Richard Woods @Richard_Autism

Feb 14 • 15 tweets • Richard_Autism/status/1493203283158126594

@threadreaderapp If anyone is wondering there are non-autistic persons diagnosed with PDA in the literature. Like these three in O'Nions (2013), see the CP/HCU column. Due to how these groups were constructed there is likely more non-autistic persons with PDA in this study.

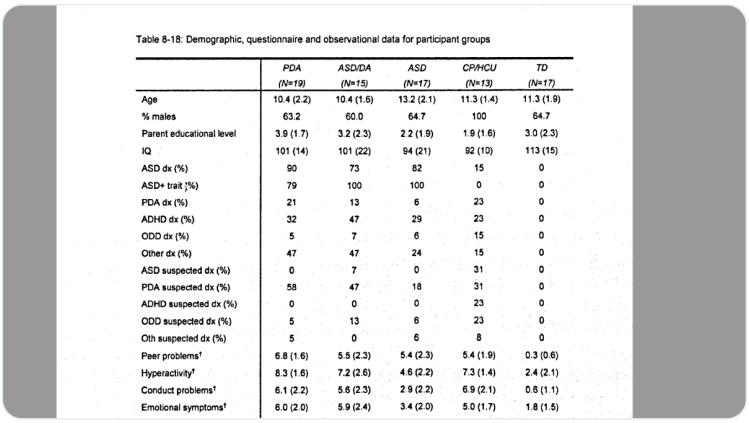


Table 8-18: Demographic, questionnaire and observational data for participant groups

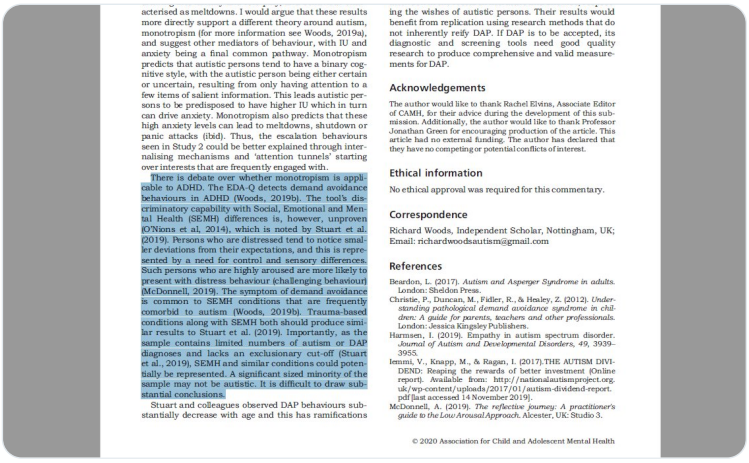
	PDA (N=19)	ASD/DA (N=15)	ASD (N=17)	CP/HCU (N=13)	TD (N=17)
Age	10.4 (2.2)	10.4 (1.6)	13.2 (2.1)	11.3 (1.4)	11.3 (1.9)
% males	63.2	60.0	64.7	100	64.7
Parent educational level	3.9 (1.7)	3.2 (2.3)	2.2 (1.9)	1.9 (1.6)	3.0 (2.3)
IQ	101 (14)	101 (22)	94 (21)	92 (10)	113 (15)
ASD dx (%)	90	73	82	15	0
ASD+ trait ‡(%)	79	100	100	0	0
PDA dx (%)	21	13	6	23	0
ADHD dx (%)	32	47	29	23	0
ODD dx (%)	5	7	6	15	0
Other dx (%)	47	47	24	15	0
ASD suspected dx (%)	0	7	0	31	0
PDA suspected dx (%)	58	47	18	31	0
ADHD suspected dx (%)	0	0	0	23	0
ODD suspected dx (%)	5	13	6	23	0
Oth suspected dx (%)	5	0	6	8	0
Peer problems†	6.8 (1.6)	5.5 (2.3)	5.4 (2.3)	5.4 (1.9)	0.3 (0.6)
Hyperactivity†	8.3 (1.6)	7.2 (2.6)	4.6 (2.2)	7.3 (1.4)	2.4 (2.1)
Conduct problems†	6.1 (2.2)	5.6 (2.3)	2.9 (2.2)	6.9 (2.1)	0.6 (1.1)
Emotional symptoms†	6.0 (2.0)	5.9 (2.4)	3.4 (2.0)	5.0 (1.7)	1.8 (1.5)

