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The educational experiences of autistic children with and without extreme demand avoidance behaviours

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ABSTRACT
Extreme demand avoidance (EDA) is increasingly described as part of the autism spectrum and is sometimes diagnosed as Pathological Demand Avoidance (PDA). Yet little is known, about the educational experiences of children with and without EDA behaviours. Using an online survey collecting both quantitative and qualitative data, 211 parents reported on the school experiences of their autistic children. 57 parents had a child with an additional diagnosis of PDA (AUT-PDA); 91 had a child with no diagnosis of PDA but, according to parent report, displayed EDA behaviours (AUT-EDA); and 63 had a child with neither a PDA diagnosis nor EDA behaviours (AUT). Results demonstrated that there were few group differences in terms of the frequency of failed school placements and exclusions. However, children in the AUT-EDA/-PDA groups had higher levels of behaviour that challenges, which were particularly high in those with a PDA diagnosis. There were no significant differences in school exclusions, but the fact that these occurred across all groups is of concern. Qualitative results suggested overwhelmingly negative school experiences for all groups but especially the AUT-EDA and AUT-PDA groups. Parents attributed such experiences to misunderstanding of their children's diagnoses and a lack of targeted support.

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Demand avoidance; autism; education; school exclusion

Over 20 years ago, Newson and Le Marechal (1998) identified what they considered to be a distinct subgroup of children who had been diagnosed with autism and/or pervasive developmental disorder but seemed to differ from the 'typical' presentations of these conditions in their apparent anxiety-driven avoidance of demands. These observations formed the basis of what is now sometimes described as extreme demand avoidance (EDA) or pathological demand avoidance (PDA), the defining feature of which is the continued avoidance of the ordinary demands of life (Christie 2007). A prevalence study conducted in the Faroe Islands (Gillberg et al. 2015) suggested that one in five autistic people may have PDA in childhood and that just under 0.2% of the population could be described as being autistic with PDA. These are tentative figures, however, as there is no consensus about how PDA should be identified.

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PDA is not included as a diagnostic category in the major diagnostic manuals (American Psychiatric Association 2013; World Health Organisation 2018) nor is it recognised – formally or informally – by many researchers, clinicians and autistic advocates (e.g. Green et al. 2018; Green 2020; Milton 2013; Moore 2020; Woods 2017, 2020). Green (2020) has expressed concern about the lack of empirical evidence for PDA as an 'entity' (Green 2020, 74) and the extent to which research and thinking in this area may be considered circular (see also Woods 2020). Gore Langton and Frederickson (2018) highlighted that this lack of recognition and understanding may lead to parents of those children who display behaviours associated with PDA (EDA behaviours) to be subject to similar judgements and blame that parents of autistic children have historically experienced (Courcy and des Rivières 2017; Langan 2011; Silverman and Brosco 2007; Waltz 2015; Wolff 2004).

There is also no consensus about PDA's relationship to autism (Gillberg et al. 2015). Newson, Le Marechal, and David (2003) originally proposed PDA as separate category within the Pervasive Developmental Disorders, distinct from autism. However, Christie (2007) highlighted the way in which changes to our understanding of autism and Pervasive Developmental Disorders have led to more people viewing Pervasive Developmental Disorders and autism as synonymous and, as such, have started to view PDA as being part of the autistic spectrum. Indeed, the PDA Society (n.d.) state that PDA should not be considered a standalone diagnosis, but a profile seen in some autistic individuals. Nevertheless, Malik and Baird (2018) identify overlaps between traits typically associated with PDA and those associated with many other conditions such as anxiety and mood disorders, conduct disorders and oppositional defiance disorder, raising more questions about the extent to which PDA should be viewed as associated solely with autism.

Despite this lack of formal recognition and the confusion about the relationship between PDA and autism, increasing numbers of families and local authorities, especially in the United Kingdom (UK), are requesting a diagnosis of PDA – either in addition to, or instead of, a diagnosis of autism (Green et al. 2018). Indeed, some parents and clinicians stress that it can be difficult to access appropriate educational support without a PDA diagnosis (Sherwin 2015). Gore Langton and Frederickson (2018) reported that some parents felt that 'the identification of PDA was the route to the professional being able to suggest appropriate management strategies' for daily living (22). It is important to note that 'appropriate' support rather than additional support was the focus here, with Gore Langton and Frederickson (2018) highlighting that different strategies are recommended to support those with PDA than are recommended to support autistic students more generally.

The importance of using these different strategies, which include allowing the child increased autonomy and avoiding rewards and sanctions, has been emphasised by some academics and practitioners (Christie 2007; Christie et al. 2012, Fidler and Christie 2019, Newson, Le Marechal, and David 2003; Ozsivadjian 2020). Others feel there is little empirical evidence for the use of such strategies (Green 2020), and still others argue that they are likely to be useful for many autistic people, not just those described as having PDA (Woods 2019). Notwithstanding, the discussion highlights the importance of considering the interactions between children and their environment rather than approaching all demand-related difficulties as being due to intrinsic (within-child) factors (Green et al. 2018; Green 2020; Ozsivadjian 2020).

Although the PDA Society (2018) suggests that school difficulties faced by children with EDA behaviours may be more pronounced than those experienced by children without EDA behaviours there is currently limited research to support this claim. In one of the few peer-reviewed studies on this topic, Gore Langton and Frederickson (2016) surveyed 49 parents of children with PDA who reported that their children faced substantial challenges at school. These challenges included high rates of school exclusion, placement breakdown (where pupils move schools due to their educational needs or because they have been excluded) and what Gore Langton and Frederickson (2016) define as 'problem behaviours' (255) (e.g. refusing to attend or comply; leaving the classroom or school site; hurting themselves, staff or other pupils). Some of these behaviours could be challenging for teachers (e.g. refusing to attend or comply and hurting staff) whereas others may impact on other children (e.g. hurting other pupils) and some have a direct impact on the children themselves (e.g. hurting self).

