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ORIGINAL ARTICLE

A Systematic Review of Pathological Demand Avoidance (PDA): A Veritable Diagnosis or a Case of Circular Logic?

Dylan Company[1] · **Joe Anthony Rotella**[1,2,3]

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Abstract

Purpose To assess the current level of evidence supporting the distinct diagnosis of PDA by evaluating the use of the diagnostic tools currently available.

Methods A comprehensive search of three bibliographic databases was undertaken, including: MEDLINE, EMBASE, and PSYCHINFO. Study selection, extraction and quality assessment were conducted independently by two reviewers via Covidence. English-language studies pertaining to the diagnosis of PDA with empirical data were included. Methodological bias was critically appraised using the QUADRAS-2.

Results 12 relevant studies were identified, nine in paediatric populations, two in adults and one in a mixed cohort. Data was usually collected via self-reported questionnaires or surveys. Two diagnostic tools were identified- the EDA-Q and the DISCO although the use of these was inconsistent. Cross-over with other conditions was also noted. Studies were all assessed as being high risk for methodological bias.

Conclusions There was considerable inconsistency in the way PDA was identified across studies with a large proportion of studies relying on subjective rather than objective measures. The methodological bias inherent to these studies raises the issue of circular logic and makes it difficult to support any of the diagnostic tools pertaining to PDA, let alone the condition itself.

Keywords Pathological demand avoidance · Autism · Neurodivergence · Diagnosis · Assessment

Introduction

Pathological Demand Avoidance (PDA), first described in the 1980s, is a proposed neurodevelopmental disorder characterised by a pattern of resistance and avoidance to the ordinary demands of daily life (Newson et al., 2003). PDA was originally described as consisting of the following features: passive early history in first year of life, a continuous resistance and avoidance to ordinary demands of daily life, surface sociability with difficulties pertaining to social identity, pride, or shame, lability of mood, comfort in role-playing, language delays, obsessive behaviour, and non-objective neurological signs such as clumsiness and physical awkwardness (Newson et al., 2003).

PDA, which is sometimes referred to as '*Extreme Demand Avoidance*' by some authors, is not formally recognised in established diagnostic references, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), or disease classification manuals, such as the International Classification of Diseases (ICD-11) (Gillberg, 2014). It remains a contentious diagnosis with several interpretations and no validated diagnostic criteria (Gillberg, 2014; Kildahl et al., 2021; Stuart et al., 2020). PDA has been proposed by some authors as a subtype within the autism spectrum whilst others suggest PDA to be a unique phenomenon (Gillberg et al., 2015; Green et al., 2018; Kildahl et al., 2021). To further compound the complexity of trying to diagnose PDA, others have reported significant associations between PDA and attention-deficit/hyperactivity disorder and oppositional

✉ Joe Anthony Rotella
joe.a.rotella@nh.org.au

[1] Department of Emergency Medicine, Northern Health, Epping, VIC, Australia

[2] Addiction Psychiatry and Toxicology, Northern Health, Epping, VIC, Australia

[3] Department of Critical Care, Melbourne Medical School, Parkville, VIC, Australia

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defiant disorder (ODD) (Egan et al. 2020; O'Nions et al. 2014a, 2014b).

The overlap in symptomatology of PDA with autism and other conditions has promoted an alternative viewpoint that symptoms attributed to PDA describes a range of challenges for many children on the autism spectrum that has flow on effects on family members and that rather than trying to group these difficulties under a diagnostic label, the focus should be on understanding the interplay between the social, sensory and cognitive sensitivities in autism and the person's social environment (Green et al., 2018). This allows for clinicians to individualise management strategies for patients and their families and create positive outcomes.

Amid scientific debate, there have been increasing requests for a diagnosis of PDA and in the modern age, there has been an increase of social media interest, online support groups, and self-professed advocates in the area (Green et al., 2018; Society, 2024). As in other aspects of medicine, there has also been an increase in advertisement of services purporting to provide treatment for PDA, despite the diagnostic quandary. This raises the potential for misdiagnosis or application of therapeutic interventions that could be unnecessary, costly or in the worst-case scenario, harmful.

For clinicians, the request to provide a diagnosis of PDA can be immensely challenging as they navigate a delicate balance between the provision of accurate and appropriate clinical care and the emotional turmoil often experienced by families desperately seeking an answer as to 'why?'. The diagnostic uncertainty and a lack of consensus surrounding PDA remains a large barrier towards identifying possible therapeutic interventions. Diagnostic questionnaires such as the Extreme Demand Avoidance Questionnaire (EDA-Q) and the Diagnostic Interview for Social and Communication Disorders (DISCO) have been proposed as tools to diagnose PDA but have yet to be formally validated (O'Nions et al. 2014a, 2014b, 2016; Wing et al. 2002).

