



Extended Research Article

A group intervention for parents and carers to recognise and understand restricted and repetitive behaviour in autistic children: a multisite RCT

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Scientific summary

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Scientific summary

Background

Restricted, repetitive and stereotyped patterns of interests, behaviours and activities [restricted repetitive behaviour (RRB)] such as repetitive movements, rigid routines, unusual preoccupations, circumscribed interests, resistance to change and sensory sensitivities form one of two key symptom domains required for a diagnosis of autism spectrum disorder (ASD). Frequently, RRBs are reported by autistic people to be enjoyable, functional and helpful. RRBs can be a source of great pleasure. They may provide a basis for friendship and can also build areas of strength, supporting skill development and yielding employment opportunities. For these reasons, and in line with the non-normalising agenda of neurodiversity, the default pathologisation of RRB should be resisted.

However, autistic people also report that restricted and repetitive behaviour (RRB) may also be an outward sign of anxiety or distress, and some behaviours can have a functional impact, causing harm to the child or restricting their access to learning or participation in their community. In addition, families can find understanding this repertoire of behaviours particularly difficult, both to understand and in terms of their family impact. Furthermore, RRB can interfere with family functioning and can cultivate negative parenting styles, which in turn may be detrimental to the autistic child's development. Currently there are no evidence-based interventions available that focus specifically on supporting parents/carers to understand and respond to their child's functionally impactful RRB.

The Understanding Repetitive Behaviour intervention (URB) was developed in collaboration with parents/carers. Understanding Repetitive Behaviours (URB) is an eight-session, parent-mediated group intervention that aims to increase parents/carers' understanding of their child's RRB and support them to develop strategies to differentiate between RRB that are beneficial or pleasurable for their child and those that have potential to cause harm (hereby known as functionally impactful RRB), and reduce engagement in these repetitive behaviours.

Objectives

1. Compare the clinical effectiveness of the URB intervention for NHS community clinical practice with psychoeducation, for the management of functionally impactful RRB in autistic children at 24 and 52 weeks follow-up.
2. Assess the cost-effectiveness and cost consequences of the URB intervention compared with an autism parent/carer psychoeducation group (Learning About Autism; LAA) at 52 weeks follow-up.

Methods

The study was a clinical and cost-effectiveness, large-scale, multisite randomised controlled trial (RCT) of the URB parent group intervention versus the LAA psychoeducation parent group (current best practice) for parents of autistic children aged 3 years to 9 years 11 months. All analyses were done under an intention-to-treat principle. The primary outcome was at 24 weeks. The economic evaluation was conducted from the perspective of both NHS costs and family access to local community services.

Parents and carers aged 18 years and older were eligible for study entry if their child met the following criteria:

1. Aged 3 to 9 years 11 months at the time of consent with a clinical diagnosis of autism spectrum disorder (ASD), across a range of functioning levels and abilities (verbal and nonverbal).
2. Parents/carers with sufficient spoken and written English to provide written informed consent and complete the assessments, including being able to identify one or more functionally impactful RRB and participate in the group-based programme.

3. Parents/carers were willing to be randomised and attend all the group sessions for the allocated arm of the study and agree to maintain their child's current medication regime up to 24 weeks (unless change is advised by the child's clinician) and agree not to participate in any other trials while involved in the trial up to 24 weeks.

Parents/carers were not eligible for study entry if their child met any of the following criteria:

1. no clinical diagnosis of autism or ASD;
2. no functionally impactful RRB could be identified;
3. currently taking part in another parent group-based programme trial;
4. had a sibling already taking part in this study;
5. parents/carers had a severe learning disability or a significant mental health disorder that would interfere with their ability to take part in a group-based programme.

Randomisation

Randomisation was at child level using an equal allocation ratio. Each parent/carer was automatically considered in their child's randomisation group. Due to the nature of the study and the few factors (age, gender and ethnicity) that needed to be accounted for in the randomisation, a minimisation scheme instead of stratified randomisation was used to minimise sample fragmentation due to the number of strata and to avoid accidental imbalance between the URB group and the LAA comparison group across the levels of age, gender and ethnicity.

Study setting

The URB and the LAA parent/carer groups were delivered in community settings in different geographical locations across the three sites in North East England and Scotland. The first participant was randomised on 13 November 2018. The final participant was randomised on 15 September 2020. Due to restrictions resulting from COVID-19, all baseline and follow-up visits were conducted via telephone after March 2020 and delivery of both interventions moved from face-to-face delivery to online platforms. A minority of families ($n = 47$) completed their participation in the trial, up to the 24-week follow-up assessment, prior to the onset of COVID-19 restrictions, and therefore only 25% of families recruited to the study experienced the trial in its original format.

The intervention

Understanding Repetitive Behaviours is designed to help parents/carers of young autistic children to recognise, understand and learn how to manage their child's functionally impactful RRB. It is an eight-week manualised intervention designed to be delivered by trained community-based professionals with knowledge and experience of working with young autistic children and their families. Each weekly session lasts for approximately two hours. Each parent/carer is provided with a manual, related weekly materials, and individual support to identify strategies to address functionally impactful RRBs. 'At home' activities are set each week for parents/carers and children to complete between sessions.

