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Examining change in the mental health of young people with epilepsy following a successful psychological intervention

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Contributors

JAS, RS, JHC, SDB and IH conceived the idea for the study with RS and JHC being Chief Investigators on the MICE study. IEN gathered the data and analysed it with JAS. IEN, JAS, SDB and RS reviewed the analysis and drafted the manuscript, which was then revised by BC, IH, JB, AEC, ED, MS, AD, RMM and JHC. IEN and JAS had full access to all the data in the study. All authors had final responsibility for the decision to submit for publication and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Abstract

Objective: Evaluate the cognitive, behavioural and affective processes involved in therapeutic change for young people with epilepsy and mental health difficulties receiving an integrated mental health intervention.

Methods: As part of a mixed methods convergent design, qualitative data were gathered in parallel to quantitative data at two timepoints in a randomised controlled trial testing the Mental Health Intervention for Children with Epilepsy in addition to usual care. Twenty-five young people and/or their families were interviewed before and after the intervention about the young person's mental and physical health, and their experience of therapy. Interview data were analysed inductively, idiographically and longitudinally using Interpretative Phenomenological Analysis combined with Framework Analysis.

Results: The young people's emotional and behaviour problems improved, mirroring the trial's quantitative outcomes. Their anxiety decreased and behaviour improved as they acquired tools and understanding through therapy. Problems, like aggressive behaviours and emotional outbursts, were also reduced, with young people gaining increased awareness and ability to self-regulate and parents learning to contain their child's impulsive behaviours.

Conclusions: The qualitative findings complement the MICE trial's significant positive quantitative results by providing insight and context to the therapeutic change, providing vivid insight into the mechanisms of therapy for individual families.

Introduction

Compared to their physically healthy peers, young people with chronic illness are two to four times more likely to develop a mental health (MH) disorder. This is especially the case in the most common neurological disorder in childhood, epilepsy, where up to 60% of young people have been found to experience one or more MH disorders (Jones et al., 2007; Reilly et al., 2014). Despite the known association between mental and physical health, MH disorders in young people with chronic illnesses are often undiagnosed (Fusar-Poli, 2019) and their treatment is inadequate, with services failing to integrate physical and mental healthcare (Dragioti et al., 2023).

The Modular Approach to Therapy for Children with Anxiety, Depression, Trauma or Conduct problems (MATCH-ADTC) is a personalised modular cognitive-behavioural intervention (Chorpita et al., 2017; Chorpita & Weisz, 2009; Chorpita et al., 2013) suitable for young people with epilepsy because it is flexible and can address multiple MH conditions simultaneously. This approach has been adapted to include epilepsy-specific content and to be delivered remotely by clinicians within physical healthcare services (Bennett, Au, et al., 2021; Shafran et al., 2020).

The effectiveness of the MATCH-ADTC was established through a multicentre pragmatic randomised controlled trial (RCT) where the Mental Health Intervention for Children with Epilepsy (MICE), based on the modified MATCH-ADTC combined with usual care, was compared to assessment-enhanced usual care. The intervention involved an initial assessment followed by weekly phone/online video calls with a clinician. Clinicians were professionals from a range of backgrounds (including consultant paediatricians, paediatric nurses, assistant psychologists and epilepsy nurse specialists) who had never before delivered psychological therapies and were specially trained over a 6-month period to deliver the intervention (Bennett, Cross, et al., 2021). The intervention was manualised and included measurements of symptoms and progress towards self-identified goals each session. The therapy was delivered over a maximum of 20 sessions followed by two booster sessions (Bennett et al., 2024).

The RCT reported significant improvements in child MH compared to controls using quantitative outcome measures at the primary endpoint of 6 months post-randomisation and the gains were maintained at 12 months. The RCT included a mixed methods convergent design (Creswell & Plano Clark, 2018), with qualitative data gathered in parallel to the quantitative data at baseline and then again six months post-randomisation.