@threadreaderapp I list 10 studies in addition to the one above where it is reasonable to view there are non-autistic persons with PDA present in. https://rationaldemandavoidancecom.files.wordpress.com/2021/08/20-june-2021-10-studies-indicating-pda-is-seen-in-non-autistic-persons.pdf

@threadreaderapp One can also question if Trundle et al (2017) case study is autistic or not as there are signs suggesting they are not autistic, but case study was only assessed for PDA, not autism. https://www.emerald.com/insight/content/doi/10.1108/JIDOB-07-2016-0013/full/html

@threadreaderapp It is possible there is a significant minority of non-autistic CYP with PDA in Stuart et al (2020) sample, as I discuss in my commentary.

Link to the article.
https://acamh.onlinelibrary.wiley.com/doi/10.1111/camh.12368



acterised 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 ing 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.

Acknowledgements

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Ethical information

No ethical approval was required for this commentary.

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References

Beardon, L. (2017). *Autism and Asperger Syndrome in adults.* London: Sheldon Press.

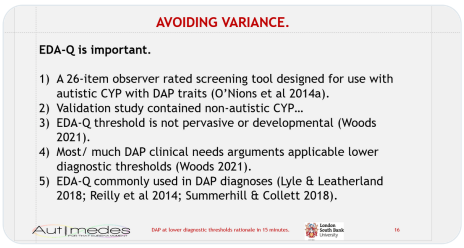
Christie, P., Duncan, M., Fidler, R., & Healey, Z. (2012). *Understanding pathological demand avoidance syndrome in children: A guide for parents, teachers and other professionals.* London: Jessica Kingsley Publishers.

Harmsen, I. (2019). Empathy in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49,* 3939–3955.

Iemmi, V., Knapp, M., & Ragan, I. (2017).THE AUTISM DIVIDEND: Reaping the rewards of better investment (Online report). Available from: http://nationalautismproject.org.uk/wp-content/uploads/2017/01/autism-dividend-report.pdf [last accessed 14 November 2019].

McDonnell, A. (2019). *The reflective journey: A practitioner's guide to the Low Arousal Approach.* Alcester, UK: Studio 3.

@threadreaderapp To point out how problematic arbitrarily choosing one's clinical experience is more important than research results & boldly claiming there are false positives with the EDA-Q, is considering HOW MUCH of our limited knowledge on PDA is based on the EDA-Q; a substantial amount.

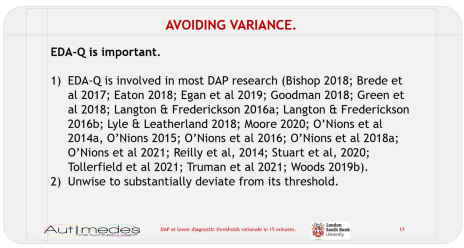


AVOIDING VARIANCE.

EDA-Q is important.

1) A 26-item observer rated screening tool designed for use with autistic CYP with DAP traits (O'Nions et al 2014a).
2) Validation study contained non-autistic CYP...
3) EDA-Q threshold is not pervasive or developmental (Woods 2021).
4) Most/ much DAP clinical needs arguments applicable lower diagnostic thresholds (Woods 2021).
5) EDA-Q commonly used in DAP diagnoses (Lyle & Leatherland 2018; Reilly et al 2014; Summerhill & Collett 2018).

AutImedes DAP at lower diagnostic thresholds rationale in 15 minutes. 16



AVOIDING VARIANCE.

EDA-Q is important.

