Pathological Demand Avoidance and the DSM-5: a rebuttal to Judy Eaton's response

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The author is autistic and acknowledges he meets the Elizabeth Newson PDA Profile.

Editorial comment

Independent scholar Richard Woods has written the following reply to Dr Judy Eaton's response to his paper on Pathological Demand Avoidance (PDA). Dr Eaton's response and Richard Woods' reply are both published in this issue of the *GAP Journal*.

Introduction

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

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

In many respects I support Judy Eaton's sentiment that those with PDA and their loved ones often face exceedingly difficult situations that can adversely impact anyone. I accept that people with PDA and their carers require appropriate support. Such extreme anxiety as Judy Eaton suggests above, as being associated with PDA is not associated with autism. Many autistic people do experience high levels of anxiety as a co-occurring condition. For a more in depth discussion on this topic, please see Woods (2020). Many autistic persons are not receiving a diagnosis and something does need to be done about this. In my view it should be more beneficial to lower clinical thresholds for autism (Woods et al, 2019), instead of adding a new autism subtype, although some argue that the autism diagnostic criteria have been broadened too much (Happé and Frith, 2020). I must stress, that I recognise Judy Eaton and her clinic are making a positive difference to many persons' lives.

The clinical need for PDA has been contested for almost two decades (Garralda, 2003; Green et al, 2018; Malik and Baird, 2018). In addition some argue PDA is also found in non-autistic people and is not confined to autistic persons (Egan, 2019; Gillberg, 2014; Malik and Baird, 2018; McElroy, 2016). This is supported by individual cases of non-autistic persons in PDA research samples (O'Nions et al, 2015; O'Nions et al, 2016; Reilly et al, 2014), in addition to other empirical evidence set

out in my initial article (Woods, 2019b).). It is ethical to challenge research when it is being used to argue that PDA is found in a proportion of autistic individuals and which did not comment on the fact that others have said PDA is not specific to autism. This following quote by Judy Eaton is applicable to the narrow conceptualising of PDA as an autism subtype:

> *"Professionals and teams working with children need to become aware of the ways in which girls can mask their difficulties, and need to move away from using the DSM as a 'bible'. Stating that someone does not fulfil criteria, when these criteria are based on upon a 'male' presentation of a disorder, is short sighted in the extreme." (Eaton, 2017, page 176).*

Despite the controversies and debates which will be clarified by further research, PDA is here to stay. Moreover, whatever PDA is, it can only be formally recognised by the diagnostic manuals, when its screening and diagnostic tools produce valid and accurate measurements (Woods, 2020). Currently, PDA has neither a standardised profile or tools that provide both valid and accurate measurements. In the commentary article I am clear on six diagnostic traits that are needed for PDA identification, but this is not universally agreed (Woods, 2019b), as they cannot be as the research is still ongoing. This situation is in some ways similar for autism as many clinicians use diagnostic profiles and tools to guide their opinion when making a diagnosis.

There is substantially greater consensus over what autism is and is not. Our current understanding of autism has certain fixed points that are well established, such as anxiety is diagnosed as a co-occurring condition (Fletcher-Watson and Happé 2019; Woods, 2020). Another fixed point is how autistic people tend to display Rigid and Repetitive Behaviours and Interests (RRBIs) as they are often beneficial for them. Contrarily, RRBIs are the result of fear of aversive thoughts that is accepted not to be the direct result of autism. These fixed points have led to the The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria but these are subject to change as research continues. Such boundaries are presently lacking from PDA. It is inappropriate to compare diagnostic practices of PDA to autism.

The DSM-5 matters to PDA

Judy Eaton mentions in her paper that all people with PDA in the critiqued research were diagnosed with autism using the criteria within DSM-5. Later she discusses how autism is portrayed in various editions of this diagnostic manual over recent decades (Eaton, 2020). However, she does not mention the position adopted by the committee called the Neurodevelopmental Disorders Workgroup that decided on what the autism criteria were for the DSM-5. The workgroup deliberately removed narrowly defined autism subtypes from the DSM-5, as all attempts to divide autism have failed through both biomarker and behavioural methods (Woods et al, 2019). Specific concerns included insignificant differences between groups of autistic persons who met the clinical threshold for Asperger's Syndrome (ie had no speech delay) and other subtypes. There is no evidence for differential treatment between subtypes (Happé, 2011). Furthermore autism subtypes were removed to reduce the stigma for all autistic persons (Happé, 2011). If the logic of the workgroup is applied to PDA, it would be excluded from the autism spectrum.

An influential study that investigated diagnostic practices across 12 specialist clinics in the United States of America, found that the best predictor of which particular subtype an autistic person was diagnosed with, was the individual clinic they attended (Fletcher-Watson and Happé 2019; Happé, 2011; Happé and Frith, 2020). These results would need to be deemed false for autism subtypes to become widely accepted again. Particularly using similar conceptualisations of autism subtypes as discrete diagnoses, the dual Autism + PDA diagnosis would not be valid for such research as it pathologises more characteristics than a traditional autism diagnosis (Moore, 2020). Research investigating differences between High Functioning Autism and Asperger's Syndrome either found no differences between the groups or any differences resulting from circular practices, such as the diagnostic methods to identify each subtype (Happé and Frith, 2020). Any future replication studies need to ensure that any difference between PDA and other subtypes is not from circular methods. Such research sets part of the evidence base required for PDA being established as an autism subtype.

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