In this paper we present the qualitative findings and use them to gain a nuanced understanding of the quantitative results. We focus on the longitudinal analysis of in-depth interviews with a subset of participants in the intervention arm of the trial. Participants were young people with epilepsy and MH difficulties and/or their parents/carers. Pre-post intervention qualitative findings are integrated with pre-post intervention quantitative measures for the intervention group to provide a rich and detailed understanding of the cognitive and affective processes involved in the therapeutic change.

The qualitative methodology combined interpretative phenomenological analysis (IPA; Smith et al., 2022) and framework analysis (Ritchie & Spencer, 2002), as done before by Smith et al. (2011). IPA allows the detailed analysis of participants' lived experience and is explicitly designed to analyse psychological constructs, thereby facilitating a mixed methods analysis. The idiographic inductive focus of IPA also enables the deep examination of complex processual and dynamic issues at a personal, individual level, which is consonant with assisting the illumination of the quantitative results. The integration of IPA and framework analysis allowed greater flexibility in the analytic strategy, affording a combination of depth and breadth to the analysis.

Methods

Ethics

The trial was prospectively registered with the ISRCTN (ISRCTN57823197) and approved by the South Central – Oxford Research Ethics Committee (18/SC/0250). Ethical approval for the final design of the qualitative component of the study was obtained as an amendment a few months after the start of the intervention.

Participants

Participants in the main trial were: recruited from UK National Health Service (NHS) epilepsy clinics; aged 3–18 years; scored above a pre-specified threshold on the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) for MH symptoms (Total Difficulty score (≥ 14) and Impact score (≥ 2)); met DSM-5 diagnostic criteria for a mental health disorder on the Development and Wellbeing Assessment (Goodman et al., 2000); caregiver prepared to participate in the study. Participants with intellectual disability (ID) and/or autism spectrum disorder (ASD) were included. Overall, 334 participants met all eligibility criteria and were randomized, 166 to the MICE intervention and 168 to the control arm.

For recruitment in the qualitative study, we adopted a purposive stratified cell design. Participants were selected according to the key variables in the trial: gender (male v female), age (below 11 v 11 and above), intellectual disability and/or autism spectrum disorder (present v absent). We had an ideal target of 3 participants per cell (good practice for IPA) which would have generated a total of 24 participants. However, the pattern of recruitment broadly followed that for the whole trial and not all cells were able to be filled and we did recruit 25 participants overall.

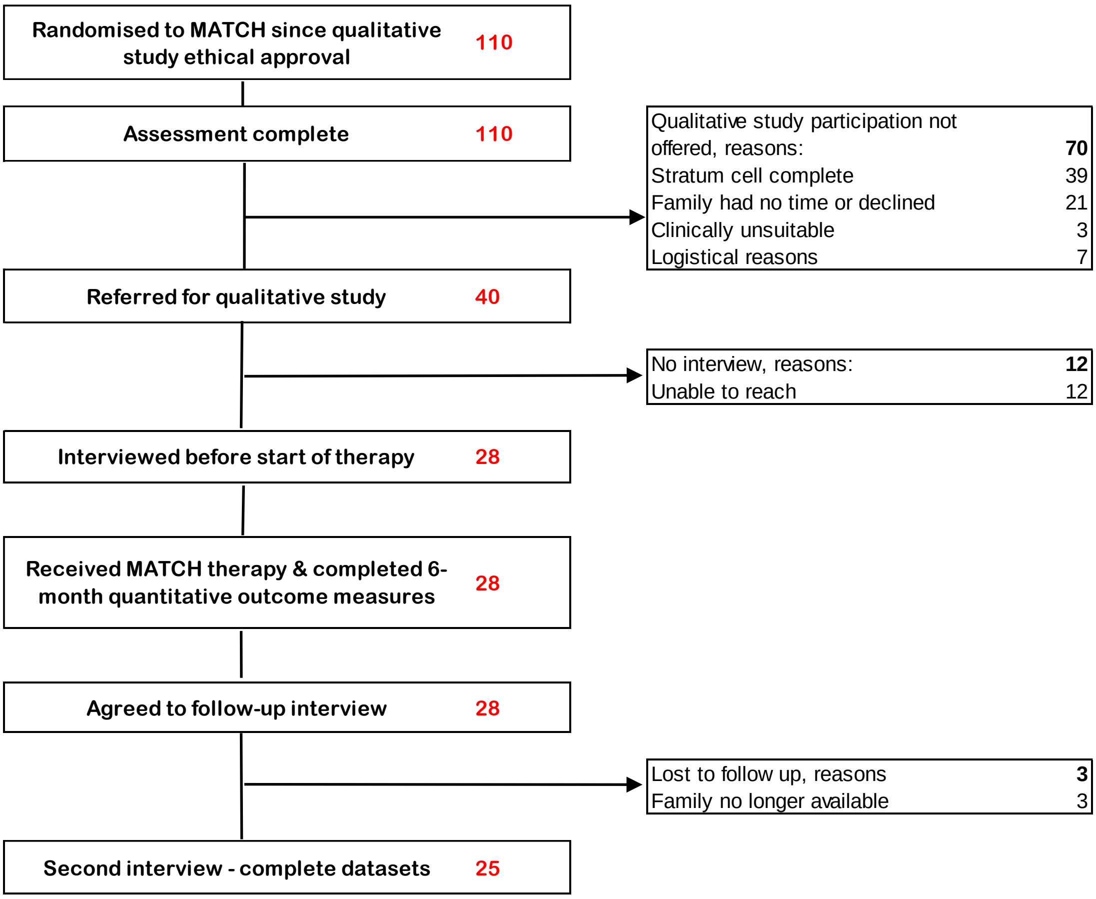
Figure 1 illustrates the flow of participants through the recruitment process for the qualitative component of the study. As participants agreed to take part, they were allocated to the sampling cells (max of 5 in each cell to account for possible attrition during the study).See Table 1 for our final sample.

