I have discussed before my concerns over why O'Nions & co found different results of "social strategic" demand avoidance to manipulative here:
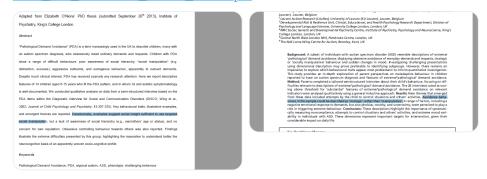
https://rationaldemandavoidancecom.files.wordpress.com/2020/07/21-may-2020-are-these-2-pda-studies-actually-needed.pdf

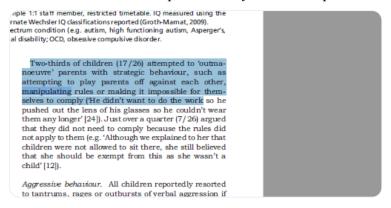Original study by O'Nions based on her PhD thesis:

http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf

And replication study here:

https://discovery.ucl.ac.uk/id/eprint/10056124/1/O%27Nions_et_al-2018-Child_and_Adolescent_Mental_Health.pdf
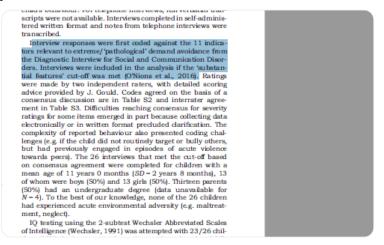
Previously, I have thought that change in "socially strategic" was due to confirmation bias, as other demand avoidance in replication study are still manipulative.

Upon further reflection & looking at different tools & papers. I think it is due to methodology of the replication study.

The 2 studies had different recruiting methods, but are both investigating the same thing, as primarily using same unvalidated interview.

The main difference in methodology between the 2 studies, in replication study the first stage of data analysis was to screen completed interviews against revised PDA DISCO questions.

This is important. One I am not sure why they did this in the replication study, as the revised DISCO questions are different to original 15 PDA DISCO questions, and revised questions have their own PDA behaviour profile.

Identifying features of 'pathological demand avoidance' using the Diag…

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obse

https://link.springer.com/article/10.1007/s00787-015-0740-2

Latter diagnostic profile, is more suggestive of autism than Newsons.
"strategies of avoidance that are essentially 'socially manipulative'"

Vs
"strategies of avoidance are essentially socially manipulative"

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

http://adc.bmj.com/content/88/7/595

normal demands, resists. A few actively resist from the start, everything is on own terms. Parents tend to adapt so completely that they are unprepared for the extent of failure once child is subjected to ordinary group demands of nursery or school; they realise child needs "velvet gloves" but don't perceive this as abnormal. Professionals too see child as puzzling but normal at first.
2. Continues to resist and avoid ordinary demands of life: Seems to feel under intolerable pressure from normal expectations; devotes self to actively avoiding these. Demand avoidance may seem the greatest social and cognitive skill, and most obsessional preoccupation. As language develops, **strategies of avoidance are essentially socially manipulative,** often adapted to adult involved; they may include: *Distracting adult:* "Look out of the window!", "I've got you a flower!", "I love your neckla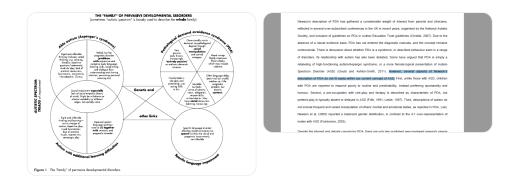ce!", "I'm going to be sick", "Bollocks!—I said bollocks!" *Acknowledging demand but excusing self:* "I'm sorry, but I can't", "I'm afraid I've got to do this first", "I'd rather do this", "I don't have to, you can't make me", "you do it, and I'll …", "Mummy wouldn't like me to". *Physically incapacitating self:* hides under table, curls up in corner, goes limp, dissolves in tears, drops everything, seems unable to look in direction of task (though retains eye contact), removes clothes or glasses, "I'm too hot", "I'm too tired", "It's too late now", "I'm handicapped", "I'm going blind/deaf/spastic", "My hands have gone flat". *Withdrawing into fantasy, doll play, animal play:* talks only to doll or to inanimate objects; appeals to doll, "My girls won't let me do that", "My teddy doesn't like this game"; "But I'm a tractor, tractors don't have hands"; growls, bites. *Reducing meaningful conversation:* bombards adult with speech (or other noises, e.g. humming) to drown out demands; mimics purposefully; refuses to speak. *(As last resort)*: outbursts, screaming, hitting, kicking; best construed as panic attack.
3. Surface sociability, but apparent lack of sense of social identity, pride, or shame: At first sight normally sociable with enough empathy to manipulate adults as shown above; but ambiguous

O'Nions et al, know this is clinically important as manipulative behaviours are not associated with autism. From original paper.

their need for control and insistence that everything is on their terms (Newson, et al., 2003).

