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Something I am struggling to understand, how many "PDA Profile of ASD" proponents, insist upon taking us their perspective seriously. Yet, they seem not to wish to respect divergent opinion, such as PDA is seen in non-autistic persons.

Or seem to consider that non-autistic persons with PDA might have the same rights as autistic persons with PDA. Or the clinical need arguments are applicable to non-autistic persons with PDA.

I back to this quote in O'Nions et al (2016b):
"At present, there is considerable controversy about the usefulness of the term pathological demand avoidance, which is distracting from the real imperative." p3

Link to O'Nions et al (2016b) below:
repository.tavistockandportman.ac.uk/2165/

"Although there are obvious differences from a classic ASD profile, our work suggests that those with substantial features of extreme/'pathological' demand avoidance have similar levels of autistic traits to those with ASD who do not show this pattern" P1.

The above quote from the same article is problematic, for two reasons; first it seems to assume that PDA is a form of autism, as implied by "classic ASD profile". Second, is the use of autistic traits. Autistic traits is something ill-defined, but it is not autism.

The point about autistic traits being different & thus not autism is mentioned here:

Studies of autistic traits in the general population are not studies of au…
Studies of autistic traits in the general population are becoming increasingly prevalent. In this letter to the editor, we caution researchers against framing a...

https://journals.sagepub.com/doi/10.1177/13623613211058515

What bothers me in the assumption of similar autistic traits with autism, is that the author's own prior scholarship points out that those with PDA can interact atypically with autism tools & autistic traits tool.

Their own scholarship admits it is problematic PDA conforming to autism understandings. Some of O'Nions research, especially from their PhD indicates there is more parts to PDA than autism-like features.

Likewise, there are at least cases of non-autistic persons in their research, before the 2016 debates article was published.

Yet, PDA needs to be an ASD.

Like the only thing that matters is that PDA must be part of the autism spectrum to provide understanding & support to a narrow range of persons we are interested in.

"Our current interest in researching PDA stems from reports and observations that this behaviour has a different quality (e.g. difficult behaviour in ASD may be to achieve a concrete goal or avoid a specific activity,...

... as opposed to persistent avoidance of any requests to maintain control), and fails to respond to the usual ASD approaches." O'Nions et al (2014a, p766).

Link to O'Nions et al (2014)
https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149

So if I am reading the quotes correctly, debates & controversies around PDA do not matter compared to interest in providing understanding & support to a group of suspected autistic persons. Which then leads to assuming PDA must be an ASD & other perspectives on PDA are mistaken?

What if other's opinions on PDA are valid? What if PDA does present as a continuum in the human population? Does that possibility not matter to "PDA Profile of ASD" supporters?

Going back to O'Nions et al (2016) quote:
"our work suggests that those with substantial features of extreme/'pathological' demand avoidance have similar levels of autistic traits to those with ASD who do not show this pattern" p1.

Note the point about "those with substantial features" of PDA. I.e., it is possible for a person to less than substantial amounts of PDA features, so there can be mild cases of PDA.

"Over the course of the research I encountered children who manifested much less marked presentations than those Newson described, and typified a number of participants; but whose parents or teachers identified PDA features in them." (O'Nions 2013, p203).

Link to O'Nions thesis.
https://ethos.bl.uk/OrderDetails.do?did=1&uin=uk.bl.ethos.814002

The previous quote notes mild presentations of PDA seem to exist. As I point out below, the threshold in which something is actually pathologised into a Disorder is relatively low:
https://www.researchgate.net/publication/353348556_Demand_Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_is_it_a_Disorder_at_a_lower_diagnostic_threshold

To repeat the point, O'Nions et al (2016):
"It should be noted that, so far, we have approached this profile from the starting point of our expertise in ASD." page2.

The above quote is important. If you are approaching PDA from perspectives of ASD. This will be a much higher threshold for PDA, than what is generally found in the DSM-5 Disorder definition.

If one assumes PDA is an ASD. This obviously impacts assumptions about nature of demand-avoidance, tools made, study design, results interpretation, ultimately to a distorted worldview & understandings of PDA.

It is similar processes to why autism criteria is biased in favour of white males.

It must be said autistic traits, are often in present in non-autistic demographics, such as anxiety. Guess what PDA is meant to be fundamentally driven by anxiety.

Yet, we are meant to blindly accept "PDA Profile of ASD" supporters outlooks, while it seems they are happy to disregard others views on the topic, including what PDA might look like?

Maybe, just maybe, it was a mistake for "PDA Profile of ASD" supporters to assume PDA is part of the autism spectrum?!?

