Richard Woods @Richard_Autism

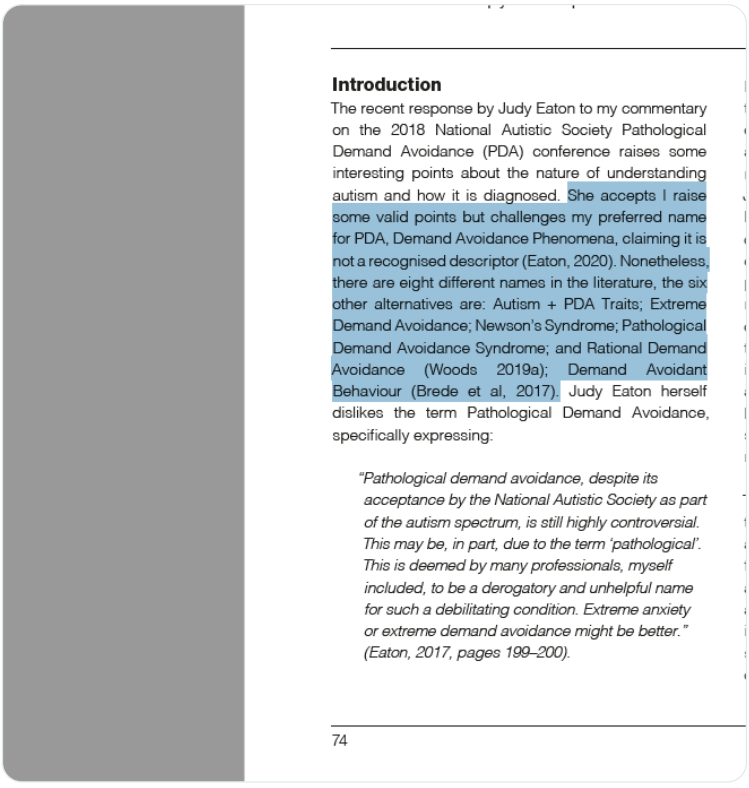
9 May • 57 tweets • Richard_Autism/status/1391308248406429697

In other news, I have realised I should probably add "Problematic Demand Avoidance" to list of names for PDA.

That I should call one clinic's PDA "Extreme Extreme Demand Avoidance" to accurately represent narrowness & seemingly absurdity of their position.

I have a list of 10 different PDA's name in print here: https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DSM-5_a_rebuttal_to_Judy_Eaton

Screen shot of the list, as I forgot to include it before



Introduction

The recent response by Judy Eaton to my commentary on the 2018 National Autistic Society Pathological Demand Avoidance (PDA) conference raises some interesting points about the nature of understanding autism and how it is diagnosed. She accepts I raise some valid points but challenges my preferred name for PDA, Demand Avoidance Phenomena, claiming it is not a recognised descriptor (Eaton, 2020). Nonetheless, there are eight different names in the literature, the six other alternatives are: Autism + PDA Traits; Extreme Demand Avoidance; Newson's Syndrome; Pathological Demand Avoidance Syndrome; and Rational Demand Avoidance (Woods 2019a); Demand Avoidant Behaviour (Brede et al, 2017). Judy Eaton herself dislikes the term Pathological Demand Avoidance, specifically expressing:

> *"Pathological demand avoidance, despite its acceptance by the National Autistic Society as part of the autism spectrum, is still highly controversial. This may be, in part, due to the term 'pathological'. This is deemed by many professionals, myself included, to be a derogatory and unhelpful name for such a debilitating condition. Extreme anxiety or extreme demand avoidance might be better." (Eaton, 2017, pages 199–200).*

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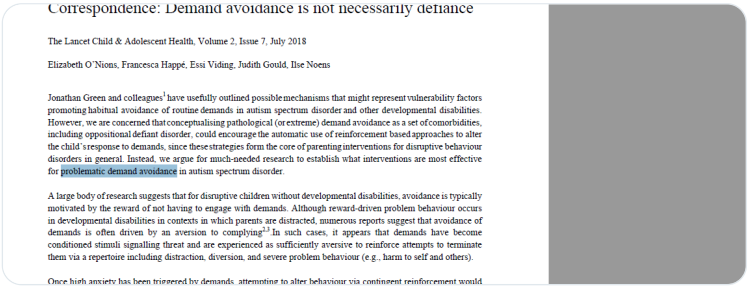
So "problematic demand avoidance" is from O'Nions et al (2018) response to Green et al (2018).

Demand avoidance is not necessarily defiance

Jonathan Green and colleagues1 have usefully outlined possible mechanisms that might represent vulnerability factors promoting habitual avoidance of routine

demands in autism spectrum disorder and ot…

https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30171-8/fulltext



Correspondence: Demand avoidance is not necessarily defiance

The Lancet Child & Adolescent Health, Volume 2, Issue 7, July 2018

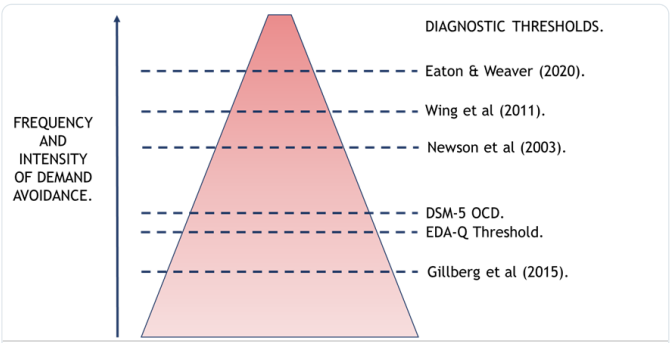
Elizabeth O'Nions, Francesca Happé, Essi Viding, Judith Gould, Ilse Noens

Jonathan Green and colleagues[1] have usefully outlined possible mechanisms that might represent vulnerability factors promoting habitual avoidance of routine demands in autism spectrum disorder and other developmental disabilities. However, we are concerned that conceptualising pathological (or extreme) demand avoidance as a set of comorbidities, including oppositional defiant disorder, could encourage the automatic use of reinforcement based approaches to alter the child's response to demands, since these strategies form the core of parenting interventions for disruptive behaviour disorders in general. Instead, we argue for much-needed research to establish what interventions are most effective for problematic demand avoidance in autism spectrum disorder.

A large body of research suggests that for disruptive children without developmental disabilities, avoidance is typically motivated by the reward of not having to engage with demands. Although reward-driven problem behaviour occurs in developmental disabilities in contexts in which parents are distracted, numerous reports suggest that avoidance of demands is often driven by an aversion to complying[2,3] In such cases, it appears that demands have become conditioned stimuli signalling threat and are experienced as sufficiently aversive to reinforce attempts to terminate them via a repertoire including distraction, diversion, and severe problem behaviour (e.g., harm to self and others).

