Richard Woods @Richard_Autism

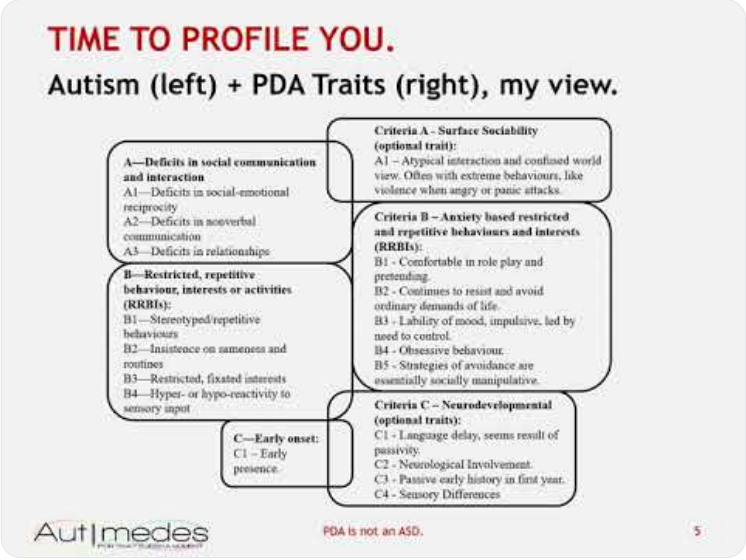
Mar 3 · 95 tweets · Richard_Autism/status/1499469044398788609

Wondering if general bias towards peer reviewed journal articles, especially carving up PhD studies into articles hampers academic discourse, & critical evaluation of research. If I should have my own thesis be published as something like a peer reviewed monograph?

It is general bias against "grey" research, like ignoring conference papers etc. Why I am reflecting upon this?

Well, PDA as per usual, how general ignoring of Newson's work & views on PDA in PDA discourse. Aspects of O'Nions PhD thesis literally make a mockery of the axiology (PDA is a form of autism), & certain studies methodology.

I contextualise assumptions which underpin "PDA Profile of ASD" from Newson's work, with Newson's work, including "grey" literature in the video below:

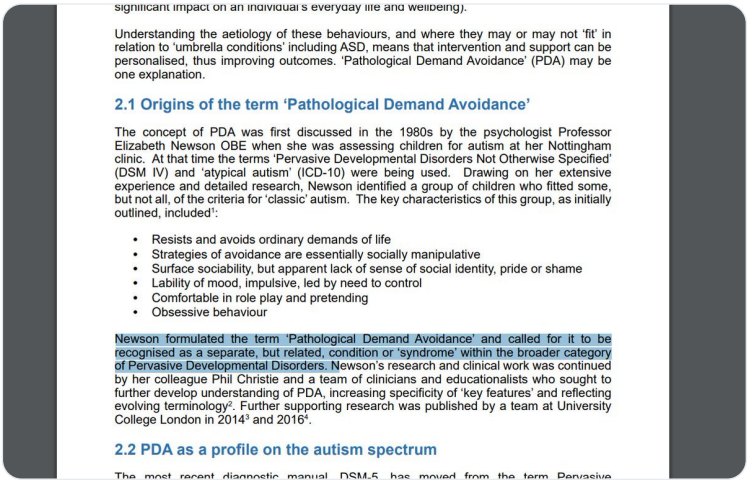


https://www.youtube.com/embed/GSIdMzDMC-w

I am clear it is simply nonsense to view PDA is a form of autism based on Newson's PDA research, as she went out for to ensure PDA could not be viewed as an ASD, both in her axiology & methodology used.

If you want an example of how selective "PDA Profile of ASD" supporters are in making the argument for PDA being a "Profile of ASD", look at this research report by the PDA Society, pretending to be clinical guidance.
https://www.pdasociety.org.uk/wp-content/uploads/2022/01/Identifying-Assessing-a-PDA-profile-Practice-Guidance.pdf

Image from page 3, showing that Newson stated PDA was a part of the Pervasive Developmental Disorders grouping.



significant impact on an individual's everyday life and wellbeing).

Understanding the aetiology of these behaviours, and where they may or may not 'fit' in relation to 'umbrella conditions' including ASD, means that intervention and support can be personalised, thus improving outcomes. 'Pathological Demand Avoidance' (PDA) may be one explanation.

2.1 Origins of the term 'Pathological Demand Avoidance'

The concept of PDA was first discussed in the 1980s by the psychologist Professor Elizabeth Newson OBE when she was assessing children for autism at her Nottingham clinic. At that time the terms 'Pervasive Developmental Disorders Not Otherwise Specified' (DSM IV) and 'atypical autism' (ICD-10) were being used. Drawing on her extensive experience and detailed research, Newson identified a group of children who fitted some, but not all, of the criteria for 'classic' autism. The key characteristics of this group, as initially outlined, included[1]:

- Resists and avoids ordinary demands of life
- Strategies of avoidance are essentially socially manipulative
- Surface sociability, but apparent lack of sense of social identity, pride or shame
- Lability of mood, impulsive, led by need to control
- Comfortable in role play and pretending
- Obsessive behaviour

Newson formulated the term 'Pathological Demand Avoidance' and called for it to be recognised as a separate, but related, condition or 'syndrome' within the broader category of Pervasive Developmental Disorders. Newson's research and clinical work was continued by her colleague Phil Christie and a team of clinicians and educationalists who sought to further develop understanding of PDA, increasing specificity of 'key features' and reflecting evolving terminology[2]. Further supporting research was published by a team at University College London in 2014[3] and 2016[4].

2.2 PDA as a profile on the autism spectrum

The most recent diagnostic manual, DSM-5, has moved from the term Pervasive

Problem is that Newson never viewed PDA to be part of the autism spectrum. Never based it on understandings of autism. Excluded cases who showed signs of autism. Created her diagnostic grouping before she reified PDA's behaviour profile. She used this at least from 1986-1996.

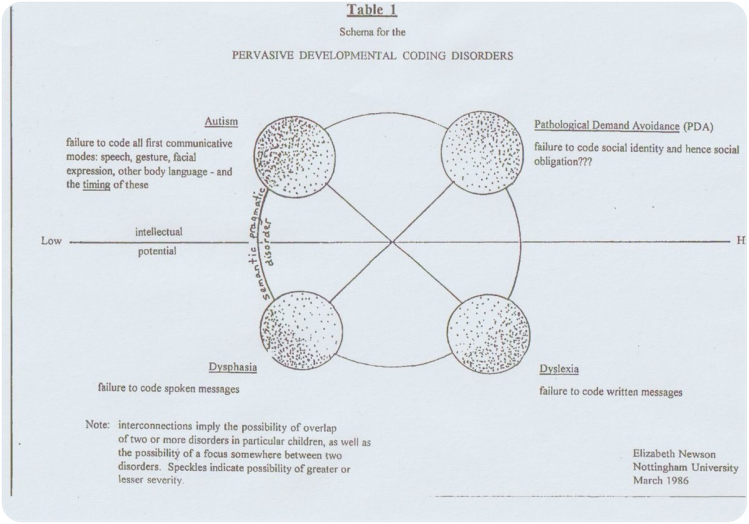


Table 1

Schema for the

PERVASIVE DEVELOPMENTAL CODING DISORDERS

Autism

failure to code all first communicative modes: speech, gesture, facial expression, other body language - and the timing of these

Pathological Demand Avoidance (PDA)

failure to code social identity and hence social obligation???

Low — intellectual potential — H

Semantic pragmatic disorder

Dysphasia

failure to code spoken messages

Dyslexia

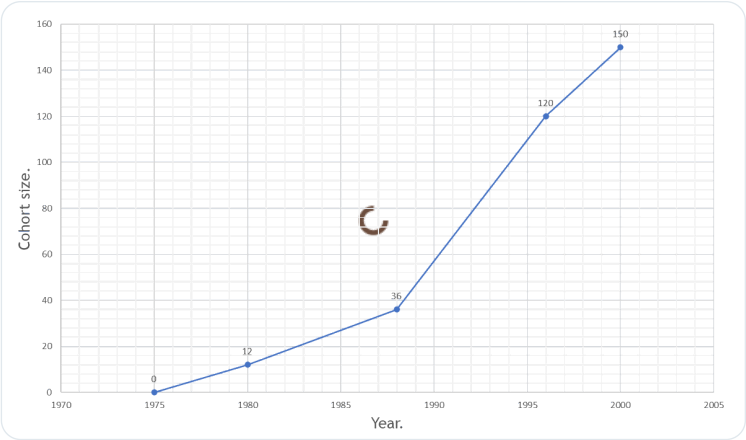
failure to code written messages

Note: interconnections imply the possibility of overlap of two or more disorders in particular children, as well as the possibility of a focus somewhere between two disorders. Speckles indicate possibility of greater or lesser severity.

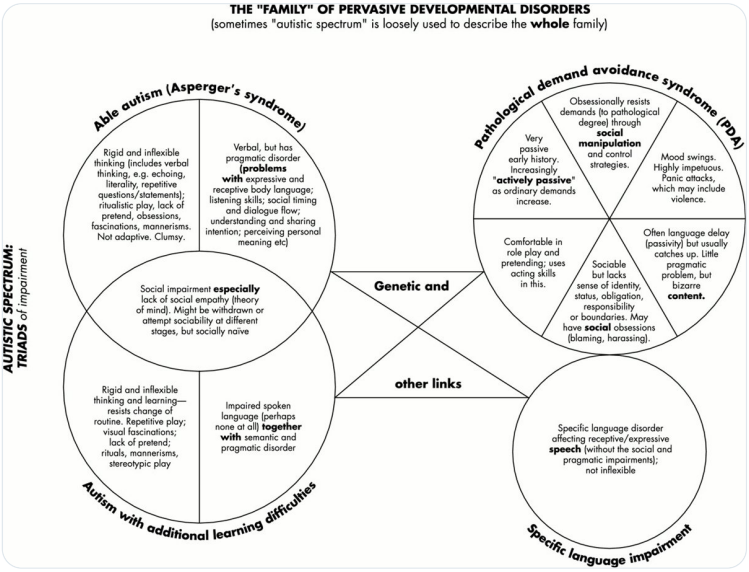
Elizabeth Newson
Nottingham University
March 1986

Newson collected the majority of her cases while using this axiology of her made up diagnostic grouping.

Data is from Newson 1996, & Newson et al 2003.



There are other issues, like Newson's conceptualisation of Pervasive Developmental Disorders does not conform with accepted versions of the diagnostic grouping, such as used in DSM-5, e.g., there are no Rett's Syndrome etc, while having PDA & Specific Language Impairment present.



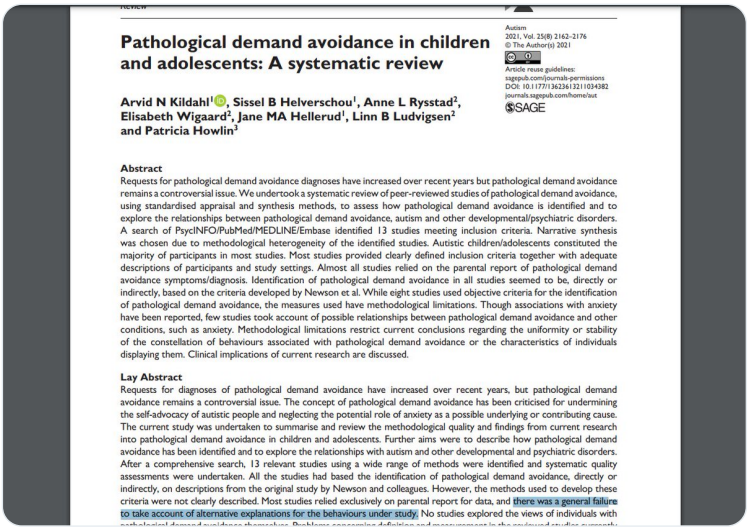
Obviously, if you are generating significant income from "PDA Profile of ASD" related activities, then you have motivations to ignore anything inconvenient like Newson's views & PDA research. Guess what, most of those behind that PDA Society research are in private practice.

Table 1: PDA Society Clinicians views Research Report Contributors private practice status.

Number.	Contributor.	Private Practice.	Independent Practice.
1	Phil Christie	No	Yes
2	Gloria Dura-Vila	Yes	No
3	Judy Eaton	Yes	No
4	Alison Hart	No	Yes
5	Libby Hill	No	Yes
6	Keith Howie	No	Yes
7	Ann Ozsivadjian	No	Yes
8	Georgie Siggers	No	Yes
9	Pat Smith	No	No
10	Lisa Summerhill	Yes	No
11	Vicki Wingrove	Yes	No
12	Julia Woollatt.	Yes	No

There is form for this from those who are significantly responsible for pushing PDA, they are the ones who have largely studied PDA to date, generally they do not consider alternate views.

See highlighted text from lay abstract of PDA systematic review.



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SAGE

Pathological demand avoidance in children and adolescents: A systematic review

Arvid N Kildahl[1], Sissel B Helverschou[1], Anne L Rysstad[2], Elisabeth Wigaard[2], Jane MA Hellerud[1], Linn B Ludvigsen[2] and Patricia Howlin[3]

Abstract

Requests for pathological demand avoidance diagnoses have increased over recent years but pathological demand avoidance remains a controversial issue. We undertook a systematic review of peer-reviewed studies of pathological demand avoidance, using standardised appraisal and synthesis methods, to assess how pathological demand avoidance is identified and to explore the relationships between pathological demand avoidance, autism and other developmental/psychiatric disorders. A search of PsycINFO/PubMed/MEDLINE/Embase identified 13 studies meeting inclusion criteria. Narrative synthesis was chosen due to methodological heterogeneity of the identified studies. Autistic children/adolescents constituted the majority of participants in most studies. Most studies provided clearly defined inclusion criteria together with adequate descriptions of participants and study settings. Almost all studies relied on the parental report of pathological demand avoidance symptoms/diagnosis. Identification of pathological demand avoidance in all studies seemed to be, directly or indirectly, based on the criteria developed by Newson et al. While eight studies used objective criteria for the identification of pathological demand avoidance, the measures used have methodological limitations. Though associations with anxiety have been reported, few studies took account of possible relationships between pathological demand avoidance and other conditions, such as anxiety. Methodological limitations restrict current conclusions regarding the uniformity or stability of the constellation of behaviours associated with pathological demand avoidance or the characteristics of individuals displaying them. Clinical implications of current research are discussed.

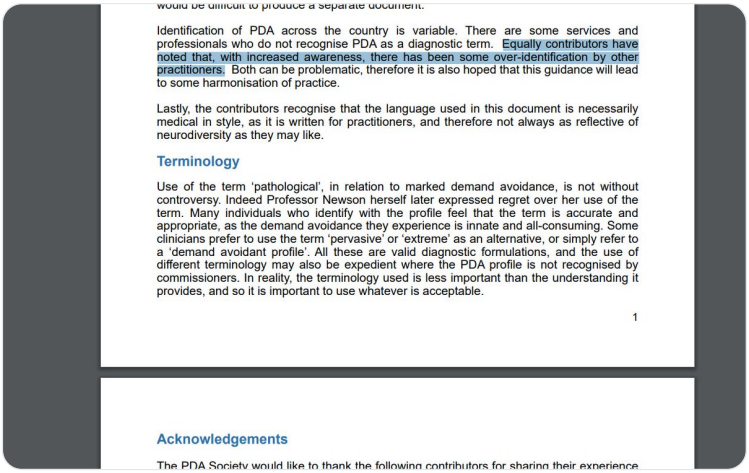
Lay Abstract

Requests for diagnoses of pathological demand avoidance have increased over recent years, but pathological demand avoidance remains a controversial issue. The concept of pathological demand avoidance has been criticised for undermining the self-advocacy of autistic people and neglecting the potential role of anxiety as a possible underlying or contributing cause. The current study was undertaken to summarise and review the methodological quality and findings from current research into pathological demand avoidance in children and adolescents. Further aims were to describe how pathological demand avoidance has been identified and to explore the relationships with autism and other developmental and psychiatric disorders. After a comprehensive search, 13 relevant studies using a wide range of methods were identified and systematic quality assessments were undertaken. All the studies had based the identification of pathological demand avoidance, directly or indirectly, on descriptions from the original study by Newson and colleagues. However, the methods used to develop these criteria were not clearly described. Most studies relied exclusively on parental report for data, and there was a general failure to take account of alternative explanations for the behaviours under study. No studies explored the views of individuals with

Why would they consider alternative explanations? They have decided they know what PDA is, & they know better than other topic experts.

"Equally contributors have noted that, with increased awareness, there has been some over-identification by other practitioners. " PDA Society 2022 p1.

Which is a rather bold &/ or misleading claim by those behind the report.



would be difficult to produce a separate document.

Identification of PDA across the country is variable. There are some services and professionals who do not recognise PDA as a diagnostic term. Equally contributors have noted that, with increased awareness, there has been some over-identification by other practitioners. Both can be problematic, therefore it is also hoped that this guidance will lead to some harmonisation of practice.

Lastly, the contributors recognise that the language used in this document is necessarily medical in style, as it is written for practitioners, and therefore not always as reflective of neurodiversity as they may like.

Terminology

Use of the term 'pathological', in relation to marked demand avoidance, is not without controversy. Indeed Professor Newson herself later expressed regret over her use of the term. Many individuals who identify with the profile feel that the term is accurate and appropriate, as the demand avoidance they experience is innate and all-consuming. Some clinicians prefer to use the term 'pervasive' or 'extreme' as an alternative, or simply refer to a 'demand avoidant profile'. All these are valid diagnostic formulations, and the use of different terminology may also be expedient where the PDA profile is not recognised by commissioners. In reality, the terminology used is less important than the understanding it provides, and so it is important to use whatever is acceptable.