It is worth noting that the concept of demand avoidance in PDA has evolved over time. Newson's original description referenced avoidance of "ordinary" demands such as task-switching in educational settings. More recently, some advocates have reframed this as avoidance of "everyday" demands including fundamental self-care activities such as hygiene and toileting, which has subsequently been associated with the proposition of a "Pervasive Drive for Autonomy." This represents a potentially significant shift in diagnostic threshold and warrants attention in any assessment of the current evidence base.

The nosological status of PDA remains contested with respect to its relationship to autism and ADHD as intersections with other conditions have also been proposed. Some authors have proposed a relationship between PDA and attachment disorders and personality disorder presentations, further complicating the diagnostic picture (Christie, 2007; Eaton, 2018). Additionally, at least in the United Kingdom since approximately 2020, where much of the PDA literature originates, there has been a shift among PDA advocates towards framing PDA as a "formulation" rather than a formal diagnosis (Society, 2023). This has implications for how the term "diagnosis" is applied throughout both the literature and clinical practice, and readers should be aware of this terminological nuance.

We sought to systematically assess the psychometric quality and clinical utility of diagnostic tools currently proposed for the identification of PDA across paediatric and adult populations, and to evaluate the methodological rigour of studies employing these tools. Whilst several reviews have examined PDA in recent years (Green et al., 2018; Haire et al., 2024; Kildahl et al., 2021), the present review is distinguished by its specific focus on the diagnostic tools proposed for PDA, its inclusion of both paediatric and adult populations, and its application of the QUADAS-2 framework to appraise methodological bias through a diagnostic accuracy lens. To our knowledge, no prior systematic review has addressed these elements in combination.

Methods

The systematic review was undertaken as per the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) reporting guidelines (Moher et al., 2009). The review was not prospectively registered, which represents a methodological limitation; we acknowledge that pre-registration is standard practice for systematic reviews and does not preclude the inclusion of heterogeneous data. A targeted search of the MEDLINE, EMBASE, PsycINFO databases from 2003 (when PDA was first described) until October 20th, 2025, was conducted. There were no limitations on date of publication or language of publication. It was noted that there was differing terminology within the literature including "extreme demand avoidance" and "pathological demand avoidance", with some literature also referencing "demand avoidant behaviours" or "demand avoidant traits" (Gillberg, 2014; Newson et al., 2003; White et al., 2022; Woods, 2019). Consequently, the search strategy included each of these terms by using broad search parameters, which are as follows: *"pathologic* demand*" OR "demand* avoidan*" OR "extreme demand avoidan*"*. This is depicted in Box 1.

Two independent reviewers performed abstract and title screening to exclude any papers irrelevant to the topic of PDA using Covidence (Innovation). Following this, a full text screen was performed to include and exclude publications as per the following outlined criteria. Inclusion criteria

1.	pathologic* demand*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kf, fx, dq, bt, nm, ox, px, rx, ui, sy, ux, mx, tc, id, tm]
2.	demand* avoidan*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kf, fx, dq, bt, nm, ox, px, rx, ui, sy, ux, mx, tc, id, tm]
3.	extreme demand avoidan*.mp. [mp=ti, ab, hw, tn, ot, dm, mf, dv, kf, fx, dq, bt, nm, ox, px, rx, ui, sy, ux, mx, tc, id, tm]
4.	1 or 2 or 3

Box 1 Description of advanced database search

included any published study with empirical data pertaining to the diagnosis of PDA in children, adolescents, or adults. Exclusion criteria included other systematic reviews, opinion articles, comments, replies, book reviews, and non-English publications.

Due to the heterogeneity of data surrounding PDA diagnosis, data extraction was performed in a more descriptive approach. Data collected from the included studies contained study aim, recruitment information, data source, sample size, subject characteristics, identification criteria, and comparisons of PDA to other neurodevelopmental disorders.

The included studies were critically appraised for methodological bias using the QUADAS-2 tool, which is used for assessing risk of bias in diagnostic accuracy studies. The QUADAS-2 (Quality Assessment of Diagnostic Accuracy Studies-2) comprises four domains: patient selection, index test, reference standard, and flow and timing (Whiting et al., 2011). Each domain is rated as low, high, or unclear risk of bias. Although not all included studies were designed primarily as diagnostic accuracy studies, the QUADAS-2 was applied because the overarching question of this review, whether available tools can validly and reliably identify PDA, is fundamentally one of diagnostic accuracy. The domains of patient selection, index test conduct, reference standard, and flow and timing are each directly relevant to this question, making the QUADAS-2 an appropriate framework for assessing methodological bias in this context. All 12 included studies were independently appraised by two reviewers.