Once high anxiety has been triggered by demands, attempting to alter behaviour via contingent reinforcement would

Now, for this Extreme Extreme Demand Avoidance. So, I am referring to the top threshold in the diagram in this blog.

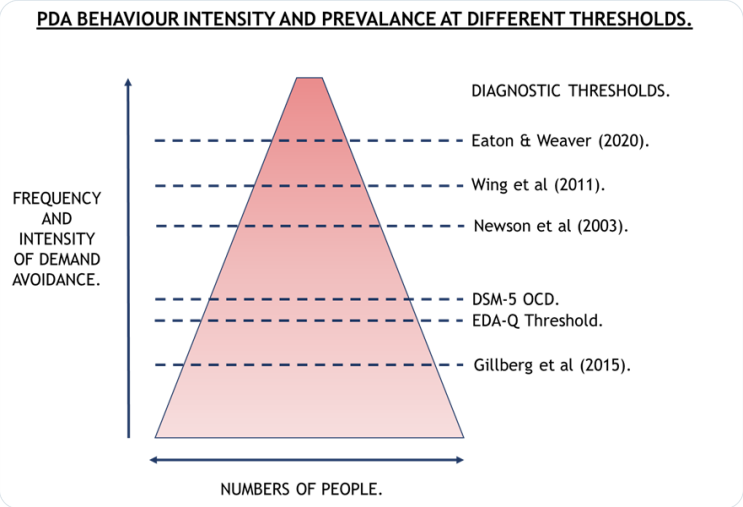


PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THR…

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…

In the blog I show how the top threshold appears to not be representative of PDA literature. From discussing it with the clinic, they seem have created that threshold from their clinical experience. This is reflected in a comment in their article.

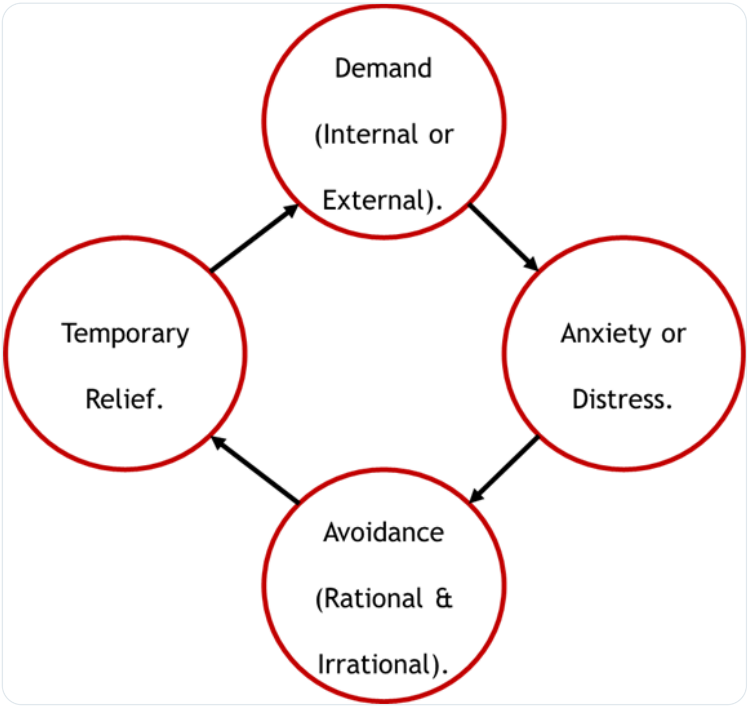


To quote article:

"combined with the extensive clinical knowledge of the assessment team, led to the development of an informal algorithm."... p37.

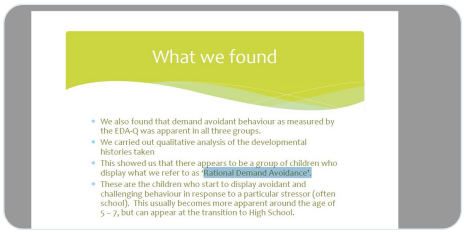
Be mindful, I have basically debunked the assertion it was constructed based with the literature.

I am confident that there is one PDA when one focuses on the demand avoidance, and that it is an anxiety based disorder. I go into reasons for this in a submitted essay.



So we have an extreme version PDA in the literature, and apparently not based on the literature (which one could view as extreme and short sighted in itself).

So the response of the authors of this extreme version of PDA, seems to be view anything below their threshold as "Rational Demand Avoidance" or Not PDA.

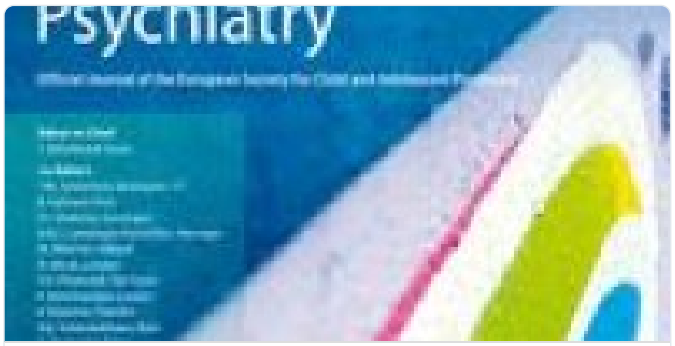


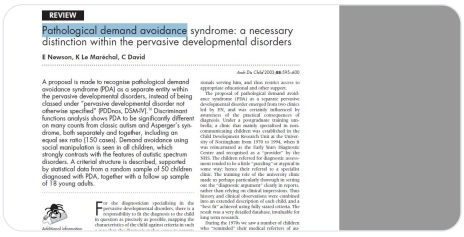
It matters when lower diagnostic thresholds are also called "Pathological Demand Avoidance" or "Extreme Demand Avoidance".