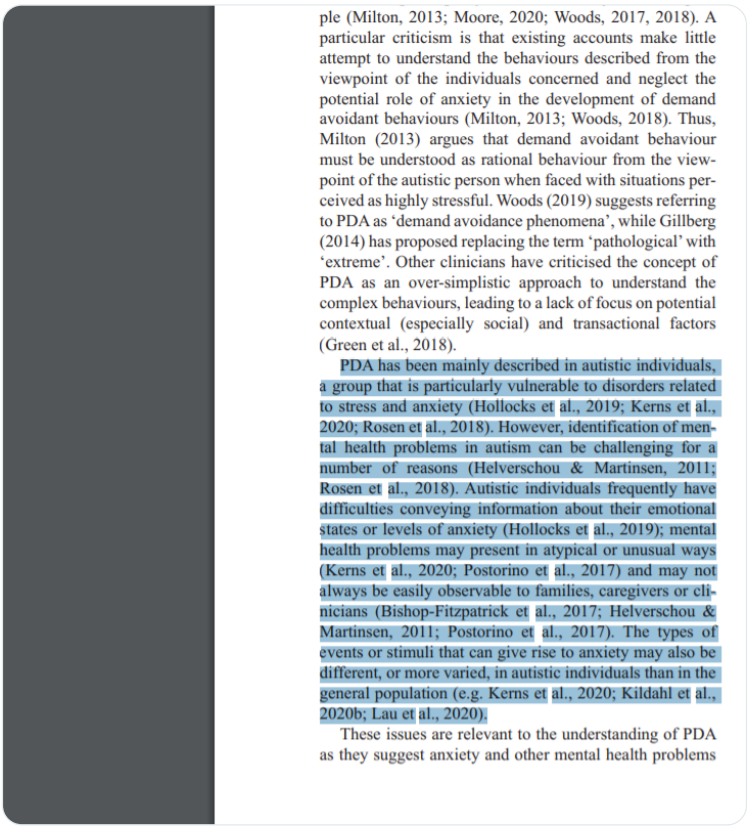
Say, we accept the views of some "PDA Profile of ASD" supporters, that PDA looks in differently in autism vs non-autistic persons, like autistic PDA has different causes.

Well, OK, but that is to be expected though, it is common for other Disorders/ conditions to present differently in autistic persons vs non-autistic persons, it does not mean that PDA is part of the autism spectrum.

This is acknowledged in the PDA literature, by Green et al (2018a), & more recently by Kildahl et al (2021).

Link to Kildahl et al systematic review.
https://journals.sagepub.com/doi/pdf/10.1177/13623613211034382

Screenshot of Kildahl et al (2021) discussing how conditions can present differently in their introduction.



ple (Milton, 2013; Moore, 2020; Woods, 2017, 2018). A particular criticism is that existing accounts make little attempt to understand the behaviours described from the viewpoint of the individuals concerned and neglect the potential role of anxiety in the development of demand avoidant behaviours (Milton, 2013; Woods, 2018). Thus, Milton (2013) argues that demand avoidant behaviour must be understood as rational behaviour from the viewpoint of the autistic person when faced with situations perceived as highly stressful. Woods (2019) suggests referring to PDA as 'demand avoidance phenomena', while Gillberg (2014) has proposed replacing the term 'pathological' with 'extreme'. Other clinicians have criticised the concept of PDA as an over-simplistic approach to understand the complex behaviours, leading to a lack of focus on potential contextual (especially social) and transactional factors (Green et al., 2018).

PDA has been mainly described in autistic individuals, a group that is particularly vulnerable to disorders related to stress and anxiety (Hollocks et al., 2019; Kerns et al., 2020; Rosen et al., 2018). However, identification of mental health problems in autism can be challenging for a number of reasons (Helverschou & Martinsen, 2011; Rosen et al., 2018). Autistic individuals frequently have difficulties conveying information about their emotional states or levels of anxiety (Hollocks et al., 2019); mental health problems may present in atypical or unusual ways (Kerns et al., 2020; Postorino et al., 2017) and may not always be easily observable to families, caregivers or clinicians (Bishop-Fitzpatrick et al., 2017; Helverschou & Martinsen, 2011; Postorino et al., 2017). The types of events or stimuli that can give rise to anxiety may also be different, or more varied, in autistic individuals than in the general population (e.g. Kerns et al., 2020; Kildahl et al., 2020b; Lau et al., 2020).

These issues are relevant to the understanding of PDA as they suggest anxiety and other mental health problems

So this tells us that one, should not be dismissing others opinions on PDA, just because it does not necessarily conform to your own.

