M.I.C.E — Mental Health Intervention for Children with Epilepsy

ACAMH Seminar May 2023
Sophie Bennett & Roz Shafran
PIs: Roz Shafran & Helen Cross
Background: mental health and epilepsy
Prevalence estimates of mental health disorders in young people with neurological conditions such as epilepsy are up to 77% in clinic samples – i.e. **up to 7 times greater** than community samples (e.g. Davies et al., 2003)
**Background**

Pilot WP1 WP2 WP3 WP4

Discussion

MICE Therapy

The evidence base

- Thousands of papers demonstrate efficacy of standard evidence-based intervention for mental health disorders in children (Weisz et al., 2012)

- Preliminary evidence that these are effective in children and young people with Long Term Conditions (LTCs)
The problem

- Mental health disorders in the context of neurological illnesses often remain undiagnosed and under-treated (e.g. Welch et al., 2018)
  - Diagnostic overshadowing?
  - Lack of understanding?

Epilepsy12 Audit – NHS national data (England only) RCPCH
Children's Commissioner - Lightning review of access to CAMHS 2016

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
But...

Children's Commissioner - Lightning review of access to Child and Adolescent Mental Health Service (CAMHS) 2016

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
...you feel like 'oh am I gonna have a seizure? I don't wanna go out because I might have a fit', like on the street. ... But I need to start to forget about it, I might go and see my, we have an Epilepsy Nurse at the hospital which I go to, and he's really lovely, he's a really nice bloke. And if I do have any problems I can always ring him, or go and see him, so I think I might go and have a chat with him soon. Book myself an appointment and go and have a chat with him about the anxiety, and whether he can suggest anything.
Background: MICE methods
Integrated identification

Consent in clinic

Strength & Difficulties Questionnaire on tablet

Online diagnostic assessment

Rate

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Intervention

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Anxiety
• Learning about Anxiety
• Using the Fear Thermometer
• Fear Ladder
• Practising
• Maintenance
• Cognitive STOP
• Wrap Up
• Booster (Anxiety)

Depression
• Getting Acquainted: Depression
• Learning about Depression: Family
• Problem Solving
• Activity Selection
• Learning to Relax
• Quick Calming
• Presenting a Positive Self
• Cognitive: BLUE
• Cognitive: TLC
• Plans for Coping
• Wrap Up
• Booster (Depression)

Behaviour
• One to one time
• Praise
• Active Ignoring
• Instructions
• Rewards
• Time Out
• Making a Plan
• Daily Report Card
• Looking Ahead
• Booster (Conduct)
Fear Ladder (example)

Date: ______________________

Filled out by:
☐ Child
☐ Mother
☐ Father
☐ Other ________________

ITEM

Pet a stranger’s dog

Pet the friend’s dog

Go to a friend’s house with a dog and look at dog while being held in same room

Go to the park where dogs are off leads and can see dogs from a long way away

Go to the park where dogs are on leads and can see dogs from a long way away

Talk about dogs while looking at a picture

Talk about dogs

Look at a picture of a large dog

Look at a picture of a small dog

Look at a picture of a puppy

How scary is this item today? Please give a rating from 0-10.

10

10

9

8

6

4

3

2

1
Anxiety Module
Depression Module
Behaviour Module

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
1. Background

2. WP1

3. WP2

4. WP3

5. WP4

6. Discussion
Goals

SMART

Specific
Measurable
Attainable
Relevant
Time Based

Goals and goal-based outcomes (GBOs)

Goal rating sheet

How close are you to the goals you want to get to?

On a scale from zero to ten, please circle the number below that best describes how close you are to reaching your goal today. Remember a score of zero means no progress has been made towards a goal, a score of ten means a goal has been reached fully, and a score of five is exactly halfway between the two.

