Richard Woods @Richard_Autism

29 May • 76 tweets • Richard_Autism/status/1398755419108122624

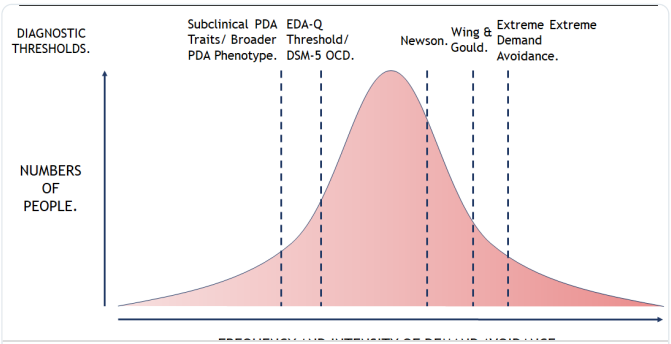
Going reading O'Nions recent work. At least they have referenced one article of mine. Ignored critique of EDA-Q in said article which is bizarre.

@HappeLab
Sigh, perhaps one day I will view O'Nions work to be equivalent to mine quality, but this is not one those days.

Extreme Demand Avoidance in Children with Autism Spectrum Disord…
Extreme/"pathological" demand avoidance (PDA) describes a presentation found in some children on the autism spectrum, characterized by obsessiv

https://link.springer.com/article/10.1007/s41252-021-00203-z

@HappeLab I doubt that article will score well on here, sigh.

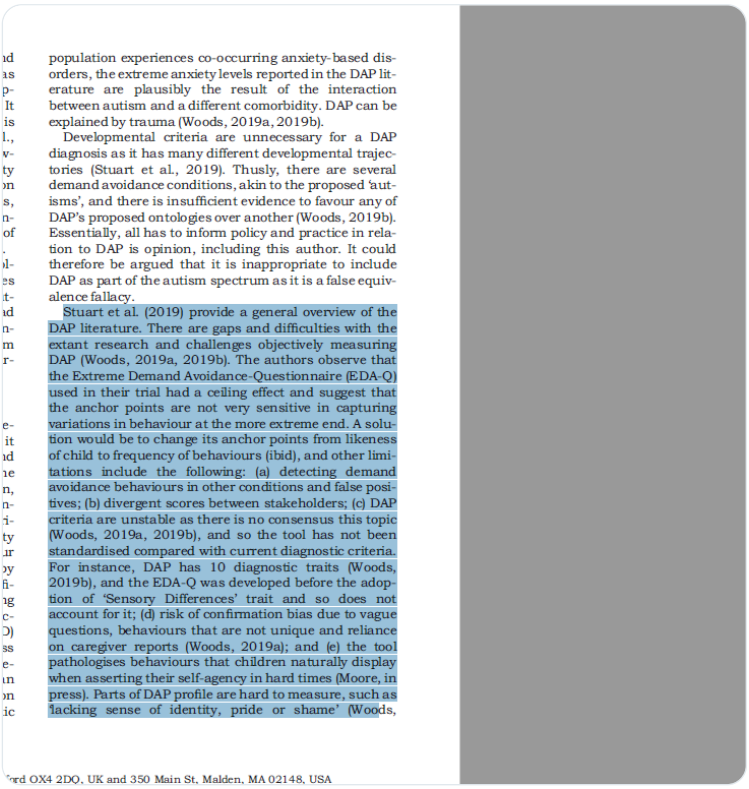


A DRAFT OF THE PATHOLOGICAL DEMAND AVOIDANCE – BALANCE…
A DRAFT OF THE PATHOLOGICAL DEMAND AVOIDANCE – BALANCED LITERATURE TOOL (PDA-BLT). Introduction. This is a quick blogpost to introduce a draft of a tool to screen PDA literature with, which assesse…

https://rationaldemandavoidance.com/2021/05/22/a-draft-of-the-pathological-demand-…

Link to article of mine. Screenshot of critique of the EDA-Q.
https://www.researchgate.net/publication/338650142_Commentary_Demand_Avoidance_Phenomena_a_manifold_issue_Intolerance_of_uncertainty_and_anxiety_a

s_explanatory_frameworks_for_extreme_demand_avoidance_in_children_and_adolescents_-_a_commentary_on_Stuar



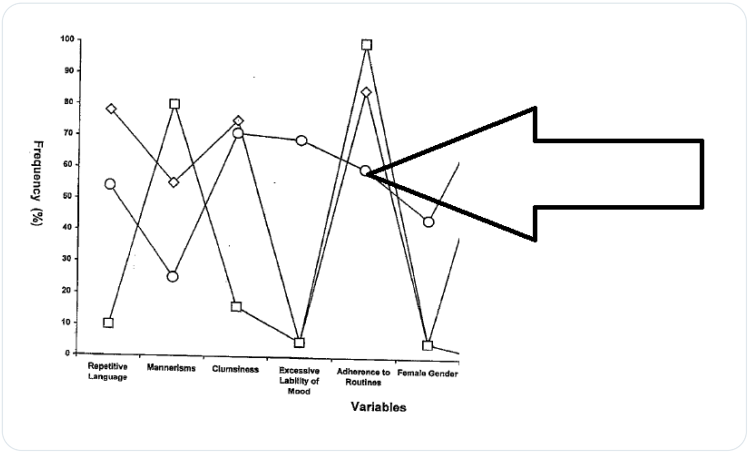
population experiences co-occurring anxiety-based disorders, the extreme anxiety levels reported in the DAP literature are plausibly the result of the interaction between autism and a different comorbidity. DAP can be explained by trauma (Woods, 2019a, 2019b).

Developmental criteria are unnecessary for a DAP diagnosis as it has many different developmental trajectories (Stuart et al., 2019). Thusly, there are several demand avoidance conditions, akin to the proposed 'autisms', and there is insufficient evidence to favour any of DAP's proposed ontologies over another (Woods, 2019b). Essentially, all has to inform policy and practice in relation to DAP is opinion, including this author. It could therefore be argued that it is inappropriate to include DAP as part of the autism spectrum as it is a false equivalence fallacy.

Stuart et al. (2019) provide a general overview of the DAP literature. There are gaps and difficulties with the extant research and challenges objectively measuring DAP (Woods, 2019a, 2019b). The authors observe that the Extreme Demand Avoidance-Questionnaire (EDA-Q) used in their trial had a ceiling effect and suggest that the anchor points are not very sensitive in capturing variations in behaviour at the more extreme end. A solution would be to change its anchor points from likeness of child to frequency of behaviours (ibid), and other limitations include the following: (a) detecting demand avoidance behaviours in other conditions and false positives; (b) divergent scores between stakeholders; (c) DAP criteria are unstable as there is no consensus this topic (Woods, 2019a, 2019b), and so the tool has not been standardised compared with current diagnostic criteria. For instance, DAP has 10 diagnostic traits (Woods, 2019b), and the EDA-Q was developed before the adoption of 'Sensory Differences' trait and so does not account for it; (d) risk of confirmation bias due to vague questions, behaviours that are not unique and reliance on caregiver reports (Woods, 2019a); and (e) the tool pathologises behaviours that children naturally display when asserting their self-agency in hard times (Moore, in press). Parts of DAP profile are hard to measure, such as 'lacking sense of identity, pride or shame' (Woods,

ord OX4 2DQ, UK and 350 Main St, Malden, MA 02148, USA

Interesting apparently O'Nions is stating that routines and structure might benefit some persons with PDA, yet ignores how this was actually in Newson's original research...
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/PDA-discriminant-functions-analysis.pdf



There seems to be a concerted effort to argue there might be a collider bias in Newson's research, instead of actually checking Newson's research statistics for if there could be a collider bias.

@HappeLab We know if there is a collider bias, then it could only be present in between 25% - 33% of Newson's cohort: Bulk of Newson's cohort was recruited after expansion of autism spectrum to include Aspergers. This is just sloppy.

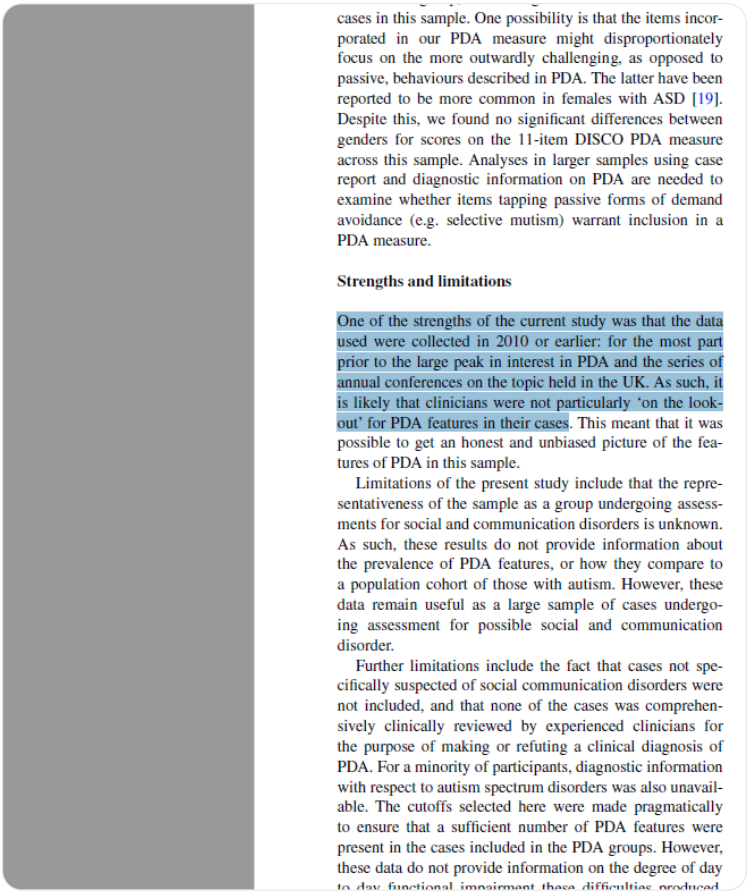
WHAT THE LITERATURE AND RICHARD WOODS SAY ABOUT NEWSO…

WHAT THE LITERATURE AND RICHARD WOODS SAY ABOUT NEWSON ET AL (2003). This is a living document, I update as I reflect upon Newson's work more and with more is said about it in the literature.…

https://rationaldemandavoidance.com/2020/10/17/what-the-literature-and-richard-wood…

@HappeLab It also does not consider other reasons for differences between PDA and autism, that are results of Newsons methodology; also more pertinently that it is demonstrably true PDA is not autism.

@HappeLab Article ignores conflict of interest present in the Being Misunderstood report, due to those who consulted on the report. Also ignores other literature, which argues growth in PDA is driven by non-autistic stakeholders & activities like conferences.



cases in this sample. One possibility is that the items incorporated in our PDA measure might disproportionately focus on the more outwardly challenging, as opposed to passive, behaviours described in PDA. The latter have been reported to be more common in females with ASD [19]. Despite this, we found no significant differences between genders for scores on the 11-item DISCO PDA measure across this sample. Analyses in larger samples using case report and diagnostic information on PDA are needed to examine whether items tapping passive forms of demand avoidance (e.g. selective mutism) warrant inclusion in a PDA measure.

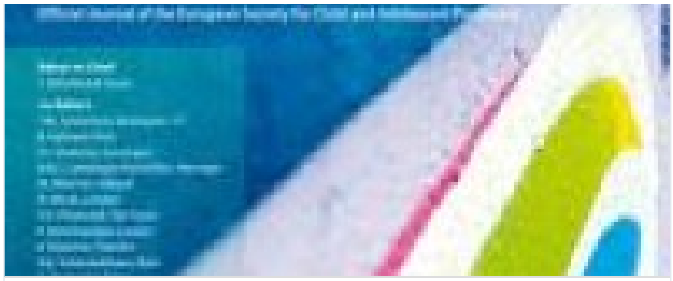
Strengths and limitations

One of the strengths of the current study was that the data used were collected in 2010 or earlier: for the most part prior to the large peak in interest in PDA and the series of annual conferences on the topic held in the UK. As such, it is likely that clinicians were not particularly 'on the lookout' for PDA features in their cases. This meant that it was possible to get an honest and unbiased picture of the features of PDA in this sample.

Limitations of the present study include that the representativeness of the sample as a group undergoing assessments for social and communication disorders is unknown. As such, these results do not provide information about the prevalence of PDA features, or how they compare to a population cohort of those with autism. However, these data remain useful as a large sample of cases undergoing assessment for possible social and communication disorder.