This feature that autism seems to affect how various conditions present, is arguably proof that autism is a real tangible way of being (tangent). Yet, it raises concerns with researching PDA mainly in autistic persons.

What it means is that one is predisposing PDA research to produce results & associated knowledge that PDA looks a certain way, which is likely different to broader population.

Which is not particularly helpful if you are respecting divergent opinion on PDA, that it presents broadly in the human population; which is one of the hypotheses about PDA.

What researching PDA mainly in autistic persons can be useful for, is trying to claim PDA is a "Profile of ASD", & then used for lobbying for such claims. This has been happening.

Some people wonder, why I think there is an agenda to make PDA accepted as a "Profile of ASD"?

So, assuming I am understanding typical key points of "PDA Profile of ASD" perspectives:
PDA is exists in autistic persons.
PDA needs different strategies to typical autism ones.
There is a clinical need for PDA in autistic persons.

PDA has RRBIs & Social Communication issues. Thus must be an ASD.

Start with the last one. Yes, PDA has RRBIs, but they are meant to be anxiety driven RRBIs. Social communication issues, are plausibly the result of the avoidance features, & those features impact social interactions. So social communication issues in PDA might not be intrinsic.

PDA is exists in autistic persons.

I think most people would accept features often mentioned with PDA are seen in autistic persons. Yet, many would also state said features are seen in non-autistic persons. PDA literature widely states there is no feature seen only in PDA.

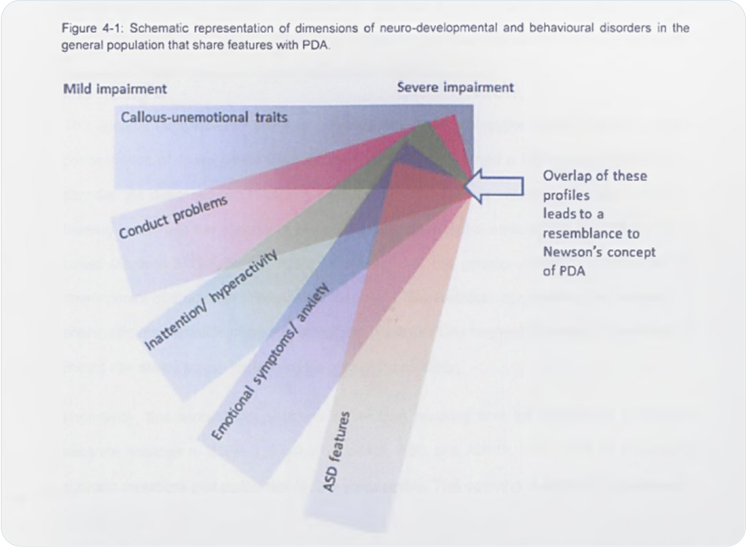
PDA needs different strategies to typical autism ones.

This one is slightly tricky. First point, it is being argued PDA strategies are simply good practice & should be more broadly practiced for other humans, including autistic persons.

Yet, the point of PDA needing separate strategies, is that those with PDA need individualised support packages. I think both "PDA Profile of ASD" supporters & those who disagree with that outlook, would say individualsed support packages are appropriate.

The difference comes down to if PDA should be used as a diagnostic entity, or if PDA features should be assigned to separate conditions, & bespoke support provided for each feature, from each condition.

Image is O'Nions, 2013, p93. So for example, one could treat the hyperactivity features, based on approaches from ADHD. This represents the approach suggested by Green et al (2018a & 2018b).



I personally prefer a transdiagnostic approach, as suggested above. Yet, in practice, if one accepts PDA is seen throughout the human population, then PDA is likely to be approached as a distinct diagnostic entity, i.e., a Disorder.

There is a clinical need for PDA in autistic persons.

As stated in prior points, I think people would recognise those presenting PDA features, at whatever levels, should receive appropriate packages; even if there is disagreement over how it is done in practice.

In order to fully answer this one, one needs to consider arguments for clinical need of PDA (which is contested).

