Exploring the presence of pathological demand avoidance in school aged children

by

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Abstract

This research studied the presence of PDA (an obsessional avoidance of life's ordinary demands along with high skills of social manipulation) in typically developing children and those diagnosed with autism, Attention Deficit Hyperactivity Disorder (ADHD) and/or anxiety disorders. Children with autism were hypothesized to have higher incidence of PDA than children without autism. Purposive sampling was used in participant recruitment. Findings should be understood within the indicated limitations. A sample of 78 participants responded to an on-line questionnaire that collected information on the presence of PDA. There was a statistically significant difference in the PDA scores for children with and without a clinical diagnosis (autism, ADHD, anxiety). Children diagnosed with autism had significantly different (higher) PDA scores than children without autism. No other comparisons were significant. The results support the hypothesis that children who have autism have more intense symptoms of PDA than those without autism.

Keywords: Pathological Demand Avoidance; Autism Spectrum Disorder; Extreme Demand Avoidance Questionnaire

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List of Acronyms

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
DISCO	Diagnostic Instrument for Social Communication Disorders.
DSM-4	Diagnostic Statistical Manual-4
DSM-5	Diagnostic Statistical Manual-5
GAD	Generalized Anxiety Disorder
ICD-10	International Classification of Disease-10
PDDNOS	Pervasive Developmental Disorder Not Otherwise Specified

Glossary

EDA-Q	Extreme Demand Avoidance Questionnaire. Psychometric used to measure the presence of PDA
Facebook Groups	A place for group communication on Facebook where people share their common interests and express their opinion
PDA	Pathological Demand Avoidance. Hypothetical new component of the autism spectrum

Chapter 1.

Introduction

Defining the parameters of psychological diagnoses is a challenge within the psychological community. Many diagnoses could be described as moving targets in that they are constructed and then reconstructed. Furthermore, some diagnoses are accepted as part of our shared lexicon of mental illness while others are not. Philosopher Ian Hacking (1998, 2002) has explored the transient nature of mental illness, specifically how only certain diagnoses become part of our ontological framework. Hacking (1998) likens the process by which diagnoses are integrated into our collective consciousness to the way in which a biological organism grows to fulfill what he calls an ecological niche. This ecological niche is used as a metaphor to explain how some psychological constructs will only thrive given a certain set of circumstances, just as an organism will only thrive if suitable surroundings are available.

Hacking (1998) argues that for a diagnosis to gain popularity, four components must be present. First, the new diagnostic construct must adhere to the current taxonomy of illness or fit into what the community already understands about the nature of illness. Second, both professionals and lay people must acknowledge the construct. Third, appropriate cultural polarities must be present in contemporary society that frame the construct. Fourth, the diagnosis must operate in some sense as a mechanism of release. In other words, it must operate as an explanation of that individual's symptomology. Therefore, a diagnosis provides a certain relief when a framework for interpreting the behavior is provided.

The evolution of the autism spectrum provides a good contemporary example of Hacking's theory. The diagnosis of autism has a long and problematic history, starting with Kanner's initial report (1943) on the condition. Kanner defined autism as an innate condition that originates from within the individual, but he also hypothesized about the role played by the child's caregivers stating,

> One other fact stands out prominently. In the whole group there are very few really warmhearted fathers and mothers. For the most part, the parents and grandparents and collateral persons are strongly preoccupied with

> abstraction of scientific, literary or artistic nature. And limited in a genuine interest in people (p. 250).

Dr. Bruno Bettelheim was instrumental in perpetuating the idea of autism as a parenting disorder that stems from a lack of affection. Dr. Bruno Bettelheim was the director of the Sonia Shankman Orthogenic School for severely disturbed children near Chicago from the early 1940s until he retired in 1970. He wrote prolifically about the relationship between children and their parents, publishing such titles as *Empty Fortress* (1972) and *A good enough parent: A book on child rearing* (1988). Bettelheim was a highly controversial figure who, since his death, has been accused of a variety of offenses. In a biographical novel journalist Richard Pollack (1998) detailed Bettelheim's transgressions including faking his credentials, exaggerating data, plagiarism and physically abusing the patients under his care.

Nevertheless, Bettelheim was arguably one of the most prominent figures in autism research. Bettelheim (1972) focused primarily on the female parent suggesting that it was a lack of maternal affection that led to a child developing autism and autism related symptoms. In his book *Empty Fortress* (1972) Bettelheim advocated for a 'parentectomy' and maintained that autism was a parenting disorder.

In contrast to Bettelheim's prominence, the work of Dr. Hans Asperger (1991) went mostly unnoticed during his lifetime. Both men, however, were considered highly controversial. Asperger was a pediatrician with an intense interest in special education, particularly the condition he called 'autistic psychopathy'. Like Bettelheim, he was trained in the traditional Viennese school of psychology. However, as Herwig Czech details in his 2018 paper, Asperger was not a Freudian but a Eugenicist. After his death it was revealed that Asperger worked closely with the Nazis and provided some of his own patients to the regime for experiments, some of which included euthanasia (Czech, 2018).

Some of Asperger's actions showed a callous disregard for people with learning differences, yet at other times his writings showed a man who recognized that his patients had intrinsic value. It was Asperger who laid the groundwork for recognizing autism as a heterogeneous spectrum disorder. In his most significant study (1991) he stated,

> This disturbance results in severe and characteristic difficulties of social integration. In many cases the social problems are so profound that they overshadow everything else. In some cases, however, the problems are compensated by a high level of original thought and experience. This can often lead to exceptional achievements in later life (Asperger, 1991, p.38).

Asperger described his patients as 'little professors' but also noted that they displayed a lack of empathy and little ability to form friendships. He found that his students would almost exclusively engage in one-sided conversation and were intensely absorbed in a limited amount of special interests (Asperger, 1991). Asperger broke new ground by describing autism as a highly nuanced and variable syndrome with a wide range of behavioral manifestations that extended well beyond the initial description by Kanner (1943). His work on Asperger's syndrome and the autism spectrum as a heterogeneous disorder was advanced by other researchers such as Lorna Wing (1981, 1991, 1997).

Not all new ideas regarding autism have been constructive and some have been deeply problematic. Andrew Wakefield's now rigorously discredited paper (Wakefield et al., 1998) erroneously linked vaccinations to the acquisition of a pervasive developmental disorder. Although Wakefield's paper was officially retracted in 2010, a Time magazine article written by Dr. Quick, a senior fellow at Harvard Medical School and Heidi Larson, Director of the Vaccine Confidence Project, stated that it took the vaccination rate in the United Kingdom almost two decades to recover from Wakefield's fraudulent research (Quick & Larson, 2018).

Thus, the history of autism as a psychological concept shows the body of knowledge evolving. This process illustrates what Hacking (1998) describes as the transient nature of mental illnesses. Their nature is fluid and our understanding of them change over time.

One currently emerging challenge to our understanding of autism is Pathological Demand Avoidance or PDA (Newson et al., 2003) which is allegedly a newly discovered part of the autism spectrum. Psychologist and researcher Dr. Elizabeth Newson first introduced PDA in the early 1980s. Newson used the PDA label to describe an individual who is putatively on the autism spectrum but presents with atypical symptomology.

