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Extended Research Article

Improving outcomes for people with autism spectrum disorders by reducing mental health problems: the IAMHealth research programme including one RCT

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Scientific summary

Improving outcomes for people with autism spectrum disorders by reducing mental health problems: the IAMHealth research programme including one RCT

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Scientific summary

Background

Autism involves pervasive impairments of reciprocal social interaction and communication as well as repetitive behaviours and interests and sensory atypicalities, including hyper- and hypo-sensitivity to different stimuli. Autism is common, occurring in ~1–1.5% of the population, lifelong and hugely expensive. Currently, there are very limited treatments for its core symptoms. There are also widely divergent views on whether core autistic traits should be a target for intervention or rather that societies and environments should be more flexible to accommodate neurodivergence (or both). However, previous research and consultation with autistic people and their families/caretakers highlighted the importance of commonly associated mental health problems (MHP). Referred to as mental health and behavioural problems (MHBP), these can lead to exclusion from everyday family life, educational and community activities, poor quality of life and increased stress for family members as well as high costs in service use and lost opportunities.

Previous research has shown elevated rates of MHBP at all ages among autistic people, affecting up to two-thirds of individuals, but at the inception of this programme, it was not known whether these problems persisted over time in the same individuals, nor what are the risk factors for persistence.

Aims and objectives

This programme focused on decreasing MHBP as a strategy for improving outcomes for autistic people and their families. These outcomes include improved mental health, quality of life and community participation for autistic people; reduced family stress; and decreased economic costs by ultimately lowering the need for high-cost (often residential) care and integration into the community. To achieve this, we focused on improved recognition, early intervention and identification of the factors that predict MHBP and influence transitions to adolescence/early adult life. Autism is a lifelong condition, and this programme reflected this through work packages focusing on key time points from early childhood to young adult life.

To achieve our aims, we addressed the following objectives:

1. We developed and validated a measure of MHBP in autism, to assist professionals in detecting these problems, identifying their causes and monitoring treatment/intervention. (Work package 1 – instrument development.)
2. We interviewed young adults and parents of autistic young people and young adults, in order to understand and describe their perception of the emergence of MHP their experiences of seeking help; and the impact of these on their lives. (Work package 2 – biographies.)
3. We undertook a longitudinal study of a cohort of autistic adolescents in order to identify the personal, family and wider environmental risk/protective factors related to persistence/desistence of MHBP from early childhood to late adolescence. A nested qualitative study investigated parents' accounts of their child's mental health trajectories. (Work package 3 – predictors.)
4. We developed and completed a pilot feasibility randomised controlled trial (RCT) of a novel intervention for parents of recently diagnosed children aimed at reducing MHBP, enhancing child and family functioning and decreasing parental stress. We compared it to a control intervention. (Work package 4 – treatment.)

Work package 1: instrument development

Methods

We undertook focus groups with autistic adolescents and adults and their parents/caretakers as well as mental health professionals. With autistic people and their parents, we wanted to identify the most effective and understandable

ways of conveying item content and appropriate scoring. To assess the instrument, participants were identified through mental health and paediatric clinics, schools for autistic children and schools with special units for autistic children. We then asked autistic people, their parents and teachers to complete the questionnaire. A subset completed the questionnaire on two occasions to obtain test–retest reliability. Exploratory factor analysis (EFA) identified the structure which was replicated in an independent sample using confirmatory factor analysis (CFA). Reliability and validity were assessed for the final solution, for each factor separately. Convergent and discriminant validity were measured against existing measures.

Key findings

Item content, presentation and response format are very important to autistic people. The Assessment of Concerning Behaviour (ACB) was completed by 255 parents, 149 autistic children and young people and 30 teachers; test–retest data were available from 121 parents and 61 children/young people. Target participants (across all respondents) had an age range of 7–29 years; self-reports were completed by youth aged 8–14 years. Male preponderance varied from 75% to 83.6%. Mean IQ varied from 63.8 to 77.8 with a range from the profound intellectual disability (ID) range to superior IQ. EFA supported a two-factor model as providing the best fit [χ^2/degrees of freedom (df) = 1.7, root-mean-square error of approximation (RMSEA) = 0.053, Comparative Fit Index (CFI) = 0.91] compared to a one- or three-factor model. This was validated by CFA on a second sample (χ^2/df = 1.7, RMSEA = 0.057, CFI = 0.88) which was compared to a one-factor model. Within-factor reliability and stability were judged satisfactory with Cronbach's weighted kappas ranging from 0.51 to 0.72 and per cent agreement from 83% to 95.5%. Concurrent, convergent and discriminant validity was supported by the pattern of correlations with other measures.

Limitations

There were relatively low completion rates by children, adolescents, and young adults, as well as teachers, in comparison with parents, meaning that a full psychometric profile could only be generated for the parent version. However, up till adult life, among autistic populations, it is usual to rely on parent report as the primary informant.

Interpretation

Co-design of a questionnaire with autistic people and their families led to a different structure and response format than is typical for questionnaires about MHBP. The ACB was subjected to stringent psychometric evaluation, including replication of the structure in a second sample, and was found to be robust.

Work package 2: biographies

Methods

Using an existing research cohort, we purposively sampled autistic young adults with previous experience of a range of MHBP. Nineteen autistic young adults aged 23–24 years were recruited. Parallel interviews were undertaken with parents. In-depth interviews explored how they understood and managed MHP. Data were analysed thematically, and this framework was shared at an early stage with the patient and public involvement (PPI) panels.