Further limitations include the fact that cases not specifically suspected of social communication disorders were not included, and that none of the cases was comprehensively clinically reviewed by experienced clinicians for the purpose of making or refuting a clinical diagnosis of PDA. For a minority of participants, diagnostic information with respect to autism spectrum disorders was also unavailable. The cutoffs selected here were made pragmatically to ensure that a sufficient number of PDA features were present in the cases included in the PDA groups. However, these data do not provide information on the degree of day to day functional impairment these difficulties produced

Screenshot if from here:

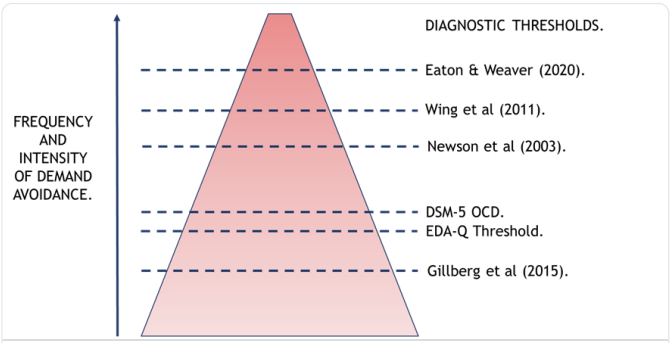


Identifying features of ‘pathological demand avoidance’ using the Diag…

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

@HappeLab It also ignores how Help4Psychology seem to have created their own PDA definitions, which are NOT representative of literature:



PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THR…

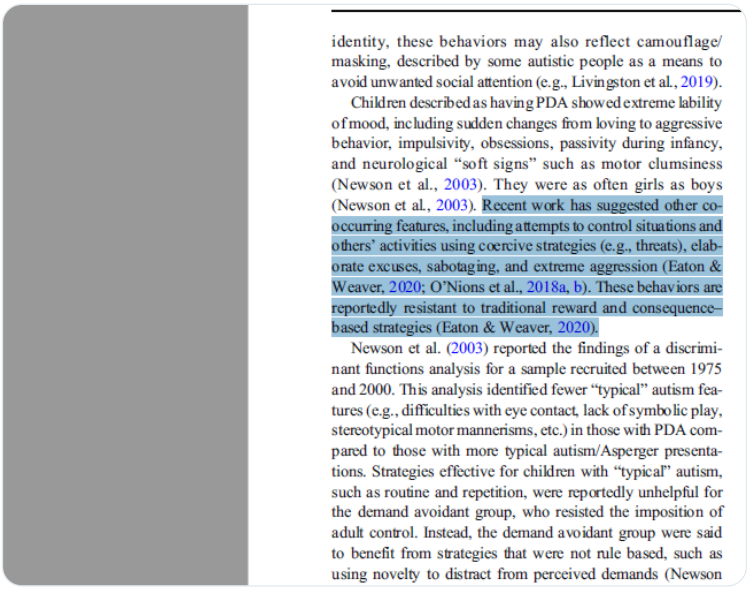
PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THRESHOLDS. NOTES ON WRITING THIS BLOG POST. This blog post has been written over a course of the last few of months. It particular in the last s…

https://rationaldemandavoidance.com/2021/04/25/pda-behaviour-intensity-and-prevala…

@HappeLab There is also no review of the use of the EDA-Q in PDA research and therefore no discussion of just HOW important the EDA-Q is to knowledge base on PDA. Likewise, no discussion on how often EDA-Q is used in diagnosing PDA.

@HappeLab This seems to be a poor quality article that come to expect from Liz O'Nions and others on PDA.

@HappeLab Another example of sloppy literature review, is discussing how behaviours seen in PDA do not respond well to reinforcement-based approaches, is described in recent work. Newson et al reported that praise, reward & punishment as ineffective, page 597



identity, these behaviors may also reflect camouflage/masking, described by some autistic people as a means to avoid unwanted social attention (e.g., Livingston et al., 2019).

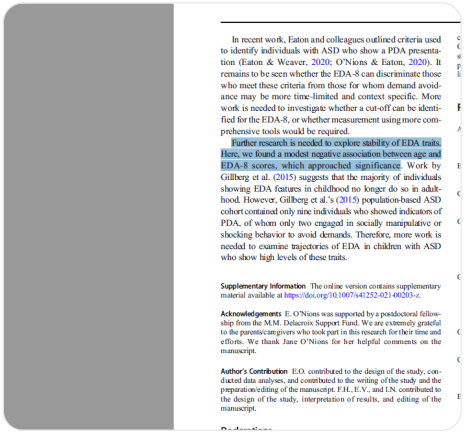
Children described as having PDA showed extreme lability of mood, including sudden changes from loving to aggressive behavior, impulsivity, obsessions, passivity during infancy, and neurological "soft signs" such as motor clumsiness (Newson et al., 2003). They were as often girls as boys (Newson et al., 2003). Recent work has suggested other co-occurring features, including attempts to control situations and others' activities using coercive strategies (e.g., threats), elaborate excuses, sabotaging, and extreme aggression (Eaton & Weaver, 2020; O'Nions et al., 2018a, b). These behaviors are reportedly resistant to traditional reward and consequence–based strategies (Eaton & Weaver, 2020).

Newson et al. (2003) reported the findings of a discriminant functions analysis for a sample recruited between 1975 and 2000. This analysis identified fewer "typical" autism features (e.g., difficulties with eye contact, lack of symbolic play, stereotypical motor mannerisms, etc.) in those with PDA compared to those with more typical autism/Asperger presentations. Strategies effective for children with "typical" autism, such as routine and repetition, were reportedly unhelpful for the demand avoidant group, who resisted the imposition of adult control. Instead, the demand avoidant group were said to benefit from strategies that were not rule based, such as using novelty to distract from perceived demands (Newson

@HappeLab
"Praise, reward, reproof, and punishment ineffective; behavioural approaches fail." Newson et al (2003, p597).
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes

@HappeLab There are good reasons why I question if O'Nions is a reputable information on PDA. Latest article is not doing much to ease my concerns.

Interesting that it seems to be another study that shows that PDA behaviours decrease with age. Then refer to Gillberg et al (2015). Again, I discuss this the article of mine I reference & I discuss implications of it.



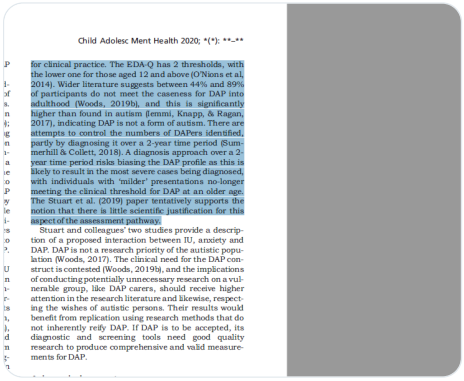
In recent work, Eaton and colleagues outlined criteria used to identify individuals with ASD who show a PDA presentation (Eaton & Weaver, 2020; O'Nions & Eaton, 2020). It remains to be seen whether the EDA-8 can discriminate those who meet these criteria from those for whom demand avoidance may be more time-limited and context specific. More work is needed to investigate whether a cut-off can be identified for the EDA-8, or whether measurement using more comprehensive tools would be required.

Further research is needed to explore stability of EDA traits. Here, we found a modest negative association between age and EDA-8 scores, which approached significance. Work by Gillberg et al. (2015) suggests that the majority of individuals showing EDA features in childhood no longer do so in adulthood. However, Gillberg et al.'s (2015) population-based ASD cohort contained only nine individuals who showed indicators of PDA, of whom only two engaged in socially manipulative or shocking behavior to avoid demands. Therefore, more work is needed to examine trajectories of EDA in children with ASD who show high levels of these traits.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s41252-021-00203-z.

Acknowledgements E. O'Nions was supported by a postdoctoral fellowship from the M.M. Delacroix Support Fund. We are extremely grateful to the parents/caregivers who took part in this research for their time and efforts. We thank Jane O'Nions for her helpful comments on the manuscript.

Author's Contribution E.O. contributed to the design of the study, conducted data analyses, and contributed to the writing of the study and the preparation/editing of the manuscript. F.H., E.V., and I.N. contributed to the design of the study, interpretation of results, and editing of the manuscript.



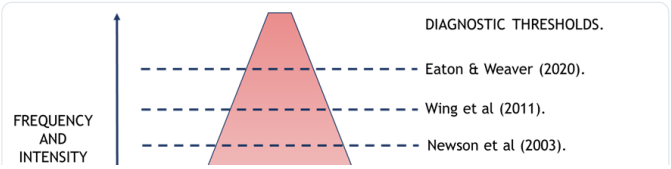
Child Adolesc Ment Health 2020; *(*): **–**

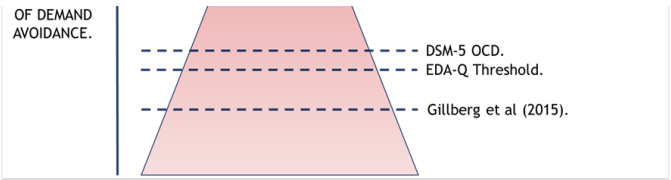
for clinical practice. The EDA-Q has 2 thresholds, with the lower one for those aged 12 and above (O'Nions et al, 2014). Wider literature suggests between 44% and 89% of participants do not meet the caseness for DAP into adulthood (Woods, 2019b), and this is significantly higher than found in autism (Lemmi, Knapp, & Ragan, 2017), indicating DAP is not a form of autism. There are attempts to control the numbers of DAPers identified, partly by diagnosing it over a 2-year time period (Summerhill & Collett, 2018). A diagnosis approach over a 2-year time period risks biasing the DAP profile as this is likely to result in the most severe cases being diagnosed, with 'individuals with 'milder' presentations no-longer meeting the clinical threshold for DAP at an older age. The Stuart et al. (2019) paper tentatively supports the notion that there is little scientific justification for this aspect of the assessment pathway.

Stuart and colleagues' two studies provide a description of a proposed interaction between IU, anxiety and DAP. DAP is not a research priority of the autistic population (Woods, 2017). The clinical need for the DAP construct is contested (Woods, 2019b), and the implications of conducting potentially unnecessary research on a vulnerable group, like DAP carers, should receive higher attention in the research literature and likewise, respecting the wishes of autistic persons. Their results would benefit from replication using research methods that do not inherently reify DAP. If DAP is to be accepted, its diagnostic and screening tools need good quality research to produce comprehensive and valid measurements for DAP.

@HappeLab It does seem a reasonable statement that this article by you & others would have benefitted from more engagement with Woods (2020).

@HappeLab I emailed O'Nions a copy of this blog post to comment on, during mid March 2021, a month before this was accepted. It is possible that they had time to read it.



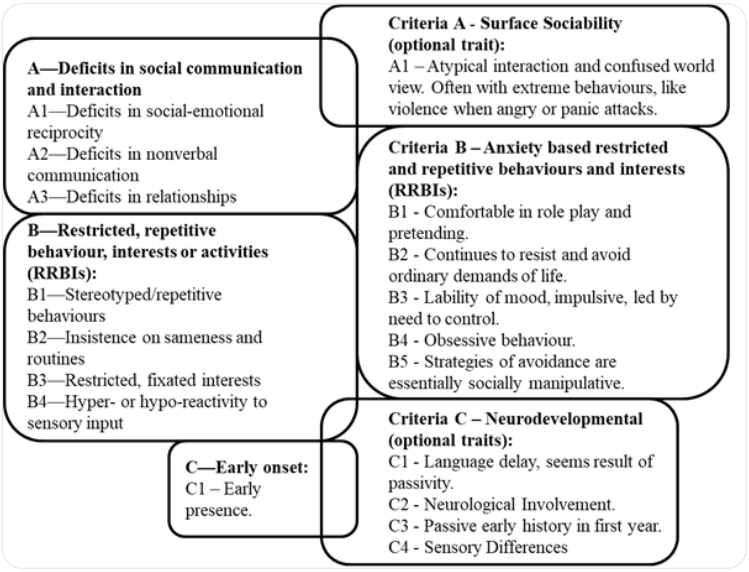


PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THR...

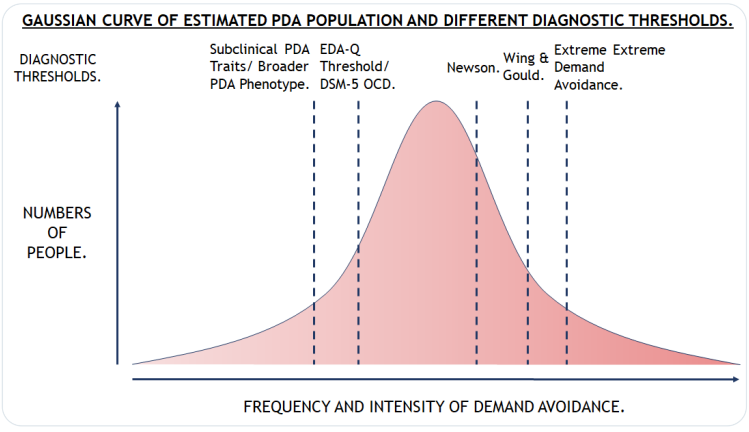
PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THRESHOLDS. NOTES ON WRITING THIS BLOG POST. This blog post has been written over a course of the last few of months. It particular in the last s…

https://rationaldemandavoidance.com/2021/04/25/pda-behaviour-intensity-and-prevala…

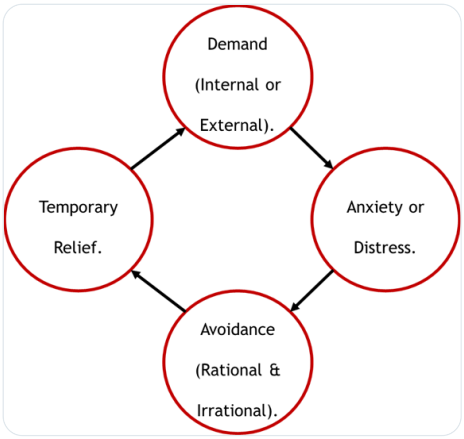
@HappeLab I also think some of Gillberg et al (2015) high drop off rate of those meeting caseness for PDA is due to their diagnostic threshold being low, the core PDA traits (as I define them) do not need to be present to meet Gillberg et al (2015) threshold.

