

Mental health intervention for a child with developmental and/or epileptic encephalopathy with spike-wave activation in sleep (D/EE-SWAS)

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ABSTRACT

Children with Developmental and Epileptic Encephalopathies experience neurodevelopmental problems from both the epileptic activity and the underlying cause of the condition. Children with Developmental and/or Epileptic Encephalopathy with spike-wave activation in sleep (D/EE-SWAS) experience cognitive and behavioral regression/stagnation that occurs in tandem with marked spike-wave activation in sleep (SWAS). Children with epilepsy often have co-occurring mental health problems that are often not recognized or supported. There is increasing evidence these co-occurring mental health problems can be treated with psychological interventions. The mental health and cognitive difficulties that accompany SWAS have a significant impact on child and family quality of life. There is limited data on the treatment of mental health difficulties for children with D/EE-SWAS. We describe the use of the Mental Health Intervention in Children with Epilepsy (MICE) in a child with D/EE-SWAS who had experienced significant cognitive regression and behavioral difficulties. The intervention was delivered with the child's parents via video and consisted of 19 sessions delivered by an assistant psychologist. The focus of the intervention was reducing behaviours of concern via evidence-based behavioural parenting strategies. The intervention resulted in clear progress towards parental chosen goals (Goal Based Outcomes) and a reduction of symptoms on validated measures of behavior. Qualitative feedback via parental interview was that the intervention was very useful, giving the parents everyday strategies that they could effectively employ with the child in the home environment. This case demonstrates that a mental health intervention based on behavioural parenting strategies can be useful for children with D/EE-SWAS.

1. Introduction

Children with epilepsy have a higher likelihood of mental health difficulties, such as neurodevelopmental and behavioral issues, when compared to both healthy children and those with other chronic health conditions [1]. These challenges are frequently unrecognized, and support is often not available [2–3]. Furthermore, the mental health difficulties often have a more significant impact on health-related quality of life (HRQoL) than seizures [4–5].

Developmental and/or Epileptic Encephalopathy with Spike-Wave Activation in Sleep (D/EE-SWAS) refers to a range of conditions characterized by the EEG findings of spike-wave activation during sleep [6]. The syndrome is linked to cognitive, behavioral, and/or motor

regression/stagnation, which normally occurs simultaneously or within a few weeks of the EEG revealing significant spike-wave activation during sleep (SWAS). This is characterized by nearly continuous, slow (1.5–2 Hz) spike-wave patterns in non-rapid eye movement (N-REM) sleep. [6]. EE-SWAS occurs in a child with normal development, while D/EE-SWAS is seen in a child with preexisting developmental delay or only language delay [6]. The magnitude of the cognitive deterioration can vary significantly, but usually leads to a decrease in the patient's intelligence quotient (IQ) [6]. A population-based study from New Zealand found a cumulative incidence of 1 in 7,800 children [7]. The etiology includes structural and acquired lesions as well as genetic causes [8].

An increasing body of research indicates that psychological

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interventions can be beneficial in reducing mental health symptoms among children with epilepsy [9]. One such intervention, the Mental Health Intervention for Children with Epilepsy (MICE), is an established therapeutic approach aimed at addressing prevalent mental health conditions in this population, such as anxiety, depression, and disruptive behavior disorders [10]. MICE is a structured program that integrates evidence-based methods, including cognitive behavioral therapy and behavioral parenting techniques, to support children and young people [10]. In a large, multisite randomized controlled trial, MICE was shown to be more effective than assessment-enhanced usual care in improving emotional and behavioral difficulties six months following randomization [11]. However, there remains a notable lack of data regarding the effects of psychological interventions on mental health difficulties, including behavioral issues, in individuals with Developmental and/or Epileptic Encephalopathies (DEEs) such as D/EE-SWAS. The present study aims to detail the application of the MICE intervention in a child diagnosed with D/EE-SWAS, using outcome measures specifically designed for children with and without Intellectual Disability (ID). Additionally, the study explores how the intervention may need to be adapted to accommodate the unique clinical features of DEE, including cognitive profiles characterized by developmental regression.

2. Method

2.1. Case Description

Patient's Medical History.