**YOUR FIRST GOAL**

Enter brief description of goal and goal number as recorded on the Goals Record Sheet

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<th>Goal not at all</th>
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<th>1</th>
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**YOUR SECOND GOAL**

Enter brief description of goal and goal number as recorded on the Goals Record Sheet

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<th>Half way to reaching this goal</th>
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<td>Goal reached</td>
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Intervention

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Intervention – Anxiety no interference

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
<table>
<thead>
<tr>
<th>WP</th>
<th>Description</th>
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<tr>
<td>WP1</td>
<td>Development of epilepsy-specific module (n=12)</td>
<td>2018</td>
</tr>
<tr>
<td>WP2</td>
<td>Training services and pilot intervention (n=2 per therapist)</td>
<td>2019</td>
</tr>
<tr>
<td>WP3</td>
<td>Randomised Controlled Trial (n=334)</td>
<td>2019 - 2023</td>
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<tr>
<td>WP4</td>
<td>Qualitative outcome and process evaluation (n=24)</td>
<td>2019 - 2023</td>
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1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Development of epilepsy-specific module (n=12)
“the study of methods and strategies to promote the uptake of interventions that have proven effective into routine practice, with the aim of improving population health”
4 Methods:

1. Literature review
2. Focus groups of patients and professionals
3. Plan do Study Act cycles (n=12 patients)
4. Qualitative interviews (n=7 families)
Results: overall changes to intervention

1. High level of consensus and substantial overlap

2. Need to personalise the intervention for the individual and context by:
   1. Anglicising the language
   2. Using epilepsy-specific examples where possible
   3. Making it explicit that the pace of the intervention and delivery may need to be adjusted on a case-by-case basis depending on the child’s intellectual ability and mode of delivery (telephone vs. face-to-face)
Results: additional modules

- A **core module** for everyone that provides education about mental health disorders and their relationship with epilepsy, enables a formulation of the maintenance of mental health disorders within epilepsy and provides links to additional resources.

  
  **If epilepsy and mental health difficulties are related, how will it get better? Will anything make a difference?**
  
  Epilepsy and mental health problems have different treatments, which can be used at the same time. Mental health problems can get better, even if the epilepsy doesn’t.

  **My child’s epilepsy is just one of many problems e.g. ADHD, Autism, learning difficulties, physical disability, a genetic condition. Will this programme still work?**
  
  Yes! Most children who have used this programme have many additional difficulties. Research has shown that these strategies work for children with many problems. Your therapist will work with you to make sure the programme suits your child’s individual needs.

  **Is the medicine that my child is taking responsible for their low mood, challenging behaviour or worries?**
  
  It is important to discuss this with your child’s epilepsy nurse/team. Some epilepsy medicines might have an effect on mood and behaviour, especially when the medicine, or the dosage, is changed.

  It does not matter what the cause of the challenging behaviour or low mood is, we still have the strategies to help. In the same way, it does not matter whether your headache was caused by a noisy room or because you banged your head, Paracetamol works just as well.
Results: additional modules

• Additional ‘interference’ modules in keeping with the structure of MATCH-ADTC:
  • Stigma
  • Parental mental health
  • Transition to adulthood
Results: training

1. A 5-day training course accompanied by a minimum of monthly supervision was therefore developed to ensure fidelity to the MATCH-ADTC model as well as facilitating delivery within busy services.

2. A ‘user-guide’ was also developed that makes it explicit how to use the manual for nurses and other health professionals unfamiliar with the delivery of mental health interventions.

3. The training course was video-taped.
Therapist Platform

Contents

1. Overview
2. Research Team Details
3. Welcome to MICE
4. Training Materials
5. Therapist Guide
6. MICE Manual
7. Therapist Materials
8. Handouts
9. Measures
MICE Programme: Work Package 2

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion

WP1: Development of epilepsy-specific module (n=12)

WP2: Training services and pilot intervention (n=2 per therapist)
Training the therapists: methods

- 27 Health Care Professionals (HCPs) from six different NHS trusts across England attended the first 5 days of training workshops

- 5 paediatricians, 5 specialist epilepsy nurses, 3 paediatric nurses, 2 mental health workers, 1 educational psychologist, and 4 assistant psychologists

- All HCPs then completed at least 1 training case of the expanded telephone delivered treatment, supported by weekly clinical consultation by a qualified clinical psychologist from the research team

- Parent reported measures of child’s mental health and quality of life

- Qualitative interviews with HCPs at the start (n = 23) and end (n = 15) of the 6-month training period
Training the therapists: 6-month outcomes