Newson's description of PDA has gathered a considerable weight of interest from parents and clinicians, reflected in several over-subscribed conferences in the UK in recent years, organised by the National Autistic Society, and inclusion of guidelines on PDA in Autism Education Trust guidelines (Christie, 2007). Due to the absence of a robust evidence base, PDA has not entered the diagnostic manuals, and the concept remains controversial. There is discussion about whether PDA is a syndrome, or describes behaviour seen in a range of disorders. Its relationship with autism has also been debated. Some have argued that PDA is simply a relabeling of high-functioning autism/Asperger syndrome, or a more female-typical presentation of Autism Spectrum Disorder (ASD) (Gould and Ashton-Smith, 2011). However, several aspects of Newson's description of PDA do not fit easily within our current concept of ASD. First, unlike those with ASD, children with PDA are reported to respond poorly to routine and predictability, instead preferring spontaneity and humour. Second, a pre-occupation with role-play and fantasy is described as characteristic of PDA, but pretend-play is typically absent or delayed in ASD (Frith, 1991; Leslie, 1987). Third, descriptions of autism do not include frequent and varied manipulation of others' mental and emotional states, as reported in PDA. Last, Newson et al. (2003) reported a balanced gender distribution, in contrast to the 4:1 over-representation of males with ASD (Fombonne, 2003).

Despite the interest and debate concerning PDA, there are only two published peer-reviewed research papers

Newson viewed demand avoidance to be manipulative in nature, see her "Autistic family" diagram. O'Nions et al, knew Newson viewed it as such, again from original paper.

Figure 1 The "family" of pervasive developmental disorders.

Revised 11 PDA DISCO questions are different to original 15. For instance revised question for social demand avoidance:

https://static-content.springer.com/esm/art%3A10.1007%2Fs00787-015-0740-2/MediaObjects/787_2015_740_MOESM1_ESM.pdf

Vs

Original social demand avoidance question:

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

Original DISCO Demand Avoidance question, in clinical format.

We can tell it is original as it correspondences to wording used in Faroe islands population study that used original 15 PDA DISCO questions.

Extreme ("pathological") demand avoidance in autism: a general popu…

Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexiste

https://link.springer.com/article/10.1007/s00787-014-0647-3

Table 1 DISCO-11 items targeting PDA: the DISCO-11 PDA scale

DISCO item and corresponding PDA symptom area	Variable name
Unusually quiet and passive in infancy (1)	UQUIET
Clumsy in gross movements (8)	CCLUMSY
Communicates through doll, puppet, toy animal etc. (5)	CDOLL
Lacks awareness of age group, social hierarchy etc. (3)	CIDENT
Rapid inexplicable changes from loving to aggression (4)	CINAPP
Uses peers as 'mechanical aids'; bossy and domineering (3) and (4)	CPEERAD
Repetitive role play—lives the part, not usual pretence (5) and (7)	CTROL
Hands seem limp and weak for unwelcome tasks (8)	CNOHAND
Repetitive questioning (7)	QUESREP
Obsessed with a person, real or fiction (7)	PERS
Blames others for own misdeeds (3)	BLAME
Harasses another person—may like or dislike them (3) and (7)	HARAS
Socially manipulative behaviour to avoid demands (2)	MANBEH
Socially shocking behaviour with deliberate intent (2) and (3)	SHOCK
Lies, cheats, steals, fantasises, causing distress to others (3) and (7)	LYING

Figures in brackets—(1) through (8)—refer to the eight defining characteristics of Newson's PDA

Also we are told 3 times this unvalidated semi-structured interview is based off original 15 PDA DISCO items.

Participant ID _____ **Date** _____

PDA items parent interview/ observational/ multi-informant rating scale
N.B. Ratings: 0= not affected 1=Minor; 2=Marked
Many items and example questions were based on those included in the "Diagnostic Interview for Social and Communication Disorders" (Wing et al., 2002).