Table 1. Allocation of participants to the purposive cells

	Age	**With ID/ASD**	**With no ID/ASD**
Male	<11	4	4
	11+	3	0
Female	<11	4	4
	11+	2	4

ID/ASD: Intellectual disability and/or autism spectrum disorder

Figure 1. Qualitative study recruitment chart



For participants in the qualitative study, Table 2 below provides aggregated information on the therapy process, including the issue addressed through therapy, who received the therapy, how many sessions were delivered and the type of change reported for the child in the qualitative results.

	N
Problem addressed during therapy	
Behaviour	13
Anxiety	5
Depression	1
Behaviour & Anxiety	5
Anxiety & Depression	1
Therapy completed with	
Parent(s)	20
Parent & young person	4
Young person alone	1
Number of sessions	
10 or less	1
Between 11 and 15	5
Between 16 and 20	9
Between 21 and 22	10
Qualitative improvement (child's behaviours and thinking)	
All aspects improved	14
Some aspects improved/some stayed the same	6
Some aspects improved/some deteriorated	4
Some aspects stayed the same/some deteriorated	1

Table 2. Features of therapy and their frequency in the qualitative sample

Recruitment procedure

After the initial therapy assessment, potential qualitative participants were invited by their therapist to take part in an interview. If they agreed, they were approached by a qualitative researcher (IEN), who was not part of the therapeutic team but had experience interviewing participants in depth on health-related topics. Informed consent for the interview had already been obtained as part of the trial's general consent procedures and was confirmed again on tape at the start of the first interview.

Young person's sex	Participant number	Young person's age	Young person's diagnosis	Interviewed at first interview	Interviewed at second interview
Male	1	10	ASD, ID	Mother	Mother
	2	5	ID	Mother	Mother
	3	7	ID	Mother	Mother
	4	9	ID	Mother	Mother
	5	9		Mother	Mother
	6	10		Mother	Mother
	7	10		Mother	Mother
	8	9		Mother	Mother
	9	11	ASD, ID	Mother	Mother
	10	15	ID	Mother	Mother
	11	17	ASD, ID	Mother	Mother
Female	12	9	ID	Father	Father
	13	10	ASD, ID	Mother	Mother
	14	7	ASD, ID	Mother	Mother
	15	5	ID	Mother & father	Mother & father
	16	8		Mother	Mother
	17	9		Mother	Mother
	18	9		Mother & daughter	Mother & daughter
	19	5		Mother	Mother
	20	15	ASD, ID	Mother	Mother
	21	17	ID	Mother	Mother
	22	13		Mother	Mother
	23	15		Mother & daughter	Daughter
	24	11		Mother & daughter	Mother & daughter
	25	15		Mother & daughter	Mother & daughter

