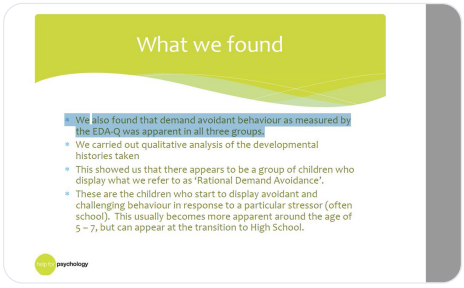
Richard Woods @Richard_Autism

19 Jun • 55 tweets • Richard_Autism/status/1406366472960712712

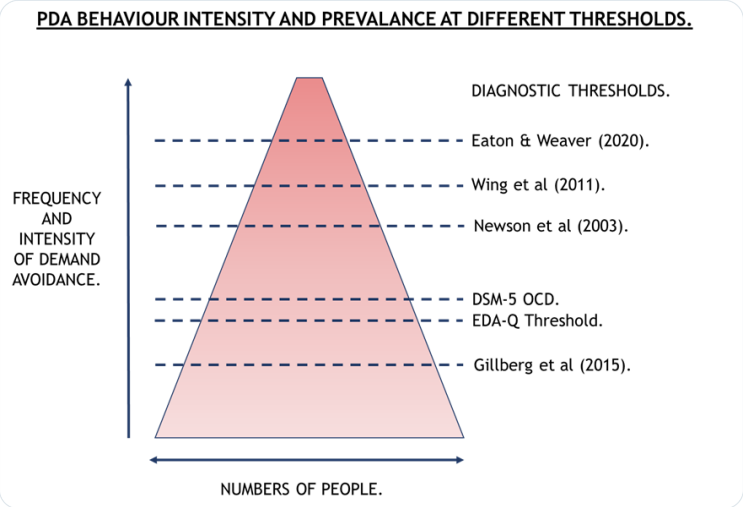
Studies showing PDA is seen outside of autism:
Absoud 2019.
Eaton 2018.
Egan et al 2019.
Flackhill et al 2017.
Newson et al 2003.
O'Nions et al 2014a.
O'Nions et al 2014b.
O'Nions et al 2015.
O'Nions et al 2016.
Reilly et al 2014.

"Profile of problematic behaviours not confined to autism" (@MAbsoud 2019, 8). https://www.pdasociety.org.uk/wp-content/uploads/2019/09/Research-Meeting-Report.pdf

EDA-Q was used as part of assessment process.
Three groups: Autism, Autism + PDA, & Other (Trauma related issues).
EDA-Q detected PDA in all three groups.



EDA-Q has substantially lower dx threshold than used by the clinic to assess for PDA.



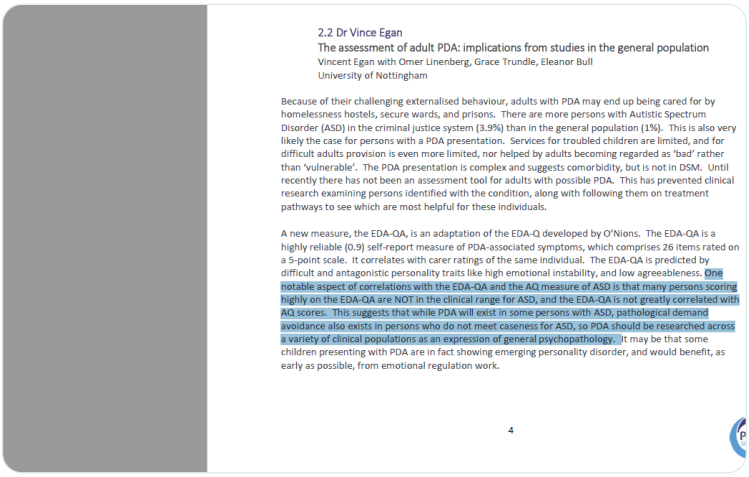
This for Eaton (2018).
Can be downloaded from here:

"One notable aspect of correlations with the EDA-QA and the AQ measure of ASD is that many persons scoring highly on the EDA-QA are NOT in the clinical range for ASD, and the EDA-QA is not greatly correlated with AQ scores...