At the time of the intervention the patient was 13 years of age and was attending a special school for children with epilepsy and neurodevelopmental difficulties. The child's early development was largely normal, with some minor concerns expressed in the preschool years regarding speech development, until he had his first seizure in April 2015. At the age of 5 he was diagnosed with epilepsy. He was assessed by a Paediatric neuropsychologist in 2015 soon after diagnosis. Assessment results indicated that general intellectual development, information processing, working memory and other memory skills were in the 'average' to 'high average' range. At that time, minor difficulties were noted with concentration, expressive language, fine motor skills and reading comprehension. School reports suggested that he was performing well across the curriculum. He underwent psychological assessment again in 2017, at which point more pressing concerns were being raised by the school regarding attention and focus, and general academic functioning (specifically reading and maths). At this stage, seizures were proving refractory to treatment, and it was identified that a severe epileptic encephalopathy was emerging. This was subsequently identified as Developmental and/or Epileptic Encephalopathy with spike-wave activation in sleep (D/EE-SWAS) associated with a *GRIN2A* mutation.

Since the onset of D/EE-SWAS, the child has experienced significant cognitive and emotional /behavioural regression. A psychological assessment in 2019 noted that his ability to focus and ability to engage with the assessment process was highly variable. He was noted to be highly distractible. Regarding motor skills he found it very difficult to hold a pen appropriately (using a palmar grasp, with the pen held loosely), and struggled to coordinate, moving the pen around the paper and he did not anchor the paper with his other hand. On several occasions during drawing, he became apparently stuck, going over and over the same lines; he drew in short spikey 'bursts' rather than as continuous lines. An attempt was made to assess the patient's cognitive functioning via selected subtests from the Wechsler Intelligence Scale for Children – Fifth UK Edition. However, he became so fixated on the Block Design subtest that he could not be moved on to do any other parts of the assessment, which was eventually abandoned after several attempts with different subtests. The Vineland-2 adaptive interview was conducted with his parents. The general adaptive behaviour composite was 57 (1st percentile). His result on all domains was 'low' (i.e. under 70).

The results suggested he met the criteria for mild intellectual disability. It was noted that the patient often displayed 'a lot of anxiety' and had repetitive 'tics'.

The patient's medication at the start of the intervention in October 2022 was: for epilepsy: Sodium valproate 23 mg/kg/day, Sultiame 1,16 mg/kg/day and for psychiatric difficulties Fluoxetine 0,37 mg/kg/day (increased to 0,47 mg/kg/day at the start of the intervention) and Guanfacine 0,047 mg/kg/day. The patient was not in receipt of any other medication, therapeutic or psychological support during the intervention. Furthermore, no other medications were changed during the intervention.

2.2. Pre-intervention diagnostic assessment.

The Development and Well-Being Assessment (DAWBA) is a structured interview tool designed to assist in making psychiatric diagnoses in children aged 2 to 17 years, based on ICD-10 and DSM-IV or DSM-5 criteria [12]. For the current patient, the DAWBA's scoring algorithm indicated a high likelihood that the child would meet diagnostic criteria for Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), and Oppositional Defiant Disorder (ODD). Additionally, notable symptoms of anxiety were reported — including fear of the dark, separation anxiety at night, and anxiety in unfamiliar environments — although these did not reach the threshold for a formal anxiety disorder diagnosis according to the DAWBA.

2.3. Study design

A pre-post design, including an initial multiple baseline assessment of the primary outcome measure, the Strengths and Difficulties Questionnaire (SDQ) [13], was used in this study. The multiple baseline assessment design [14] involved assessing the child's mental health on a number of occasions pre-intervention to gauge whether the child's mental health is stable or variable. This allowed us to more accurately attribute change to the intervention as opposed to natural variations in the child's behavior. The SDQ was administered weekly for four weeks (including baseline at week 4) prior to the start of treatment.

2.4. The intervention

The MICE intervention is a personalized, modular cognitive behavioral therapy program delivered remotely through telephone or video calls. It integrates content specific to epilepsy throughout the program, featuring one compulsory epilepsy-focused module and three additional optional modules related to epilepsy [10,15]. The intervention includes a weekly phone or online video call with the therapist, who conducts the initial face-to-face assessment. Parents are asked to complete assessment measures at home and send them to the therapist before each session. Therapeutic strategies introduced during sessions are then practiced within the home environment.

MICE employs an algorithm to personalize the intervention according to each young person's specific mental health needs, allowing for the management of multiple co-occurring conditions within the same treatment program [10]. The number of sessions ranges from a minimum of 10 to a maximum of 22, and the intervention is designed to be completed within a six-month period [10]. Additionally, participants may receive up to two booster sessions outside this timeframe, which can be scheduled between six and twelve months after randomization [10].

The intervention was delivered by assistant psychologists — individuals with an undergraduate degree in psychology who are not yet fully licensed practitioners. Their training consisted of comprehensive online sessions facilitated by experts in epilepsy and mental health, including members of the MICE team, epilepsy specialists, and clinicians with experience working with children, adolescents, and families. Ongoing support was provided through weekly supervision-of-

supervision, conducted by a member of the MICE team.

2.5. Outcome measures

The primary outcome measure for the study was the Strengths and Difficulties Questionnaire (SDQ) [14]. This 25-item screening tool is designed to assess common emotional, behavioral, and social difficulties in children and adolescents. It comprises five subscales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behavior, with each subscale containing five items rated on a scale from 0 to 2 [14]. A total difficulties score, ranging from 0 to 40, is obtained by summing the scores from all subscales except the prosocial behavior subscale [14]. In both the total and subscale scores, lower values reflect better mental health, with the exception of the prosocial subscale, where lower scores indicate fewer prosocial behaviors and therefore greater difficulty in this area [14].

Children with scores falling within the 'slightly raised,' 'high,' or 'very high' categories on the SDQ are considered to be at increased risk for mental health difficulties (SDQ_English(UK)_4-17scoring.pdf, accessed March 23rd, 2023). In this study, caregivers completed the caregiver-report version of the SDQ to evaluate the child's mental health and behavioral functioning.

Secondary Measures.

The Developmental Behaviour Checklist- 2nd Edition (DBC-2).

The DBC-2 is an assessment tool designed to evaluate behavioral and emotional difficulties in children and adolescents with intellectual disability (ID), including those with co-occurring autism spectrum disorder (ASD) [16]. The tool consists of 96 behavioral descriptions, each scored on a 3-point scale: 0 for "Not true as far as you know," 1 for "Sometimes or somewhat true," and 2 for "Often true or very true" [16]. The raw scores are then converted into standardized T-scores (DBC-T scores), allowing for comparisons across various subscales. For children aged 4 to 18 years, the revised DBC-P (parent form) was used for assessment [16]. The five subscales assess clinically significant behavioral dimensions in children with ID: Self-Absorbed, Disruptive, Communication Disturbance, Anxiety, and Socially Relating [16]. Total and subscale scores are classified into three levels of concern. A T-score below 40 is categorized as "little" concern, a score between 40 and 50 as "moderate" concern, and a score above 50 as "serious" concern [16]. A score in the "serious" concern range indicates significant behavioral and emotional issues that warrant management, treatment, and further evaluation [16]. A "moderate" concern score may suggest the need for management or treatment and could be indicative of a potential mental health diagnosis [16].

Session by session measures.

Goal Based Outcome tool (GBO) [17].

The Goal-Based Outcome (GBO) approach involved setting three initial goals at the start of treatment, which were collaboratively agreed upon by the therapist and the parent. Progress towards these goals was assessed during each session on a scale of 0 to 10, with 0 indicating no progress and 10 representing full achievement of the goal. In addition, caregiver feedback on the intervention was collected at the conclusion of the treatment through a semi-structured interview conducted by an interviewer who was not part of the MICE intervention team.

Intervention

In the first session, caregivers selected goals focused on behavioral challenges, aligning with the primary symptoms identified through the clinician-rated DAWBA.

The specific goals that were agreed were:

- Child to reduce the number of times a day that he has a tantrum ("silly moods" i.e. laying on the floor, grabbing faces, pulling down trousers) from 10 times a day to 5 times a day
- Child to sit with the family during dinner without picking food from other sibling's plate 3 times a week rather than 7

- Child to engage in self-directed play with the family for 5 min or self-directed play on his own (supported by parents) for 5 min once a day

Based on the caregivers' identified goals, the disruptive behavior module from the MICE manual was utilized, as it focuses on behavioral parenting strategies. This module incorporates practices from behavioral parenting programs recommended by NICE (2013) (Overview | Antisocial behaviour and conduct disorders in children and young people: recognition and management | Guidance | NICE accessed February 14th, 2024), including techniques such as one-on-one time, praise, rewards, effective instruction, active ignoring, time-out, as well as sessions on future planning and relapse prevention. Since no other difficulties hindered progress in the disruptive behavior module, no additional strategies from other modules were implemented. A total of 19 weekly sessions were conducted, and no modifications to the MICE intervention were necessary. However, caregivers were provided with advice regarding a specific behavior not directly related to the set goals — namely, the child's tendency to tear paper, including newspapers and documents — as the caregiver expressed concern over this behavior being particularly disruptive.