1) EDA-Q is involved in most DAP research (Bishop 2018; Brede et al 2017; Eaton 2018; Egan et al 2019; Goodman 2018; Green et al 2018; Langton & Frederickson 2016a; Langton & Frederickson 2016b; Lyle & Leatherland 2018; Moore 2020; O'Nions et al 2014a, O'Nions 2015; O'Nions et al 2016; O'Nions et al 2018a; O'Nions et al 2021; Reilly et al, 2014; Stuart et al, 2020; Tollerfield et al 2021; Truman et al 2021; Woods 2019b).
2) Unwise to substantially deviate from its threshold.

AutImedes DAP at lower diagnostic thresholds rationale in 15 minutes. 17

@threadreaderapp Link to the conference talk where I discuss how important the EDA-Q is generally to our knowledge on PDA.

(PDF) Demand Avoidance Phenomena ("Pathological"/ "Extreme" Dem…

PDF | These are slides of my 15 minute talk on why PDA can be viewed as a discrete Disorder at a lower diagnostic threshold. During the talk, I did not... | Find, read and cite all the research you n…

https://www.researchgate.net/publication/353348556_Demand_Avoidance_Phenomen…

@threadreaderapp If I was to decide what diagnostic threshold I would use for PDA, would it be based off a highly biased sample of pro "PDA Profile of ASD" clinicians, contradicting approach of @NICE @BPSOfficial @rcpsych @ArvidNK? No. It would be base on what is important in the literature.

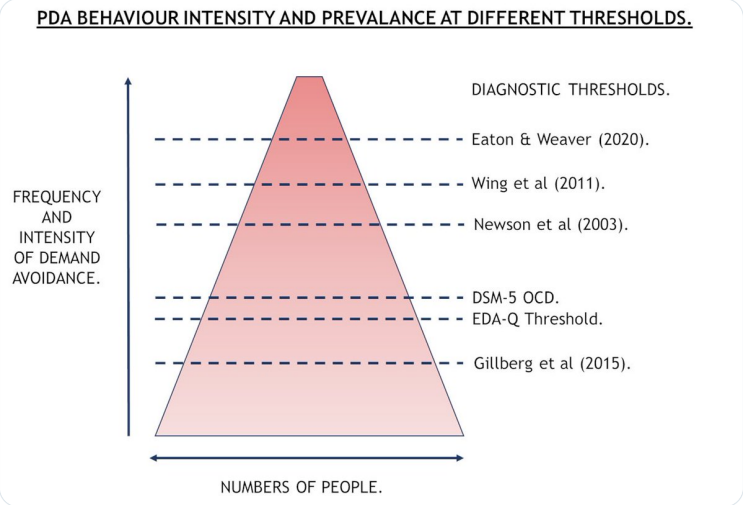
@threadreaderapp @BPSOfficial @rcpsych @ArvidNK I.e., I would not decree that other different versions of PDA diagnoses are not valid & disregard the knowledge base from the EDA-Q as it identifies PDA in non-autistic persons. I would change my mind to conform to the literature. That is what open-minded persons should do.

@threadreaderapp @BPSOfficial @rcpsych @ArvidNK Which when you consider non-autistic persons with PDA have same rights to PDA diagnoses, research, & support under UN Convention on the Rights of the Child, and The Equality Act (2011). An inclusive approach to PDA is probably a smart move to do.

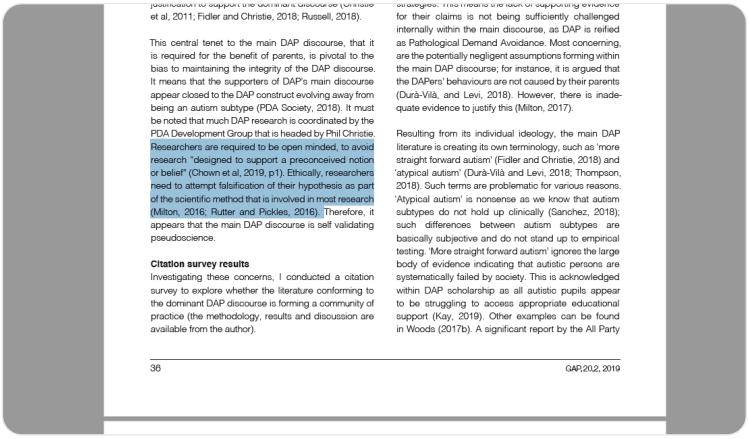
What do I know (rhetorical)?