... This suggests that while PDA will exist in some persons with ASD, pathological demand avoidance also exists in persons who do not meet caseness for ASD,...

... so PDA should be researched across a variety of clinical populations as an expression of general psychopathology". (Egan 2019, p4).

Egan 2019 link:
https://www.pdasociety.org.uk/wp-content/uploads/2019/09/Research-Meeting-Report.pdf



2.2 Dr Vince Egan

The assessment of adult PDA: implications from studies in the general population

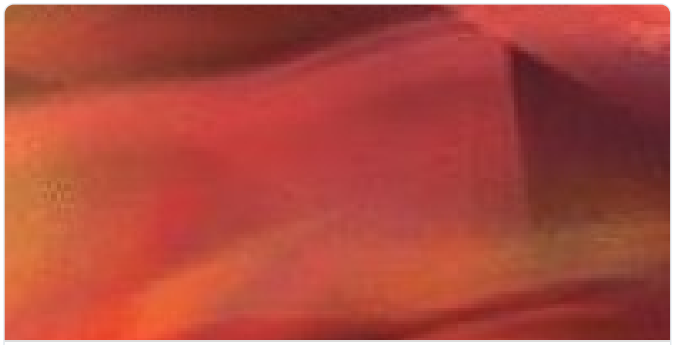
Vincent Egan with Omer Linenberg, Grace Trundle, Eleanor Bull
University of Nottingham

Because of their challenging externalised behaviour, adults with PDA may end up being cared for by homelessness hostels, secure wards, and prisons. There are more persons with Autistic Spectrum Disorder (ASD) in the criminal justice system (3.9%) than in the general population (1%). This is also very likely the case for persons with a PDA presentation. Services for troubled children are limited, and for difficult adults provision is even more limited, nor helped by adults becoming regarded as 'bad' rather than 'vulnerable'. The PDA presentation is complex and suggests comorbidity, but is not in DSM. Until recently there has not been an assessment tool for adults with possible PDA. This has prevented clinical research examining persons identified with the condition, along with following them on treatment pathways to see which are most helpful for these individuals.

A new measure, the EDA-QA, is an adaptation of the EDA-Q developed by O'Nions. The EDA-QA is a highly reliable (0.9) self-report measure of PDA-associated symptoms, which comprises 26 items rated on a 5-point scale. It correlates with carer ratings of the same individual. The EDA-QA is predicted by difficult and antagonistic personality traits like high emotional instability, and low agreeableness. One notable aspect of correlations with the EDA-QA and the AQ measure of ASD is that many persons scoring highly on the EDA-QA are NOT in the clinical range for ASD, and the EDA-QA is not greatly correlated with AQ scores. This suggests that while PDA will exist in some persons with ASD, pathological demand avoidance also exists in persons who do not meet caseness for ASD, so PDA should be researched across a variety of clinical populations as an expression of general psychopathology. It may be that some children presenting with PDA are in fact showing emerging personality disorder, and would benefit, as early as possible, from emotional regulation work.

4

Link to article validating the EDA-QA.



The Measurement of Adult Pathological Demand Avoidance Traits

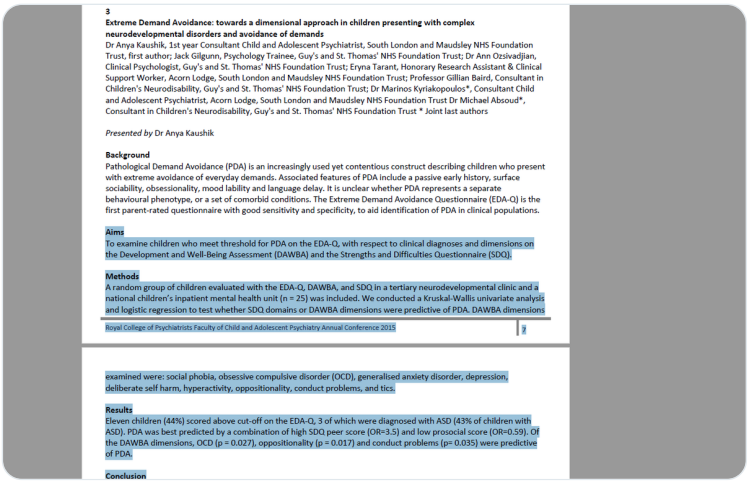
Pathological ("extreme") demand avoidance (PDA) involves obsessively avoiding routine demands and extreme emotional variability. It is clinical