Exploratory research on PDA spanned several decades and it wasn't until 2003 that Newson, along with her colleagues Le Marechal and David published an initial study, *Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders* (2003) that described the PDA profile. Newson, Le Marechal and David's goal was to illustrate an autonomous new component of the Pervasive Developmental Disorder – Not Otherwise Specified (PDDNOS) category of the autism spectrum.

In this seminal work, Newson et al. (2003) sampled 150 children (75 females and 75 males) diagnosed with autism spectrum disorder (ASD). They selected cases which were in a diagnostic sense puzzling or atypical, that is, which presented with some manifestations that were similar to the Diagnostic Statistical Manual-4 (DSM-4) (American Psychiatric Association, 2000) description of autism but which also presented with one central characteristic, an "obsessional avoidance of the ordinary demands of life coupled with a degree of sociability that allowed social manipulation as a major skill" (Newson et al., 2003, p. 596). The team described the cases as,

> children who "reminded" their medical referrers of autism but were clearly not typical of autism. Sometimes autism was rejected or questioned because of the child's imaginative ability, especially in non-echolalic role play; often the child seemed unusually sociable, though in an "odd" way, and language development was atypical of autism and less pragmatically disordered than in Asperger's syndrome (Newson et al., 2003, p. 595).

These contradictions in symptomology led Newson et al. (2003) to suggest that there was a fundamental problem in teasing out the most applicable diagnosis and this could hinder families receiving suitable and effective services. Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) is not only cumbersome for parents but leaves them in a limbo of atypicality. For a child (or adult) to be atypical of better-known conditions can, in practice, reduce the understanding of the professionals serving him or her and thus restrict access to appropriate educational and other support (Newson et al., 2003).

The discrepancy that Newson and her colleagues found between the DSM-4 criteria for ASD and their own clinical observations led to the identification of eight key indicators of PDA:

1) Passive early history in the first years of life, meaning that the child does not engage with persons or toys readily or with enthusiasm;

2) Continues to resist ordinary demands of life and will engage in many levels of social manipulation and outrageous behaviors in order to avoid them;

3) Surface sociability but apparent lack of social identity;

4) No pride or shame which is tied into the outrageous behaviors;

5) Liability and mood with a need to control;

6) Comfortable in role play and pretending;

7) Language delay seems the result of passivity;

8) Obsessive behavior.

These eight indicators illustrate differences between the PDA construct and the DSM-4 criteria of ASD with regard to pretend play, social manipulation and impulsivity. Even for behaviors that are similar to both PDA and ASD, the function of behaviors may differ. For example, obsessive behavior in someone with PDA is more focused on avoiding demands, whereas the obsessive nature of someone with ASD is more based on an interest in order and arrangements (Newson et al., 2003). Newson et al. (2003) proposed that PDA should be considered an autonomous construct separate from both high functioning autism and Asperger's syndrome on the grounds that a separate diagnosis would reduce confusion within the healthcare system, facilitate the development of interventions and increase funding to address PDA. They stated,

> there is a responsibility to fit the diagnosis to the child in question as precisely as possible, mapping the characteristics of the child against criteria in such a way that the diagnosis makes sense to parents in terms of the child they know and leads them to a better understanding and more appropriate services (Newson et al., p. 595).

Nevertheless, PDA remains controversial. Some professionals recognize PDA while others reject its existence and insist that the symptoms are the result of other similar and already established behavior disorders such as Attention Deficit Hyperactivity Disorder (ADHD) or conduct disorder.

Still, Newson et al. (2003) are not the sole advocates for more research into the profile of PDA. As Dr. Christopher Gillberg (2014) explained, "Experienced clinicians

throughout child psychiatry, child neurology, and pediatrics will testify to its existence and the very major problems encountered when it comes to intervention and treatment" (p. 769). In the same article, Gillberg stated that there is "virtually no research" (p. 769) on PDA and noted that this is a pressing concern because "PDA is a very real clinical problem… intervention and treatment rest almost exclusively on guesswork, clinical experience and trial and error" (p. 769).

To date, Gillberg, C., Gillberg, I. C., Thompson, L., Biskupsto, R., & Billstedt, E. (2015) are the only researchers to have conducted a population study into the prevalence of PDA. Gillberg et al. (2015) screened for PDA among a sample of children who had already been given an ASD diagnosis, meaning that this research omitted the possibility of finding PDA in a non-ASD population.

The PDA profile is still in its formative stages and new suggestions regarding the profile are emerging. Considering how much our understanding of autism has changed over time, PDA as a new piece of the autism spectrum cannot be ruled out. To glean further insight into the PDA profile, however, it would be informative to explore beyond the assumption that PDA is a part of the autism spectrum.

Purpose of This Research

This study administered the most reliable psychometric measure of PDA to date, the Extreme Demand Avoidance Questionnaire (EDA-Q), to a sample of parents with children who were typically developing or who had a pertinent diagnosis.

The purpose of this research was to study the extent to which the PDA profile presents itself in school aged children who were typically developing or who had been diagnosed with ASD, Attention Deficit Hyperactivity Disorder (ADHD), anxiety disorders or other clinical diagnoses.

The hypothesis investigated in this research was that children with an ASD diagnosis would have significantly higher scores on measures of PDA than children without ASD.

Also, of interest was a comparison of the results by gender. A North American surveillance study conducted Maenner MJ, et al. (2020) reported that males were

approximately four times more likely than females to be identified with ASD. If PDA was a part of the autism spectrum disorder, then there might be a discernable difference in the prevalence of male to female children with PDA.

Chapter 2.

Research Review

There is a paucity of peer reviewed published research that investigates the Pathological Demand Avoidance (PDA) profile. As noted in the previous chapter, the first published paper on PDA was Newson et al. (2003) *Pathological demand avoidance syndrome; a necessary distinction within the pervasive developmental disorders*. Subsequent literature has focused on four general themes: the identification and measurement of a PDA profile relative to other disorders; the impact of PDA on an individual's ability to function (e.g., at school); treatment approaches for PDA; and, PDA resources for lay persons.

The Identification and Measurement of PDA

According to O'Nions, E., Christie, P., Gould, J., Viding, E., and Happé, F., (2014a) "The concept of PDA has grown in popularity during the last decade, particularly in the UK where the description originated" (p. 408). Concurrently, the question of PDA's legitimacy has seemingly created tension between experts such as doctors and researchers, and lay people such as parents and caregivers.

In their exploration of the PDA behavioral profile, O'Nions, E., Viding, E., Greven, C. U., Ronald, A., & Happé, F., (2014b) addressed the issue of legitimation stating,

> PDA has become increasingly widely used by some clinicians, teachers and parents in the United Kingdom and has come to arouse strong emotions. There is disagreement and debate as to whether PDA is truly a syndrome, or whether it labels specific behaviors seen in children with a range of disorders (pp. 538-539).

O'Nions et al. (2014b) aimed to contrast the PDA profile with the better known ASD disorders and conduct disorders that are characterized by callous or non-emotional traits. These researchers stated that,

> these findings could indicate that the PDA group has ASD with co-morbid conduct problems, plus additional extreme emotional symptoms, [but] this does not fully accommodate the main difficulties in PDA… Specifically, poor social cognition associated with autism appears inconsistent with

> instrumental use of social manipulation. Impoverished imagination in autism is inconsistent with role play and excessive fantasy engagement in PDA (e.g., taking on the role of a teacher when interacting with peers and telling tall tales). While children with conduct problems may resist complying in order to pursue their own interests – for example, to avoid a task they dislike – obsessive avoidance of even simple requests, regardless of the personal consequences, goes beyond this (O'Nions et al., 2014b, p. 543).