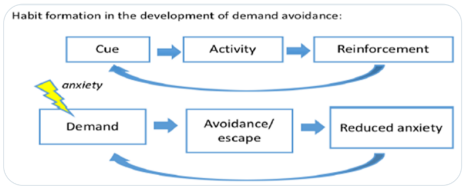


@HappeLab I refer to Gillberg et al (2015) threshold as "Subclinical PDA Traits/ Broader PDA Phenotype".



@HappeLab Point is that if Gillberg et al (2015) are diagnosing persons who do contain most features of the Demand Management Cycle, which is informed by some of O'Nions research. It is unlikely PDA behaviours would be developed & maintained as a CYP matures.



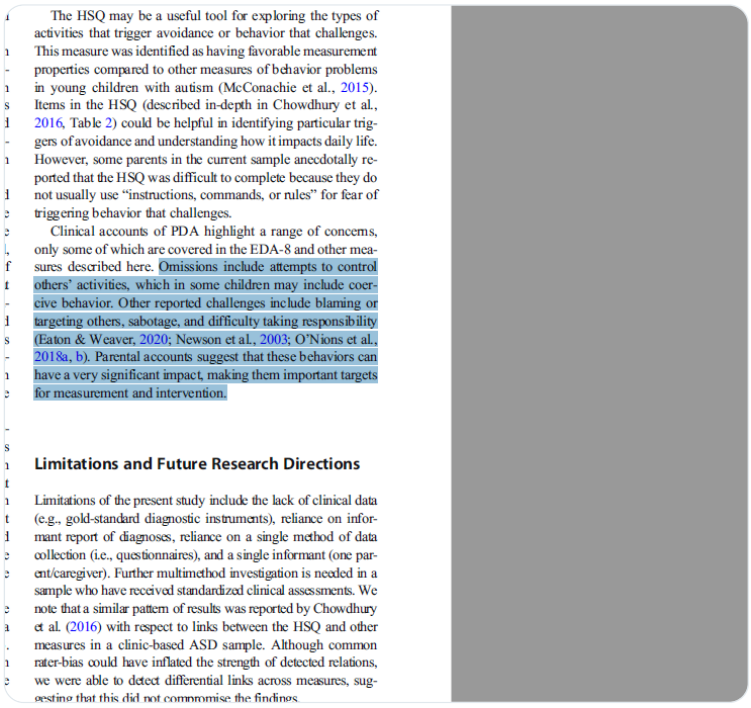


@HappeLab Thus explaining why it why Gillberg et al (2015) decrease so much in their sample.

I notice mention of "strategic" or "manipulative" social demand avoidance behaviours. This is a plus point.

Current view is that both descriptors can be applied, potentially changing with context.

Glad targeting behaviours with intent was mentioned.



The HSQ may be a useful tool for exploring the types of activities that trigger avoidance or behavior that challenges. This measure was identified as having favorable measurement properties compared to other measures of behavior problems in young children with autism (McConachie et al., 2015). Items in the HSQ (described in-depth in Chowdhury et al., 2016, Table 2) could be helpful in identifying particular triggers of avoidance and understanding how it impacts daily life. However, some parents in the current sample anecdotally reported that the HSQ was difficult to complete because they do not usually use "instructions, commands, or rules" for fear of triggering behavior that challenges.

Clinical accounts of PDA highlight a range of concerns, only some of which are covered in the EDA-8 and other measures described here. Omissions include attempts to control others' activities, which in some children may include coercive behavior. Other reported challenges include blaming or targeting others, sabotage, and difficulty taking responsibility (Eaton & Weaver, 2020; Newson et al., 2003; O'Nions et al., 2018a, b). Parental accounts suggest that these behaviors can have a very significant impact, making them important targets for measurement and intervention.

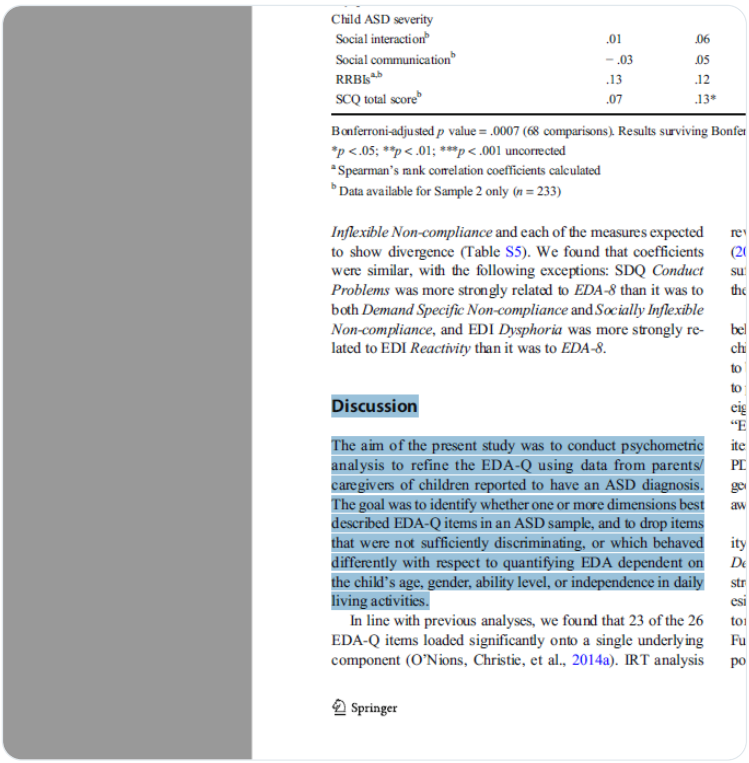
Limitations and Future Research Directions

Limitations of the present study include the lack of clinical data (e.g., gold-standard diagnostic instruments), reliance on informant report of diagnoses, reliance on a single method of data collection (i.e., questionnaires), and a single informant (one parent/caregiver). Further multimethod investigation is needed in a sample who have received standardized clinical assessments. We note that a similar pattern of results was reported by Chowdhury et al. (2016) with respect to links between the HSQ and other measures in a clinic-based ASD sample. Although common rater-bias could have inflated the strength of detected relations, we were able to detect differential links across measures, suggesting that this did not compromise the findings.

@HappeLab cannot say I am impressed with this apparent "obsession" with researching PDA in autism & fallacious axiom that PDA is an ASD.

@HappeLab There seem to be an issue of selective referencing. No mention of EDA-Q detecting PDA in non-autistic persons. Presumably, you & others would say PDA is an ASD, EDA-Q was detecting autistic persons, because it was detecting PDA. Or "false positives"

@Happe This research by yourself, O'Nions & others is about refining EDA-Q's ability to detect PDA in autistic CYPs, so there is a COI in not reporting the EDA-Q detects PDA in non-autistic persons; as it is a lot harder to justify this research's rationale.



Child ASD severity		
Social interaction[b]	.01	.06
Social communication[b]	− .03	.05
RRBIs[a,b]	.13	.12
SCQ total score[b]	.07	.13*

Bonferroni-adjusted p value = .0007 (68 comparisons). Results surviving Bonfer
*p < .05; **p < .01; ***p < .001 uncorrected
[a] Spearman's rank correlation coefficients calculated
[b] Data available for Sample 2 only (n = 233)

Inflexible Non-compliance and each of the measures expected to show divergence (Table S5). We found that coefficients were similar, with the following exceptions: SDQ *Conduct Problems* was more strongly related to *EDA-8* than it was to both *Demand Specific Non-compliance* and *Socially Inflexible Non-compliance*, and EDI *Dysphoria* was more strongly related to EDI *Reactivity* than it was to *EDA-8*.

Discussion

The aim of the present study was to conduct psychometric analysis to refine the EDA-Q using data from parents/caregivers of children reported to have an ASD diagnosis. The goal was to identify whether one or more dimensions best described EDA-Q items in an ASD sample, and to drop items that were not sufficiently discriminating, or which behaved differently with respect to quantifying EDA dependent on the child's age, gender, ability level, or independence in daily living activities.

In line with previous analyses, we found that 23 of the 26 EDA-Q items loaded significantly onto a single underlying component (O'Nions, Christie, et al., 2014a). IRT analysis

Springer

@HappeLab It begs the question, why not also do this research for PDA in non-autistic persons? Oh, PDA is seen in non-autistic persons, PDA cannot be autism. Means one cannot assume PDA is autism. So it is easier to not mention it and avoid such issues.

@HappeLab Links to where EDA-Q has detected PDA in non-autistic persons.

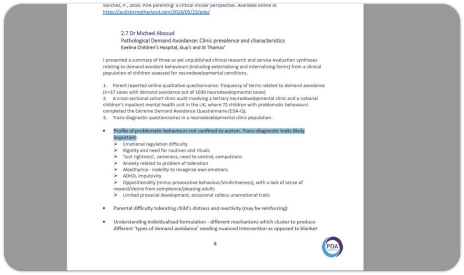
Pathological Demand Avoidance in a population-based cohort of childr…
Childhood epilepsy is associated with a range of neurobehavioural comorbidities including Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spec…
https://www.sciencedirect.com/science/article/abs/pii/S0891422214003461?via%3Dihub

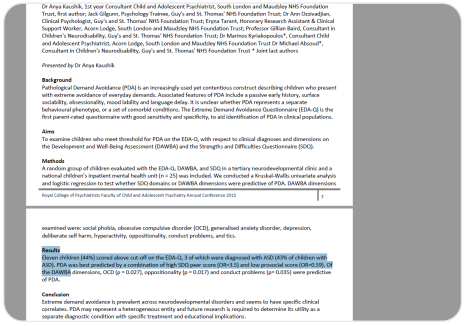
&
https://www.pdasociety.org.uk/wp-content/uploads/2019/09/Research-Meeting-Report.pdf
&

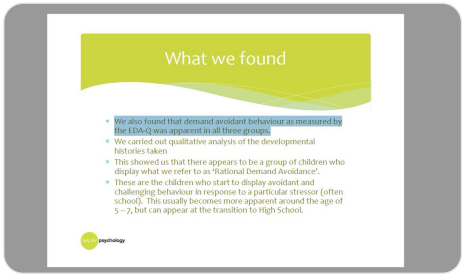
Pathological demand avoidance (PDA) 2018 presentations

pda conference 2018

https://www.autism.org.uk/what-we-do/professional-development/past-conferences/pd…





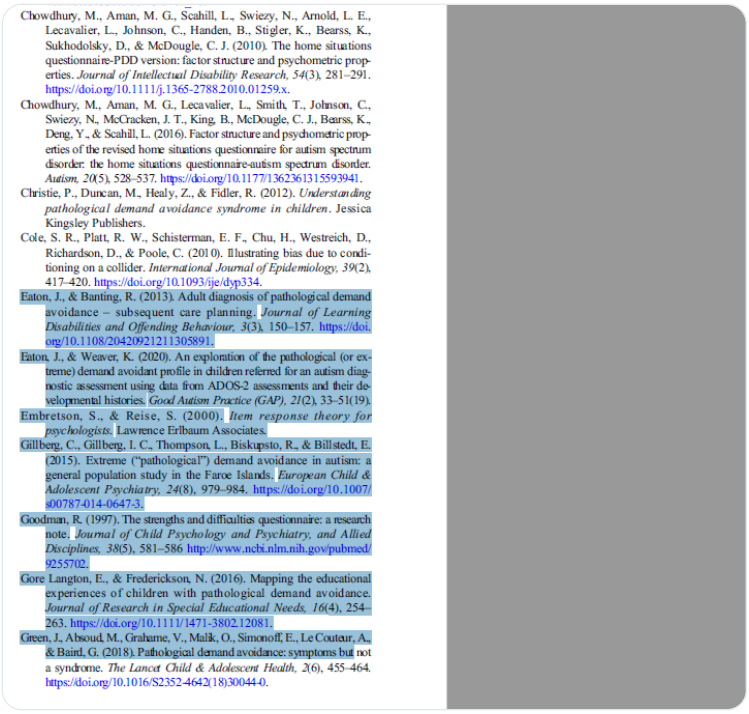


@HappeLab unless O'Nions has referenced Garralda in their PhD thesis, it would appear that she has not yet referenced their article in print...

Pathological demand avoidance syndrome: a necessary distinction wit…

A proposal is made to recognise pathological demand avoidance syndrome (PDA) as a separate entity within the pervasive developmental disorders, instead of being classed under "pervasive developmental…

https://adc.bmj.com/content/88/7/595.responses#pathological-demand-avoidance-syn…



Chowdhury, M., Aman, M. G., Scahill, L., Swiezy, N., Arnold, L. E., Lecavalier, L., Johnson, C., Handen, B., Stigler, K., Bearss, K., Sukhodolsky, D., & McDougle, C. J. (2010). The home situations questionnaire-PDD version: factor structure and psychometric properties. *Journal of Intellectual Disability Research, 54*(3), 281–291. https://doi.org/10.1111/j.1365-2788.2010.01259.x.

