Guided self-help for depression in autistic adults: the ADEPT feasibility RCT

Ailsa Russell,1* Daisy Gaunt,2 Kate Cooper,1 Jeremy Horwood,2 Stephen Barton,3 Ian Ensum,4 Barry Ingham,5 Jeremy Parr,6 Chris Metcalfe,2 Dheeraj Rai,7 David Kessler7 and Nicola Wiles8

1Centre for Applied Autism Research, Department of Psychology, Faculty of Humanities and Social Sciences, University of Bath, Bath, UK
2Bristol Randomised Trials Collaboration, Population Health Sciences, Bristol Medical School, University of Bristol, Bristol, UK
3Newcastle Cognitive and Behavioural Therapies Centre, Northumberland, Tyne and Wear NHS Foundation Trust, Newcastle upon Tyne, UK
4BASS Adult Autism Service, Avon & Wiltshire Mental Health Partnership NHS Trust, Bristol, UK
5Northumberland, Tyne and Wear NHS Foundation Trust, Newcastle upon Tyne, UK
6Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK
7School of Social and Community Medicine, Bristol Medical School, University of Bristol, Bristol, UK
8Centre for Academic Mental Health, Population Health Sciences, Bristol Medical School, University of Bristol, Bristol, UK

*Corresponding author a.j.russell@bath.ac.uk

Declared competing interests of authors: Chris Metcalfe reports grants from the UK National Institute for Health Research (NIHR) Health Technology Assessment (HTA) programme during the conduct of the study. He and Stephen Baston report grants from the NIHR HTA, Public Health Research, Health Services and Delivery Research, Programme Grants for Applied Research and Research for Patient Benefit programmes since 2009. Chris Metcalfe is also a co-director of the Bristol Randomised Trials Collaboration, a UK Clinical Research Collaboration-registered trials unit in receipt of NIHR support funding. Nicola Wiles reports grants from the University of Bristol during the conduct of the study.
Scientific summary

The ADEPT feasibility RCT
Health Technology Assessment 2019; Vol. 23: No. 68
DOI: 10.3310/hta23680

NIHR Journals Library www.journalslibrary.nihr.ac.uk
Scientific summary

Background

High rates of common mental health problems, such as anxiety and depression, have been reported across the lifespan in autism. Treatments for common mental health problems that are recommended in clinical guidelines and available in the NHS include psychological interventions based on cognitive–behavioural therapy. Cognitive–behavioural therapy has been found to be clinically effective as a treatment for clinically significant anxiety in autism if it is adapted in line with the needs of autistic people. There has been less research in depression in this group, with a small number of studies using combined anxiety and depression cognitive–behavioural therapy protocols or of small pilot studies of group cognitive–behavioural therapy interventions for depression in young people. Furthermore, the NHS care pathway for mild to moderate depression comprises low-intensity psychological interventions (National Institute for Health and Care Excellence. Clinical Guidelines 90. Depression in Adults: Recognition and Management. London: NICE; 2009). This involves the use of self-help materials, either alone or guided, and includes behavioural activation. Guided self-help and behavioural activation have not been adapted for autism.

Our research aimed to begin to address the gap in the evidence base by developing a low-intensity intervention for depression that is based on behavioural activation and adapted for autistic adults.

Objectives

- To develop a low-intensity intervention for depression adapted for adults with autism spectrum disorder based on National Institute for Health and Care Excellence recommendations and training materials to guide therapists in supporting the intervention.
- To investigate the feasibility and the patient and therapist acceptability of the low-intensity intervention.
- To estimate the rates of recruitment and retention for a large-scale randomised controlled trial.
- To identify the most appropriate outcome measure for a large-scale randomised controlled trial.

Methods

The study comprised a pilot feasibility randomised controlled trial with a nested qualitative evaluation. During the development phase of the study (the initial 6 months), we developed materials for a guided self-help intervention and an accompanying therapist manual. The guided self-help intervention comprised materials for nine sessions to be delivered weekly, and facilitated by a ‘coach’ or therapist guide. The materials were designed to guide patients through behavioural activation by recording and noticing information about their activities, behaviour and feelings. Autism-specific adaptations included using visual aids to convey psychological concepts; having a clear and consistent structure to the intervention and the format of the materials; having a session on noticing positive feelings; and taking a structured, prompted approach to planning homework tasks. Autistic adults (n = 2) gave feedback about the design, format, clarity and proposed structure of the intervention materials.

Participants (n = 70) were recruited at two trial sites: Avon & Wiltshire Mental Health Partnership Trust and Northumberland, Tyne and Wear NHS Trust. A research register was used at each site. Participants were adults with a diagnosis of autism spectrum disorder and depression with a Patient Health Questionnaire-9 items score of ≥ 10. Participants were not eligible if they had attended more than six sessions of cognitive–behavioural therapy for depression in the previous 6 months or had concomitant psychosis.
untreated epilepsy, alcohol/substance dependence, a current risk of suicide such that a low-intensity intervention would not meet their needs and/or literacy levels such that the guided self-help materials would be inaccessible to them.