Results

The initial literature search identified 102 papers from Embase, MEDLINE and PsycINFO databases that met the a priori inclusion criteria. Four duplicates were removed. After abstract and title screening, 46 papers were identified as relevant and went on to full text screening. A full text screening of the 46 papers was performed by applying the inclusion and exclusion criteria, which identified 12 papers suitable for data extraction (Fig. 1).

The collected data from all included studies is presented in Table 1.

Patient Characteristics

Of the 12 included studies, two studies were in an adult cohort (Egan et al., 2019, 2020), nine studies were in a paediatric cohort (Gillberg et al. 2015; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2016, 2018a, 2018b, 2021; Reilly et al. 2014; Stuart et al. 2020), and one involved a mixed cohort of adult and paediatric participants (Doyle & Kenny, 2022). The mean ages of PDA individuals within the child and adolescent sample studies (Gillberg et al. 2015; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2016, 2018a, 2018b, 2021; Reilly et al. 2014; Stuart et al. 2020) ranged from 7 years (Reilly et al., 2014) to 15.7 years (O'Nions et al. 2018a, 2018b).

Four studies did not provide information on participant gender (Doyle & Kenny, 2022; Egan et al., 2020; Egan et al., 2019; O'Nions et al., 2021). Of the eight studies which reported gender of PDA individuals, seven studies had mostly male PDA individuals (Gillberg et al. 2015; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2016; Reilly et al. 2014; Stuart et al. 2020), with the remaining study (O'Nions et al. 2018a, 2018b) reporting 50% of PDA individuals identifying as male. The ratio of male to female participants ranged from 1:1 (O'Nions et al. 2018a, 2018b) to 3:1 (Reilly et al., 2014) across studies.

Participant Recruitment

In eight of the included studies, participants (both individuals and parents) were recruited via self-selection after viewing advertisements on online platforms or pamphlets in relevant healthcare or education settings (Doyle & Kenny, 2022; Egan et al. 2019, 2020; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2021; Stuart et al. 2020). Of the remaining studies, participants were recruited

