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Dec 5, 2021 · 45 tweets · [Richard\\_Autism/status/1467524924579450896](https://twitter.com/Richard_Autism/status/1467524924579450896)

So, some of you will be aware, that I think we should not be using the ADOS (an observational assessment tool for autism) on those with PDA, as doing so seems to cause those with PDA to express distress behaviours. Is it that an unimportant issue?

Yes, conducting an ADOS assessment on those with PDA, does seem to often cause them to express avoidance features. O'Nions PhD research included conducting just under 100 ADOS assessments, many of them autistic CYP.

Attempted to do an ADOS assessment on 96 CYP. Only able to complete 76. "18 children for whom testing could not be completed, avoidance of demands was a significant factor for 9." O'Nions 2013, p142.

Due to how O'Nions grouped the samples, the ADOS was conducted upon, & then decided who had PDA or not was done based on data analysis. It is not possible to state how many of those not completing the ADOS probably had PDA.

This is from a footnote on page 142. 6 displayed avoidance to the extent that testing could not take place. Of these, three had extreme reactions (tantrums/ outbursts of physical violence), which also occurred in three participants who did complete testing,

Three participants could not be tested due to extreme avoidance plus learning difficulties. Testing was suspended for seven participants due to learning/ concentration difficulties.

A further 2 participants were excluded prior to analyses due to learning difficulties, and 2 asked to leave the session early on in the protocol.

This is unclear, how O'Nions thought 18 could not be completed if one tries to count them.

There does seem to 9 with demand-avoidance who were excluded.

Worth noting O'Nions (with others) created their own ADOS algorithm, & ADOS items for PDA. This is in chapter 8 of O'Nions thesis.

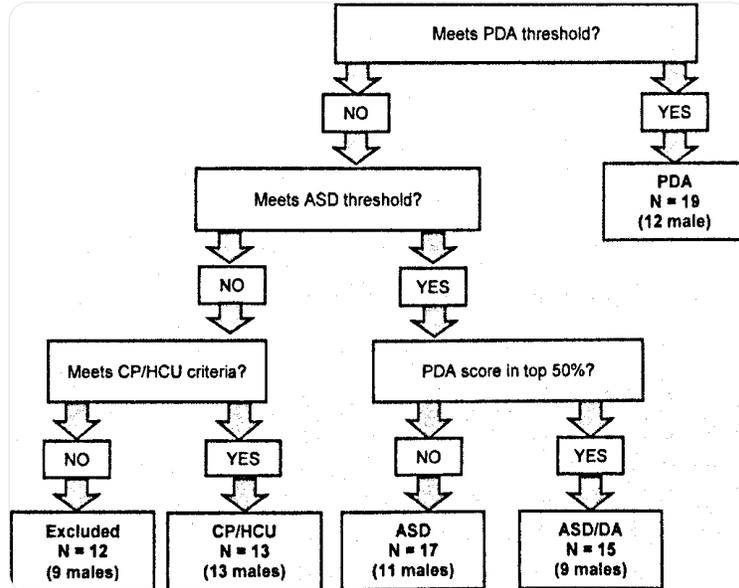
It is clear that the ADOS is not designed to assess for PDA in the chapter.

To be clear that they apparently had 17 Typically developing controls. Assessed 76 cases, mix of autism, PDA & conduct problems.

The issue is that O'Nions & others created an algorithm to identify PDA, using responses from various questionnaires, to differentiate PDA between autism, and conduct problems.

They did not use the full EDA-Q, but an unvalidated 11-item version, items chosen due t being theoretically similar to Newson's descriptions. I have some issues with, considering later O'Nions suggests reducing number of PDA traits,. as some do not cluster in her EDA-Q study

Method they used to separate out groups is from page p175.



So there is apparently a separate PDA group, but also a group of autistic persons with PDA.

"Using the PDA trait-measure cut-off score ( $\geq 13$ ) described above; 80% of the PDA group also met the ASD threshold (described in Section 8.3.1.1); and 63% met criteria for CP/HCU." O'Nions (2013, p174).

So 80% of those with PDA in this study.

Numbers of CYP with equals 19 (PDA by itself group) +15 (ASD+PDA group) = 34  
CYP with PDA.

So  $100\% - 80\% = 20\%$ .

So  $[(34/100)*20] = 6.8$ , rounding up gives us 7 persons with PDA who it seems reasonable to think were NOT autistic.