See Newson et al (2003):
https://adc.bmj.com/content/88/7/595

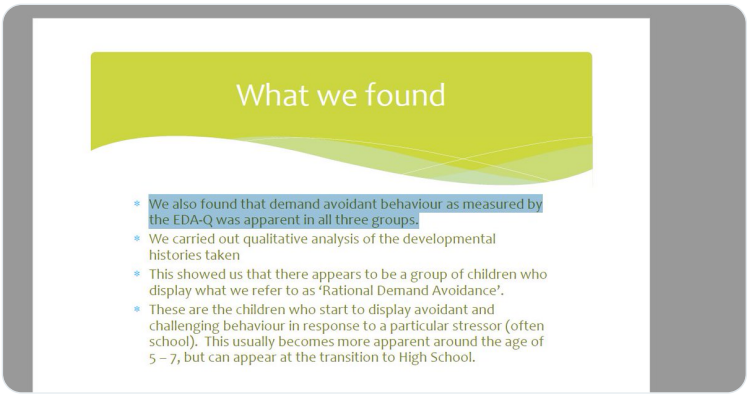
O'Nions et al (2014), with the EDA-Q validation paper.
https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149

Gillberg et al (2015) for Faroe Islands paper:



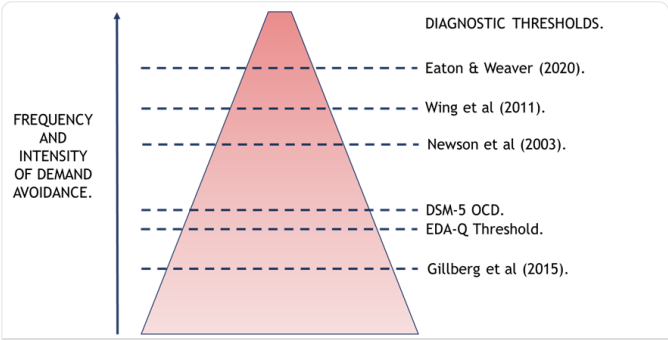


To be clear the clinic in question is developing a tool to screen for its version of PDA. No idea what happens to those with PDA at lower thresholds. Clinic views EDA-Q as being too easy to meet threshold on/ "false positives".



To be clear the EDA-Q title is "Extreme Demand Avoidance-Questionnaire".

The EDA-Q detects PDA at non-pervasive levels, i.e. some view it as not being "extreme enough" for PDA From:



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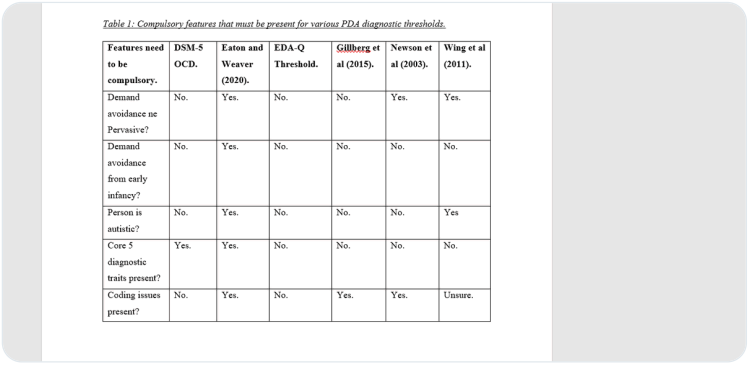
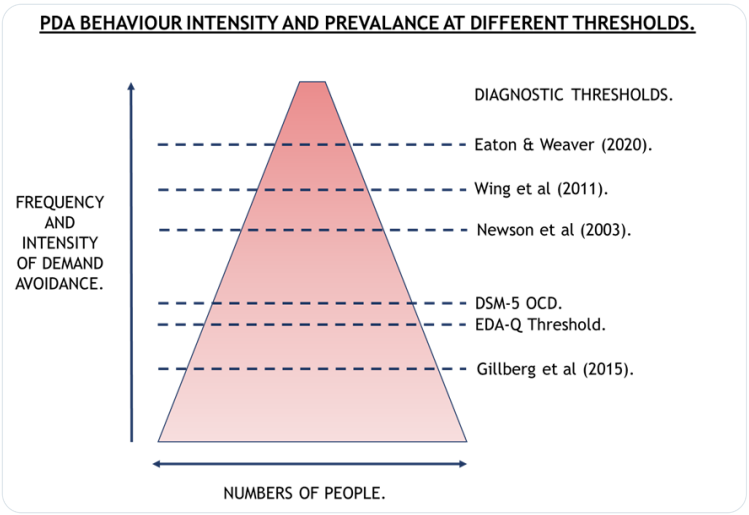


Table 1: Compulsory features that must be present for various PDA diagnostic thresholds.

Features need to be compulsory.	DSM-5 OCD.	Eaton and Weaver (2020).	EDA-Q Threshold.	Gillberg et al (2015).	Newson et al (2003).	Wing et al (2011).
Demand avoidance ne Pervasive?	No.	Yes.	No.	No.	Yes.	Yes.
Demand avoidance from early infancy?	No.	Yes.	No.	No.	No.	No.
Person is autistic?	No.	Yes.	No.	No.	No.	Yes
Core 5 diagnostic traits present?	Yes.	Yes.	No.	No.	No.	No.
Coding issues present?	No.	Yes.	No.	Yes.	Yes.	Unsure.

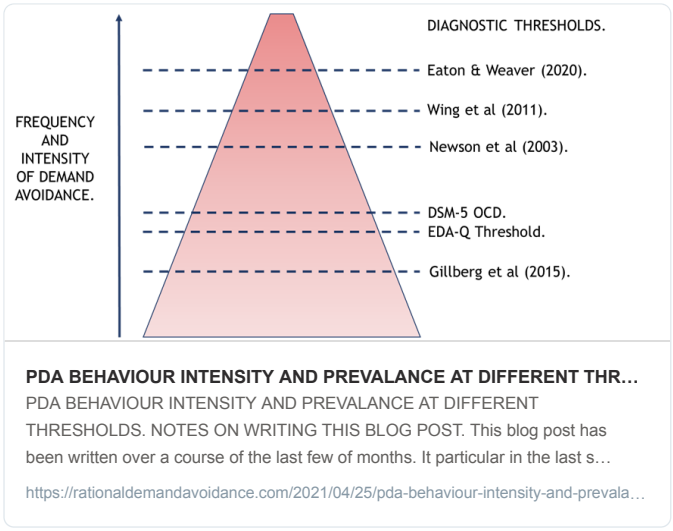
Now I need to create a Gaussian curve of PDA population, one end would Extreme Extreme Demand Avoidance & other Gillberg et al (2015).

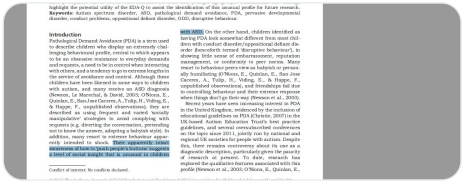


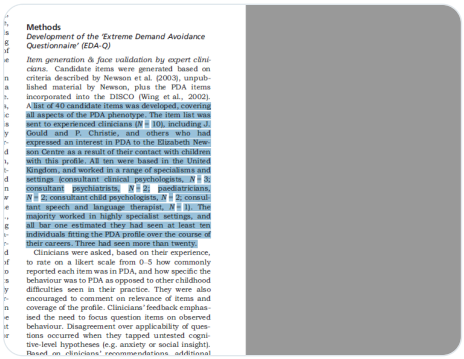
I am still working out a suitable name for Gillberg et al (2015). I have:
Non - Extreme Demand Avoidance.
Barely clustering together PDA traits.
Sub clinical PDA.
Broader PDA Phenotype.