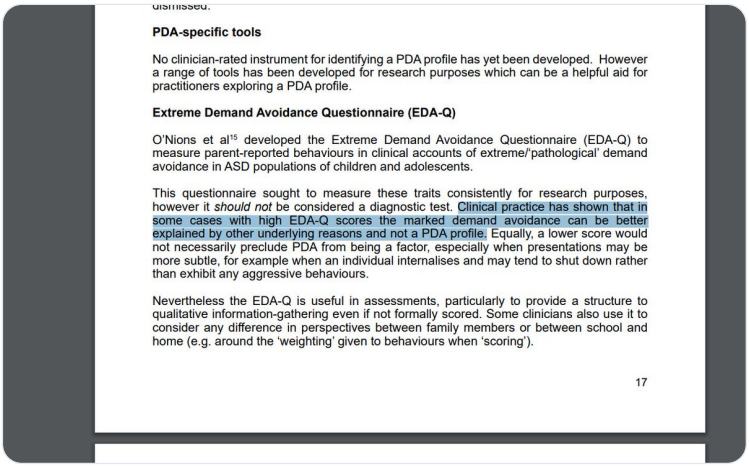
1

Acknowledgements

The PDA Society would like to thank the following contributors for sharing their experience

"Clinical practice has shown that in some cases with high EDA-Q scores the marked demand avoidance can be better explained by other underlying reasons and not a PDA profile" PDA Society 2022 p17.

Another bold &/ or misleading claim.



dismissed.

PDA-specific tools

No clinician-rated instrument for identifying a PDA profile has yet been developed. However a range of tools has been developed for research purposes which can be a helpful aid for practitioners exploring a PDA profile.

Extreme Demand Avoidance Questionnaire (EDA-Q)

O'Nions et al[15] developed the Extreme Demand Avoidance Questionnaire (EDA-Q) to measure parent-reported behaviours in clinical accounts of extreme/'pathological' demand avoidance in ASD populations of children and adolescents.

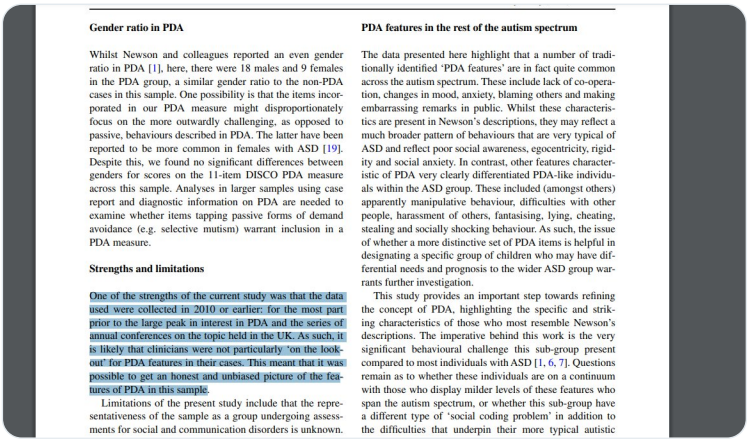
This questionnaire sought to measure these traits consistently for research purposes, however it *should not* be considered a diagnostic test. Clinical practice has shown that in some cases with high EDA-Q scores the marked demand avoidance can be better explained by other underlying reasons and not a PDA profile. Equally, a lower score would not necessarily preclude PDA from being a factor, especially when presentations may be more subtle, for example when an individual internalises and may tend to shut down rather than exhibit any aggressive behaviours.

Nevertheless the EDA-Q is useful in assessments, particularly to provide a structure to qualitative information-gathering even if not formally scored. Some clinicians also use it to consider any difference in perspectives between family members or between school and home (e.g. around the 'weighting' given to behaviours when 'scoring').

17

At least since 2016 "PDA Profile of ASD" supporters have assumed they know better than others. See this paragraph from O'Nions et al 2016b, p418.

Get an unbiased & accurate image of PDA as an autism subgroup. Despite PDA's nature being highly contested in PDA literature in 2015.



Gender ratio in PDA

Whilst Newson and colleagues reported an even gender ratio in PDA [1], here, there were 18 males and 9 females in the PDA group, a similar gender ratio to the non-PDA 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.

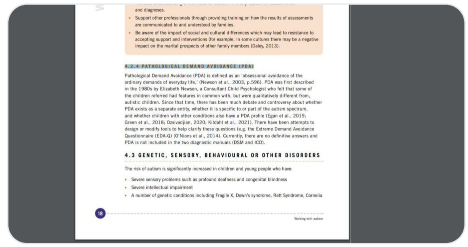
PDA features in the rest of the autism spectrum

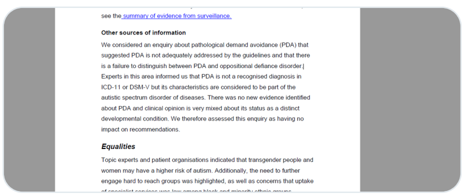
The data presented here highlight that a number of traditionally identified 'PDA features' are in fact quite common across the autism spectrum. These include lack of co-operation, changes in mood, anxiety, blaming others and making embarrassing remarks in public. Whilst these characteristics are present in Newson's descriptions, they may reflect a much broader pattern of behaviours that are very typical of ASD and reflect poor social awareness, egocentricity, rigidity and social anxiety. In contrast, other features characteristic of PDA very clearly differentiated PDA-like individuals within the ASD group. These included (amongst others) apparently manipulative behaviour, difficulties with other people, harassment of others, fantasising, lying, cheating, stealing and socially shocking behaviour. As such, the issue of whether a more distinctive set of PDA items is helpful in designating a specific group of children who may have differential needs and prognosis to the wider ASD group warrants further investigation.

This study provides an important step towards refining the concept of PDA, highlighting the specific and striking characteristics of those who most resemble Newson's descriptions. The imperative behind this work is the very significant behavioural challenge this sub-group present compared to most individuals with ASD [1, 6, 7]. Questions remain as to whether these individuals are on a continuum with those who display milder levels of these features who span the autism spectrum, or whether this sub-group have a different type of 'social coding problem' in addition to the difficulties that underpin their more typical autistic

I track the PDA debate over time in this conference talk, so it is clear, there is substantial amount of academic debate over what PDA was in 2015, when O'Nions et al (2016a) was published.
https://www.researchgate.net/publication/356109997_Demand-Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_It's_four_schools_of_thought_and_how_you_may_conceptualise_it

Tells us that much PDA research, & efforts to get PDA recognised as a "Profile of ASD" are unscientific & unethical. Especially as reputable independent parties have equally respected divergent views on PDA, & not assumed PDA as an ASD. @NICEComms @BPSOfficial @rcpsych @ArvidNK





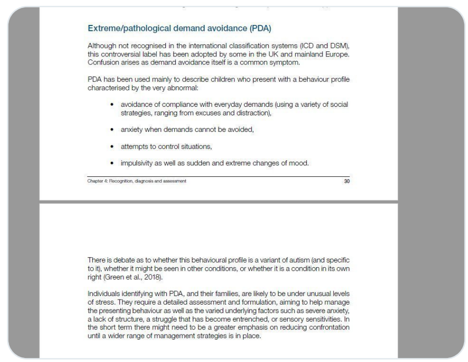
see the summary of evidence from surveillance.

Other sources of information

We considered an enquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiance disorder. Experts in this area informed us that PDA is not a recognised diagnosis in ICD-11 or DSM-V but its characteristics are considered to be part of the autistic spectrum disorder of diseases. There was no new evidence identified about PDA and clinical opinion is very mixed about its status as a distinct developmental condition. We therefore assessed this enquiry as having no impact on recommendations.

Equalities

Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake



Extreme/pathological demand avoidance (PDA)

Although not recognised in the international classification systems (ICD and DSM), this controversial label has been adopted by some in the UK and mainland Europe. Confusion arises as demand avoidance itself is a common symptom.

PDA has been used mainly to describe children who present with a behaviour profile characterised by the very abnormal:

- avoidance of compliance with everyday demands (using a variety of social strategies, ranging from excuses and distraction),
- anxiety when demands cannot be avoided,
- attempts to control situations,
- impulsivity as well as sudden and extreme changes of mood.

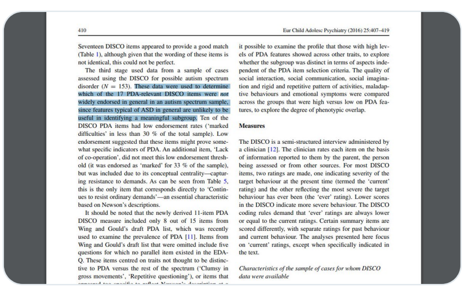
Chapter 4: Recognition, diagnosis and assessment 30

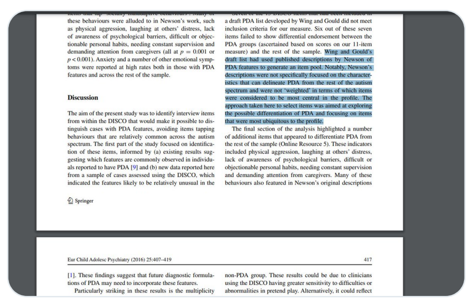
There is debate as to whether this behavioural profile is a variant of autism (and specific to it), whether it might be seen in other conditions, or whether it is a condition in its own right (Green et al., 2018).

Individuals identifying with PDA, and their families, are likely to be under unusual levels of stress. They require a detailed assessment and formulation, aiming to help manage the presenting behaviour as well as the varied underlying factors such as severe anxiety, a lack of structure, a struggle that has become entrenched, or sensory sensitivities. In the short term there might need to be a greater emphasis on reducing confrontation until a wider range of management strategies is in place.

To be clear O'Nions et al (2016a) did view PDA as an autism subgroup.

Image is from p410 & 416.
https://link.springer.com/content/pdf/10.1007/s00787-015-0740-2.pdf





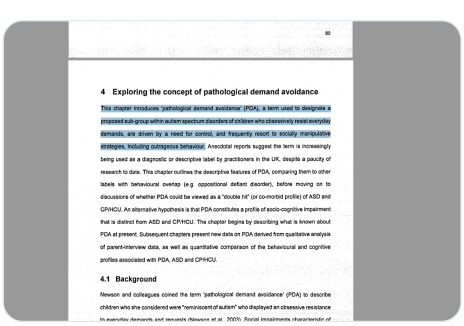
This has taken me onto something which has been nagging me most of today. How the axiom PDA is a part of the autism spectrum, actually decreases the quality of O'Nions PhD studies.

Did O'Nions view PDA to be part of the autism spectrum in 2013? Yes.

"A further source of contention is whether it is etiologically and cognitively 'distinct' from ASD as we know it" P81.

Note, how it is implied that ASD will evolve to include PDA.

Images from pages 81, 86.

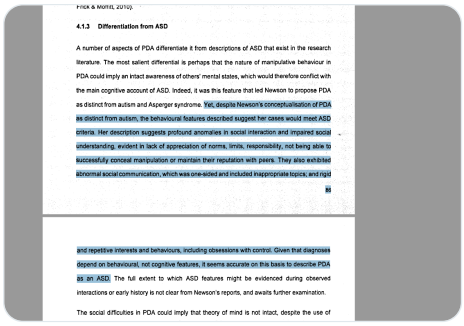


4 Exploring the concept of pathological demand avoidance

This chapter introduces 'pathological demand avoidance' (PDA), a term used to designate a proposed sub-group within autism spectrum disorders of children who obsessively resist everyday demands, are driven by a need for control, and frequently resort to socially manipulative strategies, including outrageous behaviour. Anecdotal reports suggest the term is increasingly being used as a diagnostic or descriptive label by practitioners in the UK, despite a paucity of research to date. This chapter outlines the descriptive features of PDA, comparing them to other labels with behavioural overlap (e.g. oppositional defiant disorder), before moving on to discussions of whether PDA could be viewed as a "double hit" (or co-morbid profile) of ASD and CP/HCU. An alternative hypothesis is that PDA constitutes a profile of socio-cognitive impairment that is distinct from ASD and CP/HCU. The chapter begins by describing what is known about PDA at present. Subsequent chapters present new data on PDA derived from qualitative analysis of parent-interview data, as well as quantitative comparison of the behavioural and cognitive profiles associated with PDA, ASD and CP/HCU.

4.1 Background

Newson and colleagues coined the term 'pathological demand avoidance' (PDA) to describe children who she considered were "reminiscent of autism" who displayed an obsessive resistance



4.1.3 Differentiation from ASD

A number of aspects of PDA differentiate it from descriptions of ASD that exist in the research literature. The most salient differential is perhaps that the nature of manipulative behaviour in PDA could imply an intact awareness of others' mental states, which would therefore conflict with the main cognitive account of ASD. Indeed, it was this feature that led Newson to propose PDA as distinct from autism and Asperger syndrome. Yet, despite Newson's conceptualisation of PDA as distinct from autism, the behavioural features described suggest her cases would meet ASD criteria. Her description suggests profound anomalies in social interaction and impaired social understanding, evident in lack of appreciation of norms, limits, responsibility, not being able to successfully conceal manipulation or maintain their reputation with peers. They also exhibited abnormal social communication, which was one-sided and included inappropriate topics, and rigid

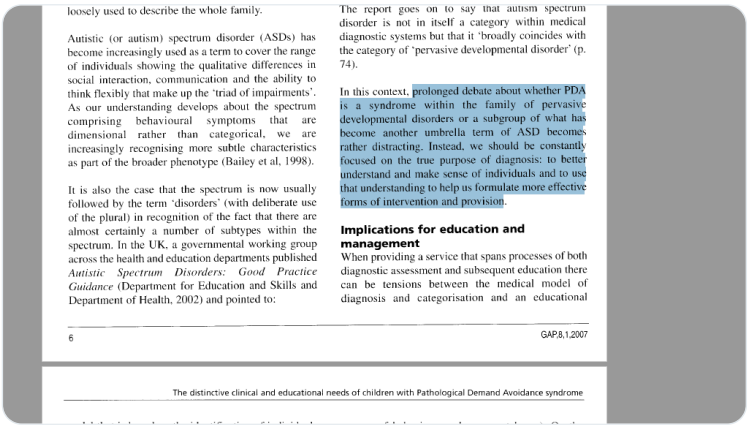
and repetitive interests and behaviours, including obsessions with control. Given that diagnoses depend on behavioural, not cognitive features, it seems accurate on this basis to describe PDA as an ASD. The full extent to which ASD features might be evidenced during observed interactions or early history is not clear from Newson's reports, and awaits further examination.

The social difficulties in PDA could imply that theory of mind is not intact, despite the use of

It also seems reasonable to point out hypocrisy of stating PDA should be viewed as an ASD, as diagnoses are made on a behavioural level. If cognitive reasons behind the behaviours are different to autism, PDA logically cannot be an ASD!

It is rather hypocritical in the context, in how Christie consistently argues for avoiding debates over what PDA is, & we should maintain the integrity over how PDA is understood, while pro "PDA Profile of ASD" supporters are happy to undermine integrity of autism!

Image from p6 of Christie 2007, where argues against debating what PDA is.



loosely used to describe the whole family.

Autistic (or autism) spectrum disorder (ASDs) has become increasingly used as a term to cover the range of individuals showing the qualitative differences in social interaction, communication and the ability to think flexibly that make up the 'triad of impairments'. As our understanding develops about the spectrum comprising behavioural symptoms that are dimensional rather than categorical, we are increasingly recognising more subtle characteristics as part of the broader phenotype (Bailey et al, 1998).

It is also the case that the spectrum is now usually followed by the term 'disorders' (with deliberate use of the plural) in recognition of the fact that there are almost certainly a number of subtypes within the spectrum. In the UK, a governmental working group across the health and education departments published *Autistic Spectrum Disorders: Good Practice Guidance* (Department for Education and Skills and Department of Health, 2002) and pointed to:

The report goes on to say that autism spectrum disorder is not in itself a category within medical diagnostic systems but that it 'broadly coincides with the category of 'pervasive developmental disorder' (p. 74).

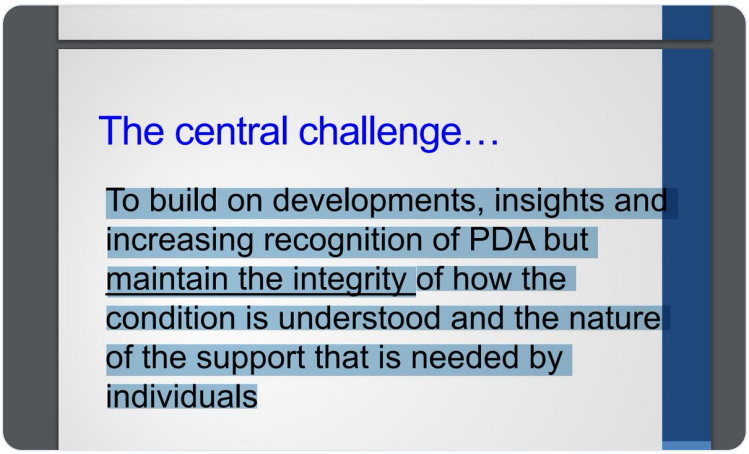
In this context, prolonged debate about whether PDA is a syndrome within the family of pervasive developmental disorders or a subgroup of what has become another umbrella term of ASD becomes rather distracting. Instead, we should be constantly focused on the true purpose of diagnosis: to better understand and make sense of individuals and to use that understanding to help us formulate more effective forms of intervention and provision.