Chowdhury, M., Aman, M. G., Lecavalier, L., Smith, T., Johnson, C., Swiezy, N., McCracken, J. T., King, B., McDougle, C. J., Bearss, K., Deng, Y., & Scahill, L. (2016). Factor structure and psychometric properties of the revised home situations questionnaire for autism spectrum disorder: the home situations questionnaire-autism spectrum disorder. *Autism, 20*(5), 528–537. https://doi.org/10.1177/1362361315593941.

Christie, P., Duncan, M., Healy, Z., & Fidler, R. (2012). *Understanding pathological demand avoidance syndrome in children*. Jessica Kingsley Publishers.

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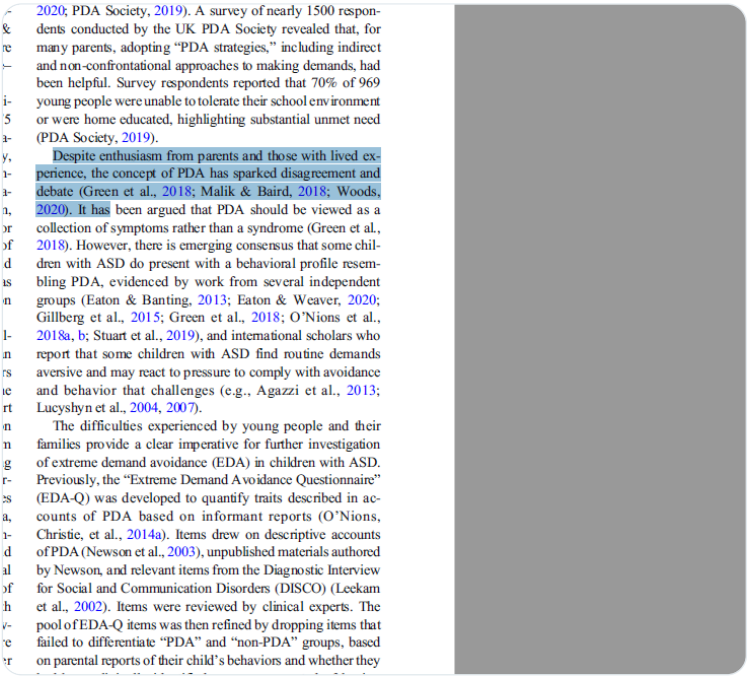
@HappeLab An obvious place to cite Garralda (2003) would have been here, with those disagreeing with PDA. Then again, considering the article is juxtaposing disagreement against caregivers & those with lived experience of PDA.



2020; PDA Society, 2019). A survey of nearly 1500 respondents conducted by the UK PDA Society revealed that, for many parents, adopting "PDA strategies," including indirect and non-confrontational approaches to making demands, had been helpful. Survey respondents reported that 70% of 969 young people were unable to tolerate their school environment or were home educated, highlighting substantial unmet need (PDA Society, 2019).

Despite enthusiasm from parents and those with lived experience, the concept of PDA has sparked disagreement and debate (Green et al., 2018; Malik & Baird, 2018; Woods, 2020). It has been argued that PDA should be viewed as a collection of symptoms rather than a syndrome (Green et al., 2018). However, there is emerging consensus that some children with ASD do present with a behavioral profile resembling PDA, evidenced by work from several independent groups (Eaton & Banting, 2013; Eaton & Weaver, 2020; Gillberg et al., 2015; Green et al., 2018; O'Nions et al., 2018a, b; Stuart et al., 2019), and international scholars who report that some children with ASD find routine demands aversive and may react to pressure to comply with avoidance and behavior that challenges (e.g., Agazzi et al., 2013; Lucyshyn et al., 2004, 2007).

The difficulties experienced by young people and their families provide a clear imperative for further investigation of extreme demand avoidance (EDA) in children with ASD. Previously, the "Extreme Demand Avoidance Questionnaire" (EDA-Q) was developed to quantify traits described in accounts of PDA based on informant reports (O'Nions, Christie, et al., 2014a). Items drew on descriptive accounts of PDA (Newson et al., 2003), unpublished materials authored by Newson, and relevant items from the Diagnostic Interview for Social and Communication Disorders (DISCO) (Leekam et al., 2002). Items were reviewed by clinical experts. The pool of EDA-Q items was then refined by dropping items that failed to differentiate "PDA" and "non-PDA" groups, based on parental reports of their child's behaviors and whether they

@HappeLab Citing Garralda (2003) then undermines this juxtaposition as it is disagreement with PDA before growth in interest in PDA... Also seems to no mention of Wing's consistent critique of PDA over two decades either...

@HappeLab Likewise a lack of coverage with why PDA has been controversial before growth in interest in PDA.

@HappeLab Seems observation of "cherry picking"/ "selective referencing" is valid.

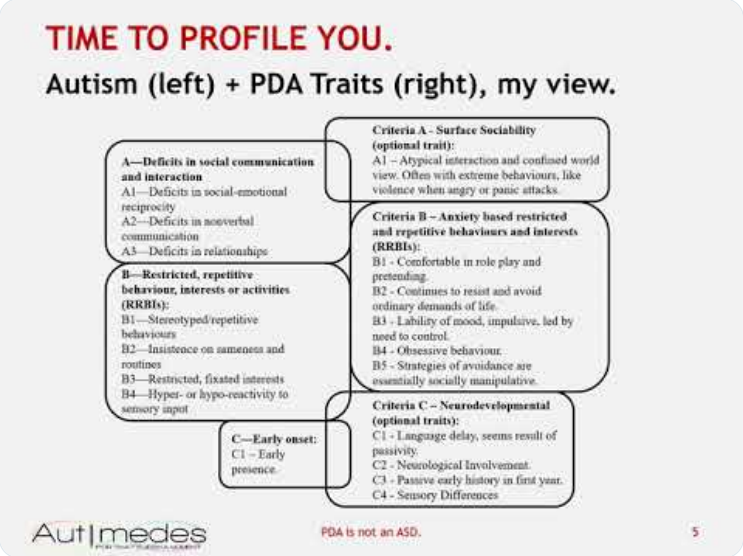
Not the first either in articles by yourself, O'Nions & others, I might point out. osf.io/8sbvw/

@HappeLab At least this latest article, substantiates my point the reviewer of this submission of mine was talking male bovine excrement, as O'Nions does view PDA to be autism in their latest article.

@HappeLab "Across the broader autism spectrum as we now know it," p2.

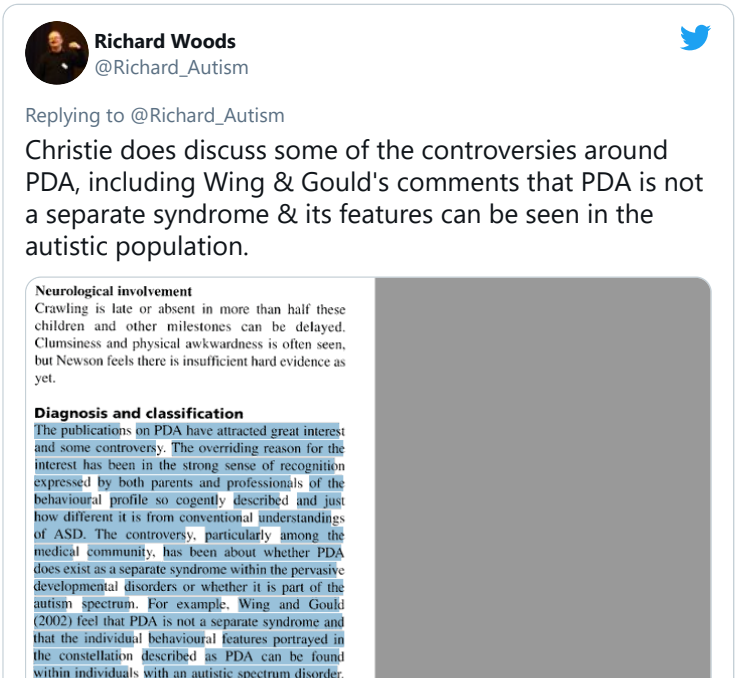
I have no idea what you & others are specifically referring to here?

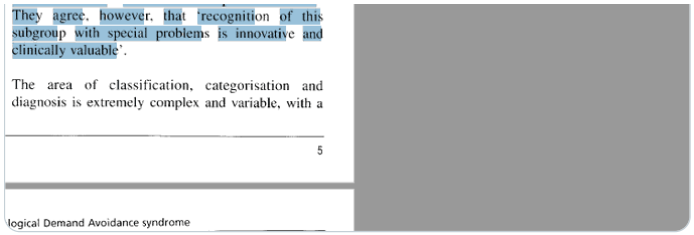
There is NO agreed definition of what broader autism spectrum is & discuss this here:



https://www.youtube.com/embed/GSIdMzDMC-w

@HappeLab This article of yours and others, seems to support my view that a prematurely formed a community of practice surrounding fallacious assumption "PDA is an ASD", and that such research is a self-validation exercise.




They agree, however, that 'recognition of this subgroup with special problems is innovative and clinically valuable'.

The area of classification, categorisation and diagnosis is extremely complex and variable, with a

5

logical Demand Avoidance syndrome

7:42 AM · May 22, 2021

1 Copy link to Tweet

@HappeLab previous tweet contains a screenshot of where Christie (2007) discusses PDA's controversies, Wing and Gould's views on PDA.

@HappeLab
"The last ten years have seen a rapid increase in interest in PDA in the UK," (O'Nions et al, 2021, p2).

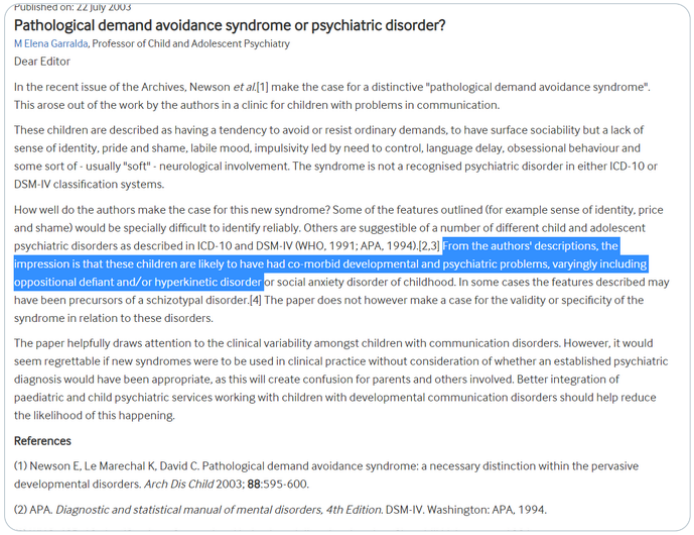
Sets time period of rise in interest in PDA is discussed in & strong disagreements over it. Article seems not to cover earlier critique.

@HappeLab not reviewing the literature for research results on the EDA-Q seems to be substantial error. Especially when omitting Garralda (2003), as some of their observations are supported by research with EDA-Q.

Richard Woods
@Richard_Autism

Replying to @Richard_Autism

Page 183 discuss features are associated with ADHD, like impulsivity and poor planning, which support critique of Garralda that CYP with PDA might have co-occurring ADHD. Hyperkinetic Disorder is ICD-10's name for ADHD.


Published on: 22 July 2003

Pathological demand avoidance syndrome or psychiatric disorder?

M Elena Garralda, Professor of Child and Adolescent Psychiatry

Dear Editor

In the recent issue of the Archives, Newson *et al*.[1] make the case for a distinctive "pathological demand avoidance syndrome". This arose out of the work by the authors in a clinic for children with problems in communication.

These children are described as having a tendency to avoid or resist ordinary demands, to have surface sociability but a lack of sense of identity, pride and shame, labile mood, impulsivity led by need to control, language delay, obsessional behaviour and some sort of - usually "soft" - neurological involvement. The syndrome is not a recognised psychiatric disorder in either ICD-10 or DSM-IV classification systems.

How well do the authors make the case for this new syndrome? Some of the features outlined (for example sense of identity, price and shame) would be specially difficult to identify reliably. Others are suggestible of a number of different child and adolescent psychiatric disorders as described in ICD-10 and DSM-IV (WHO, 1991; APA, 1994).[2,3] From the authors' descriptions, the impression is that these children are likely to have had co-morbid developmental and psychiatric problems, varyingly including oppositional defiant and/or hyperkinetic disorder or social anxiety disorder of childhood. In some cases the features described may have been precursors of a schizotypal disorder.[4] The paper does not however make a case for the validity or specificity of the syndrome in relation to these disorders.

The paper helpfully draws attention to the clinical variability amongst children with communication disorders. However, it would seem regrettable if new syndromes were to be used in clinical practice without consideration of whether an established psychiatric diagnosis would have been appropriate, as this will create confusion for parents and others involved. Better integration of paediatric and child psychiatric services working with children with developmental communication disorders should help reduce the likelihood of this happening.

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(1) Newson E, Le Marechal K, David C. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Arch Dis Child* 2003; **88**:595-600.

(2) APA. *Diagnostic and statistical manual of mental disorders, 4th Edition*. DSM-IV. Washington: APA, 1994.