https://link.springer.com/article/10.1007/s10803-018-3722-7

"associations between PDA, ADHD, and conduct disorder, the latter two diagnoses of which can be linked to the environment, poor early caregiving and attachments (Kumsta et al, 2015)." (Flackhill et al 2017, p65).

"Eleven children (44%) scored above cut-off on the EDA-Q, 3 of which were diagnosed with ASD (43% of children with ASD)." N = 25. Flackhill et al (2017) are discussing Kaushik et al (2015).

Screenshot of Kaushik et al (2015) conference proceedings.



3

Extreme Demand Avoidance: towards a dimensional approach in children presenting with complex neurodevelopmental disorders and avoidance of demands

Dr Anya Kaushik, 1st year Consultant Child and Adolescent Psychiatrist, South London and Maudsley NHS Foundation Trust, first author; Jack Gilgunn, Psychology Trainee, Guy's and St. Thomas' NHS Foundation Trust; Dr Ann Ozsivadjian, Clinical Psychologist, Guy's and St. Thomas' NHS Foundation Trust; Eryna Tarant, Honorary Research Assistant & Clinical Support Worker, Acorn Lodge, South London and Maudsley NHS Foundation Trust; Professor Gillian Baird, Consultant in Children's Neurodisability, Guy's and St. Thomas' NHS Foundation Trust; Dr Marinos Kyriakopoulos*, Consultant Child and Adolescent Psychiatrist, Acorn Lodge, South London and Maudsley NHS Foundation Trust Dr Michael Absoud*, Consultant in Children's Neurodisability, Guy's and St. Thomas' NHS Foundation Trust * Joint last authors

Presented by Dr Anya Kaushik

Background

Pathological Demand Avoidance (PDA) is an increasingly used yet contentious construct describing children who present with extreme avoidance of everyday demands. Associated features of PDA include a passive early history, surface sociability, obsessionality, mood lability and language delay. It is unclear whether PDA represents a separate behavioural phenotype, or a set of comorbid conditions. The Extreme Demand Avoidance Questionnaire (EDA-Q) is the first parent-rated questionnaire with good sensitivity and specificity, to aid identification of PDA in clinical populations.

Aims

To examine children who meet threshold for PDA on the EDA-Q, with respect to clinical diagnoses and dimensions on the Development and Well-Being Assessment (DAWBA) and the Strengths and Difficulties Questionnaire (SDQ).

Methods

A random group of children evaluated with the EDA-Q, DAWBA, and SDQ in a tertiary neurodevelopmental clinic and a national children's inpatient mental health unit (n = 25) was included. We conducted a Kruskal-Wallis univariate analysis and logistic regression to test whether SDQ domains or DAWBA dimensions were predictive of PDA. DAWBA dimensions

examined were: social phobia, obsessive compulsive disorder (OCD), generalised anxiety disorder, depression, deliberate self harm, hyperactivity, oppositionality, conduct problems, and tics.