Although O'Nions et al. (2014b) acknowledged that the PDA profile matched some of the criteria for both the ASD and conduct disorder constructs, they also advocated for an increase in efforts to study PDA. They stressed that the "Development and refinement of a diagnostic algorithm for PDA based on Newson's criteria will be an important step in facilitating future research studies and designating boundaries with other constructs" (p. 542).

To further identify the core features of PDA, O'Nions et al. used semi-structured interviews, which are "widely used as an assessment tool for autism spectrum conditions" (O'Nions et al. 2014a, p. 408), and self-report questionnaires, the researchers established a PDA phenotype. As O'Nions et al. (2014a) noted, "This study brings the field a step closer to a clinician-rated measure of PDA features and highlights the need for further elucidation of the PDA phenotype" (p. 407). O'Nions et al. (2014a, 2016) then established content for their Extreme Demand Avoidance questionnaire (EDA-Q), which helps to identify the presence of a PDA profile by comparing Newson's profile of PDA to items on the Diagnostic Instrument for Social and Communication Disorders (DISCO) and identifying items that matched. They found that the established 'core features' of PDA were reported or had high endorsement rates (66% or higher) in the Autism Spectrum Disorder (ASD) sample in most areas.

Gillberg et al. (2015) used the EDA-Q as the measurement tool to screen the entire ASD population of the Faroe Islands for PDA. The researchers found that 0.2 % of the population met the criteria for ASD giving them a sample of 67 individuals between 15-24 years of age. Of those with ASD, 1 in 5, or 20 percent met the EDA-Q criteria for PDA. The researchers felt that the results of the study would have good generalizability. They concluded that "Clearly, unless the Faroe Islands is an extremely atypical population from which no generalized conclusions can be drawn, PDA/EDA is quite common in ASD" (p. 983). Further, they stated that:

> In our study, several of the individual PDA reported symptoms occurred together (motor clumsiness, unaware of social hierarchy, love–aggression swings, bossy-domineering and repetitive role play), and more than half of the PDA items were significantly more prevalent in the PDA group than in the non-PDA group. This supports the notion of PDA as a more valid clinical condition than just a mere collection of ad hoc lumped problems (p. 984).

Measures other than the EDA-Q have been developed to help identify demand avoidance behaviors. Originally published in 2010 and modified in 2015, the Coventry Grid was "an attempt to summarize the differences between the behavior of children with Autistic Spectrum Disorder and those with significant attachment problems." (Flackhill, C., James, S., Soppitt, R., & Milton, K., 2017 p. 44). Eaton, J., Duncan, K., and Hesketh, (2018) altered the Coventry Grid interview to include a demand avoidant profile. The work to incorporate the PDA profile into a previously established clinical measurement tool, the Coventry Grid, shows an increasing awareness of PDA as a distinguishable profile.

The PDA profile continues to evolve. Recently O'Nions et al. (2018) explored several additional dimensions of the PDA profile. O'Nions et al. (2018) conducted semi-structured interviews with parents of 26 children with a PDA diagnosis. The reported behavior was grouped into unique subthemes including; noncompliance in conjunction with the component of insistence that others comply with their wishes, aggressive behavior, and lack of sense of responsibility or sensitivity to the distress of others. Noting that the "child's attempts to control situations and others' activities as major areas of difficulty…this controlling dimension has yet to be systematically researched in the context of ASD" (p. 225). O'Nions et al. (2018) advocated for further studies that could "examine triggers or mitigating factors that make certain demands more tolerable. Large-scale investigations could also explore how these dimensions relate to age, gender, ability level, core ASD symptoms and comorbid features (e.g. anxiety, ADHD)" (p. 225).

Gender differences are known to play a role in ASD, but it is not known whether they also affect PDA diagnosis or symptoms. A study conducted by Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D., (2012) focused on gender differences in the manifestation of ASD symptoms. The research found that there was evidence for "a distinct female ASD phenotype" (p. 1310) and that females and males show significant differences in the area of repetitive and stereotypic behaviors (RSB). Males exhibit more RSBs more frequently and more intensely than their female

counterparts (Mandy et al., 2012). Mandy et al. (2012) suggested that these differences in presentations were problematic because “females are less likely to be identified as cases, or for diagnosis to be delayed, prejudicing them from receiving appropriately targeted health care, early interventions and educational resources” (p. 1312).

In Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B., (2013), *A review of the Role of Female Gender in Autism Spectrum Disorder*, the authors found discrepancies in presentation, particularly in individuals who were considered high functioning. They state, “for those females who present with an atypical phenotype, however, they will be considered “odd” rather than being formally or accurately diagnosed” (p. 17).

PDA and Institutions

In 2016, Gore-Langton and Fredrickson (2016) mapped the educational experiences of children with PDA. They administered a questionnaire to 42 parents of children who have been identified by clinical reports as having a PDA profile. Gore-Langton and Frederickson found that most children with the PDA profile experienced “high levels of problem behavior in school and receive a corresponding high level of special educational support and professional involvement” (2016, p. 2). Further, they found that children with a PDA profile often experience “high rates of exclusion and placement breakdown” (2016, p. 2) with only 48% of the sample group’s children still in mainstream education. The study concluded that despite these results, most parents reported having relatively good experiences with the education system overall.

In 2017, Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E., (2017) published a study that found most of the students they interviewed had negative school experiences. The team used interviews with 9 “intellectually able” students, school staff and their parents to attempt to map their gradual school disengagement and how to go about reintegrating the learners back into school. The team found that “children’s perceived unmet needs, as well as inappropriate approaches by previous school staff in dealing with children’s difficulties were felt to cause decline in children’s mental health and behavior and ultimately led to their exclusion from school” (2017 para.3) They identified four strategies for integrating these learners back into an educational environment: 1) make substantial adjustments to the physical environment; 2) promote strong staff-student relationships; 3) understand the students’ specific needs; and 4)

target efforts towards improving student wellbeing. All of the students interviewed were successfully reintegrated into a school, albeit in specialized programs that concentrated on reintegrating previously excluded students on the autism spectrum.

Lyle and Leatherland (2018) initiated a case study that explored strategies to use with a young learner with a strong PDA profile who engaged in extreme demand avoidance behaviors in the classroom. They noted that the learner "failed to respond to tried and tested interventions indicated for autistic learners such as visual timetables, structured learning, and other TEACH (treatment and education of autistic and communication handicapped children) strategies" (p. 35). The researchers concluded that successful inclusion of this student was based on all staff and caregivers following a positive behavior support plan and a focus on training, flexibility and adapting tasks based on the learner's self-regulation needs.

