

Editorial: Demand avoidance — pathological, extreme or oppositional?

Since its inception in 1980, the term PDA (Pathological Demand Avoidance) has generated much debate; indeed, arguably few subjects have generated such controversy in the neurodevelopmental literature. While the debate continues as to whether or not PDA is an entity (Green et al., 2018; Malik & Baird, 2018), research is moving into more practical arenas, including trying to understand why some children present with problematic demand avoidant behaviour, in order to provide practical support to families who have a child or children who present with demand avoidant behaviour, which can place a considerable burden on both parents and siblings, as well as limiting the child's opportunities for social and emotional development.

In this issue of *Child and Adolescent Mental Health*, the starting point for the debate is a research article by Stuart et al. (2020). They present data from two studies which begin to look for underlying factors contributing to an anxious need for control, which is regarded as the central driver for PDA, although hitherto this has not been formally studied. In study 1, using qualitative measures they demonstrate a direct relationship between Intolerance of Uncertainty (IU) and controlling Extreme Demand Avoidance (EDA) behaviour, and an indirect relationship between IU and meltdown behaviour, via anxiety. This holds clinically, as children who cannot tolerate uncertainty are prone to controlling their environments to make them more predictable; and anxiety often precedes a meltdown. Qualitative examples of this are demonstrated in study 2, with controlling behaviour, avoidant behaviour and aggressive behaviour in response to demands being described. However, much of the variance was not explained by either IU or anxiety, indicating that these may form just part of a puzzle. Cognitive inflexibility (Malik & Baird, 2018) and a reduced response to social reinforcements or punishment (O'Nions & Noens, 2018) have also been proposed as potential mechanisms for demand avoidant behaviour.

Green (2020) then provides us with a commentary on the paper, highlighting the potential usefulness of identifying underlying processes leading to a PDA presentation. However, he also highlights some of the conceptual problems with researching something that is as yet not adequately defined. For example, how can someone be diagnosed as having PDA if it is not a recognised diagnosis? He also highlights the circularity in investigating something that as yet has no nosological validity by using descriptions from a self-selecting sample, thus approaching from an a priori standpoint of the validity of PDA as a construct; and the biases inherent in the design of the study, thus limiting the robustness of the findings. He also revisits the concept of transactional perspectives proposed in the 2018 paper; that is that rather than difficulties being driven by factors that are intrinsic to the child, they are a product of transactions within the environment, for example, as with any of us,

when we both cannot understand and when we are misunderstood, we are more likely to act in a way that is less than ideal.

The authors respond (Grahame, Stuart, Honey, Freeston, 2020a; Grahame, Stuart, Honey, Freeston, 2020b) by highlighting that the first point in itself leads to a circularity within the debate. As they highlight, diagnostic systems evolve and it may be that PDA, given the consistency between parent and professional's observations of a very particular profile of behaviours, may yet earn a place in classification systems. However, until that moment, we remain limited by anecdote and circular discussions, and as the authors say, what we really need at this point is more accurate description of these behaviours and better measurement.

Finally, Woods (2020) provides a commentary from a central standpoint that PDA is not specific to autism. In line with Green, he raises the point that there are inherent biases in the methodology chosen by Stuart et al., as well as problems using measures which simply confirm a pre-existing standpoint. He also interprets the findings to provide support for monotropism, a processing style involving attending to only certain salient pieces of information, leading to uncertainty and anxiety as end products rather than mediators. He also touches on an area which is increasingly garnering academic interest, which is the overlap between traumatic stress responses, and some of the emotional and behavioural responses observed in autistic people (see Kerns et al., 2015; Rumball, 2019, for a review).

Grahame et al. (2020a, 2020b) provide a robust response to this critique, repeating the message that they are neither supporting nor refuting PDA as an entity, but seeking to provide evidence for mechanisms in those in whom PDA has been identified. They fully acknowledge the limitations but ultimately seek to focus on supporting families coping with very challenging situations, and also, clinical services for whom the evidence base on which to proceed are weak.