Results

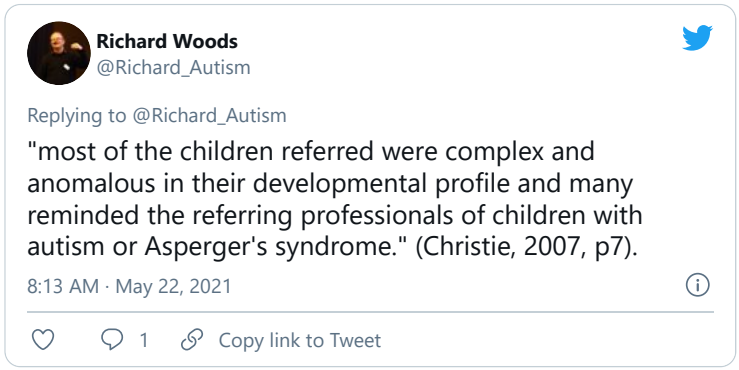
Eleven children (44%) scored above cut-off on the EDA-Q, 3 of which were diagnosed with ASD (43% of children with ASD). PDA was best predicted by a combination of high SDQ peer score (OR=3.5) and low prosocial score (OR=0.59). Of the DAWBA dimensions, OCD (p = 0.027), oppositionality (p = 0.017) and conduct problems (p= 0.035) were predictive of PDA.

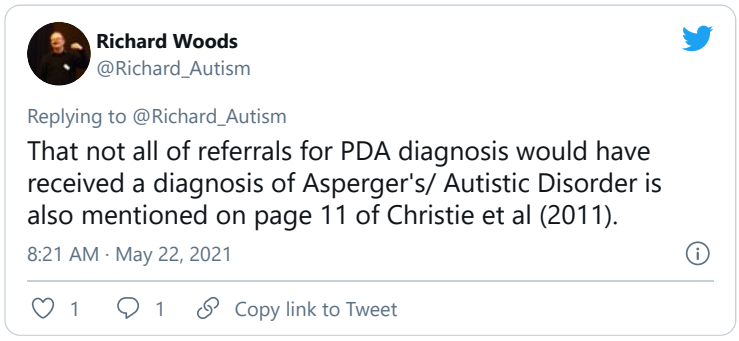
Conclusion

Link to Flackhill et al (2017).
https://www.ingentaconnect.com/contentone/bild/gap/2017/00000018/00000001/art00009

A link to Newson et al (2003).
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf

It is accepted that Newson et al (2003) cohort contains non-autistic persons in it. Not all of Newson's cohort meet DSM-5 autism criteria (Eaton & Weaver 2020, p35; Soppitt 2021, p311).





"The children referred for diagnostic assessment tended to be a little “puzzling” or atypical in some way: hence their referral to a specialist clinic" (Newson et al 2003, p595).

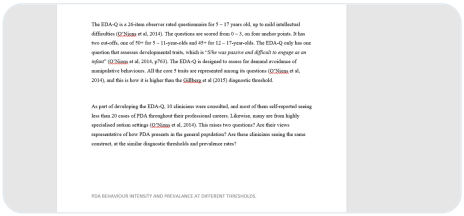
"During the 1970s we saw a number of children who “reminded” their medical

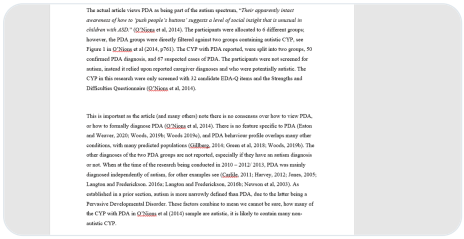
referrers of autism, but were clearly not typical of autism." (Newson et al 2003 p595).

A link to Christie (2007).
https://www.ingentaconnect.com/contentone/bild/gap/2007/00000008/00000001/art00002

