

Thread:

So tonight I have been trying to figure out why the wording for DISCO items is different between oONionsLiz and <a href="mailto:oONion

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 took based off 15 DISCO items.

_	Num ber.□		O'Nions et a1 (2016).□	O'Nions et a1 (2015).□
	10	Blam es others for own misdeeds 0	Blaming other people:	Blam es others in appropriately/makes false
				accusations0
	20	Clum sy in: gross m ovem ents □	N/Ap	N/Ap
	30	Communicates through doll, puppet, toy	N/Ap	Communicates indirectly (e.g. through doll,
		anim al, etc.□		props, picture cards, puppet, toy anim al, or as-
				a persona)0
	40	Lacks awareness of a ge group, social	(Lacks) Awareness of own identity:	Lacks awareness/is not concerned about age-
		hierarchy, etc. □		group or social hierarchy□
	50	Hands seem limp and weak for unwelcome-	N/Ao	Unusually quiet & passive in infancy; hands
		taskso		lim p for unwelcom e tasks□
	60	Harasses another person-may like or dislike	Harassment of others⊃	Obsessed with a particular person, real or
		them □		fictional ²
	70	Obsessed with a person, real or fiction o	N/Ap	Obsessed with a particular person, real-or-
				fictional0
	\$0	Rapidinex plicable changes from loving to	Inappropriate sociability (rapid, inex plicable¶	Rapid, inexplicable changes from loving to-
		aggression ©	changesfrom loving to aggression)	aggression©
	90	Repetitive questioning:	One-sided-social-approaches=	Takes control of the conversation through
			**	repetitive-questioning/interrupting=
_	100	Repetitive role play-lives the part, not usual	Repetitive acting outroles0	play/imaginative play-lives the part, not the
		pretence ©	-	usualpretence0
	110	Socially manipulative behaviour to a void-	Apparently manipulative behaviour□	Socially manipulative behaviour to avoid
		dem ands□		dem ands□
	120	Socially shocking behaviour with deliberate	Socially shocking behaviour	Socially shocking behaviour with deliberate
		intent ©	, , ,	intent0
	130	Lies, cheats, steals, fantasises, causing	Fantasising lying cheating stealing	Fantasises, tells tall tales≎
		distress to others□	0,000	
	140	Unusually quiet and passive in infancy o	Unusually quiet and passive in infancyo	Unusually quiet & passive in infancy; hands-
	1			lim p for unwelcom e task s□
	150	Uses peers as 'm echanical aids': bossvand-	Using age peers as mechanical aids bossy!	Difficulties interacting with peers- bossy and
		dom ineering □	and domineering□	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.



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

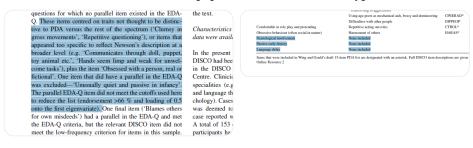
 $\label{lem:http://www.pdaresource.com/files/An%20examination%20of%20the%20behaviour al%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf$

Which is based off <u>@ONionsLiz</u> 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 <u>@ONionsLiz</u> aimed to try and make PDA a stable autism subtype (which is highly questionnable exercise).

The wording from items from the 2 earlier studies indicates PDA actions are manipulative and done with intent, while the later <u>@ONionsLiz</u> 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 invovlement and speech delay). Mainly as such features are too common in autism population to useful to a subtype.



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.

mpared between ole. This allowed Identification of DISCO PDA indicators ferences between or possible ASD The first part of the study aimed to ascertain which PDA ew schedule conitems might prove discriminating. This involved three stages. First, results from the EDA-Q study were used to irs at the time of he most acute the identify 'core features' of PDA (high endorsement rates in the PDA group and high loadings on the first principal This made it pos-PDA features had component [9]). Our criteria for an item to make the shortlist 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. ca 1 dataile a list of the 18 FDA O it

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

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

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 sy evidenced by th discriminant fun (see website).

The other state aspects are most avoidance using sof cases, and children. Lability interest in role perfeatures which it teach and adults.

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).

els of PDA features showed across whether the subgroup was distinct in pendent of the PDA item selection of social interaction, social communic tion and rigid and repetitive pattern tive behaviours and emotional sympacross the groups that were high vetures, to explore the degree of phenorem.

