EMPOWERING PARENTS: Using parental training to reduce anxiety for children and young people with Autism.

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Overview of presentation

1. Background on why we conducted the parental training study
2. Objectives of the study
3. Methodology
4. Inclusion and exclusion criteria
5. Procedure
6. Outcome measures
7. Findings
8. Limitations
9. Summary and Conclusion of the study
10. Implications for Practice and Policy
Why conduct parental training research?

• Anxiety is a common co-occurring condition across autism (Rodgers et al., 2012)
  
  • Prevalent in around 40% of CYP with autism (van Steensel et al., 2011) compared to 27% of typically developing (TD) CYP (Costello et al., 2005)
  
  • CYP with autism have higher anxiety levels compared to TD CYP, this difference increases with IQ. (van Steensel & Heeman, 2017)
  
  • Demand for anxiety support outweighs specialist provision in the UK, including Northern Ireland (NAS, 2010)
Objectives

To determine the...

• efficacy of parental training, as a method of support in reducing the anxiety experienced by CYP with autism.

• impact of anxiety management training on parental feelings of efficacy in relation to them managing their CYP’s anxiety.
Methodology

• A mixed methods approach

• Ethical approval - Office for Research Ethics Committees Northern Ireland (OREC NI)

• A feasibility pilot Study - Parents of CYP (10 years -18 years) with autism - Northern Ireland and Republic of Ireland
Inclusion Criteria

Parent/caregiver attending sessions should:

• Reside with a CYP with a formal diagnosis of autism
• Have good verbal ability and no cognitive impairment
• Be committed to attending all five anxiety management workshops and participate in pre and post workshop assessments and interviews

The CYP with autism should:

• Have observable anxiety within home or school
• Aged between 10 years and 18 years
• Be in mainstream school
Exclusion Criteria

The CYP with autism should not:

• Have any additional behavioural or mental health difficulties

• Be on any medication for anxiety or difficulties with mood or behaviour

• Be currently receiving any other intervention for anxiety
Procedure

- Online registration form
  - Inclusion/exclusion criteria applied

- Information Sheets & Consent
  - Return consent forms

- Pre Intervention
  - Complete 3 Postal Questionnaires

- Training Workshops
  - Attend 5 parent training workshops

- 6 Weeks post intervention
  - Complete 3 postal questionnaire
  - Participate in a telephone interview
### Outcome measures

<table>
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<tr>
<th>Demographic profile</th>
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<td>Developed by MCA: Education Level; Current interventions; Previous training</td>
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<tr>
<td>24 Item Questionnaire: Separation Anxiety; Uncertainty; Performance Anxiety; Anxious Arousal</td>
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<tr>
<th>Nisonger Child Behaviour Rating Scale (NCBRF) 1995</th>
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<tr>
<td>A standardised instrument for assessing child and adolescent behaviour with intellectual and developmental disabilities</td>
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<tr>
<th>Johnston and Mash parent Self-Efficacy Scale 1989</th>
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<tr>
<td>16 item Likert-Scale Questionnaire</td>
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<td>Parental Confidence: Satisfaction &amp; Efficacy</td>
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<th>Telephone Interview</th>
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<td>13 Questions: Likes/ dislikes; Impact of training on CYP anxiety</td>
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Intervention – 5 Parent Training Workshops

• 1 - **Theory**, research and assessment of anxiety
• 2 - **Action** - identifying triggers of anxiety, psycho-educating child on emotions
• 3 - **Sensory Processing**
• 4 - **Strategies**
• 5. **De-sensitisation** (Facing your fear.
Intervention - 5 Parent Training Workshops

• A presentation
• Worksheets
• Active participation during session
• Homework
• Reflection on previous weeks homework
Examples

• Learn to identify sensory related behaviours e.g. sensory training
• Manage sensory environment e.g. noise, temperature, lighting
• ‘Calm Kit’
• Deep pressure techniques and strategies
Examples

Identify emotions – 5 point scale

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<th>5</th>
<th>4</th>
<th>3</th>
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<tr>
<td><strong>Feels Like</strong></td>
<td>I’m going to break down (cry, begin pacing, bang my head).</td>
<td>My stomach is starting to hurt and I’m having difficulty concentrating.</td>
<td>I’m feeling uneasy and I’m starting to sweat.</td>
<td>I feel ok. I can handle the situation</td>
</tr>
<tr>
<td><strong>What I can do</strong></td>
<td>I can request to leave the room and go to the quiet room.</td>
<td>I can ask to talk to an adult. I can listen to my calming music (headphones).</td>
<td>I can refer to my coping cards and use deep breathing.</td>
<td>Self-talk and reassure myself I can do it!</td>
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Examples

• Individualised system to communicate growing anxiety e.g. traffic lights, volcano, kettle, thermometer

• Access to a quite space

• Access to special interest

• Negotiate when the child is calm
Examples

• Go to your relaxing place (guided imagery)
• Look at the picture of your relaxing place
• Do your breathing exercises
• Feel your body relax
Face your Fear

How parents could support their child

• Record and reflect
• Practice using individualised strategies (e.g. breathing)
• Try desensitizing strategies around anxiety trigger / fear
• Step by step
• Model appropriate and positive behavior (parents)
• Celebrate all success
• Parents anxiety
Data Analysis

• All data was anonymised

• Descriptive statistics - demographic information and responses to items within each questionnaire

  • The NCBRF (1995) and ASC-ASD –P (2015), total scores and scores within each subscale were categorised as ‘never’, ‘sometimes’, ‘often’ or ‘always’ occurring.

  • The Johnston and Mash Parent Self Efficacy Scale (1989) scores were categorised as either ‘high’, ‘moderate’ or ‘low’.