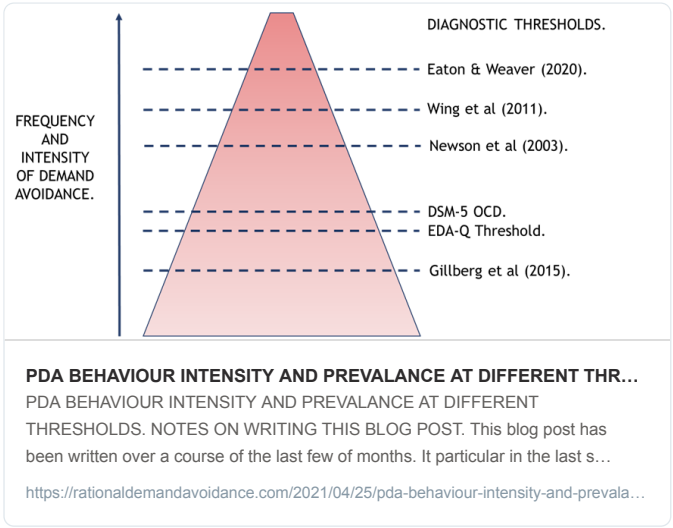
O'Nions (2014a) is the development of the Extreme Demand Avoidance-Questionnaire (EDA-Q) and can be accessed here:
https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149

These two screenshots explain the rationale for their being non-autistic persons in O'Nions et al (2014a).





The above screenshots explaining the rationale for non-autistic CYP in O'Nions et al (2014a), can be found on this blog post here:



O'Nions et al (2014b) is the Exploring the behavioural profile article, which can be found here:
https://journals.sagepub.com/doi/pdf/10.1177/1362361313481861

Most of the arguments for how there are non-autistic CYP in O'Nions et al (2014a) are also pertinent to O'Nions et al (2014b). There are some important differences; e.g. 2014b article was based on O'Nions masters research, 2014a is based on their PhD research

Arguments around those CYP with PDA diagnoses with an autism dx, this information is not provided. However, 25 CYP with PDA, were screened with an autism screening tool, the CAST (O'Nions et al 2014b, p540).

As this was done before O'Nions PhD research, O'Nions (2014b) data would have

been collected during a time PDA was mainly diagnosed as a stand alone diagnosis.

"On the CAST (measuring autistic traits), 72% of the PDA group met the ‘at-risk’ cut off for ASD (a raw score > 14), compared to 79% of the ASD group" (O'Nions et al 2014b, p540).

More of the PDA group did not meet threshold on the CAST screening tool, than autism.
With N = 25. 1 CYP with PDA = 4%.
Thus, 28% not meeting CAST threshold could indicate 7 CYP with PDA are not autistic.

I know that some would go, Richard, 21% of autistic CYP did not meet threshold on CAST. To some extent I accept this is a good point. Yet there are important differences in the numbers.

Screening typically aim to have a false negative rate of about 25%. So the 21% of diagnosed autistic CYP, is actually within the expected error margin of the CAST. Yet, 28% of CYP with PDA is not.

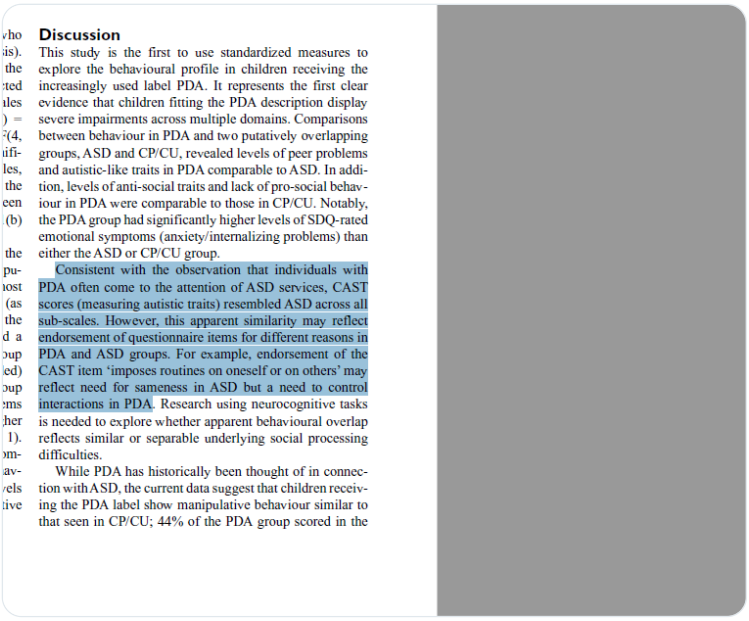
Suppose we accept that 21% false negative rate of the autistic CYP, is applicable for CYP with PDA. This would still give us 2 (rounding up) CYP with PDA who are NOT autistic.