Other researchers have suggested that many people who are seen as unsavory 'characters' by society might be afflicted with PDA. For example, Trundle, G., Craig, L.A. & Stringer, I., (2017) published an anecdotal case study that examined the life of a 23-year-old prisoner who had a long history of institutionalization and aggressive behaviors. The researchers cross-referenced the prisoner's behaviors with the established criteria for both PDA and Antisocial Personality Disorder. They found considerable overlap between both constructs but argued that the prisoner's high level of social manipulation in conjunction with aggression and non-compliance were particularly strong indicators for PDA. Although Trundell et al. (2017) acknowledge the limitations of their research in terms of generalizability, they pose the question: if society were to accept PDA as a legitimate construct, how would it change our perception of people who exhibit symptoms of the disorder?

Treatment Approaches for PDA

A paper by Phil Christie (2007) proposing PDA specific treatment approaches was presented at the World Autism Congress held in Cape Town South Africa. In the paper, *The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines to good practice*, Christie (2007) emphasized differences between traditional interventions and functional strategies for learners with a PDA profile. Christie stated that, "…the key differences are in emphasis. The use of

structure routine and behavioral principles of reward that are usually effective for children with autism or Asperger's Syndrome are rarely so for children with PDA" (p. 6). He therefore advocated for a different treatment emphasizing a highly flexible approach that allowed for educators and caregivers to coordinate the level of adult demand with the child's perceived level of anxiety (Christie, 2007).

In July 2018, *The Lancet Child and Adolescent Health* published a short correspondence from O'Nions, Happe, Viding, Gould and Noens in which they argued that PDA should be framed as the result of anxiety. As such, they argued that traditional behavior management techniques would not be effective as a deterrent to escalating behavior. They suggested that "Once high anxiety is triggered by demands, attempting to alter behavior via contingent reinforcement would be ineffective because it would not address the function of the behavior: to reduce anxiety" (2018, para.3)

Summerhill and Collett (2018) published *Developing a multi-agency assess pathway for children and young people thought to have Pathological Demand Avoidance profile*. In this paper, Summerhill and Collett (2018) argued for a collaborative approach when assessing and treating clients who presented with a PDA profile. They acknowledged that PDA remains controversial and pointed out that this was problematic for improving awareness and developing effective behavior intervention plans. They suggested that clinicians who diagnose individuals in the Specialist Assessment Services (SAS) and professionals who design and implement the intervention plan for Support Services Autism teams, communicate openly and regularly about clients with a PDA profile. The authors further suggested several steps that included data collection and sharing as well as implementing recommended PDA strategies and completion of the EDA-Q. These steps were intended to ensure that client needs are well understood and addressed. They concluded that all involved professionals should receive training in the needs of individuals with PDA and continue to work on developing a body of knowledge for the PDA profile**.**

PDA Resources for Lay Persons

By 2015, PDA had become prevalent within the narrative of mental illness in the United Kingdom. This was evidenced by books such as *Can I tell you about Pathological Demand Avoidance Syndrome?* (Fidler & Christie, 2015) and *Understanding*

Pathological Demand Avoidance Syndrome in Children: A guide for parents, teacher, and other professionals (Duncan, M., Healy, Z., Fidler, R., & Christie, P., 2012). Additionally, one can type PDA into any Internet search engine and quickly find self-advocacy videos posted by people who identify as having a PDA profile as well as videos that offer tips for interacting with those who allegedly have it. However, PDA is not listed in the DSM-5 and the ICD-10 at this time.

The literature shows that the PDA profile is of interest to the autism community, but it remains controversial. People are becoming more active in seeking explanations for the PDA disorder and information about treatments. Specific treatment centers such as the Elizabeth Newson Center in Nottinghamshire and The Lorna Wing Institute in Kent have training and development programs specifically geared towards PDA interventions, while numerous non-profit organizations such as the PDA Society and the Autism Education Trust offer resources to help with PDA interventions. The Pathological Demand Avoidance group on Facebook currently has over 4,900 members (PDA Global Group, www.facebook.com).

In summary, a review of research regarding PDA shows that the definition and measurement of PDA continues to evolve. There is ongoing debate about whether the PDA profile is a legitimate disorder, and if so, whether it is a unique disorder or an atypical manifestation of the better-known ASD disorders and/or conduct disorders. Like ASD, does PDA occur more often in male children than female children?

Clinicians in child psychiatry, child neurology and pediatrics have observed that children with PDA profiles have some characteristics in common with autism but also have some important differences such that they may not respond well to some of the approaches commonly used to intervene with and treat autistic children (Gillberg, 2014). Some researchers and clinicians have described PDA as stemming from anxiety and have advocated for a treatment approach that is highly flexible and responsive to a child's perceived level of anxiety (Newson et al. 2003, Gillberg 2014, Christie 2006, Christie et al., 2012, Christie & Fidler 2015, Summerhill & Collett, 2016).

Many parents of children with a conduct disorder have reported that the PDA profile is an accurate description of their child's behavior, more so than an autism diagnosis. This acceptance of PDA as a legitimate diagnosis has supported the

development and release of related publications, on-line sites, and education and treatment programs.

Successful intervention and treatment of individuals with a PDA profile is important. Children with PDA symptoms can have major problems interacting with others and succeeding in school.

Chapter 3.

Methods

A review of literature pertinent to PDA revealed the existence of many unanswered questions. This research addressed the following questions:

1. Does the presence of reported PDA symptoms in school-aged children differ by whether or not they have any clinical diagnoses (i.e.," typically" versus "non typically" developing)?

2. Does the presence of reported PDA symptoms in school-aged children differ by whether or not they have a clinical diagnosis specific to ASD? Anxiety Disorders? ADHD? Other conduct disorders?

3. Does the presence of reported PDA symptoms in school-aged children differ between males and females?

Participants

The interests of this study necessitated the selection of a difficult to obtain sample: parents caring for school age children ages 6 to 17 years old with or without a clinical diagnosis of ASD, ADHD, anxiety disorder or other conduct disorder. Parents with children younger than 5 years of age were not eligible to participate as the psychometric test used had an age cut off of 5 years. The sample was also limited to participants with the ability to connect to the Internet via a computer, tablet or cell phone, as the survey link could only be accessed online. Also, the participants had to possess a working proficiency in English to complete the survey, which was written in English.

Given the infrequency of the clinical diagnoses of PDA among children in the general population (e.g., 1 in 66 for autism) (Autism Spectrum Disorder Among Children and Youth in Canada, 2018), a simple random sample would have had to be impractically large to yield an adequate sample for each of the diagnosis. Thus, an alternative sampling frame was developed using the Internet. Participants were recruited through purposive sampling via the use of social media, specifically Facebook. Target groups were identified on Facebook by entering several key terms into the Facebook search bar including the words "parenting", "support group", "ADHD", "PDA", and "Conduct Disorder". The Facebook groups were identified by using two key word

combinations in the search (i.e., Parenting and ADHD, Parenting and PDA, and Parenting and Conduct Disorder).

The Facebook groups found from the search were reviewed for their size (number of members) and recent posting activity (the amount of posts over the preceding 24-hour period). Larger and more active Facebook groups were selected as it was likely that these Facebook groups would yield more participants than smaller, inactive Facebook groups.

This resulted in the following Facebook groups being identified for participation in the study: PDA Global Group (Pathological Demand Avoidance), ADHD Together-Support Group, and Parents of Children with Conduct Disorder. Following the Facebook group selection, the administrators of the Facebook groups were contacted to request permission to post an online link to the study's survey instrument. The three group administrators each agreed to allow a link to the study's survey instrument.

