

Extreme/'pathological' demand avoidance

Liz O'Nions^{1,2,3}, Francesca Happé² & Essi Viding^{1,2}

¹ Developmental Risk and Resilience Unit, Division of Psychology and Language Sciences, University College London, UK.

² MRC Social, Genetic & Developmental Psychiatry Centre, Institute of Psychiatry, Psychology & Neuroscience, King's College London, UK.

³ Parenting and Special Education Unit, KU Leuven, Belgium.

Correspondence to: liz.onions@kuleuven.be

Accepted for publication in British Psychological Society DECP Debate, issue 160

In recent years, there has been growing interest in extreme/'pathological' demand avoidance – a constellation of symptoms that characterises some children on the autism spectrum. The term 'pathological demand avoidance' (PDA) was first described by psychologist Elizabeth Newson in the 1980s, and is increasingly used by practitioners in the UK who want to highlight specific behavioural challenges and needs of a subset of children on the autism spectrum. Individuals with this presentation display an obsessive resistance to complying with everyday demands and requests, coupled with an intense need for control. Other characteristics include strategic avoidance behaviours that appear to reflect an awareness of what might cause diversion or upset (e.g. distraction, excuses, manipulation of rules, socially shocking behaviours) (Newson, 1988; Newson, Le Maréchal & David, 2003).

Although there are obvious differences from a classic ASD profile, our work suggests that those with substantial features of extreme/'pathological' demand avoidance have similar levels of autistic traits to those with ASD who do not show this pattern (O'Nions et al., 2014a; O'Nions et al., 2016). Indeed, the work that conceptualised this profile as distinct from autism (albeit part of a spectrum of pervasive developmental disorders) was undertaken at a time when autism had a much narrower definition than it has today, as reflected by changes in prevalence estimates (Fombonne, Quirke & Hagen, 2011).

One reason why extreme/'pathological' demand avoidance has sparked considerable interest is that behaviour in individuals displaying this pattern is often so extreme that it results in exclusion even from specialist schools (Gore Langton & Frederickson, 2015). Everyday demands can trigger outbursts of rage, physical attack, or self-injury, even in children in late childhood/ adolescence, and in children who do not have learning disabilities (Newson, Le Maréchal & David, 2003). One boy reportedly gave staff in his residential placement 'consequences' when demands were placed on him by smearing faeces and urine. Parents have reported needing assistance from police and ambulance services to restrain their child during violent meltdowns, apparently related to perceived pressure to conform. Teachers and staff in residential settings also report that these children can be disabling for staff, and put extreme pressure on the setting as a whole (e.g. Eaton & Banting, 2012).

Need for control, a further key feature of this presentation, is evident in less extreme but nonetheless problematic features, such as domineering behaviour towards peers and adults. It may also underpin extreme impulsivity and sudden changes in mood, also common in children with this profile. Intriguingly, some children are reportedly better able to comply with requests whilst adopting a fictitious role than 'as themselves'. Role play can also be used as a means of exerting control (e.g. adopting the role of a teacher and giving instructions to peers) (Newson, Le Maréchal & David, 2003).

Findings from work we have carried out analyzing interview data from a clinic sample suggests that features of extreme/'pathological' demand avoidance are dimensional within the autism spectrum, and occur across a range of severity in terms of core autistic features and intellectual disability (O'Nions et al., 2016). Evidence for a more balanced gender ratio in extreme/'pathological' demand avoidance compared to ASD without these features (Newson, Le Maréchal & David, 2003; O'Nions et al., 2014a; O'Nions et al., 2014b; Gillberg et al., 2015), and reports that demand avoidance is more common in females than males with ASD (Kopp and Gillberg, 2011) has led to suggestions that extreme/'pathological' demand avoidance could be a more female-typical ASD presentation (Gould and Ashton-Smith, 2011). One population-based study estimated the prevalence of extreme/'pathological' demand avoidance features in ASD including use of socially manipulative/ shocking behaviour to avoid demands at approximately one

in twenty-five (Gillberg et al., 2015). However, other features such as non-compliance with demands may be considerably more common.