ASD: autism spectrum disorder
ID: Intellectual disability

Table 3. Participant demographics and interviewees

Data collection

Interviews were carried out remotely. Table 3 shows how interviewees were mostly parents who, depending on their choice, were interviewed with or without their child. Participants were interviewed twice: following randomisation before therapy started and shortly after the 6-month quantitative measures had been gathered. Interviews lasted between 33 and 94 minutes, with an average of 64 minutes.

Questions concerned the experience of epilepsy and MH and the relationship between the two. Some questions addressed the child's experience e.g., "How does having epilepsy affect [child's] everyday life?" or "Please can you tell me about a particular time recently when you know that [child] has felt [feeling]. What do you think it was like for them?". Others explored the parent's experience e.g. "How does [child] having epilepsy affect your everyday life?" or "Please can you tell me about a particular time recently when you know that [child] has felt [feeling]. What was it like for you?". During the second interview, questions like those in the first interview were asked, to enable a longitudinal pre-post intervention comparison, alongside specific questions on the therapeutic process, such as "How did you find the treatment for [child]'s difficulties?" and "What would you say was the most useful part of the treatment for you?". In the second interview participants were also asked a few customised questions, to follow up issues that had been relevant to them during the first interview, using this format: "I remember last time you were concerned about [topic], how does that feel now?"

Qualitative analysis

The analysis of anonymised interview transcripts followed IPA guidelines combined with framework analysis. Initially, a set of interviews was analysed inductively to produce a table of personal experiential themes (PETs) and subthemes. Then each participant's two tables of

PETs (from baseline and 6-months) were compared to generate longitudinal PETs describing elements of change and/or continuity between the two timepoints (Neale, 2021).

After completing the analysis for the first 6 participants, recurring thematic areas were identified and used to create a framework to inform the analysis for the remaining 19 participants. Categories in the framework included Child's Health, Child's Behaviour, Child's Thinking, Child's School, Parent's Behaviour, Parent's Thinking and Parent's Feeling. Within these broad categories, each participant's analysis remained inductive. The output from this phase was a table of longitudinal PETs for each participant. The main analysis of data from all timepoints was led by IEN, assisted by JAS.

Next, considering one category at a time, the tables of individual longitudinal PETs were analysed for patterns, the most obvious being improvement, deterioration, or no change, and for specific aspects within those patterns. For example, improvements in the child's behaviour included experiences related to fear, anger and aggressive behaviour. This phase resulted in tables of cross-case themes.

Results

In this article we focus primarily on those aspects of the qualitative analysis found to be relevant for many young people, namely emotional problems (anxiety and fear, which improved for 15 young people) and behaviour problems (angry, aggressive and impulsive behaviour which improved for 13 young people). These findings will be explored through analysis of participants' own words and/or the words of their parents, comparing the young people's experience prior to the intervention with their experience six months later, to exemplify their change processes. Given the large sample (25 participants), quotes have been selected to illustrate a range of experiences from a varied demographic, including families with younger and older children, with or without ID and/or ASD.

Improvement in emotional problems

Anxiety was a common problem among participants: 40% of participants in the trial had anxiety as their primary MH disorder. As shown in Table 2, the behaviour of most participants improved, so our focus here is on exemplifying how. At the start of the trial, Beth, the mother of Annie aged 9 described her daughter's panic in these terms:

> *"Something will trigger, it will remind her or she'll panic about something and then, she finds it quite difficult once she's in that siphon of worrying to get out [...] she keeps going [short repeated inbreaths of air] and it'll go up and up and up and she'll get her, she'll talk faster and she'll like fidget like this and everything just seems really heightened, and no matter what you say, she can appreciate that point of view but it doesn't relate to her […] and then she'll just either get really like this aggressive like panic mode or she'll just cry and cry and cry and you can't calm her down" (Beth, mother of Annie, Baseline)*[1]