- All therapists deemed competent

- Statistically significant improvements in: symptoms of mental health problems ($p = 0.01; \text{Cohen's } d = 0.62$), total impact of mental health problems ($p = 0.03; \text{Cohen's } d = 0.52$), anxiety and depression symptoms ($p = 0.02; \text{Cohen's } d = 0.57$) and quality of life ($p = 0.01; \text{Cohen's } d = 0.57$)

Feasibility of telephone-delivered therapy for common mental health difficulties embedded in pediatric epilepsy clinics

Sophie D. Bennett *, Christy Au, Sarah Byford, Bruce Chorpita, Anna E. Coughtrey, J. Helen Cross, Emma Dalrymple, Peter Fonagy, Tamsin Ford, Isobel Heyman, Amy Lewins, Rona Moss-Morris, Colin Reilly, Laila Xu, Boz Shatran

Great Ormond Street Hospital for Children, NIHR Foundation Trust, UK
Training the therapists: 6-month outcomes

I think it’s a really good, obviously high-quality, well researched giftbox, almost. It’s like a greatest hits compilation of mental health support and psychological therapies which can be used interchangeably. So yes, it’s like having your favourite CD in your car.”
(Therapist)

“Yes, the sessions feel completely relevant. I mean, things that we’re talking about are completely relevant to what we’re dealing with and going through.”
(Parent)

“A greatest hits compilation of mental health support”: A qualitative study of health professionals’ perceptions of modular CBT in pediatric epilepsy services
Anna E. Coughtry, Sophie D. Bennett, Alice Sibelli, Bruce Chorpita, Emma Dalrymple, Peter Fonagy, Tamsin Ford, Isobel Heyman, Rona Moss-Morris, MICE Study Team, Brian C.F. Ching, Roz Shaffran.
MICE Programme: Work Package 3

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion

- Development of epilepsy-specific module (n=12)
- Training services and pilot intervention (n=2 per therapist)
- Randomised Controlled Trial (n=334)
Work Package 3: the trial

- Randomised Controlled trial
- MICE + Usual Care versus Assessment Enhanced Usual Care (Control)
- Primary outcome: Strengths and Difficulties Questionnaire
- Secondary outcomes: Quality of Life, Mental Health of child and parent
- Safety data
- Acceptability – Experience of Service Questionnaire

Sites:
- Great Ormond Street
- Barnet
- Lewisham and Greenwich
- NELFT
- UCLH
- Whittington

Patient Identification Centres (PIC):
- Sherwood Forest
- Cambridge
- Northern Ireland
- Mid Yorkshire
- Surrey
- Suffolk
- Belfast

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Randomised between 28 August 2019 and 21 February 2022

Around 25% with Autism Spectrum Disorder (ASD) diagnoses

Around 40% with intellectual disability diagnoses

Around 65% reported having a seizure in the past three months
1. Background

Randomised between 28 August 2019 and 21 February 2022

2. WP1

Around 55% reported “Disruptive behaviour”

3. WP2

Around 40% reported “Anxiety”

4. WP3

Around 5% reported “Depression”

5. WP4

6. Discussion
Of the 166 participants randomised to the MICE arm, 164 had at least 1 therapy session.

Number of therapy sessions ranged between one to 22 - median n=16.

21 therapists provided therapy sessions as a main therapist on the trial.
What does this look like in real life?
Meet Alex: Anxiety

- 9-year-old
- Female
- No seizure activity at baseline
- SDQ Total: Very High (24)
- SDQ Impact: Very High (10)
- Diagnosis on the Development And Well Being Assessment: Social Phobia
Presenting difficulties

• Alex was struggling in new social situations:
  • For example, making new friends that are loyal or speaking in front of her peers
• Alex was struggling being in crowded spaces:
  • For example, going on trains or in busy places
• This led to withdrawing and avoidant behaviour, for example choosing to stay home when possible
• This also led Alex to get upset, for example: becoming irritable or tearful
1. To talk to a new friend at school

