

Behaviour in boys and men with fragile X syndrome

Report of the talk given at the Fragile X Society's Conference June 2005

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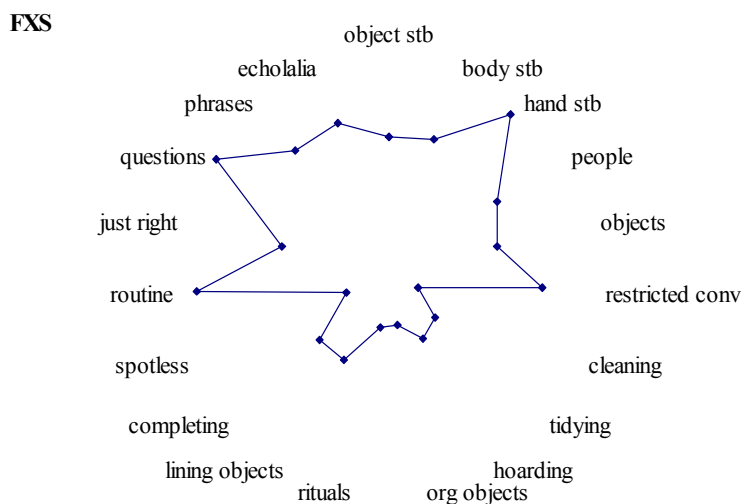
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Thank you to all of the parents and carers who took part in our study of behaviour in boys and men with fragile X syndrome. The project was very successful and we received nearly 200 responses.

We compared the behaviour of individuals with fragile X syndrome to a group of individuals with intellectual disability of mixed cause and six other genetic syndrome groups including: Cornelia de Lange, Cri du Chat, Angelman, Lowe, Prader-Willi and Smith Magenis syndromes. In particular, we were interested in finding out more about repetitive behaviour, hyperactivity, mood and challenging behaviour in these syndrome groups and how the behaviours might be associated.

Repetitive Behaviour in Fragile X Syndrome

The figure below demonstrates the pattern of repetitive behaviour identified in fragile X syndrome. Each point around the circle represents a different type of repetitive behaviour. The closer the dots are to the edge of the circle, the more frequently the behaviour is occurring.



In fragile X syndrome, the pattern is very wide suggesting that a number of different forms of repetitive behaviour occur at high frequency in the syndrome. We identified several types of repetitive behaviours, which occurred at much higher frequencies compared to all the other groups included in the study. These were: hand stereotypies,

restricted conversation, lining up objects, tidying up, preference for routine, repetitive phrases/signs, echolalia and 'just right' behaviours. We concluded that these behaviours were characteristic of Fragile X syndrome.

Challenging Behaviour in Fragile X Syndrome

We found that just over half of the boys and men with fragile X syndrome had shown aggression or self-injury at the time we surveyed. Whilst self-injury was more common in fragile X than the mixed intellectual disability group (about four times more common) aggression occurred at about the same rates. Also, self-injury by biting was much more common in fragile X syndrome than the mixed group.

In combination these findings tell us that self-injury by biting is part of what is called the 'behavioural phenotype' of fragile X syndrome for boys and men but aggression is not. The questions that then arise are: why is this behaviour more common in boys and men in Fragile X syndrome and can we reduce it? Now we are sure about the behaviours we need to focus on, our future research can try to look at both environmental and biological causes.

Affect, Autistic-like Behaviour, Overactivity and Impulsivity in Fragile X Syndrome

We also looked at affect (high or low mood), autistic like behaviour, overactivity and impulsivity (acting without thinking) in the boys and men. We found that in comparison to other syndromes boys and men with fragile X syndrome showed high levels of overactivity and impulsivity and high levels of autistic-like behaviours (although we can't say whether this is 'true' autism as we only used a broad screening measure).

Interestingly, we also found that men and boys with fragile X syndrome experienced very positive mood in comparison to other groups and we don't think this has been reported before. From the reports of parents and carers it seems that boys and men with fragile X syndrome smile and laugh more and don't seem to experience low mood quite so often. This is an intriguing finding that we will pursue.

Finally, we found that some of these characteristics were associated with self-injury. Those boys and men who showed self-injury were more impulsive and overactive and showed more repetitive behaviours. We think this means that there might be an underlying problem of behaviour regulation in those showing self-injury. It has been suggested that impulsivity (acting without thinking) and repetitive behaviours indicate that people find it difficult to monitor and stop their own behaviour. So, when a behaviour like self-injury is learned the person will find it hard to stop this behaviour when something in the environment acts as a trigger. We need to do more work on this but we think there might be implications for teaching people 'self-talk' in order to monitor their own behaviour more easily.

This research report was published in the Fragile X Society's Newsletter, Winter 2005 Issue No 36, Research & Conference Report Supplement.

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