Sorry this is a bit of a tangent, but it gives me more evidence that PDA is seen in non-autistic persons.

Data for different groups in the study is in table on page 176 of the thesis.

"Diagnoses of PDA reported by parents were not used to inform group allocation, given the limited and variable usage of PDA as a diagnostic term, and the absence of an algorithm in clinical use to differentiate this profile from others." P140.

Or O'Nions & her co-researchers did not trust a PDA dx in this study, it literally meant diddly squat.

"Therefore, unusual behavioural features may have reflected a style of interacting (which was inappropriate for the context), rather than a functional impairment in interactions per se." O'Nions (2013 p198).

The above quote is commenting on how PDA interacts with ADOS, i.e., atypically & that those with PDA might not even have impairment in social interactions.

Now these are all points are relevant to a certain private (who I do actually respect for diagnosing autism in under represented groups/ complex cases), using the ADOS in those it suspected autistic persons with PDA.

Link to O'Nions thesis, before I go too far forward.

<https://ethos.bl.uk/OrderDetails.do?did=1&uin=uk.bl.ethos.814002>

In the clinic's later paper, using ADOS on autistic persons it suspected having PDA. It reports entire range of avoidance features often associated with PDA. From excuses all the way through to threats of violence.

"While such excuses did, at times feel comical, it was always important to remember these were children whose anxiety appeared to be driving their need to be avoidant." Eaton & Weaver (2020, p35).

Link to the paper below:

<https://www.ingentaconnect.com/contentone/bild/gap/2020/00000021/00000002/art00005>

Why does this matter, even under PDA theory, as proposed by Christie & Fidler, such as their matching the dials concept. It would appear problematic advocating the use of the ADOS with those suspected of PDA.

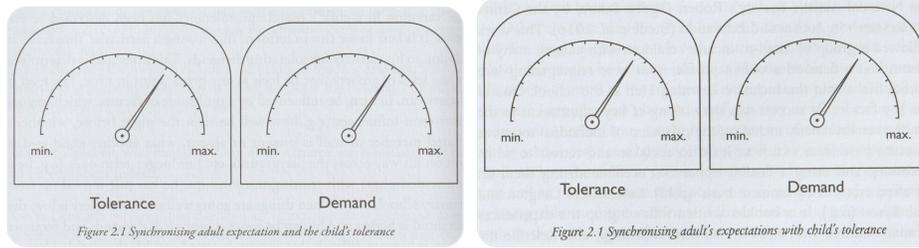


Image can be found on page 52 of Christie et al (2012) book.

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.

Point of the dials is, that a person's with PDA's anxiety levels vary over time & are context specific. That their anxiety level directly impact their tolerance towards demands. So that one should aim to match demands placed upon with PDA, to their present tolerance levels.

I have spoken about this issue from a transactional stress based model. Even if you ignore that & work with Christie's & Fidler's matching the dial concept. That still acknowledges anxiety levels are contextual & is affected by how others are interacting with those with PDA.

"His level of anxiety can, in turn, be influenced by multitude of factors, which in include short-term influences (e.g.,

...

whether a trusted member of staff is present or absent, what another child said to him on the way across the playground, etc.)" p51.

One can view that if those suspected of PDA, are displaying avoidance behaviours due to anxiety (even suspected), especially if such features are increasing in "severity". Then it is probably because those with PDA find the situation aversive.

I am struggling to see how it is ethical to place those who are suspected of having high anxiety levels, through a process which seems to often cause them more stress (anxiety), hence the displays of various distress related features.

Avoidance features are viewed as relating to distress, such as panic by the likes of the PDA Society.

