



SPECIAL REPORT

Part 1: Examining the Function of Challenging Behaviour in Lowe Syndrome

BY ALICIA KUTSCH, EMMA SHEPHERD, JANE WAITE & PROF. CHRIS OLIVER

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Why study behaviours that challenge in Lowe Syndrome?

When we talk about behaviours that challenge we mean any behaviour which may put the person or those around them at risk, or which may limit the person's engagement with community facilities or home life.

Research in rare genetic syndromes has shown that having a particular syndrome can place a person at increased risk of showing behaviours that challenge.

Research has also shown that these behaviours may serve a purpose (or *function*) for individuals with intellectual disabilities, and that this purpose (or function) varies from syndrome-to-syndrome.

Lowe Syndrome (LS) has been shown to be one of the syndromes where there is greater risk of behaviours that challenge, yet very few studies have looked at the function of these behaviours.

This article reports on the first stage in a large study being carried out by the Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham. It investigated the function associated with self-injury, aggression, and temper

outbursts to develop a greater understanding of how behaviour may develop and be maintained in Lowe syndrome.

Greater understanding of what causes an individual to engage in behaviours that challenge will lead to more effective interventions in the future.

The behaviours that we explored were:

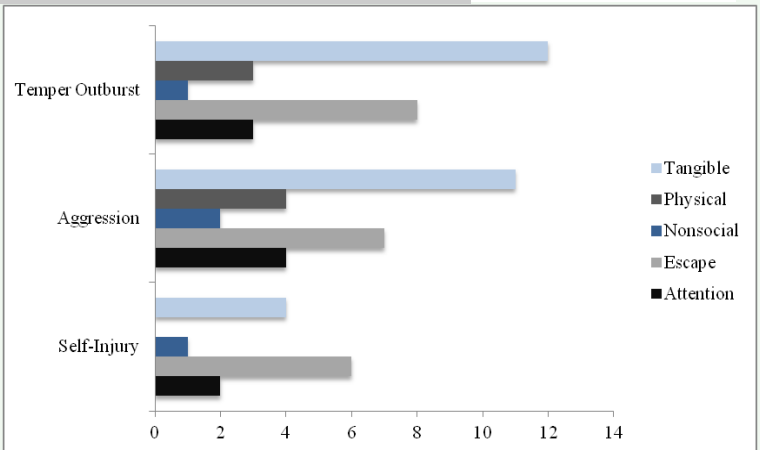
Self-injurious behaviour (e.g. head-banging)

Aggressive behaviour (e.g. hair pulling, hitting out at others)

Temper-outbursts

Behaviours often serve one of five functions:

- **Tangibles** – to obtain desired objects or items
- **Physical** – because the person is experiencing pain or feeling unwell
- **Non-Social** – to self-stimulate because the person enjoys the sensation.
- **Escape** – because demands / people / tasks are removed.
- **Attention** – to receive social attention from another person.



Above: Number of individuals whose behaviour served each function.

What is the function of challenging behaviours in Lowe Syndrome?

Results from this study showed that over half of individuals with Lowe syndrome showed at least one form of behaviour that challenged.

Self-injury was most likely to be related to a desire to "escape" from a disliked situation or task demand while aggression and temper outbursts were most likely to be related to a desire to access objects or items in the environment. See graph above.

These results fit with previous research that has reported that temper outbursts in Lowe syndrome occur when

individuals' 'needs are not met immediately'. However, what is unclear is whether temper outbursts occur because the person has learnt that the desired object is usually given following a temper-outburst or whether simply waiting for needs to be met is very overwhelming for individuals with Lowe syndrome due to difficulties regulating emotions. Researchers at the University of Birmingham are currently analysing data collected at the Lowe Syndrome Association conference to answer this question.

For 6 out of 10 individuals with Lowe syndrome, temper outbursts are triggered when a person is motivated to obtain a preferred object or activity.

What Can Help?

Professionals:

Sharing the findings of this research with anyone who is involved in your child's care may help them to understand how best to support you.

If you need additional support to target behaviours that challenge, you should contact a professional who is experienced in administering behavioural interventions. In the UK, this is likely to be a psychologist.

Websites:

A number of websites provide support and advice for people who engage in behaviours that challenge, and those that support them. It should be noted that (as mentioned previously) there is little research dedicated to behaviour in Lowe Syndrome specifically, however the principles for assessing and intervening and treating challenging behavior should be able to be applied across syndromes, to good effect.

- www.findresources.co.uk/common-issues
- www.challengingbehaviour.org.uk/
- www.scope.org.uk/Support/Parents/Behaviour/What-is-challenging-behaviour
- <http://www.skillsforcare.org.uk/Skills/>
- <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/challenging-People-whose-behaviour->

Ongoing Research

The research described here is only a very small part of a much broader investigation into behaviour in LS.

Many of you took part in the research at the LS conference back in June 2015, and will therefore be aware of the fact that we are in the process of producing:

- **Further research outputs**
- **Individualised feedback reports**
- **More research summaries**

As this is part of a larger study, further work will look at responses from parent interviews regarding the nature of behaviours that challenge. This is to obtain a better understanding of the antecedents (events/situations which trigger the challenging behavior) and consequences (how others respond/ what happens after the behavior). Responses may shed light on the forms of self-injury commonly reported in Lowe syndrome (i.e. head banging, hand biting).

Result from cognitive assessments will also be analysed in order to understand the relationship between cognitive aspects of the syndrome and the presentation behaviours.

Contact Details

Dr Jane Waite
0121 414 4909

Centre for Neurodevelopmental Disorders Website:
www.findresources.co.uk

Conclusion

This research project has highlighted that:

- More than half of the participants reported showing at least one or more behaviours that challenge.
- These behaviours may serve a number of functions for people with LS.
- Self-injury was most likely to function to escape from demands.
- Aggression and temper outbursts were most likely to function to access tangible items; however, they may be related to the frustration associated with waiting.

Thank you!