Gore Langton and Frederickson's (2016) study did not distinguish, however, between children with EDA behaviours with or without a formal PDA diagnosis. This distinction is important as there may be differences in the ways that professionals respond to the needs of children with a formal PDA diagnosis which, in turn, may affect their educational experiences. Their study also lacked an autistic comparison group (those without EDA behaviours). Thus, it is unclear whether children with EDA behaviours (with or without a formal diagnosis of PDA) are at particular risk of negative school experiences compared to children with an autism diagnosis alone.

The current study

The present study sought to extend Gore Langton and Frederickson's (2016) work by directly comparing the educational experiences of autistic children with and without EDA behaviours, and with and without a PDA diagnosis. To achieve this aim, we developed an online survey for parents and carers of autistic children, asking them to provide information about their children's diagnoses and to complete questionnaires measuring their children's autistic features, behaviour that challenges,[1] and current/previous school experiences. Parents were specifically asked whether their child had a formal diagnosis of PDA. They were also asked to complete the Extreme Demand Avoidance Questionnaire (EDA-Q) (O'Nions et al. 2014) to measure the degree of EDA behaviours. In so doing, we explored (a) within-child factors by measuring their autistic features and PDA behaviours, and (b) the interactions between the child and their environment by analysing parent comments about their educational environment and experiences.

Method

Participants

An online survey was advertised to parents and carers of autistic children and young people in the UK, via the websites and online forums of local and national autism charities, as well as the PDA Society. To be eligible to participate, respondents needed to reside in the UK and have a school-aged child (4-18 years) with an autism diagnosis. In total, 273 parents completed the survey, of which 62 (23%) were excluded because they either had a child over 18 years ($n = 4$, 1%) or under 4 years ($n = 1$, >1%); lived outside the UK ($n = 1$, >1%), or reported that their child did not have an autism diagnosis ($n = 56$, 21%).

The remaining 211 respondents were included in the analysis; they comprised 200 biological parents, seven adoptive parents and four grandparents. Most were female ($n = 204$, 97%), with a mean age of 44 years (range = 27–80 yrs). Full demographics are presented in Table 1.

Group allocation

On the basis of parental information regarding PDA diagnosis and level of EDA behaviours (see Measures below), respondents were divided into three groups: (1) an autism (AUT) group ($n = 63$; 30%), i.e. those with children who had an autism diagnosis but no PDA diagnosis *and* who scored below the threshold for EDA behaviours on the EDA-Q (O'Nions et al. 2014); (2) an AUT-EDA group ($n = 91$, 43%), i.e. those with children who had an autism diagnosis but no PDA diagnosis *and* who scored above threshold on the EDA-Q; (3) an AUT-PDA group ($n = 57$, 27%), i.e. parents with children who had both an autism diagnosis *and* a PDA diagnosis. As expected, most children in the latter group scored above threshold on the EDA-Q (Mdn=60.00, range = 22–74). The EDA-Q scores of ten children, however, fell below the threshold (Mdn=44.00, range = 22–46). Given that meeting threshold on the EDA-Q is not required for a PDA diagnosis, we have included these ten children in the PDA group. We also conducted analyses excluding these ten children to examine their influence on the results.

Measures

The online survey contained six parts. *Parts 1 and 2* collected demographic information about respondents and their children, respectively. *Part 3* included ten items assessing parental views on their children's current and previous educational experiences (taken directly from the *Educational Experiences Questionnaire, EE-Q*; Gore Langton and Frederickson 2016). These focussed on:

Table 1. Background data on parent respondents from the AUT, AUT-EDA and AUT-PDA groups.

		Group		
		AUT ($n = 63$)	AUT-EDA ($n = 91$)	AUT-PDA ($n = 57$)
Gender	Female	62 (98%)	88 (97%)	54 (95%)
	Male	1 (2%)	3 (3%)	3 (5%)
Age (in years)	Median	44.5	43.2	43.8
	Range	30.1–65.9	29.8–80.2	27.4–69.2
Relationship to child	Biological parent	60 (95%)	87 (96%)	53 (93%)
	Adoptive parent	2 (3%)	4 (4%)	1 (2%)
	Grandparent	1 (2%)	0	3 (5%)

(a) number of school exclusions, both fixed term (i.e. exclusion for a fixed period of time due to perceived behavioural problems and formally recorded in school and student records), and informal (i.e. parents asked to collect their child from school for reasons other than illness; not recorded formally as an exclusion);
(b) behaviour that challenges (e.g. refusing to attend or comply; leaving the classroom or school site; hurting themselves, staff or other pupils) displayed by the children during what parents felt was the most difficult term that their child has ever had at school; and
(c) level of support provided by different educational professionals, and how helpful that support was perceived to be (using an open text box).

Part 4 asked parents to complete two standardised questionnaires on their child's behaviour. First, in the 26-item *Extreme Demand Avoidance Questionnaire (EDA-Q)* (O'Nions et al. 2014), they rated the likelihood of their child displaying each EDA behaviour on a four-point Likert scale, ranging from 'not true' (score of 0) to 'very true' (score of 3) (note: some items are reverse coded). Higher scores reflect higher levels of EDA behaviours. Scores ≥ 50 for 5- to 11-year-olds, or ≥ 45 for 12- to 17-year-olds are described by O'Nions et al. (2014) as being indicative of PDA. The EDA-Q has good levels of sensitivity (.80) and specificity (.85), and high internal consistency (Cronbach's $\alpha = .93$; O'Nions et al. 2014); in the current study Cronbach's $\alpha = 0.90$.

Second, following Gore Langton and Frederickson (2016), parents completed the 25-item *Strengths and Difficulties Questionnaire (SDQ)* (Goodman 1997), which assessed children's emotional and behavioural difficulties more generally. Parents rated each item on a three-point scale, ranging from 'not true' (score of 0) to 'certainly true' (score of 2) (note: again, some items are reverse coded). Higher scores reflect greater emotional and behavioural difficulties (0-13 = 'typical', 14-16 = 'borderline' and ≥17 = 'atypical'). This scale has previously been used by researchers to explore behaviours associated with PDA (Gore Langton and Frederickson 2016; O'Nions et al. 2014). The scale's reliability with autistic adolescents has been estimated as moderate, with Cronbach's α ranging from 0.53–0.70 (Simonoff, Jones, and Baird 2013). In the current study, reliability estimates were also moderate ($\alpha>0.69$ for all subscales, except parent-rated peer problems, $\alpha = 0.59$).

Part 5 asked parents to report on their child's autistic features using the 65-item *Social Responsiveness Scale–2 (SRS-2)* (Constantino and Gruber 2012). Parents rated their children's behaviour on a four-point scale, ranging from 'not true' (score of 0) to 'almost always true' (score of 3). Certain items are reverse coded and then scores are summed to yield a total score. Higher scores reflect greater severity, with T scores ≥66 indicative of an autism profile, and T-scores ≥76 indicative of 'severe' difficulties associated with a clinical diagnosis of autism. Internal consistency estimates for the SRS-2 are high ($\alpha>0.94$) (Bruni 2014; Nelson et al. 2016); in the current study $\alpha = 0.93$.

Finally, in *Part 6*, parents were invited to share 'anything else you would like to tell us about your child or their experience of education' in an open text box.

Procedure

Ethical approval was obtained via the Department of Psychology and Human Development at UCL Institute of Education. Responses to the online survey, powered by SurveyMonkey, were collected over six months (January to June 2017).

Data analysis

Quantitative data. First, we sought to compare the behavioural characteristics of children in the three groups. Due to non-normality of distributions, the data did not meet the required assumptions for parametric tests, hence Kruskall-Wallis tests were used for group comparisons (AUT, AUT-EDA, AUT-PDA) on key demographic variables, scores on the EDA-Q, SDQ and SRS-2, and educational experiences. Due to the number of questionnaires used and resulting number of comparisons, a cautious p level of 0.01 was set to reduce the possibility of Type 1 errors, however we also highlight and discuss (tentatively) instances where p <.05. We predicted that higher scores on the EDA-Q would be linked to higher scores on the SDQ, indicating greater emotional and behavioural challenges for children with elevated EDA behaviours. There were no clear predictions regarding the SRS-2, given the ambiguity within the literature about the extent to which PDA is part of the autism spectrum (Gillberg et al. 2015).

Second, we compared children's educational experiences across the three groups. These included frequencies of failed placements, formal exclusions, informal exclusions (which are illegal in the UK and yet still widely used; Atkinson 2013), and the extent of behaviour that challenges during the children's most difficult term at school. We predicted that, compared with children in the AUT group, those with AUT-EDA and AUT-PDA would have poorer educational experiences, including significantly (i) more fixed-term and informal exclusions and (ii) greater levels of behaviour that challenges. We were also interested in the professional support they received and what aspects of this support were helpful. Because of a lack of previous research in this area, no predictions were made concerning potential differences between the AUT-EDA and AUT-PDA groups.

Qualitative data. Parents' views about professional support were analysed using content analysis (Mayring 2015), in which responses were divided into categories. Categories were not pre-defined but arose from the analysis of the data which was undertaken by one researcher (CT). Once the categories were established, the number of responses in each category was recorded.

We also sought to understand parents' views about their children's education. To this end, parents' responses in Part 6 were analysed by three authors (CT, LC, EP) using thematic analysis (Braun and Clarke 2006). CT, who led the analysis, is an educator specialising in supporting students who display traits associated with PDA. EP and LC are autism researchers who have not worked directly with children with PDA. An inductive approach was employed, whereby data were coded without reference to any pre-existing coding schemes or preconceptions. Initially, the authors independently familiarised themselves with the data, reading and re-reading the transcripts, and assigning codes to data extracts. They then conferred regularly to discuss preliminary codes, which were completed for each group separately. The authors liaised several times to review themes and subthemes, focusing on semantic (surface-level) features of the data, resolving discrepancies and deciding on the final definitions of themes and subthemes.

Results

Group profiles

Child characteristics. There were no significant differences between the three groups on key parent-reported background variables, including children's age, gender, reported use of language, and perceived level of cognitive ability (all p values $\geq .09$; see Table 2). As expected, given the group allocation criteria, there were significant group differences on the EDA-Q (see Table 3). Planned comparisons showed that the EDA-Q scores of the AUT group were significantly lower than those of the AUT-EDA and AUT-PDA groups (ps $<.001$). There were no significant differences in the latter two groups' EDA-Q scores ($p = 1.00$).

There were significant group differences on the SDQ (see Table 3). Planned comparisons indicated that children in the AUT group had lower SDQ scores, reflective of fewer

Table 2. Child characteristics in the AUT, AUT-EDA and AUT-PDA groups.

		Group			
		AUT ($n = 63$)	AUT-EDA ($n = 91$)	AUT-PDA ($n = 57$)	Group Comparison
Gender	Female	16 (25%)	27 (30%)	17 (30%)	$\chi^2(4, N = 211) = 1.08, p = .90$
	Male	46 (73%)	61 (67%)	39 (68%)	
	Other gender identity	1 (2%)	3 (3%)	1 (2%)	
Age (in years)	Mean (SD)	10.34 (3.70)	10.58 (3.56)	9.70 (2.88)	$F(2, 207) = 1.14, p = .32$
	Range	5–18	4–18	4–16	
Parent reported level of cognitive ability	Above average	23 (37%)	42 (46%)	28 (49%)	$\chi^2(6, N = 211) = 7.32, p = .30$
	Average	22 (35%)	30 (33%)	18 (32%)	
	Mild or moderate intellectual disability	12 (19%)	15 (16%)	11 (19%)	
	Severe intellectual disability	6 (10%)	4 (4%)	0	
Parent reported use of spoken language	Completely typical	14 (22%)	22 (24%)	21 (37%)	$\chi^2(6, N = 211) = 10.84, p = .09$
	Difficulties with pragmatic or social language	26 (41%)	43 (47%)	29 (51%)	
	Difficulties expressing needs using spoken language	10 (16%)	9 (10%)	3 (5%)	
	Other[a]	13 (21%)	17 (19%)	4 (7%)	
Parent reported co-occurring diagnoses	ADHD[b]	13 (21%)	28 (31%)	23 (40%)	
	Dyslexia	3 (5%)	6 (7%)	3 (5%)	
	Dyspraxia	9 (14%)	12 (13%)	6 (11%)	
	Oppositional Defiance Disorder	1 (2%)	8 (9%)	3 (5%)	
	Conduct Disorder	0	2 (2%)	0	
	Anxiety	12 (19%)	23 (25%)	9 (16%)	
	Social, Emotional, Mental Health Difficulties	6 (10%)	21 (23%)	8 (14%)	
	Other[c]	12 (19%)	16 (18%)	6 (11%)	

Notes: [a] Examples of descriptions of language use listed in the 'other' category included selective mutism, using overly formal language and using language that was not age appropriate; [b] Attention Deficit Hyperactivity Disorder; [c] Examples of diagnoses listed in the 'other' category included Sensory Processing Disorder, attachment disorder, selective mutism and post-traumatic stress disorder. Due to rounding, some total percentages exceed and some fall below 100%.

Table 3. Behavioural characteristics of the AUT, AUT-EDA and AUT-PDA groups.

		Group			
		AUT Median Range	AUT-EDA Median Range	AUT-PDA Median Range	Group Differences
EDA-Q[a] Total Score	*n*	63	91	57	$H(2) = 120.28$ $p < .001$
	Median	35.00	59.00	60.00	AUT < AUT-EDA = AUT-PDA
	Range	6–49	45–75	22–74	
SDQ[b] Total Difficulties score	*n*	62[d]	91	57	$H(2) = 32.00$ $p < .001$
	Median	22.00	26.00	26.00	AUT < AUT-EDA = AUT-PDA
	Range	8–33	16–37	15–37	
SRS-2[c] T-Score	*n*	63	91	57	$H(2) = 15.76$ $p < .001$
	Median	82.00	88.00	84.00	AUT = AUT-PDA < AUT-EDA
	Range	57–90	62–90	51–90	

Notes: [a]EDA-Q = Extreme Demand Avoidance Questionnaire (O'Nions et al. 2014); [b]SDQ = Strengths and Difficulties Questionnaire (Goodman 1997); [c]SRS-2 = Social Responsiveness Scale – 2nd Edition (Constantino and Gruber 2012); [d]One participant did not complete this section.

emotional and behavioural difficulties, than children in the other two groups (*ps*<.001). There was no significant difference in the SDQ scores of the AUT-EDA and AUT-PDA groups ($p = 1.00$).

Significant group differences were also observed on the SRS-2. Post-hoc analyses showed that the AUT-EDA group had significantly higher scores, reflecting greater autistic features, than the AUT group ($p<.001$), but this did not reach significance in the AUT-PDA ($p = .03$) group. There was no significant difference between the SRS-2 scores of the children in the AUT and AUT-PDA groups ($p = .89$).

Educational placements

There were no significant group differences regarding type of current school placement, reported level of formal educational support received at school (including whether they had a statement of Special Educational Needs or an Education Health and Care Plan; see Table 4), or whether school placement was mainstream without support or included additional support (e.g. with a support assistant) (*ps*>.20).

Exclusions. The fixed term and informal exclusions experienced by children in each group are reported in Table 5. Contrary to expectations, there were no group differences in the frequency of fixed-term exclusions ($H(2) = 5.77$ $p = .06$, $n = 205$). Group differences in the frequency of informal exclusions failed to reach the specified level of significance ($H(2) = 7.20$, $p = .03$, $n = 187$).

Behaviour that challenges. As predicted, the AUT group was generally reported to display fewer specific behavioural difficulties than the other two groups (see Table 6). One exception to this pattern, however, related to hurting or attempting to hurt other pupils and staff: parents reported similar rates of these behaviours among children in the AUT group and those in the AUT-EDA group. On most other variables, parents in the AUT-PDA group reported higher levels of behaviour that challenges than those in the AUT-EDA group who in turn reported higher levels of such behaviour than those in the AUT group. The exceptions here were refusal to attend and hurting or attempting to hurt themselves (where there were no significant differences between the AUT-EDA and AUT-PDA groups).

Table 4. Details on the children's educational placements in the AUT, AUT-EDA and AUT-PDA groups.

		Group			
		AUT ($n = 63$)	AUT-EDA ($n = 87$)	AUT-PDA ($n = 55$)	
Region of the UK in which the child was educated	North of England	9 (14%)	15 (17%)	5 (9%)	
	East of England	13 (21%)	14 (16%)	9 (16%)	
	Midlands	9 (14%)	18 (21%)	11 (20%)	
	South of England	32 (51%)	34 (39%)	26 (47%)	
	Scotland	0	3 (3%)	4 (7%)	
	Wales	0	3 (3%)	0	
		AUT ($n = 63$)	EDA ($n = 91$)	PDA ($n = 57$)	Group Comparisons
Type of education provision	Mainstream School No additional support	21 (33%)	21 (23%)	7 (12%)	$\chi^2(20, N = 211) = 23.46, p = .27$
	Mainstream class with a support assistant	16 (25%)	21 (23%)	12 (21%)	
	Mainstream school with an autism resource base	3 (5%)	2 (2%)	5 (9%)	
	Mainstream school with a non-autism specialist resource base	1 (2%)	4 (4%)	1 (2%)	
	Special needs or autism resource base in general special school	1 (2%)	2 (2%)	0 (0%)	
	General special school	6 (10%)	4 (4%)	6 (11%)	
	Autism special school	7 (11%)	8 (9%)	6 (11%)	
	Currently not in education	1 (2%)	5 (5%)	4 (7%)	
	At home with no professional support	4 (6%)	6 (7%)	6 (11%)	
	At home with professionals who come into the home	1 (2%)	3 (3%)	2 (4%)	
	Other	2 (3%)	15 (17%)	8 (14%)	
Nature of formal educational support	An EHCP[a]	27 (43%)	42 (46%)	29 (51%)	$\chi^2(10, N = 211) = 4.82, p = .90$
	A Statement of SEN[b]	7 (11%)	11 (12%)	9 (16%)	
	School Action[c]	2 (3%)	1 (1%)	1 (2%)	
	School Action Plus[d]	5 (8%)	6 (7%)	4 (7%)	
	None of the above	19 (30%)	27 (30%)	10 (18%)	
	Unknown	3 (5%)	4 (4%)	4 (7%)	

Notes: [a]Education, Health and Care Plan – a legal document issued by Local Authorities in the UK, which identifies a child or young person's additional needs and the support required to meet those needs; [b]A statement of special educational needs is a legal document issued by Local Authorities in the UK until 2014 and still available in Wales. It outlines the provision needed to meet a child or young person's special educational needs; [c]School Action support is support provided within a mainstream UK school to meet children's special educational needs without additional funding or support from the Local Authority; [d]At School Action Plus level, support is still provided by the school but specialist advice is sought from the Local Authority (e.g. from a Local Authority Specialist Teacher). Due to rounding, some total percentages fall below 100%.

Supplementary analyses excluding the ten children in the PDA group who did not meet threshold on the EDA-Q revealed an identical pattern of results to those reported above.[2]

Professional support

Results of the content analysis on parents' experiences of professional support for their child are reported in Table 7. It is noteworthy that many parents ($n = 25$) were unable to identify a helpful professional and instead described a lack of professional support. That said, access to diagnosis was the most common comment made about the helpfulness of

Table 5. Information ahout the children's experiences of exclusion for the AUT, AUT-EDA and AUT-PDA groups (note: not all participants provided this information).

	Group		
	AUT	AUT-EDA	AUT-PDA
Informal exclusions (*n*, %)	21 (43%)	48 (41%)	35 (67%)
Fixed term exclusions (*n*, %)	12 (20%)	30 (34%)	22 (40%)

professionals' involvement ($n = 49$), and this was particularly true for the AUT-EDA ($n = 21$) and AUT-PDA ($n = 14$) groups. Understanding and helping others to understand EDA behaviours ($n = 40$), and the provision of practical strategies ($n = 38$), were the second and third most common comments raised, respectively. The provision of practical strategies was particularly important for the AUT group ($n = 18$).

Qualitative analysis

Analyses of the open-ended responses revealed that parents – across all groups – described predominantly negative school experiences for their children, such as 'a rollercoaster ride through education' (AUT group). We identified five themes (see Figure 1), that were similar across all groups (AUT, AUT-EDA, AUT-PDA). Whilst the themes are presented for the entire sample, we note below any instances of group differences.

Being misunderstood is a challenge for children* and *parents. Parents perceived their children's negative educational experiences to be caused, at least in part, by professionals'

Table 6. Information about the children's behaviour that challenges in their most difficult term at school (as identified by parents), for the AUT, AUT-EDA and AUT-PDA groups.[a]

	Group			
	AUT $n = 63$ Median (Range)	AUT-EDA $n = 91$ Median (Range)	AUT-PDA $n = 55$ Median (Range)	Group Differences
Refusal to attend	2 (0-4)	3 (0-4)	3 (0-4)	$H(2) = 18.32, p < .001$ AUT < AUT-EDA = AUT-PDA
Refusal to comply	2 (0-4)	3 (0-4)	3 (0-4)	$H(2) = 23.52, p < .001$ AUT < AUT-EDA < AUT-PDA
Hurting or attempting to hurt self	1 (0-4)	2 (0-4)	2 (0-4)	$H(2) = 15.17, p = .001$ AUT < AUT-EDA = AUT-PDA
Hurting or attempting to hurt pupils	1 (0-4)	1 (0-4)	2 (0-4)	$H(2) = 13.99, p = .001$ AUT = AUT-EDA < AUT-PDA
Hurting or attempting to hurt staff	0 (0-4)	0 (0-4)	2 (0-4)	$H(2) = 17.81, p < .001$ AUT = AUT-EDA < AUT-PDA
Leaving or attempting to leave the classroom	1 (0-4)	3 (0-4)	3 (0-4)	$H(2) = 24.30, p = <.001$ AUT < AUT-EDA < AUT-PDA
Leaving or attempting to leave the school site	0 (0-3)	0 (0-4)	2 (0-4)	$H(2) = 33.86, p < .001$ AUT < AUT-EDA < AUT-PDA

[a] Parents rated their child's behaviour on a Likert scale ranging from 0 = Never to 4 = Always.

Table 7. Information about the support from professionals that parents in the AUT, AUT-EDA and AUT-PDA groups found most helpful. The three most commonly reported professionals are shown here. More detail is available in supplementary material.

	Group				
Category	AUT	AUT-EDA	AUT-PDA	Total	Illustrative Quote
Access to diagnosis	14	22	14	49	'The clinical psychologist ensured that my child received the correct diagnosis' (AUT-EDA)
Understanding and helping others understand EDA behaviours	12	17	11	40	'SALT was understanding and gave me an insight into why things happen.' (AUT)
Practical strategies	18	10	10	38	'The educational psychologist told the school about helpful strategies' (AUT)

lack of understanding of autism and, in some cases, PDA: 'We are currently very restricted in terms of accessing basic services due to chronic lack of PDA understanding (and ASD!)' (AUT-EDA). In the few instances in which parents reported a positive experience, they felt their child was understood by school staff: 'School have got the measure of him and support him brilliantly' (AUT).