9:43 AM · May 24, 2021

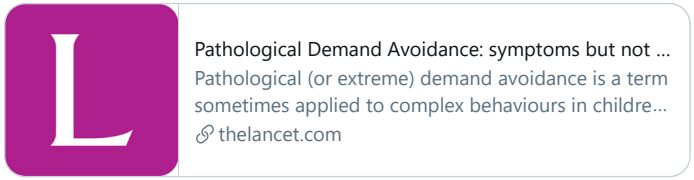
1 1 Copy link to Tweet

Richard Woods

@Richard_Autism

Replying to @Richard_Autism

"High SDQ conduct and hyperactivity scores plus a clinical diagnosis of anxiety were highly predictive of scores above the pathological demand avoidance threshold on the EDA-Q" (Green et al, 2018, p461-462).

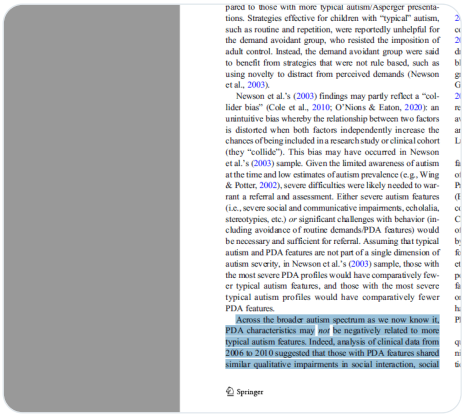


8:44 AM · May 22, 2021

1 1 Copy link to Tweet

@HappeLab previous tweets show where at least one of Garralda (2003) observations are supported by research results, with EDA-Q and EDA-QA.

@HappeLab There does seem to be a COI in not discussing such research results & Garralda, as it undermines attempts to try and support the view PDA as an ASD in the article.



pared to those with more typical autism/Asperger presentations. Strategies effective for children with "typical" autism, such as routine and repetition, were reportedly unhelpful for the demand avoidant group, who resisted the imposition of adult control. Instead, the demand avoidant group were said to benefit from strategies that were not rule based, such as using novelty to distract from perceived demands (Newson et al., 2003).

Newson et al.'s (2003) findings may partly reflect a "collider bias" (Cole et al., 2010; O'Nions & Eaton, 2020): an uninituitive bias whereby the relationship between two factors is distorted when both factors independently increase the chances of being included in a research study or clinical cohort (they "collide"). This bias may have occurred in Newson et al.'s (2003) sample. Given the limited awareness of autism at the time and low estimates of autism prevalence (e.g., Wing & Potter, 2002), severe difficulties were likely needed to warrant a referral and assessment. Either severe autism features (i.e., severe social and communicative impairments, echolalia, stereotypies, etc.) *or* significant challenges with behavior (including avoidance of routine demands/PDA features) would be necessary and sufficient for referral. Assuming that typical autism and PDA features are not part of a single dimension of autism severity, in Newson et al.'s (2003) sample, those with the most severe PDA profiles would have comparatively fewer typical autism features, and those with the most severe typical autism profiles would have comparatively fewer PDA features.

Across the broader autism spectrum as we now know it, PDA characteristics may *not* be negatively related to more typical autism features. Indeed, analysis of clinical data from 2006 to 2010 suggested that those with PDA features shared similar qualitative impairments in social interaction, social

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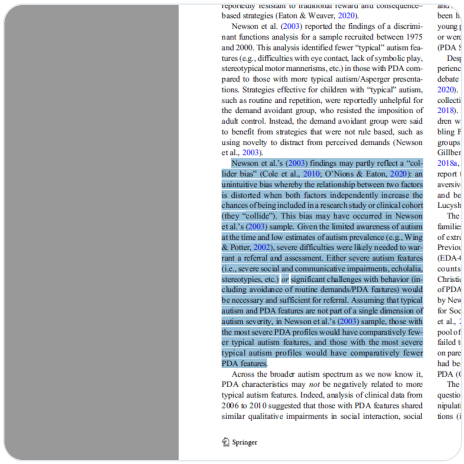

based strategies (Eaton & Weaver, 2020).

Newson et al. (2003) reported the findings of a discriminant functions analysis for a sample recruited between 1975 and 2000. This analysis identified fewer "typical" autism features (e.g., difficulties with eye contact, lack of symbolic play, stereotypical motor mannerisms, etc.) in those with PDA compared to those with more typical autism/Asperger presentations. Strategies effective for children with "typical" autism, such as routine and repetition, were reportedly unhelpful for the demand avoidant group, who resisted the imposition of adult control. Instead, the demand avoidant group were said to benefit from strategies that were not rule based, such as using novelty to distract from perceived demands (Newson et al., 2003).

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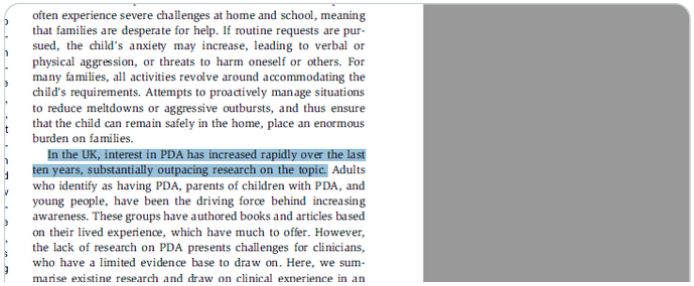
@HappeLab If one acknowledges Garralda is correct PDA has features of ADHD, then it contradicts assertions PDA is autism. As PDA cannot be more than its constituent parts. A + B + C ≠ A.

Richard Woods
@Richard_Autism

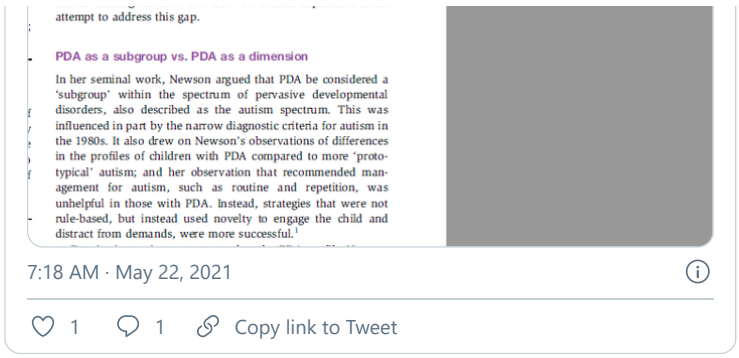
Replying to @Richard_Autism

Screenshot and link for first quote.
linkinghub.elsevier.com/retrieve/pii/S...



often experience severe challenges at home and school, meaning that families are desperate for help. If routine requests are pursued, the child's anxiety may increase, leading to verbal or physical aggression, or threats to harm oneself or others. For many families, all activities revolve around accommodating the child's requirements. Attempts to proactively manage situations to reduce meltdowns or aggressive outbursts, and thus ensure that the child can remain safely in the home, place an enormous burden on families.

In the UK, interest in PDA has increased rapidly over the last ten years, substantially outpacing research on the topic. Adults who identify as having PDA, parents of children with PDA, and young people, have been the driving force behind increasing awareness. These groups have authored books and articles based on their lived experience, which have much to offer. However, the lack of research on PDA presents challenges for clinicians, who have a limited evidence base to draw on. Here, we summarise existing research and draw on clinical experience in an


attempt to address this gap.

PDA as a subgroup vs. PDA as a dimension

In her seminal work, Newson argued that PDA be considered a 'subgroup' within the spectrum of pervasive developmental disorders, also described as the autism spectrum. This was influenced in part by the narrow diagnostic criteria for autism in the 1980s. It also drew on Newson's observations of differences in the profiles of children with PDA compared to more 'prototypical' autism; and her observation that recommended management for autism, such as routine and repetition, was unhelpful in those with PDA. Instead, strategies that were not rule-based, but instead used novelty to engage the child and distract from demands, were more successful.[1]

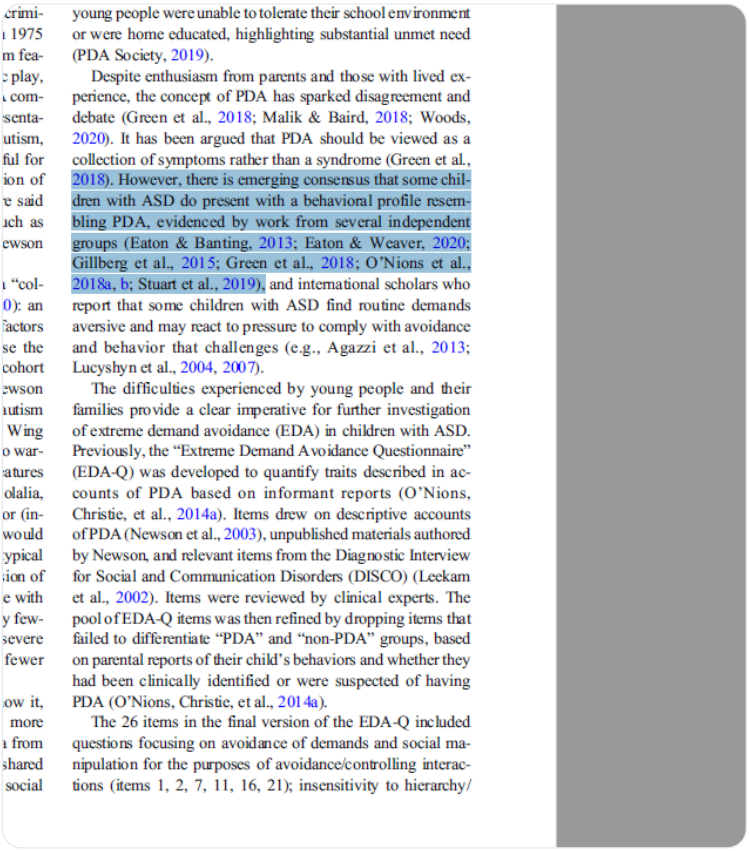
7:18 AM · May 22, 2021

1 1 Copy link to Tweet

@HappeLab I would suggest that, perhaps a contributing factor in why growth in PDA has outstripped its research, is because certain "leading experts" (includes more than authors of this article) are not providing balanced & accurate information on PDA?

@HappeLab It would be substantially harder to justify forming a community of practice, and doing certain research, if one accurately portrays contested nature of PDA & credits certain research results to those who first predicted them.

@HappeLab I am pretty certain that you and others in the article have misrepresented the literature, in stating many independent research groups have shown PDA to be present in autistic persons. Certainly have overstated the case.

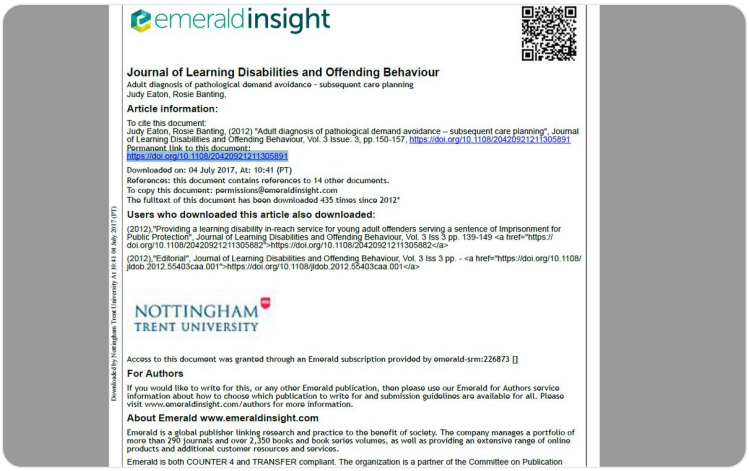

young people were unable to tolerate their school environment or were home educated, highlighting substantial unmet need (PDA Society, 2019).

Despite enthusiasm from parents and those with lived experience, the concept of PDA has sparked disagreement and debate (Green et al., 2018; Malik & Baird, 2018; Woods, 2020). It has been argued that PDA should be viewed as a collection of symptoms rather than a syndrome (Green et al., 2018). However, there is emerging consensus that some children with ASD do present with a behavioral profile resembling PDA, evidenced by work from several independent groups (Eaton & Banting, 2013; Eaton & Weaver, 2020; Gillberg et al., 2015; Green et al., 2018; O'Nions et al., 2018a, b; Stuart et al., 2019), and international scholars who report that some children with ASD find routine demands aversive and may react to pressure to comply with avoidance and behavior that challenges (e.g., Agazzi et al., 2013; Lucyshyn et al., 2004, 2007).

The difficulties experienced by young people and their families provide a clear imperative for further investigation of extreme demand avoidance (EDA) in children with ASD. Previously, the "Extreme Demand Avoidance Questionnaire" (EDA-Q) was developed to quantify traits described in accounts of PDA based on informant reports (O'Nions, Christie, et al., 2014a). Items drew on descriptive accounts of PDA (Newson et al., 2003), unpublished materials authored by Newson, and relevant items from the Diagnostic Interview for Social and Communication Disorders (DISCO) (Leekam et al., 2002). Items were reviewed by clinical experts. The pool of EDA-Q items was then refined by dropping items that failed to differentiate "PDA" and "non-PDA" groups, based on parental reports of their child's behaviors and whether they had been clinically identified or were suspected of having PDA (O'Nions, Christie, et al., 2014a).