This quote vividly illustrates the spiral of Annie's escalating panic and anxiety. It starts with a trigger and then quickly develops into something uncontrollable. Annie got caught up in a "*siphon*" of short breaths, fast talk and nervous movement which excluded the world around her and culminated in a flood of tears. For this reason, Annie's therapy objectives included helping her recognize and manage her anxiety. At 6 months, the mother described what had been done:

> *I would still describe her as very anxious, she worries about everything, but it doesn't necessarily take over everything now. So the minute there's something that's a bit oh, you'll see her go [gasp] and think about it, and*

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[1] All names of participants (parents and young people) are pseudonyms.

> *it's still, but then she can kind of let it go […] the things that she still talks about [from therapy] was the bit where we were talking about alarms and what's real and what, like a warning, and what's sort of fake or not as important […] I think she's really taken on board what is a worry that you can kind of keep and what you can kind of let go […] it just feels a bit more on a level, a bit more controlled, a bit more managed (Beth, mother of Annie, 6-months post-randomisation)*

Annie continued to worry about things but learning about anxiety mechanisms enabled her, at the first sign of worry (gasp), to recognise what was happening and "*let it go,*" before it built up into a full-blown panic. The result was, in her mother's words, a "*more controlled*" anxiety which kept Annie "*on a level*". In line with the aims of therapy, Annie's anxiety remained in the background and, through a better understanding of herself, she became able to self-manage.

Claire, aged 15, also started the trial with severe anxiety:

> *The worst time is in the morning, almost always on school morning. And I don't get any warning symptoms, 'cause I wake up, and then it's, you know, it's just sudden. I can't... I'm having that anxiety attack, and I'm shaking, and sort of any external input just makes it worse. And so I've got no warning signs to use any techniques on it. So we just have to, you know, we're trying to just let it pass and try and, we say "one thing at a time" (Claire, Baseline)*

Anxiety had become part of Claire's daily routine, and because none of the techniques she had tried had been successful, she just let it take its course. The description she gives in the quote above is of a highly disempowering experience, emphasized by her use of the plural to indicate how even her parents were helpless in dealing with her anxiety. Six months later, her life had changed substantially:

> *I've been fine for [sighs] I don't know how long, for a very long time. I mean, if I can't remember when the last time was, then that obviously means something. I do believe that's thanks to MICE [...] One of them [techniques], for example, was how to change really negative thoughts into happier thoughts, you know? So say you saw your friends being happy and you thought, "oh, they're happier without me." Then you get to go, "actually, no, they're having fun, that's that." [...] One of the really helpful ones was scheduling, so I've actually learnt how to use the calendar on my phone, which is really helpful. 'Cos then, you know, I know I've got something to work towards if it's at the end of the week or going out with a friend. (Claire, 6-months post-randomisation)*

Claire could not remember her last panic attack and ascribed her change to the therapy. Claire's confidence in explaining the underlying mechanisms of the techniques she had learnt suggests an understanding of her own psychological processes and control over her responses which is in sharp contrast with her previous helplessness. Also notable is the fact that her parents were not mentioned and that in her second interview she chose to be without them. While learning to manage her anxiety, Claire also developed her independence and autonomy during therapy.

For some participants, fear was associated with specific triggers. For example, Diane, the mother of Eric, aged 11 and with ID, described how he was afraid of using stairs:

> *Yesterday we went for our daily walk and we had to cross over a little bridge. It's not very high up, so you've got stairs that take you up [...] all*

> *the way up he was shaking, and normally it's going down which is where his fears are. So now it's also going up, which is relatively new. And he was shaking all the way up, clinging onto my arms, telling me he was nervous (Diane, mother of Eric, Baseline)*

Eric's fear of stairs was new and Diane couldn't explain it. It was quite a disabling fear, so overcoming it was agreed as a therapy objective:

> *He was scared of going up and down stairs, terrified, all of a sudden, out of nowhere, terrified. Now it's like that never happened [...] [therapist] gave us some steps to do and stuff. And I was kind of being there for Eric, so basically I was showing him my nerves, it was making him more anxious [...] Whereas once I kind of got over that, it was like, "Eric, downstairs, off you go, you're a big boy now!" and he gets rewarded at the end (Diane, mother of Eric, 6-months post-randomisation)*

This illustrates the multifactorial nature of Eric's change. The therapist worked on his fear using the Fear Ladder, a list used to identify a series of tasks to which Eric could be exposed to overcome his fears. These were used in conjunction with rewards. However, through the gradual exposure process, a parallel fear was revealed in his mother and she identified it as an inhibiting factor for the child. Once Diane became aware of this mechanism, she too overcame her fears, stopped showing Eric her anxiety, and he simply followed her cue. For Diane, there was also a reattribution of how "being there", which she probably originally saw as a positive, was now contributing to the problem, not helping it.

In the case of Annie and Claire, the emotional problem was reduced by giving the young person tools that made them feel empowered and able to exercise some control over their own emotions. In the case of Eric, it was his mother Diane who learnt to regulate her emotions and become more confident with him.

Improvement in behaviour problems

Behaviour problems were even more frequent than anxiety problems, particularly in the younger participants. Of all participants in the trial, 56% had disruptive behaviour as their primary MH disorder. At the start of the trial, Felix, aged 10 often felt very angry, in a manner that his mother Georgia found upsetting:

> *Seeing red and lashing out [...] I actually asked him once [what it felt like] and didn't really like the response [...]. He said "it's good to get it out." Which is fine and probably quite reasonable, but is also a little bit unaware of the other people that it affects (Georgia, mother of Felix, Baseline)*

Georgia described Felix's rages as "*lashing out*," and found his unawareness difficult. Six months later, his awareness had improved and his anger was more contained:

> *He still gets quite angry, but it's much better than it was [...] he realises he's frustrated and can kind of contain it a bit better [...] he's definitely learning and I think the counselling particularly, has made him aware that his behaviour affects other people (Georgia, mother of Felix, 6-months post-randomisation)*

Felix's surges of anger were still a feature. The therapy made him more aware of the effects of his behaviour on those around him.

In contrast, Holly, aged 9, who also experienced severe anger and was interviewed with her mother Isla, seemed already self-aware at baseline:

> *I'm usually angry from when I wake up until I go to bed and sometimes I have no idea why […] I just feel really angry and I just feel like I could punch something or hurt somebody […] After you've felt angry, sometimes you feel sad for what you've done or when you've been screaming and shouting (Holly, Baseline)*

Anger was a a feature of Holly's daily life and, although she could not understand why she was angry, she was very articulate in describing her feelings while angry and remorseful afterwards. Six months later, she described managing her anger with an anxiety management technique called STOP (an acronym for Scared, Thoughts, Other Thoughts and Praise):

> *The STOP worked 'cause it would stop me shouting [...] I was really angry but then, instead of thinking about being late, I thought of other thoughts which is part of it for the T, and then I thought of a different thought of that my day might be good, and then it just makes you feel happier and it just makes you feel in a different mood (Holly, 6-months post-randomisation)*

Holly developed the ability to identify triggering thoughts, defuse her anger and change her mood by intentionally bringing in an alternative thought. The STOP technique gave Holly some power over her impulses.

Many of the young people's behaviour problems had an impulsive quality and this was particularly true in the case of those with ASD and/or ID. For example, the aggressive behaviour of Julia, aged 10, with ASD and ID, was initially described by her mother Kate like this:

> *The tantrums have got worse and she sometimes gets stuck in, I can only describe it as a loop […] then she gets hysterically upset [...] she does lash*

> *out, I don't think she realizes how strong her legs are, so I do get kicked when trying to help get her dressed (Kate, mother of Julia, Baseline)*

Kate's words emphasised the unintentionality and uncontrollability of Julia's behaviour and her own passivity when facing it. Six months later, Kate's tone was very different:

> *On the whole she's a bit better disciplined, if one strategy doesn't work, I now feel much more enabled to try other things to help her and help her behaviour, let her have time out [...] I've got better at reading her a bit (Kate, mother of Julia, 6-months post-randomisation)*

Julia's behaviour had become more "*disciplined*" and Kate was making this happen by using the MICE techniques. The emphasis now is less on Julia's behaviour and more on Kate's control of it. Between the two interviews there had been a shift for Kate, from being a victim, to being able to manage Julia's behaviour. In so doing, Kate had also become closer to Julia and learnt to understand her better.