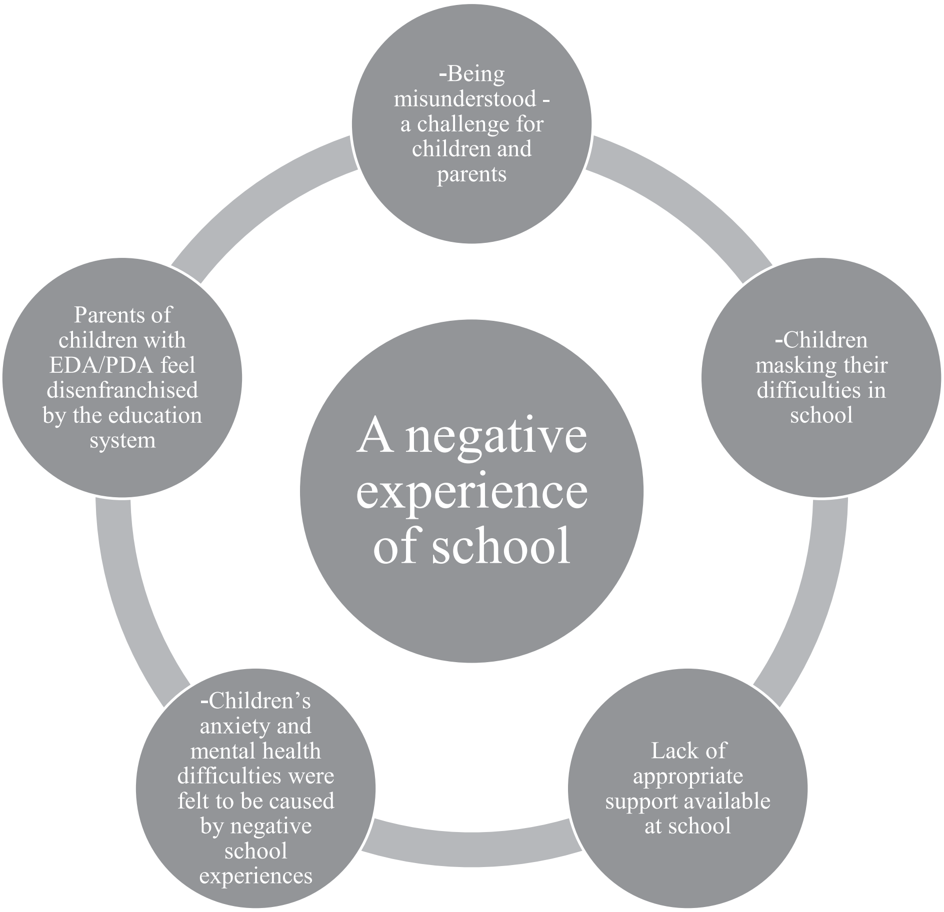

Figure 1. Themes identified in parents' responses to the open survey question.

Parents of children with EDA behaviours (with and without a diagnosis of PDA) felt that the schools' misunderstandings were attributable to their children's unusual presentation: 'Because he doesn't look or behave like a 'typical' autistic child, the school have struggled to accept that his behaviour is not deliberate and that his reactions are due to anxiety, not disobedience'. Parents also reported that teachers did not necessarily 'believe' in the existence of PDA (AUT-EDA).

For parents whose children displayed elevated levels of demand avoidance (AUT-EDA and AUT-PDA groups), being misunderstood took on a different meaning. Parents described how school staff 'tried strategies that work with many autistic children but they don't work with my child' (AUT-EDA). Another parent described the contrast between the two approaches: 'When his school tried using strategies that help children with autism, things got worse, anxiety increased and he ended up out of school (signed off with anxiety). Now PDA strategies and support are being used, he is thriving in a large mainstream school' (AUT-EDA). Indeed, many parents of children in the AUT-EDA and AUT-PDA groups explained how they, themselves, were often made to feel at fault for their children's behaviour, 'like a criminal and a liar by the school and the education system' (AUT-EDA). This apparent parent-blaming caused tensions between parents and the school: 'School number 4 decided to prosecute me instead of helping us' (AUT-EDA).

Children masking their difficulties in school. Across all groups, some parents felt that the misunderstanding and mistrust of parents by school staff were rooted in their child's ability to 'mask her difficulties in school. School do not see her difficulties cause her anxiety and that could be the cause of the majority of meltdowns after school. They say it's home but she spends more time in school than with us' (AUT-EDA). Masking was also believed to be the cause of some children's needs not being recognised by the school: 'My daughter totally masked her behaviour at school and right up until the first day she didn't attend was described as a model pupil. They didn't understand or believe that she was having often violent meltdowns at home on a nightly basis' (AUT-EDA).

Parents also described how this masking took its toll on the children ('my daughter has developed some excellent masking strategies but they drain her of cognitive, social and emotional energy'; AUT) and could have very serious consequences for their mental health ('Rapid descent into depression, self-harm and suicidal behaviour at start of year 9. Had been masking for many years'; AUT-PDA). This masking seemed to lead to 'increasing difficulties before/after school' (AUT-EDA), often resulting in overload ('He masks his emotions in school but then has overloads at home due to school'; AUT-EDA) and behaviour that challenges ('My child tries very hard to fit in at school with her peers, almost obsessively so. This results in exhaustion and anxiety at home, and that in turns leads to meltdowns and/or overly rigid or odd behaviour at home, but not at school'; AUT).

Lack of appropriate support available at school. Parents described the 'constant battle to get support at school' (AUT-PDA), and the 'very limited support provided, just enough to make it through the school day but not enough to help with specific areas of difficulty' (AUT-EDA). Parents provided many potential reasons for this lack of support, including academic achievement ('because he is achieving reasonably well academically there seems to be very little support available to help him'; AUT), 'staff shortages' (AUT-PDA), and a lack of resources ('school admit struggling but have no more additional resources'; AUT-PDA). Even if several hours of support were provided, parents reported that this support did not necessarily meet their children's needs: 'Coping in mainstream even with 32 hours of support is a real struggle most days and school don't always get it and are not flexible with their approach' (AUT-PDA).