Prior to launching the survey, the study's purpose and design was reviewed and approved by the University's Ethics Review Board regarding the use of human subjects. An informed consent document was provided as the first screen of the survey instrument. This screen informed respondents of the voluntary and confidential nature of the survey and gave information as to how to contact the University's Ethics Review Board.

The survey also included an indication of consent for the data collected to be uploaded to a database for future research. Respondents entered "I agree" to indicate they understood the content of the information provided and proceeded to the survey instrument. If the respondent did not enter "I agree" they were released from the survey and did not proceed to the survey instrument.

A link to the survey was posted on the selected Facebook group sites from May 4, 2019 to August 30, 2019. No identifying information was requested for completing the survey and all data collected remained anonymous.

Instrument

The psychometric screening tool selected for this study was the Extreme Demand Avoidance Questionnaire (EDA-Q) (Appendix A) developed by O'Nions et al. (2014a, 2014b, 2016) and used with the authors' permission. To develop the items on the EDA-Q, O'Nions et al. (2016) utilized an already established and widely used assessment tool, the Diagnostic Instrument for Social and Communication Disorders (DISCO), as a framework for selecting prospective items for the EDA-Q. O'Nions et al. (2016) cross-referenced items from the DISCO with Newson et al. (2014b) original PDA profile. Potential EDA-Q items were selected based on Newson's PDA criteria, as well as unpublished material provided by Newson (O'Nions et al. 2014a).

In the design of the EDA-Q, age is an important factor. O'Nions et al. (2014a) reported that EDA-Q must be scored in relation to two age categories. Children aged 5 to 11 years with scores of 50 or over were considered to present with a PDA profile, whereas those aged 12 to 17 years with scores 45 and over were considered to present with a PDA profile. O'Nions et al. indicate, "A significant relationship between age and EDA-Q score was detected across the entire sample F (1,322) =26.82, $p < .001$, r^2= 8% suggesting that the severity of PDA features decreases with age" (2014a, p. 18).

To create an EDA-Q score, respondents rated each of their child's target behaviors on two dimensions, Frequency and Intensity, using a scale of 0 to 3 points. Higher scores on the EDA-Q signified more prevalent and/or intense behaviors (PDA symptoms). Scores on behavioral dimensions are combined into an individual's score on the EDA-Q. Groups of EDA-Q scores form continuous data.

In addition to the EDA-Q, respondents in this study were asked to identify the child's age, gender and whether the child currently had a clinical diagnosis. The survey instrument was created on the Survey Monkey platform and was composed of the items on the EDA-Q plus the three classification questions.

Analysis

Data for all questions were categorized, coded, and entered into Excel spreadsheets. The SPSS version 25 program was used for analysis, providing statistics

to describe the occurrence of PDA within the sample and by sample subgroups. The mean, mode, median and range were calculated for the EDA-Q scores for age groups, gender, and diagnostic groups.

For many individuals with behavior-based diagnosis, that is, a diagnosis established via observation of behavior exclusively, it is common to receive more than one diagnosis. For example, Simonoff et al. (2008) reported that 70-72% of individuals diagnosed on the autism spectrum had a co-occurring disorder, most commonly Anxiety Disorder, Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder and Oppositional Defiant Disorder. These individuals may seem to present with conflicting symptomology, which means they may fit into more than one already established behavioral category making a definitive diagnosis somewhat elusive.

If a respondent reported that their child was diagnosed with more than one disorder, then each disorder was counted in its respective diagnostic group. All clinical diagnoses were counted but each reported clinical diagnosis was counted separately ensuring that one diagnosis did not outweigh another.

Respondents were divided into the following groups**:** child diagnosed on the Autism Spectrum Disorder (ASD), child diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), child diagnosed with anxiety disorder, child with other diagnosis, and child with no diagnosis, that is, typically developing.

The results were analyzed to determine the number of participants in each diagnostic group who scored high enough on the EDA-Q to present with the PDA profile. Second, a series of *t*-tests were run to compare PDA test scores (the dependent variable) based on whether or not a child had any diagnosis and whether they had a specific diagnosis. In addition, a comparison was made to determine if proportionately more male children had PDA than female children, and whether males had more pronounced symptoms of PDA, that is, higher scores on the EDA-Q.

The research questions called for a comparison of group means. Therefore, two independent sample *t*-tests were used. The assumptions for the *t*-test (*NCSS Statistical Software*, Two-Sample *t*-test) could largely be met. Data on the dependent variable (scores on the EDA-Q) were continuous, the two samples being compared were independent (no relationship between the individuals in one sample as compared to the

other) and a Levene's test of HOV was run. If the samples were of equal variance, the equal variance assumed analysis of the *t*-test was used. If the results showed that the samples were not equal variance, the equal variance not assumed *t*-test was used.

Purposive sampling was used and may have differed from a simple random sample in the degree of sample bias (the degree to which sample values vary from population values). Thus, care was taken to present the findings in appropriate context when inferences were made about the population.

Research Design

This research had a small sample and an untested approach to constructing the frame. Also, this research used an ex post facto design, which is a systematic empirical inquiry in which the researcher does not have direct control of independent variables because they have already occurred, or because they inherently cannot or should not be manipulated (e.g., due to ethical reasons). In an ex post facto design, cause-effect relationships are more difficult to establish than in experiments (Salkind, *Sage Research Methods*, 2010). Thus, one could legitimately find that higher PDA scores are associated with anxiety, but not that anxiety 'causes' PDA.

Chapter 4.

Results

Sample Size

In total there were 93 respondents to the survey. Seventy-eight (78) respondents completed the survey in its entirety and these responses were used in the analysis. Eleven (11) responses were eliminated due to being incomplete, (3 did not indicate a gender and 8 did not indicate an age). Another 4 responses were eliminated because those responses were singular within that diagnosis category; with only one response with that diagnosis, a group could not be constructed, nor a mean calculated and analyzed.

Forty-four (44) responses were from parents of children 6 to 11 years of age and 34 responses were from parents of children 12 to 17 years of age. Fifty-three (53) responses were from parents with male children and 25 responses were from parents with female children.

With regard to the diagnosis among the children of respondents, 15 were identified as Typically Developing, 41 were reported as being on the Autism Spectrum, 29 were reported as having a diagnosis of ADHD, and 12 were reported as having an Anxiety Disorder (Generalized Anxiety Disorder/Social Anxiety Disorder) as seen in table 4.1. Two (2) were reported as having major depression. The major depression diagnostic category was not used in the analysis because there were too few responses in that category to yield an accurate analysis. Twenty-one (21) respondents reported having more than one clinical diagnosis as seen in table 4.2.

Table 4.1. Number of Responses by Diagnostic Groups

	Diagnostic Groups			
	Typical Developing	ASD	ADHD	Anxiety Disorder
Number of Responses	15	41	29	12

NOTE: Respondents could report more than one diagnosis.

Table 4.2. Number of Single, Dual and Multiple Diagnoses

	Number of Diagnoses		
Number of children with one or more diagnoses	Single diagnosis	Dual diagnoses	Multiple diagnoses
67	46 (69%)	13 (19%)	8 (12%)

Age, Gender and Diagnoses EDA-Q Statistics

Table 4.3 shows EDA-Q results reported for the children by age groups. The 78 children were divided into two age groups: six to eleven years of age and twelve to 17 years of age. These groupings were required by the EDA-Q because the cutoff EDA-Q scores for the presence of PDA was different for each of these age groups.