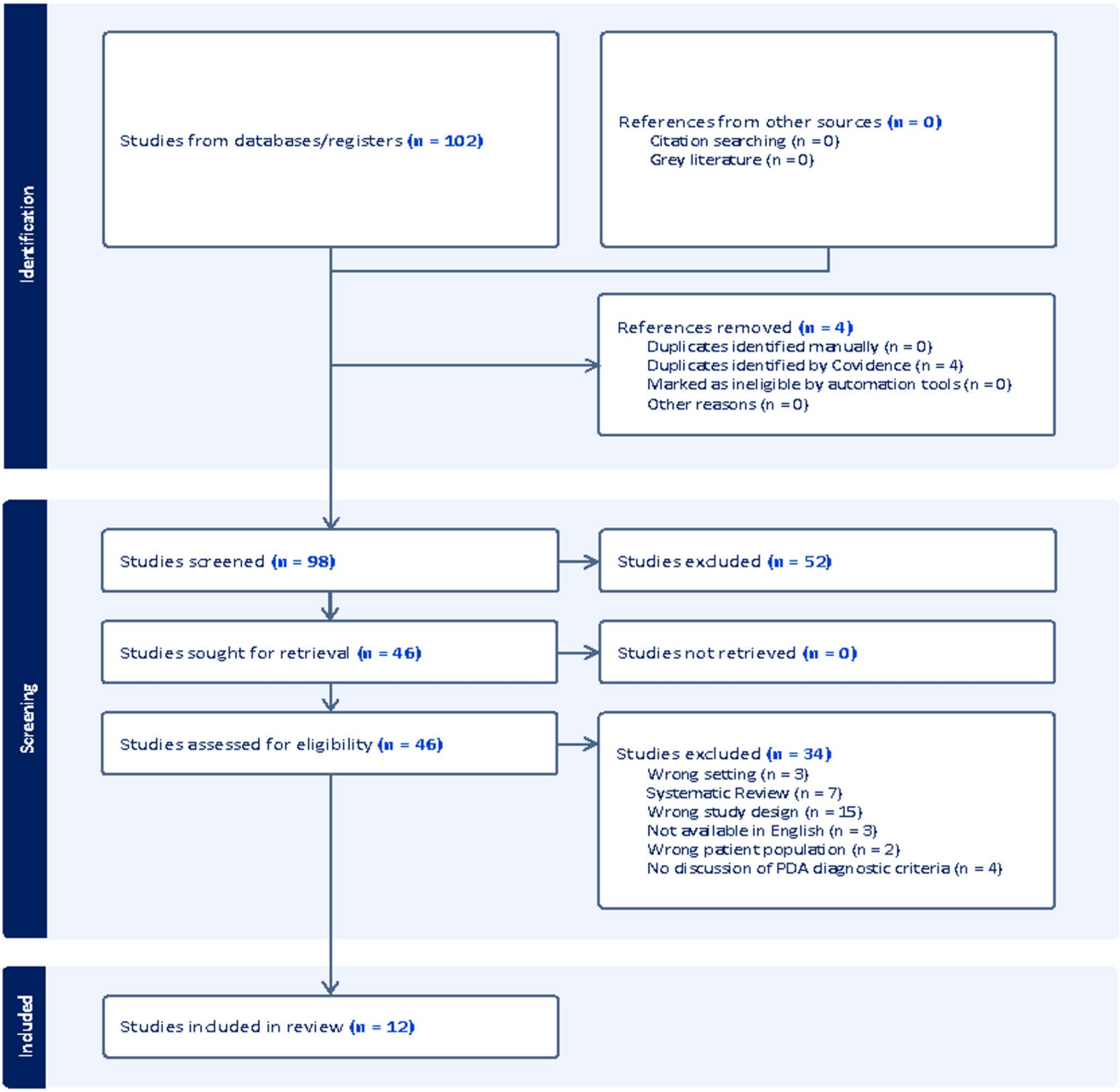


Fig. 1 PRISMA flow diagram

via population screening surveys (Gillberg et al., 2015), referrals from a specialist diagnostic and assessment centre for Autism (O'Nions et al., 2016), referrals to the research group from relevant healthcare and education third parties (O'Nions et al. 2018a, 2018b), and purposive sampling by the research study psychologist (Reilly et al., 2014).

Collection of Sample Data

For the two studies within an adult population, data was collected via self-administered hard-copy questionnaires (Egan et al., 2019) or online surveys (Egan et al., 2020). The study involving a mixed paediatric and adult PDA cohort (Doyle & Kenny, 2022) used a mixed methodology including online surveys and interviews with either the parent/carer of the child with PDA, or the individual with PDA themselves. The nine studies involving paediatric PDA cohorts (Gillberg et al. 2015; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2016, 2018a, 2018b, 2021; Reilly et al. 2014; Stuart et al. 2020) utilised a variety of methods for data collection including parental questionnaires in five studies (Langton and Frederickson 2016; O'Nions et al.

Table 1 Properties of the included studies

Source	Aim of the study	Recruitment methodology	Source of data	Sample size	Characteristics	PDA diagnostic method	Comparisons to other developmental or behavioural disorders
1. (Doyle & Kenny, 2022)	Establish the prevalence of PDA via national survey in Ireland	Self-selection via advertisements on online platforms and pamphlets in health services and libraries	Parent or self-administered online survey and interview with researcher	11 PDA individuals 264 parents of PDA individuals (Total sample: 335)	No detailed discussion of PDA subject characteristics. Includes paediatric and adult PDA individuals.	Self-identification or parental report	"Some practitioners refer to this profile as Oppositional Defiant Disorder or Conduct Disorder" "Consistent with a diagnosis of pathological demand avoidance, which is a specific form of ASD characterized by.."
2. (Egan et al., 2019)	Measure adult PDA traits using EDA-QA	Self-selection via advertisements on online platforms	Self-administered questionnaires	92 (Total sample: 347)	Age: ≥ 18 years.	Self-identification	"29 individuals reporting self-identified ASD also reported having PDA"
3. (Egan et al., 2020)	Assess predictors of PDA	Self-selection via advertisements on online platforms	Self-administered online survey	12 (Total sample: 132)	Age: ≥ 18 years.	Self-reported diagnoses	"The correlation between ASD and PDA was small, and did not predict PDA" Significant correlation between ADHD and PDA
4. (Gillberg et al., 2015)	Establish prevalence of PDA within individuals with ASD in the Faroe Islands	Population screening surveys	Interview of parents by clinical psychologist	Possible PDA: 9 (Total sample: 50)	Age: 7–24 years. Gender: 55.6% male.	DISCO (PDA score≥5) and clinical impression	"Three of the nine individuals with PDA had Asperger syndrome, three had atypical autism, and three had a diagnosis of autistic disorder."
5. (Langton & Frederickson, 2016)	Explore educational experiences of individuals with PDA	Self-selection via advertisements on online platforms	Parental questionnaires (including EDA-Q)	42 (Total sample: 51)	Age: mean of 11.33 years. Gender: 66.7% male	Parental report, EDA-Q	"82% of the children with a PDA diagnosis also had another form of ASC diagnosis"
6. (O'Nions, Christie, et al., 2014)	Development and preliminary evaluation of EDA-Q	Self-selection via advertisements on online platforms and pamphlets at schools	Parental questionnaires	PDA: 50 Suspected PDA: 67 (Total sample: 326)	PDA: Age: mean of 11.51 years. Gender: 62% male. PDA suspected: Age: mean of 10.06 years. Gender: 53.7% male.	Parental report	PDA: 16.3% ADHD diagnosis. 10% ODD diagnosis. 66% ASD diagnosis PDA suspected: 22.4% ADHD diagnosis. 7.5% ODD diagnosis. 52.2% ASD diagnosis.
7. (O'Nions, Viding, et al., 2014)	Explore the behavioural profile of PDA	Self-selection via advertisements on online platforms	Parental questionnaires	25 (Total sample: 92)	Age: mean of 11.69 years. Gender: 68% male.	Parental report	"The pathological demand avoidance group displayed comparable levels of autistic traits and peer problems to the autism spectrum disorders group"
8. (O'Nions et al., 2016)	Identify features of PDA using the DISCO	Participants recruited through Lorna Wing Centre[a]	Interview (DISCO) of parents by clinician	Suspected PDA: 27 (Total sample: 153)	Age: mean of 15.7 years. Gender: 67% male.	DISCO	26/27 suspected PDA met the criteria for ASD

