Methods of Studying Pathological Demand Avoidance in Children and Adolescents: A Scoping Review Protocol

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Abstract

The construct of pathological demand avoidance (PDA) is relatively new and contested. Clinical reports indicate a population who obsessively resist everyday demands and have a need for control which is pervasive and extreme in nature. Individuals struggle in their daily lives with significant impact on families. The construct has no agreed definition, and the diversity of conceptualisations of PDA have impacted the research on PDA and clinical guidance for PDA. The proposed scoping review aims to map this initial evidence base with a focus on how PDA is conceptualised, and the methods used to study PDA, in samples of children and adolescents. The methodological framework provided by Arksey and O'Malley (2005) and the PRISMA-ScR checklist will be employed. There is a need to identify rigorous and reliable methodological approaches to support future researchers in making balanced judgements about how to research PDA and to provide guidance for clinicians who are supporting a vulnerable group.

Keywords

pathological demand avoidance; extreme demand avoidance; demand avoidance behaviours; methods; autism.

Introduction

Pathological Demand Avoidance (PDA) is a behavioural profile understood by many to be expressed in people with autism (Green et al., 2018; Newson et al., 2003; O' Nions et al., 2016; Stuart et al., 2020). PDA was first described by Newson in the 1980s, as the pattern of presenting an obsessive resistance to ordinary everyday demands and need for control which is pervasive and extreme in nature (Newson et al., 2003). PDA involves impairments in social interaction, communication, and rigid and repetitive behaviours (Newson et al., 2003) but the presentation differs from classic autism as special interests tend to be focused on people as well as those with the profile showing increased social understanding (Newson et al., 2003; O' Nions et al., 2018), comfort in role play (Newson et al., 2003), maladaptive behaviours, and emotionality (O' Nions et al., 2014; 2016). Only one epidemiological study exists, based in the Faroe Islands, which indicates that 1-20% of the autism population met the criteria for PDA (Gilberg et al., 2015).

Defining Pathological Demand Avoidance

PDA has similarities with other disorders, including oppositional defiance disorder (ODD) (O' Nions et al., 2013), conduct disorder (CD) (O' Nions et al., 2014b), attachment difficulties (Eaton et al., 2018), and antisocial personality disorder (ASPD) (Trundle et al., 2017). Therefore, some researchers question the validity of PDA as a construct within ASD, seeing it as either occurring across disorders (Gilberg et al., 2015) as a set of comorbidities (Malik & Baird, 2018), or as a stand-alone entity (O' Nions et al., 2014).

Evidently, the profile needs a precise definition (Sopitt, 2021). Comparing PDA and ODD profiles, children with PDA tend to engage in socially shocking behaviour, whereas children with ODD seek to maintain social status (O' Nions et al., 2013). Regarding CD, children with PDA experience higher levels of anxiety and emotionality (O' Nions et al., 2014) and strategies for CD do not appear to improve outcomes for those with PDA (Newson

et al., 2003; Eaton & Banting, 2012). Eaton et al. (2018) acknowledges that challenging behaviour, poor emotional literacy, and social difficulties seen in PDA are reflective of attachment disorders but maintains that the underlying causes are different (Eaton et al., 2018). For a population of adults, Egan et al. (2020) found that behaviours associated with ASPD and ADHD better predicted PDA than measures of autism.

Critics argue that in the context of autism, demand avoidance behaviours are rational, not pathological and use the term in discussion (rational demand avoidance) to highlight that avoidance may be an appropriate response to inappropriate demands for an autistic person (Moore, 2020; Woods, 2018). Gilberg (2014) advocates for using the term *extreme* demand avoidance to be clear on the intensity to which the avoidance affects day-to-day life.

Methods of Studying PDA

In the research on PDA in children and adolescents, there are quantitative and qualitative studies. Some studies using quantitative methods require formal diagnosis of PDA for inclusion (O' Nions et al., 2014), and some allow parent report of the profile using the Diagnostic Interview for Social and Communication Disorders (DISCO) (Gilberg et al., 2015) or the Extreme Demand Avoidance Questionnaire (EDA-Q) (Stuart et al., 2020; O'Nions et al., 2018). Others have examined the usefulness of the Autism Diagnostic Observation Schedule II (ADOS-II) in diagnosis (Eaton & Weaver, 2020).

There are fewer qualitative studies but of those, very few have included the voice of the child or adolescent with PDA. This is generally consistent in studies of young people with autism (Fayette & Bond, 2018; dePape & Lindsay, 2016; Pellicano et al., 2014; Tesfaye et al., 2019) and is problematic given that there is increasing recognition for the importance of including the views of young people on matters that affect their lives (Fayette & Bond, 2017). In addition, it is known that including the first-hand experiences of young people with autism

in research can have a positive impact on the participants (Bailey et al., 2015; Graham & Fitzgerald, 2010; Grypdonck, 2006; Keith et al., 2018).