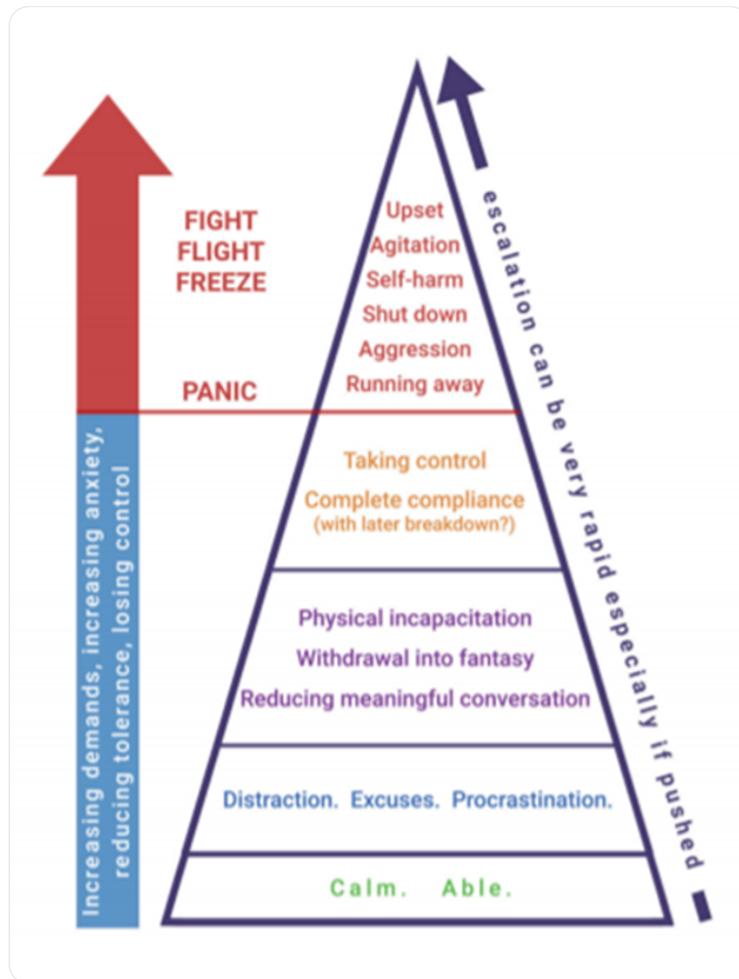


Image is from this booklet, on page 7.

<https://www.pdasociety.org.uk/wp-content/uploads/2021/04/What-is-PDA-booklet-website-v2.1.pdf>

So why are those with PDA seem to being given extra stress for via the ADOS? Apparently, because some parties/ persons view PDA to be an ASD. The purpose of the ADOS is mainly to assist in diagnosing autism...

Do those with PDA need to be assessed with the ADOS? No, because there other tools which asses for PDA features. An example, see table 1 on this semi-structured interview below:

<https://acamh.onlinelibrary.wiley.com/action/downloadSupplement?doi=10.1111%2Fcamh.12242&file=camh12242-sup-0001-Supinfo.pdf>

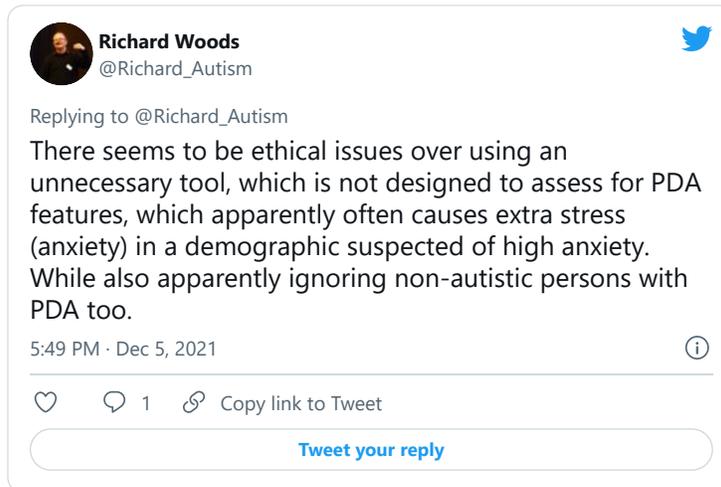
There are also other tools to assess for autism, besides the ADOS.

There seems to be ethical issues over using an unnecessary tool, which is not designed to assess for PDA features, which apparently often causes extra stress (anxiety) in a demographic suspected of high anxiety. While also apparently ignoring non-autistic persons with PDA too.

I am wondering, is this an unimportant issue? Am I making too much fuss over something which is not important?

Whatever the answer, it does seem predictable that using the ADOS on those suspected with PDA, seems to be problematic.

Also need to point out, that those with PDA can interact atypically with the ADOS too, to probably ethical issues against using the ADOS with those suspected of PDA.



<https://www.youtube.com/embed/xFiUWN3y9ho>

[@threadreaderapp](#) please can you unroll again?

Thank you in advance.