Back to the EDA-Q. The EDA-Q views PDA as an ASD, assumes PDA has coding issues (which is not assumption I would necessarily make). Views social demand avoidance to manipulative...

... Specialised autism experts consulted. Attempted to validate EDA-Q in autistic CYP. There seems to be non-autistic persons in the two PDA groups. O'Nions has not provided a robust reason to assume all CYP with PDA are autistic.







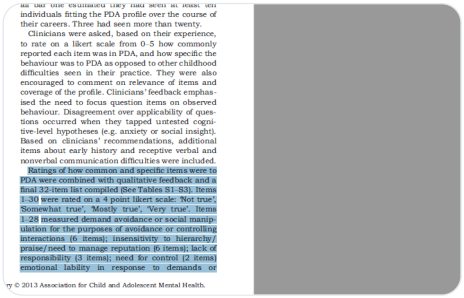
Methods

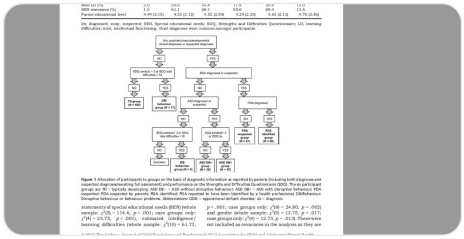
Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q)

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 cf. 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 coverage of the profile. Clinicians' feedback emphasised the need to focus question items on observed behaviour. Disagreement over applicability of questions 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 nonverbal 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 (See Tables S1–S3). Items 1–30 were rated on a 4 point likert scale: 'Not true', 'Somewhat true', 'Mostly true', 'Very true'. 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





The point I am making here, is that if the tool that was designed by some autism expert researchers (at least Happe is) & over 10 other autism experts detects PDA in non-autistic persons - it should tell you that PDA is NOT autism.

I.e. it is highly questionable for any clinic, including a specialised autism and PDA clinic to discard the EDA-Q because it does not conform to their wishes.

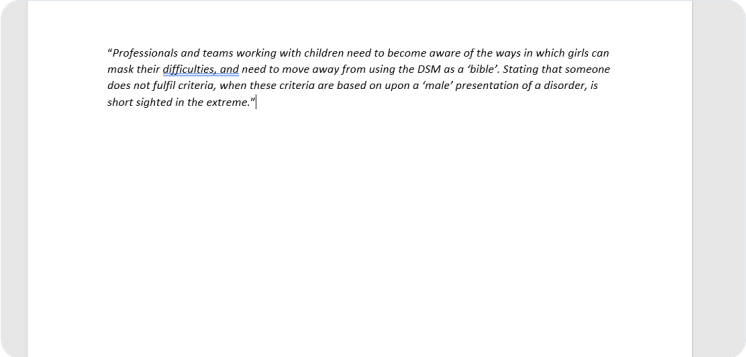
There are other reasons to, such as sheer amount of our PDA knowledge that is related to the EDA-Q.

To me, that is nothing to do with science, but seems a self-validation exercise, especially when this seems to be going of the clinic's staff' opinions on autism and PDA.

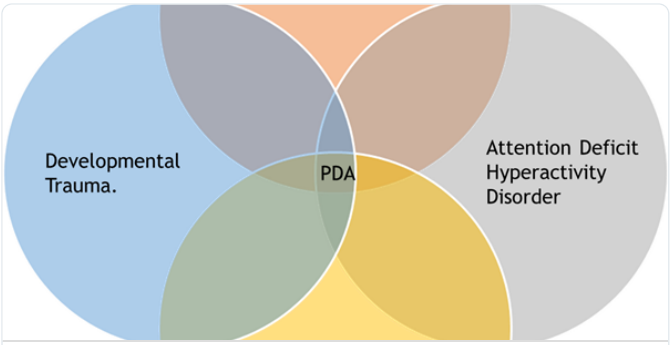
I do not wish to make this point. Considering one of clinic's staff makes the quote of:

"Professionals and teams working with children need to become aware of the ways in which girls can mask their difficulties,...

... and need to move away from using the DSM as a 'bible'. Stating that someone does not fulfil criteria, when these criteria are based on upon a 'male' presentation of a disorder, is short sighted in the extreme."



It appears, one can make an equally valid statement about their position on PDA. That their position is short-sighted in the "extreme"; i.e. is an extreme position.



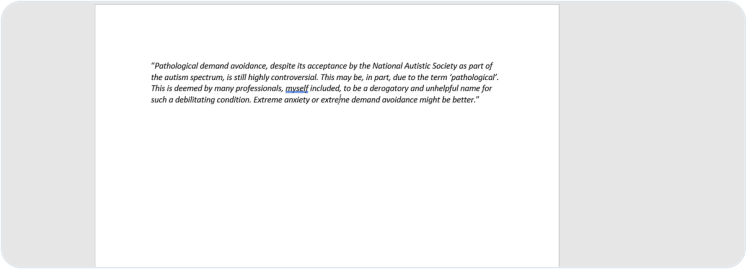
A DRAFT OF THE PATHOLOGICAL DEMAND AVOIDANCE – BELIEFS S…
A DRAFT OF THE PATHOLOGICAL DEMAND AVOIDANCE – BELIEFS SCALE (PDA-BS). Introduction. This blog post is an expanded debate entry I have started on Researchgate about a tool to assess a person's beli…
https://rationaldemandavoidance.com/2021/04/30/a-draft-of-the-pathological-demand-…

That is pretty much my rationale for "Extreme Extreme Demand Avoidance" name.

I am intending to make a Gaussian curve image later of PDA population.

I am going to clarify a bit more of the rationale for the names.

So Extreme Extreme Demand Avoidance is reflective of the clinic does not "Pathological" descriptor, viewing it as demeaning.



The point behind these suggested names is it possible for a person to meet its diagnostic threshold, without having core PDA traits present & therefore cannot reliably be sure Demand Management Cycle is present.