Another example comes from Liam, aged 5 with ID and his mother Monica. At the beginning of the study, Monica was concerned about taking Liam out of the house due to her inability to regulate his impulsive behaviours:

> *I have to be very careful with him, when I go out with him, sometimes he just runs off the road (Monica, mother of Liam, Baseline)*

Accordingly, crossing the road was agreed as a therapy objective and six months later Monica said:

> *I'll tell him off sometimes at the beginning, but that doesn't really work, so, I give him (a) reward […] Like the whole week if you don't cross without waiting for me then you won't get the hot chocolate, for example. So, he will keep that in mind [laughs] and now he just changed habit to not cross*

> *the road before me (Monica, mother of Liam, 6-months post-randomisation)*

Before the therapy, Monica used to tell Liam off when he crossed the road on his own but found that the system did not work. Following the therapist’s advice, she introduced rewards to encourage Liam to wait for her before crossing the road. This was a simple strategy that resolved a potentially very big problem, by applying basic positive reinforcement principles to embed alternative behaviour patterns and help contain impulsive ones.

The examples above all concern behaviours that were initially perceived as being uncontrollable and that were perceived through therapy as being controllable, and appeared to be brought somewhat under control, using the suggested techniques. Felix and Holly were given the tools to recognize their feelings and self-manage their behaviour. The angry feelings remained, but they were empowered to regulate them. For Julia and Liam, who had an ID and had impulsive behaviours, the means for tackling the problem were their mothers. Kate and Monica were taught to use basic behavioural techniques to redirect their children towards more suitable behaviours. Here the mothers were empowered with respect to their children’s behaviour. In all cases, change occurred through very simple strategies that enabled the protagonists to manage the previously uncontrollable situation.

Quantitative measures and results

The primary outcome measure for the trial was the SDQ Total Difficulties Score (Goodman, 1997) reported by the parent/carer, where a higher score indicates more symptoms of a mental health disorder in the young person. As reported in Bennett et al. (2024), there was a significant between-group effect in favour of the MICE arm. The treatment effect observed at six months was maintained at 12 months with an adjusted difference in SDQ difficulties of -2·0 (95% CI -3·2 to -0·9; p<0·0001; effect size 0·4) between arms.

Thus the qualitative and quantitative parts of the study are consonant in both showing improvements as a result of the intervention. Of course, they are focused on different things and expressed in different ways. The quantitative analysis shows an improvement for the intervention group greater than that for the control group on a standardized measure of participant mental health; the qualitative analysis compares participants' accounts before and after the intervention and demonstrates how they cumulatively show an improvement in key aspects of the young person's mental health- anxiety and behavioural problems. The qualitative analysis also makes visible the family's perception of change and their sensemaking around it.

To facilitate an even closer comparison between quantitative and qualitative findings, we examined the secondary outcome measures. The mood/behaviour subscale in the PedsQL (Follansbee-Junger et al., 2016) measures a child's wellbeing through feelings of sadness, fear, anxiety and tension, while the executive functioning subscale measures a child's attention, impulsivity and ability to obey orders. The Anxiety, Panic, and Separation Anxiety subscales from the RCADS (Chorpita et al., 2000) address anxiety.

What the quantitative measures showed is that the young people receiving therapy became less anxious and showed fewer behavioural problems between baseline and 6-month follow-up and that this was significantly greater than any improvement for participants in the control group (Bennett et al., 2024). Thus we have findings which are more directly congruent with our qualitative results and therefore easier to consider together. In the Discussion which follows we examine these qualitative and quantitative outcomes together and speak to the significant contribution this synthesis offers.

