolalia
-to show speech anomalies in terms of pragmatics
-to show (or have shown) tiptoe walking
-to show compulsive adherence to routines

PDA children are MORE likely:

-to be female
-to resist demands obsessively (100%)
-to be socially manipulative (100% by age six)
-to show normal eye contact
-to show excessive lability of mood
-to show social mimicry (includes gestures and personal style)
-to show role play (more extended and complete than mimicry)
-to show other types of symbolic play

EDUCATION AND HANDLING

Given that children with PDA resist the demand that they be educated, along with other demands, it is predictable that they will be more difficult to educate to their ‘potential’ even than autistic children, and certainly more difficult than Asperger children. For most children with PDA, the avoidance strategies already discussed come into play; and because they are seen as more sociable, they may also be seen as naughty and disruptive at first, rather than as vulnerable and painfully sensitive. The child cannot help her need to avoid demands, but her apparently robust resistance can make teachers determined to control her behaviour, despite their rapid experience that confrontation is not effective.

The Guidelines that have been worked out, which have relevance for both teachers and parents, are based on the experiences of both (8). While autistic/Asperger children are helped by rules, routine and consistency, children with PDA need variety, flexibility and novelty. A central principle is that ‘what works today may not work tomorrow, but it might work in a week’s time’: the child recognises strategies once they have worked, and avoids them determinedly on the next occasion, so that it is necessary to have ready a whole repertoire of different ideas, and to adapt them wherever necessary. A keyworker approach, helpful for autistic children, is especially necessary for PDA children, who respond to a personal relationship but also will test this to extremes; the child is helped by knowing her keyworker’s limits, while the keyworker needs an intimate knowledge of the child’s own range of strategies and how to get around them.

An indirect approach is the most effective; the keyworker needs to disguise the extent of the demand made, often using language to do this. For instance, where we would simplify language with an autistic child, often a much more complex sentence will camouflage a demand for a PDA child: ‘I wonder whether it would be a good idea if we....’ tends to be more effective than ‘Do this for me please’. Similarly, it is almost always better to reduce the pressure on a primary-age child by spreading the load among a number of participants: allowing the child to show dolls, toy animals or puppets how to do the task, rather than asking him to do it.

A heavy amount of time needs to be invested in monitoring whether learning has actually taken place; some children learn an apparently amenable manner for the classroom, which can mask a ‘switching off’ of real attention, described by some teachers as ‘switching off her brain as she walks in the door’. One child who was making no progress at 13 was found not

to understand what she read, despite her teachers' impression of her attentiveness. The more disruptive children may well need full-time 1:1 staffing if they are both to access the curriculum and allow other children to do so.

These are exceptionally challenging children to teach, needing massive support; but they are also exceptionally interesting for a teacher who likes to be kept on her toes and has the necessary sense of humour, patience, creativity and flexibility. It is also observable that a teacher with a certain amount of charisma is likely to be the most successful, since the child's own interest has to be re-earned on a daily basis. The guidelines certainly seem to have some success (some have described them as 'a lifeline' or as having 'turned the child around'), but it is recognised that they are not easy for some schools to put into practice, since they need commitment to the child's inclusion and a readiness to adapt very considerably indeed. Anecdotally, it seems that children with PDA have a higher rate of exclusion (from specialist schools as well as mainstream) than do autistic children; it would be useful to investigate such exclusions, and to know the conditions under which they occur (and what happens to the children involved, who can be very difficult to get back into school).

These guidelines, currently the subject of further research, are available in much more extended form on the PDA contact website <http://www.pdacontact.org.uk> or from the correspondent.