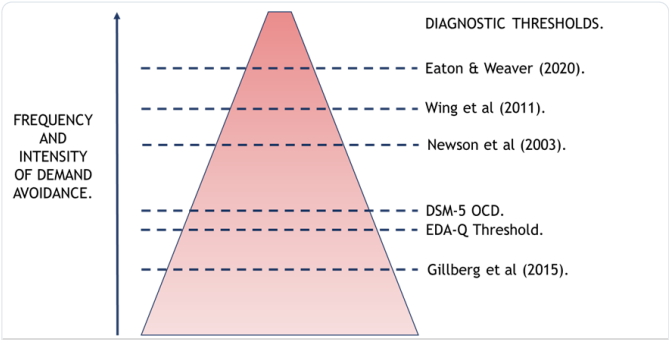
Replying to @Richard_Autism

I am still working out a suitable name for Gillberg et al (2015).
I have:
Non - Extreme Demand Avoidance.
Barely clustering together PDA traits.
Sub clinical PDA.
Broader PDA Phenotype.

9:06 AM · May 9, 2021

1 Copy link to Tweet

I explain how core PDA traits might not be present at Gillberg et al (2015) threshold, here:



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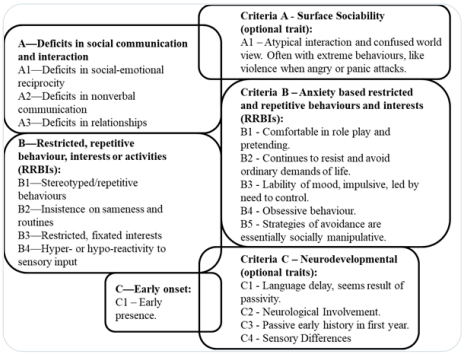
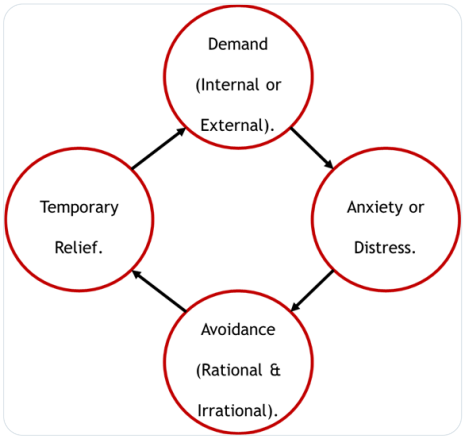
https://rationaldemandavoidance.com/2021/04/25/pda-behaviour-intensity-and-prevala…

Core PDA traits are set out in this diagram comparing PDA traits vs DSM-5 autism criteria.

The other image shows the Demand Management Cycle.





The point I am trying to make, is that one cannot be sure core traits are present, one cannot assume what is being diagnosed is actually PDA, sharing universal features of the proposed Disorder. It is one of the reasons why I prefer EDA-Q threshold.

Reason why EDA-Q is important to our PDA knowledge base.

Richard Woods

@Richard_Autism

Replying to @Richard_Autism

I.e. it is highly questionable for any clinic, including a specialised autism and PDA clinic to discard the EDA-Q because it does not conform to their wishes.

There are other reasons to, such as sheer amount of our PDA knowledge that is related to the EDA-Q.

9:17 AM · May 9, 2021

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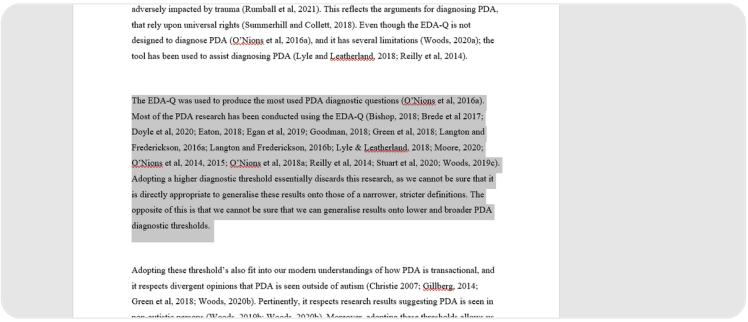

adversely impacted by trauma (Rumball et al, 2021). This reflects the arguments for diagnosing PDA, that rely upon universal rights (Summerhill and Collett, 2018). Even though the EDA-Q is not designed to diagnose PDA (O'Nions et al, 2016a), and it has several limitations (Woods, 2020a); the tool has been used to assist diagnosing PDA (Lyle and Leatherland, 2018; Reilly et al, 2014).

The EDA-Q was used to produce the most used PDA diagnostic questions (O'Nions et al, 2016a). Most of the PDA research has been conducted using the EDA-Q (Bishop, 2018; Brede et al 2017; Doyle et al, 2020; Eaton, 2018; Egan et al, 2019; Goodman, 2018; Green et al, 2018; Langton and Frederickson, 2016a; Langton and Frederickson, 2016b; Lyle & Leatherland, 2018; Moore, 2020; O'Nions et al, 2014, 2015; O'Nions et al, 2018a; Reilly et al, 2014; Stuart et al, 2020; Woods, 2019e). Adopting a higher diagnostic threshold essentially discards this research, as we cannot be sure that it is directly appropriate to generalise these results onto those of a narrower, stricter definitions. The opposite of this is that we cannot be sure that we can generalise results onto lower and broader PDA diagnostic thresholds.

Adopting these threshold's also fit into our modern understandings of how PDA is transactional, and it respects divergent opinions that PDA is seen outside of autism (Christie 2007; Gillberg, 2014; Green et al, 2018; Woods, 2020b). Pertinently, it respects research results suggesting PDA is seen in

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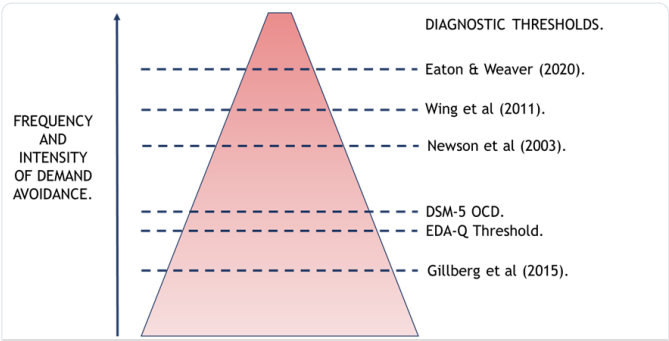

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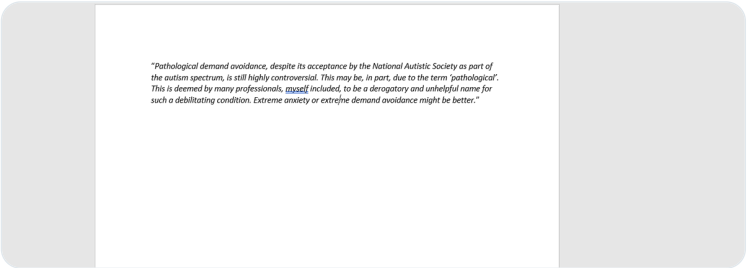
https://rationaldemandavoidance.com/2021/04/25/pda-behaviour-intensity-and-prevala…

Also, the clinic's suggested name of "Extreme Anxiety" is important, as it also means name of "Extreme Extreme Demand Avoidance" is reflective of their position.