Eliciting the voice of those children and adolescents with a PDA profile may be challenging. Egan et al. (2019) outlined that careful consideration for adults is needed as the individual may be resistant to engage with structures and requirements imposed by another. If the primary diagnosis is autism, there may also be an incomprehension of the need to communicate (Egan et al., 2019). Self-report tools to measure PDA would need to be low in demand (Egan et al., 2019). Identifying ways to communicate with children and adolescents with autism and PDA is a worthwhile consideration for ethical, reliable, and valid outcomes of research.

Stuart et al. (2020 p. 60) writes that “empirical attempts to explore the underlying mechanisms of PDA are of clear value”, however researchers need guidance on the most suitable methods for achieving this knowledge. Grahame et al. (2020, p.77) suggests that “accurate description of these [PDA] behaviours and better measurement” is needed to identify “origin, genetics, correlates, developmental course and, most importantly, interventions, at various levels to reduce distress” caused by the likely use of traditional autism strategies which can be counterproductive (Christie, 2007).

Rationale

This scoping review is needed to inform research and practice on a presentation which currently lacks formal recognition. The field of research on PDA is so new so there is no review of methodologies indicating how people can approach measuring PDA in children and adolescents. A synthesis of existing methods of studying PDA would help researchers make evidenced-based decisions about how to operationalise PDA and how to select the most effective methods for collecting information about PDA. The current deliberation in the literature about the presentation of PDA has significant impacts on diagnostic practices (O’

Nions et al., 2014) and interventions for families and children who face persistent challenges (Christie et al., 2012; Gore-Langton & Frederickson, 2015; Doyle et al., 2020). Therefore, there is a pressing need for a scoping review to examine the conceptualisation of PDA and the methods used to research it. Rigorous and reliable methodological approaches need to be identified to support future researchers make balanced judgements and inform clinical guidelines.

Aims and Research Questions

The aim of the proposed scoping review will be to map and synthesise the available methods for studying PDA in children and adolescents, in keeping with the authors' professional area of educational psychology applied in school contexts. In preparation for this protocol, a search of the literature determined that there were few empirical studies and no systematic reviews of PDA in children and adolescents. The most notable contribution was an overview of empirical work by key researchers in the PDA field (O' Nions & Eaton, 2020) outlining how the profile emerges in autism and the arguments for clinical recognition, however, the authors did not articulate the methods which were used. Following this initial search, we selected to use a scoping review methodology given that there is limited empirical research on PDA and that the field would most benefit at this time from a review of foundational procedures such as methodologies for studying PDA in children and adolescents.

Compared with systematic literature reviews, scoping reviews address broad topics where many different study designs are applicable (Arksey & O' Malley, 2005). Arksey and O'Malley's (2005) framework supports the inclusion of studies of varying quality given that the research questions of scoping reviews are not premised on the quality of information on a given topic. Adhering to the scoping review method as defined by Colquhoun et al. (2014), means that the intended scoping review will address an exploratory research question, and

will use systematic search techniques and an evidence synthesis to map key concepts, types of evidence and gaps in methodologies.

The primary research question that will guide the review is “what methods are used to study pathological demand avoidance in children and adolescents?” The primary research question will be addressed by answering a series of secondary research questions:

1. How is PDA in children and adolescents conceptualised in studies?
2. What quantitative methods are used to study PDA in children and adolescents?
3. What qualitative methods are used to study PDA in children and adolescents?
4. Given the available evidence, how reliable are the quantitative tools used to study PDA in children and adolescents?
5. Given the available evidence, how trustworthy are the qualitative tools used to study PDA in children and adolescents?

Methods

The methodological framework presented by Arksey and O'Malley (2005) is well established and widely used for scoping reviews as it provides a clear structure to enable an iterative, rigorous, and reproducible process. The framework has been adapted by the Joanna Briggs Institute (Peters et al., 2015) and in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) extension checklist for scoping reviews (PRISMA-ScR) (Tricco et al., 2018). There is no PRISMA-P (protocol) checklist available for a scoping review protocol thus the PRISMA-P designed for systematic reviews (Moher et al., 2015) will be used with some adaptations to suit a scoping methodology. Arksey and O'Malley's (2005) framework involves five steps, (a) identifying the research question, (b) identifying relevant studies, (c) selecting studies, (d) charting and collating data and (e) disseminating and reporting results.

Eligibility Criteria

Studies will be included if they focus on the construct of PDA in children (2.5 to 9 years) and/ or adolescents (10 to 18 years), use quantitative, qualitative, or mixed methods designs, and are written in English. Non-English language papers will be acknowledged, and their existence documented. Published or unpublished studies since the origins of the PDA construct in the 1980s will be included to capture all available methods. To maintain a high standard of scientific quality, the threshold for including studies is that they are peer reviewed, which permits the inclusion of doctoral dissertations which are peer reviewed at viva, as a form of grey literature. Conference papers and reports published by organisations will not be included unless they have been peer-reviewed. The age range was selected based on the average age at first diagnosis (van't Hof et al., 2020) and the end of adolescence. Studies focused on another related and named disorder, for example oppositional defiance disorder or conduct disorder or attachment difficulties or autism will be excluded unless the study is also of pathological or extreme demand avoidant behaviour.