@threadreaderapp @BPSOfficial @rcpsych @ArvidNK The point of basing a diagnostic threshold on what is important in the literature, like the EDA-Q is that it means one can generalise research results onto the diagnosed population sample.

@threadreaderapp @BPSOfficial @rcpsych @ArvidNK If one accepts a high PDA dx threshold, one would need to replicate many PDA studies involving the EDA-Q, to be sure research results are applicable to higher diagnostic thresholds.



@threadreaderapp @BPSOfficial @rcpsych @ArvidNK Also choosing your clinical opinion is worth more than other topic experts' views & research results, is by definition prioritising one outlook of PDA over another, which is an unscientific & unethical way to conduct PDA research. As I mention here:



et al, 2011; Fidler and Christie, 2018; Russell, 2018).

This central tenet to the main DAP discourse, that it is required for the benefit of parents, is pivotal to the bias to maintaining the integrity of the DAP discourse. It means that the supporters of DAP's main discourse appear closed to the DAP construct evolving away from being an autism subtype (PDA Society, 2018). It must be noted that much DAP research is coordinated by the PDA Development Group that is headed by Phil Christie. Researchers are required to be open minded, to avoid research "designed to support a preconceived notion or belief" (Chown et al, 2019, p1). Ethically, researchers need to attempt falsification of their hypothesis as part of the scientific method that is involved in most research (Milton, 2016; Rutter and Pickles, 2016). Therefore, it appears that the main DAP discourse is self validating pseudoscience.

Citation survey results

Investigating these concerns, I conducted a citation survey to explore whether the literature conforming to the dominant DAP discourse is forming a community of practice (the methodology, results and discussion are available from the author).

for their claims is not being sufficiently challenged internally within the main discourse, as DAP is reified as Pathological Demand Avoidance. Most concerning, are the potentially negligent assumptions forming within the main DAP discourse; for instance, it is argued that the DAPers' behaviours are not caused by their parents (Durà-Vilà, and Levi, 2018). However, there is inadequate evidence to justify this (Milton, 2017).

Resulting from its individual ideology, the main DAP literature is creating its own terminology, such as 'more straight forward autism' (Fidler and Christie, 2018) and 'atypical autism' (Durà-Vilà and Levi, 2018; Thompson, 2018). Such terms are problematic for various reasons. 'Atypical autism' is nonsense as we know that autism subtypes do not hold up clinically (Sanchez, 2018); such differences between autism subtypes are basically subjective and do not stand up to empirical testing. 'More straight forward autism' ignores the large body of evidence indicating that autistic persons are systematically failed by society. This is acknowledged within DAP scholarship as all autistic pupils appear to be struggling to access appropriate educational support (Kay, 2019). Other examples can be found in Woods (2017b). A significant report by the All Party

@threadreaderapp @BPSOfficial @rcpsych @ArvidNK Link to where I discuss it is unethical prioritising one view of PDA over another.
https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

@threadreaderapp @BPSOfficial @rcpsych @ArvidNK I think I have made the point that the actions of those behind this research report, do seem to comparable to the actions of the UK Tories.
https://www.pdasociety.org.uk/wp-content/uploads/2022/01/Identifying-Assessing-a-PDA-profile-Practice-Guidance.pdf

@threadreaderapp @BPSOfficial @rcpsych @ArvidNK I will stop this time.

@threadreaderapp please could you unroll?

Thank you in advance.

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