Extreme Demand Avoidance Questionnaire

O'Nions, Christie, Gould, Viding, & Happé (2014)

The scale can be completed for children aged 5 – 17 years

More information about the scale is provided on the final page (O'Nions, 2018, unpublished document)

| Name of child | : |
|---------------|---|
| Date of birth | : |
| Completed by | : |
| Date | : |

Completion instructions

Please answer the questions thinking about the child's behaviour during the last six months. Please read each item carefully and fill in the answer that best applies.

For each question, you can choose from four possible options: 'Not', 'Somewhat true', 'Mostly true' and 'Very True'. Please try to fill in all items. There are no right or wrong answers.

The questionnaire should be completed by parents, carers or teachers who have had frequent (almost daily) contact with the child during the past six months.

| | | Not true | Some- what true | Mostly true | Very true |
|----|--|----------|--------------------|----------------|--------------|
| 1 | Obsessively resists and avoids ordinary demands and requests. | | | | |
| 2 | Complains about illness or physical incapacity when avoiding a request or demand. | | | | |
| 3 | Is driven by the need to be in charge. | | | | |
| 4 | Finds everyday pressures (e.g. having to go on a school trip/ visit dentist) intolerably stressful. | | | | |
| 5 | Tells other children how they should behave, but does not feel these rules apply to him/herself. | | | | |
| 6 | Mimics adult mannerisms and styles (e.g. uses phrases adopted from teacher/parent to tell other children off). | | | | |
| 7 | Has difficulty complying with demands unless they are carefully presented. | | | | |
| 8 | Takes on roles or characters (from TV/real life) and 'acts them out'. | | | | |
| 9 | Shows little shame or embarrassment (e.g. might throw a tantrum in public and not be embarrassed). | | | | |
| 10 | Invents fantasy worlds or games and acts them out. | | | | |
| 11 | Good at getting round others and making them do as s/he wants. | | | | |
| 12 | Seems unaware of the differences between him/herself and authority figures (e.g. parents, teachers, police). | | | | |
| 13 | If pressurised to do something, s/he may have a 'meltdown' (e.g. scream, tantrum, hit or kick). | | | | |
| 14 | Likes to be told s/he has done a good job. | | | | |
| 15 | Mood changes very rapidly (e.g. switches from affectionate to angry in an instant). | | | | |
| 16 | Knows what to do or say to upset specific people. | | | | |
| 17 | Blames or targets a particular person. | | | | |
| 18 | Denies behaviour s/he has committed, even when caught red handed. | | | | |
| 19 | Seems as if s/he is distracted 'from within'. | | | | |
| 20 | Makes an effort to maintain his/her reputation with peers. | | | | |
| 21 | Uses outrageous or shocking behaviour to get out of doing something. | | | | |
| 22 | Has bouts of extreme emotional responses to small events (e.g. crying/giggling, becoming furious). | | | | |
| 23 | Social interaction has to be on his or her own terms. | | | | |
| 24 | Prefers to interact with others in an adopted role, or communicate through props/toys. | | | | |
| 25 | Attempts to negotiate better terms with adults. | | | | |
| 26 | S/he was passive and difficult to engage as an infant. | | | | |

EDA-Q, O'Nions, Christie, Gould, Viding & Happé (2014)

How to generate a total score the EDA-Q (O'Nions et al., 2014):

| Questions 1 - 26 (apart from questions 14 and 20): | | | | |
|--|-----|--|--|--|
| Not true | = 0 | | | |
| Somewhat true | = 1 | | | |
| Mostly true | = 2 | | | |
| Very true | = 3 | | | |
| Questions 14 & 20: | | | | |
| Not true | = 3 | | | |
| Somewhat true | = 2 | | | |
| Mostly true | = 1 | | | |
| Very true | = 0 | | | |

Interpreting total scores based on informant reports (based on results of O'Nions et al., 2014):

<u>Age 5 - 11 years</u>: A total score of 50 or more identified those at high risk of showing features of Extreme Demand Avoidance based on parent report.

<u>Age 12 - 17 years</u>: A total score of 45 or more identified those at high risk of showing features of Extreme Demand Avoidance based on parent report.

Please note that the EDA-Q is not a diagnostic instrument. It was developed for research purposes to quantify resemblance to the profile of pathological demand avoidance as described by Newson, Le Maréchal & David (2003).

Reference

O'Nions, E., Christie, P., Gould, J., Viding, E. & Happé, F. (2014). Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): Preliminary observations on a trait measure for Pathological Demand Avoidance. *Journal of Child Psychology and Psychiatry, 55,* 758–768.

Information about the EDA-Q

O'Nions, 2018, unpublished document

Why was the EDA-Q developed?

The 'Extreme Demand Avoidance Questionnaire' (EDA-Q) was developed to measure behaviours reported in clinical accounts of extreme/'pathological' demand avoidance (PDA). The questionnaire has allowed us to measure these traits consistently for research purposes.

Extreme/'pathological' demand avoidance (PDA) has been described as a sub-group within the autism spectrum (Newson, Le Maréchal & David, 2003). Indeed, individuals who resemble the descriptions of PDA have a lot in common, so it is useful to study them as a group.

However, sub-groups inevitably cause disagreement about where the boundary should lie in terms of who does and doesn't meet criteria. An alternative is to think about extreme demand avoidance traits as a continuous dimension. This reflects the reality: features such as non-compliance with routine requests occur in varying concentrations in individuals with ASD - there are no natural cut-points (e.g. O'Nions et al., 2016).

We have used the EDA-Q to study behaviours in the context of ASD. Although we suspect that those with the highest levels of these behaviours would also meet criteria for ASD, at present, there have been no studies of how the distributions of EDA and ASD traits overlap in population representative samples.

How to interpret scores on the EDA-Q

In our study of parent-reported behaviours in children and adolescents, for children aged 5 to 11, a score of 50 and over, and for children aged 12 to 17, a score of 45 and over indicated an elevated risk of parents reporting that the child had been clinically identified as having a profile resembling PDA.

Importantly, given that there is no diagnostic algorithm for PDA, it is not possible for any measure to identify those who would and wouldn't meet diagnostic criteria. Therefore, scores on the EDA-Q should be interpreted dimensionally. Individuals scoring above the cut-offs could be described as having 'high EDA traits' based on informant reports.

Where can I find more information about the EDA-Q?

A description of how the measure was developed and the preliminary validation of it can be found here: http://discovery.ucl.ac.uk/1422617/1/O%27Nions_EDAQ_accepted.pdf Please contact Liz O'Nions (liz.onions@kuleuven.be) if you have any questions about the measure.

References

- Newson, E., Le Maréchal, K. & David, C. (2003) Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Arch. Dis. Child.*, 88, 595-600.
- O'Nions, E., Christie, P., Gould, J., Viding, E. & Happé, F. (2014) Development of the 'Extreme Demand Avoidance Questionnaire' (EDA-Q): Preliminary observations on a trait measure for Pathological Demand Avoidance. *JCPP*, 55, 758-768.
- O'Nions, E., Gould, J., Christie, P., Gillberg, C., Viding, E., & Happé, F. (2016) Identifying features of 'Pathological Demand Avoidance' using the Diagnostic Interview for Social and Communication Disorders ('DISCO'). *ECAP*, 25, 407-419.