Implications for education and management

When providing a service that spans processes of both diagnostic assessment and subsequent education there can be tensions between the medical model of diagnosis and categorisation and an educational

Slide 62 from a 2016 conference talk of Christie's. Link to slides. https://www.dp.dk/decentrale-enheder/dansk-psykolog-forenings-selskab-for-borneneuropsykologi/wp-content/uploads/sites/29/2016/04/Towards-an-Understanding...Denmark-Nov-2016.pdf

He has argued this in his more recent conference talks. One can view this ideology in the 2022 PDA Society research report, which Christie contributed towards.



As I argue here, such an approach is unethical & unscientific, as researchers, including clinicians taking part in studies should not be favouring any one outlook of what PDA is over another.

(PDF) Commentary: Demand Avoidance Phenomena, a manifold issue…
PDF | Demand Avoidance Phenomena (DAP) is a neutral term for Pathological Demand Avoidance, which is sometimes conceptualised as an autism subtype.... | Find, read and cite all the research you need …
https://www.researchgate.net/publication/338650142_Commentary_Demand_Avoidan…

Again it is worth stating that reputable independent bodies who are not invested in "PDA Profile of ASD", have all equally respected divergent views on PDA, including @NICEComms @BPSOfficial @rcpsych @ArvidNK. Suggesting problem is with "PDA Profile of ASD" supporters...

10 Autism 00(0)

Discussion

The methodological quality of peer-reviewed studies of PDA

The reviewed studies suggest that there is a subset of autistic children and adolescents who display behaviours involving persistent avoidance of perceived demands. However, methodological limitations of the studies reviewed restrict conclusions regarding the specific behaviours or constellation of behaviours that are characteristic of PDA; why and/or how they develop; or the distinguishing features of individuals displaying them. If demand avoidant behaviours do comprise a separate developmental disorder or a trait or subtype in autism, this requires greater evidence of behavioural stability. However, to date there have been no longitudinal studies of the trajectories of PDA behaviours, although two cross-sectional studies (Gillberg et al., 2015; O'Nions et al., 2016) described individuals who had displayed these behaviours in the past but no longer did so when the research was conducted. Currently, we still lack adequate information regarding the uniformity of demand avoidant behaviours, across individuals or over time. Notably, all identified studies had been conducted in Western Europe (mainly in a small number of UK centres), and knowledge from other countries and cultures is lacking.

Methods of identifying or measuring PDA

Despite its ongoing influence on the field, the study that originally described PDA (Newson et al., 2003) does not provide systematic information on how the criteria for PDA were developed; it is also unclear whether these criteria remained exactly the same over the time period that data were collected (1975–2000), and there is a risk of circularity due to its design (Green et al., 2018). These are important limitations since all subsequent studies, including the construction of the EDA-Q, are, to some degree, based on Newson et al.'s criteria. Furthermore, while the development and selection of items for the EDA-Q is fully described by O'Nions, Christie, et al. (2014), the pre-identification of groups in that study (again based on parental report) remains a significant methodological limitation.

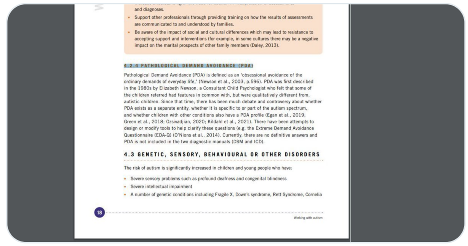
groups. As no further group comparisons have been conducted, it remains unclear whether PDA constitutes a distinct condition or merely reflects a difference in severity of 'disruptive' behaviours.

Most of the studies relied exclusively on parental report for inclusion criteria and identification of PDA. This heightens the risk of relationships between measures being confounded by common method, reporting, and confirmation bias (Green, 2020). Diagnostic studies in autism suggest that the validity of proxy reports varies according to informants' expectations, competence, observational skills and relationship with the autistic person (Havdahl et al., 2017; Helverschou & Martinsen, 2011) and are not always in line with reports from the autistic individuals themselves (e.g. Kalvin et al., 2020). Moreover, there is a possibility that parental reports may also have been affected by pre-existing ideas and understandings of PDA gleaned from the PDA web forums and conferences from which they were recruited.

The relationship between PDA, autism and other neurodevelopmental conditions

The majority of participants with PDA in most of the included studies were autistic, and apart from Study (3), there have been few comparisons or analyses of PDA symptoms in other groups. Although one of the case studies reported co-occurring ADHD and epilepsy (Reilly et al., 2014), information about any wider associations with these or other neurodevelopmental conditions is lacking. The association with intellectual ability is also unclear. One study specifically excluded individuals with severe intellectual disabilities from analyses because 'it is difficult to envisage the whole PDA phenotype developing in an individual with severe or profound general cognitive dysfunction' (Gillberg et al., 2015, p. 981). In other studies, information about IQ was often lacking. Those studies reporting level of intellectual abilities included participants across the IQ range, from individuals with severe intellectual disability to those reported as being of superior intelligence.

The relationship between PDA and psychiatric



and diagnoses.

- Support other professionals through providing training on how the results of assessments are communicated to and understood by families.
- Be aware of the impact of social and cultural differences which may lead to resistance to accepting support and interventions (for example, in some cultures there may be a negative impact on the marital prospects of other family members (Daley, 2013).

4.2.4 PATHOLOGICAL DEMAND AVOIDANCE (PDA)

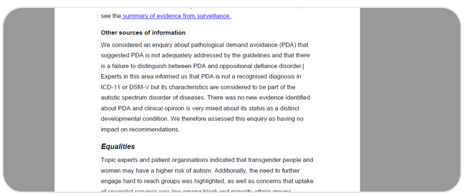
Pathological Demand Avoidance (PDA) is defined as an 'obsessional avoidance of the ordinary demands of everyday life,' (Newson et al., 2003, p.596). PDA was first described in the 1980s by Elizabeth Newson, a Consultant Child Psychologist who felt that some of the children referred had features in common with, but were qualitatively different from, autistic children. Since that time, there has been much debate and controversy about whether PDA exists as a separate entity, whether it is specific to or part of the autism spectrum, and whether children with other conditions also have a PDA profile (Egan et al., 2019; Green et al., 2018; Ozsivadjian, 2020; Kildahl et al., 2021). There have been attempts to design or modify tools to help clarify these questions (e.g. the Extreme Demand Avoidance Questionnaire (EDA-Q) (O'Nions et al., 2014). Currently, there are no definitive answers and PDA is not included in the two diagnostic manuals (DSM and ICD).

4.3 GENETIC, SENSORY, BEHAVIOURAL OR OTHER DISORDERS

The risk of autism is significantly increased in children and young people who have:

- Severe sensory problems such as profound deafness and congenital blindness
- Severe intellectual impairment
- A number of genetic conditions including Fragile X, Down's syndrome, Rett Syndrome, Cornelia

18 Working with autism



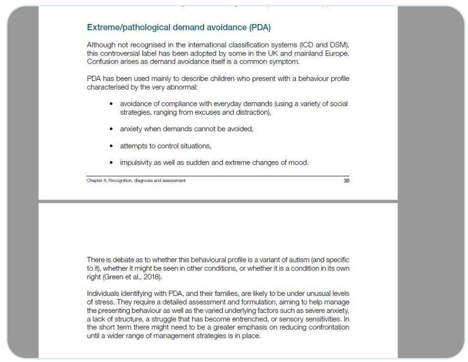
see the summary of evidence from surveillance.

Other sources of information

We considered an enquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiance disorder. Experts in this area informed us that PDA is not a recognised diagnosis in ICD-11 or DSM-V but its characteristics are considered to be part of the autistic spectrum disorder of diseases. There was no new evidence identified about PDA and clinical opinion is very mixed about its status as a distinct developmental condition. We therefore assessed this enquiry as having no impact on recommendations.

Equalities

Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake



Extreme/pathological demand avoidance (PDA)

Although not recognised in the international classification systems (ICD and DSM), this controversial label has been adopted by some in the UK and mainland Europe. Confusion arises as demand avoidance itself is a common symptom.

PDA has been used mainly to describe children who present with a behaviour profile characterised by the very abnormal:

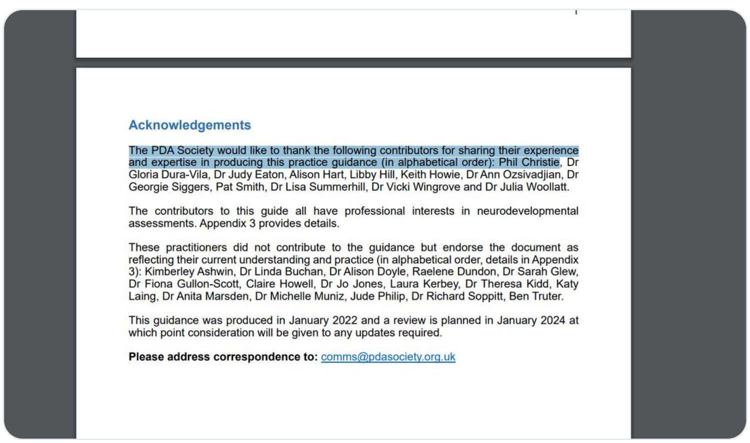
- avoidance of compliance with everyday demands (using a variety of social strategies, ranging from excuses and distraction),
- anxiety when demands cannot be avoided,
- attempts to control situations,
- impulsivity as well as sudden and extreme changes of mood.

Chapter 4: Recognition, diagnosis and assessment 30

There is debate as to whether this behavioural profile is a variant of autism (and specific to it), whether it might be seen in other conditions, or whether it is a condition in its own right (Green et al., 2018).

Individuals identifying with PDA, and their families, are likely to be under unusual levels of stress. They require a detailed assessment and formulation, aiming to help manage the presenting behaviour as well as the varied underlying factors such as severe anxiety, a lack of structure, a struggle that has become entrenched, or sensory sensitivities. In the short term there might need to be a greater emphasis on reducing confrontation until a wider range of management strategies is in place.

Image from p2 of PDA Society 2022 showing Christie contributed to that research report, which pretends to be clinical guidelines on PDA.



Acknowledgements

The PDA Society would like to thank the following contributors for sharing their experience and expertise in producing this practice guidance (in alphabetical order): Phil Christie, Dr Gloria Dura-Vila, Dr Judy Eaton, Alison Hart, Libby Hill, Keith Howie, Dr Ann Ozsivadjian, Dr Georgie Siggers, Pat Smith, Dr Lisa Summerhill, Dr Vicki Wingrove and Dr Julia Woollatt.

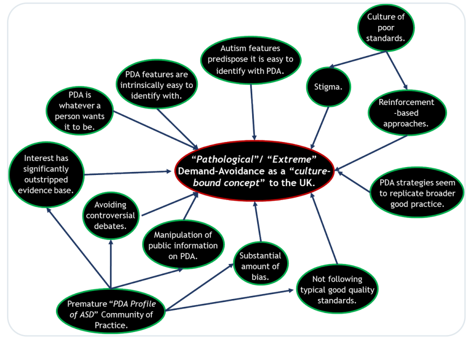
The contributors to this guide all have professional interests in neurodevelopmental assessments. Appendix 3 provides details.

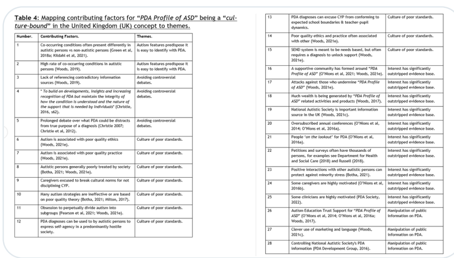
These practitioners did not contribute to the guidance but endorse the document as reflecting their current understanding and practice (in alphabetical order, details in Appendix 3): Kimberley Ashwin, Dr Linda Buchan, Dr Alison Doyle, Raelene Dundon, Dr Sarah Glew, Dr Fiona Gullon-Scott, Claire Howell, Dr Jo Jones, Laura Kerbey, Dr Theresa Kidd, Katy Laing, Dr Anita Marsden, Dr Michelle Muniz, Jude Philip, Dr Richard Soppitt, Ben Truter.

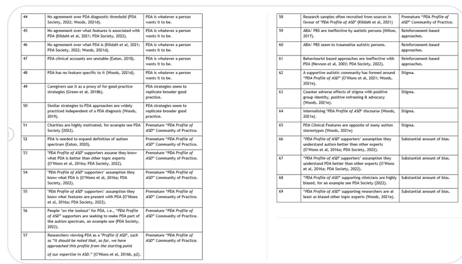
This guidance was produced in January 2022 and a review is planned in January 2024 at which point consideration will be given to any updates required.

Please address correspondence to: comms@pdasociety.org.uk

Worth mentioning the contributing factors for there being a "bubble"/ "culture-bound concept" for "PDA Profile of ASD". First two images show themes of about 70 contributing factors. Final 2 images show table of contributing factors. Note how debate is being manipulated.

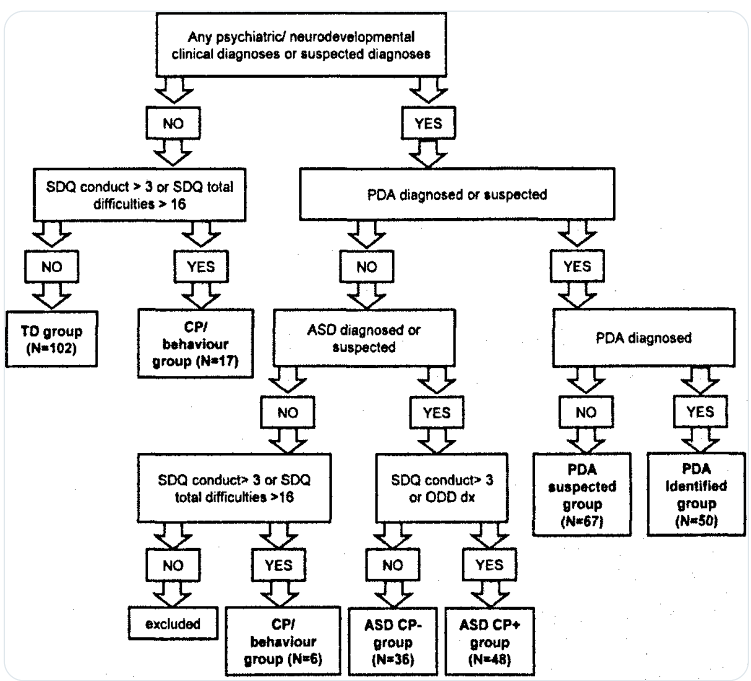




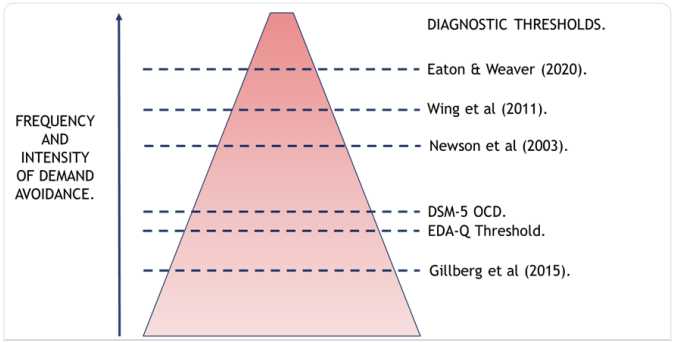


I am going to give three examples of how the axiom PDA is a form of autism in O'Nions thesis undermines the quality of the PhD studies.

First one is assuming PDA is a form of autism & how PDA only presents in autistic persons, for group allocation in EDA-Q validation study (chapter 7). See the diagram from p123



I have discussed the issues with this approach in this blog post.



PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THR…

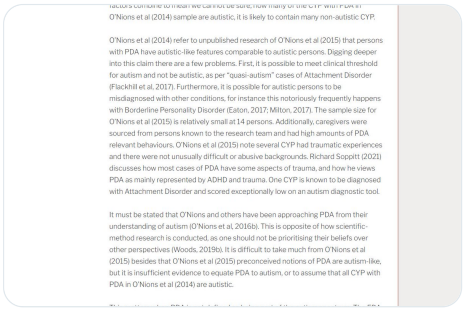
PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THRESHOLDS. NOTES ON WRITING THIS BLOG POST. This blog post has been written over a course of the last few of months. It particular in the last s…

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

Screenshots of several paragraphs setting out the case it is reasonable to assume there are non-autistic CYP in the two PDA groups.

The actual article views PDA as being part of the autism spectrum, "*Their apparently intact awareness of how to 'push people's buttons' suggests a level of social insight that is unusual in children with ASD.*" (O'Nions et al, 2014). The participants were allocated to 6 different groups; however, the PDA groups were directly filtered against two groups containing autistic CYP, see Figure 1 in O'Nions et al (2014, p761). The CYP with PDA reported, were split into two groups, 50 confirmed PDA diagnosis, and 67 suspected cases of PDA. The participants were not screened for autism, instead it relied upon reported caregiver diagnoses and who were potentially autistic. The CYP in this research were only screened with 32 candidate EDA-Q items and the Strengths and Difficulties Questionnaire (O'Nions et al, 2014).

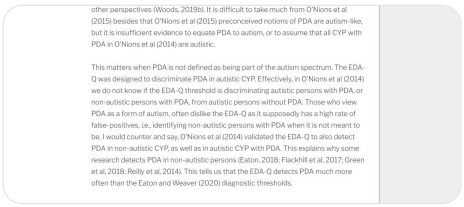
This is important as the article (and many others) note there is no consensus over how to view PDA, or how to formally diagnose PDA (O'Nions et al, 2014). There is no feature specific to PDA (Eaton and Weaver, 2020; Woods, 2019b; Woods 2019c), and PDA behaviour profile overlaps many other conditions, with many predicted populations (Gillberg, 2014; Green et al, 2018; Woods, 2019b). The other diagnoses of the two PDA groups are not reported, especially if they have an autism diagnosis or not. When at the time of the research being conducted in 2010 – 2012/ 2013, PDA was mainly diagnosed independently of autism, for other examples see (Carlile, 2011; Harvey, 2012; Jones, 2005; Langton and Frederickson, 2016a; Langton and Frederickson, 2016b; Newson et al, 2003). As established in a prior section, autism is more narrowly defined than PDA, due to the latter being a Pervasive Developmental Disorder. These factors combine to mean we cannot be sure, how many of the CYP with PDA in O'Nions et al (2014) sample are autistic, it is likely to contain many non-autistic CYP.