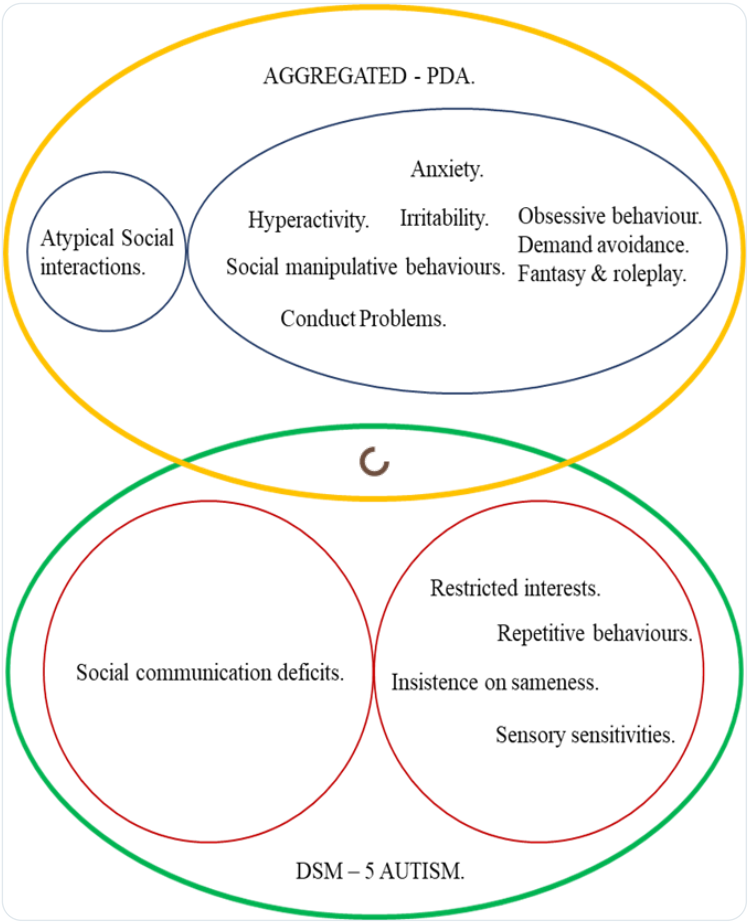
Some of the arguments for clinical need for PDA, are superfluous, as they seem the result of awareness raising & research efforts to recognise it as an ASD.

A supportive community has formed around the diagnosis, both those identifying with PDA (Thompson 2019), & caregivers (O'Nions et al 2021).

Autistic persons with DAP & families want it, & their difficulties warrant it (O'Nions et al 2021); specific the part about wanting the construct. Although, I should not that broader cuts to SEND support are also likely a factor.

Other arguments about PDA clinical need:
Needed to explain a person's actions & PDA does this better than autism/ other accepted Disorders (Christie 2007; Newson et al 2003).
Although problematic due to issues with PDA theory & lack of consensus over PDA.

I do accept the point that PDA does seem to better explain some features than autism, but that is more due to me thinking PDA is a distinct set of features which are NOT autism. See the image below.



Another clinical need reason.
DAP has distinct educational strategies, different to “traditional” autism strategies (Christie 2007; Newson et al 2003).

Touched upon this before. Some would question the effectiveness of "traditional" autism strategies, as @milton_damian does here: https://kar.kent.ac.uk/62694/431/Natures%20answer%20to%20over%20conformity.pdf

Other reasons for clinical need for PDA.
“Praise, reward, reproof, and punishment ineffective; behavioural approaches fail.” Newson et al (2003, p597)
Reinforcement-based approaches may remove CYP only coping mechanism to aversive environments (O’Nions & Eaton 2020).

Another reason for PDA's clinical need.
PDA diagnosis needed to protect CYP from caregiver interventions for disruptive behaviour disorders (O’Nions & Neons 2018).

These three previous reasons for PDA's clinical need seem fair to me. The issue is though, that they are applicable to non-autistic persons though...

"t is likely that many of the original cohort of children assessed by Newson and her team would today meet the diagnostic criteria for Autism Spectrum Disorder using DSM 5." Eaton & Weaver (2020, p34).

Link to above quoted article:
https://www.ingentaconnect.com/contentone/bild/gap/2020/00000021/00000002/art00005

This observation has been made elsewhere by Richard Soppitt (2021, p311):
“Given that most of Newson’s original PDA sample would now fulfil the broader ASD criteria, where do you stand on its relationship with the autistic continuum?”

Soppitt, R. (2021). Pathological/ Extreme Demand Avoidance (PDA/ EDA). In: Peer, L., & Reid, G (Eds.), Special Educational Needs: A Guide for Inclusive Practice (pp. 296-314). London, Sage Publications Limited.

Last reason for clinical need for PDA
Difficulties faced by persons with DAP & their families requires validation & support (O’Nions et al 2021).
Seems fair. Would also be applicable to non-autistic persons with PDA & their families.

Surely, understanding & validating the difficulties faced, can also be achieved with a transdiagnostic approach.