Table 1 (continued)

Source	Aim of the study	Recruitment methodology	Source of data	Sample size	Characteristics	PDA diagnostic method	Comparisons to other developmental or behavioural disorders
9. (O'Nions et al., 2018)	Identify parental concerns about PDA behaviours in children with comorbid ASD and PDA	Participants referred to the research group "via specialist conferences (N = 6), enquiries to the team (N = 4), educational/child psychologists (N = 3), web groups (N = 13) or specialist educational provisions (N = 3)"	Parents completed semi-structured interview via telephone (*N* = 12) or self-administered (*N* = 17)	Suspected PDA: 3 PDA: 26 (Total sample: 82)	Age: mean of 11 years. Gender: 50% male.	EDA-Q and DISCO	26/26 PDA subjects were reported to have a diagnosis of ASD
10. (O'Nions et al., 2021)	Refinement of the EDA-Q using parent/carer report data	Self-selection via advertisements on online platforms	Parental questionnaires (including EDA-Q)	103 (Total sample: 334)	Age: <17 years.	Parental report, EDA-Q	Not available
11. (Reilly et al., 2014)	4 case studies of PDA in subjects with epilepsy	Identified via research study psychologist by observation and parent/teacher reports	Parental questionnaire (EDA-Q)	4 (Total sample: 4)	Age: mean of 7 years. Gender: 75% male.	EDA-Q and clinical impression[b]	3 ASD 1 ADHD
12. (Stuart et al., 2020)	Explore intolerance of uncertainty in PDA	Self-selection via advertisements on online platforms	Parental online survey and telephone interview	PDA: 69 Suspected PDA: 151 (Total sample: 220)	PDA: Age: 4–17 years. Gender: 63.8% male. Suspected PDA: Age: 4–17 years. Gender: 66.2% male.	Parental report, EDA-Q	PDA: 89% ASD diagnosis Suspected PDA: 50% ASD diagnosis 1 ODD

PDA: Pathological Demand Avoidance; DISCO: Diagnostic Interview for Social and Communication Disorders; EDA-Q: Extreme Demand Avoidance Questionnaire; EDA-QA: Extreme Demand Avoidance Questionnaire—Adult version; ASD: Autism Spectrum Disorder; ASC: Autism Spectrum Condition; ADHD: Attention-deficit/hyperactivity disorder; ODD: Oppositional Defiant Disorder; IQ: Intelligence Quotient.

[a]The Lorna Wing Centre for Autism is a specialist diagnostic and assessment centre located in the United Kingdom.

[b]1 participant in this study did not meet the EDA-Q cut-off score of 50 proposed by O'Nions et al. (2014a, 2014b) but was found to have had PDA based on clinical impression.

2014a, 2014b, 2021; Reilly et al. 2014), parent interviews by a clinician in three studies (Gillberg et al. 2015; O'Nions et al. 2016, 2018a, 2018b), and a parent online survey and telephone interview in one study (Stuart et al., 2020).