O'Nions et al (2014b) is an interesting paper, in how it details differences between autism, PDA and conduct disorder. It makes many good points, highlighting how it is problematic viewing PDA as an ASD. This is a tangent.

"PDA often come to the attention of ASD services, CAST
scores (measuring autistic traits) resembled ASD across all sub-scales...

... However, this apparent similarity may reflect endorsement of questionnaire items for different reasons in PDA and ASD groups...

... For example, endorsement of the CAST item ‘imposes routines on oneself or on others’ may reflect need for sameness in ASD but a need to control interactions in PDA." (O'Nions et al 2014b, p541).



Discussion

This study is the first to use standardized measures to explore the behavioural profile in children receiving the increasingly used label PDA. It represents the first clear evidence that children fitting the PDA description display severe impairments across multiple domains. Comparisons between behaviour in PDA and two putatively overlapping groups, ASD and CP/CU, revealed levels of peer problems and autistic-like traits in PDA comparable to ASD. In addition, levels of anti-social traits and lack of pro-social behaviour in PDA were comparable to those in CP/CU. Notably, the PDA group had significantly higher levels of SDQ-rated emotional symptoms (anxiety/internalizing problems) than either the ASD or CP/CU group.

Consistent with the observation that individuals with PDA often come to the attention of ASD services, CAST scores (measuring autistic traits) resembled ASD across all sub-scales. However, this apparent similarity may reflect endorsement of questionnaire items for different reasons in PDA and ASD groups. For example, endorsement of the CAST item 'imposes routines on oneself or on others' may reflect need for sameness in ASD but a need to control interactions in PDA. Research using neurocognitive tasks is needed to explore whether apparent behavioural overlap reflects similar or separable underlying social processing difficulties.

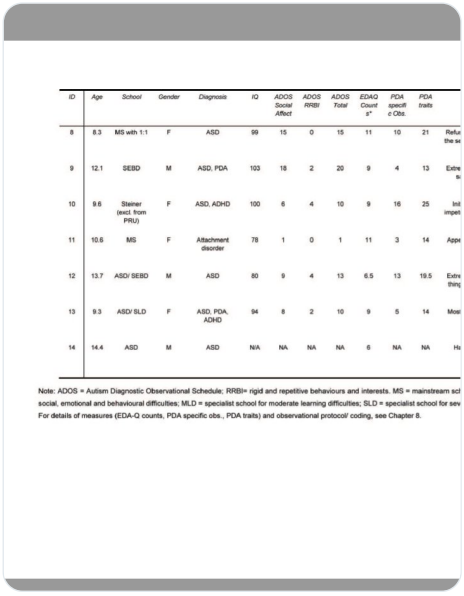
While PDA has historically been thought of in connection with ASD, the current data suggest that children receiving the PDA label show manipulative behaviour similar to that seen in CP/CU; 44% of the PDA group scored in the

This text from (O'Nions et al 2014b) is important as it states that similarities between PDA and autism maybe superficial, because of CYP PDA do things for different reasons compared to autistic CYP.

It means there is probably more than 2 non-autistic CYP with PDA among the 25 PDA cohort in O'Nions et al (2014b).

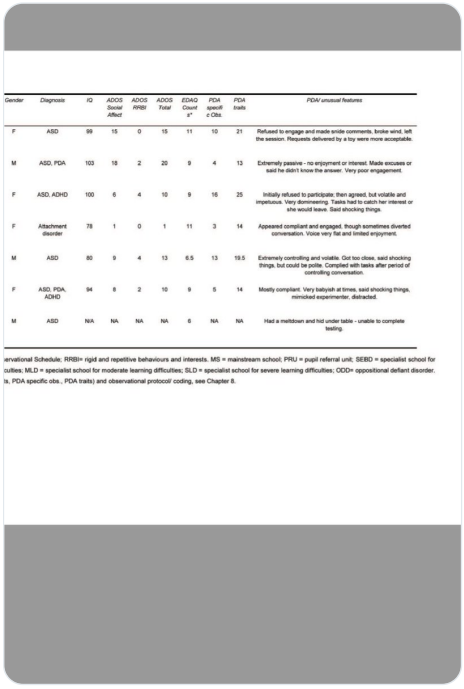
The remaining three should pretty quick to do.

