

Extreme (“pathological”) demand avoidance in autism: a general population study in the Faroe Islands

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Abstract Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexistent in spite of the frequent reference to the condition in clinical practice. The total population of 15 to 24-year-olds in the Faroe Islands was screened for ASD, and 67 individuals were identified who met diagnostic criteria for ASD (corresponding to a general population prevalence of ASD of almost 1 %). Of these 67, 50 had parents who were interviewed using the Diagnostic Interview for Social and Communication Disorders (DISCO-11) which contains 15 “PDA-specific” items. Nine individuals met criteria for “possible clinical diagnosis of PDA”, meaning that almost one in five of all with ASD also had indications of having had PDA in childhood, and that 0.18 % of the total population had had the combination of ASD and PDA. However, at the time of assessment, only one of the 9 individuals with possible PDA

still met “full criteria”. PDA possibly constitutes a considerable minority of all cases with ASD diagnosed in childhood, but criteria for the condition are unlikely to be still met in later adolescence and early adult life.

Keywords Pathological demand avoidance · Extreme demand avoidance · Autism spectrum disorder · Population study · Faroe Islands · Prevalence · Gender

Introduction

In 1980, Elisabeth Newson, in a speech to the East Midland Section of the British Paediatric Society, presented the first twelve cases of what she believed to be a “new” and separate syndrome and that she referred to as Pathological Demand Avoidance (PDA). Even though PDA has attracted clinical attention in the UK and other parts of Europe, with the exception of two papers e-published in late 2013 [9, 10], virtually no research has been published in the field so far [5].

PDA is said [5] to be characterised by (1) a passive early history in the first year of life, (2) extreme resistance to and avoidance of virtually all everyday life demands (using strategies that appear to be socially manipulative), (3) apparent lack of a sense of social identity, pride or shame, (4) lability of mood and impulsivity, led by the need to be in control, (5) appearing comfortable in role playing and pretend play, (6) language delay (proposed by Newson to be a result of passivity), (7) obsessive behaviour (not least shown in all aspects of demand avoidance), and (8) “neurological involvement” (as evidenced by clumsiness, soft signs, or, more rarely epilepsy or fits). There is no agreed algorithm as to the level of symptoms at which a definitive “diagnosis” of PDA is supposed to be made.

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In spite of the almost complete lack of scientific study of the condition, there has been considerable dispute and debate as to whether or not PDA should be regarded as a variant of autism spectrum disorders (ASDs). The resistance typical of PDA (which could be construed as resistance to change/insistence on sameness), the obsessive behaviour, some of the social impairment problems, the language delay and the “neurological involvement” are all also typical/common in ASD. However, the apparently socially manipulative behaviour is not characteristic of ASD, and is, in fact, by some, considered to be an exclusionary criterion for a diagnosis of ASD. Wing et al. [18] suggested that PDA might be a “double hit”, that PDA is an additional problem in ASD but not due to ASD. Related to this, in another study, it was shown in a small group of boys with ASD who also had psychopathic tendencies [12].

There has been no previous study of the prevalence of PDA in the general population. We recently conducted a total population study of ASD in the Faroe Islands [6]. In that study we covered all the symptoms of PDA in an interview with a parent of individuals suspected of suffering from ASD. We therefore decided that these data would provide a good opportunity to get a handle on the prevalence of PDA (or, at least, PDA symptoms) in the general population of individuals with a diagnosis of ASD.

Methods

The Faroe Islands autism general population study

The whole Faroese population of individuals born in the years from 1985 to 1994 has been screened twice for ASD, once in 2002, and then again in 2009 [1, 6]. In brief, all individuals in the age group were screened, using the Autism Spectrum Screening Questionnaire (ASSQ) [2], in school, hospital and clinic register. Forty-three individuals with ASD were found and diagnosed in the first screening (at age 7–16 years), and another 24 in the second (at ages 15–24 years). Thus, in total, there were 67 individual (49 males/18 females) with ASD identified at the time of the latter screening. Children/adolescents/young adults who screened positive were clinically examined by an experienced clinical psychologist in depth, including face-to-face interviews with the proband and one or both parents. The parent interview included the DISCO (see below). The diagnostic evaluation for each participant was then discussed with one member of the research group. Our final PDA decision was not only based on PDA item from DISCO but also from the general impression of how the avoiding demands was or had been frequent in the participant.