3. Results

3.1. Pre-post: SDQ and DBC-2

The SDQ scores are shown in Fig. 1 whilst the scores at baseline assessment and 6-month follow-up are shown in Table 1. The total SDQ score for the three weeks before intervention and baseline were stable at all 4 assessment points. At six-month assessment the total score had reduced from 28 points to 23 points. The subscale scores reduced for three subscales; Conduct, Peer and Emotional (indicating better functioning), did not change for Attention/Hyperactivity and increased for prosocial (indicating better functioning). The subscale with the biggest change was Conduct with a 3-point decrease and change from 'high' to 'close to average'.

On the DBC-2 the T score total reduced from T-Score 65 to T-Score 62 (see Table 2). The biggest change in the DBC was for the Disruptive scale where the range of concern changed from 'Serious' to 'Moderate' and the T-score decreased from 61 to 48.

3.2. Session-By-Session measures

Weekly measures (symptom tracking and goal-based outcomes) were analysed visually (see Fig. 2). Scores for all three goals were 1 at the first session and increased to 9, 9 and 7 respectively at the final session suggesting improvement all three areas.

3.3. Interview with father after the intervention

The patient's father felt that participation in the intervention was very positive for the family. Before the intervention, X's behaviour was making it difficult to go anywhere or do anything. Previous interventions had been medical i.e. seeing a psychiatrist and trying a range of psychiatric medications. The strategies that worked best were 'praise' and 'active ignoring'. 'Effective instruction' was also helpful. 'Using rewards' was harder to implement as the boy's father felt it was difficult to find rewards that were sufficiently motivating.

The patient's father felt that he had developed a closer relationship with his son as a result of the intervention. The father reported feeling much happier and also that he felt that his son was much happier. He reported that they as parents felt that they can go out and do things that they would have just otherwise not done and that he felt more relaxed when he was with him. After the intervention, his father would be surprised if he 'had a tantrum' whereas previously, they were very frequent.

The patient's father felt that the online format suited the family as they did not have to take time off work, or just needed to finish work