So Number 11 out of 14 CYP with PDA in O'Nions et al (2015).



ID	Age	School	Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Count s*	PDA specifi c Obs.	PDA traits	
8	8.3	MS with 1:1	F	ASD	99	15	0	15	11	10	21	Refus the se
9	12.1	SEBD	M	ASD, PDA	103	18	2	20	9	4	13	Extre fa
10	9.6	Steiner (excl. from PRU)	F	ASD, ADHD	100	6	4	10	9	16	25	Init impet
11	10.6	MS	F	Attachment disorder	78	1	0	1	11	3	14	Appe
12	13.7	ASD/ SEBD	M	ASD	80	9	4	13	6.5	13	19.5	Extre thing
13	9.3	ASD/ SLD	F	ASD, PDA, ADHD	94	8	2	10	9	5	14	Mos
14	14.4	ASD	M	ASD	N/A	NA	NA	NA	NA	6	NA	NA	Hi

Note: ADOS = Autism Diagnostic Observational Schedule; RRBI= rigid and repetitive behaviours and interests. MS = mainstream sch social, emotional and behavioural difficulties; MLD = specialist school for moderate learning difficulties; SLD = specialist school for sev For details of measures (EDA-Q counts, PDA specific obs., PDA traits) and observational protocol/ coding, see Chapter 8.



Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Count s*	PDA specifi c Obs.	PDA traits	PDA/ unusual features
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.
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.
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.
F	Attachment disorder	78	1	0	1	11	3	14	Appeared compliant and engaged, though sometimes diverted conversation. Voice very flat and limited enjoyment.
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.
F	ASD, PDA, ADHD	94	8	2	10	9	5	14	Mostly compliant. Very babyish at times, said shocking things, mimicked experimenter, distracted.
M	ASD	N/A	NA	NA	NA	NA	6	NA	NA	Had a meltdown and hid under table - unable to complete testing.

ervational Schedule; RRBI= rigid and repetitive behaviours and interests. MS = mainstream school; PRU = pupil referral unit; SEBD = specialist school for culties; MLD = specialist school for moderate learning difficulties; SLD = specialist school for severe learning difficulties; ODD= oppositional defiant disorder. ls, PDA specific obs., PDA traits) and observational protocol/ coding, see Chapter 8.

This example is important as CYP with PDA is diagnosed with attachment disorder, not autism and scores extremely low on the ADOS (an autism assessment tool).

"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...

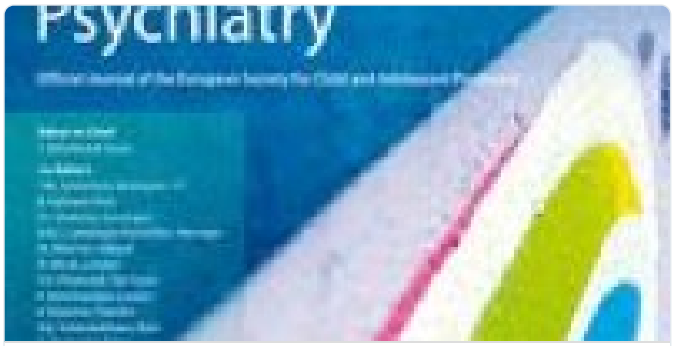
... Interviews included here are the 14 examples most resembling Newson's descriptions of PDA." (O'Nions et al 2015, p3).