• Telephone interviews - thematic content analysis.
Results

Potential participants
• N = 225

Inclusion / Exclusion criteria
• N = 25

Consent
• N = 13

Dropouts
• N = 2

Incomplete postal questionnaire
• N = 1

Total participants completed the full study
• N = 10
Demographic Information

• All English speaking Mothers (N = 4 NI, N = 6 ROI)
• Aged between: 41 – 50 years (90%), 51 – 60 years (10%)
• 3rd level education (50%) or above (40%)
• 60% were employed and 40% stay at home mums
• 90% were married, 10% separated
• 80% had received no anxiety training or interventions prior to the study
• All the participants had sons Aged 10 -14 years
  • With a diagnosis of Autism (50%); Asperger’s Syndrome (40%); or Autism Spectrum Disorder and Dyspraxia (10%)

Anxiety Levels Pre Anxiety Training Workshops

Anxiety Levels Post Anxiety Training Workshops

Number of Parents

0 1 2 3 4 5 6 7 8 9 10 11 12

Total Score Pre Intervention

Total Score Post Intervention

Performance Anxiety

Performance Anxiety

Anxious Arousal

Anxious Arousal

Separation Anxiety

Separation Anxiety

Uncertainty

Uncertainty

None to a little anxiety

Mild Anxiety

Moderate Anxiety

High Anxiety

Nisonger Positive Behaviours Pre Anxiety Training Workshops

- Not True / Very Unlikely
- Sometimes True
- Very Likely True
- Always True

Nisonger Positive Behaviours Post Anxiety Training Workshops

- Post Intervention compliant/calm
- Post Intervention adaptive / social
- Total Positive Behaviours Post Intervention

Number of Parents

0 1 2 3 4 5 6 7 8 9

Not True / Very Unlikely
Sometimes True
Very Likely True
Always True

Nisonger Problem Behaviours Pre Anxiety Training Workshops

Nisonger Problem Behaviours Post Anxiety Training Workshops

Not really a Problem
A Mild Problem
A Moderate Problem
A Severe Problem
Johnston and Mash Parent Self Efficacy Scale (1989)

Parent Confidence Pre Training

Parent Confidence Post Training

high
moderate
low
Follow-up research with parents
(Telephone interview)

• Amongst all the participants (n=11) who took part in the anxiety training workshops it was reported that all of the parent’s had:
  • Found the training very helpful
  • Used aspects of the training with their child
  • Reported their child’s levels of anxiety had decreased
  • Shared the training with others i.e. family members, friends
  • Rated their satisfaction with the overall training as ‘very satisfied’
  • Reported that they would recommend the training to others
• How confident or empowered did you feel delivering these anxiety strategies?

“I feel much more empowered. As a parent you are seeing what is causing his anxiety. I’m now taking control of the situation now and not dependent on teachers or other experts”.

“Yes I’m definitely more confident. There is more open communication at home now and I don’t try to be this super human person who is calm all the time, happy all the time and who is in control of everything”.

• Overall what impact has the training you received had upon your child, you and your family?

“I am more confident that I am able to manage better. My son still takes time to grasp things but that is the way he is but I believe he will get there and will benefit from the training”

“It’s been really positive. It has highlighted sometimes that I need to take a step back and revisit strategies. My son is now taking responsibility for himself and is doing things independently and is now coming to me and my husband for support so it has empowered him”
Limitations

• Small sample size
• Parents of boys with ASD - may not be reflective of all individuals across the autism spectrum.
• Low coverage of anxiety within the NCBRF (1995), questionnaire - may not be a sensitive measure of anxiety in CYP with autism.
• Parental bias
Summary of Findings

• A positive impact on uncertainty levels for CYP – parents reported 60% decrease for their child.

• Evident increase in adaptive and social behaviour for 80% of CYP and a marked reduction in problem behaviour for 40%- suggesting CYP were empowered to recognise and manage their anxiety.

• Previous research highlights that training for parents of CYP with autism is effective in decreasing problem behaviours (Matson et al., 2009; Crone and Mehta., 2016)
Summary of Findings

• Anxiety management training had a positive impact on parental feelings of efficacy in relation to them managing their CYP’s anxiety.
  • Schultz et al (2011) found … parents have less stress while showing an increased level of parenting competency through participation in intervention procedures for their CYP with autism.

• Parental training, as a method of support in reducing the anxiety experienced by CYP with autism is beneficial.
  • training for parents of CYP with autism is effective in decreasing problem behaviours (Matson et al., 2009; Crone and Mehta., 2016)
Conclusion

• Parental training, as a method of support in reducing the anxiety experienced by CYP with autism:
  • Increased parental knowledge, awareness and application of appropriate strategies
  • Effectively increased positive behaviours
  • Increased parental confidence
  • Offered more open communication between parents and CYP with autism
Future Research

- Employing a larger sample size including parents of CYP with autism of both genders
- Consider the impact of anxiety training for the entire family
- Including a broader age and ability range of CYP with autism
Research indicates that Parental Training

• Provides support (McConachie & Diggle, 2007)
• Effective for reducing disruptive behaviour (Posterino et al., 2017)
• Increase confidence and reduce stress (Montes and Halterman, 2007)
Implications

For Practice
• Parental training as a mode of supporting CYP with autism may be beneficial.
• Every CYP with autism is different; one strategy does not fit all or every situation.
• Involving CYP in the training and intervention process can reap benefits when employing supportive strategies.

For Policy
• Wider availability of parental training offered following assessment.
• Cost effective - considering demand on professional waiting lists and current economic cuts.
References


References


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