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14 May 20 · 22 tweets · [Richard_Autism/status/126104998092993313](#)



Thread:

So tonight I have been trying to figure out why the wording for DISCO items is different between [@ONionsLiz](#) and [@GillbergCentre](#) PDA research. Yes, I emailed them to clarify why.

Links to respective PDA DISCO articles:



Identifying features of 'pathological demand avoidance' us

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obsessive resistance to everyday demands and...

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

and



Extreme ("pathological") demand avoidance in autism: a gen

Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexistent in spite of the frequent reference to...

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

So I tabulated the respective entries for each article and cross-checked against relevant entries from a tool based off 15 DISCO items.

| Number | Gillberg et al (2014) | O'Nions et al (2016) | O'Nions et al (2013) |
|--------|--|--|---|
| 10 | Blames others for own misdeeds | Blaming other people | Blames others inappropriately in an false accusation |
| 30 | Clumsy in gross movements | N/A | N/A |
| 30 | Communicates indirectly (e.g. through doll, prop, picture cards, puppet, toy animal, etc.) | N/A | Communicates indirectly (e.g. through doll, prop, picture cards, puppet, toy animal, or a person) |
| 40 | Lacks awareness of age group, social hierarchy, etc. | (Lack) Awareness of own identity | Lack awareness is not concerned about age group or social hierarchy |
| 50 | Hands seem limp and weak for unwellcome tasks | N/A | Unusually quiet & passive in infancy; hands limp for unwellcome tasks |
| 60 | Harms another person—in a playful or dislike them | Harmment of others | Obsessed with a particular person, real or fictional |
| 70 | Obsessed with a person, real or fictional | N/A | Obsessed with a particular person, real or fictional |
| 80 | Rapidly pleasurable changes from loving to aggression | Inappropriate sociability (rapid, unpleasurable changes from loving to aggression) | Rapid, unpleasurable changes from loving to aggression |
| 90 | Repetitive questioning | One-sided social approaches | Lack control of the conversation through repetitive questioning/ interrupting |
| 100 | Repetitive role play—lives the part, not usual pretence | Repetitive acting out roles | play in a genuine play—lives the part, not the usual pretence |
| 110 | Socially manipulative behaviour to avoid demands | Apparently manipulative behaviour | Socially manipulative behaviour to avoid demands |
| 120 | Socially shocking behaviour with deliberate intent | Socially shocking behaviour | Socially shocking behaviour with deliberate intent |
| 130 | Lies, cheats, steals, fantasises, causing distress to others | Fantasising, lying, cheating, stealing | Fantasises, tells tall tales |
| 140 | Unusually quiet and passive in infancy | Unusually quiet and passive in infancy | Unusually quiet & passive in infancy; hands limp for unwellcome tasks |
| 150 | Uses peers as 'mechanical aids', bossy and domineering | Using age peers as mechanical aids, bossy and domineering | Difficulties interacting with peers- bossy and domineering |

Wider context to this is that I am also trying to work out why PDA Development Group changed PDA dx criteria, i.e. their specific motivations for each change vs Newson's dx criteria. Or even can PDA criteria be changed to this.

| Elizabeth Newson's Criteria (Newson et al., 2003, p.597) | PDA Development Group's Criteria (Green et al., 2018, p.457) |
|---|--|
| Comfortable in role play and pretending | Appears comfortable in role play and pretence |
| Continues to resist and avoid ordinary demands of life | Resists and avoids the ordinary demands of life |
| Lability of mood, impulsive, led by need to control | Experiences excessive mood swings and impulsivity |
| Obsessive behaviour | Displays obsessive behaviour that is often focused on other people |
| Strategies of avoidance are essentially socially manipulative | Uses social strategies as part of avoidance, eg. distracting, giving excuses |
| Surface sociability, but apparent lack of sense of social identity, pride, or shame | Appears sociable, but lacks understanding |

Seems to me that using the other semi-structured interview from here: <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>

Which is based off @ONionsLiz PhD thesis research. That the wording from Gillberg article is more accurate interpretation of 15 unvalidated items.

One could use these items to probe a bit deeper as potential decision making around PDA dx criteria. The @ONionsLiz aimed to try and make PDA a stable autism subtype (which is highly questionable exercise).

The wording from items from the 2 earlier studies indicates PDA actions are manipulative and done with intent, while the later @ONionsLiz DISCO paper uses wording that suggests the opposite.

It is also worth noting that it was decided to ignore the developmental PDA criteria (passive early history, neurological involvement and speech delay). Mainly as such features are too common in autism population to useful to a subtype.

questions for which no parallel item existed in the EDA-Q. These items centred on traits not thought to be distinctive to PDA versus the rest of the spectrum ('Clumsy in gross movements', 'Repetitive questioning'), or items that appeared too specific to reflect Newson's description at a broader level (e.g. 'Communicates through doll, puppet, toy animal etc.', 'Hands seem limp and weak for unwellcome tasks'), plus the item 'Obsessed with a person, real or fictional'. One item that did have a parallel in the EDA-Q was excluded—'Unusually quiet and passive in infancy'. The parallel EDA-Q item did not meet the cutoffs used here to reduce the list (endorsement >66 % and loading of 0.5 onto the first eigenvariate). One final item ('Blames others for own misdeeds') had a parallel in the EDA-Q and met the EDA-Q criteria, but the relevant DISCO item did not meet the low-frequency criterion for items in this sample.

the text.