2. To visit a busy place (e.g. a concert, restaurant, shop etc.) and feel calm (i.e. without feeling anxious or panicked)

3. To fall asleep every week day without needing to use an iPad to distract from anxiety
• Alex completed 21 sessions of only anxiety module:
  • Assessment
  • Epilepsy Specific Module for Youth (ESMY)
  • Learning about anxiety
  • Using the Fear Thermometer
  • Fear ladder
  • Practicing
  • Maintenance
  • Cognitive STOP
  • Wrap Up
  • X2 Boosters
  • X3 Review

• Alex and her mother were primarily present during sessions

• No interference throughout treatment
Fear Ladder

Date: ______________

Filled out by:
- ☐ Child
- ☐ Mother
- ☐ Father
- ☐ Other ______________

ITEM

10. Asking a person at school to hang out
7. Talking to a person you’ve never spoken to before
5. Talking to a person you know but are not friends with
5. Answering questions in class
4. Not having all equipment needed
2. Talking to a person you are friends with

How scary is this item today? Please give a rating from 0-10.
To talk to a new friend at school

To visit a busy place (e.g. a concert, restaurant, shop etc.) and feel calm (i.e. without feeling anxious or panicked)

To fall asleep every week day without needing to use an iPad to distract from anxiety
### Pre-Post Outcomes

#### SDQ Total

<table>
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<tr>
<th>Follow Up Point</th>
<th>SDQ Total Difficulties</th>
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<tbody>
<tr>
<td>Baseline</td>
<td>25</td>
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<tr>
<td>6-month</td>
<td>10</td>
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</table>

#### SDQ Impact Score

<table>
<thead>
<tr>
<th>Follow Up Point</th>
<th>SDQ Impact Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>10</td>
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<tr>
<td>6-month</td>
<td>4</td>
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1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Alex can see a brighter future for herself and we can see a brighter future for us as a family.

...once again from Alex and the whole family.
THANK YOU SO MUCH

...without your understanding, patience and professionalism and the advice and tools you gave her to success.

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
But my patient is anxious because of Seizures... what do I do?
Meet Jo: Anxiety about epilepsy

- 16-year-old
- Female
- Seizure activity at baseline
- SDQ Total: Very High (26)
- SDQ Impact: Very High (6)
- Diagnosis on the DAWBA: Separation and Generalised Anxiety Disorder
Presenting difficulties

- Jo would become very anxious when separated from her mother
  - Particularly she would worry about having a seizure when alone

- Jo worries about a range of topics including:
  - Catching COVID-19
  - Having seizures in public
  - Being in crowded places
  - Travelling by bus
  - Socialising with others

- Jo would be overactive and struggle to concentrate so would find it hard to calm down
SMART Goals

1. For Jo to talk with her friends about her epilepsy

2. For Jo to worry less about doing things on her own in public, meaning she can be more independent and do things on her own (e.g. walk to see her friends in the park on her own, go shopping on her own)

3. For Jo to feel more confident, meaning she can get a bus on her own (to visit friends/family/go shopping)
• Jo completed 19 sessions of the Anxiety module:
  • Assessment
  • ESMY
  • Learning about anxiety
  • Fear Thermometer
  • Fear Ladder
  • Practicing
  • Cognitive STOP
  • Problem solving
  • Learning to relax
  • Wrap Up
  • X2 Boosters
  • X1 Review

• Jo and her mother were primarily present during sessions
ITEM

1. Going to a busy supermarket by myself and staying there for three minutes
2. Messaging a friend who doesn’t know I have epilepsy to tell him about it
3. Hanging out with a group of friends and talk about ‘epilepsy’
4. Going to the supermarket in a quiet side by myself for three minutes
5. Going to the park with my friends and telling them about my epilepsy medication
6. Going to the supermarket with mum
7. Go to the corner shop within a few people in it
8. Go to the corner shop with a few people in it
9. Message a friend about something unrelated to epilepsy
10. Practice a friend to eat (related to epilepsy)

How scary is this item today? Please give a rating from 0-10.
STOP will be an important part of getting braver. When we talk about STOP, S stands for scared, T stands for thoughts, O stands for other thoughts, and P stands for praise. Let’s learn more about STOP.