Background information:
Diagnosis:
Date that diagnosis was given:
School history (Include number of schools attended, types of schools, exclusion from schools, outside help etc):

(A) Avoids demands using socially manipulative strategies

1. Obsessively resists and avoids ordinary demands, led by need to control   0 | 1 | 2

Everything must be on his or her own terms, unable to accept reasonable limits. If pressured to comply, may result in an extreme reaction, or a breakdown in the relationship. Parents devoted to discover how much they have crippled to handling the child with velvet gloves when they start school. S/he may also be indifferent to/ reject praise or react badly to it (e.g. tearing up his/her work).

- How did things go when A started nursery/ school?
- Does A strongly resist attempts to make him or her do things, or change his or her behaviour? What sorts of requests does A avoid?
- Does everything have to be on his/ her terms? What happens if you push A to comply or accept limits?
- Does A dislike praise?

Adapted from Elizabeth O'Nions' PhD thesis (submitted September 26th 2013), Institute of Psychiatry, King's College London.

Abstract

"Pathological Demand Avoidance" (PDA) is a term increasingly used in the UK to describe children, many with an autism spectrum diagnosis, who obsessively resist ordinary demands and requests. Children with PDA show a range of difficult behaviours: poor awareness of social hierarchy; "social manipulation" (e.g. distraction, excuses), aggressive outbursts, and outrageous behaviour, apparently to subvert demands. Despite much clinical interest, PDA has received scarcely any research attention. Here we report descriptive features of 14 children aged 8-15 years who fit the PDA pattern, and in whom IQ and autistic symptomatology is well-documented. We conducted qualitative analysis on data from a semi-structured interview based on the PDA items within the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002; Journal of Child Psychology and Psychiatry, 43:307-325). Key behavioural traits, illustrative examples, and emergent themes are reported. Paradoxically, examples suggest social insight sufficient to use targeted social manipulation, but a lack of awareness of social hierarchy (e.g., own/others' age or status), and no concern for own reputation. Obsessive controlling behaviour towards others was also reported. Findings illustrate the extreme difficulties presented by this group; highlighting the imperative to understand better the neurocognitive basis of an apparently uneven socio-cognitive profile.

Keywords

Pathological Demand Avoidance, PDA, atypical autism, ASD, phenotype, challenging behaviour

equal gender balance associated with this profile (Newson et al., 2003).

Twenty-nine parents of children with an autism spectrum diagnosis reporting features of extreme/'pathological' demand avoidance aged 7 years 10 months to 16 years 11 months completed the semistructured interview (N = 12 by telephone, N = 17 using a self-administered electronic or written format). The interview was developed for research purposes to capture behaviours relevant to pathological demand avoidance as described by Newson et al. (2003). It has not been validated and is not presumed to assay behaviours that are necessarily specific to this presentation. It consisted of 22 questions, with 55 subquestions, drawing on content from the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002) and from an interview developed by Newson et al. (2003). Parents completed the interview by commenting on whether their child displayed the target behaviours and providing relevant examples of their child's behaviour. For telephone interviews, full verbatim transcripts were not available. Interviews completed in self-administered written format and notes from telephone interviews were transcribed.

Interview responses were first coded against the 11 indicators relevant to extreme/'pathological' demand avoidance from the Diagnostic Interview for Social and Communication Disor-

So what seems to happened is that filtering sample in replication study has biased the results to become "autism-like" due to having "socially strategic" demand avoidance.

Then again, the "socially strategic" result can also be explained by confirmation bias due as other demand avoidance is manipulative. Both sets tend to take advantage of rules & social norms.

If the methodology of replication study has biased its results to create "socially strategic", why are revised 11 PDA DISCO questions different to original 15?

Simple answer, O'Nions & others are trying to make PDA a meaningful autism subgroup.
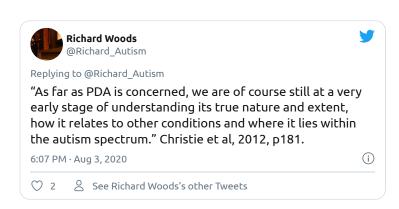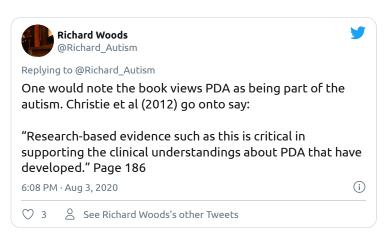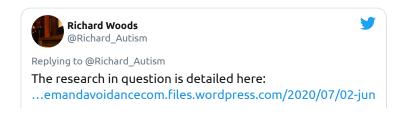
Seventeen DISCO items appeared to provide a good match (Table 1), although given that the wording of these items is not identical, this could not be perfect.