Key findings

Young adults adopted self-management strategies rather than seeking advice or intervention from more conventional sources, including clinical services. Factors contributing to this included beliefs about the causes of MHP and increased vulnerability with the context of a diagnosis of autism, knowledge of self-management and, based on prior experiences, a view that professional support or intervention was unavailable or inadequate. Where help was sought, this was only at the point of psychological distress becoming very apparent to parents (typically due to concomitant physical symptoms such as significant weight loss) who typically either initiated or supported help-seeking.

Limitations

The study focused on young adults without learning difficulties (IQ < 70). There was an under-representation of females and people from ethnic minority backgrounds in the cohort from which we recruited. This means that we have only a partial understanding of these issues for autistic adults.

Interpretation

Young autistic adults and their families may hold erroneous beliefs about autism and mental health, and, as a result, struggle to discern when they might need mental health support. Negative or unhelpful experiences of mental health support during childhood and the teenage years may engender a suspicion or reluctance to seek help from mental health services. There were few systematic opportunities for autistic young people or their parents to learn about autism, including its implications for mental health. In addition, health and social care professionals need to be aware of the high rate of MHBP in autistic people and that autistic people may not recognise their own MHBP or feel confident in seeking professional help for them.

Work package 3: predictors

Methods

We followed up the QUEST cohort, a sample of 277 autistic children first assessed at age 4–9 (Wave 1) and followed up at ages 11–16 (Wave 2) and 13–18 years (Wave 3). A particular focus was on the role of family factors, including maternal stress and mental health and family child-rearing practices, alongside wider environmental experiences, such as type of schooling and bullying, on MHBP. MHBP were assessed with parent- and teacher-reported questionnaire measures at Wave 2 and parent- and self-reported questionnaires and parental psychiatric interview for the intensive subset at Wave 3. These were conceptualised in three domains: emotional problems, behavioural problems and attention deficit hyperactivity disorder (ADHD) symptoms. Parents reported on their own MHP at each Wave.

Regression analysis and structural equation modelling were used to examine longitudinal relationships.

A nested qualitative study of parents (n = 33) of autistic teenagers (15–19 years), purposively recruited from the cohort, sought to collect parents' accounts of their child's mental health from diagnosis to the present, their beliefs and observations about the factors which affected it, and the impacts of MHBP on them as parents.

Key findings

We demonstrated moderate to strong persistence of mental health symptoms and diagnoses in autistic children over more than 10 years. Once initial comorbidity of symptom domains was accounted for, stability was largely within domain. Adolescent adaptive functioning was predicted not only by early childhood autistic symptoms and IQ and ADHD symptoms.

Higher parental MHP at Wave 1 was found to be associated with lower child IQ (β = 0.2), but not autistic symptoms.

The nested qualitative study revealed that multiple factors may protect against, or increase the risk of, MHBP during a child's life. These include bio-psychological (e.g. IQ, communication skills, puberty, social and cognitive development) and social ecological factors (e.g. parenting skills, family and school environment) factors.

Parents described feeling skilled and competent in supporting their autistic child until the early teenage years, when they encountered new, more challenging difficulties.

Limitations

The QUEST cohort is ascertained from a population of children diagnosed in two London boroughs before age 4 years. Thus, while this is a carefully characterised population, it reflects children diagnosed early in life and does not include those with more subtle presentations who may only be recognised as having autism later. The nested qualitative study focused only on parents' accounts.

Interpretation

Mental health and behavioural problems showed moderate to strong stability from early childhood to adolescence, supporting the importance of early detection and appropriate intervention. While parents self-report high levels of MHP, these do not appear to be strong predictors of subsequent child MHBP. Nevertheless, the association between parent MHP and child IQ suggests that clinicians should attend to the well-being of parents, especially those whose

children have ID. Efforts to minimise the risk of MHBP among autistic children and teenagers need to be multifaceted with interventions and support available for children, parents and schools.

Work package 4: treatment

Methods

This was a pilot feasibility RCT comparing a 12-week group behavioural parenting intervention [Predictive Parenting (PP)] to an attention control [psychoeducation (PE)]. Parents of 62 4- to 8-year-old autistic children were randomised to PP (n = 31) or PE (n = 31). The primary outcome was a blinded observational measure of child behaviours that challenge. Secondary outcomes included observed child compliance and parenting behaviours; parent- and teacher- reported child emotional and behavioural problems; self-reported parenting practices, parental stress, self-efficacy and well-being.

Key findings

Recruitment, retention, completion of measures, treatment fidelity and parental satisfaction were high for both interventions. There were no significant differences on other measures.

Limitations

Predictive Parenting was compared to an active intervention of PE delivered by experienced clinicians. Although recommended by many professionals, PE is not routinely available as treatment as usual and thus this comparison does not reflect the potential augmentation of current practice that could be conferred by PP. This is a pilot feasibility trial that requires a definitive evaluation including estimation of cost-effectiveness.

Interpretation

Predictive Parenting is an acceptable and feasible intervention to deliver. The MHBP it is tackling are important targets for intervention.

Conclusions

We have shown that MHBP in autistic people at different time points show high levels of persistence in the same individuals, highlighting the importance of early recognition and targeted, autism-specific interventions. Furthermore, our finding that young autistic adults may have difficulty recognising MHP as distinct from autistic symptoms increases the need for autism-specific instruments to detect MHBP, such as the ACB. Co-design of instruments with autistic people and their parents may be important in using language and formats that assist autistic people and those informing on their symptoms to provide accurate accounts leading to timely help. Interventions should be offered from early childhood and more work is required to identify the most effective and cost-effective treatments.

Study registration

This study is registered as Current Controlled Trials ISRCTN91411078.

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