In this lively debate, while the controversy continues, some headway is made in terms of understanding why some young people present with such a rigid and maladaptive response to everyday demands. What is really needed now is a shift in direction towards help for families, beyond simplistic and generalised statements about individual formulations and identification of risk factors, and collaborative treatment plans. Neither is a complete reduction in demands realistic or helpful in learning to deal with the real world; therefore, many strategies focus on an alteration in the way demands are presented, rather than a removal of demand, to induce a sense of control and choice within the child, while at the same time, helping them learn that it is acceptable, or possibly even desirable, for others to be in control at times. Only adequate definitions and an understanding of the mechanisms leading to problem behaviours can result in truly

model-driven treatment plans. As Grahame and colleagues suggest, if IU is a central driver of demand avoidant behaviours, then programmes to increase tolerance of uncertainty, or perhaps more specifically, *tolerance of not being in control*, using graded hierarchies, may bear some fruit.

Despite being currently thought of as part of the autism spectrum, typical ASD (Autism Spectrum Disorder) strategies tend not to work, which is why some nosological distinction may be necessary, in order to avoid inappropriate strategies being trialled. For example, having structure and routine to family life is reported by many to be helpful in reducing underlying anxiety caused by daily uncertainty, but many parents report that visual timetables or reward charts are rejected due to being perceived as a form of control. At their core, strategies for managing the anxiety, intolerance or whatever is driving the aversion to being controlled involve creating a sense of the child having a degree of control, while the adults around the child remain quietly in control and contain the child's emotions in a way that feels safe for the child.

Many children with demand avoidant presentations are at risk of exclusion from mainstream educational placements and finding an alternative can be challenging. While an accurate and honest description of a child's needs is essential in securing an EHCP (Education, Health and Care Plan), complex behavioural needs such as demand avoidance can be perceived as being too challenging for many SEN (Special Educational Needs) schools, including schools specialising in autism, to manage, and SEMH (Social, Emotional Mental Health) schools may not have the right peer group for young people with spectrum difficulties. Therefore, it is crucial for both health and education to develop a robust evidence base to understand the driving mechanisms for demand avoidant behaviour, and develop specific strategies for managing what can be very challenging behaviours.

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References

- Grahame, V., Stuart, L., Honey, E., & Freeston, M. (2020a). Response: Demand Avoidance Phenomena: a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents – a response to Woods (2020). *Child and Adolescent Mental Health*, 25, 71–73.
- Grahame, V., Stuart, L., Honey, E., & Freeston, M. (2020b). Response: Anxiety and behaviour in and beyond ASD; does the idea of 'PDA' really help? – A response to Green (2020). *Child and Adolescent Mental Health*, 25, 77–78.
- Green, J. (2020). Commentary: Anxiety and behaviour in and beyond ASD; does the idea of 'PDA' really help? – a commentary on Stuart et al (2020). *Child and Adolescent Mental Health*, 25, 74–76.
- Green, J., Absoud, M., Grahame, V., Malik, O., Simonoff, E., Le Couteur, A., & Baird, G. (2018). Pathological demand avoidance: Symptoms but not a syndrome. *The Lancet Child & Adolescent Health*, 2, 455–464.
- Kerns, C.M., Newschaffer, C.J., & Berkowitz, S.J. (2015). Traumatic childhood events and autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45, 3475–3486.
- Malik, O., & Baird, G. (2018). Commentary: PDA - what's in a name? Dimensions of difficulty in children reported to have an ASD and features of extreme/pathological demand avoidance: a commentary on O'Nions et al (2018). *Child and Adolescent Mental Health*, 23, 387–388.
- O'Nions, E., & Noens, I. (2018). (2018) Commentary: Conceptualising demand avoidance in an ASD context – a response to Osman Malik & Gillian Baird. *Child and Adolescent Mental Health*, 23, 389–39.
- Rumball, F. (2019). A systematic review of the assessment and treatment of posttraumatic stress disorder in individuals with autism spectrum disorders. *Review Journal of Autism and Developmental Disorders*, 6, 294–324.
- Stuart, L., Grahame, V., Honey, E., & Freeston, M. (2020). Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents. *Child and Adolescent Mental Health*, 25, 59–67.
- Woods, R. (2020). Commentary: Demand Avoidance Phenomena a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents – a commentary on Stuart et al (2020). *Child and Adolescent Mental Health*, 25, 68–70.