O'Nions et al (2014) sample are autistic, it is likely to contain many non-autistic CYP.

O'Nions et al (2014) refer to unpublished research of O'Nions et al (2015) that persons with PDA have autistic-like features comparable to autistic persons. Digging deeper into this claim there are a few problems. First, it is possible to meet clinical threshold for autism and not be autistic, as per "quasi-autism" cases of Attachment Disorder (Flackhill et al, 2017). Furthermore, it is possible for autistic persons to be misdiagnosed with other conditions, for instance this notoriously frequently happens with Borderline Personality Disorder (Eaton, 2017; Milton, 2017). The sample size for O'Nions et al (2015) is relatively small at 14 persons. Additionally, caregivers were sourced from persons known to the research team and had high amounts of PDA relevant behaviours. O'Nions et al (2015) note several CYP had traumatic experiences and there were not unusually difficult or abusive backgrounds. Richard Soppitt (2021) discusses how most cases of PDA have some aspects of trauma, and how he views PDA as mainly represented by ADHD and trauma. One CYP is known to be diagnosed with Attachment Disorder and scored exceptionally low on an autism diagnostic tool.

It must be stated that O'Nions and others have been approaching PDA from their understanding of autism (O'Nions et al, 2016b). This is opposite of how scientific-method research is conducted, as one should not be prioritising their beliefs over other perspectives (Woods, 2019b). It is difficult to take much from O'Nions et al (2015) besides that O'Nions et al (2015) preconceived notions of PDA are autism-like, but it is insufficient evidence to equate PDA to autism, or to assume that all CYP with PDA in O'Nions et al (2014) are autistic.

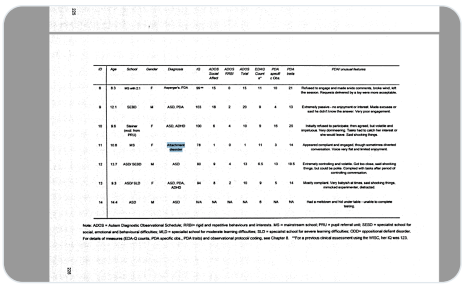


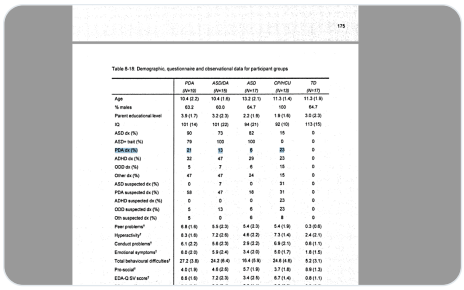
other perspectives (Woods, 2019b). It is difficult to take much from O'Nions et al (2015) besides that O'Nions et al (2015) preconceived notions of PDA are autism-like, but it is insufficient evidence to equate PDA to autism, or to assume that all CYP with PDA in O'Nions et al (2014) are autistic.

This matters when PDA is not defined as being part of the autism spectrum. The EDA-Q was designed to discriminate PDA in autistic CYP. Effectively, in O'Nions et al (2014) we do not know if the EDA-Q threshold is discriminating autistic persons with PDA, or non-autistic persons with PDA, from autistic persons without PDA. Those who view PDA as a form of autism, often dislike the EDA-Q as it supposedly has a high rate of false-positives, i.e., identifying non-autistic persons with PDA when it is not meant to be. I would counter and say, O'Nions et al (2014) validated the EDA-Q to also detect PDA in non-autistic CYP, as well as in autistic CYP with PDA. This explains why some research detects PDA in non-autistic persons (Eaton, 2018; Flackhill et al, 2017; Green et al, 2018; Reilly et al, 2014). This tells us that the EDA-Q detects PDA much more often than the Eaton and Weaver (2020) diagnostic thresholds.

Despite this there are good reasons from O'Nions thesis, it was a stupid idea assume CYP with PDA are autistic. We know this as there are non-autistic CYP with PDA in two other studies in the thesis. Also O'Nions did not trust PDA diagnoses for study in Chapter 8.

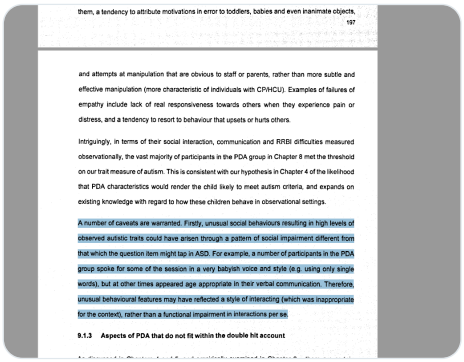
Chapter 5 cohort had one CYP with attachment disorder & only scored ONE on ADOS. There are at least three non-autistic CYP diagnosed with PDA in Chapter 8 cohort.





O'Nions thesis makes it clear that those with PDA can interact atypically with tools (including ADOS) which assess for autism features/ autistic traits.

Images should have page numbers on them.



them, a tendency to attribute motivations in error to toddlers, babies and even inanimate objects,

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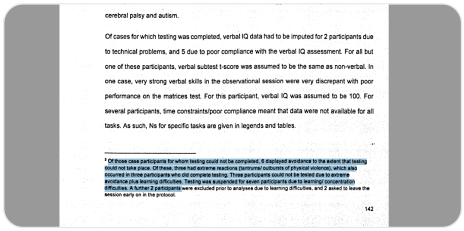
and attempts at manipulation that are obvious to staff or parents, rather than more subtle and effective manipulation (more characteristic of individuals with CP/HCU). Examples of failures of empathy include lack of real responsiveness towards others when they experience pain or distress, and a tendency to resort to behaviour that upsets or hurts others.

Intriguingly, in terms of their social interaction, communication and RRBI difficulties measured observationally, the vast majority of participants in the PDA group in Chapter 8 met the threshold on our trait measure of autism. This is consistent with our hypothesis in Chapter 4 of the likelihood that PDA characteristics would render the child likely to meet autism criteria, and expands on existing knowledge with regard to how these children behave in observational settings.

A number of caveats are warranted. Firstly, unusual social behaviours resulting in high levels of observed autistic traits could have arisen through a pattern of social impairment different from that which the question item might tap in ASD. For example, a number of participants in the PDA group spoke for some of the session in a very babyish voice and style (e.g. using only single words), but at other times appeared age appropriate in their verbal communication. 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.

9.1.3 Aspects of PDA that do not fit within the double hit account



cerebral palsy and autism.

Of cases for which testing was completed, verbal IQ data had to be imputed for 2 participants due to technical problems, and 5 due to poor compliance with the verbal IQ assessment. For all but one of these participants, verbal subtest t-score was assumed to be the same as non-verbal. In one case, very strong verbal skills in the observational session were very discrepant with poor performance on the matrices test. For this participant, verbal IQ was assumed to be 100. For several participants, time constraints/poor compliance meant that data were not available for all tasks. As such, Ns for specific tasks are given in legends and tables.

[9] Of those case participants for whom testing could not be completed, 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 suspected 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.

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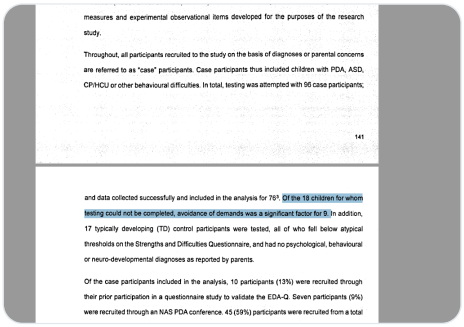

measures and experimental observational items developed for the purposes of the research study.

Throughout, all participants recruited to the study on the basis of diagnoses or parental concerns are referred to as "case" participants. Case participants thus included children with PDA, ASD, CP/HCU or other behavioural difficulties. In total, testing was attempted with 96 case participants;

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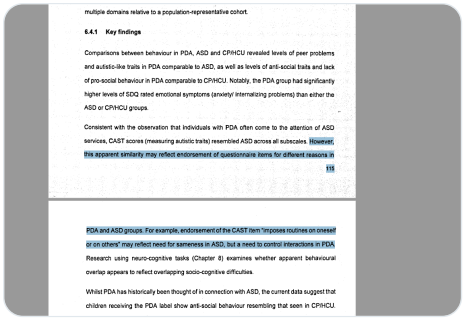
and data collected successfully and included in the analysis for 76[9]. Of the 18 children for whom testing could not be completed, avoidance of demands was a significant factor for 9. In addition, 17 typically developing (TD) control participants were tested, all of who fell below atypical thresholds on the Strengths and Difficulties Questionnaire, and had no psychological, behavioural or neuro-developmental diagnoses as reported by parents.

Of the case participants included in the analysis, 10 participants (13%) were recruited through their prior participation in a questionnaire study to validate the EDA-Q. Seven participants (9%) were recruited through an NAS PDA conference. 45 (59%) participants were recruited from a total



multiple domains relative to a population-representative cohort.

6.4.1 Key findings

Comparisons between behaviour in PDA, ASD and CP/HCU revealed levels of peer problems and autistic-like traits in PDA comparable to ASD, as well as levels of anti-social traits and lack of pro-social behaviour in PDA comparable to CP/HCU. Notably, the PDA group had significantly higher levels of SDQ rated emotional symptoms (anxiety/ internalizing problems) than either the ASD or CP/HCU groups.

Consistent with the observation that individuals with PDA often come to the attention of ASD services, CAST scores (measuring autistic traits) resembled ASD across all subscales. However, this apparent similarity may reflect endorsement of questionnaire items for different reasons in

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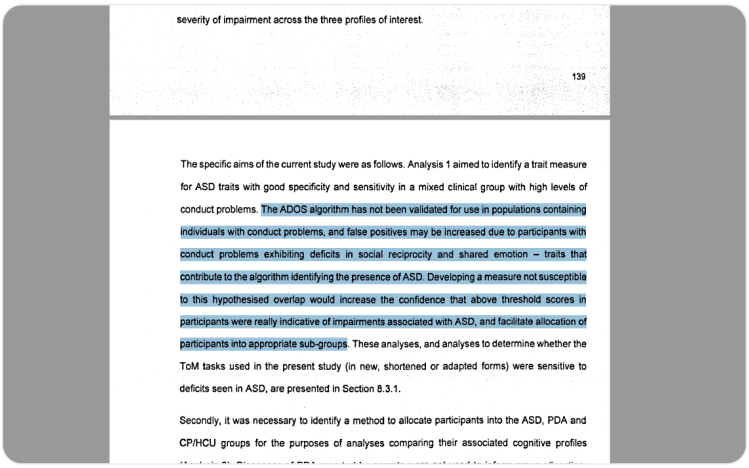
PDA and ASD groups. For example, endorsement of the CAST item "imposes routines on oneself or on others" may reflect need for sameness in ASD, but a need to control interactions in PDA. Research using neuro-cognitive tasks (Chapter 8) examines whether apparent behavioural overlap appears to reflect overlapping socio-cognitive difficulties.

Whilst PDA has historically been thought of in connection with ASD, the current data suggest that children receiving the PDA label show anti-social behaviour resembling that seen in CP/HCU.

Image from chapter 8 points out there is no validated ADOS algorithm for PDA, nor is there one designed to assess PDA features. ADOS2 is not designed to assess PDA features, I know this as the publisher told me.



severity of impairment across the three profiles of interest.

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The specific aims of the current study were as follows. Analysis 1 aimed to identify a trait measure for ASD traits with good specificity and sensitivity in a mixed clinical group with high levels of conduct problems. The ADOS algorithm has not been validated for use in populations containing individuals with conduct problems, and false positives may be increased due to participants with conduct problems exhibiting deficits in social reciprocity and shared emotion – traits that contribute to the algorithm identifying the presence of ASD. Developing a measure not susceptible to this hypothesised overlap would increase the confidence that above threshold scores in participants were really indicative of impairments associated with ASD, and facilitate allocation of participants into appropriate sub-groups. These analyses, and analyses to determine whether the ToM tasks used in the present study (in new, shortened or adapted forms) were sensitive to deficits seen in ASD, are presented in Section 8.3.1.

Secondly, it was necessary to identify a method to allocate participants into the ASD, PDA and CP/HCU groups for the purposes of analyses comparing their associated cognitive profiles

O'Nions also created her ADOS items to assess for PDA & algorithm, which I will discuss later.

Curious thing is that these points of O'Nions research are not discussed in Eaton & Weaver ADOS PDA research, despite authors being in contact with O'Nions.

Image showing that Eaton & Weaver were in contact with O'Nions, see their acknowledgements.

An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment

An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and their developmental histories

Judy Eaton and Kaylee Weaver, London

Editorial comment

This paper is in two parts. The first part analyses the scores on Module 3 of the ADOS-2 of 136 children diagnosed with autism following an autism diagnostic assessment at a specialist multidisciplinary clinic. From all the information collected during the assessment, it was concluded that 65 (47 per cent) of the children in this sample had both autism and a Pathological Demand Avoidant (PDA) profile. The authors therefore compared scores on Module 3 of the ADOS-2 of the two groups. They concluded that these scores successfully differentiated children with autism only, from those with autism with a PDA profile. The ADOS-2, Module 3 may therefore be a useful assessment tool for qualified clinicians to use as part of their diagnostic formulation. The authors acknowledge that this does not constitute evidence that autism with a PDA profile is a discrete autism subgroup or that similar types of behaviours to those

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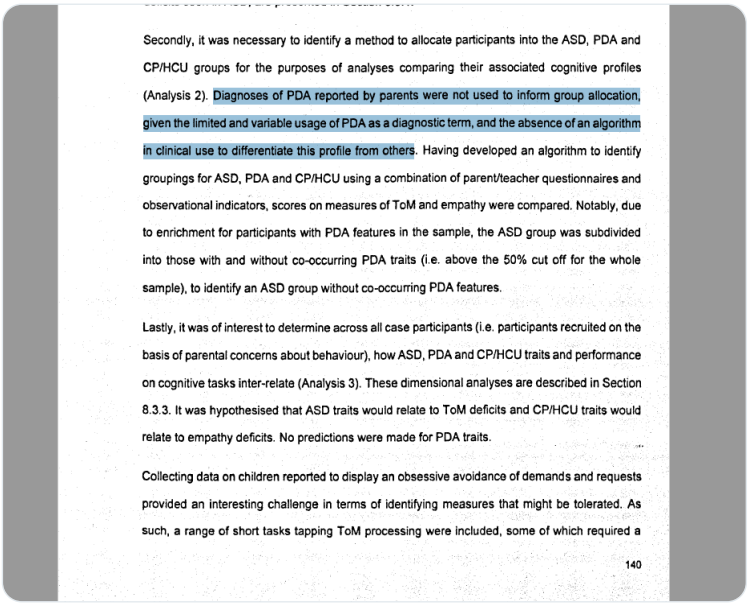
Acknowledgements
The authors gratefully acknowledge the support and feedback on early drafts of this paper from Dr Liz O'Nions and Professor Francesca Happe. They also are grateful to the many families who gave consent for their children's data to be included in the study.

The authors received no financial support for the research, authorship or publication of this paper.

It is worth mentioning that due to the apparent pattern of ignoring most things inconvenient by "PDA Profile of ASD" supporters...

Back to the point that O'Nions did not trust PDA diagnoses in chapter 8.



Secondly, it was necessary to identify a method to allocate participants into the ASD, PDA and CP/HCU groups for the purposes of analyses comparing their associated cognitive profiles (Analysis 2). 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. Having developed an algorithm to identify groupings for ASD, PDA and CP/HCU using a combination of parent/teacher questionnaires and observational indicators, scores on measures of ToM and empathy were compared. Notably, due to enrichment for participants with PDA features in the sample, the ASD group was subdivided into those with and without co-occurring PDA traits (i.e. above the 50% cut off for the whole sample), to identify an ASD group without co-occurring PDA features.

Lastly, it was of interest to determine across all case participants (i.e. participants recruited on the basis of parental concerns about behaviour), how ASD, PDA and CP/HCU traits and performance on cognitive tasks inter-relate (Analysis 3). These dimensional analyses are described in Section 8.3.3. It was hypothesised that ASD traits would relate to ToM deficits and CP/HCU traits would relate to empathy deficits. No predictions were made for PDA traits.

Collecting data on children reported to display an obsessive avoidance of demands and requests provided an interesting challenge in terms of identifying measures that might be tolerated. As such, a range of short tasks tapping ToM processing were included, some of which required a

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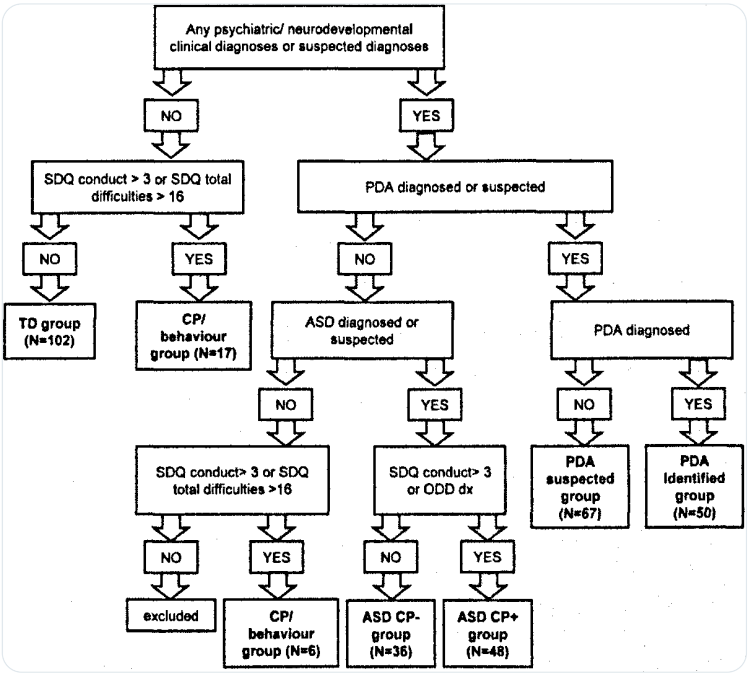
So O'Nions thesis has multiple examples of PDA interacting with autism/ autistic traits tools. Multiple non-autistic CYP in multiple studies. Did not trust PDA diagnoses in Chapter. Why then view PDA as a form of autism in group creation in chapter 7?