Children's anxiety and mental health difficulties were felt to be caused by negative school experiences. Parents described how their children's mental health issues often resulted from 'inappropriate, unsupportive early [school] experience[s]' and caused 'lasting trauma' (AUT-EDA). In response to these negative experiences, some parents reported home educating their children, which they felt reduced anxiety: 'School did not suit him. He is much happier out of it. All the stress of having to deal with the situations gone. Can now concentrate on learning and living' (AUT). Others echoed this view, suggesting that 'there has been huge progress in some areas of her development. Her anxiety issues are greatly reduced and so she is more able to complete tasks and concentrate. School was completely wrong for her, home ed is amazing!' (AUT-EDA).

Educators needing to be flexible in their approach. Some parents of children in the AUT-EDA and AUT-PDA groups questioned whether 'education' in any traditional way or sense will ever 'fit' my son. Even in a specialist school who understand his complex presentation … everything is still too rigid for him to relax and (mentally/physically) be in a place ready for learning' (AUT-PDA).

Parents reported some encouraging sentiments, however. For example, some parents of children with a PDA diagnosis felt that their children were able to be engaged in education with the right approach: 'The mainstream school has had to be very flexible to ensure she keeps attending, and they have offered 'fun' sessions to keep her interested' (AUT-PDA). A greater level of understanding was often the difference between a positive educational experience and a negative one: 'Her education has been a very varied experience depending on the people who have been around her and their understanding and willingness to support us' (AUT-PDA).

Discussion

To our knowledge, this is the first study to examine the educational experiences of autistic children with and without elevated EDA behaviours, including those with and without a PDA diagnosis. There were clear parallels in the educational experiences of the AUT, AUT-EDA and AUT-PDA groups, with all reporting overwhelmingly negative school experiences. Notwithstanding these similarities, there were subtle group differences. Quantitatively, these were related primarily to behaviour that challenges. Qualitatively, these were associated with parents' attributions for their children's negative school experiences.

Autistic children with an additional PDA diagnosis appeared to be having a more difficult educational experience than those without the diagnosis, even when they displayed similar levels of EDA behaviours (as measured by the EDA-Q). According to their parents, the AUT-PDA group displayed more behaviour that challenges during their most difficult term at school than autistic children without a PDA diagnosis (irrespective of their levels of EDA behaviours). Stuart et al. (2020) identified behaviour that challenges such as aggression, as a 'last resort' behavioural response to uncertainty. It is possible that autistic children with an additional PDA diagnosis are responding with aggression when other attempts to reduce uncertainty and control their environment have failed.

While group differences regarding reported exclusions did not reach significance, the high number of fixed term exclusions and the finding that a total of 104 children had been informally excluded from school, is very concerning. Although informal exclusions are not unusual (Atkinson 2013; Brede et al. 2017; Mccluskey 2015; Watling 2004), they are illegal in the UK (Deparment for Education, DfE 2012). The Department for Education (DfE) in the UK also emphasises that it is unlawful to exclude a child from school due to their special educational needs and that schools have a duty under the 2010 Equality Act to make reasonable adjustments to enable students to access schooling (DfE 2012). Nevertheless, disproportionate numbers of pupils with special educational needs are excluded from school (Brede et al. 2017; DfE 2015; Mccluskey et al. 2015; Sproston, Sedgewick, and Crane 2017), including high numbers of autistic students (Brede et al. 2017). Exclusion from school has been found to be linked to marginalisation (Mccluskey et al. 2015) and disrupted education, which can exacerbate existing learning difficulties (Pirrie et al. 2011) as well as leading to subsequent social exclusion, unemployment, mental health difficulties and incarceration (Gill, Quilter-Pinner, and Swift 2017). As such, the higher rates of informal exclusion of students with a PDA diagnosis have the potential to lead to negative outcomes for these children, not just throughout their education but throughout their life.

It should also be noted that children with an additional PDA diagnosis (the AUT-PDA group) were not alone in experiencing difficulties at school. Parents of those with EDA behaviours (the AUT-EDA group) also reported considerable difficulties. The overwhelmingly negative school experiences reported by the parents of children with EDA behaviours and/or a PDA diagnosis are consistent with existing research in this area. Gore Langton and Frederickson (2016) found that parents of children with PDA reported their children to experience high levels of school exclusions and failed placements, as well as high levels of behaviour that challenges during their most difficult term at school. There have been suggestions that the school difficulties faced by children with EDA are more pronounced than those faced by autistic children without EDA behaviours (PDA Society 2018). The current findings provide the first empirical support for this claim.

Parents' qualitative responses indicated several potential reasons for this pattern. It is important to note that many of these potential factors leading to a negative school experience are factors external to the child and centre instead on the practice and understanding of those around them, particularly the education professionals with whom they interact. Green et al. (2018), Woods (2019) and Ozsivadjian (2020) emphasise the importance of considering the transactional relationship between children and their environment and several aspects of the qualitative findings provide support for this emphasis. First, many parents felt that their children were misunderstood by school staff. A lack of teacher awareness of hidden conditions and disabilities has been raised in the literature with regard to a number of different needs including epilepsy (Bishop and Boag 2006), Type 1 diabetes (Fried et al. 2018), Attention Deficit Hyperactivity Disorder (ADHD) (Kos, Richdale, and Hay 2006) and paediatric brain injury (Linden et al. 2013). Brede et al. (2017) also highlight that the hidden nature of some conditions can lead to difficulties being misconstrued as behavioural issues.

Parents in our AUT-EDA and AUT-PDA groups reported that for them and their children, misunderstandings arose due to differences in their children's presentation, which did not fit the 'standard' profile of autistic children. Similar issues have been raised for other minority autistic groups, including girls. Moyse and Porter (2015) found that teachers were unaware of the hidden support needs of autistic girls, which often resulted in them being undersupported in school; Cridland et al. (2014) have also highlighted the need for greater awareness of the needs of autistic girls. These findings suggests that teacher awareness of the varied presentations of autism (including elevated EDA behaviours) may need to be improved, perhaps by adapting teacher training to ensure that teachers are better equipped to understand children's individual needs and to apply this knowledge in practice.

Second, parents reported their children masking their difficulties at school. Masking (or 'putting on my best normal'; Hull et al. 2017, 2591) is common among autistic children (Cook, Ogden, and Winstone 2017) and adults (Hull et al. 2017, 2020). Here, parents across all three groups reported that masking had a detrimental effect on children's mental health (see also Cage, Monaco, and Newell 2018; Cook, Ogden, and Winstone 2017; Lai et al. 2017). It is, therefore, imperative that children's hidden needs are understood both by educators and by the children themselves. Psychoeducation programmes such as PEGASUS (Gordon et al. 2015) may also support children and young people to better understand their diagnosis, particularly their profile of strengths and challenges.

Third, parents reported feeling misunderstood, and even blamed, for their children's difficulties by professionals. Historically, parent blame has been very much part of the discourse surrounding autism (Langan 2011; Silverman and Brosco 2007; Waltz 2015; Wolff 2004) and more recent research has reported that parents of autistic children can still feel blamed for their children's behaviour (e.g. Courcy and des Rivières 2017; Neely-Barnes et al. 2011; Waltz 2015). Gore Langton and Frederickson (2018) suggest that parents of children with EDA may experience similar judgements to those experienced by parents of autistic children before autism became more widely known and understood. The current data suggest that professionals need to work collaboratively with parents to ensure better understanding of children's complex needs (see also Charman et al. 2011). Specialist training for professionals in recognising and meeting autistic children's varying needs, may also go some way to remedying this issue.

Negative school experiences, across all groups, were reported to have profound consequences, particularly with respect to the children's mental health. Similar to Brede et al. (2017), many parents in the current study felt that elevated anxiety was a direct consequence of their children's negative school experiences. While our data cannot demonstrate a causal relationship between anxiety and negative school experiences, elevated anxiety is thought to be a key characteristic of autistic children with EDA behaviours (with or without a diagnosis of PDA; see Christie et al. 2012). As such, anxiety might mediate the relationship between EDA behaviours and children's negative school experiences.

While the data described in this paper cannot speak to the utility of PDA as a diagnostic 'label', the findings raise questions about the role the diagnosis plays in enabling school staff to understand and support students who display EDA behaviours. For example, when asked which professional had been the most helpful to them and why, parents (particularly those in the AUT-EDA and AUT-PDA groups) most frequently identified those individuals who had helped them to access a diagnosis for their child. This result concords with the findings of Gore Langton and Frederickson (2018), whose parents felt that their child's PDA diagnosis led to better support. Given the controversy that exists surrounding the use of PDA as a diagnostic label (Green et al. 2018, 2020; Milton 2013; Moore 2020; Woods 2017, 2020), an important next step in research will be to examine the extent to which a diagnosis of PDA is perceived as helpful to people and why.

Limitations. There are several limitations of this research. First, the study relied specifically on the views and perspectives of parents, rather than those of educators or, importantly, of children and young people themselves. This was particularly relevant for questions about behaviour that challenges, where parents were identifying the 'most difficult term' their children had experienced, an item taken directly from Gore Langton and Frederickson's (2016) study. Parents' perception of the most difficult school term may vary from that of the child or their teacher – or even between parents themselves. Caution is warranted when interpreting these particular findings from this questionnaire item. Second, whilst their negative experience of education is consistent with the literature in this area (Ashburner, Ziviani, and Rodger 2010; Brede et al. 2017; Green et al. 2005; Humphrey 2015; Humphrey and Symes 2010; Rowley et al. 2012), the current study, as with previous studies, involved a self-selecting sample. As such, parents whose children have had a more negative experience of education may have been more likely to complete the survey. Nevertheless, there were some respondents who reported having positive schooling experiences. Third, the cross-sectional nature of this study meant that it was not possible to establish causal relationships between EDA behaviours and educational experiences, nor was it possible to establish whether the anxiety reported by many parents was a consequence or a cause of children's negative school experiences. This is an important direction for future research. Fourth, the SDQ was used to measure children's emotional and behavioural difficulties in order to facilitate comparison with previous studies of children with EDA behaviours, but caution is warranted given the moderate reliability estimates in our samples. Finally, as we do not have a comprehensive overview of each child's educational and diagnostic history (or indeed any formal information on their diagnoses), it is not possible to assess to what extent the diagnosis of PDA has enabled, if at all, those children with elevated EDA behaviours to access the support that best meets their needs.

Conclusion

This study highlights the challenges autistic children experience during their education and the particular difficulties that are faced by those with EDA, especially with regard to behaviours that challenge. Further questions remain, however, about whether differential diagnosis can play a role in helping professionals better meet the distinct needs of individual autistic children (see Green et al. 2018).

Notes

1. We define behaviour that challenges as including: refusing to attend or comply; leaving the classroom or school site; and hurting themselves, staff or other pupils. While Gore Langton and Frederickson (2016) describe these as ‘problem behaviours’ (p.255), we have chosen to use the term behaviour that challenges as recommended by NICE (2018) guidelines, emphasising that while the behaviours may challenge others, they may be functional for the individual.
2. Given the fairly large sample, we also conducted supplementary analyses exploring the impact of gender on our results. There were few significant differences between boys, girls and those of other gender identities on most variables, although some differences were noted. First, in the AUT group, only boys experienced informal exclusions, $H(2) = 10.60$, $p = .005$. Second, boys in the AUT ($H\ (2) = 9.18$, $p = .01$) and AUT-EDA ($H\ (2) = 8.96$, $p = .01$) groups were more likely than girls and those of other gender identities to hurt or attempt to hurt other pupils.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Declaration of interest

One author (CT) provides training and consultancy to schools, colleges and families about supporting the needs of children and young people who display behaviours associated with extreme demand avoidance and volunteers with the PDA Society.

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