Identification of PDA

Whilst seven of twelve (58.3%) studies utilised objective measures such as the EDA-Q or DISCO to enrol individuals within the study (Gillberg et al. 2015; Langton and Frederickson 2016; O'Nions et al. 2016, 2018a, b, 2021; Reilly et al. 2014; Stuart et al. 2020), three of these eight studies relied upon parental reports or parental suspicions of a PDA diagnosis to initially enrol individuals with PDA into the study, with varying degrees of application of the EDA-Q afterwards to confirm the PDA diagnosis in the participants (Langton & Frederickson, 2016; O'Nions et al., 2021; Stuart et al., 2020). For instance, Langton and Frederickson (2016) used the EDA-Q to exclude participants who did not meet the proposed cut-off score[1] (Langton & Frederickson, 2016), whilst Stuart et al. (2020) used the EDA-Q as a continuous measurement tool and did not include or exclude participants based on EDA-Q scores (Stuart et al., 2020). Within the one study (Reilly et al., 2014) which utilised the

[1] The suggested EDA-Q cut-off score to identify individuals at risk of significant symptoms of PDA is 50 or above for children aged 5–11 years and 45 or above for children aged 12–17 years (O'Nions et al. 2014a, 2014b).

EDA-Q alone to identify individuals with PDA, one participant was reported to have scored below the proposed EDA-Q cut-off score and yet was still included for the purposes of the study.

This review identified that eight of the 12 (66.7%) included studies used self-reports or parental reports of PDA as a method for identifying study participants with PDA (Doyle & Kenny, 2022; Egan et al., 2020; Egan et al., 2019; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2021; Stuart et al. 2020). As previously mentioned, three studies supplemented parental reports with the EDA-Q to varying degrees (Langton & Frederickson, 2016; O'Nions et al., 2021; Stuart et al., 2020), however, the remaining five studies relied solely upon the individual or parent's report of PDA as the threshold for recognising PDA (Doyle & Kenny, 2022; Egan et al. 2019, 2020; O'Nions et al. 2014a, 2014b).

Conditions Comorbid to PDA

Three of the 12 included studies report a crossover in PDA and ODD symptomatology (Doyle & Kenny, 2022; O'Nions et al. 2014a, 2014b; Stuart et al. 2020), with two of those studies explicitly reporting comorbid ODD and PDA diagnoses (O'Nions et al. 2014a, 2014b; Stuart et al. 2020). Three studies reported a relationship between PDA and ADHD (Egan et al. 2020; O'Nions et al. 2014a, 2014b; Reilly et al. 2014), with one study outlining that ADHD is a predictor of PDA (Egan et al., 2020), and the other two studies reporting comorbid diagnoses of PDA and ADHD (O'Nions et al. 2014a, 2014b; Reilly et al. 2014). Eleven studies reported a relationship between PDA and autism to varying degrees (Doyle & Kenny, 2022; Egan et al. 2019, 2020; Gillberg et al. 2015; Langton and Frederickson 2016; O'Nions et al. 2014a, 2014b, 2018a, 2018b; Reilly et al. 2014; Stuart et al. 2020) which ranged from loose correlations (Reilly et al., 2014) to all PDA participants in the sample having a comorbid diagnosis of autism (O'Nions et al. 2018a, 2018b).

Critical Appraisal of Methodological Bias

Overall, all included studies were assessed as being high risk of bias in all four domains of the QUADAS-2 tool. None of the studies had methodologies that avoided inappropriate exclusions, and the common theme of self-selection and parental report introduced a high risk of bias. Similarly, there was no appreciable reference standard in any of the included studies.

Discussion

This review sought to characterise the current level of evidence surrounding the identification and diagnosis of pathological demand avoidance. Much of the work published on PDA since Newson's seminal paper in 2003 has acknowledged and used Newson's original description of the PDA profile to recognise and collate information on PDA. This itself poses several problems including but not limited to (1) the development of Newson's original criteria for PDA was not systemically explained, and (2) Newson's specialist centre received referrals for children with more severe behavioural disturbances. It is important therefore to recognise that this PDA profile serves as the basis for almost all of the PDA literature and thus are all subject to the same bias. This has also been observed and reported in previous studies (Green et al., 2018; Kildahl et al., 2021).

It is also important to recognise that PDA's clinical description has itself evolved over time. Woods documents how PDA traits were progressively reframed to appear more "autism-like" between 2015 and 2020, raising questions about whether this evolution reflects genuine advances in understanding or a rhetorical repositioning of PDA as an ASD profile (Woods, 2022). The "Pervasive Drive for Autonomy" framing may represent a further stage in this progression. This variability means that not all PDA cases in existing research necessarily conform to Newson's original descriptions, and this heterogeneity is rarely acknowledged in the published literature.