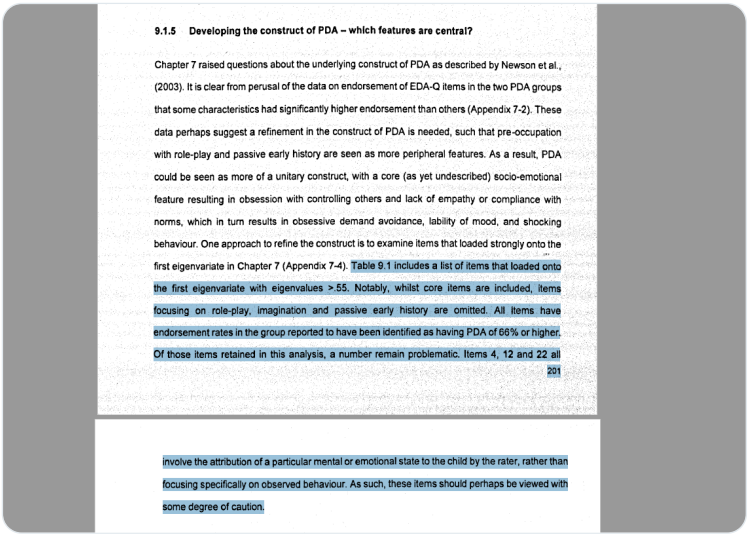


Because O'Nions has an axiom PDA is a form of autism. Also presumably their supervisors @HappeLab & Essi Viding, O'Nions herself & examiners missed these points?

Either way, it does seem a silly idea to view CYP with PDA as autistic in Chapter 7, based on info present in thesis.

It also explains why EDA-Q detects PDA in non-autistic CYP, because PDA groups in the study (Chapter 7) contains some non-autistic CYP with PDA in them. Hence O'Nions also validated EDA-Q to detect PDA in non-autistic CYP with PDA.

There are other limitations from Chapter 7 (validating the EDA-Q) due to assuming PDA is a form of autism. So apparently 2 Newson's PDA traits did not cluster, Passive Early History & Comfortable in roleplay & pretend.



9.1.5 Developing the construct of PDA – which features are central?

Chapter 7 raised questions about the underlying construct of PDA as described by Newson et al., (2003). It is clear from perusal of the data on endorsement of EDA-Q items in the two PDA groups that some characteristics had significantly higher endorsement than others (Appendix 7-2). These data perhaps suggest a refinement in the construct of PDA is needed, such that pre-occupation with role-play and passive early history are seen as more peripheral features. As a result, PDA could be seen as more of a unitary construct, with a core (as yet undescribed) socio-emotional feature resulting in obsession with controlling others and lack of empathy or compliance with norms, which in turn results in obsessive demand avoidance, lability of mood, and shocking behaviour. One approach to refine the construct is to examine items that loaded strongly onto the first eigenvariate in Chapter 7 (Appendix 7-4). Table 9.1 includes a list of items that loaded onto the first eigenvariate with eigenvalues >.55. Notably, whilst core items are included, items focusing on role-play, imagination and passive early history are omitted. All items have endorsement rates in the group reported to have been identified as having PDA of 66% or higher. Of those items retained in this analysis, a number remain problematic. Items 4, 12 and 22 all

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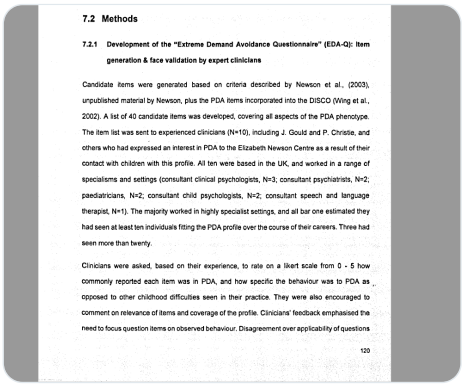
involve the attribution of a particular mental or emotional state to the child by the rater, rather than focusing specifically on observed behaviour. As such, these items should perhaps be viewed with some degree of caution.

EDA-Q items were rated by autism specialist clinicians. Located PDA features to deficits within the person.



7.2 Methods

7.2.1 Development of the "Extreme Demand Avoidance Questionnaire" (EDA-Q): Item generation & face validation by expert clinicians

Candidate items were generated based on criteria described by Newson et al., (2003), unpublished material by Newson, plus the PDA items incorporated into the DISCO (Wing et al., 2002). A list of 40 candidate items was developed, covering all aspects of the PDA phenotype. The item list was sent to experienced clinicians (N=10), including J. Gould and P. Christie, and others who had expressed an interest in PDA to the Elizabeth Newson Centre as a result of their contact with children with this profile. All ten were based in the UK, and worked in a range of specialisms and settings (consultant clinical psychologists, N=3; consultant psychiatrists, N=2; paediatricians, N=2; consultant child psychologists, N=2; consultant speech and language therapist, N=1). The majority worked in highly specialist settings, and all bar one estimated they had seen at least ten individuals fitting the PDA profile over the course of their careers. Three had seen more than twenty.

Clinicians were asked, based on their experience, to rate on a likert scale from 0 - 5 how commonly reported each item was in PDA, and how specific the behaviour was to PDA as opposed to other childhood difficulties seen in their practice. They were also encouraged to comment on relevance of items and coverage of the profile. Clinicians' feedback emphasised the need to focus question items on observed behaviour. Disagreement over applicability of questions

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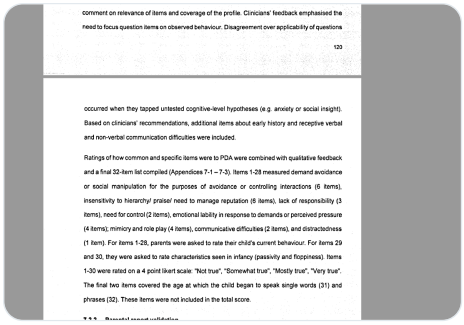

comment on relevance of items and coverage of the profile. Clinicians' feedback emphasised the need to focus question items on observed behaviour. Disagreement over applicability of questions

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occurred when they tapped untested cognitive-level hypotheses (e.g. anxiety or social insight). Based on clinicians' recommendations, additional items about early history and receptive verbal and non-verbal communication difficulties were included.

Ratings of how common and specific items were to PDA were combined with qualitative feedback and a final 32-item list compiled (Appendices 7-1 – 7-3). Items 1-28 measured demand avoidance or social manipulation for the purposes of avoidance or controlling interactions (6 items), insensitivity to hierarchy/ praise/ need to manage reputation (6 items), lack of responsibility (3 items), need for control (2 items), emotional lability in response to demands or perceived pressure (4 items), mimicry and role play (4 items), communicative difficulties (2 items), and distractedness (1 item). For items 1-28, parents were asked to rate their child's current behaviour. For items 29 and 30, they were asked to rate characteristics seen in infancy (passivity and floppiness). Items 1-30 were rated on a 4 point likert scale: "Not true", "Somewhat true", "Mostly true", "Very true". The final two items covered the age at which the child began to speak single words (31) and phrases (32). These items were not included in the total score.

There are something things to comment upon these EDA-Q results with these 2 traits not clustering.

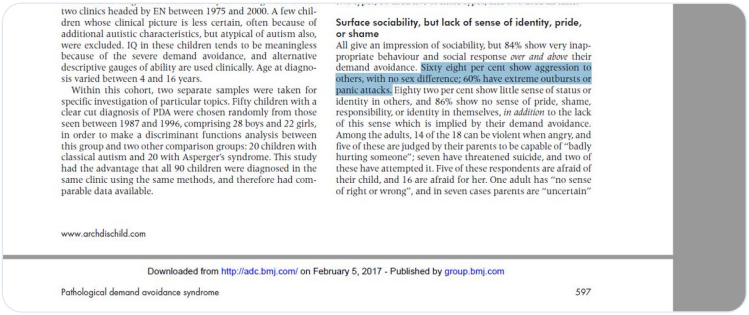
First point, Newson conceptualised PDA to have developmental features, despite this she did NOT require ALL her features to be present for a person to receive a PDA dx. Also, Newson acknowledged persons can transition into PDA, i.e., PDA does not need to be from early infancy.

So one needs to be aware of Newson's bias when engaging with her PDA traits, that some features might be present due to Newson's bias. E.g., panic attacks being caused by deficits in social identity/ pride/ shame; when panic attacks are not caused by such deficits.

"Clearly no child will show all the behavioural examples listed, any more than all autistic children show the whole repertoire of autistic behaviours; but every child with clear-cut PDA will manifest the overall complex pattern, not merely one or two features."

That is from Newson et al (2003) supplementary notes. We also know that Newson gave percentages for various features, few, if any are 100% across her entire cohort.

Image from p596 showing about 60% of Newson's cohort had panic attacks & she attributed to trait with deficits in social identity/ pride/ shame.



two clinics headed by EN between 1975 and 2000. A few children whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded. IQ in these children tends to be meaningless because of the severe demand avoidance, and alternative descriptive gauges of ability are used clinically. Age at diagnosis varied between 4 and 16 years.

Within this cohort, two separate samples were taken for specific investigation of particular topics. Fifty children with a clear cut diagnosis of PDA were chosen randomly from those seen between 1987 and 1996, comprising 28 boys and 22 girls, in order to make a discriminant functions analysis between this group and two other comparison groups: 20 children with classical autism and 20 with Asperger's syndrome. This study had the advantage that all 90 children were diagnosed in the same clinic using the same methods, and therefore had comparable data available.

Surface sociability, but lack of sense of identity, pride, or shame

All give an impression of sociability, but 84% show very inappropriate behaviour and social response *over and above* their demand avoidance. Sixty eight per cent show aggression to others, with no sex difference; 60% have extreme outbursts or panic attacks. Eighty two per cent show little sense of status or identity in others, and 86% show no sense of pride, shame, responsibility, or identity in themselves, *in addition* to the lack of this sense which is implied by their demand avoidance. Among the adults, 14 of the 18 can be violent when angry, and five of these are judged by their parents to be capable of "badly hurting someone"; seven have threatened suicide, and two of these have attempted it. Five of these respondents are afraid of their child, and 16 are afraid for her. One adult has "no sense of right or wrong", and in seven cases parents are "uncertain"

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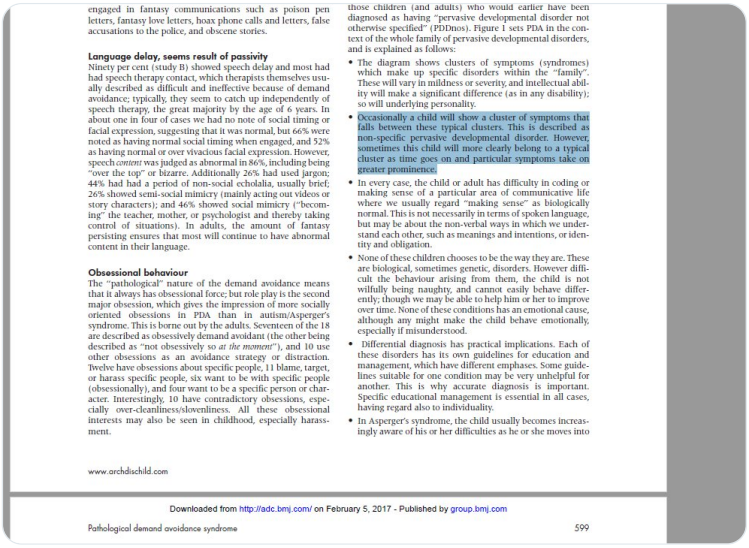
Image from p598 showing that persons can transition into PDA. Worth mentioning PDA's Developmental features are generic in nature, so it is possible Newson attributed them to PDA due to confirmation bias.



engaged in fantasy communications such as poison pen letters, fantasy love letters, hoax phone calls and letters, false accusations to the police, and obscene stories.

Language delay, seems result of passivity

Ninety per cent (study B) showed speech delay and most had had speech therapy contact, which therapists themselves usually described as difficult and ineffective because of demand avoidance; typically, they seem to catch up independently of speech therapy, the great majority by the age of 6 years. In about one in four of cases we had no note of social timing or facial expression, suggesting that it was normal, but 66% were noted as having normal social timing when engaged, and 52% as having normal or over vivacious facial expression. However, speech *content* was judged as abnormal in 86%, including being "over the top" or bizarre. Additionally 26% had used jargon; 44% had had a period of non-social echolalia, usually brief; 26% showed semi-social mimicry (mainly acting out videos or story characters); and 46% showed social mimicry ("becoming" the teacher, mother, or psychologist and thereby taking control of situations). In adults, the amount of fantasy persisting ensures that most will continue to have abnormal content in their language.

Obsessional behaviour

The "pathological" nature of the demand avoidance means that it always has obsessional force; but role play is the second major obsession, which gives the impression of more socially oriented obsessions in PDA than in autism/Asperger's syndrome. This is borne out by the adults. Seventeen of the 18 are described as obsessively demand avoidant (the other being described as "not obsessively so *at the moment*"), and 10 use other obsessions as an avoidance strategy or distraction. Twelve have obsessions about specific people, 11 blame, target, or harass specific people, six want to be with specific people (obsessionally), and four want to be a specific person or character. Interestingly, 10 have contradictory obsessions, especially over-cleanliness/slovenliness. All these obsessional interests may also be seen in childhood, especially harassment.

those children (and adults) who would earlier have been diagnosed as having "pervasive developmental disorder not otherwise specified" (PDDnos). Figure 1 sets PDA in the context of the whole family of pervasive developmental disorders, and is explained as follows:

- The diagram shows clusters of symptoms (syndromes) which make up specific disorders within the "family". These will vary in mildness or severity, and intellectual ability will make a significant difference (as in any disability); so will underlying personality.
- Occasionally a child will show a cluster of symptoms that falls between these typical clusters. This is described as non-specific pervasive developmental disorder. However, sometimes this child will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.
- In every case, the child or adult has difficulty in coding or making sense of a particular area of communicative life where we usually regard "making sense" as biologically normal. This is not necessarily in terms of spoken language, but may be about the non-verbal ways in which we understand each other, such as meanings and intentions, or identity and obligation.
- None of these children chooses to be the way they are. These are biological, sometimes genetic, disorders. However difficult the behaviour arising from them, the child is not willfully being naughty, and cannot easily behave differently; though we may be able to help him or her to improve over time. None of these conditions has an emotional cause, although any might make the child behave emotionally, especially if misunderstood.
- Differential diagnosis has practical implications. Each of these disorders has its own guidelines for education and management, which have different emphases. Some guidelines suitable for one condition may be very unhelpful for another. This is why accurate diagnosis is important. Specific educational management is essential in all cases, having regard also to individuality.
- In Asperger's syndrome, the child usually becomes increasingly aware of his or her difficulties as he or she moves into

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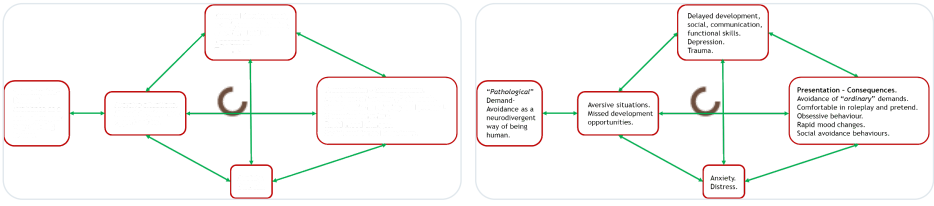
Under transactional models/ accounts of PDA, persons can transition into PDA throughout lifespan. So it makes sense that Passive Early history trait might not cluster with core PDA traits.



However, if one views comfortable in roleplay & pretense features in PDA as being a form of dissociation/ escape from distress/ anxiety from demands, one would expect this trait to cluster with other demand-avoidance traits.

One would definitely expect comfortable in roleplay & pretense features to cluster with other demand-avoidance traits under a transactional model/ approach to PDA. While EDA-Q routes such features to intrinsic deficits within the person, not transactional with environment.

It is possible that this aspect of the results from Chapter 7/ EDA-Q validation study is due to axiom of O'Nions PDA is a form of autism.

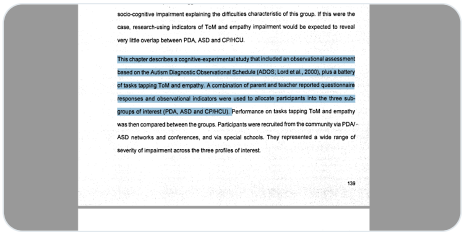
Why am I am talking about PDA traits clustering, or not clustering together based on EDA-Q?

Also because this information should have informed O'Nions methodology for Chapter 8 study, particularly her algorithm for creating her PDA group.

As stated previously O'Nions created her own algorithm for identifying PDA, including ADOS features.