Measures

The DISCO is a semi-structured inte a clinician [12]. The clinician rates of information reported to them by being assessed or from other sour

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.

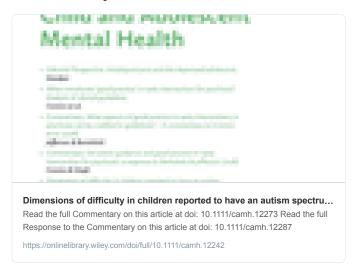
This makes sense, their threshold of 30% is comparable to many common autism comorbids, that when interacting with autism can potentially explain PDA. It would explain certain research results:

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

<u>a commentary on the 2018 National Autistic Society PDA Conference</u> This should be obvious to most people! What is interesting is <u>@ONionsLiz</u> 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.

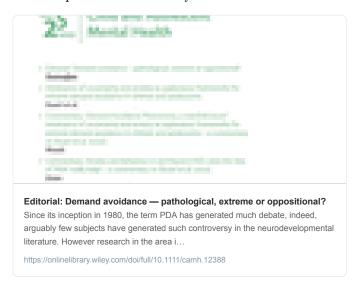
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After <u>@ONionsLiz</u> DISCO research, their is essentially a replication study with same tool, but results suggests behaviours "socially strategic". While other actions are manipulative in nature.

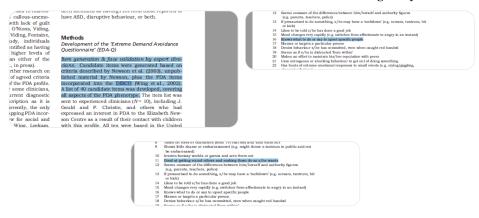


Reading between the lines, what seems to be happening is that PDA criteria and literature is being controlled to try and make it conform closer to autism understandings. While ignoring/ disagreeing with things that undermine that PDA is autism narrative.

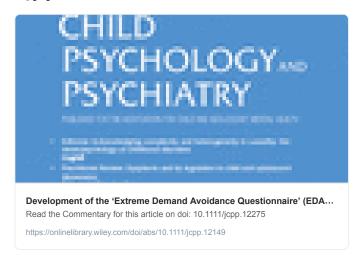
Worth noting that if PDA Development Group research is basing clinical diagnostic tools of carer report based research; there is obviously going to be an overlap between carers & clinicians responses. Also incredibly circular:



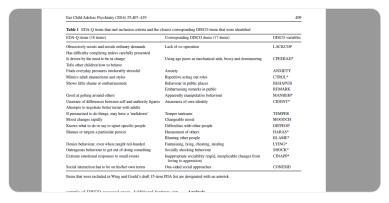
itself views PDA actions as with intent and manipulative. EDA-Q is based off Newson's dx criteria & unvalidated DISCO items. i.e. ones in Gillberg study.



Link to EDA-Q paper.



Is important as <u>@ONionsLiz</u> 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.



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, p.1). 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 pa (Durà-Vilà, and Levi, 2018). However, there is quate evidence to justify this (Milton, 2017).

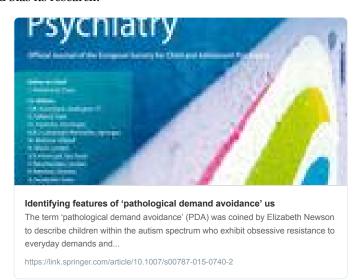
Resulting from its individual ideology, the main literature is creating its own terminology, such as 's straight forward autism' (Fidler and Christie, 2018; 'atypical autism' (Durà-Vilà and Levi, 2018; Thom 2018). Such terms are problematic for various rea 'Atypical autism' is nonsense as we know that at subtypes do not hold up clinically (Sanchez, 2 such differences between autism subtypes basically subjective and do not stand up to emp testing. 'More straight forward autism' ignores the body of evidence indicating that autistic persons systematically failed by society. This is acknowled within DAP scholarship as all autistic pupils to be struggling to access appropriate educat support (Kay, 2019). Other examples can be f

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:



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 investigat

This study provide the concept of PDA, ing characteristics of descriptions. The imp significant behaviour compared to most indi remain as to whether with those who displa span the autism spect a different type of 's the difficulties that a features.

Identifying sub-gro ioural features could by

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.

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