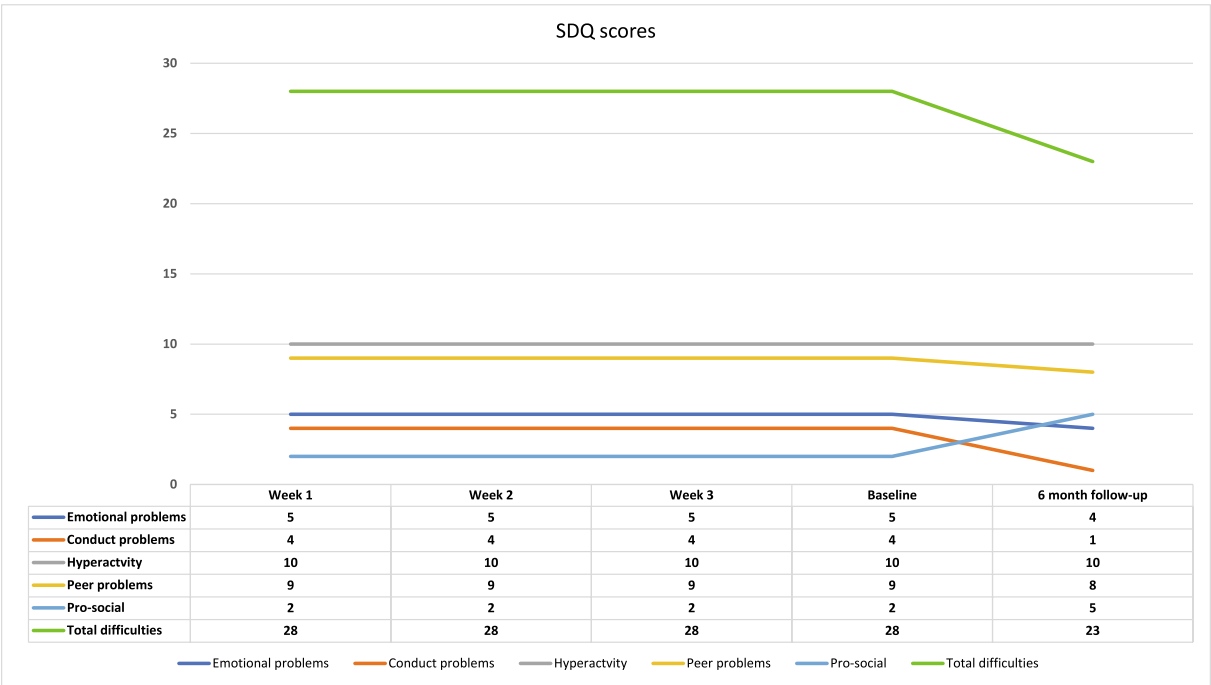


Fig. 1.

Table 1
Scores on the SDQ at baseline and Follow-up.

Subscale	Baseline	6 months after intervention
Emotional problems	5 (High)	4 (Slightly Raised)
Conduct problems	4 (High)	1 (Close to Average)
Hyperactivity	10 (Very High)	10 (Very High)
Peer problems	9 (Very High)	8 (Very High)
Pro-social	2 (Very Low)	5 (Very Low)
Total difficulties	28	23

Table 2
Score on the DBC-2 at baseline and Follow-up.

Subscale	Baseline T Scores	6 months T scores
Disruptive	61 (Serious Concern)	48 (Moderate Concern)
Self Absorbed	74 (Serious Concern)	77 (Serious Concern)
Communication Disturbance	55 (Serious Concern)	59 (Serious Concern)
Anxiety	47 (Moderate Concern)	55 (Serious Concern)
Social Relating	60(Serious Concern)	58 (Serious Concern)
Total	65(Serious Concern)	62(Serious Concern)

slightly earlier and could do it during the school day, and did not have to travel.

4. Discussion

There is very limited evidence for mental health interventions for children with DEEs where both epilepsy and the underlying genetic condition may contribute to neurodevelopmental stagnation or regression. The results of the current case study show that a mental health intervention focusing on parent training for behavioral problems delivered with the child’s parents via video was helpful in reducing specific behaviors of concern, and in reducing scores on subscales which measure disruptive behavior on standardized measures of behavior. Given the lack of evidence for children with epilepsy and DEEs the results are promising and suggest that further research with more robust design in these children is warranted in the future.

In relation to scores on the SDQ, the reduction in the total score of 5

points is similar in magnitude to the reduction found in the large RCT study of the MICE intervention [11]. The largest reduction in scores came from the conduct scale and this changed from ‘high’ to ‘average’ category suggesting the change was of clinical significance. The fact that largest change was in the area of conduct which taps into disruptive behavior is not surprising given that the focus of the intervention was on goals related to behavior. There is a large evidence base suggesting that parent training can reduce behavioral concerns in children [18,19] including children with intellectual disability [20] and these approaches are likely to be useful in children with DEEs.

The reduction in the SDQ score was mirrored on the DBC-2 where the main reduction was seen on the disruptive behavior subscale, which taps into similar difficulties as the conduct scale on the SDQ. The reduction in difficulties on the DBC-2 Disruptive Behavior subscale suggests that the DBC-2 may also be a useful measure for assessing outcomes in studies of children with epilepsy and ID, including DEEs. Given that there are few appropriate screening tools for mental health and behavioral disorders in individuals with ID, which hampers the detection of psychiatric comorbidities [21] the DBC2 is a promising tool in this population given that the SDQ may not be useful in children with more severe levels of ID [22,23].

The improvement in the GBO score over the course of the intervention across all three goals suggested that the intervention was particularly effective in addressing goals chosen by the child’s parents and thus reflects real life concerns. The qualitative feedback provided via post intervention interview adds to the evidence that the intervention gave small but meaningful gains that were particularly helpful for the child’s family. It allowed them to go out more together as a family and also improved the relationship between the child and parents.