There is only one reason why you create ADOS features & algorithm for identifying PDA, if you want PDA to be diagnosed as a form of autism! Slight tangent.

Images show that O'Nions developed own algorithm to identify PDA, & used versions of tools as not designed to be, including EDA-Q. Only used 11 questions & used them to cover Newson's traits, including comfortable in roleplay & pretend.



socio-cognitive impairment explaining the difficulties characteristic of this group. If this were the case, research-using indicators of ToM and empathy impairment would be expected to reveal very little overlap between PDA, ASD and CP/HCU.

This chapter describes a cognitive-experimental study that included an observational assessment based on the Autism Diagnostic Observational Schedule (ADOS; Lord et al., 2000), plus a battery of tasks tapping ToM and empathy. A combination of parent and teacher reported questionnaire responses and observational indicators were used to allocate participants into the three sub-groups of interest (PDA, ASD and CP/HCU). Performance on tasks tapping ToM and empathy was then compared between the groups. Participants were recruited from the community via PDA/ - ASD networks and conferences, and via special schools. They represented a wide range of severity of impairment across the three profiles of interest.

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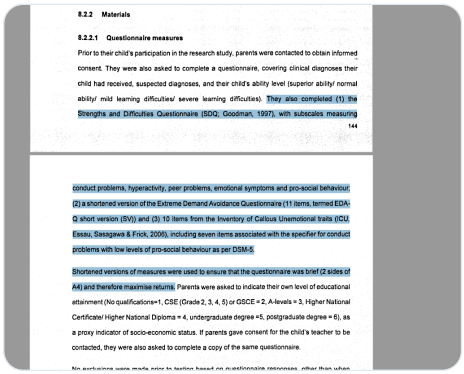

8.2.2 Materials

8.2.2.1 Questionnaire measures

Prior to their child's participation in the research study, parents were contacted to obtain informed consent. They were also asked to complete a questionnaire, covering clinical diagnoses their child had received, suspected diagnoses, and their child's ability level (superior ability/ normal ability/ mild learning difficulties/ severe learning difficulties). They also completed (1) the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), with subscales measuring

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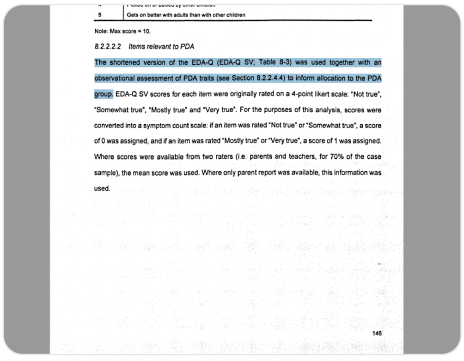
conduct problems, hyperactivity, peer problems, emotional symptoms and pro-social behaviour; (2) a shortened version of the Extreme Demand Avoidance Questionnaire (11 items, termed EDA-Q short version (SV)) and (3) 10 items from the Inventory of Callous Unemotional traits (ICU; Essau, Sasagawa & Frick, 2006), including seven items associated with the specifier for conduct problems with low levels of pro-social behaviour as per DSM-5.

Shortened versions of measures were used to ensure that the questionnaire was brief (2 sides of A4) and therefore maximise returns. Parents were asked to indicate their own level of educational attainment (No qualifications=1, CSE (Grade 2, 3, 4, 5) or GSCE = 2, A-levels = 3, Higher National Certificate/ Higher National Diploma = 4, undergraduate degree =5, postgraduate degree = 6), as a proxy indicator of socio-economic status. If parents gave consent for the child's teacher to be contacted, they were also asked to complete a copy of the same questionnaire.



5	Gets on better with adults than with other children

Note: Max score = 10.

8.2.2.2.2 Items relevant to PDA

The shortened version of the EDA-Q (EDA-Q SV, Table 8-3) was used together with an observational assessment of PDA traits (see Section 8.2.2.4.4) to inform allocation to the PDA group. EDA-Q SV scores for each item were originally rated on a 4-point likert scale: "Not true", "Somewhat true", "Mostly true" and "Very true". For the purposes of this analysis, scores were converted into a symptom count scale: if an item was rated "Not true" or "Somewhat true", a score of 0 was assigned, and if an item was rated "Mostly true" or "Very true", a score of 1 was assigned. Where scores were available from two raters (i.e. parents and teachers, for 70% of the case sample), the mean score was used. Where only parent report was available, this information was used.

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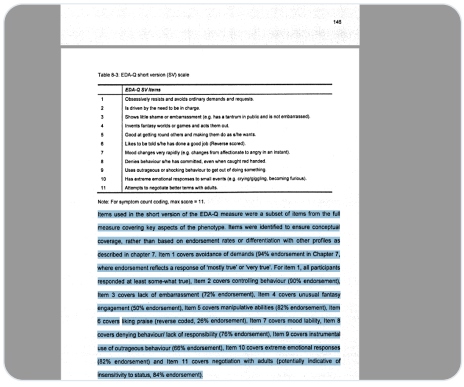

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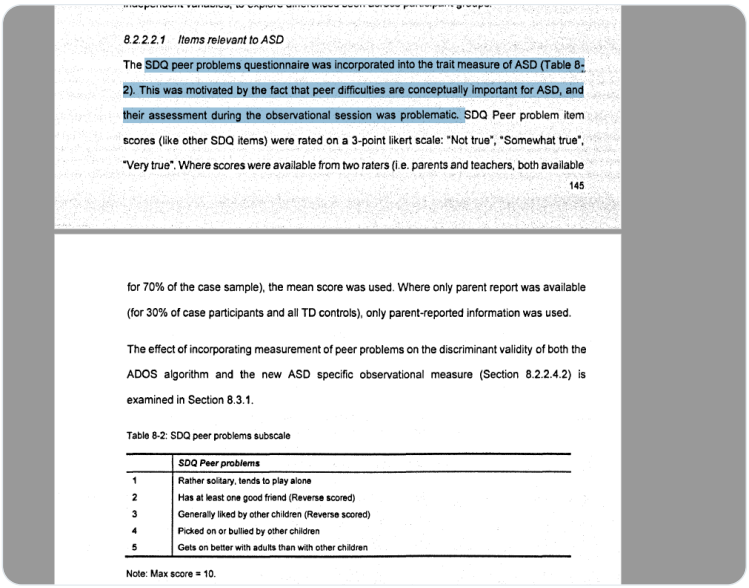
Table 8-3. EDA-Q short version (SV) scale

	EDA-Q SV items
1	Obsessively resists and avoids ordinary demands and requests.
2	Is driven by the need to be in charge.
3	Shows little shame or embarrassment (e.g. has a tantrum in public and is not embarrassed).
4	Invents fantasy worlds or games and acts them out.
5	Good at getting round others and making them do as s/he wants.
6	Likes to be told s/he has done a good job (Reverse scored).
7	Mood changes very rapidly (e.g. changes from affectionate to angry in an instant).
8	Denies behaviour s/he has committed, even when caught red handed.
9	Uses outrageous or shocking behaviour to get out of doing something.
10	Has extreme emotional responses to small events (e.g. crying/giggling, becoming furious).
11	Attempts to negotiate better terms with adults.

Note: For symptom count coding, max score = 11.

Items used in the short version of the EDA-Q measure were a subset of items from the full measure covering key aspects of the phenotype. Items were identified to ensure conceptual coverage, rather than based on endorsement rates or differentiation with other profiles as described in chapter 7. Item 1 covers avoidance of demands (94% endorsement in Chapter 7, where endorsement reflects a response of 'mostly true' or 'very true'. For item 1, all participants responded at least some-what true), item 2 covers controlling behaviour (50% endorsement), item 3 covers lack of embarrassment (72% endorsement), item 4 covers unusual fantasy engagement (50% endorsement), item 5 covers manipulative abilities (82% endorsement), item 6 covers liking praise (reverse coded, 26% endorsement), item 7 covers mood lability, item 8 covers denying behaviour/ lack of responsibility (76% endorsement), item 9 covers instrumental use of outrageous behaviour (66% endorsement), item 10 covers extreme emotional responses (82% endorsement) and item 11 covers negotiation with adults (potentially indicative of insensitivity to status, 84% endorsement).

Also used a subscale of the Strengths & Difficulties Questionnaire in way it is not designed for indicating if a person/ CYP is autistic. There are many reasons why a person might score highly on peer problems subscale, including due to PDA features.



8.2.2.2.1 Items relevant to ASD

The SDQ peer problems questionnaire was incorporated into the trait measure of ASD (Table 8-2). This was motivated by the fact that peer difficulties are conceptually important for ASD, and their assessment during the observational session was problematic. SDQ Peer problem item scores (like other SDQ items) were rated on a 3-point likert scale: "Not true", "Somewhat true", "Very true". Where scores were available from two raters (i.e. parents and teachers, both available

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for 70% of the case sample), the mean score was used. Where only parent report was available (for 30% of case participants and all TD controls), only parent-reported information was used.

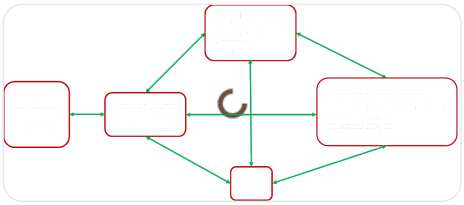
The effect of incorporating measurement of peer problems on the discriminant validity of both the ADOS algorithm and the new ASD specific observational measure (Section 8.2.2.4.2) is examined in Section 8.3.1.

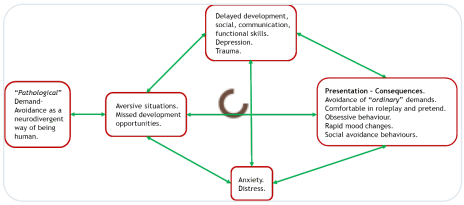
Table 8-2: SDQ peer problems subscale

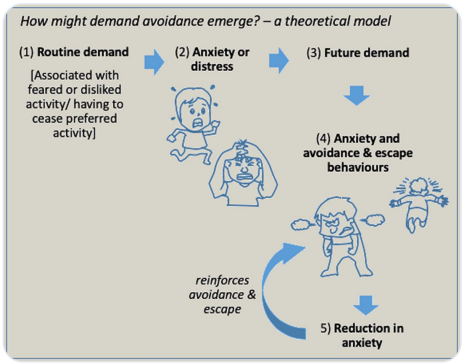
	SDQ Peer problems
1	Rather solitary, tends to play alone
2	Has at least one good friend (Reverse scored)
3	Generally liked by other children (Reverse scored)
4	Picked on or bullied by other children
5	Gets on better with adults than with other children

Note: Max score = 10.

Reason why I say this, is that purpose of PDA social avoidance features is to change nature of social situation, or terminate social interaction to remove aversive demands. Also having rapid mood changes is often going to be off putting for people.

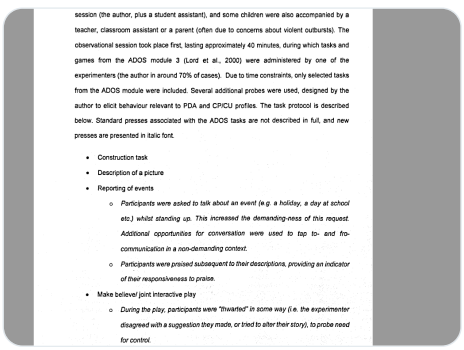






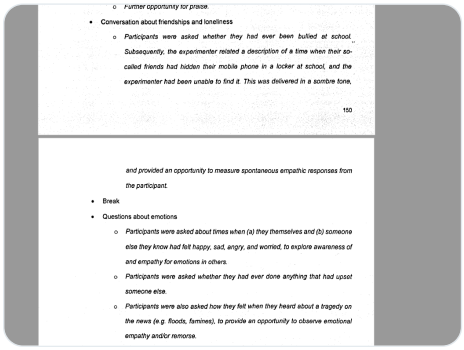
It is circular to view a person as being autistic due to PDA features, just because a person scores highly on peer problems sub-scale is not a reliable indicator a person is autistic or not.

O'Nions did create new ADOS items to assess for PDA, including a new protocol, which they administered in about 70% of CYP in chapter 8 cohort.



session (the author, plus a student assistant), and some children were also accompanied by a teacher, classroom assistant or a parent (often due to concerns about violent outbursts). The observational session took place first, lasting approximately 40 minutes, during which tasks and games from the ADOS module 3 (Lord et al., 2000) were administered by one of the experimenters (the author in around 70% of cases). Due to time constraints, only selected tasks from the ADOS module were included. Several additional probes were used, designed by the author to elicit behaviour relevant to PDA and CP/CU profiles. The task protocol is described below. Standard presses associated with the ADOS tasks are not described in full, and new presses are presented in italic font.

- Construction task
- Description of a picture
- Reporting of events
  - *Participants were asked to talk about an event (e.g. a holiday, a day at school etc.) whilst standing up. This increased the demanding-ness of this request. Additional opportunities for conversation were used to tap to- and fro-communication in a non-demanding context.*
  - *Participants were praised subsequent to their descriptions, providing an indicator of their responsiveness to praise.*
- Make believe/ joint interactive play
  - *During the play, participants were "thwarted" in some way (i.e. the experimenter disagreed with a suggestion they made, or tried to alter their story), to probe need for control.*



- *Further opportunity for praise.*
- Conversation about friendships and loneliness
  - *Participants were asked whether they had ever been bullied at school. Subsequently, the experimenter related a description of a time when their so-called friends had hidden their mobile phone in a locker at school, and the experimenter had been unable to find it. This was delivered in a sombre tone,*

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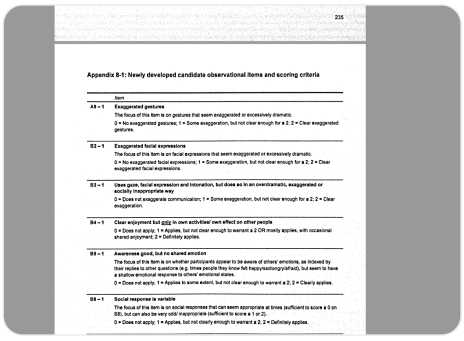
and provided an opportunity to measure spontaneous empathic responses from the participant.

- Break
- Questions about emotions
  - *Participants were asked about times when (a) they themselves and (b) someone else they know had felt happy, sad, angry, and worried, to explore awareness of and empathy for emotions in others.*
  - *Participants were asked whether they had ever done anything that had upset someone else.*
  - *Participants were also asked how they felt when they heard about a tragedy on the news (e.g. floods, famines), to provide an opportunity to observe emotional empathy and/or remorse.*

A couple of screenshots to show ADOS items O'Nions created.



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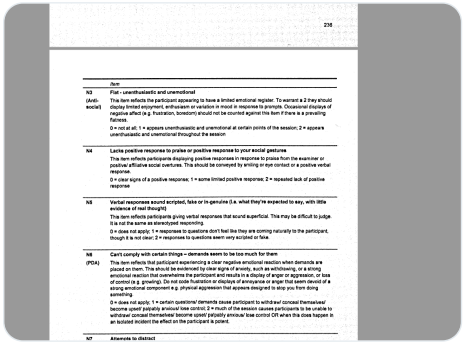
Appendix 8-1: Newly developed candidate observational items and scoring criteria

	Item
A8 – 1	**Exaggerated gestures** The focus of this item is on gestures that seem exaggerated or excessively dramatic. 0 = No exaggerated gestures; 1 = Some exaggeration, but not clear enough for a 2; 2 = Clear exaggerated gestures.
B2 – 1	**Exaggerated facial expressions** The focus of this item is on facial expressions that seem exaggerated or excessively dramatic. 0 = No exaggerated facial expressions; 1 = Some exaggeration, but not clear enough for a 2; 2 = Clear exaggerated facial expressions.
B3 – 1	**Uses gaze, facial expression and intonation, but does so in an overdramatic, exaggerated or socially inappropriate way** 0 = Does not exaggerate communication; 1 = Some exaggeration, but not clear enough for a 2; 2 = Clear exaggeration.
B4 – 1	**Clear enjoyment but only in own activities' own effect on other people** 0 = Does not apply; 1 = Applies, but not clear enough to warrant a 2 OR mostly applies, with occasional shared enjoyment; 2 = Definitely applies.
B5 – 1	**Awareness good, but no shared emotion** The focus of this item is on whether participants appear to be aware of others' emotions, as indexed by their replies to other questions (e.g. times people they know felt happy/sad/angry/afraid), but seem to have a shallow emotional response to others' emotional states. 0 = Does not apply; 1 = Applies to some extent, but not clear enough to warrant a 2; 2 = Clearly applies.
B6 – 1	**Social responses is variable** The focus of this item is on social responses that can seem appropriate at times (sufficient to score a 0 on B8), but can also be very odd/ inappropriate (sufficient to score a 1 or 2). 0 = Does not apply; 1 = Applies, but not clearly enough to warrant a 2; 2 = Definitely applies.



