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# PDA and mental health

I currently work as part of a small team in East Anglia that are regularly commissioned to assess highly complex young people who often present with extreme (pathological) avoidance of the demands of everyday life. The term pathological demand avoidance (PDA) was first used in the 1980's by Elizabeth Newson and was used to describe a group of children referred for assessment who had some features of autism or Asperger's syndrome but did not quite 'fit' either diagnosis.

At the time these children were often given a diagnosis of atypical autism or pervasive developmental disorder, not otherwise specified (PDD-NOS), which was not particularly helpful for parents or professionals. It was found that, although not typical of autism, they were typical of each other.

Over the years the clinical description of PDA has been slowly refined. Liz O'Nions at the Institute of Psychiatry in London developed the EDA-Q (Extreme Demand Avoidance Questionnaire) and the National Autistic Society now considers PDA to be a behaviour profile that is seen in some individuals on the autism spectrum. Over the years PDA has evoked a great deal of controversy and discussion amongst professionals.

## Characteristics of PDA

The first sign of difficulty reported by parents is often extreme avoidance of any demands (usually starting by about 18 months and much more than just the 'terrible two's'). Avoidance strategies when faced with any demands increase, ranging from:

- excuses (my legs are broken, my tummy hurts)
- outright refusal
- 'almost' doing something but not quite.

Children with PDA can appear superficially sociable, particularly the girls. However, friendships often fail as they can become too controlling. The child appears to have an overwhelming need

for control, often driven by high levels of anxiety. Moods can switch suddenly from calm to 'meltdown' often with no apparent trigger. Meltdowns can feel like a panic attack.

There can be obsessive behaviour but this can often be the desire to have things their own way and some children with PDA will react with violence when they feel there is no escape from a situation they find difficult. They may threaten or even attack teachers, family and friends and may have little or no recall of the event afterwards. Pretend play in children with PDA tends to appear superficially better than in autistic children - they are often good at role playing and can be excellent actors and actresses. Most children with PDA will have sensory difficulties.

## PDA in adulthood

There is currently little or no research available into how PDA changes/develops into adulthood, although adults who do identify features of PDA in themselves report a variety of outcomes; some find employment or become self-employed.

Others, particularly young adults with PDA, continue to experience difficulties in living independently and maintaining employment. Some, particularly those who have never had a formal diagnosis or received support for their difficulties, report significant mental health difficulties.

In our practice we have been gathering a large amount of information about both children and adults with a PDA behavioural profile over the past two years. We are hoping to establish the key presenting features and will be collaborating with Prof Francesca Happe and Dr Liz O'Nions at UCL over the next few months to formally analyse our data.

## Common mental health concerns in individuals with PDA

One aspect which has become clear are the types and frequency of mental health difficulties experienced by this group:

- social anxiety (OCD, Panic disorder)
- depression
- social withdrawal (often attributed to schizophrenia)
- bi-polar presentation
- brief cyclical/recurrent psychotic episodes
- non-psychotic hallucinations
- catatonia/paranoid states
- post-traumatic stress disorder (PTSD)
- self-harm
- anorexia nervosa and other eating disorders

## Supporting individuals with PDA and mental health concerns

Many of the issues faced by both young people and adults with PDA are similar to those faced by many autistic people, namely:

- difficulties with communication
- difficulties with friendships and relationships
- self-esteem difficulties
- inflexible thinking
- sensory processing problems.

However what appears to be an additional factor for those with the PDA profile is extremely high levels of anxiety and an exaggerated fight, flight or freeze response which can lead to loss of control and 'meltdown'.

Whilst some of the mental health challenges outlined above may be due to a predisposition towards co-morbidity seen in many autistic people, the risk of some could be minimised if the individual was helped from an early age to manage anxiety levels. Again, as with other autistic people emotions and the physical response to stress and anxiety can be difficult to identify. Programmes such as adapted cognitive behavioural therapy and Dialectical Behaviour Therapy (DBT) may help to increase emotional awareness.

DBT was initially developed for use with young women with Borderline Personality Disorder (Linehan 1993). However the skills training elements can be helpful in improving emotional awareness, and in self-monitoring difficult and distressing behaviour. They include:

- interpersonal effectiveness
- emotion regulation
- distress tolerance
- mindfulness.

## Case study

L is a fifteen year old young woman with a diagnosis of autism, with the PDA profile. At the time of the referral she was experiencing very low mood and was constantly seeking for items with which to self-harm. Due to her lack of danger awareness, her parents were concerned she may accidentally cause serious injury. L also reported hearing two 'voices' in her head:

- one she described as the 'good' version of herself
- the other the 'bad' version – a very angry voice that told her that she was useless and should self-harm.

These voices were causing L great distress.

It was not possible to engage L in direct therapy as she was too anxious and the 'demand' of having to talk during a specific appointment time was too much for her.

The approach which was ultimately taken was to conduct sessions via Skype with L's mother (with whom she has a close and trusting relationship). This meant that L did not have to physically engage with the therapist if she did not feel able to, and ideas and suggestions for

managing anxiety and challenging the negative voice were given to her in a non-direct manner. This allowed L to absorb and think about the suggestions given and ultimately to reduce her anxiety levels.

It appears that when working with this group of young people, similar approaches to those described above for managing behaviour (low demand, offering choice, indirect questions, flexibility) can also be effective for helping to manage mental health issues.

## References

Linehan, M.M., 1993, Cognitive-Behavioral Treatment of Borderline Personality Disorder (Diagnosis and Treatment of Mental Disorders), New York, Guilford Press