It should be noted that several additional tools have been proposed or used in PDA assessment beyond those identified in this review, including the ADOS-1 PDA items (O'Nions, 2013), ADOS-2 adapted scoring (Eaton & Weaver, 2020), the ASSQ-REV (Kopp & Gillberg, 2011), the Coventry Grid Interview plus PDA (Eaton, 2018), and a semi-structured 22-item interview (O'Nions et al. 2018a, 2018b). The absence of these tools from the included studies, which is partly attributable to the exclusion of grey literature from this review and further underscores the fragmented and inconsistent state of the PDA assessment evidence base.

This review identified large variability in the diagnosis of PDA. The findings of this review support other studies in this area which suggest varied measures in identifying PDA, with some studies using the EDA-Q or DISCO but the majority relying on self-report (Kildahl et al., 2021; O'Nions & Eaton, 2020). All the included studies were critically appraised as having a high risk of bias because of their design and recruitment methodology. This is in keeping with the observations made in an earlier systematic review examining PDA in children and adolescents (Kildahl et al., 2021).

As mentioned, the use of the EDA-Q across studies was noticeably different, lending confusion to the role the EDA-Q plays in reaching a PDA diagnosis. Five studies used the EDA-Q, however, three of these studies initially relied upon a parental report of the diagnosis, thus subjecting the identification of PDA in these studies to confirmation bias (Croskerry, 2002). It is also important to recognise that the EDA-Q does not have established psychometric properties currently, but preliminary data exhibits good content validity and internal consistency (Asunta et al. 2019; O'Nions et al. 2014a, 2014b; Stuart et al. 2020).

The DISCO was the other diagnostic tool for PDA used within three studies in this review, which also had a large amount of variance in its application (4, 8, 9). As the DISCO was originally designed as a diagnostic instrument for autism, an appropriation of the DISCO to identify PDA involves a selection of relevant items in the interview that are deemed indicative of representing Newson's description of PDA features (Gillberg et al., 2015; Newson et al., 2003; O'Nions et al., 2016; Wing et al., 2002). This itself poses issues for two reasons. Firstly, the base understanding of the PDA profile is being elicited from Newson's original description of PDA features rather than incorporating further data that has been published on PDA since 2003, thereby potentially skewing the utility of the tool. Secondly, the individual choices to select specific items from the DISCO as indicative of PDA introduces a large amount of variability and bias into the scoring tool being used to identify PDA. Although each of the three studies in this review recognised the necessity of selecting relevant PDA items in the DISCO, the selected set of PDA items was different across the three studies (4, 8, 9). This approach lacks consistency and is akin to creating three variations of the same tool. Furthermore, it contributes to the heterogeneity of the literature on PDA and acts as a barrier towards external validation of the DISCO.

A third tool, the Extreme Demand Avoidance Questionnaire – Adult Version (EDA-QA), was proposed by Egan et al. (2019) as an adaptation of the EDA-Q. It was not used to identify participants in either adult study, but rather to measure PDA traits in individuals who already self-identified or self-reported a prior diagnosis (Egan et al. 2019; O'Nions et al. 2014a, 2014b). Like its predecessors, the EDA-QA derives from Newson's criteria, originally developed in children aged 4–16, making it inherently prone to spectrum bias when applied to adults. This concern is compounded by the consistent findings across multiple studies (Christie 2007; Gillberg et al. 2015; O'Nions et al. 2014a, 2014b; Stuart et al. 2020) that PDA-characteristic behaviours decline substantially with age at a rate that appears greater than the age-related behavioural attenuation seen in autism or ADHD (Woods, 2020). This raises further questions about construct validity and whether the adult tool is measuring the same phenomenon at all.

This review identified that much of the published evidence relies on self-report or parental report to identify PDA. By extension, it can be concluded that a substantial proportion of the published evidence pertaining to PDA is subject to recall bias and groupthink amongst individuals who may be actively seeking a confirmatory diagnosis of PDA (Raphael, 1987; Resnik & Smith, 2020). Previous studies have made similar observations regarding recruitment by self-selection (Green et al., 2018; Kildahl et al., 2021). Interestingly, Langton and Frederickson (2016) reported "*no significant difference in the EDA-Q scores for PDA identified by a professional versus suspected by a parent*". This may indicate a lack of utility of the EDA-Q, or it may indicate that parents' perceptions of PDA have been affected by exposure to PDA forums or conferences – locations in which many participants were initially recruited from and thus can introduce groupthink or bandwagon bias (Cohen & Rothschild, 1979; Resnik & Smith, 2020). Consistent with previous studies, the majority of studies recruited from overlapping sources (e.g., Elizabeth Newson Centre or PDA society website), raising concerns about sample duplication and limiting independence of the evidence base (Haire et al., 2024; Kildahl et al., 2021).