Table 4.3. EDA-Q Statistics by Age Group

	EDA-Q Statistics			
Age Group	Mean	Mode	Median	Range
6 -11 years (n=44)	43	48	43	18-56
12-17 years (n=34)	46	44	42	18-63

The twelve to17 year age group had a higher mean EDA-Q score when compared to the six to eleven year age group. The mode and median EDA-Q score were higher for the six to eleven year age group when compared to the twelve to 17 year age group. The range for the six – eleven year age group was smaller than for the twelve-17 year age group. The upper range of the EDA-Q score for the six – eleven year age group was 56 and the upper range of the EDA-Q score for the twelve-17 year age group was higher at 63.

The EDA-Q statistics for age groups did not differ by very much. Given that the mean, mode and median for the age groups showed little variation, it appears that the sample was not skewed by the age groups.

Table 4.4 shows EDA-Q results reported for the children by gender. Of the 78 children 25 were female and 53 were male.

Table 4.4. EDA-Q Statistics by Gender

	EDA-Q Statistics			
Gender	Mean	Mode	Median	Range
Female (n=25)	43	45	44	19-56
Male (n=53)	39	39	43	18-63

The female children's EDA-Q score mean, mode and median were higher than those EDA-Q statistics for the male children. The upper range of EDA-Q scores for male children was 63 and the upper range of the EDA-Q scores for female children was lower at 56.

The EDA-Q statistics for age gender did not differ by very much. Given that the mean, mode and median for gender showed little variation, it appears that the sample was not skewed by gender.

Table 4.5. EDA-Q Statistics by Age Group and Diagnosis

	EDA-Q Statistics			
Diagnosis	Mean	Mode	Median	Range
Typically Developing				
6-11 years (n=9)	34	n/a*	32	18-58
12-17 years (n=6)	27	19	19	19-47
ASD				
6-11 years (n=21)	45	39/48**	44	35-56
12-17 years (n=20)	45	42	43.5	34-63

EDA-Q Statistics				
Diagnosis	Mean	Mode	Median	Range
ADHD				
6-11 years (n=19)	42	53	43	24-53
12-17 years (n=4)	46	53	45.5	36-54
Anxiety				
6-11 years (n=8)	47	41	49.5	41-53
12-17 years (n=4)	42	n/a*	41.5	36-54

*n/a: Frequency of EDA-Q scores were singular. No modality.
** Bi-modal distribution of EDA-Q scores

Table 4.5 shows the EDA-Q scores for the children by age and diagnostic group.

For the typically developing group the EDA-Q mean and median scores were higher for the six-eleven year age group when compared to the twelve-17 year age group. The typically developing EAD-Q score range was also wider for the six-eleven year age group when compared to the twelve-17 year age group.

For the ASD diagnostic group there was little difference in the EDA-Q score means and medians for the two age groups. The mode EDA-Q scores for the 6-11 year age group showed a bi-modal distribution at 39 and 48 whereas the 12-17 year age group had a mode of 42. The ASD diagnostic group range for the 12-17 year age group was wider when compared to the 6-11 year age group.

For the ADHD diagnostic group, the EDA-Q scores for the mean and median were higher for the 12-17 year age group compared to the 6-11 year age group. The ADHD diagnostic group EDA-Q score mode for both age groups was the same at 53. For the ADHD diagnostic group EDA-Q range score the 12-17 year age group had a reduced dispersion of EDA-Q scores when compared to the 6-11 year age group's EDA-Q score range.

For the Anxiety diagnostic group, the 6-11 year age group had higher EDA-Q score mean and mode when compared to the 12-17 year age group. For the Anxiety

diagnostic group EDA-Q range score the 12-17 year age group had a greater distribution of scores when compared to the 6-11 year age group.

Given that the mean, mode and median by diagnostic groups showed little variation, it appears that the sample was not skewed for the diagnostic groups.

Comorbidity within Diagnostic Groups

The presence of a PDA profile within each of the identified clinical diagnostic groups varied. Of the 41 children with an ASD clinical diagnosis, 17 presented with a PDA profile. Of the 29 children with an ADHD clinical diagnosis, 10 presented with a PDA profile. Of the 12 children with anxiety disorders, 6 presented with a PDA profile (Table 4.6).

The participants were asked to identify all clinical diagnosis that were identified with their child. Comorbidity was factored into the study by treating all clinical diagnosis as equal and using the EDA-Q score for each identified clinical diagnosis. The number of children with a single clinical diagnosis was 46. Thirteen (13) children had two clinical diagnoses and eight children had three or more clinical diagnoses (Table 4.2).

Regarding the ASD diagnostic group, 25 ASD children had a single clinical diagnosis of which 12 ASD children presented with a PDA profile. With regard to ADHD comorbidity with ASD, 10 ASD children also had an ADHD diagnosis, three of which had a PDA profile. With regard to a clinical diagnosis of an anxiety disorder, six ASD children also had an anxiety disorder clinical diagnosis of which two had a PDA profile. The effect of the comorbidity on the ASD diagnostic group was to increase the number of children who presented a PDA profile. However, the comorbidity also increased the number of children without a PDA profile. As a result, the mean EDA-Q scores used to determine the presence of PDA had little effect on the outcome of this statistically significant finding.

With regard to the ADHD diagnostic group, the comorbidity with ASD and anxiety disorder increased the presence of the PDA profile with the ADHD diagnostic group. The single ADHD diagnosis had 13 children without the PDA profile and showed only two of the ADHD diagnosis presenting with a PDA profile. The introduction of the comorbidity with ASD increased the single ADHD diagnostic group by five as well as adding five to

the PDA profile of the ADHD diagnosis group. With regards to the comorbidity with the anxiety disorder, one child was added to the single ADHD diagnostic group but three children were added to the ADHD diagnostic group with a PDA profile. Even with these additions to the ADHD diagnostic group PDA profiles, the ADHD diagnostic group retained the finding that there was no significant difference in the EDA-Q mean scores within the ADHD diagnostic group.

The anxiety disorder group had the smallest number of children at twelve members of which six presented with a PDA profile. Comorbidity was found throughout the anxiety disorder diagnosis group contributing five of the six PDA profile; three overlapped with ASD and two overlapped with ADHD. The single anxiety disorder group also had one child with an anxiety disorder, three children also having an ASD diagnosis and two children also having an ADHD diagnosis. Even with the prevalence of the comorbidities within anxiety disorder, there was no significant difference found in the anxiety disorder diagnostic group. However, given the small size of the anxiety disorder diagnostic group and the comorbidity overlap further work would be required to obtain a representative sample for the anxiety disorder diagnostic group in order to clarify the role of PDA.

PDA by Diagnostic Groups

In the sample of seventy-eight (78) respondents, 24 (31%) reported scores on the EDA-Q high enough for their child to be considered as having a PDA profile as seen in table 4.6.