Investigation of the underlying cognitive and emotional processes in children with extreme/'pathological' demand avoidance is the essential next step to shed light on how it relates to ASD features. For example, children with extreme/'pathological' demand avoidance may display the cognitive rigidity/ obsessive behaviour characteristic of ASD, but with a focus (atypically) on resisting attempts to make them submit to requests from others (Gillberg et al., 2015). Research into the drivers of behaviour in this profile is in its infancy, but will prove essential in improving our understanding of the presenting features, and informing the development of targeted management approaches.

Extreme/'pathological' demand avoidance and profiles with behavioural overlap

In view of the very difficult behaviour that characterises extreme/'pathological' demand avoidance, it is not surprising that parallels have been drawn with disruptive behaviour disorders, such as oppositional defiant disorder (ODD) and conduct disorder (CD). ODD is defined in DSM-5 as a pattern of angry/ irritable mood, argumentative/ defiant behaviour or vindictiveness, and CD as a pattern of persistent violation of societal norms and the rights of others (American Psychiatric Association, 2013). Notably, there are several important differences in the behavioural presentation compared to extreme/'pathological' demand avoidance.

Firstly, simple demands and requests are usually acceptable to children with ODD/CD given sufficient inducement. In addition, aggression usually occurs in contexts in which there is either provocation (e.g. threat or frustration), or instrumental gain (e.g. theft of goods, increase in status) (Frick & Viding, 2009). In contrast, children with features of extreme/'pathological' demand avoidance resort to aggression, violence and embarrassing behaviour, such as a 13-year old refusing to change out of their pyjamas before going to school, a 15-year old lying down in a school corridor and refusing to move. This occurs in contexts that to most children appear to be mundane situations. Adopting these bizarre behaviours when no obvious provocation exists means that individuals with this profile are frequently viewed as infantile and irksome by peers.

Another area of overlap between children with ODD/CD and children with extreme/'pathological' demand avoidance is in instrumental use of shocking/aggressive behaviour, such as targeted provocation of peers, or spoiling/ destruction of siblings' possessions. Notably, children with extreme/'pathological' demand avoidance typically employ these behaviours in a relatively socially un-sophisticated and obvious manner. This contrasts to children with ODD/CD, who can be very apt at avoiding detection. This apparent overlap has led to discussion of whether extreme/'pathological' demand avoidance may combine neurocognitive impairments associated with ASD and disturbances in empathic behaviour (Wing, Gould & Gillberg, 2011; O'Nions et al., 2014a).

It should be noted that, so far, we have approached this profile from the starting point of our expertise in ASD. It remains possible that behaviours that resemble descriptions of extreme/'pathological' demand avoidance could be found in other populations, such as children with other neurodevelopmental phenotypes (Reilly et al., 2014; Gillberg, 2014) or attachment problems (Moran, 2010). Further studies that systematically examine whether individuals displaying this pattern meet diagnostic thresholds for ASD on gold-standard tools are needed to begin to explore these possible overlaps.

One challenge is that research conducted outside of clinical settings typically relies on volunteer samples of parents, who are often highly motivated and committed to furthering understanding of their child's difficulties. This research is helpful in demonstrating that features of extreme/'pathological' demand avoidance can occur in children who, to the best of our knowledge, have not experienced unusually difficult or challenging rearing environments. However, it does present challenges for clinicians who encounter children who have been exposed to a wider spectrum of environmental risks. Research in clinical settings that can address exposure to risk factors will prove essential in furthering our understanding of this profile, although given that neurodevelopmental disorders in parents and/or children may affect risk exposures (e.g. by impairing attachment processes), it may be difficult to disentangle the true origins of behavioural difficulties.

Management strategies and PDA

In the context of ASD in general, and extreme/'pathological' demand avoidance in particular, disturbances in cognitive processes likely play a fundamental role in the origins of maladaptive behaviours. However, dynamic interplay between child behaviours, caregiver behaviours and situational factors may impact its course.

Descriptions of extreme/'pathological' demand avoidance suggest that behavioural management approaches used in specialist settings for ASD (e.g. routine and structure), or recommended in good practice guidelines (e.g. use of reinforcement to reduce maladaptive behaviours; Volkmar et al., 2014) are often ineffective (Newson, Le Maréchal & David, 2003). One explanation for the apparent lack of efficacy of rewards is that they are contingent on complying, and so can serve to exacerbate the child's sense that the adult is taking control. Praise for good work may also lead them to destroy whatever it was they were praised for, which could be interpreted as 'avoiding demands in retrospect' (Newson, Le Maréchal & David, 2003).