Table 1 DISCO-11 items targeting PDA: the DISCO-11 PDA scale

DISCO item and corresponding PDA symptom area	Variable name
Unusually quiet and passive in infancy (1)	UQUIET
Clumsy in gross movements (8)	CCLUMSY
Communicates through doll, puppet, toy animal etc. (5)	CDOLL
Lacks awareness of age group, social hierarchy etc. (3)	CIDENT
Rapid inexplicable changes from loving to aggression (4)	CINAPP
Uses peers as ‘mechanical aids’; bossy and domineering (3) and (4)	CPEERAD
Repetitive role play—lives the part, not usual pretence (5) and (7)	CTROL
Hands seem limp and weak for unwelcome tasks (8)	CNOHAND
Repetitive questioning (7)	QUESREP
Obsessed with a person, real or fiction (7)	PERS
Blames others for own misdeeds (3)	BLAME
Harasses another person—may like or dislike them (3) and (7)	HARAS
Socially manipulative behaviour to avoid demands (2)	MANBEH
Socially shocking behaviour with deliberate intent (2) and (3)	SHOCK
Lies, cheats, steals, fantasises, causing distress to others (3) and (7)	LYING

Figures in brackets—(1) through (8)—refer to the eight defining characteristics of Newson’s PDA

Diagnostic Interview for Social and Communication Disorders (The DISCO)

The DISCO (Diagnostic Interview for Social and Communication Disorders) is an investigator-based interview for diagnosis within the autism spectrum. It was developed by Lorna Wing and Judith Gould from the Children’s Handicaps, Behaviours and Skills schedule (HBS) [15] long before the currently most used autism diagnostic interview, the ADI-R (Autism Diagnostic Interview-Revised) [8]. This interview—aimed for use with someone who knew the individual well when he was young (most often one of the parents)—has been continually updated over the years. The versions currently most used are the DISCO-10 [16] and the DISCO-11 [17]. The DISCO covers a wide variety of problems relevant to the diagnosis of ASD and related disorders, and it includes algorithms (based on specified DISCO items) for a number of named subgroups subsumed under the broad ASD umbrella. There are detailed algorithms for childhood autism, atypical autism, Asperger syndrome according to ICD-10, Asperger syndrome according to Gillberg and Gillberg, and for social impairment according to Wing and Gould. The DISCO includes a separate category of PDA and specifies a number of symptoms considered by the DISCO originators to cover that phenotype (see Table 1). The 15 PDA items from the DISCO-10 will be referred to in this context as the DISCO-11 PDA scale.

As can be gleaned from Table 1 there is only one of Newson's original PDA criteria that is not covered by these items, viz. language delay. Language delay is a separate item in the DISCO-11, not grouped with the 15 PDA items in the interview, and data on language delay will be presented separately in the "Results" section.

Diagnostic groups for PDA study

Fifty (36 males, 14 females) of the 67 individuals with ASD had a DISCO-11 interview (at follow-up), and of these, 12 had autistic disorder, 14 had atypical autism/PDDNOS, and 24 had Asperger syndrome. Half of the Asperger group was identified only at the second screening. Of those with autistic disorder, 9 had severe intellectual developmental disability (IDD) defined as having an IQ score below 50 (they were all those with severe IDD in the study). Those with severe IDD were excluded from some of the analyses regarding the rate of PDA in subgroups, given that it is difficult to envisage the whole PDA phenotype developing in an individual with severe or profound general cognitive dysfunction. The individuals for whom a DISCO-11 interview was obtained were 15–24 years at the time of assessment (mean 19.1 years; SD 2.6 years).

IQ levels

Wechsler Intelligence Scales for Children (WISC-R or WISC-III) [13] or the Wechsler Adult Intelligence Scale-Revised (WAIS-R) [14] (in individuals over the age of 16 years) were used to obtain IQ levels, WISC in the majority of cases at screening 1 and WAIS-R at screening 2. Those who were not tested at screening 1 were tested at screening 2. IQ sub-categories were defined as follows: SMR = IQ 20–50, MMR = IQ 51–70, NA = IQ 71–85, A = IQ > 85.