The 26 items in the final version of the EDA-Q included questions focusing on avoidance of demands and social manipulation for the purposes of avoidance/controlling interactions (items 1, 2, 7, 11, 16, 21); insensitivity to hierarchy/

@HappeLab first point, Eaton & Banting is a adult case study... It is literally in the article title.
https://doi.org/10.1108/20420921211305891



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Judy Eaton, Rosie Banting,

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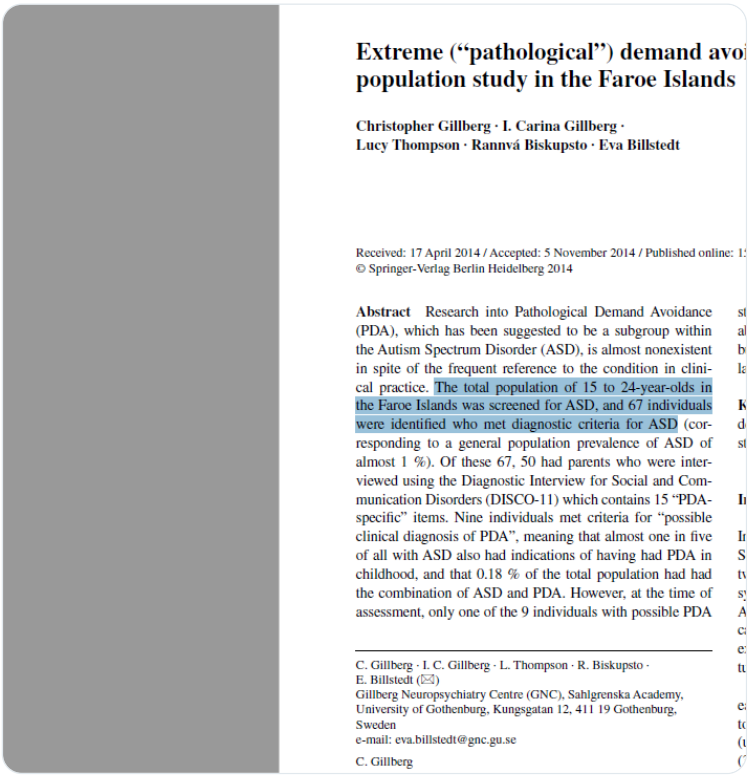
[@HappeLab](#) Gillberg et al (2015), the age range of participants is 15 - 24, mean 19.1 years; SD 2.6 years (p981). Hardly children here.



Extreme ("pathological") demand avoi
population study in the Faroe Islands

Christopher Gillberg · I. Carina Gillberg ·
Lucy Thompson · Rannvá Biskupsto · Eva Billstedt

Received: 17 April 2014 / Accepted: 5 November 2014 / Published online: 1
© Springer-Verlag Berlin Heidelberg 2014

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

C. Gillberg · I. C. Gillberg · L. Thompson · R. Biskupsto ·
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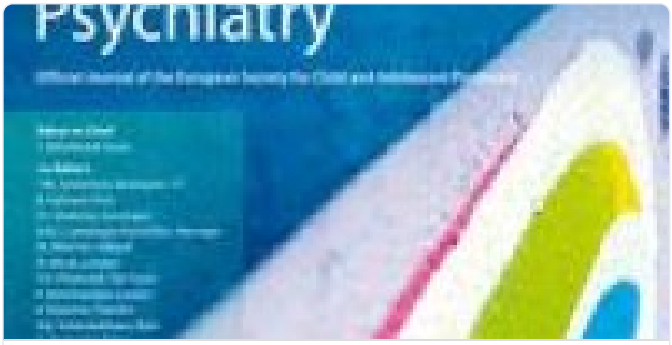
Sweden
e-mail: eva.billstedt@gnc.gu.se

C. Gillberg

[@HappeLab](#) Also contradicting Gillberg et al (2015) prediction that PDA can be seen in up to a few percent of human populations. Also Gillberg's view PDA is common and possibly a new type of childhood disorder.



Extreme ("pathological") demand avoidance in autism: a general popu…
Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexiste

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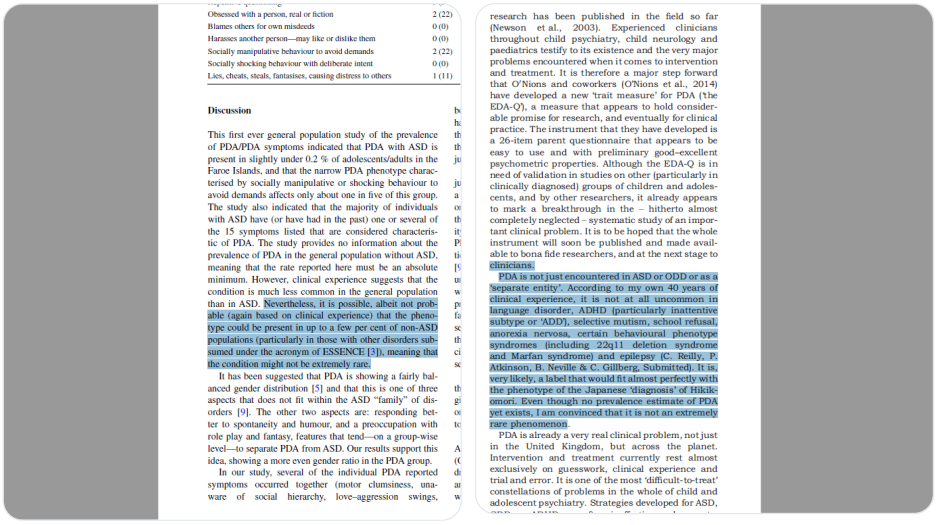
https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.12275



Obsessed with a person, real or fiction 2 (22)
Blames others for own misdeeds 0 (0)
Harasses another person—may like or dislike them 0 (0)
Socially manipulative behaviour to avoid demands 2 (22)
Socially shocking behaviour with deliberate intent 0 (0)
Lies, cheats, steals, fantasises, causing distress to others 1 (11)

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.

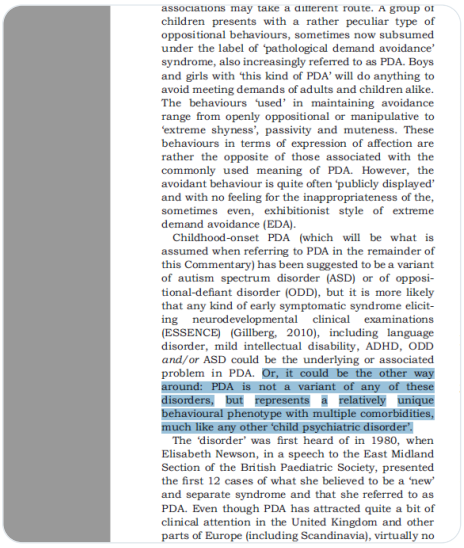
It has been suggested that PDA is showing a fairly balanced gender distribution [5] and that this is one of three aspects that does not fit within the ASD "family" of disorders [9]. The other two aspects are: responding better to spontaneity and humour, and a preoccupation with role play and fantasy, 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,

research has been published in the field so far (Newson et al., 2003). Experienced clinicians throughout child psychiatry, child neurology and paediatrics testify to its existence and the very major problems encountered when it comes to intervention and treatment. It is therefore a major step forward that O'Nions and coworkers (O'Nions et al., 2014) have developed a new 'trait measure' for PDA ('the EDA-Q'), a measure that appears to hold considerable promise for research, and eventually for clinical practice. The instrument that they have developed is a 26-item parent questionnaire that appears to be easy to use and with preliminary good–excellent psychometric properties. Although the EDA-Q is in need of validation in studies on other (particularly in clinically diagnosed) groups of children and adolescents, and by other researchers, it already appears to mark a breakthrough in the – hitherto almost completely neglected – systematic study of an important clinical problem. It is to be hoped that the whole instrument will soon be published and made available to bona fide researchers, and at the next stage to clinicians.

PDA is not just encountered in ASD or ODD or as a 'separate entity'. According to my own 40 years of clinical experience, it is not at all uncommon in language disorder, ADHD (particularly inattentive subtype or 'ADD'), selective mutism, school refusal, anorexia nervosa, certain behavioural phenotype syndromes (including 22q11 deletion syndrome and Marfan syndrome) and epilepsy (C. Reilly, P. Atkinson, B. Neville & C. Gillberg, Submitted). It is, very likely, a label that would fit almost perfectly with the phenotype of the Japanese 'diagnosis' of Hikikomori. Even though no prevalence estimate of PDA yet exists, I am convinced that it is not an extremely rare phenomenon.

PDA is already a very real clinical problem, not just in the United Kingdom, but across the planet. Intervention and treatment currently rest almost exclusively on guesswork, clinical experience and trial and error. It is one of the most 'difficult-to-treat' constellations of problems in the whole of child and adolescent psychiatry. Strategies developed for ASD,



associations may take a different route. A group of children presents with a rather peculiar type of oppositional behaviours, sometimes now subsumed under the label of 'pathological demand avoidance' syndrome, also increasingly referred to as PDA. Boys and girls with 'this kind of PDA' will do anything to avoid meeting demands of adults and children alike. The behaviours 'used' in maintaining avoidance range from openly oppositional or manipulative to 'extreme shyness', passivity and muteness. These behaviours in terms of expression of affection are rather the opposite of those associated with the commonly used meaning of PDA. However, the avoidant behaviour is quite often 'publicly displayed' and with no feeling for the inappropriateness of the, sometimes even, exhibitionist style of extreme demand avoidance (EDA).

Childhood-onset PDA (which will be what is assumed when referring to PDA in the remainder of this Commentary) has been suggested to be a variant of autism spectrum disorder (ASD) or of oppositional-defiant disorder (ODD), but it is more likely that any kind of early symptomatic syndrome eliciting neurodevelopmental clinical examinations (ESSENCE) (Gillberg, 2010), including language disorder, mild intellectual disability, ADHD, ODD *and/or* ASD could be the underlying or associated problem in PDA. Or, it could be the other way around: PDA is not a variant of any of these disorders, but represents a relatively unique behavioural phenotype with multiple comorbidities, much like any other 'child psychiatric disorder'.

The 'disorder' was first heard of in 1980, when Elisabeth Newson, in a speech to the East Midland Section of the British Paediatric Society, presented the first 12 cases of what she believed to be a 'new' and separate syndrome and that she referred to as PDA. Even though PDA has attracted quite a bit of clinical attention in the United Kingdom and other parts of Europe (including Scandinavia), virtually no

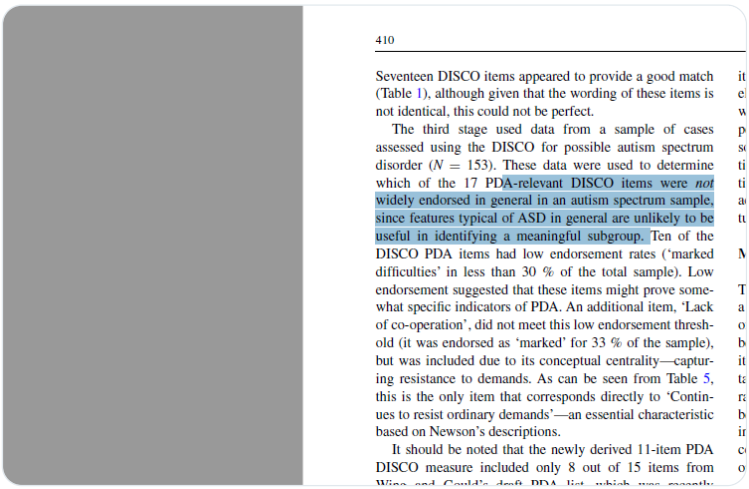
@HappeLab Simple rebuttal to O'Nions et al (2015) is that they viewed PDA to be autism subgroup.

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

While at the same they ignored the ongoing debates in PDA literature, including contradictory results & views.
osf.io/8sbvw/



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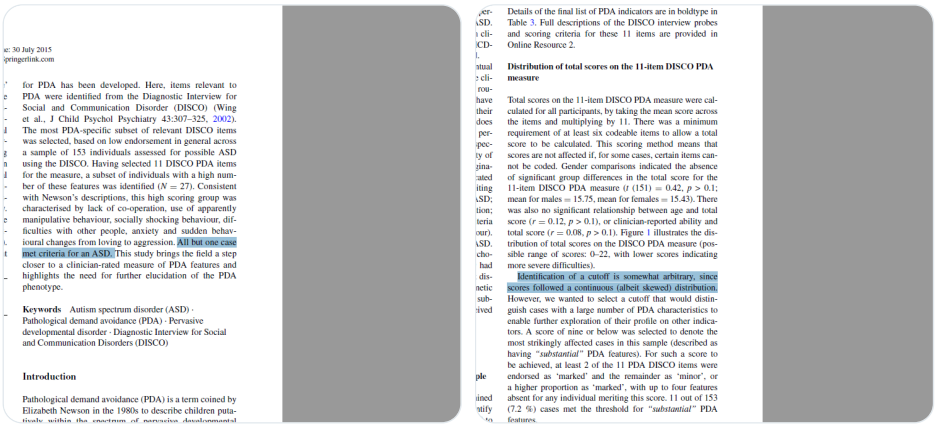
Seventeen DISCO items appeared to provide a good match (Table 1), although given that the wording of these items is not identical, this could not be perfect.