Clinical accounts recommend that parents/ teachers adopt a non-confrontational, collaborative approach, using specific strategies to 'depersonalise' or distract from demands. Examples include using overly polite language to disguise demands, playing dumb and asking for the child's help, or letting them select which of a set of tasks they will agree to complete (Newson, Le Maréchal & David, 2003; Christie, 2007; Eaton & Banting, 2012; Christie et al., 2012). A key-worker approach is recommended, in which rapport can develop between the child and a set of trusted individuals. Anecdotal reports suggest that adopting these approaches can have a positive impact, even where other interventions appear to have failed.

At present, little is known about why real or perceived demands provoke obsessive resistance. Factors that are may be conflated with demands could play a role, such as impairments in receptive communication. Ongoing work by Freeston et al. (personal communication, 22nd April 2016) suggests that anxiety related to uncertainty contributes to need for control in children with features of extreme/'pathological' demand avoidance. As such, it will be important to test whether managing predictability in certain aspects of the child's day-to-day life (e.g. limiting unstructured time with peers, giving

advance warning regarding non-routine events) is helpful in reducing problem behaviour and promoting well-being.

The aforementioned strategies focus on the pragmatic need to allow individuals to function with a minimum of distress to themselves and others. The rationale is that by reducing negative affect in relation to demands, opportunities for learning and positive development arise, and incidents of extreme behaviour become less frequent (Christie et al., 2012). However, reports suggest that getting teachers and caregivers 'on board' with strategies that in essence collude with the child's need for control is often challenging (Eaton & Banting, 2012). It is deeply ingrained in adults to react with anger to behaviours that transgress social norms or hurt others, in particular if they appear to be employed in a strategic manner to gain attention or create disruption. In the context of typical development, such responses serve an important function in socialisation. Recognition and acceptance that, in the context of extreme/'pathological' demand avoidance, these behaviours represent a 'lagging skill' and are beyond the child's voluntary control, appears to be key in motivating caregivers to accept a collaborative approach (e.g. Newson, Le Maréchal & David, 2003; Christie, 2007; Eaton & Banting, 2012).

Conclusion

It is imperative that research on this profile addresses the current gaps in our knowledge regarding the underpinnings of resistance to demands and requests. We are engaged in the next steps of such research, including studies to better map the cognitive and emotional processing profile of these children, as well as systematic investigation into behavioural strategies and management practices.

At present, there is considerable controversy about the usefulness of the term pathological demand avoidance, which is distracting from the real imperative. Children who exhibit this very problematic behavioural profile need to have their difficulties complying with demands and extreme/controlling behaviour fully addressed in assessments, as it is these behaviours that typically create the most challenge for families and schools. Appropriate description and formulation of the child's difficulties is the starting point for the identification of potential management strategies and appropriate

educational support. It is essential that this help is provided to these very vulnerable individuals and their families.

Despite increasing awareness of extreme/'pathological' demand avoidance at a grassroots level, we receive numerous emails from parents unable to access support or advice from clinical services. When parents are told that services 'don't acknowledge PDA', they are left feeling that their child is being wilfully misunderstood and their concerns actively ignored - an exceptionally demoralizing experience for families already strained to breaking point. Lack of awareness among clinical teams that these features can have a neurodevelopmental origin, rather than necessarily resulting from ineffective parenting practices or attachment problems (e.g. Kopp & Gillberg, 2011; Newson, Le Maréchal & David, 2003; Perkins & Wolkind, 1991; Wolff, 1995), creates further discord - particularly with parents who have made enormous personal sacrifices in their attempts to support their child effectively.

To conclude, acceptance of the behaviours that form part of the description of extreme/'pathological' demand avoidance is necessary to move forward in addressing the severe behavioural pattern associated with this profile and identifying the 'lagging skills' that underpin it. Considerably more research on the topic is needed to address how best to foster positive development in individuals displaying these features.

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