- Forty-one (41) respondents reported a child's diagnosis of ASD and of those, 17 children or 41% presented with a PDA profile.
- Twenty-nine (29) respondents reported a child's diagnosis of ADHD and of those, 10 children or 34% presented with a PDA profile.
- Twelve (12) respondents reported a child's diagnosis of anxiety and of those, 6 children or 50% presented with the PDA profile.
- Fifteen (15) respondents reported that their child had no diagnosis (Typically Developing) and of those, 2 children or 13% presented with a PDA profile.

Table 4.6. Children with a PDA Profile by Diagnostic Groups

Diagnostic Groups	Children with PDA		
	Number of Children	Number of Children with PDA	Percent of Children with PDA
Total Sample	78	24	31%
ASD	41	17	41%
ADHD	29	10	34%
Anxiety	12	6	50%
Typically Developing	15	2	13%

PDA by Presence or Absence of a Diagnosis and by Gender

Using the EDA-Q score as the dependent variable, a series of *t*-tests were run comparing the EDA-Q mean scores by whether or not the child had a diagnosis as seen in table 4.7. The *t*-tests between children with a diagnosis and those without showed two comparisons that were statistically significant.

There was a significant difference in the EDA-Q scores for children who were Typically Developing (M = 32.20, SD = 7.5); and children who were Not Typically Developing (M = 44.56, SD = 13.1); t (76) = 3.516, $p < .01$. This suggested that children who are Not Typically Developing have more intense symptoms of PDA than Typically Developing children.

Children who were diagnosed with ASD had a higher score on the EDA-Q (M = 46.20, SD = 11.3) than children without ASD (M = 37.73, SD = 6.7); t (76) = -3.979, $p <$ 01 This suggested that children who have an ASD clinical diagnosis have more prominent symptoms of PDA.

The remaining *t*-tests were not significant. Children who were diagnosed with Anxiety Disorder had a higher score on the EDA-Q (M = 46.83, SD = 10.4) than children without Anxiety Disorder (M = 41.33, SD = 6.0): t (76) = -1.770 $p > .05$, but the difference was not significant.

Similarly, children who were diagnosed with ADHD also had a slightly higher mean score (*M* = 42.59*, SD* = 11.2) than children without ADHD (*M* = 41.94, *SD* = 7.9); *t* (76) = -.274, *p* > .05.

With respect to gender, male children had an EDA-Q mean score (*M* = 42.11, *SD* = 10.6) very similar to that of female children (42.32, *SD* = 9.8) resulting in no significant difference *t* (76) = .084 *p* > .05. In the ASD group there were more males (*n* = 29) compared to females (*n* = 12), the ratio of male to female children was 2.4 to 1.0, over twice as many males to females. In the PDA group there were more males (*n* = 11) compared to females (*n* = 8) but the ratio was less pronounced at 1.4 to 1.0.

Table 4.7. Diagnosis and Presence of PDA

	PDA Results			
Diagnostic Group	Mean PDA Score	Standard Deviation	*t* score	*p* value
Typically Developing	32.20	7.5	3.516 *	.003
Not Typically Developing	44.56	13.1		
ASD	46.20	11.3	-3.979*	.000
No ASD	37.73	6.7		
ADHD	42.59	11.2	-.274	.785
No ADHD	41.94	7.9		
Anxiety	46.83	10.4	-1.770	.081
No Anxiety	41.33	6.0		

Chapter 5.

Discussion and Interpretation of Results

The purpose of this research was to study the extent to which the PDA profile presents itself in school-age children who are typically developing or who have been diagnosed with ASD, Anxiety Disorders, Attention Deficit Hyperactivity Disorder (ADHD) or other clinical diagnoses.

The hypothesis was that those with ASD would have significantly different scores on the EDA-Q when compared to those without an ASD diagnosis. This is based on the premise that if PDA is part of the autism spectrum, then children with an ASD diagnosis will have significantly higher scores on the measures of PDA than children without ASD.

PDA and Typically Developing

The typically developing group comprised 15 children of which two scored high enough on the EDA-Q to present a PDA profile. The non-typically developing group comprised those children who had a clinical diagnosis: 41 with an ASD diagnosis, 29 with an ADHD diagnosis, and 12 with an anxiety disorder diagnosis. (Table 4.6).

The results from this study showed a statistically significant difference between the scores of children who were reported as typically developing and children who were reported as having a clinical diagnosis (i.e., non-typically developing). Children with at least one clinical diagnosis were significantly more likely to have a PDA profile when compared to the typically developing group. This finding suggests that indicators of PDA appear more frequently when children have a clinical diagnosis.

PDA and ASD

With regard to children identified with a clinical diagnosis, only the ASD group showed a statistically significant difference in their presentation of PDA. Children with an ASD diagnosis had higher scores on the EDA-Q than children who did not have an ASD diagnosis (Table 4.7). The finding was significant and supports the working hypothesis of this study suggesting that PDA may be another component of the autism spectrum

(Newson et al. 2003, Christie, 2007, Fidler Christie, 2012, Gillberg, 2014, O'Nions et al., 2014b, Fidler & Christie, 2015). However, as this study was focused on PDA, the sample may not reflect the full range of the autism spectrum. Younger children could not be included in the sample as EDA-Q is designed for older children. A broader and more representative sample could address some of these deficiencies.

PDA and ADHD

The results of this study show that there no significant differences between the ADHD group and non-ADHD diagnosis group with regard to the presence of PDA. This result coheres with the clinical definition of ADHD. In examining the ADHD profile there are two main areas that clinicians assess, inattention and hyperactivity/impulsivity (DSM-5, 2013), neither of which has been suggested as a part of the PDA profile. This implies that ADHD does not appear to be significantly related to the PDA profile. Although there was comorbidity between ADHD and ASD, and, ADHD and anxiety disorder, it did not affect this result as the number ADHD children with a PDA profile remained small when compared to the number of ADHD children without a PDA profile.

PDA and Anxiety

Children with a clinical diagnosis of anxiety disorder also had scores on the EDA-Q that were on average, higher than children without an anxiety diagnosis (Table 4.7), but the difference was not significant. Nevertheless, half of parents who reported that their child had been diagnosed with an Anxiety Disorder (*n* = 12) also recorded a sufficient score on the EDA-Q to present with a PDA profile (n = 6). Researchers and clinicians such as O'Nions et al. (2018) and Christie (2007) maintain that PDA and anxiety are closely tied. The comorbidity rate in regard to anxiety disorder and ASD, and, anxiety disorder and ADHD was relatively high. Out of the anxiety group of twelve, five respondents also reported a diagnosis of ASD and five respondents reported a diagnosis of ADHD. It would be interesting to investigate this relationship further with a larger more representative sample.

PDA and Clinical Diagnoses

These clinical diagnosis findings may imply that PDA cannot be diagnosed in isolation. Previous research on the PDA profile suggests that PDA is not a stand-alone diagnosis but instead an additional profile to be added to the broader diagnostic category of ASD (Newson et al., 2003, Christie, 2007, Fidler & Christie, 2012, Gillberg, 2014, O'Nions et al., 2014b, Fidler & Chirstie, 2015). The results of this study would lend support to the theory that PDA is an additional component of an already established behavioral diagnosis such as autism spectrum disorder.