This case study employed a multiple baseline assessment to establish that the child’s behavior and emotional functioning was stable before the intervention, suggesting that the change may be causally attributable to the intervention. This approach is valuable in case studies and study designs with small sample sizes. The use of standardized measures for mental health in the general pediatric population and the ID population was also useful in showing that the intervention in a child with a DEE was effective according to both measures. The child in the current study had an intellectual disability in the mild range and the MICE

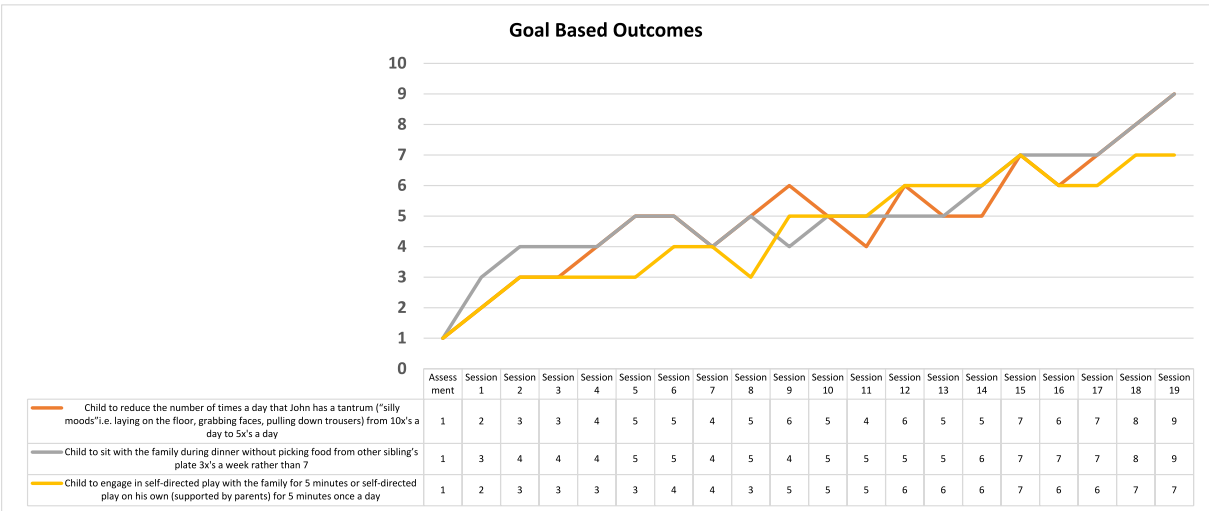


Fig. 2.

intervention did not require adaptations. However, many children with DEEs have intellectual disability in the moderate, severe or profound range and thus research is needed to explore whether the MICE intervention will need to be adapted to accommodate these children’s level of intellectual disability. In the current study the child did not undergo EEG investigation during the course of intervention. Given the possible relationship between spike-wave activation in sleep and behavioral and cognitive changes, future research will benefit from undertaking sleep EEGs during the course of the intervention.

5. Summary

Children with DEEs often have a complex combination of cognitive and behavioral problems. In individuals with DEEs, mental health issues often become the biggest concern for families, eclipsing seizures as their major concern. Stagnation or regression in cognitive skills may be particularly difficult for the affected child and family. The current case study shows that evidence based mental health intervention delivered via Telehealth may be useful in this population and provides important insights for future more comprehensive trials of this intervention.

Ethical Approval

This project has been approved by Oxford Research Ethics committee (18/SC/0250) Research Ethics Committee. Informed consent was received from the participants.

CRedit authorship contribution statement

C. Reilly: Writing – review & editing, Writing – original draft, Supervision, Methodology, Data curation, Conceptualization. **Roz Shafran:** Writing – review & editing, Supervision, Methodology, Conceptualization. **Helen Cross:** Writing – review & editing, Methodology, Conceptualization. **Millie Wagstaff:** Writing – review & editing, Project administration, Investigation. **Bhavna Sidhpara:** Writing – review & editing, Investigation, Data curation. **J. Idowu:** Writing – review & editing, Investigation, Data curation. **C. Meades:** Writing – original draft, Methodology, Data curation. **S.D. Bennett:** Writing – review & editing, Supervision, Investigation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence

the work reported in this paper.

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