The third stage used data from a sample of cases assessed using the DISCO for possible autism spectrum disorder ($N = 153$). These data were used to determine which of the 17 PDA-relevant DISCO items were *not* widely endorsed in general in an autism spectrum sample, since features typical of ASD in general are unlikely to be useful in identifying a meaningful subgroup. Ten of the DISCO PDA items had low endorsement rates ('marked difficulties' in less than 30 % of the total sample). Low endorsement suggested that these items might prove somewhat specific indicators of PDA. An additional item, 'Lack of co-operation', did not meet this low endorsement threshold (it was endorsed as 'marked' for 33 % of the sample), but was included due to its conceptual centrality—capturing resistance to demands. As can be seen from Table 5, this is the only item that corresponds directly to 'Continues to resist ordinary demands'—an essential characteristic based on Newson's descriptions.

It should be noted that the newly derived 11-item PDA DISCO measure included only 8 out of 15 items from

@HappeLab we also know that O'Nions et al (2015) used an arbitrary threshold to categorise who had PDA and did not have PDA. That one of the persons with PDA was not autistic.



e: 30 July 2015
springerlink.com

for PDA has been developed. Here, items relevant to PDA were identified from the Diagnostic Interview for Social and Communication Disorder (DISCO) (Wing et al., J Child Psychol Psychiatry 43:307–325, 2002). The most PDA-specific subset of relevant DISCO items was selected, based on low endorsement in general across a sample of 153 individuals assessed for possible ASD using the DISCO. Having selected 11 DISCO PDA items for the measure, a subset of individuals with a high number of these features was identified ($N = 27$). Consistent with Newson's descriptions, this high scoring group was characterised by lack of co-operation, use of apparently manipulative behaviour, socially shocking behaviour, difficulties with other people, anxiety and sudden behavioural changes from loving to aggression. All but one case met criteria for an ASD. This study brings the field a step closer to a clinician-rated measure of PDA features and highlights the need for further elucidation of the PDA phenotype.

Keywords Autism spectrum disorder (ASD) · Pathological demand avoidance (PDA) · Pervasive developmental disorder · Diagnostic Interview for Social and Communication Disorders (DISCO)

Introduction

Pathological demand avoidance (PDA) is a term coined by Elizabeth Newson in the 1980s to describe children puta-

Details of the final list of PDA indicators are in boldtype in Table 3. Full descriptions of the DISCO interview probes and scoring criteria for these 11 items are provided in Online Resource 2.

Distribution of total scores on the 11-item DISCO PDA measure

Total scores on the 11-item DISCO PDA measure were calculated for all participants, by taking the mean score across the items and multiplying by 11. There was a minimum requirement of at least six codeable items to allow a total score to be calculated. This scoring method means that scores are not affected if, for some cases, certain items cannot be coded. Gender comparisons indicated the absence of significant group differences in the total score for the 11-item DISCO PDA measure (t (151) = 0.42, $p > 0.1$; mean for males = 15.75, mean for females = 15.43). There was also no significant relationship between age and total score ($r = 0.12$, $p > 0.1$), or clinician-reported ability and total score ($r = 0.08$, $p > 0.1$). Figure 1 illustrates the distribution of total scores on the DISCO PDA measure (possible range of scores: 0–22, with lower scores indicating more severe difficulties).

Identification of a cutoff is somewhat arbitrary, since scores followed a continuous (albeit skewed) distribution. However, we wanted to select a cutoff that would distinguish cases with a large number of PDA characteristics to enable further exploration of their profile on other indicators. A score of nine or below was selected to denote the most strikingly affected cases in this sample (described as having *"substantial"* PDA features). For such a score to be achieved, at least 2 of the 11 PDA DISCO items were endorsed as 'marked' and the remainder as 'minor', or a higher proportion as 'marked', with up to four features absent for any individual meriting this score. 11 out of 153 (7.2 %) cases met the threshold for *"substantial"* PDA features.

@HappeLab so one can argue that O'Nions et al (2015) arbitrarily decided to view PDA as an ASD. Due to arbitrary cut-off it is difficult to take much from that research.

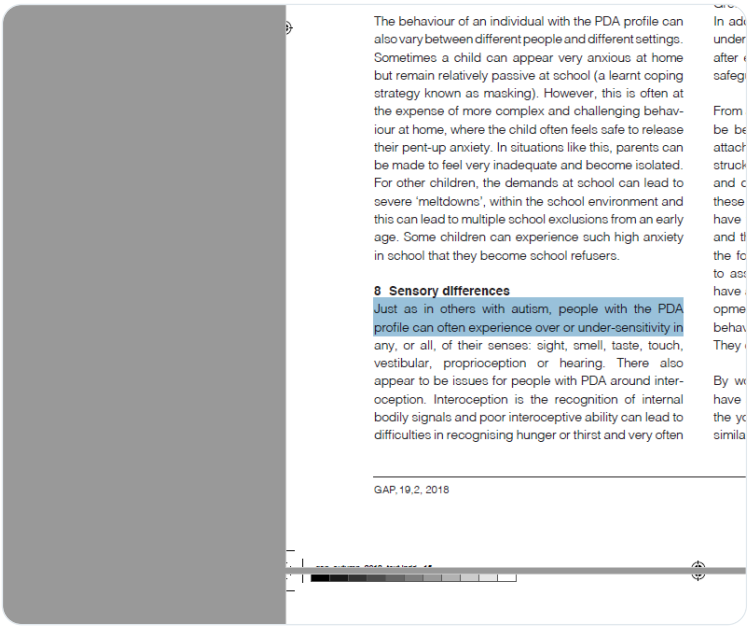
@HappeLab Just because some have chosen to view PDA as an ASD subgroup & have pursued a research agenda to support their outlook, does not mean that other perspectives on PDA are less than the authors of O'Nions et al (2015).

@HappeLab as pointed out earlier in the thread we already know that at least of the divergent opinion on PDA is valid, e.g., that PDA has characteristics that can be attributed towards ADHD.

@HappeLab The point I am making here, just because there is a lack of evidence into divergent perspectives of PDA, does not meant that you, or O'Nions or other "PDA is an ASD" advocates can state PDA is an ASD subtype/ subgroup/ profile.

@HappeLab Or likewise, claim there is a consensus around what PDA is. That is not science, research should not be done to support a particular outlook at the expense of others.

@HappeLab The same points are equally applicable to other research referenced in O'Nions et al (2018) and Eaton and Weaver (2020), which both view PDA to be an ASD.



The behaviour of an individual with the PDA profile can also vary between different people and different settings. Sometimes a child can appear very anxious at home but remain relatively passive at school (a learnt coping strategy known as masking). However, this is often at the expense of more complex and challenging behaviour at home, where the child often feels safe to release their pent-up anxiety. In situations like this, parents can be made to feel very inadequate and become isolated. For other children, the demands at school can lead to severe 'meltdowns', within the school environment and this can lead to multiple school exclusions from an early age. Some children can experience such high anxiety in school that they become school refusers.

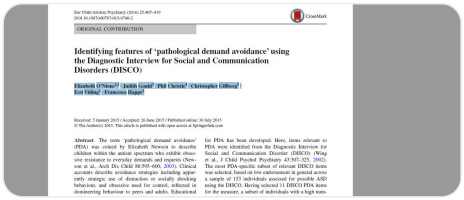
8 Sensory differences

Just as in others with autism, people with the PDA profile can often experience over or under-sensitivity in any, or all, of their senses: sight, smell, taste, touch, vestibular, proprioception or hearing. There also appear to be issues for people with PDA around interoception. Interoception is the recognition of internal bodily signals and poor interoceptive ability can lead to difficulties in recognising hunger or thirst and very often

GAP.19.2, 2018

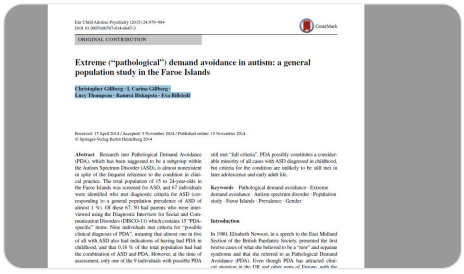
@Happe The point so far, is that most of these examples so far covered are not exactly independent are they?

@HappeLab O'Nions et al (2015) has similar authors with O'Nions et al (2018). Likewise Christopher Gillberg co-authored O'Nions et al (2015) & Gilllberg et al (2015). Not too mention you & O'Nions were assisted Eaton & Weaver.



ORIGINAL CONTRIBUTION

Identifying features of 'pathological demand avoidance' using the Diagnostic Interview for Social and Communication Disorders (DISCO)

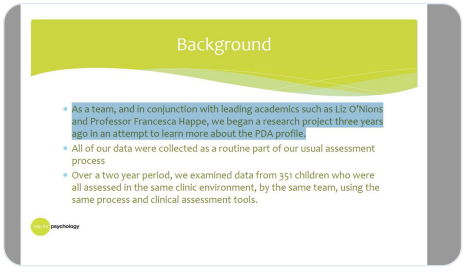


ORIGINAL CONTRIBUTION

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

Child and Adolescent Mental Health

Dimensions of difficulty in children reported to have an autism spectrum diagnosis and features of extreme/'pathological' demand avoidance



Background

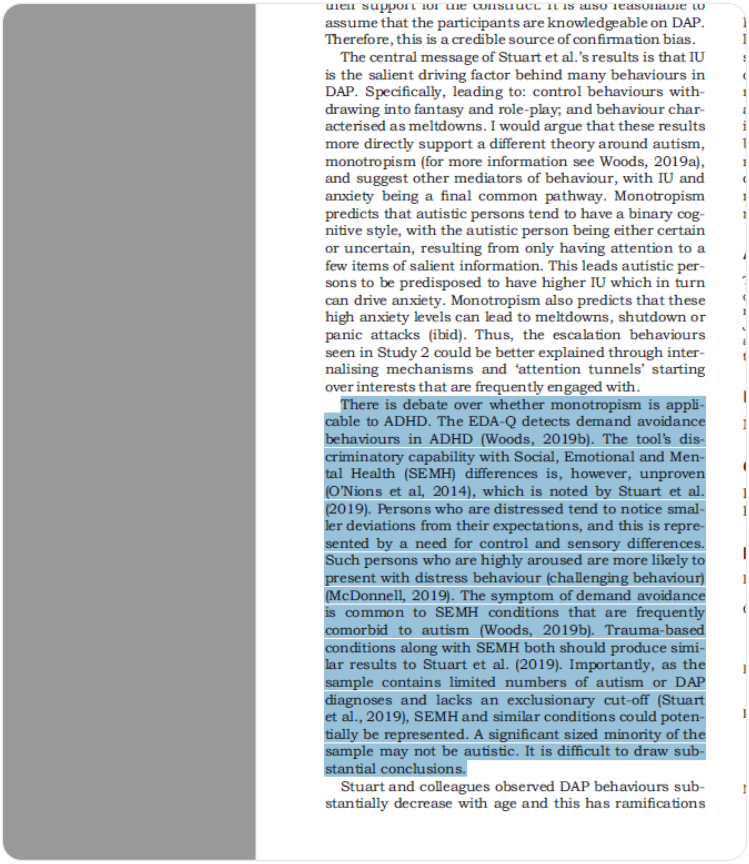
- As a team, and in conjunction with leading academics such as Liz O'Nions and Professor Francesca Happe, we began a research project three years ago in an attempt to learn more about the PDA profile.
- All of our data were collected as a routine part of our usual assessment process
- Over a two year period, we examined data from 351 children who were all assessed in the same clinic environment, by the same team, using the same process and clinical assessment tools.

@HappeLab I would also add that Eaton and Weaver developed their PDA definitions based on their clinical opinions, which is insufficient rationale to warrant

adopting them.

@HappeLab It is beg the question, what if a different created their own PDA definitions and made a partnership with researchers. Would you be equally supportive of such efforts?

@HappeLab Stuart et al (2020) is referenced, the issue here is that one cannot be sure their sample is entirely autistic, as I mention on my commentary on their article (which O'Nions et al 2021 references).
https://www.researchgate.net/publication/338650142_Commentary_Demand_Avoidance_Phenomena_a_manifold_issue_Intolerance_of_uncertainty_and_anxiety_as_explanatory_frameworks_for_extreme_demand_avoidance_in_children_and_adolescents_-_a_commentary_on_Stuar



their support for the construct. It is also reasonable to assume that the participants are knowledgeable on DAP. Therefore, this is a credible source of confirmation bias.

The central message of Stuart et al.'s results is that IU is the salient driving factor behind many behaviours in DAP. Specifically, leading to: control behaviours withdrawing into fantasy and role-play; and behaviour characterised as meltdowns. I would argue that these results more directly support a different theory around autism, monotropism (for more information see Woods, 2019a), and suggest other mediators of behaviour, with IU and anxiety being a final common pathway. Monotropism predicts that autistic persons tend to have a binary cognitive style, with the autistic person being either certain or uncertain, resulting from only having attention to a few items of salient information. This leads autistic persons to be predisposed to have higher IU which in turn can drive anxiety. Monotropism also predicts that these high anxiety levels can lead to meltdowns, shutdown or panic attacks (ibid). Thus, the escalation behaviours seen in Study 2 could be better explained through internalising mechanisms and 'attention tunnels' starting over interests that are frequently engaged with.