This review has outlined that there is a substantial variability in not only the uptake of the proposed diagnostic measures (EDA-Q and DISCO) to identify PDA for studies, but also considerable inconsistency in the application of the EDA-Q and DISCO. Coupled with a lack of external validation of these tools, it is challenging to make strong recommendations about a suitable diagnostic method at present. This ultimately poses the question of whether the above work is an example of circular logic, a logical fallacy where the argument in question begins with what is trying to be proved by said argument- in other words, the diagnostic test identified PDA in this person because the person who underwent the diagnostic test has PDA.

We acknowledge that diagnostic overlap is not in itself unusual. The DSM-5 explicitly recognises that most diagnostic categories exist as continua and overlap with one another. Our concern is not that PDA overlaps with other conditions per se, but rather that the current evidence base has not demonstrated sufficient specificity or incremental validity to support PDA as a distinct and reliably identified diagnostic entity. The question of what is uniquely driving the PDA presentation, beyond constructs already captured by existing diagnoses, remains unanswered.A related consideration is the risk of prematurely classifying PDA as a 'profile of autism'. Prior to 2015, much of the PDA literature explicitly noted features that distinguished PDA from autism. The subsequent shift towards framing PDA within

the autism spectrum, rather than as a distinct phenomenon, may risk misattributing non-autistic presentations as autism and could inadvertently compromise the integrity of autism as a diagnostic category. We believe these concerns are consistent with this review's conclusions regarding circular logic and inadequate validation of PDA diagnostic tools. A broader concern, beyond the scope of this review but relevant to its conclusions, is the potential for harm associated with premature application of the PDA label. Concerns have been raised regarding the stigmatising potential of the "pathological" descriptor, with reports of adverse educational and social consequences for children attributed with PDA (Woods, 2022). These concerns reinforce the importance of a rigorous, validated evidence base before widespread clinical adoption.

Lived experience accounts represent an important facet of the broader discussion surrounding PDA. Many such individuals prefer identity-first language (e.g., "PDAer"); this manuscript uses person-first language for consistency with much of the included literature, rather than as a normative stance. A recent phenomenological study explored the subjective experience of adults who self-identify with PDA, identifying themes of chronic stress, social masking and autonomy-seeking as central to participants' accounts (Kenny & Doyle, 2024). Whilst this work provides valuable qualitative insight, it shares a key methodological limitation with much of the quantitative literature reviewed here: participants were self-selecting and identification as having PDA was not independently verified. This underscores the need for future research to integrate lived experience perspectives alongside more rigorous diagnostic methodology, rather than in place of it.

A limitation of this review is the inclusion of only English articles, therefore obscuring literature on PDA outside of the English-speaking world. Secondly, the lack of uniformity in the methodologies and research designs across the literature poses challenges in drawing consistent and generalised conclusions. Additionally, the differing terminology for PDA in the literature complicates the integration of research findings. Lastly, there was a small sample size of 12 studies from which we were able to draw conclusions in this review. This is largely due to the lack of research into PDA, and partially due to the inclusion and exclusion criteria utilised in this review.

A further limitation is the exclusion of grey literature, which likely contributed to the omission of several potentially relevant tools and studies — for example, ADOS-2 PDA adapted scoring (Eaton & Weaver, 2020), the Coventry Grid Interview plus PDA (Eaton, 2018), and studies identified in scoping reviews such as (Haire et al., 2024). We acknowledge that our search did not systematically capture Eaton and Weaver (2020) due to its primary framing around ADOS-2 methodology rather than PDA diagnosis per se (Eaton & Weaver, 2020). Future reviews in this area should consider expanding eligibility criteria to include grey literature, given the extent to which PDA research exists outside traditional academic publishing. Additionally, this review did not identify studies specifically examining PDA in non-speaking individuals or those with intellectual disability, although limited literature exists in this area (Reilly et al., 2014). The absence of this population from the evidence base represents a significant gap, as existing tools may have limited applicability in these groups.

Conclusion

This review attempted to address the current utilisation of proposed tools to identify PDA in children, adolescents, and adults. It was found that there is inconsistency in the way PDA is identified across studies, with a substantial proportion of studies relying on subjective rather than objective measures. The suggestion of circular logic makes the ability to support a distinct diagnosis of PDA highly improbable at this stage.

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Data Availability All data relevant to the study are included in the article.

Declarations

Conflict of interest JAR reports a non-financial personal connection to the topic, as their child has previously been assigned a diagnosis of Pathological Demand Avoidance. This did not influence the methodology, analysis, or conclusions of this systematic review.

Ethical Approval Not applicable.

Patient Consent Not applicable.

Permission to Reproduce Material from Other Sources Not applicable.

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