Statistical analyses

This is a descriptive study and simple descriptive statistics will be used throughout. The items on the DISCO-11 PDA scale will be referred to as symptoms if endorsed at interview. Individual PDA symptoms will be reported as proportions of groups and subgroups affected. A collapsed Total PDA—score summing all (out of the 15) symptoms endorsed (range 0–15 in any given individual)—will also be reported. Individuals with a Total PDA score of 5 or more were—based on clinical experience, not on systematic evidence—considered High-scorers, suggesting that in clinical practice they would have been given a diagnosis of PDA. "Classic PDA" was defined as Total PDA score of 5 or more and including the presence of socially manipulative or shocking behaviour to avoid demands.

Groups will be compared using Chi square tests (with Yates's correction whenever appropriate). Mann–Whitney *U* test was used to test differences regarding IQ sub-categories in the PDA group versus non-PDA group.

Ethics

The study was approved by the Medical Ethics Committee of the Faroe Islands. All individuals involved in the study provided informed consent. Some of the young adult individuals with ASD did not want their parents to be interviewed, and, in other cases, parents were reluctant to do a whole DISCO interview again (seeing as they had often been interviewed in accordance with this long interview several years ago).

Results

Prevalence of PDA and classic PDA

Nine individuals (5 males, 4 females) were High-scorers and had a Total PDA score of 5 or more on the DISCO-11 (ever or currently) indicating a possible clinical Diagnosis of PDA (Table 2). Two of these nine had severe IDD (18 % of the whole DISCO-rated High-scorer group). Given that the prevalence of ASD in the cohort was 0.94 % [6], the prevalence of PDA with ASD in the general population of the Faroe Islands was, at least 0.13 % (95 % CI 0.07 %, 0.24 %). When the prevalence estimate was based on the proportion of the DISCO-interviewed group rather than on actual "counted cases", the rate was 0.18 % (95 % CI 0.01 %, 0.3 %).

Socially manipulative or shocking behaviour to avoid demands

Six of the 50 individuals with ASD who had a DISCO interview had "ever" shown socially manipulative or shocking behaviour to avoid demands (regardless of whether or not they were High-scorers). Three of these were reported to still show such behaviour in late teenage/young adult age.

Three of the nine individuals with PDA had Asperger syndrome, three had atypical autism, and three had a diagnosis of autistic disorder. Only two of the high-scoring group showed socially manipulative or shocking behaviour to avoid demands. This small "group" (one male, one female), with the "classic" PDA phenotype, corresponded to 4 % of the whole DISCO-rated group with ASD, and a general population rate of Classic PDA with ASD of 0.04 %.

Only 11 individuals (22 % of the ASD group with a DISCO-11 interview) had no PDA DISCO-11 item

Table 2 Characteristics in ASD group having 5 or more DISCO PDA symptoms

Sex	IQ	Language delay yes/no	PDA characteristics according to DISCO
Male	NAIQ	Yes	Clumsy gross movements. Lacks awareness of age group, social hierarchy. Rapid inexplicable changes from loving to aggression. Uses peers as 'mechanical aids'. Repetitive role play. Hands seem limp and weak for unwelcome tasks. Repetitive questioning. Socially manipulative behaviour to avoid demands
Male	AIQ	Yes	Clumsy gross movements. Lacks awareness of age group, social hierarchy. Uses peers as 'mechanical aids'. Repetitive role play. Obsessed with a person, real or fiction
Male	MMR	Yes	Unusually quiet and passive in infancy. Clumsy gross movements. Lacks awareness of age group, social hierarchy. Repetitive role play. Repetitive questioning. Obsessed with a person, real or fiction
Female	NAIQ	Yes	Unusually quiet and passive in infancy. Clumsy gross movements. Lacks awareness of age group, social hierarchy. Rapid inexplicable changes from loving to aggression. Repetitive role play
Female	SMR	Yes	Clumsy gross movements. Lacks awareness of age group, social hierarchy. Rapid inexplicable changes from loving to aggression. Uses peers as 'mechanical aids'. Repetitive role play. Hands seem limp and weak for unwelcome tasks
Female	MMR	No	Unusually quiet and passive in infancy. Clumsy gross movements. Lacks awareness of age group, social hierarchy. Rapid inexplicable changes from loving to aggression. Repetitive role play. Repetitive questioning. Socially shocking behaviour with deliberate intent
Male	SMR	Yes	Unusually quiet and passive in infancy. Lacks awareness of age group, social hierarchy. Rapid inexplicable changes from loving to aggression. Uses peers as 'mechanical aids'. Socially manipulative behaviour to avoid demands. Lies, cheats, steals, fantasises, causing distress to others
Male	MMR	Yes	Clumsy gross movements. Lacks awareness of age group, social hierarchy. Rapid inexplicable changes from loving to aggression. Uses peers as 'mechanical aids'. Repetitive role play. Repetitive questioning
Female	NEAR AVERAGE IQ	No	Unusually quiet and passive in infancy. Clumsy gross movements. Rapid inexplicable changes from loving to aggression. Repetitive role play. Hands seem limp and weak for unwelcome tasks. Repetitive questioning