There is debate over whether monotropism is applicable to ADHD. The EDA-Q detects demand avoidance behaviours in ADHD (Woods, 2019b). The tool's discriminatory capability with Social, Emotional and Mental Health (SEMH) differences is, however, unproven (O'Nions et al, 2014), which is noted by Stuart et al. (2019). Persons who are distressed tend to notice smaller deviations from their expectations, and this is represented by a need for control and sensory differences. Such persons who are highly aroused are more likely to present with distress behaviour (challenging behaviour) (McDonnell, 2019). The symptom of demand avoidance is common to SEMH conditions that are frequently comorbid to autism (Woods, 2019b). Trauma-based conditions along with SEMH both should produce similar results to Stuart et al. (2019). Importantly, as the sample contains limited numbers of autism or DAP diagnoses and lacks an exclusionary cut-off (Stuart et al., 2019), SEMH and similar conditions could potentially be represented. A significant sized minority of the sample may not be autistic. It is difficult to draw substantial conclusions.

Stuart and colleagues observed DAP behaviours substantially decrease with age and this has ramifications

@HappeLab That leaves Green et al (2018). I can categorically say that one has been misrepresented as it was collected by @MAbsoud & he has been clear there were non-autistic CYP with PDA in his dataset...

On Tuesday 8th January 2019, the PDA Society hosted a research meeting to share current findings, thinking and insights around the 'PDA profile' of autism by academic researchers and other stakeholde…

https://www.pdasociety.org.uk/research-meeting-report/#:~:text=On%20Tuesday%208t…

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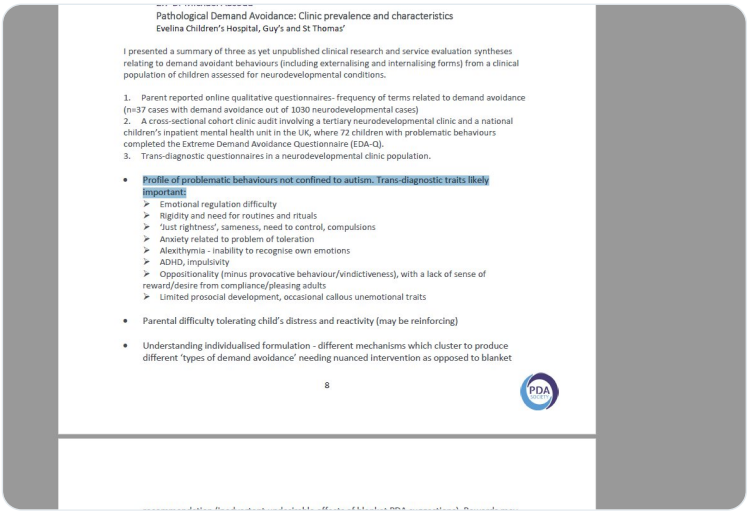
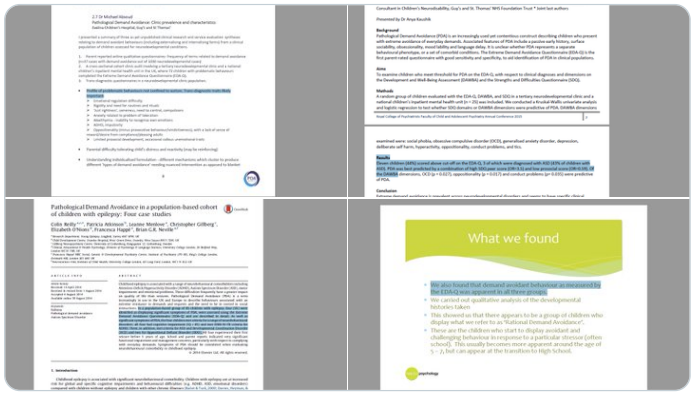


@HappeLab The simple counter point all these "independent" research groups detecting PDA in autistic persons, is to list all the research groups & examples of non-autistic persons in the PDA literature...

Richard Woods
@Richard_Autism

Replying to @Richard_Autism

@HappeLab Links to where EDA-Q has detected PDA in non-autistic persons.
sciencedirect.com/science/articl…
&
pdasociety.org.uk/wp-content/upl…
&
autism.org.uk/what-we-do/pro…



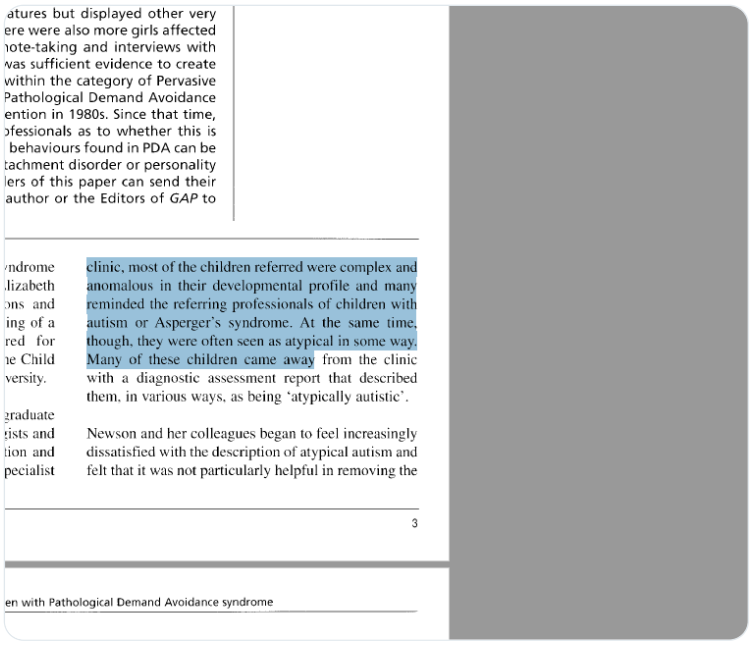
9:52 AM · May 30, 2021

1 Copy link to Tweet

@HappeLab previous tweet mentions where EDA-Q has detected PDA in non-autistic persons.

@HappeLab previous tweet sets out how there are non-autistic persons with PDA in Newson's cohort, and this is supported by similar statements in Newson et al (2003), Christie (2007) and Christie et al (2011).

@HappeLab "most of the children referred were complex and anomalous in their developmental profile and many reminded the referring professionals of children with autism or Asperger's syndrome." (Christie, 2007, p3).
https://www.ingentaconnect.com/contentone/bild/gap/2007/00000008/00000001/art00002



atures but displayed other very
ere were also more girls affected
note-taking and interviews with
was sufficient evidence to create
within the category of Pervasive
Pathological Demand Avoidance
ention in 1980s. Since that time,
ofessionals as to whether this is
behaviours found in PDA can be
tachment disorder or personality
lers of this paper can send their
author or the Editors of *GAP* to

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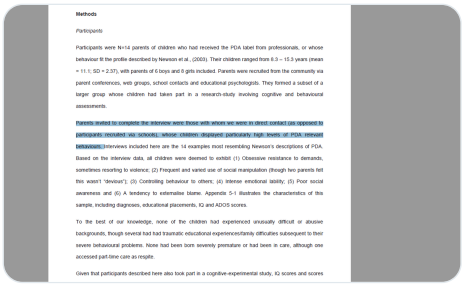
clinic, most of the children referred were complex and anomalous in their developmental profile and many reminded the referring professionals of children with autism or Asperger's syndrome. At the same time, though, they were often seen as atypical in some way. Many of these children came away from the clinic with a diagnostic assessment report that described them, in various ways, as being 'atypically autistic'.

Newson and her colleagues began to feel increasingly dissatisfied with the description of atypical autism and felt that it was not particularly helpful in removing the

3

en with Pathological Demand Avoidance syndrome

@HappeLab There's an example of an non-autistic CYP with PDA, who has attachment disorder, from research in O'Nions PhD thesis. Important to note CYP with PDA were known to researchers, which contradicts view PDA is specific to autism!
http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf



Methods

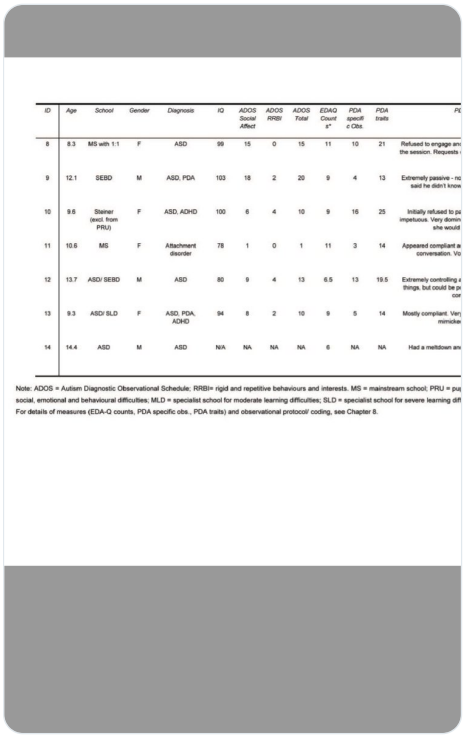
Participants

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 experiencesfamily 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.

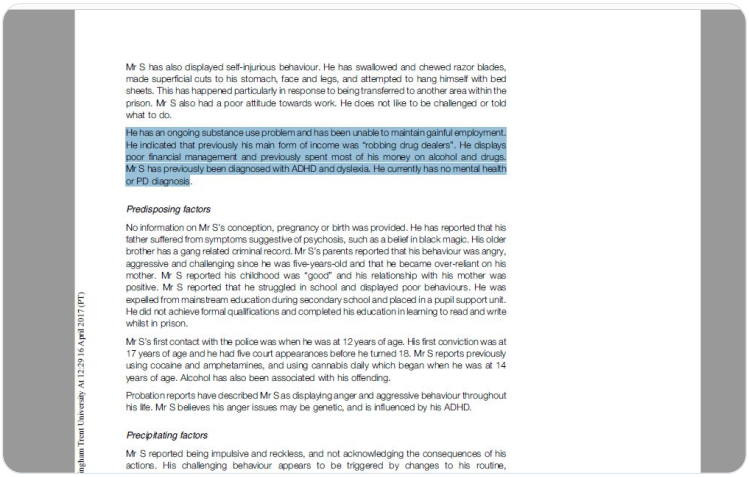
Given that participants described here also took part in a cognitive-experimental study, IQ scores and scores



ID	Age	School	Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Count s*	PDA specifi c Obs.	PDA traits	PD
8	8.3	MS with 1:1	F	ASD	99	15	0	15	11	10	21	Refused to engage an the session. Requests
9	12.1	SEBD	M	ASD, PDA	103	18	2	20	9	4	13	Extremely passive - no said he didn't know
10	9.6	Steiner (excl. from PRU)	F	ASD, ADHD	100	6	4	10	9	16	25	Initially refused to pa impetuous. Very domin she would
11	10.6	MS	F	Attachment disorder	78	1	0	1	11	3	14	Appeared compliant a conversation. Vis
12	13.7	ASD/ SEBD	M	ASD	80	9	4	13	6.5	13	19.5	Extremely controlling things, but could be p cor
13	9.3	ASD/ SLD	F	ASD, PDA, ADHD	94	8	2	10	9	5	14	Mostly compliant. Very mimicke
14	14.4	ASD	M	ASD	N/A	NA	NA	NA	NA	6	NA	NA Had a meltdown an

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

@HappeLab There is also a good candidate for a non-autistic person with PDA in Trundle et al (2017). Adult was assessed for PDA, not autism. Diagnosed with ADHD dyslexia, has substance issues (off the top of my head).
https://dx.doi.org/10.1108/JIDOB-07-2016-0013



Mr S has also displayed self-injurious behaviour. He has swallowed and chewed razor blades, made superficial cuts to his stomach, face and legs, and attempted to hang himself with bed sheets. This has happened particularly in response to being transferred to another area within the prison. Mr S also had a poor attitude towards work. He does not like to be challenged or told what to do.

He has an ongoing substance use problem and has been unable to maintain gainful employment. He indicated that previously his main form of income was "robbing drug dealers". He displays poor financial management and previously spent most of his money on alcohol and drugs. Mr S has previously been diagnosed with ADHD and dyslexia. He currently has no mental health or PD diagnosis.

Predisposing factors

No information on Mr S's conception, pregnancy or birth was provided. He has reported that his father suffered from symptoms suggestive of psychosis, such as a belief in black magic. His older brother has a gang related criminal record. Mr S's parents reported that his behaviour was angry, aggressive and challenging since he was five-years-old and that he became over-reliant on his mother. Mr S reported his childhood was "good" and his relationship with his mother was positive. Mr S reported that he struggled in school and displayed poor behaviours. He was expelled from mainstream education during secondary school and placed in a pupil support unit. He did not achieve formal qualifications and completed his education in learning to read and write whilst in prison.

Mr S's first contact with the police was when he was at 12 years of age. His first conviction was at 17 years of age and he had five court appearances before he turned 18. Mr S reports previously using cocaine and amphetamines, and using cannabis daily which began when he was at 14 years of age. Alcohol has also been associated with his offending.

Probation reports have described Mr S as displaying anger and aggressive behaviour throughout his life. Mr S believes his anger issues may be genetic, and is influenced by his ADHD.

Precipitating factors

Mr S reported being impulsive and reckless, and not acknowledging the consequences of his actions. His challenging behaviour appears to be triggered by changes to his routine,

I think I am done for now, @threadreaderapp please can you unroll?

Thank you in advance.

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