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	Item
N3 (Anti-social)	**Flat – unenthusiastic and unemotional** This item reflects the participant appearing to have a limited emotional register. To warrant a 2 they should display limited enjoyment, enthusiasm or variation in mood in response to prompts. Occasional displays of negative affect (e.g. frustration, boredom) should not be counted against this item if there is a prevailing flatness. 0 = not at all; 1 = appears unenthusiastic and unemotional at certain points of the session; 2 = appears unenthusiastic and unemotional throughout the session
N4	**Lacks positive response to praise or positive responses to your social gestures** This item reflects participants displaying positive responses in response to praise from the examiner or positive affiliative social overtures. This should be conveyed by smiling or eye contact or a positive verbal response. 0 = clear signs of a positive response; 1 = some limited positive response; 2 = repeated lack of positive response
N5	**Verbal responses sound scripted, fake or ingenuine (i.e. what they're expected to say, with little evidence of real thought)** This item reflects participants giving verbal responses that sound superficial. This may be difficult to judge. It is not the same as stereotyped responding. 0= does not apply; 1 = responses to questions don't feel like they are coming naturally to the participant, though it is not clear; 2 = responses to questions seem very scripted or fake.
N6 (PDA)	**Can't comply with certain things – demands seem to be too much for them** This item reflects that participant experiencing a clear negative emotional reaction when demands are placed on them. This should be evidenced by clear signs of anxiety, such as withdrawing, or a strong emotional reaction that overwhelms the participant and results in a display of anger or aggression, or loss of control (e.g. growing). Do not code frustration or displays of annoyance or anger that seem devoid of a strong emotional component e.g. physical aggression that appears designed to stop you from doing something. 0 = does not apply; 1 = certain questions/ demands cause participant to withdraw/ conceal themselves/ become upset/ palpably anxious/ lose control; 2 = much of the session causes participants to be unable to withdraw/ conceal themselves/ become upset/ palpably anxious/ lose control OR when this does happen in an isolated incident the effect on the participant is potent.
N7	**Attempts to distract**

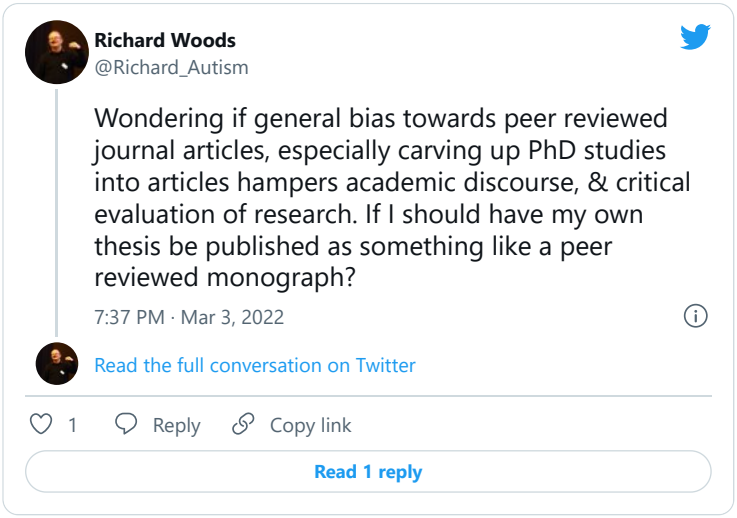
The point is that it is difficult to take much from Chapter 8 results due to how O'Nions created the groups in her sample. With many tools not being used as intended, or being used in an unvalidated way. Ignoring contradictory information.

Would have simpler & more rigorous to use either EDA-Q to screen for PDA, or to use PDA diagnoses to inform groups for comparison. However, one cannot do that if using an axiom PDA is a form of autism & is trying to create an ADOS to identify PDA as an ASD, as O'Nions was doing.

One can see that O'Nions axiology, impacted their methodology, in the process undermining the rigour of study in chapter 8. Fact O'Nions did not trust PDA diagnoses, & had multiple non-autistic CYP with PDA in chapter 8 cohort is not mentioned in Chapter 7 write up or article.

This takes me back to the point that generally "PDA Profile of ASD" supporters ignore anything which is inconvenient. How if such information from O'Nions thesis was widely discussed in PDA literature, it would impact how seriously their research is taken.

Same point about Newson's axiology & methodology treating PDA as something different to autism, was widely discussed in PDA literature, it is likely many would not view PDA as a form of autism.



These examples are making me wonder if there are better ways for me have my PhD research be engaged with, by the public, & other scholars. Also reflecting upon how focus on published articles limits academic debate on pertinent points.

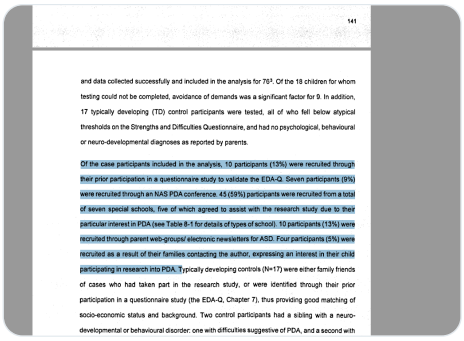
https://www.youtube.com/embed/xFiUWN3y9ho

@threadreaderapp Please could you unroll?

Thank you in advance.

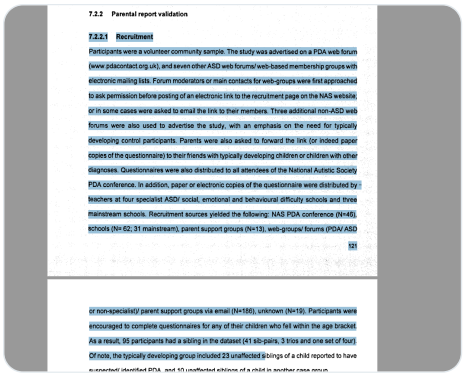
I am going to analyse some of the issues with Chapter 8. In order to do this, I am going to compare sample recruitment method for O'Nions two other chapters using a PDA dx. Chapters 7 & 8.

Images from pages 110, 121, & 142. All used a mix of recruitment from various schools (often autism specialist), snowball sampling (including from PDA forums etc) & NAS PDA conferences.



and data collected successfully and included in the analysis for 76[3]. Of the 18 children for whom testing could not be completed, avoidance of demands was a significant factor for 9. In addition, 17 typically developing (TD) control participants were tested, all of who fell below atypical thresholds on the Strengths and Difficulties Questionnaire, and had no psychological, behavioural or neuro-developmental diagnoses as reported by parents.

Of the case participants included in the analysis, 10 participants (13%) were recruited through their prior participation in a questionnaire study to validate the EDA-Q. Seven participants (9%) were recruited through an NAS PDA conference. 45 (59%) participants were recruited from a total of seven special schools, five of which agreed to assist with the research study due to their particular interest in PDA (see Table 8-1 for details of types of school). 10 participants (13%) were recruited through parent web-groups/ electronic newsletters for ASD. Four participants (5%) were recruited as a result of their families contacting the author, expressing an interest in their child participating in research into PDA. Typically developing controls (N=17) were either family friends of cases who had taken part in the research study, or were identified through their prior participation in a questionnaire study (the EDA-Q, Chapter 7), thus providing good matching of socio-economic status and background. Two control participants had a sibling with a neuro-developmental or behavioural disorder: one with difficulties suggestive of PDA, and a second with



7.2.2 Parental report validation

7.2.2.1 Recruitment

Participants were a volunteer community sample. The study was advertised on a PDA web forum (www.pdacontact.org.uk), and seven other ASD web forums/ web-based membership groups with electronic mailing lists. Forum moderators or main contacts for web-groups were first approached to ask permission before posting of an electronic link to the recruitment page on the NAS website, or in some cases were asked to email the link to their members. Three additional non-ASD web forums were also used to advertise the study, with an emphasis on the need for typically developing control participants. Parents were also asked to forward the link (or indeed paper copies of the questionnaire) to their friends with typically developing children or children with other diagnoses. Questionnaires were also distributed to all attendees of the National Autistic Society PDA conference. In addition, paper or electronic copies of the questionnaire were distributed by teachers at four specialist ASD/ social, emotional and behavioural difficulty schools and three mainstream schools. Recruitment sources yielded the following: NAS PDA conference (N=46), schools (N= 62; 31 mainstream), parent support groups (N=13), web-groups/ forums (PDA/ ASD

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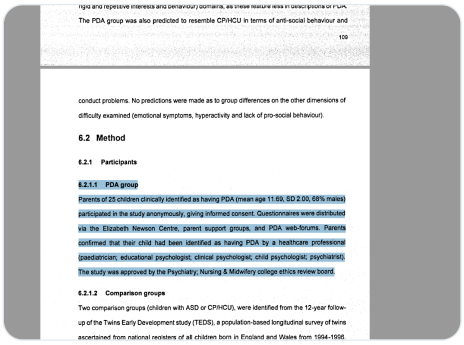
or non-specialist)/ parent support groups via email (N=166), unknown (N=19). Participants were encouraged to complete questionnaires for any of their children who fell within the age bracket. As a result, 95 participants had a sibling in the dataset (41 sib-pairs, 3 trios and one set of four). Of note, the typically developing group included 23 unaffected siblings of a child reported to have



The PDA group was also predicted to resemble CP/HCU in terms of anti-social behaviour and

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conduct problems. No predictions were made as to group differences on the other dimensions of difficulty examined (emotional symptoms, hyperactivity and lack of pro-social behaviour).

6.2 Method

6.2.1 Participants

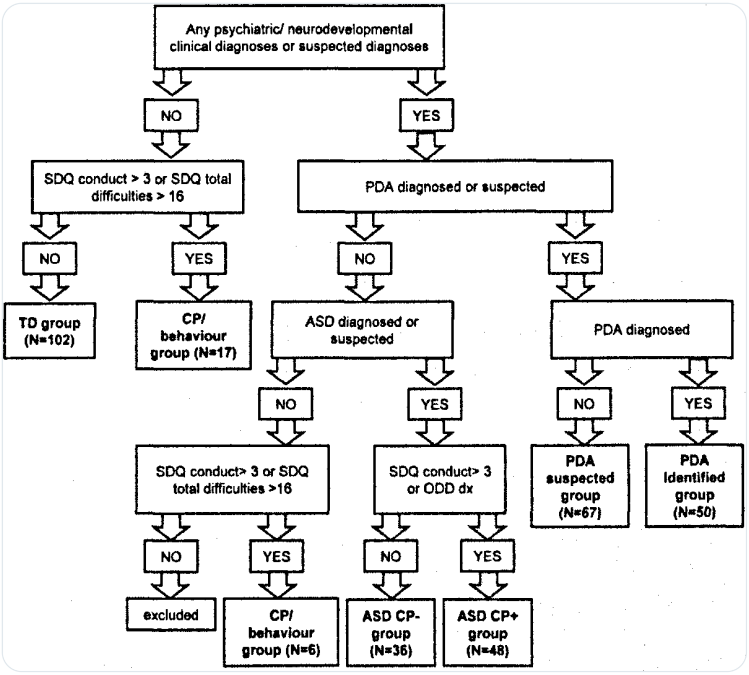
6.2.1.1 PDA group

Parents of 25 children clinically identified as having PDA (mean age 11.69, SD 2.00, 68% males) participated in the study anonymously, giving informed consent. Questionnaires were distributed via the Elizabeth Newson Centre, parent support groups, and PDA web-forums. Parents confirmed that their child had been identified as having PDA by a healthcare professional (paediatrician, educational psychologist, clinical psychologist, child psychologist, psychiatrist). The study was approved by the Psychiatry, Nursing & Midwifery college ethics review board.

6.2.1.2 Comparison groups

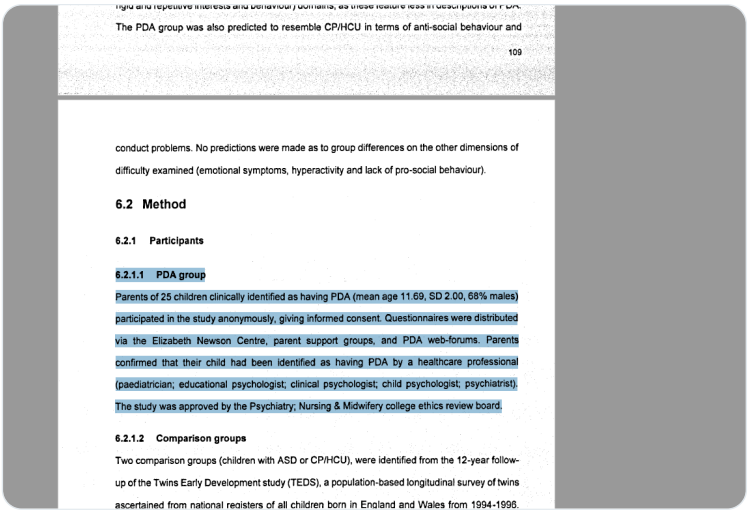
Two comparison groups (children with ASD or CP/HCU), were identified from the 12-year follow-up of the Twins Early Development study (TEDS), a population-based longitudinal survey of twins ascertained from national registers of all children born in England and Wales from 1994-1996.

I have also included recruitment strategy from chapter 7, EDA-Q validation study, as it used PDA dx.



One reason for this, is that if you do not trust PDA diagnoses in one study , then you do not trust them ALL your PhD studies. Obviously has not happened.

In relation to Chapter 6 having 25 PDA diagnoses & used similar recruitment strategies to Chapter 7 & 8, it is reasonable that some of these 25 CYP with PDA are not autistic. Yet O'Nions happily accepted PDA dx.



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109

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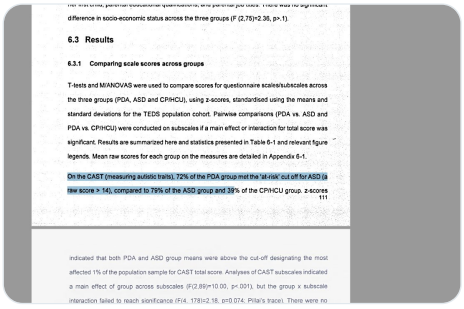
There are methodological differences. Chapter 6 screened for autistic traits using CAST, Chapter 7 did NOT screen for autism... no recording of autism diagnoses with CYP with PDA groups, & sometimes only indicators of autism were used.

CAST was used to screen for autistic traits in Chapter 6. PDA group only had 72% meeting threshold vs 79% in autism group. Which corresponds to about 2 CYP with PDA not meeting threshold on CAST vs autistic CYP. O'Nions also notes those with PDA can interact atypically with CAST.



difference in socio-economic status across the three groups (F (2,76)=2.36, p>.1).

6.3 Results

6.3.1 Comparing scale scores across groups

T-tests and M/ANOVAS were used to compare scores for questionnaire scales/subscales across the three groups (PDA, ASD and CP/HCU), using z-scores, standardised using the means and standard deviations for the TEDS population cohort. Pairwise comparisons (PDA vs. ASD and PDA vs. CP/HCU) were conducted on subscales if a main effect or interaction for total score was significant. Results are summarized here and statistics presented in Table 6-1 and relevant figure legends. Mean raw scores for each group on the measures are detailed in Appendix 6-1.

On the CAST (measuring autistic traits), 72% of the PDA group met the 'at-risk' cut off for ASD (a raw score > 14), compared to 79% of the ASD group and 39% of the CP/HCU group. z-scores

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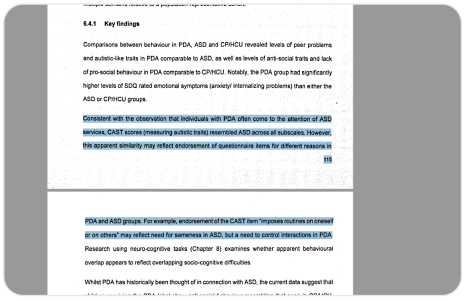
indicated that both PDA and ASD group means were above the cut-off designating the most affected 1% of the population sample for CAST total score. Analyses of CAST subscales indicated a main effect of group across subscales ($F(2,89)=10.00$, $p<.001$), but the group x subscale interaction failed to reach significance ($F(4, 178)=2.18$, $p=0.074$; Pillai's trace). There were no



6.4.1 Key findings

Comparisons between behaviour in PDA, ASD and CP/HCU revealed levels of peer problems and autistic-like traits in PDA comparable to ASD, as well as levels of anti-social traits and lack of pro-social behaviour in PDA comparable to CP/HCU. Notably, the PDA group had significantly higher levels of SDQ rated emotional symptoms (anxiety/ internalizing problems) than either the ASD or CP/HCU groups.

Consistent with the observation that individuals with PDA often come to the attention of ASD services, CAST scores (measuring autistic traits) resembled ASD across all subscales. However, this apparent similarity may reflect endorsement of questionnaire items for different reasons in

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PDA and ASD groups. For example, endorsement of the CAST item "imposes routines on oneself or on others" may reflect need for sameness in ASD, but a need to control interactions in PDA. Research using neuro-cognitive tasks (Chapter 8) examines whether apparent behavioural overlap appears to reflect overtapping socio-cognitive difficulties.

Whilst PDA has historically been thought of in connection with ASD, the current data suggest that

What this means there are likely false positives in PDA group meeting threshold on CAST, i.e., the 72% CYP with PDA in chapter 6 meeting threshold on PDA is likely higher than actual numbers of CYP with PDA in Chapter cohort meeting threshold on CAST.

It is also worth stating that autistic traits are not the same thing as autism. That persons with anxiety, or depression can score highly on autistic traits tests, like the CAST. So O'Nions CYP with PDA scoring highly on CAST is NOT a good indicator these CYP are autistic or not.

From this article.
https://journals.sagepub.com/doi/10.1177/13623613211058515

autism as a spectrum, providing a framework for conceptualizing autism as a continuum extending to subclinical levels, studies of autistic traits in the general population were rare before measures such as the Autism Quotient were available. This and similar questionnaires are easy to administer and facilitate rapid, large-scale data collection, particularly when administered online. Perhaps not coincidentally, studies on autistic traits have increased at twice the rate of studies of autism over the last decade (Mottron & Bzdok, 2020), with a surge occurring during the COVID-19 pandemic as researchers moved to remote data collection.