AIQ average IQ, *NAIQ* near average IQ, *MMR* mild mental retardation, *SMR* severe mental retardation

endorsed ever. Twenty of the 50 (40 %) DISCO-11-rated individuals had no current PDA symptom endorsed.

Language delay

Seven of the nine individuals in the PDA group had language delay. However, no differences in prevalence regarding language delay (late onset of meaningful words or late onset of combining 2–3 words in communicative utterances) were found between the PDA group and non-PDA groups.

Individual PDA items endorsed

The three most frequent PDA symptoms in the PDA group were (1) clumsiness, (2) rapid inexplicable changes from loving to aggression, and (3) repetitive role play, affecting 8 of 9 in the PDA group (Table 3). Seven were reported to (4) lack awareness of age group, social hierarchy, etc. and 6 were described as (5) using peers as 'mechanical aids', and (6) being bossy and domineering. Being (7) unusually

quiet and passive in infancy and engaging in (8) repetitive questioning were also common in the PDA group, affecting 5 of 9. All these symptoms were very much more common in the PDA group than in the non-PDA group (significance levels between .001 and .016). Only two individuals in the total study group of 50 were reported to be/or have been obsessed with a person, real or fiction. Both of these belonged in the PDA group.

Gender aspects

The male:female ratio in the PDA group was 1.3:1, whereas in the non-PDA DISCO-11-interviewed group it was 3.1:1. The difference between the two groups did not reach statistical significance, but this, possibly, could be due to small numbers.

IQ aspects

IQ was found to be lower in the PDA group than in the non-PDA group (mean rank 16.8 versus 27.4, $p = .035$).

Table 3 Frequency of PDA symptoms in the PDA group compared to the non-PDA group

PDA symptoms	PDA group <i>n</i> = (%)	Non-PDA group <i>n</i> = (%)	<i>p</i> level
Unusually quiet and passive in infancy	5 (56)	10 (24)	.016
Clumsy in gross movements	8 (89)	10 (24)	.001
Communicates through doll, puppet, toy animal, etc.	0 (0)	0 (0)	1.0
Lacks awareness of age group, social hierarchy, etc.	7 (78)	10 (24)	.004
Rapid inexplicable changes from loving to aggression	8 (89)	10 (24)	.001
Uses peers as ‘mechanical aids’; bossy and domineering	6 (67)	9 (22)	.015
Repetitive role play—lives the part, not usual pretence	8 (89)	12 (30)	.002
Hands seem limp and weak for unwelcome tasks	3 (33)	5 (12)	.144
Repetitive questioning	5 (56)	3 (7)	.003
Obsessed with a person, real or fiction	2 (22)	0 (0)	.029
Blames others for own misdeeds	0 (0)	1 (2)	1.0
Harasses another person—may like or dislike them	0 (0)	1 (2)	1.0
Socially manipulative behaviour to avoid demands	2 (22)	1 (2)	.083
Socially shocking behaviour with deliberate intent	0 (0)	1 (2)	1.0
Lies, cheats, steals, fantasises, causing distress to others	1 (11)	1 (2)	.331

Discussion

This first ever general population study of the prevalence of PDA/PDA symptoms indicated that PDA with ASD is present in slightly under 0.2 % of adolescents/adults in the Faroe Islands, and that the narrow PDA phenotype characterised by socially manipulative or shocking behaviour to avoid demands affects only about one in five of this group. The study also indicated that the majority of individuals with ASD have (or have had in the past) one or several of the 15 symptoms listed that are considered characteristic of PDA. The study provides no information about the prevalence of PDA in the general population without ASD, meaning that the rate reported here must be an absolute minimum. However, clinical experience suggests that the condition is much less common in the general population than in ASD. Nevertheless, it is possible, albeit not probable (again based on clinical experience) that the phenotype could be present in up to a few per cent of non-ASD populations (particularly in those with other disorders subsumed under the acronym of ESSENCE [3]), meaning that the condition might not be extremely rare.