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

It should be noted that the newly derived 11-item PDA

Richard Woods @Richard_Autism

Replying to @Richard_Autism

"As far as PDA is concerned, we are of course still at a very early stage of understanding its true nature and extent, how it relates to other conditions and where it lies within the autism spectrum." Christie et al, 2012, p181.

6:07 PM · Aug 3, 2020

♡ 2   👤 See Richard Woods's other Tweets

Richard Woods @Richard_Autism

Replying to @Richard_Autism

One would note the book views PDA as being part of the autism. Christie et al (2012) go onto say:

"Research-based evidence such as this is critical in supporting the clinical understandings about PDA that have developed." Page 186

6:08 PM · Aug 3, 2020

♡ 3   👤 See Richard Woods's other Tweets

Richard Woods @Richard_Autism

Replying to @Richard_Autism

The research in question is detailed here:
…emandavoidancecom.files.wordpress.com/2020/07/02-jun

I go into more detail here about how such PDA research is a self-validation exercise.
https://rationaldemandavoidancecom.files.wordpress.com/2020/08/03-august-2020-pda-as-a-self-validation-exercise.pdf

Now before tying off the thread I need to point out the EDA-A itself is designed to be used with Newson's behaviour profile. Including the original 15 PDA DISCO questions, which are also based off Newson's PDA profile.

Development of the 'Extreme Demand Avoidance Questionnaire' (EDA...
Read the Commentary for this article on doi: 10.1111/jcpp.12275

https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149

Methods
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 United Kingdom, 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

So this "socially strategic" results can be explained by using 11 revised DISCO items, especially one item which has "Apparently manipulative behaviour", that is "autism-like" compared to "Socially manipulative behaviour to avoid demands".

This shows why it is important to only use tools with the behaviour profile they are designed for. Otherwise one undermines the validity of their PDA research.

This is a major issue with Help4Psychology research, as they use EDA-Q, 11 revised PDA DISCO questions with NAS's behaviour profile. Neither EDA-Q or any PDA DISCO item are designed to be used with that behaviour profile!

I am not making this up.

https://network.autism.org.uk/sites/default/files/ckfinder/files/Further%20exploring%20the%20PDA%20profile%20-%20evidence%20from%20clinical%20cases%20-%20Dr%20Judy%20Eaton.pdf

NAS PDA criteria. https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30044-0/fulltext
&
https://www.autism.org.uk/about/what-is/pda.aspx

Our Criteria for PDA

* Examination of the current literature combined with the extensive clinical knowledge of the assessment team, led to the development of an informal algorithm which was used to determine whether a child met the criteria for the Pathological (or Extreme) Demand Avoidant profile:
* The child or young person displayed (or was reported to have displayed) the main features outlined in the revised Newson checklist, the NAS website, the EDA-Q and the specific questions included in the DISCO. These were recorded as part of the child's developmental history.

Panel 2: Features of pathological demand avoidance, according to the National Autistic Society, in 2017[6]
* Resists and avoids the ordinary demands of life
* Uses social strategies as part of avoidance, eg, distracting, giving excuses
* Appears sociable, but lacks understanding
* Experiences excessive mood swings and impulsivity
* Appears comfortable in role play and pretence
* Displays obsessive behaviour that is often focused on other people

pathological demand avoidance suggests that the difficulty in the child-environment transactions are a

these apparent social abilities can often mask difficulty with processing and understanding communication and social situations.

The distinctive features of a demand avoidant profile include:

* resists and avoids the ordinary demands of life
* uses social strategies as part of avoidance, for example, distracting, giving excuses
* appears sociable, but lacks some understanding
* experiences excessive mood swings and impulsivity
* appears comfortable in role play and pretence
* displays obsessive behaviour that is often focused on other people.

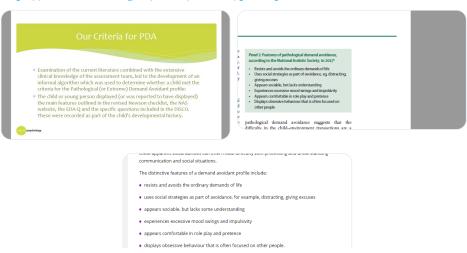This is in addition to my other critique of Help4Psychology PDA research.

https://rationaldemandavoidancecom.files.wordpress.com/2020/07/19th-april-2020-help4psychology-research-limitations.pdf

I think that is it for this thread. @threadreaderapp please unroll?

• • •