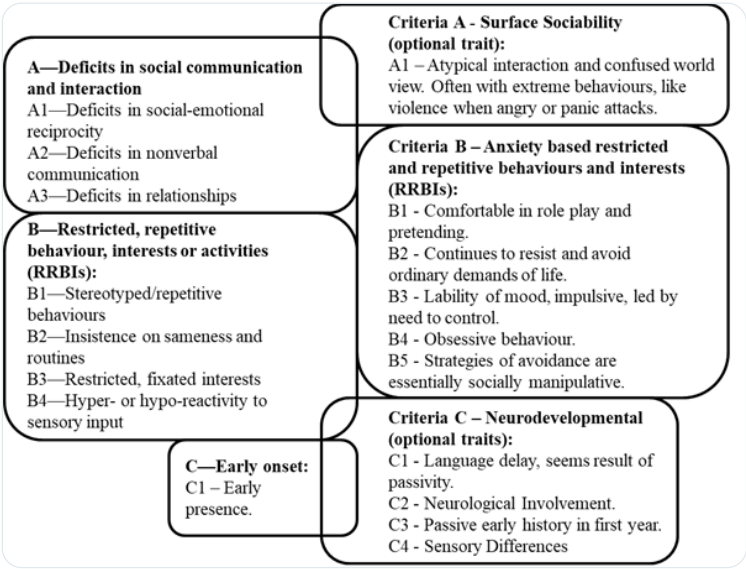


"Pathological demand avoidance, despite its acceptance by the National Autistic Society as part of the autism spectrum, is still highly controversial. This may be, in part, due to the term 'pathological'. This is deemed by many professionals, myself included, to be a derogatory and unhelpful name for such a debilitating condition. Extreme anxiety or extreme demand avoidance might be better."

Pertinently, "Extreme Anxiety" supports my critique, behaviours being pathologised by high ADOS scores in their research are caused by anxiety & that its because ADOS

is interacting atypically with PDA behaviours as ADOS is not designed to assess PDA features

The point is ADOS mainly assesses for autistic social communication differences (Category A DSM-5 autism criteria). ADOS is atypically interacting with PDA's anxiety based RRBIs and hence provided invalid social communication scores for it.



I will restate this, the case that PDA is an ASD, does genuinely appear to be on thin ice (so to speak).

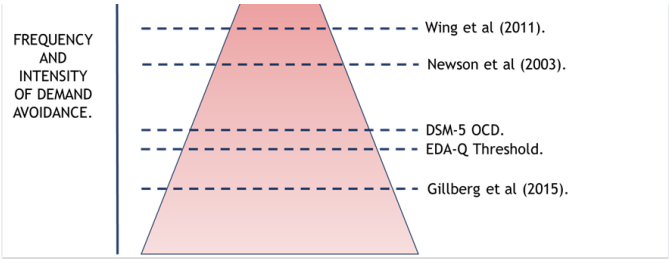
Article showing how ADOS mainly assesses autistic social communication differences & how it is possible to meet DSM-5 autism threshold scoring only on Category A questions.

How well are DSM-5 diagnostic criteria for ASD represented in standar…
Five years after the publication of DSM-5 in 2013, three widely used diagnostic instruments have published algorithms designed to represent its (sub-)crite

https://link.springer.com/article/10.1007/s00787-020-01481-z

Theoretically possible for non-autistic person to meet DSM-5 autism threshold by expressing anxiety based demand avoidance RRBIs...

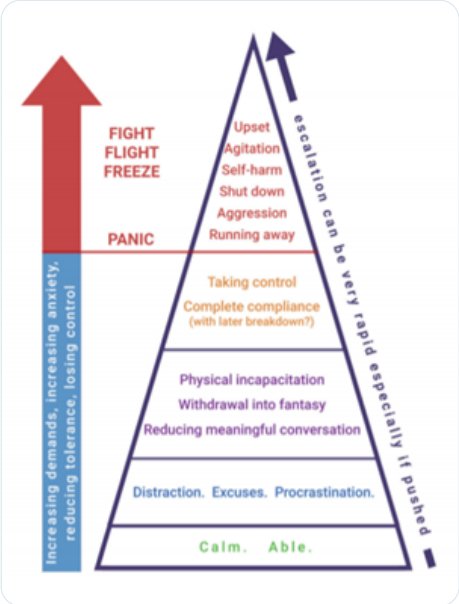
The core PDA traits are RRBIs in nature. See the blog post, where I argue PDA can be viewed as a form of OCD and Related Disorders.

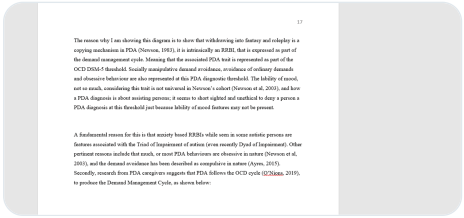


PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THR...

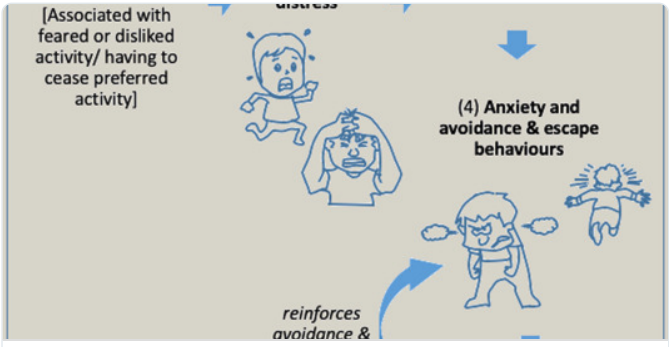
PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THRESHOLDS. NOTES ON WRITING THIS BLOG POST. This blog post has been written over a course of the last few of months. It particular in the last s…

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





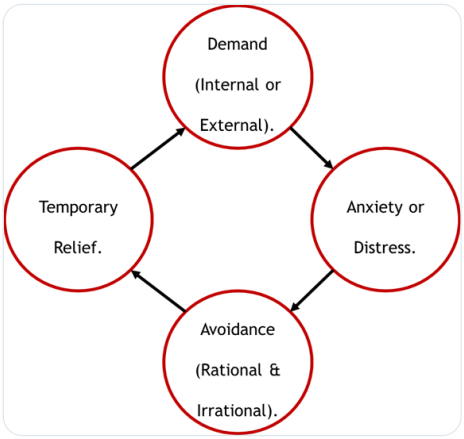
"It is helpful to remember that children with a PDA profile are not deliberately difficult. If the socially strategic behaviour is seen for what it is e a scripted and limited strategy for ensuring predictability and control," P 415