S is the first letter in the word scared. Let’s learn more about feeling scared.

Unscramble the letters below to find other words for feeling scared.

ERVOUNS

IERWROD

DAARIF

See if you can figure out how the people below are feeling.

<table>
<thead>
<tr>
<th>This person feels</th>
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<tr>
<td>How do you know?</td>
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Separation Anxiety Symptoms

Anxiety Symptom Score

Session by session data

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
Generalised Anxiety Symptoms

Anxiety Symptom Score

Session 1  Session 2  Session 3  Session 4  Session 7  Session 8  Session 9  Session 11  Session 12  Session 13  Session 14  Session 15  Session 16  Session 17  Session 18

Goals Over Time

Goal Based Outcome Score

Session

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion

To talk with her friends about her epilepsy

To worry less about doing things on her own in public, meaning she can be more independent and do things on her own (e.g. walk to see her friends in the park on her own, go shopping on her own)

To feel more confident, meaning she can get a bus on her own (to visit friends/family/go shopping
Meet Henry: Behaviour and Anxiety

- 13-year-old
- Male
- Very severe seizure activity at baseline
- SDQ Total: Very High (27)
- SDQ Impact: Very High (9)
- Diagnosis on the DAWBA: ASD, Generalised Anxiety
Presenting difficulties

- Henry was experiencing symptoms of anxiety, disruptive behaviour and hyperactivity

- Henry expressed a fear of dogs

- Henry demonstrated challenging behaviours
  - Harming himself in response to change or loud unpredictable noises

- Henry was becoming increasingly withdrawn
SMART Goals

1. For Henry to be able to get ready for school in the morning without hitting, spitting, hair pulling or asking repeatedly if he’s going to school.

2. For Henry to be able to interact with his support assistant at school in the mornings (or when people visit, or going to somebody else’s house).

3. For Henry to be able to go shopping (in a small shop) with mum at least once a week without asking whether or not there will be other children more than three times.
Henry completed a total of 20 sessions of the anxiety module followed by the behavioural module:
- Assessment
- ESMY
- Learning about anxiety
- Fear Thermometer
- Fear Ladder
- Practising
- One to one time
- Praise
- Active ignoring
- Instructions
- Rewards
- Problem solving
- X2 Boosters
- X1 Review

Henry’s mother was primarily present during sessions
Goal Based Outcome Score

To be able to get ready for school in the morning without hitting, spitting, hair pulling or asking repeatedly if he’s going to school

To be able to interact with his support assistant at school in the mornings (or when people visit, or going to somebody else’s house)

To be able to go shopping (in a small shop) with mum at least once a week without asking whether or not there will be other children more than three times
1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion
MICE was excellent in general, has been super helpful with my daughter who had quite complex physical and behavioural needs.

It is not a one-size-fits-all programme and is really tailored to my child.

Being fixed isn't the objective, but changing the scale of intensity of impact is.

With the techniques I have learnt in therapy, I have a tool kit to make things I find difficult more manageable.

MICE treatment had given me hope and a sense of accomplishment.
MICE Programme: Work Package 4

1. Background
2. WP1
3. WP2
4. WP3
5. WP4
6. Discussion

WP1: Development of epilepsy-specific module (n=12)

WP2: Training services and pilot intervention (n=2 per therapist)

WP3: Randomised Controlled Trial (n=334)

WP4: Qualitative outcome and process evaluation (n=24)
MICE Programme: Work Package 4

Qualitative outcome and process evaluation (n=24)
Findings from the MICE Trial

Join us in our presentation and discussion of key research findings of the MICE study and the implications for practice and policy.

Get tickets

June 19th 2023
10:00-13:00
Including Lunch
Hybrid Event

Findings from the Mental Health Intervention for Children with Epilepsy (MICE) Trial

Work Package 4 and beyond
Discussion

- Positive effect on children and young people
- And their families
- Model for other chronic illnesses?
- How do we implement it in clinical practice?
- How do you get trained in MICE?

Gos-tr.mice@nhs.net

https://forms.office.com/e/Babnv5xhun
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