PDA and Gender

A North American surveillance study conducted by Maenner MJ et al. (2016) suggested males were four times more likely than females to be identified with ASD (p. 1). Consistent with what has been observed in other studies of autism, the current study found more male children (*n* = 29) than female children (*n* = 12) in the ASD diagnostic group at a ratio of 2.4 males to 1.0 female.

Given the argument that PDA could be a component of the autism spectrum disorder, one might question whether there would be a higher ratio of male children to female children in the PDA group. In this study, the ratio of 1.4 males to 1.0 female in the PDA group was lower than the ratio of 2.4 to 1.0 in the ASD group. Furthermore, on the EDA-Q, both male and female children had a mean score of 42 (Table 4.7). Although the sample size of this study is small, and the level of generalizability uncertain, the lack of difference in PDA scores is interesting. This suggests that gender is consequential in PDA. The role of gender should continue to be investigated. For example, O'Nions et al. (2018) have advocated for further studies that could "examine triggers or mitigating factors that make certain demands more tolerable. Large-scale investigations could also explore how these dimensions relate to age, gender, ability level, core ASD symptoms and comorbid features (e.g. anxiety, ADHD)" (p. 225).

Limitations

This study has limitations of data collection and sampling, including co-morbidity, target sampling, exclusive groups, and more efficient sorting to increase validity of reporting. The sample should not be viewed as representative of the general population.

Data Collection Limitations

The measurement technique used in this study, self-report, is inherently subjective and this could have led to the results having at least some degree of bias. One can speculate that if the respondents are participating members of specialized Facebook groups, they might already have some preconceived notions about their child's behavior and that this could impact the objectivity of reporting of the presence of PDA related behaviors as well as their frequency and intensity. The quality of reporting can also be influenced by family dynamics. A study by Najman, J. M. et al. (2001) that looked at self-reports on behavior of both mothers and their children concluded that "Emotionally unimpaired mothers perceive their children to have relatively fewer behavior problems than do their youth. By contrast, impaired mothers perceive their children to have more behavior problems than do the youth themselves" (p.193).

Sampling Limitations

The generalizability of these results was limited by the purposive approach to the sampling. The degree to which the sample characteristics differ from population parameters is a measure of "sample bias". Generalization to the population is restricted by the degree to which the sample differs from the target population.

When a sample is drawn from a target population, as in this case regarding the presence of PDA, it is desirable that the sample reflect the population values as accurately as possible. However, a tradeoff needed to be made between obtaining sufficient participant numbers for the presence of PDA within the diagnostic groups and the generalizability of the sample to a school age population. In this study, PDA within diagnostic groups was the condition that took precedence. As PDA is not its own separate clinical diagnosis then it is more likely be detected as part of other clinical diagnoses.

This study drew its sample from websites that catered to parents who were seeking behavioral support for their child, so it is possible that the reporting parent was already experiencing difficulties in managing their child's behavior. Therefore, the sample could be biased towards families with more pronounced behavioral challenges. In addition, if the respondents were participating members of specialized Facebook groups, they might already have some preconceived notions about their child's behavior and may manifest at least some degree of reporter bias of PDA related behaviors.

In addition, a more representative sample would be necessary to flesh out a fuller picture of how the typically developing group relates to their non-typically developing peers in regard to the measures of PDA.

Conclusion and Recommendations for Future Research

Although small, this study contributed to the exploration of several pivotal questions in regard to the PDA profile. This study showed that the behaviors associated with the PDA profile appeared to be more closely associated with ASD than with the other clinical diagnoses. If PDA were a new component of the autism spectrum it would broaden our current perception of this often-confounding disorder. Historically, paradigm shifts such as PDA have happened in regard to ASD so there is a precedent for including a new profile. Supplementary exploration would serve to further elucidate the PDA profile.

It would be valuable to broaden the exploration of the relationship between the PDA profile and certain relevant comorbid combinations. For example, in this study both the ASD group and the Anxiety Disorder group had relatively high scores on the EDA-Q with means of 46.20 and 46.83 respectively as seen in table 4.7. Pursuing whether or not certain co-occurring disorders are more or less likely to manifest in a PDA profile could provide additional insight into its dimensions. The link between anxiety disorders and the presence of PDA is another area for research particularly with regard to the role environment may play in the manifestation of PDA. However, exploring these aspects of PDA research would necessitate a more representative sample for each diagnosis to improve the generalizability of the subsequent results.

Obtaining a larger sample size through the addition of a snowball component to the existing purposive sampling may not obtain a more representative sample because the added sample participants may have the same biases as the original sample participants. A larger sample frame through school districts or boy's and girl's clubs may not yield a viable sample because of the study's focus on diagnoses that are relatively rare.

A stronger approach to representativeness in the sample would be to consider clinics and treatment centers by inviting families to participate in the study. This would generate a sample with selected clinical diagnostic groups. In addition, the clinical diagnosis could be verified by the clinic or treatment center thereby improving the validity of any future study. Families in the study could also report on their child with a diagnosis, as well as those siblings without a clinical diagnosis. Furthermore, longitudinal studies may also be possible within a clinical setting.

If possible, future research could also include other specific conduct orders such as oppositional defiance disorder or disruptive mood disorder so long as the representativeness of the sample could be maintained.

This study represents another step in exploring how PDA may manifest itself in children. It is important that further studies be conducted to further understand the presence of the PDA profile and to ultimately inform any specific methodological supports this possible diagnostic group may find beneficial.

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Appendix.

Extreme demand avoidance questionnaire (EDA-Q)

To be completed by parent and/or teacher. One box to be ticked per question.

		Not true	Somewhat true	Mostly true	Very true
1	Obsessively resists and avoids ordinary demands and requests.				
2	Complains about illness or incapacity when avoiding a request or demand.				
3	Is driven by the need to be in charge.				
4	Finds everyday pressures (e.g. having to go on a school trip/ visit dentist) intolerably stressful.				
5	Tells other children how they should behave but does not feel these rules apply to him/herself.				
6	Mimics adult mannerisms and styles (e.g. uses phrases adopted from teacher/parent to tell other children off).				
7	Has difficulty complying with demands unless they are carefully presented.				
8	Takes on roles or characters (from TV/real life) and 'acts them out'.				
9	Shows little shame or embarrassment (e.g. might throw a tantrum in public and not be embarrassed).				

10	Invents fantasy worlds or games and acts them out.				
11	Good at getting around others and making them do as s/he wants.				
12	Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police).				
13	If pressurised to do something, s/he may have a ‘meltdown’ (e.g. scream, tantrum, hit or kick).				
14	Likes to be told s/he has done a good job.				
15	Mood changes very rapidly (e.g. switches from affectionate to angry in an instant).				
16	Knows what to do or say to upset specific people.				
17	Blames or targets a particular person.				
18	Denies behaviour s/he has committed, even when caught red handed.				
19	Seems as if s/he is distracted 'from within'.				
20	Makes an effort to maintain his/her reputation with peers.				
21	Uses outrageous or shocking behaviour to get out of doing something.				
22	Has bouts of extreme emotional responses to small events (e.g. crying/giggling, becoming furious).				

23	Social interaction has to be on his or her own terms.				
24	Prefers to interact with others in an adopted role or communicate through props/toys.				
25	Attempts to negotiate better terms with adults.				
26	S/he was passive and difficult to engage as an infant.				