It has been suggested that PDA is showing a fairly balanced gender distribution [5] and that this is one of three aspects that does not fit within the ASD “family” of disorders [9]. The other two aspects are: responding better to spontaneity and humour, and a preoccupation with role play and fantasy, features that tend—on a group-wise level—to separate PDA from ASD. Our results support this idea, showing a more even gender ratio in the PDA group.

In our study, several of the individual PDA reported symptoms occurred together (motor clumsiness, unaware of social hierarchy, love–aggression swings,

bossy-domineering and repetitive role play), and more than half of the PDA items were significantly more prevalent in the PDA group than in the non-PDA group. This supports the notion of PDA as a more valid clinical condition than just a mere collection of ad hoc lumped-problems.

Our study cannot resolve whether or not PDA might be just another subgroup within the ASD group of disorders, a condition commonly coexisting with other disorders, or a “discrete” disorder in its own right. Our results show that PDA does coexist with ASD in a considerable minority of cases, but we know, from clinical experience, that PDA characteristics can also be identified in other conditions including language disorder and epilepsy (Reilly [9], in progress). Selective mutism [7] is a not-extremely-uncommon condition (actually with a similar prevalence as we have found for PDA with ASD) that usually presents in pre-school to school-age children who avoid (in an extreme fashion) talking to unfamiliar persons. Individuals with selective mutism show the same stubbornness and intensity that the PDA group does. Also, many experienced clinicians in the field of selective mutism, have proposed that selective mutism often coexists with autism.

Indirectly, results from our study suggest that PDA in the context of ASD might have a relatively good outcome, given that of the nine indications of a diagnosis of PDA, only one still reported to have sufficient remaining symptoms at age 15–24 years to “qualify” for such a diagnosis.

There are also some similarities between PDA and ADHD with or without oppositional defiant disorder (ODD)/conduct disorder (CD). However, whereas children with PDA often fail in terms of friendship with peers and are viewed as odd and frightening to others, children with ODD and CD are usually motivated to maintain a

good reputation with peers and to conform to peer norms [9, 10]. In a recently published study, children with PDA were compared to children with ASD and to children with conduct problems (CD) and callous unemotional traits [9, 10]. The authors reported that the PDA group displayed comparable levels of autistic traits as the ASD group and comparable levels of antisocial traits as those seen in the CD group. However, there were more emotional problems reported in the PDA group compared to the ASD group and the CD group.

These similarities and differences between PDA and other conditions emphasise the need for recognising this group of children (and probably also adults) who are extremely demand avoidant. A convincing argument for this term—or, perhaps more operationally correct “extreme demand avoidance (EDA)” [4, 10]—is that these children are already widely clinically recognised in Europe, and that they present huge challenges to parents and professionals. Children with PDA very often have several ASD symptoms and will most likely benefit from interventions based upon ASD know-how—including preparation prior to changes, visual support and structure. However, a child with PDA might experience these interventions as too demanding, and therefore might need adjustments according to PDA/EDA such as an even longer period of preparation than other children with ASD but no PDA need. Our clinical experience with this group also suggests that taking a mild “authoritarian” stance with a degree of coaxing and persuasion can be really helpful.

The major limitation of the present study is the small sample size even though the numbers are based on the general population in the Faroe Islands. Another limitation is that albeit clinically examined, the study group was not assessed specifically with PDA in mind (although the small sample size meant the research team were familiar with all participants, and that the PDA findings were supported by the clinical impressions gained). No comparison with a non-ASD-group regarding PDA symptoms was carried out. Finally, the PDA DISCO items have not been validated against an identified PDA population, so our findings must be taken as preliminary and no definitive conclusions can be drawn from them. What our results suggest is that PDA is a relatively rare, but possibly not-extremely-uncommon condition and that ASD and PDA can exist together. Clearly, unless the Faroe Islands is an extremely atypical population from which no generalised conclusions can be drawn, PDA/EDA is quite common in ASD.

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Conflict of interest None of the five authors have a conflict of interest to declare.

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