The point here is this non-autistic CYP with PDA was part of a sample chosen to reflect researcher's views on PDA, including high PDA behaviours. It is difficult to argue that this non-autistic CYP with PDA is substantially different to PDA in autistic CYP.

A link to O'Nions et al (2015), An examination of the behavioural features associated with PDA using a semi-structured interview:
http://pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf

Moving onto O'Nions et al (2016). Had N = 27 Persons with PDA. However, "All but one case met criteria for an ASD." p407.

Link to O'Nions et al (2016), Identifying features of 'pathological demand avoidance' using the DISCO.



Identifying features of 'pathological demand avoidance' using the Diag...
The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obse

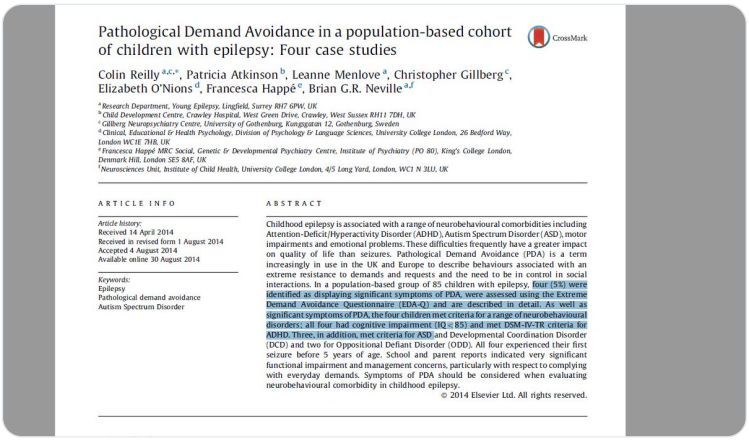
https://link.springer.com/article/10.1007/s00787-015-0740-2

The study is Reilly et al (2014), containing 4 case studies of CYP with PDA.

"In a population-based group of 85 children with epilepsy, four (5%) were identified as displaying significant symptoms of PDA, were assessed using the Extreme Demand Avoidance Questionnaire (EDA-Q) and are described in detail...

... all four had cognitive impairment (IQ < 85) and met DSM-IV-TR criteria for ADHD. Three, in addition, met criteria for ASD..." (Reilly et al 2014, p3236).

Reilly et al (2014) has one non-autistic CYP with PDA.



Pathological Demand Avoidance in a population-based cohort of children with epilepsy: Four case studies

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ABSTRACT

Childhood epilepsy is associated with a range of neurobehavioural comorbidities including Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), motor impairments and emotional problems. These difficulties frequently have a greater impact on quality of life than seizures. Pathological Demand Avoidance (PDA) is a term increasingly in use in the UK and Europe to describe behaviours associated with an extreme resistance to demands and requests and the need to be in control in social interactions. In a population-based group of 85 children with epilepsy, four (5%) were identified as displaying significant symptoms of PDA, were assessed using the Extreme Demand Avoidance Questionnaire (EDA-Q) and are described in detail. As well as significant symptoms of PDA, the four children met criteria for a range of neurobehavioural disorders; all four had cognitive impairment (IQ ≤ 85) and met DSM-IV-TR criteria for ADHD. Three, in addition, met criteria for ASD and Developmental Coordination Disorder (DCD) and two for Oppositional Defiant Disorder (ODD). All four experienced their first seizure before 5 years of age. School and parent reports indicated very significant functional impairment and management concerns, particularly with respect to complying with everyday demands. Symptoms of PDA should be considered when evaluating neurobehavioural comorbidity in childhood epilepsy.

Link to final study in this list, Reilly et al (2014),
PDA in a population-based cohort of children with epilepsy: Four case studies:

Pathological Demand Avoidance in a population-based cohort of childr…
Childhood epilepsy is associated with a range of neurobehavioural comorbidities including Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spec…
https://www.sciencedirect.com/science/article/abs/pii/S0891422214003461?via%3Dihub

@neuroteachers I believe that is all 10 studies covered.

@threadreaderapp Please can you unroll.

Thank you in advance.

• • •