Search Strategy/ Information Sources

The search strategy was designed on the basis of discussion between the first and second author. The first author will conduct a comprehensive search of multiple databases to identify all relevant studies on PDA in children and adolescents. Similar terms and spelling variants will be included manually in the search string. Boolean terms, AND/OR, will be used to separate the keywords and the use of 'truncation*' and wildcards will also reveal related terms. Searches will combine terms as outlined below. Details of the search records such as date of search, database, keywords, number of studies identified, and the number of studies meeting inclusion criteria will be appropriately documented in Microsoft Excel. Final search results will be exported into EndNote and duplicates removed.

The following bibliographic databases will be searched: Proquest (PsychInfo, Educational Research Information Center, and Proquest premium social sciences collection); Scopus; EBSCO host and JSTOR, to identify peer reviewed journal articles. Grey literature will be identified by searching an extensive set of dissertation databases: Proquest Dissertations, Open Access Theses and Dissertations, Stanford University Libraries (Searchworks), Melvyl, World Cat Dissertations and Theses, Ethos, Cambridge University Library Theses Catalogue (Apollo), and Oxford University Research Archive; the first ten pages of Google Scholar, and key professional organisations of the PDA Society UK and PDA North America.

Search String

Abstracts, titles, and keywords of the databases will be searched for the following search terms as appropriate as per Table 1.

Table 1

Database Search Terms

String 1 Pathological Demand Avoidance	"pathological demand avoidance" OR "extreme demand avoidance" OR "demand avoidance phenomena" OR "rational demand avoidance" OR "demand avoidant behavior"
String 2 Children and Adolescents	child* OR "school refus*" OR "high school" OR "secondary school" OR "elementary school" OR "junior school" OR "junior high school" OR "high school" OR "senior high school" OR "middle school" OR adolescen* OR youth OR "young person" OR "young people" OR boys OR girls OR "middle school" OR preschool OR playschool OR kindergarten OR "special school" OR "pre-school" OR "play-school" OR classroom OR class OR school OR pupil OR student

Screening and Selection Process

The reviewers will meet before the review to pre-plan as recommended by Lockwood et al. (2019). LH, the first author will be the primary reviewer. All titles and abstracts identified by the search strategy will be evaluated against the eligibility criteria and research question by LH and JS independently to ensure rigour and consistency. The inter-rater

agreement (Cohen's kappa coefficient (κ) statistic) between reviewers will be calculated at this stage. Following this, full texts will be examined by LH. Where full papers cannot be obtained, assistance will be sought from the university library or paper author. If the reviewers disagree on the eligibility of a paper, they will meet to build consensus. The new PRISMA flow diagram for reviews including searches of other sources (Page et al., 2020) will report screening results once the review has been completed.

Data Extraction

PRISMA-ScR recommends data charting as the most appropriate method of extracting data for scoping reviews (Tricco et al., 2018). Initial a priori categories and framework will be developed by examining a random selection of studies of quantitative and qualitative designs, however charting will be an iterative process with categories added/reviewed if needed. A data extraction form in Microsoft Excel will be used to extract details pertaining to:

- Study characteristics including date of publication, title, authors, study location, aims, participants age range, sample size, nationality and gender, date of data collection and study design.
- Conceptualisation of the construct of PDA.
- Quantitative and qualitative methods used for studying PDA including:
 - Evidence of validity of measures and reliability statistics in quantitative research and,
 - trustworthiness of qualitative research evidenced in visibility of methods (questionnaires, behavioural data, systematic observation of behaviour, diagnostic behaviour tools), sampling rationale, creation of questions and justification for interview schedules, software used, kappa statistics, analysis method, reflexivity, coding structure and density.

Data Synthesis / Analysis

A narrative synthesis will describe the findings of the review alongside quantification of some results which may include tables and summary statistics in areas such as: study characteristics, methods, lengths of questionnaires and reliability statistics.

Timeframe

The review will take place between July and December 2021. As per JBI guidance (2019), any subsequent deviation from the protocol will be made clear in the scoping review. At the current time there are no plans for updating however if there is a significant amount of time between completing review and submission this will be necessary.

Conclusion

The interest in PDA is increasing but it is not without its controversies. Lack of understanding of the construct leads to differences in the way we study it. This has implications for vulnerable populations awaiting recognition and support. Scoping reviews are used to inform research agendas and identify implications for policy and practice (Tricco et al., 2018). As such, it is anticipated the proposed study will contribute to the existing body of knowledge on PDA, identify gaps in knowledge on the topic, inform future research directions and provide evidence-based information to strengthen research practices and thus policy on and intervention for PDA to improve lives for those affected.

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