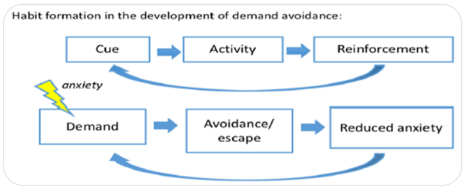


Extreme/'pathological' demand avoidance: an overview

Pathological demand avoidance (PDA) was coined in the 1980s to describe children on the spectrum of pervasive developmental disorders who show an obsessive resistance to everyday demands, an extreme …

https://www.paediatricsandchildhealthjournal.co.uk/article/S1751-7222(20)30156-6/fullt…





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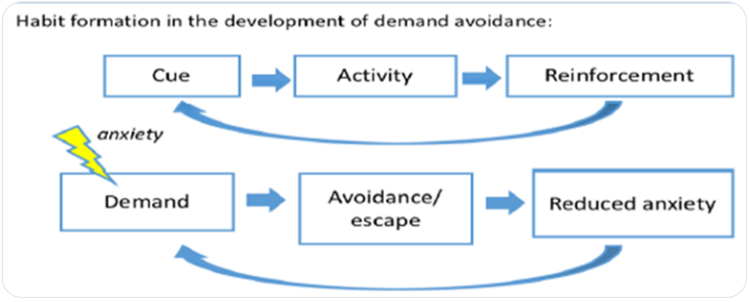
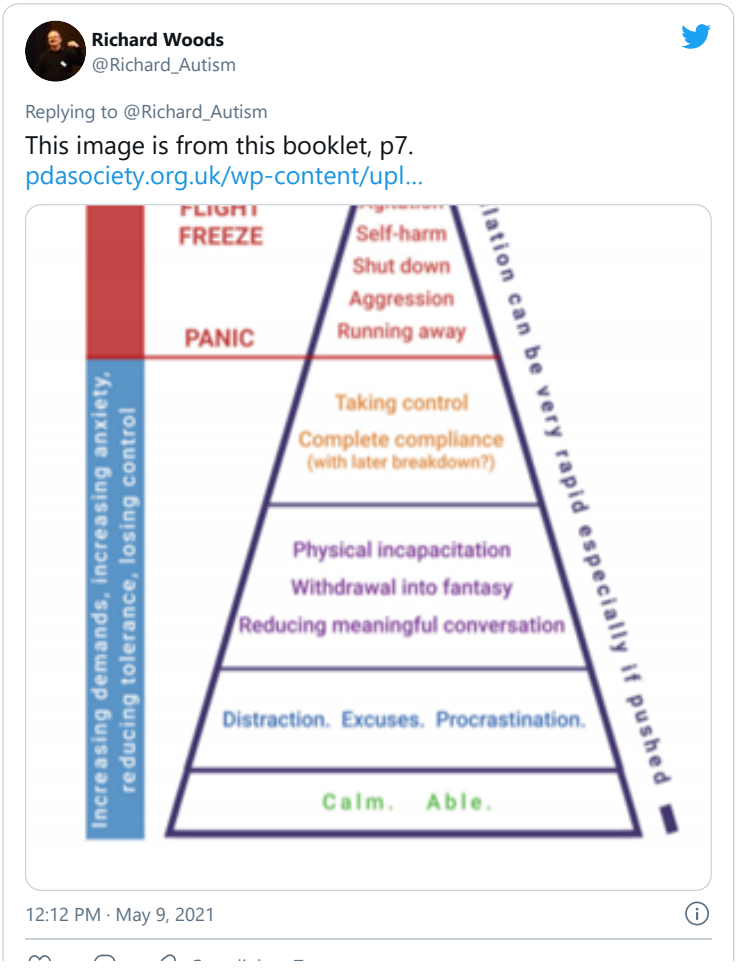
https://lizonions.files.wordpress.com/2019/09/1909childbehaviourparentingstrategiessummary.pdf

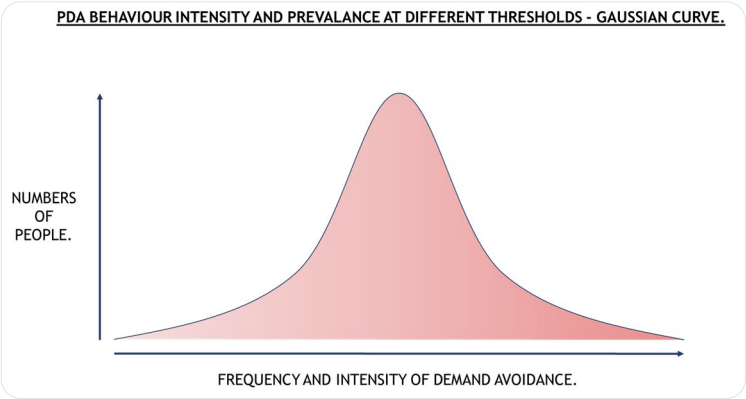




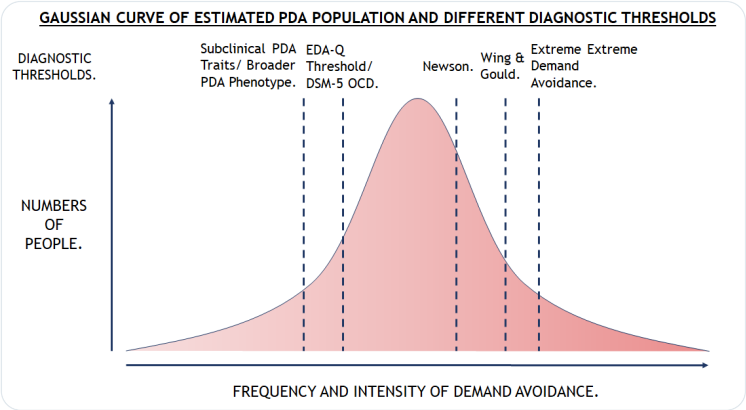
Copy link to Tweet

This might seem like a tangent, but I am substantiating what I am saying to make it harder for others to dismiss.

I have a rough Gaussian Curve done, just need to map out the diagnostic thresholds and refine it.



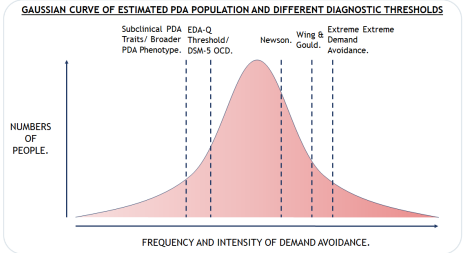
This is my best guess at this, others might produce something different to this.