Research on autistic traits has produced some notable benefits. Recognizing the continuity between autism and autistic traits in the general population underscores that autism is a natural form of human diversity. Examining autistic traits can also generate hypotheses about how these traits interact with other relevant constructs. However, traits in the general population replicate in autistic populations is not clear. Autistic trait questionnaires require no clinical judgment and are not intended as diagnostic assessments. Unlike the diagnosis of autism, autistic traits are typically measured through self-report surveys and contain items that are often interpreted differently by autistic and non-autistic individuals (Gernsbacher et al., 2017). Furthermore, because autistic traits are separable in the general population but co-occur in autism, isolated "traits" may represent socialized characteristics that bear little or no relevance to autism (Mottron & Bzdok, 2020). Autistic

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traits are also not unique to autism. They often are found at high levels in non-autistic people with anxiety, schizophrenia, and other conditions and vary among autistic people. Additionally, many autistic people do not meet clinical cutoffs on autistic trait questionnaires.

Third, studies of autistic traits in the general population can reinforce deficit frameworks that can exacerbate autism stigma. Many trait studies examine whether "deficits" found in autism, such as poor social outcomes, extend to those with subclinical autistic traits. Increasingly, however, such outcomes are recognized as relational, not individual. Both within autism (Crompton et al., 2020) and within autistic traits in the general population (Bolis et al., 2021), communication efficacy and interpersonal connection are better predicted by compatibility between partners rather than individual traits. That is, individual traits do not always drive impairments. Instead, consistent with the social model of disability, whether an impairment

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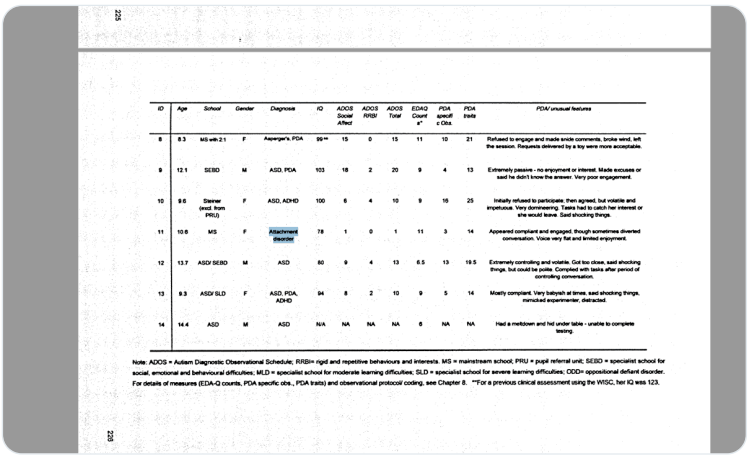
References

Bolis, D., Lahnakoski, J. M., Seidel, D., Tamm, J., & Schilbach, L. (2021). Interpersonal similarity of autistic traits predicts friendship quality. *Social Cognitive and Affective*

Considering the variation of PDA diagnoses which are present in Chapters 6, 7, 8, with non-autistic persons with PDA being present in ALL three studies & the qualitative study in Chapter 5.

Image from p226.



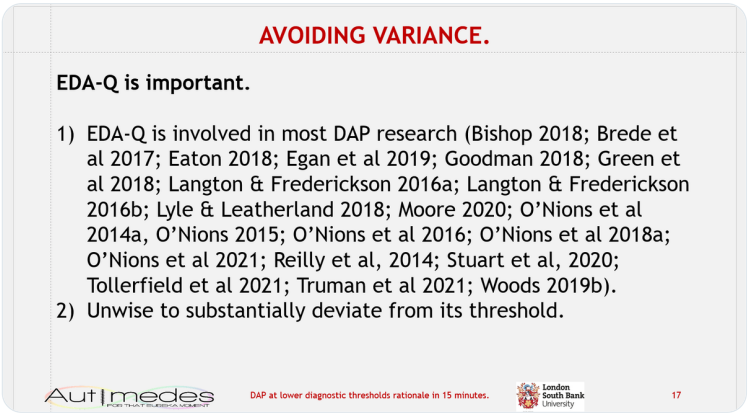
ID	Age	School	Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Count s*	PDA specif c Obs	PDA traits	PDA/ unusual features
8	8.3	MS with 2:1	F	Asperger's, PDA	99**	15	0	15	11	10	21	Refused to engage and made snide comments, broke wind, left the session. Requests delivered by a toy were more acceptable.
9	12.1	SEBD	M	ASD, PDA	103	18	2	20	9	4	13	Extremely passive - no enjoyment or interest. Made excuses or said he didn't know the answer. Very poor engagement.
10	9.6	Steiner (med. from PRU)	F	ASD, ADHD	100	6	4	10	9	16	25	Initially refused to participate, then agreed, but volatile and impetuous. Very domineering. Tales had to catch her interest or she would leave. Said shocking things.
11	10.6	MS	F	Attachment disorder	78	1	0	1	11	3	14	Appeared compliant and engaged, though sometimes diverted conversation. Voice very flat and limited enjoyment.
12	13.7	ASD/ SEBD	M	ASD	80	9	4	13	6.5	13	19.5	Extremely controlling and volatile. Got too close, said shocking things, but could be polite. Complied with tasks after period of controlling conversation.
13	8.3	ASD/ SLD	F	ASD, PDA, ADHD	94	8	2	10	9	5	14	Mostly compliant. Very babyish at times, said shocking things, mimicked experimenter, distracted.
14	14.4	ASD	M	ASD	N/A	NA	NA	NA	6	NA	NA	Had a meltdown and hid under table - unable to complete testing.

Note: ADOS = Autism Diagnostic Observational Schedule; RRBI= rigid and repetitive behaviours and interests. MS = mainstream school, PRU = pupil referral unit; SEBD = specialist school for social, emotional and behavioural difficulties; MLD = specialist school for moderate learning difficulties; SLD = specialist school for severe learning difficulties; ODD= oppositional defiant disorder. For details of measures (EDA-Q counts, PDA specific obs., PDA traits) and observational protocol coding, see Chapter 8. **For a previous clinical assessment using the WISC, her IQ was 123.

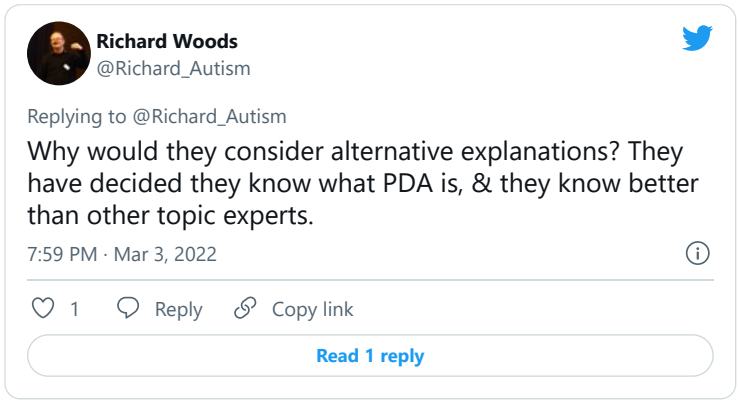
Shows it is arbitrary of O'Nions to choose to ignore PDA diagnoses in chapter 8 & was purely done due to their axiom PDA is a form of autism.

It also shows their created algorithm for PDA is not UNREPRESENTATIVE of PDA as a construct in chapters 5, 6 & 7, i.e., not the same throughout O'Nions thesis. Despite O'Nions viewing PDA as a form of autism.

This matters not only due to the quality of O'Nions thesis & limiting what conclusions can be drawn. It also undermines much of our knowledge base on PDA, due to their thesis studies being fundamental to much subsequent PDA research. E.g., EDQ-Q is used at least 20 studies.



The poor quality of O'Nions PhD studies affects much of our understanding of PDA, partly due to their erroneous axiom PDA is a form of autism. Which is obviously ignored by many "PDA Profile of ASD" supporters.



“It should be noted that, so far, we have approached this profile from the starting point of our expertise in ASD.” O’Nions et al 2016b, p2.

Image is from p2.

Link to the quote.
https://discovery.ucl.ac.uk/id/eprint/1493137/7/O'Nions_Debate_article_accepted_typeset.pdf

reflected by changes in prevalence estimates (Fombonne, Quirke & Hagen, 2011).

in twenty-five (Gillberg et al., 2015). However, other features such as non-compliance with demands may be considerably more common.

Investigation of the underlying cognitive and emotional processes in children with extreme/'pathological' demand avoidance is the essential next step to shed light on how it relates to ASD features. For example, children with extreme/'pathological' demand avoidance may display the cognitive rigidity/ obsessive behaviour characteristic of ASD, but with a focus (atypically) on resisting attempts to make them submit to requests from others (Gillberg et al., 2015). Research into the drivers of behaviour in this profile is in its infancy, but will prove essential in improving our understanding of the presenting features, and informing the development of targeted management approaches.

Extreme/'pathological' demand avoidance and profiles with behavioural overlap

In view of the very difficult behaviour that characterises extreme/'pathological' demand avoidance, it is not surprising that parallels have been drawn with disruptive behaviour disorders, such as oppositional defiant disorder (ODD) and conduct disorder (CD). ODD is defined in DSM-5 as a pattern of angry/ irritable mood, argumentative/ defiant behaviour or vindictiveness, and CD as a pattern of persistent violation of societal norms and the rights of others (American Psychiatric Association, 2013). Notably, there are several important differences in the behavioural presentation compared to

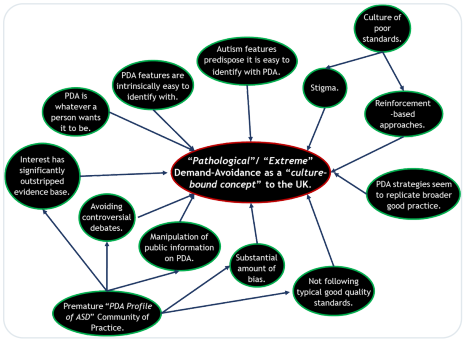
Another area of overlap between children with ODD/CD and children with extreme/'pathological' demand avoidance is in instrumental use of shocking/aggressive behaviour, such as targeted provocation of peers, or spoiling/ destruction of siblings' possessions. Notably, children with extreme/'pathological' demand avoidance typically employ these behaviours in a relatively socially un-sophisticated and obvious manner. This contrasts to children with ODD/CD, who can be very apt at avoiding detection. This apparent overlap has led to discussion of whether extreme/'pathological' demand avoidance may combine neurocognitive impairments associated with ASD and disturbances in empathic behaviour (Wing, Gould & Gillberg, 2011; O'Nions et al., 2014a).

It should be noted that, so far, we have approached this profile from the starting point of our expertise in ASD. It remains possible that behaviours that resemble descriptions of extreme/'pathological' demand avoidance could be found in other populations, such as children with other neurodevelopmental phenotypes (Reilly et al., 2014; Gillberg, 2014) or attachment problems (Moran, 2010). Further studies that systematically examine whether individuals displaying this pattern meet diagnostic thresholds for ASD on gold-standard tools are needed to begin to explore these possible overlaps.

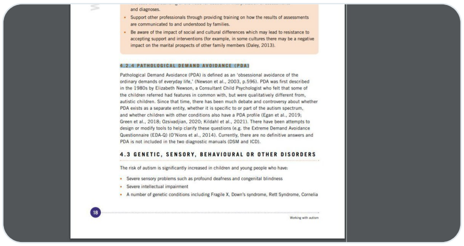
One challenge is that research conducted outside of clinical settings typically relies on

The bias present in those researching PDA as a "Profile of ASD" would explain why they have not considered such matters. Why O'Nions & others have ignored such things.

There are only really one group of people responsible making bold/ misleading claims PDA is a "Profile of ASD".



In the process producing poor quality research, which has been recognised by independent parties @NICEComms @BPSOfficial @rcpsych & @ArvidNK, who all equally respected divergent views on PDA. Unlike group producing poor quality research & making bold/ misleading claims on PDA.


and diagnoses.

- Support other professionals through providing training on how the results of assessments are communicated to and understood by families.
- Be aware of the impact of social and cultural differences which may lead to resistance to accepting support and interventions (for example, in some cultures there may be a negative impact on the marital prospects of other family members (Daley, 2013).

4.2.4 PATHOLOGICAL DEMAND AVOIDANCE (PDA)

Pathological Demand Avoidance (PDA) is defined as an 'obsessional avoidance of the ordinary demands of everyday life,' (Newson et al., 2003, p.596). PDA was first described in the 1980s by Elizabeth Newson, a Consultant Child Psychologist who felt that some of the children referred had features in common with, but were qualitatively different from, autistic children. Since that time, there has been much debate and controversy about whether PDA exists as a separate entity, whether it is specific to or part of the autism spectrum, and whether children with other conditions also have a PDA profile (Egan et al., 2019; Green et al., 2018; Ozsivadjian, 2020; Kildahl et al., 2021). There have been attempts to design or modify tools to help clarify these questions (e.g. the Extreme Demand Avoidance Questionnaire (EDA-Q) (O'Nions et al., 2014). Currently, there are no definitive answers and PDA is not included in the two diagnostic manuals (DSM and ICD).

4.3 GENETIC, SENSORY, BEHAVIOURAL OR OTHER DISORDERS

The risk of autism is significantly increased in children and young people who have:

- Severe sensory problems such as profound deafness and congenital blindness
- Severe intellectual impairment
- A number of genetic conditions including Fragile X, Down's syndrome, Rett Syndrome, Cornelia

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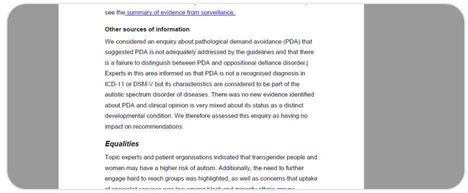
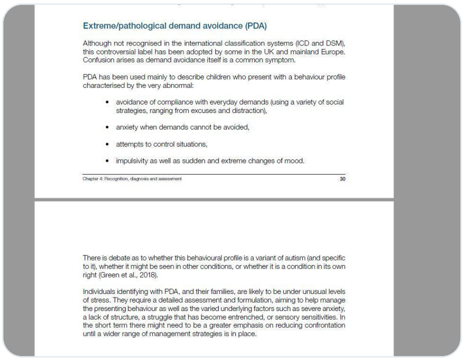

see the summary of evidence from surveillance.

Other sources of information

We considered an enquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiance disorder. Experts in this area informed us that PDA is not a recognised diagnosis in ICD-11 or DSM-V but its characteristics are considered to be part of the autistic spectrum disorder of diseases. There was no new evidence identified about PDA and clinical opinion is very mixed about its status as a distinct developmental condition. We therefore assessed this enquiry as having no impact on recommendations.

Equalities

Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake


Extreme/pathological demand avoidance (PDA)

Although not recognised in the international classification systems (ICD and DSM), this controversial label has been adopted by some in the UK and mainland Europe. Confusion arises as demand avoidance itself is a common symptom.

PDA has been used mainly to describe children who present with a behaviour profile characterised by the very abnormal:

- avoidance of compliance with everyday demands (using a variety of social strategies, ranging from excuses and distraction),
- anxiety when demands cannot be avoided,
- attempts to control situations,
- impulsivity as well as sudden and extreme changes of mood.

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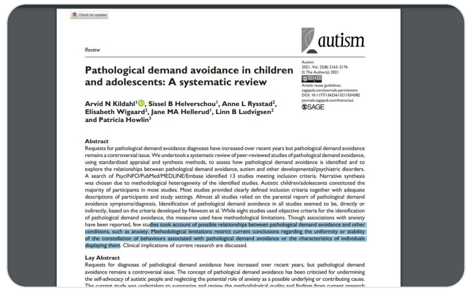
There is debate as to whether this behavioural profile is a variant of autism (and specific to it), whether it might be seen in other conditions, or whether it is a condition in its own right (Green et al., 2018).

Individuals identifying with PDA, and their families, are likely to be under unusual levels of stress. They require a detailed assessment and formulation, aiming to help manage the presenting behaviour as well as the varied underlying factors such as severe anxiety, a lack of structure, a struggle that has become entrenched, or sensory sensitivities. In the short term there might need to be a greater emphasis on reducing confrontation until a wider range of management strategies is in place.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Pathological demand avoidance in children and adolescents: A systematic review

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Abstract
Requests for pathological demand avoidance diagnoses have increased over recent years but pathological demand avoidance remains a controversial issue. We undertook a systematic review of peer-reviewed studies of pathological demand avoidance, using standardised appraisal and synthesis methods, to assess how pathological demand avoidance is identified and to explore the relationships between pathological demand avoidance, autism and other developmental/psychiatric disorders. A search of PsycINFO/PubMed/MEDLINE/Embase identified 13 studies meeting inclusion criteria. Narrative synthesis was chosen due to methodological heterogeneity of the identified studies. Autistic children/adolescents constituted the majority of participants in most studies. Most studies provided clearly defined inclusion criteria together with adequate descriptions of participants and study settings. Almost all studies relied on the parental report of pathological demand avoidance symptoms/diagnosis. Identification of pathological demand avoidance in all studies seemed to be, directly or indirectly, based on the criteria developed by Newson et al. While eight studies used objective criteria for the identification of pathological demand avoidance, the measures used have methodological limitations. Though associations with anxiety have been reported, few studies took account of possible relationships between pathological demand avoidance and other conditions, such as anxiety. Methodological limitations restrict current conclusions regarding the uniformity or stability of the constellation of behaviours associated with pathological demand avoidance or the characteristics of individuals displaying them. Clinical implications of current research are discussed.

Lay Abstract
Requests for diagnoses of pathological demand avoidance have increased over recent years, but pathological demand avoidance remains a controversial issue. The concept of pathological demand avoidance has been criticised for undermining the self-advocacy of autistic people and neglecting the potential role of anxiety as a possible underlying or contributing cause.

Yes, it can be important to consider "grey" literature when having academics debates, as I have shown using two examples from PDA literature. It is making me wonder how I should publish my PhD studies and research, to avoid such problems.

On that note.@threadreaderapp please can you unroll again?

Thank you in advance?

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