Discussion

The emotional and behavioural improvement of participants in the qualitative part of the study was reflected in the improvement in MH observed for participants in the trial. The qualitative analyses complement the quantitative results by providing insight and context to the therapeutic change.

The SDQ measures a child's emotional difficulties in general and in terms of impact on their everyday life, the mood/behaviour subscale in the PedsQL measures a child's feelings of sadness, fear, anxiety and tension. The Anxiety, Panic, and Separation Anxiety subscales from the RCADS consider comparable psychological constructs. These measures significantly improved for participants in the intervention arm when compared to the control arm, suggesting that the therapy had been effective in tackling these problems despite the heterogeneous demographics of participants. The qualitative data supported these findings and provided detail on the particular ways in which the process occurred for individual young people. For instance, Annie evolved from having crippling anxiety attacks to learning to recognise warning signs and letting go of her anxious thoughts to avoid an escalation. For her, understanding anxiety mechanisms was important. With Eric, the tool was a Fear Ladder, but also a change in his mother's approach.

The SDQ and the executive functioning subscale of the PedsQL which concern problems of attention, impulsivity and obeying orders, speak to the experiences we described as behavioural problems. Participants showed signs of irrepressible anger, emotional outbursts and impulsivity at baseline which were also tackled through therapy. As with emotions, several techniques were used, including the STOP method for changing thoughts and other parenting techniques such as time out.

Therapy had a positive impact on all the interviewed young people and/or their families, although it should be noted that therapy was relatively lengthy with a large amount of input which could potentially limit implementation into routine clinical services. Nevertheless, those with the cognitive ability to respond to therapy directly acquired new understandings or techniques that they applied in their daily lives, gaining confidence and an increased sense of control. What clearly emerges from the qualitative findings is that while the young people's emotions remained, what changed was their response to them. The young people's attribution of change to their efforts and skills mastered through repetition and guidance should protect them from relapse, given that a young person understanding an intervention has been shown to be related to their engagement and use of skills (Becker et al., 2018), as well as findings that an awareness of the capacity for mental change (i.e., "growth mindset"; Dweck & Leggett, 1988), can potentiate the effects of evidence-based therapies (Schleider & Weisz, 2018).

The consistency between findings from the qualitative and quantitative components of this mixed methods study is striking, with the former providing contextual information and pointing to perceived mechanisms of change, in addition to illustrating the process working for individual families. Such consistency adds value to findings derived from each of the methods separately, and offers a deeper and broader understanding of complex issues, increasing the confidence in the research findings and their interpretation (Adu et al., 2022). In implementation science, qualitative methods are identified as a means of describing what is happening and why (Hamilton & Finley, 2019). By adopting a qualitative longitudinal design, our study uses pre-post intervention comparisons to illustrate what is happening in terms of change in a nuanced manner.

Qualitative research has the potential to play a pivotal role in closing the research-practice gap and facilitating take up of research recommendations (Munro & Savel, 2016). Consistent with the literature on patient stories, e.g., Fischer and Thies (2023), it is our experience in disseminating findings from our studies to healthcare professionals, patients and the public, that sharing the participant's journey captures attention, is emotionally engaging and generates interest in the topic in a different way to the quantitative findings.

Reflections

In this article the focus is on participants' narratives of improvement, because these were the majority and the most useful to understand the intervention's perceived mechanisms. However, a few participants did not benefit from the intervention. We also used stratification to make our sample representative of the overall study population, but, as can be seen in Table 1, some cells remained incomplete (e.g. older boys) for different reasons, including families declining to participate or families not agreeing to follow-up, which, again, could be linked to the perceived benefit of the intervention.

To increase the trustworthiness of findings, the researcher conducting the interviews and the analysis (IEN) kept a reflexive diary and collaborated on the analysis with a senior researcher (JAS) who also acted as auditor.

Conclusions

This study combined quantitative and qualitative data to gain context and insight into the change mechanisms within the MICE intervention. The qualitative findings demonstrated how the quantitatively-measured improvements occurred in the everyday lives of the participants and how closely linked they were to the strategies that participants acquired through the therapy.

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