I have taken the arguments for PDA's clinical need from here, about 17minutes to 20 minutes (hence why it might accidentally say DAP, instead of PDA in previous tweets):

https://www.youtube.com/embed/22ESXsCnisM

Despite some of the issues present, with the reasons for clinical need for PDA. Most of the reasons seem applicable to PDA in non-autistic persons with it.

Even the points about a supportive community forming around PDA for autistic persons, even this one should be applicable to non-autistic persons with PDA. Surely a community would form around non-autistic persons with PDA if it is widely acknowledged in PDA debates?

So from what I can tell from a "clinical need" perspective, PDA should be supported in non-autistic persons too. There are also ethical & leval arguments for supporting PDA in non-autistic persons, like I set out here:
https://www.researchgate.net/publication/353417488_Rights_of_non-autistic_children_and_young_persons_with_PDA

The point is, I am trying to show that there can easily be a more a cohesive & less dichotomous approach to PDA, than often seems the case. There are areas of overlap, between core positions of "PDA Profile of ASD" supporters & their critics/ those who disagree with them.

There are even points that would often be made by "PDA Profile of ASD" supporters, which I consider to have merit & I think many persons would also accept to have some merit.

Should there be such a dichotomy over PDA in print, & in online debates on PDA? Well, no. I go into reasons here:
https://www.researchgate.net/publication/355427579_Demand-Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_As_a_biopower_identity

So if one looks at my approach to PDA, with it being a common mental disorder. It accepts:
General arguments for clinical need for PDA.
It accepts that PDA is "real"/ a "thing".
That persons with PDA should receive appropriate support packages based on stress management.

My approach to PDA as a common disorder still accepts:
Perspectives & general rights of autistic persons with PDA.

Yet, my approach PDA also equally respects the perspectives & rights of non-autistic persons with PDA; to diagnoses, research & support.

The point is, that my approach tries to be inclusive and accommodating of diverse opinions on PDA, while accepting current understandings of autism &, mental disorders as broad spectrum based constructs.

Where am I going with this?

Am I the bad guy for advocating for an ethical, inclusive approach to PDA? No.

Am I the bad guy for advocating for typical research & practice standards to be applied to PDA? No.

Should there fundamentally be a different approach to PDA, instead of "PDA Profile of ASD"?

From what I can tell yes. Even if you ignore legal, ethical, clinical need arguments. Present approach is likely to distorted & biased knowledge on PDA.

We should be taking a broad inclusive approach to PDA, either:
1) Before investigating PDA in autistic persons, for if there are differences to PDA in autism vs outside autism.
2) Parallel simultaneously investigating PDA broadly with many groups & narrow with autistic persons.

What about those who think they know what PDA looks like, & it is a distinct thing in autistic persons, thus it must present in a small, narrowly rigid way?

First point, independent reputable parties, like @NICE & @bps are equally respecting divergent opinions on PDA. So that is a clue any person's/ parties' views are insufficient to warrant treating PDA as an ASD.

If you warrant another example. Uta Frith seems to think we should return to narrow autism subtypes, akin to what she experienced earlier in her life. I think most persons would take a dim outlook to returning to narrow autism subtypes...

Link to article recent article by Uta calling for a return to narrow autism subtypes.
https://onlinelibrary.wiley.com/doi/full/10.1002/aur.2578

The point of this thread, has been me reflecting upon if it is possible to try & bridge the gap in perspectives.

How many "PDA Profile of ASD" proponents, insist upon taking us their perspective seriously. Yet, they seem not to wish to respect divergent opinion,

Is it possible to potentially collaborate with "PDA Profile of ASD" supporters?
To work with them?

Well, I doubt they often understand the nature & rationale for much/ most critique, or divergent opinions on PDA.

It is problematic, when they seem intent on assuming PDA is a "Profile of ASD", & following an agenda which supports that outlook. A fundamentally lack of respecting divergent opinion on PDA.

Reflecting on use of "divergent opinion on PDA". Divergent from what? The notion & discourse of "PDA Profile of ASD". Why am I needing to state this, because that notion is a "culture-bound concept" to the UK. Despite all the controversy, different opinions & lack of evidence.

Just the fact "PDA Profile of ASD" is a "culture-bound concept", to the UK, with broader context of PDA; suggests there is an agenda to make PDA accepted as a part of the autism spectrum. Yet, we are supposed to believe, it is all coincidental.

Is it possible to potentially collaborate with "PDA Profile of ASD" supporters?
To work with them?

If there is an agenda to make "PDA Profile of ASD" accepted. Which appears to be the case. Then answer would be no, in many situations. It maybe yes when agenda's mutually align.

@threadreaderapp unroll?

Thank you in advance.

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