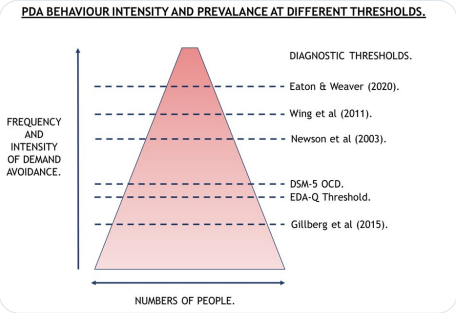


Extreme Extreme Demand Avoidance = Eaton and Weaver (2020).
Subclinical PDA Traits/ Broader PDA Phenotype = Gillberg et al (2015).
Newson = Newson et al (2003).
Wing & Gould = Wing et al (2011).

I could not decide between what was a suitable name for Gillberg et al (2015), so I chose two names which should clinically mean the same thing: "Subclinical PDA Traits/ Broader PDA Phenotype". Others might disagree, would be open to other suggestions.

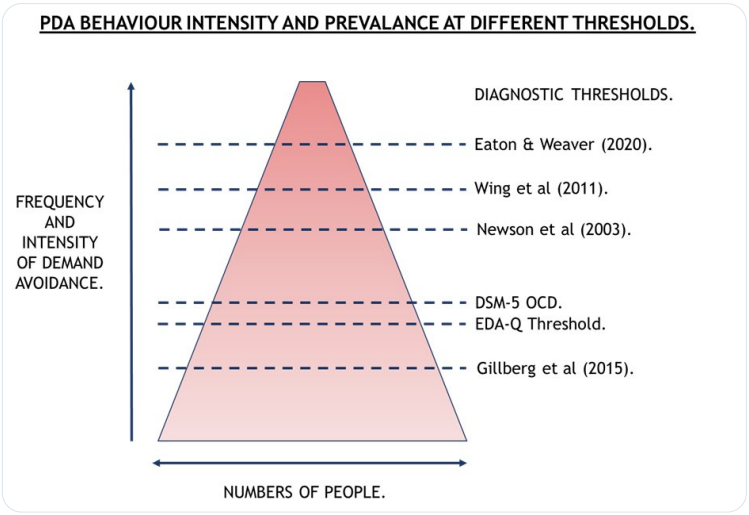
I have tried to keep the same style that I used in the previous version of the image, so people should be familiar with what I am meaning in the new Gaussian Curve image.



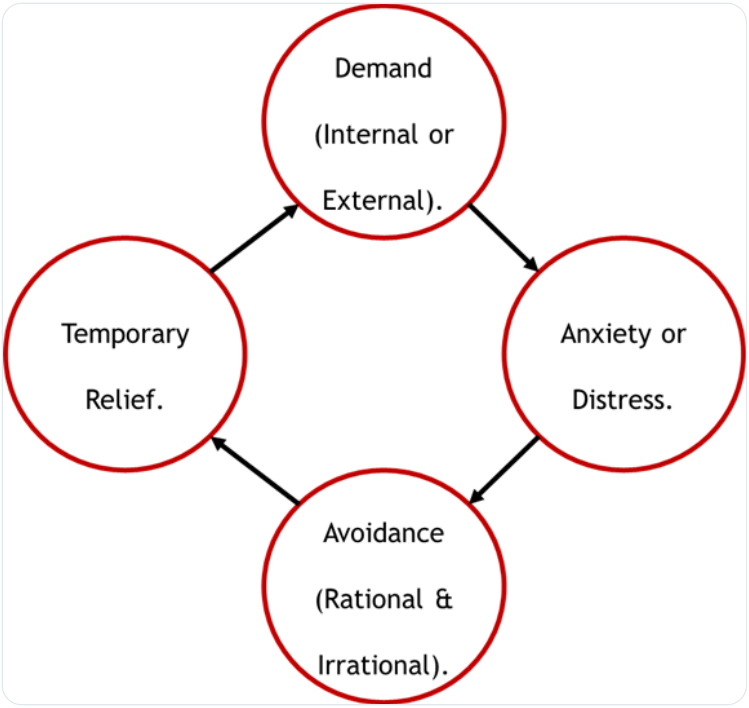


Same features include gradients, for light to dark, for light for lower frequency and intensity levels versus dark for higher frequency and intensity PDA behaviour levels.

I need to point out that not all the persons in this diagram would necessarily transfer over to a Gaussian curve of PDA population.



Reason for this is, that many/ most persons at Gillberg et al (2015) or below are not displaying all core PDA traits & displaying Demand Management Cycle. I.e. these people should not count as having Pathological/ Rational/ Extreme Demand Avoidance.



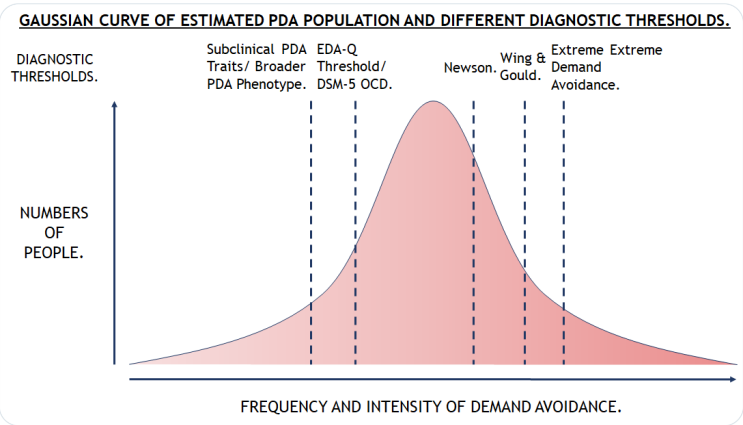
Although, saying this, I am tempted to rename "Extreme Extreme Demand Avoidance", to "Extreme Rational Demand Avoidance" to highlight, how I & @milton_damian would view it to be same construct throughout.

Main reason for sticking for "Extreme Extreme Demand Avoidance" is to respect clinics views over naming PDA.

I have also merged the DSM-5 OCD and EDA-Q thresholds as I consider them to be at comparable levels, but I admit this might not be the case. I figured it is better to reduce information being provided to not confuse people.

I changed the name of the diagram to "Gaussian curve of estimated PDA population and different diagnostic thresholds" to better represent what is actually be portrayed in it.

I think this is the version I will be using going forward, besides maybe minor tweaks.



I would welcome feedback on this diagram.

@threadreaderapp Please could you unroll.

Thank you in advance.

• • •