Characteristics data were available

In the present DISCO had been in the DISCO Centre. Clinicians specialities (e.g. and language therapy). Cases was deemed to case reported was A total of 153 participants had

| | | |
|---|---|--|
| <p>Comfortable in role play and pretending (Obsessive behaviour (often social in nature))</p> <p>Neurological involvement</p> <p>Passive early history</p> <p>Repetitive questioning</p> | <p>Using age peers as mechanical aids, bossy and domineering</p> <p>Difficulties with other people</p> <p>Repetitive acting out roles</p> <p>Harmment of others</p> <p>None included</p> <p>None included</p> <p>None included</p> | <p>CPEERAD*</p> <p>DIFFEOP</p> <p>CTIRAS*</p> <p>IBARAS*</p> |
|---|---|--|

Items that were included in Wing and Gould's draft 15-item PDA list are designated with an asterisk. Full DISCO item descriptions are given in Online Resource 2.

There are a number methodological weaknesses that I am not exactly thrilled with. Firstly, they used the EDA-Q data to inform decisions around DISCO items, this is based on carer reports. i.e. not from clinical practice.

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Identification of DISCO PDA indicators

The first part of the study aimed to ascertain which PDA items might prove discriminating. This involved three stages. First, results from the EDA-Q study were used to identify 'core features' of PDA (high endorsement rates in the PDA group and high loadings on the first principal component [9]). Our criteria for an item to make the short-list were an endorsement rate of 66 % or higher in the data from those reported to have PDA ($N = 50$) and an eigenvalue > 0.5 loading onto the first principal component. *Olivia Pascoe, I. details a list of the 18 EDA-Q items*

This ignores how Newson said her criteria were remarkably robust over 15 years worth of research:

Yes, I know @ONionsLiz DISCO paper was taking a difference approach to Newson.

Figure 1: The timing of persons' developmental disorders

adolescence. This, combined with an increasing wish for friends (often unfulfilled) may lead to clinical depression, and a need for informed and sensitive counselling.

The descriptive criteria, first produced in 1988 from clinical notes before the statistical studies had been undertaken, remain surprisingly robust, both between children and, equally important, from childhood to adulthood. They were revised in 1995, with very little change except to include language delay, and finally revised for this paper to take account of the statistical studies quoted in the notes; even so, changes have been more in terms of organisation of the criterial concepts (to make stating of the "diagnostic argument" easier

and Asperger's syndrome, evidenced by the discriminant function (see website).

The other statistical aspects are most avoidance using social interaction, social communication and rigid and repetitive patterned behaviours and emotional symptoms across the groups that were high features, to explore the degree of phenotypic

Second (in addition to the arbitrary threshold issues): Is relying on features that are not too specific in autistic population to define a subtype. This can ignore pertinent features within a person.

(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).

Measures

The DISCO is a semi-structured interview for a clinician [12]. The clinician rates the degree of information reported to them by the individual being assessed or from other sources.

More obviously, if a feature is not generally representative of autism, it is unlikely to be representative of the triad of impairment which underpins autism dx criteria. I.e. it is essentially defining a subtype on features not associated to autism.

This makes sense, their threshold of 30% is comparable to many common autism comorbidities, that when interacting with autism can potentially explain PDA. It would explain certain research results:

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

This should be obvious to most people!

What is interesting is @ONionsLiz study investigating PDA behaviours viewed them as being manipulative (pre her DISCO research). Importantly this research notes that manipulative behaviour makes difficult viewing PDA as autism.

<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>

After @ONionsLiz DISCO research, their is essentially a replication study with same tool, but results suggests behaviours "socially strategic". While other actions are manipulative in nature.



Dimensions of difficulty in children reported to have an autism spectru...
Read the full Commentary on this article at doi: 10.1111/camh.12273 Read the full Response to the Commentary on this article at doi: 10.1111/camh.12287
<https://onlinelibrary.wiley.com/doi/full/10.1111/camh.12242>

Reading between the lines, what seems to be happening is that PDA criteria and literature is being controlled to try and make it conform closer to autism understandings. While ignoring/ disagreeing with things that undermine that PDA is autism narrative.

Worth noting that if PDA Development Group research is basing clinical diagnostic tools of carer report based research; there is obviously going to be an overlap between carers & clinicians responses. Also incredibly circular:



Editorial: Demand avoidance — pathological, extreme or oppositional?
Since its inception in 1980, the term PDA has generated much debate, indeed, arguably few subjects have generated such controversy in the neurodevelopmental literature. However research in the area i...
<https://onlinelibrary.wiley.com/doi/full/10.1111/camh.12388>

Must be said @ONionsLiz DISCO items were matched against EDA-Q items. EDA-Q

itself views PDA actions as with intent and manipulative. EDA-Q is based off Newson's dx criteria & unvalidated DISCO items. i.e. ones in Gillberg study.

Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q)

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.

12 Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police)

13 If pressurised to do something, s/he may have a 'meltdown' (e.g. scream, tantrum, hit or kick)

14 Likes to be told s/he has done a good job

15 Mood changes very rapidly (e.g. switches from affectionate to angry in an instant)

16 Knows what to do or say to upset specific people

17 Blames or targets a particular person

18 Denies behaviour s/he has committed, even when caught red handed

19 Seems as if s/he is distracted from within

20 Makes an effort to maintain his/her reputation with peers

21 Uses outrageous or shocking behaviour to get out of doing something

22 Has bouts of extreme emotional responses to small events (e.g. crying, giggling, screaming, etc.)

9 Takes on roles or characters from TV/movies and acts them out

10 Shows little shame or embarrassment (e.g. might throw a tantrum in public and not be embarrassed)

11 Invents fantasy worlds or games and acts them out

12 Good at getting round others and making them do as s/he wants

13 Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police)

14 If pressurised to do something, s/he may have a 'meltdown' (e.g. scream, tantrum, hit or kick)

15 Likes to be told s/he has done a good job

16 Mood changes very rapidly (e.g. switches from affectionate to angry in an instant)

17 Knows what to do or say to upset specific people

18 Blames or targets a particular person

19 Denies behaviour s/he has committed, even when caught red handed

20 Seems as if s/he is distracted from within

Link to EDA-Q paper.

Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q)
 Read the Commentary for this article on doi: 10.1111/jcpp.12275
<https://onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149>

Is important as @ONionsLiz were matched to various EDA-Q items. Tells us that using EDA-Q research to inform new PDA DISCO items is that they should have kept the original wording. i.e PDA actions are manipulative.

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Table 1 EDA-Q items that met inclusion criteria and the closest corresponding DISCO items that were identified

| EDA-Q items (18 items) | Corresponding DISCO items (17 items) | DISCO variables |
|---|--|-----------------|
| Obsessively resists and avoids ordinary demands | Lack of co-operation | LACKCOOP |
| Has difficulty complying unless carefully presented | | |
| Is driven by the need to be in charge | Using age peers as mechanical aids, bossy and domineering | CFERAD* |
| Tells other children how to behave | | |
| Finds everyday pressures intolerably stressful | Anxiety | ANXIETY |
| Mimics adult mannerisms and styles | Repetitive acting out roles | CTROL* |
| Shows little shame or embarrassment | Behaviour in public places | BEHAPUB |
| | Embarrassing remarks in public | REMARK |
| Good at getting around others | Apparently manipulative behaviour | MANBEH* |
| Unaware of differences between self and authority figures | Awareness of own identity | CIDENT* |
| Attempts to negotiate better terms with adults | | |
| If pressurised to do things, may have a 'meltdown' | Temper tantrums | TMPERM |
| Mood changes rapidly | Changeable mood | MOODCH |
| Knows what to do or say to upset specific people | Difficulties with other people | DIFPEOP |
| Blames or targets a particular person | Harassment of others | HARAS* |
| | Blaming other people | BLAMBL* |
| Denies behaviour, even when caught red-handed | Fantasying, lying, cheating, stealing | LYING* |
| Outrageous behaviour to get out of doing something | Socially shocking behaviour | SHOCK* |
| Extreme emotional responses to small events | Inappropriate sociability (rapid, inexplicable changes from being to aggression) | CINAPP* |
| Social interaction has to be on his/her own terms | One-sided social approaches | CONESID |

Items that were included in Wing and Gould's draft 15-item PDA list are designated with an asterisk

2016 PDA DISCO study items were matched to various EDA-Q items

Seems PDA Development Group based research contains certain amount of confirmation bias, I standby the comment such PDA research appears self-validating pseudoscience. Could argue to start PDA research again from Newson's descriptions using scientific method.

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

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

the DAPers' behaviours are not caused by their p... (Durà-Vilà, and Levi, 2018). However, there is inadequate evidence to justify this (Milton, 2017).

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

Link to my article where make previous observation:

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

Worth pointing out irony of PDA Development Group research suggesting interest in PDA could bias its research:



Identifying features of 'pathological demand avoidance' us

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obsessive resistance to everyday demands and...

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

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. As such, these results do not provide information about the prevalence of PDA features, or how they compare to a population cohort of those with autism. However, these

... rants further investigation

This study provides the concept of PDA, identifying characteristics of descriptions. The important significant behaviours compared to most individuals remain as to whether with those who display span the autism spectrum a different type of 'social' the difficulties that these features.

Identifying sub-group behavioural features could further

Although from engaging with them I am pretty sure PDA Development Group would argue research not conforming to their views PDA is an autism subtype is biased and not valid.