Learning About Autism is an 8-week manualised parent/carer psychoeducation group that acted as an attentional control. It is designed for parents/carers of young autistic children and focuses on understanding what is autism. It is designed to be run in the community with trained professionals who have experience of working with young autistic children and their families. Each weekly session lasts for approximately 2 hours. The groups offer parents and carers psychoeducation to develop understanding of autism and what that means for their child. LAA did not include any specific information about the role and functions of RRB, or tailored strategies to manage functionally impactful RRB.

Primary clinical outcome measure

Clinical Global Impression – Improvement scale (CGI-I) provides a standardised framework to assess how much behaviour has improved or worsened relative to the child's baseline state using a seven-point scale. A trained researcher, blind to group allocation, rated global improvement in how much the child's functionally impactful RRB had changed over the 24 weeks (from baseline to primary end point). The data included available child outcome measures from baseline and week 24 [Social Responsiveness Scale – Second Edition (SRS-2) (baseline only), parent/carer and teacher Repetitive Behaviour Questionnaire – 2 (RBQ-2), Adaptive Functioning (Vineland Adaptive Behaviour Scales 3 (VABS-3), target behaviour vignettes (TBVs)] to make the rating about change for each child.

Economic evaluation: To assess the costs and benefits of the URB intervention a cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and cost-consequence analysis (CCA) were carried out. For the CEA the primary outcome is the cost per incremental improvement of CGI-I scale. For the CUA, QALYs were used as the primary outcome, both for the parent/carer's quality of life (using the EQ-5D-5L) and for the child's quality of life [using the Child Health Utility 9D (CHU-9D)]. The secondary outcomes were expressed using a balance sheet approach for the CCA, summarising the costs and which of the secondary outcome measures favour LAA and which favour URB.

Secondary clinical outcomes measures: Secondary outcome measures at the level of the child included parent/carer and teacher reports of the child's RRB (RBQ-2 and Teachers RBQ), RRB TBVs and VABS-3. Secondary outcome measures at the level of the parent/carer and family included measures of parent/carer self-efficacy (PSE), parent/carer stress [Autism Parenting Stress Index (APSI)], parent/carer well-being [Warwick-Edinburgh Mental Well-being Scale (WEMWBS)] and family functioning [Autism Family Experience Questionnaire (AFEQ)].

Results

Fidelity analysis indicated that both URB and LAA were delivered with fidelity to the manual. Five SAEs were reported during the duration of the study, none of which were deemed to be associated with participation.

Thirty-one per cent of data were missing at the primary end point. According to the initial sample size calculation for this study, to detect a 20% improvement rate between the URB intervention and LAA group at 24 weeks (proportion of events in the URB 25% and LAA 5%), assuming 10% intra-parent/carer group correlation and equal allocation ratio a minimum of 179 families were estimated to be needed to achieve 80% power ($N = 224$, 90% power). A post hoc power calculation based on the data available at the primary end point ($N = 155$) and the same parameters used in the initial sample size calculation indicated 70–75% of the power is retainable. This means that with the available data at 24 weeks, the trial collected less than expected follow-up data and so is unable to answer, with any certainty, whether or not the URB intervention is effective compared to the LAA group.

No evidence of a difference was found between the URB and LAA arms for the primary outcome measure (CGI-I) at 24 weeks.

Analysis of the secondary outcomes indicates improvement in targeted functionally impactful RRB identified by parents/carers at baseline at 10 and 24, but not 52 weeks and reduction in impact on the family unit for those families who were randomised to the URB arm, but not those who attended the LAA. Improvement in parental functioning (self-efficacy, stress and well-being) and family functioning were apparent across both intervention programmes, with no evidence of differences between the two approaches.

Regarding the results of the economic evaluations for the CEA, the incremental cost per additional child achieving the target difference in CGI-I was £36,700 for URB compared with LAA. For the CUA using the imputed data set ($n = 199$), the incremental cost per QALY for URB compared with LAA is £44,500. At a threshold of £20,000 per QALY there is a 37% chance of URB being considered cost-effective compared to a 63% chance of LAA being considered cost-effective. For the child's QALYs using the CHU-9D, LAA was both less costly and slightly more effective.

Conclusion

Strengths and limitations

This is the first large-scale RCT to investigate the clinical and cost-effectiveness of an early intervention for autistic children focusing on functionally impactful RRB – a research priority highlighted by parents of young autistic children. The RCT also used an attentional control, a new development in the evaluation of early interventions in autism. The primary outcome provided a standardised framework of overall functioning rather than simply assessing changes in the specific behaviours targeted using the intervention. Both interventions were delivered by practitioners based in the community rather than in specialist centres and the fidelity of delivery of both interventions was high even taking into account the changes necessitated by the COVID-19 pandemic.

Unfortunately, probably at least in part due to the COVID-19 pandemic, the relatively high attrition rate at 24 weeks meant that the study collected less than expected data at the primary end point. We are also aware that there are other potential factors that may have contributed to our lack of difference between the URB and LAA parent groups.

Areas for further research

Future research should focus on trying to determine what the mechanisms of change in functionally impactful RRB are for autistic children. Future research could potentially focus on a longer longitudinal follow-up, which could be utilised in economic modelling studies over a longer time horizon. In addition, different approaches to measuring benefit for parent/carer interventions for autistic children could be utilised to capture both potential positive change and adverse outcomes that are relevant to families of autistic children and meet the priorities of the autism community. These should include relevant non-health effects. From a methodological point of view, it will be important to determine how recruitment and retention of families can be improved and specifically how participation of autistic people from non-white backgrounds can be improved.

Trial registration

This trial is registered as ISRCTN15550611.

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