Participants were randomly allocated to guided self-help or treatment as usual. There were no constraints on treatment as usual. Randomisation was stratified by trial site and minimised by depression severity and antidepressant medication.

There were several measures of depression (two self-report measures and an interview measure). Other outcomes included measures of anxiety, obsessive–compulsive symptoms, social function and quality of life, and health and voluntary service use measured using a pilot questionnaire.

Quantitative outcomes were measured 10, 16 and 24 weeks post randomisation. Participants were invited to participate in the qualitative study 10 weeks post randomisation.

The qualitative study used purposive sampling to select participants to capture maximum variation in views and experiences. A topic guide was developed. Data were digitally recorded, transcribed verbatim and analysed thematically supported by qualitative data analysis software NVivo10 (QSR International, Warrington, UK).

Results

The study fulfilled the objectives as outlined. It was possible to recruit the target number of participants within the time frame proposed. Engagement with guided self-help was good, and the majority of participants completed the intervention in full. The qualitative study found that the guided self-help intervention was well received by participants and coaches alike. Suggestions for improvements were made.

The rate of retention in the guided self-help group was high (86%) at 24 weeks and this compared favourably with the rate (54%) at the same time point in the treatment as usual group. The qualitative study provided some clues to account for the differential rates of attrition, and suggested that the guided self-help had enhanced credibility at the point of randomisation for many participants, with several reasons hypothesised.

The inter-rater reliability for the interview measure of depression was poor, and hence the prespecified sensitivity to change analyses should be interpreted with caution.

The study was not powered to detect any differences between the groups on the outcome measures; however, the findings do provide very preliminary evidence that the guided self-help intervention may be effective in reducing depression symptoms.

Conclusions

Implications for health care
A low-intensity psychological intervention for depression adapted for autism is feasible and may be helpful in treating depression. It can be evaluated using randomised trial methods.

Recommendations for research

- A full-scale randomised controlled trial examining the clinical effectiveness and cost-effectiveness of this intervention would contribute to the evidence base and care pathways for autistic adults with co-occurring common mental health problems.
- A future trial incorporating a treatment as usual group would benefit from stakeholder involvement at the design stage to tackle the issue of low rates of retention.
Trial registration

This trial is registered as ISRCTN54650760.

Funding

Funding for this study was provided by the Health Technology Assessment programme of the National Institute for Health Research (NIHR). This study was also supported by the NIHR Biomedical Research Centre at the University Hospitals Bristol NHS Foundation Trust and the University of Bristol.
Criteria for inclusion in the Health Technology Assessment journal

Reports are published in Health Technology Assessment (HTA) if (1) they have resulted from work for the HTA programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

Reviews in Health Technology Assessment are termed ‘systematic’ when the account of the search appraisal and synthesis methods (to minimise biases and random errors) would, in theory, permit the replication of the review by others.

HTA programme

Health Technology Assessment (HTA) research is undertaken where some evidence already exists to show that a technology can be effective and this needs to be compared to the current standard intervention to see which works best. Research can evaluate any intervention used in the treatment, prevention or diagnosis of disease, provided the study outcomes lead to findings that have the potential to be of direct benefit to NHS patients. Technologies in this context mean any method used to promote health; prevent and treat disease; and improve rehabilitation or long-term care. They are not confined to new drugs and include any intervention used in the treatment, prevention or diagnosis of disease.

The journal is indexed in NHS Evidence via its abstracts included in MEDLINE and its Technology Assessment Reports inform National Institute for Health and Care Excellence (NICE) guidance. HTA research is also an important source of evidence for National Screening Committee (NSC) policy decisions.

This report

The research reported in this issue of the journal was funded by the HTA programme as project number 14/43/02. The contractual start date was in December 2015. The draft report began editorial review in June 2018 and was accepted for publication in March 2019. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HTA programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HTA programme or the Department of Health and Social Care.

© Queen’s Printer and Controller of HMSO 2019. This work was produced by Russell et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
NIHR Journals Library Editor-in-Chief

Professor Ken Stein  Professor of Public Health, University of Exeter Medical School, UK

NIHR Journals Library Editors

Professor John Powell  Chair of HTA and EME Editorial Board and Editor-in-Chief of HTA and EME journals. Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Senior Clinical Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May  Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals) and Editor-in-Chief of HS&DR, PGfAR, PHR journals

Professor Matthias Beck  Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Senior Scientific Advisor, Wessex Institute, UK

Dr Peter Davidson  Consultant Advisor, Wessex Institute, University of Southampton, UK

Ms Tara Lamont  Director, NIHR Dissemination Centre, UK

Dr Catriona McDaid  Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

Professor William McGuire  Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads  Professor of Wellbeing Research, University of Winchester, UK

Professor John Norrie  Chair in Medical Statistics, University of Edinburgh, UK

Professor James Raftery  Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma  Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts  Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, UK

Professor Jonathan Ross  Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein  Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton  Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood  Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk