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Research Paper

Subjective and objective memory in a community-derived sample of people with epilepsy: Evidence from the crimes and four doors tests

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ABSTRACT

Subjective self-reports of difficulties with memory are relatively common in people with epilepsy, though these do not always align with performance on objective memory tasks. The current study gathered qualitative and quantitative subjective reports of memory function in a group of people with epilepsy who were recruited via the charity Epilepsy Action, along with controls. Participants also carried out one of two recently developed experimental tasks (Crimes or Four Doors) that provide objective measures of long-term memory and forgetting, along with an additional verbal learning and recall task, each of which assess retention over a one-week period. Relative to controls, people with epilepsy reported memory problems across all the subjective measures, while also showing more objective forgetting on Crimes and Four Doors. When combining the epilepsy and control samples, subjective forgetting and memory satisfaction correlated with objective delayed recall and forgetting. Within the epilepsy sample, delayed recall correlated with subjectively experienced forgetting. These findings provide new evidence for subjective and objective memory difficulties in epilepsy and indicate the need for development of appropriate tools to detect atypical forgetting in this population.

1. Introduction

People with epilepsy often report difficulties with their memory [1], but these do not always align with outcomes on objective memory tasks [2,3]. Many people with epilepsy referred for memory assessment fall in the normal range on neuropsychological assessment [4], and express concerns about their memory that are not always matched by those of clinical practitioners [5]. One important dimension to consider is the timeframe over which memory and forgetting are recorded. Atypical or 'accelerated' long-term forgetting (ALF) may be a relatively common issue in people with epilepsy [6], defined as greater forgetting over hours, days, or weeks following initial learning. Several studies have reported apparent patterns of ALF in at least some epilepsy patients [e.g., 7], though this is not always observed [8]. This form of increased forgetting may underlie some of the lived experiences and subjective reports of people with epilepsy. Objective tests of memory over longer intervals are required to detect such issues and to avoid domain-specific mismatch with subjective memory difficulties [9] but are often not included in empirical research and neuropsychological batteries [7,10]. As many patients with atypical forgetting will produce intact performance on standard tests with short retention periods, misdiagnosis may result.

Challenges remain in developing appropriate tests for clinical use [11,12]. One pair of tasks that have recently shown promise in capturing memory and forgetting are the Crimes and Four Doors tasks. Initial work with healthy young and older adults [13–16] demonstrated that these tasks are relatively quick to administer, acceptable to participants, and provide tests of verbal (Crimes) or visual (Four Doors) material in which the same information can be sampled at different test points. They have subsequently been extended to individuals with epilepsy. Laverick et al. [17] found evidence of increased forgetting on these tests over a one-week period, relative to controls, in a small group of clinically derived epilepsy patients (N = 14). Allen et al. [18] then extended these findings using remote implementation with a larger (N = 49), heterogeneous group of people with epilepsy who were derived from the community.

Building on this, the current study aimed to be the first to explore

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how these patterns of delayed memory and forgetting performance on Crimes and Four Doors tasks align with subjective reports of memory ability, at a group and individual level. We addressed this in the diverse sample of patients reported in Allen et al. [18] who were derived from the community and living with a managed epilepsy condition.

Firstly, we examined the subjective memory problems that people with epilepsy report across a brief set of qualitative and quantitative self-report measures, comparing with a control group without epilepsy. Based on prior studies, we predicted self-reported memory difficulties on quantitative measures of memory function, specifically MMQ memory satisfaction and novel targeted questions concerning long-term memory and forgetting. We also expected at least some people with epilepsy to provide qualitative descriptions of memory problems caused by their epilepsy, potentially offering further insight regarding the lived experiences of these individuals.

Secondly, we have already shown evidence of increased forgetting over a one-week period in the epilepsy group on Crimes and Four Doors [18]. We report further analysis of this dataset (and data from a measure of extended verbal memory adopted from a published neuropsychological test battery, the BMIPB-II) using a slightly updated sample, to provide full reporting of objective outcomes alongside subjective measures. This enables us to consider group differences in both subjective and objective measures using the same sample.

Thirdly, we examined the relationship between subjective and objective memory at an individual level, doing so across the whole sample and then within the epilepsy group, to explore whether self-reported memory complaints show any relationship with delayed memory performance. Although the broader picture regarding links between subjective and objective difficulty is rather mixed [3], there is some evidence for a stronger relationship when using measures of memory over extended time periods [19], though these studies have typically recruited patients via clinical routes with more severe epilepsy. If such subjective–objective links are observable in samples including people with epilepsy recruited from the community, and our objective measures are sensitive to this, then we would expect to find that individuals who self-report reduced memory ability also tend to show reduced performance and more forgetting at the one-week test.

2. Method

2.1. Participants

The sample is very similar to that reported by Allen et al. [18], with one additional individual with epilepsy now included (participant 8984). There were 82 participants who initially completed the three components of the study. In line with Allen et al. [18], all analysis focuses on individuals achieving the a priori criterion score of 15/20 (75 %) correct recall after a maximum of three rounds of presentation on the Crimes or Four Doors task in session 1 (i.e., the short delay test). This was implemented to ensure appropriate and matched initial performance across participants and resulted in 75 participants in the final sample. There were 45 people with a diagnosis of epilepsy (35 females, 10 males, mean age 45.6 years, range 22–79), recruited via the charity Epilepsy Action using advertisements on their website and newsletter (see Table 1 for key characteristics). There were 30 control participants (22 females, 10 males, mean age 44.5 years, range 22–74) without epilepsy in the final sample, recruited via online and word-of-mouth advertisement. Controls were required to have no known neurological disorder. They were recruited to ensure group-level age-matching with the epilepsy participants, and the two groups were well-matched in this regard, $t(73) = 0.31$, $p = 0.76$, $d = 0.07$. The sample size was selected primarily to detect differences between groups on the objective measures of memory at the long delay (one-week) test point [see 18] but are also suitable to observe large ($d = 0.8$) group effects on the subjective outcomes that are the main focus of the present work (two-tailed, alpha = 0.05, 80 % power, indicates minimum of 26 per group).

Table 1
Characteristics of the epilepsy sample (N = 45).

	Count (with %)
Temporal lobe epilepsy (TLE)	23 (51 %)
Generalized epilepsy	12 (27 %)
Juvenile myoclonic epilepsy	3 (7 %)
Focal aware seizures	4 (9 %)
Other or blank	3 (7 %)
Medication (polytherapy/monotherapy/none)	22/21/2 (49 %/47 %/4%)
Average duration of epilepsy in years (SD)	21.66 (SD = 17.2)
TLE lateralization where reported (Left/Right/Bilateral)	10/6/3

2.2. Design, Materials, & Procedure

Quantitative subjective outcomes were implemented within a between-subjects design, comparing people with epilepsy and controls. For the primary objective measures of memory, a 2x2x2 mixed design was used, with between-subjects factors of population group (epilepsy vs. controls) and test group (Crimes vs. Doors), and the within-subject factor of test point (short delay and one-week). Participants were randomly assigned to each test group using a 1:1 ratio, with the constraint that any individual with colour vision difficulties were assigned to the Crimes group.

An overview of the schedule is set out in Fig. 1. All participants initially indicated their interest in taking part via an online form. They were then contacted via email by a researcher, who provided a detailed information sheet and gave the participants time to decide whether they would like to participate. The testing schedule involved one online pre-test questionnaire, followed by two 'live' one-to-one sessions implemented using the online experimental software platform Gorilla [20] and presented via the remote communication platform Zoom and its screen-sharing functions. Participants completed the online questionnaire before the first live session. All recruitment and data collection took place during 2022.

2.3. Questionnaires

The online questionnaire involved questions regarding demographics, vision, and mood, and was implemented using onlinesurveys.co.uk. General mood over the past week was assessed on a 5-point scale (see Supplementary Materials). If the participant indicated a diagnosis of epilepsy, they were asked further questions specific to their condition, including epilepsy diagnosis, status, and medication, and a free-text response question probing how they felt their memory had been affected.

All participants then completed the MMQ Satisfaction subscale [21], an 18-question set using a 5-point Likert scale (e.g., *I have confidence in my ability to remember things*, and *I worry that I will forget something important*). Responses to this scale were scored according to the published and openly available manual [21], reverse-scoring questions where appropriate, and producing a total raw score (with a higher score indicating more satisfaction, and a score range of 0–72). Scores were also categorised following the published and freely available MMQ manual, by converting raw scores to T-scores based on the manual's normative sample and then applying the recommended categorisation of interpretation (very low T-score < 20; low 20–29; below average 30–39; average 40–60; above average 60–70; high 71–80; very high > 80).

This was followed by three additional 5-point scale questions (1 = strongly agree; strongly disagree) designed to index the individual's subjective experience of their immediate memory (*I often feel that I forget things in the moment. For example, remembering a phone number I'm in the process of ringing or the name of someone I've just met*), long-term memory (*I often feel that I forget things over minutes or hours. For example, what I need to buy when I go to the shops and don't have a list*) and long-term

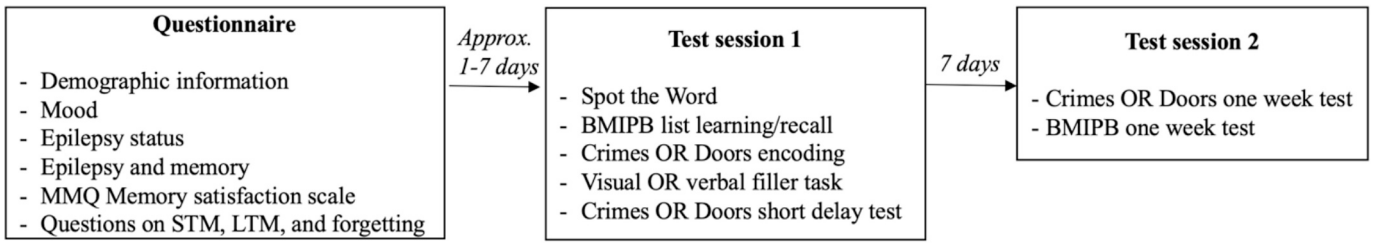

Fig. 1. Timeline of questionnaire and live sessions.

forgetting (*I often feel that I forget things more quickly over a few days or weeks, compared to friends or family that are a similar age to me*).

2.4. Cognitive testing in the live sessions

Each participant took part in two live sessions conducted on an individual basis with a researcher over Zoom. Session 1 lasted around 45 min and consisted of Spot the Word (a measure of verbal intelligence based on lexical decision, [22]), BMIPB-II (Brain Injury Rehabilitation Trust Memory and Information Processing Battery) list learning and recall [23], and the encoding and short-delay test phase for Crimes or Doors. The one-week test lasted around 15 min and included long-delay tests for Crimes or Doors, and BMIPB-II list recall.

As the primary focus of the current work is the subjective measures, we only briefly describe the details of the cognitive testing here. We refer the reader to Allen et al. [18] for a more detailed description of the full testing protocol for the live sessions. Briefly, the Crimes Test involves four fictional vignettes each describing a relatively minor crime (along with location, victim, and perpetrator), presented verbally by the researcher. The Four Doors test consists of four composite photographic visual scenes, each involving a door of different type and colour, a surrounding wall, a decorative feature, and an animal. For each test, the crimes or doors were presented serially, with a recall check immediately after presentation of each to ensure initial encoding. Following encoding and a 60-second filled delay (with a visual distractor task for the Crimes group, and a verbal task for the Doors group), the short delay test was presented, involving 20 cued recall questions probing different associative aspects of the crimes or doors (e.g., *Who committed the crime against the young woman?; What animal was in front of the house door?)*. A learning-to-criterion approach was adopted, with participants repeating the encoding and short delay test phases if they failed to reach a minimum score of 15/20 correct (75 %) on each round. This cycle was repeated up to three times for each participant, with performance on the final testing round carried forward. The main outcome variables for these tasks are number correct at the short-delay and one-week tests and change in performance between these test points.

The BMIPB-II list learning task [23] involved auditory-verbal presentation of a sequence of 15 words across five learning and immediate recall trials (A1-A5), an interference trial on a different 15-word sequence (B), and then a delayed recall attempt of list A (A6). Recall of items (from lists A and B) was then attempted in the long delay test one week later. The main outcome variables for present purposes are number correctly recalled from list A at the initial A6 delay and long delay tests, along with change in performance between these test points. All participants carried out this task.

2.5. Data analysis

Data were inspected using Q-Q plots and Shapiro-Wilks tests to check normality. Quantitative subjective outcomes were analysed using independent samples t-tests, or their non-parametric equivalent (Mann-Whitney test) when non-normally distributed, to examine whether the subjective experience of memory ability differed between the epilepsy and control groups. Outcomes on Crimes and Four Doors were analysed within a 2x2x2 mixed ANOVA with population group and test group as between subjects factors, and test point as within subjects factor, to confirm whether the epilepsy and control groups differed in their memory performance at the short delay vs. the one-week delay, and whether this varied with test materials. Here, the primary outcome of interest was the interaction between test point and population group. Change in performance between the test points (one week – short delay) was also examined, in a 2x2 mixed ANOVA (with population group and test group as factors). Similarly, BMIPB list recall was analysed within a 2x2 mixed ANOVA, with population group and test point (short delay, i.e. A6 test, vs. one-week) as factors, along with an independent samples *t*-test examining performance change. Finally, evidence for a relationship between subjective and objective outcomes was examined using Spearman's Rho (to allow for any outcomes that were not normally distributed) with age partialed out, firstly across the whole sample, and then separately within the epilepsy and control groups.

3. Results

Analyses were carried out in JASP 0.19. The epilepsy and control groups did not differ in verbal intelligence as measured by Spot the Word (control scaled score *Mean* = 8.97, *SE* = 0.49; epilepsy *Mean* = 9.49, *SE* = 0.38), $t(73) = 0.85$, $p = 0.40$, $d = 0.20$, or in level of education (classified using the International Standard Classification of Education (ISCED), control *Median* = 6, *IQR* = 5–7, epilepsy *Median* = 6, *IQR* = 4–6.5, $U = 658.50$, $p = 0.68$. The epilepsy group reported lower mood (reverse coded, $M = 3.68$, $SE = 0.17$) than controls ($M = 4.55$, $SE = 0.13$), $t(71) = 3.81$, $p < 0.001$, $d = 0.91$.

3.1. Subjective measures

3.1.1. Does your epilepsy affect your memory?

In response to the question "does your epilepsy affect your memory?', of the 45 people with epilepsy, 37 participants responded "yes", 8 responded "don't know", and 0 responded "no". The 37 who responded yes were then asked to provide a typed free-text description of how they felt their memory was affected. All responses are listed in Table S1 in Supplementary Materials. A range of details were provided, touching on different issues including types of memory problem, forgetting, possible causes, and strategies that participants use in response. There was considerable variability in detail provided between respondents, with some providing detailed responses (e.g., *There are episodes in my life that I have absolutely no recollection of at all – family events, holidays, places I have been to, things I have done…… The memories just do not exist whatsoever, as if it never happened. After a seizure, the few days prior in particular seem to be 'swiped' from my brain, as if it's rebooting. Also immediately after a seizure I have no idea where I am, what day it is, what I'm doing…and family have to tell me all that information as I come round (this is possibly just part of coming round from the seizure as opposed to memory however). I find it very hard to retain information now generally – I struggled whilst studying and this continues now at work and in life. I write notes and to-do lists to help aid my memory,* participant 6971).

Content of the free text responses was categorized along several dimensions, including different types of memory and cognitive difficulty,

and the individual's sense of how this related to their epilepsy. An initial screening of all responses was carried out independently by two researchers to identify possible categories, which were then agreed between them. A first researcher then categorized response content as relating to each of these agreed categories, with the outcomes of this categorization then reviewed and suggestions for amendment made by a second researcher. Responses could fall into multiple categories. This revealed a range of apparent problems with memory (see Table 2). The most frequently reported types were identified as being associated with episodic memory, forgetting, short-term memory, semantic/verbal memory retrieval, prospective memory, and learning, along with general (otherwise undefined) memory problems. Six patients mentioned having to use memory aids in their everyday lives. Finally, although the question specifically probed memory difficulties, four respondents also indicated problems with other aspects of cognition (attention, concentration, speed of processing).

3.2. Quantitative subjective measures

Fig. 2 shows descriptive statistics for each of the quantitative subjective measures of memory (see also a raincloud plot for the MMQ outcomes in Fig. S1 of Supplementary Materials). Analysis of MMQ raw scores indicated that the control group reported significantly higher memory satisfaction, t (73) = 7.35, $p < 0.001$, $d = 1.73$. Distribution of individuals across MMQ response categories significantly differed between groups, $X^2 = 18.88$, $p < 0.001$, with around half the epilepsy group reporting low or below average memory satisfaction, while nearly all controls reported average or above average satisfaction. For the three questions about specific aspects of memory (examined using non-parametric Mann-Whitney tests), the epilepsy group reported significantly lower scores (indicating more problems) with short-term memory, $U = 1006.50$, $p < 0.001$, *rank biserial correlation effect size (r)* = 0.49, long-term memory, $U = 1025$, $p < 0.001$, $r = 0.52$, and forgetting, $U = 1130$, $p < 0.001$, $r = 0.67$.

3.3. Objective measures

Outcomes from the objective memory measures are presented in Figs. 3 and 4. Key outcomes are also reported in Table S2 and as raincloud plots (Figs. S2-S5) in Supplementary Materials.

Table 2
Categories, frequency, and examples of memory difficulties drawn from free text responses provided by people with epilepsy who felt their condition had affected their memory (N = 37). Note that some responses could be scored in multiple categories.

Type of difficulty	Count (with %)	Examples
Short-term memory	15 (41 %)	*My brain is a sieve so holding onto information that is communicated to me during verbal conversations is very hard.* (participant 2659).
Episodic memory	17 (46 %)	*A lot of things and events in past few years have totally vanished. Places I've been to and people I've met that are fairly important but it's gone. Like an eraser has removed them!* (9367).
Semantic memory and word retrieval	11 (30 %)	*I find it harder to remember the words I'm looking for during conversations* (2483).
Prospective memory	7 (19 %)	*Remember to take medication at right times* (1690).
Forgetting	16 (43 %)	*I think I forget more, faster. It seems more difficult for information to 'go in'* (5872).
Learning	5 (14 %)	*Much harder to try to learn new information* (1970).
Undefined memory	9 (24 %)	*I couldn't remember simple things…Gradually over the years my memory has worsened generally (4292).*
Relies on memory aids	6 (16 %)	*I write notes and to-do lists to help aid my memory* (6971).

3.4. Crimes and Four Doors

A mixed 2x2x2 ANOVA (test point; delay vs. one-week; test group, Crimes vs. Four Doors; population group, controls vs. epilepsy) showed a main effect of test point, $F(1,71) = 159.58$, $p < 0.001$, $\eta_p^2 = 0.69$, and population group, $F(1,71) = 8.56$, $p = 0.005$, $\eta_p^2 = 0.11$. There was no effect of test group, $F(1,71) = 1.25$, $p = 0.27$, $\eta_p^2 = 0.02$. Of primary interest, the test point by population group interaction was significant, $F(1,71) = 9.66$, $p = 0.003$, $\eta_p^2 = 0.12$. Planned comparisons revealed no group difference on the short delay test (controls $M = 17.83$, $SE = 0.35$, PWE $M = 17.18$, $SE = 0.28$), $t(73) = 1.47$, $p = 0.15$, $d = 0.35$, but the epilepsy group was less accurate on the one-week test (controls $M = 13.47$, $SE = 0.80$, PWE $M = 9.87$, $SE = 0.73$), $t(73) = 3.25$, $p = 0.002$, $d = 0.77$. There was no interaction between test point and test group, $F(1,71) = 0.05$, $p = 0.83$, $\eta_p^2 < 0.01$, and no three-way interaction, $F(1,71) = 0.85$, $p = 0.36$, $\eta_p^2 = 0.01$.

3.5. Absolute change between the short delay and one-week tests

A 2x2 ANOVA (test group x population group) indicated an effect of population group, $F(1,71) = 9.66$, $p = 0.003$, $\eta_p^2 = 0.12$, but no effect of test group, $F(1,71) = 0.05$, $p = 0.83$, $\eta_p^2 < 0.01$, and no interaction, $F(1,71) = 0.85$, $p = 0.36$, $\eta_p^2 = 0.01$. The epilepsy group showed a higher rate of absolute loss ($M = -7.28$, $SE = 0.59$) compared to controls ($M = -4.40$, $SE = 0.72$).

3.6. BMIPB-II list learning and recall

A mixed 2x2 ANOVA (test point, short delay vs. one week; population group, control vs. epilepsy) indicated a main effect of test point, $F(1,73) = 259.08$, $p < 0.001$, $\eta_p^2 = 0.78$, with accuracy declining between the first post-interference short-delay trial (A6) and again to the one-week test. There was no significant effect of population group, $F(1,73) = 2.18$, $p = 0.144$, $\eta_p^2 = 0.03$, or interaction, $F(1,73) = 0.02$, $p = 0.89$, $\eta_p^2 < 0.01$. The same results emerged when using the A5 test as the session 1 measure, instead of A6.

To summarize the various objective outcomes, the control and epilepsy groups performed very similarly at the short delay test, and did not differ in the learning trials required to reach criterion either (see supplementary materials). More forgetting on the long delay (one-week) test was apparent for people with epilepsy, though with variability in both groups, and many in the epilepsy group showing similar profiles to the controls. Variability and forgetting were also apparent for the BMIPB-II list learning long delay task, but the two groups showed similar levels of performance on this measure.

3.7. Relationship between subjective and objective measures

A Spearman's Rho correlational analysis was carried out on all participants (with age partialed out), including MMQ (raw score), the three questions on STM, LTM, and forgetting, along with long-delay (one-week) performance on Crimes/Doors (C/D) and List recall, and change in performance between the short delay and the long delay tests. Short-delay performance is not included in the reported outcomes as our focus was on one-week retention and forgetting, but no significant correlations ($p \geq 0.05$) were observed with any subjective measure.

Outcomes are shown in Table 3a. The subjective measures all intercorrelated, though it is particularly notable that memory satisfaction was particularly strongly (negatively) correlated with subjectively experienced forgetting. There were correlations between the objective measures as well. Turning to the relationship between subjective and objective outcomes, higher memory satisfaction (MMQ) was associated with better performance and less forgetting on the Crimes/Doors long delay test. Subjectively reported problems with LTM and forgetting were associated with lower Crimes/Doors performance on the long delay test. Subjective forgetting also correlated with observed change in

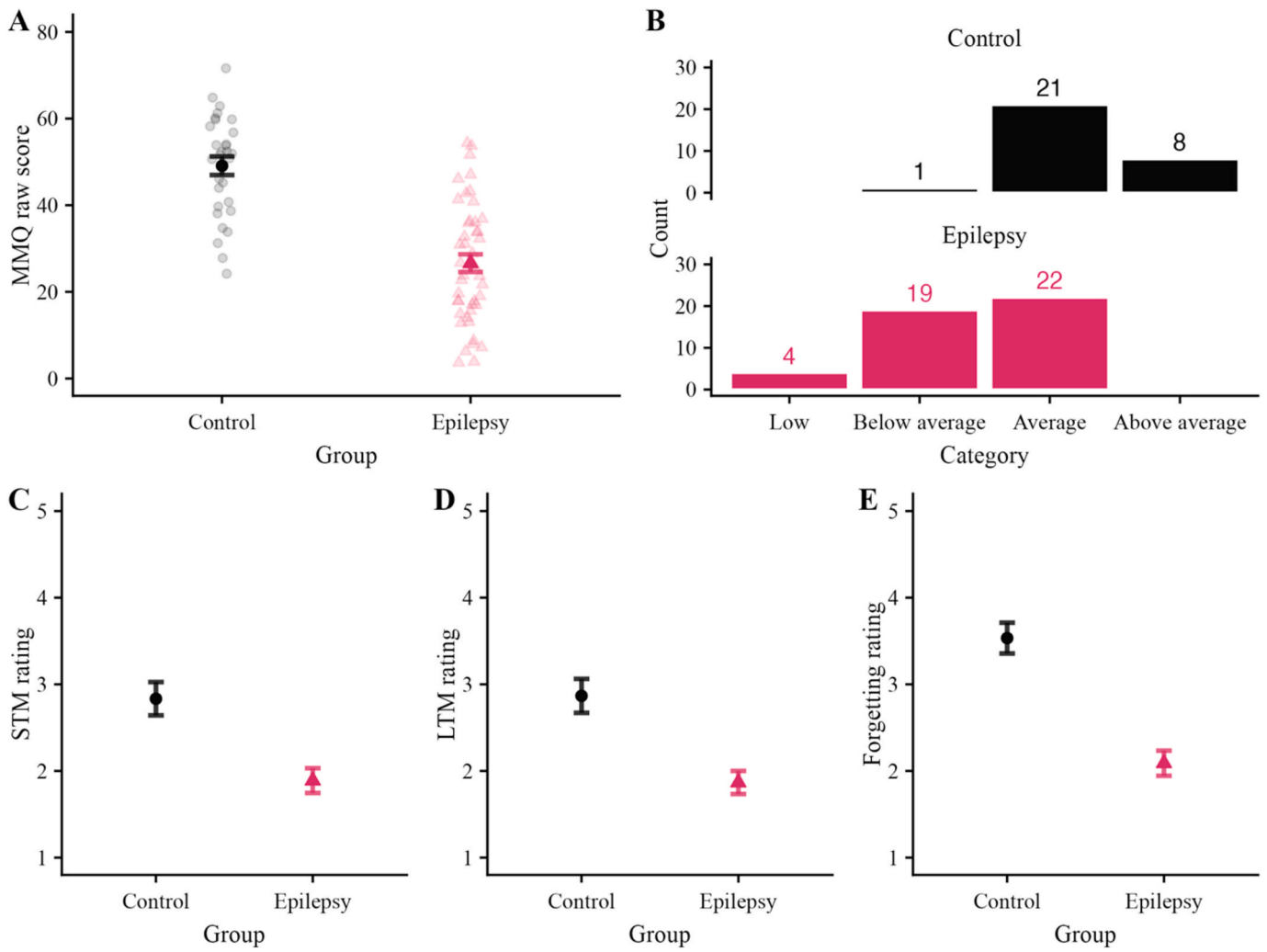

Fig. 2. Quantitative subjective outcomes for the epilepsy and control groups, showing a). MMQ memory satisfaction raw scores (means and SE, with individual participants shown in lighter points), b). distribution of participants across MMQ memory satisfaction categories, c-e). mean ratings (and SE) on questions regarding different aspects of memory. Lower ratings indicate lower subjective ability.

performance over the one-week period. No other correlations between subjective and objective measures were significant (see Supplementary Materials for full reporting of p values).

We then repeated these analyses separately for each of the epilepsy and control groups, to examine any intercorrelations within each subgroup. The correlations for the control group are reported for full transparency (3c), though this was not a focus of the present work. For the epilepsy group (Table 3b), we again see correlations within the sets of subjective and objective outcomes. We also observed a significant correlation between subjective forgetting and recall performance at the one-week test on Crimes/Doors. The other correlations between subjective and objective measures that were found across the whole sample were in the same direction here but were not statistically significant (see Supplementary Materials for p values).

4. Discussion

Our aim in this online study was to explore subjective memory difficulties in a community-derived sample of people with epilepsy, to present alongside performance on recently developed objective measures of memory and forgetting over time (Crimes and Four Doors, along with BMIPB List recall), and to examine any relationships between responses on these subjective and objective measures. Several important findings emerged.

4.1. Subjective memory

Firstly, our epilepsy sample self-reported experiencing considerable memory difficulties. A majority felt that their epilepsy had affected their memory, and their qualitative descriptions of these effects were wide-ranging and informative, indicating difficulties with memory that were sometimes severe and profound. The varying nature of these memory complaints fell into several categories, but particularly apparent were difficulties in immediate memory, episodic memory and forgetting. This frequent reporting of memory difficulties aligned with outcomes on the quantitative subjective measures. The epilepsy group reported lower satisfaction with their memory (on the MMQ), and difficulties in short-term memory, long-term memory, and forgetting as measured by our additional questions that were designed to target these specific aspects of memory. These findings replicate and extend previous evidence of self-reported memory problems in epilepsy [19,24] using both qualitative and quantitative (online) subjective measures including items probing specific aspects of memory and forgetting in a diverse community-derived sample of people living with epilepsy. They indicate a range of subjectively experienced difficulties that impact on different timeframes and types of information, with increased forgetting emerging as a commonly reported factor on qualitative and quantitative measures.

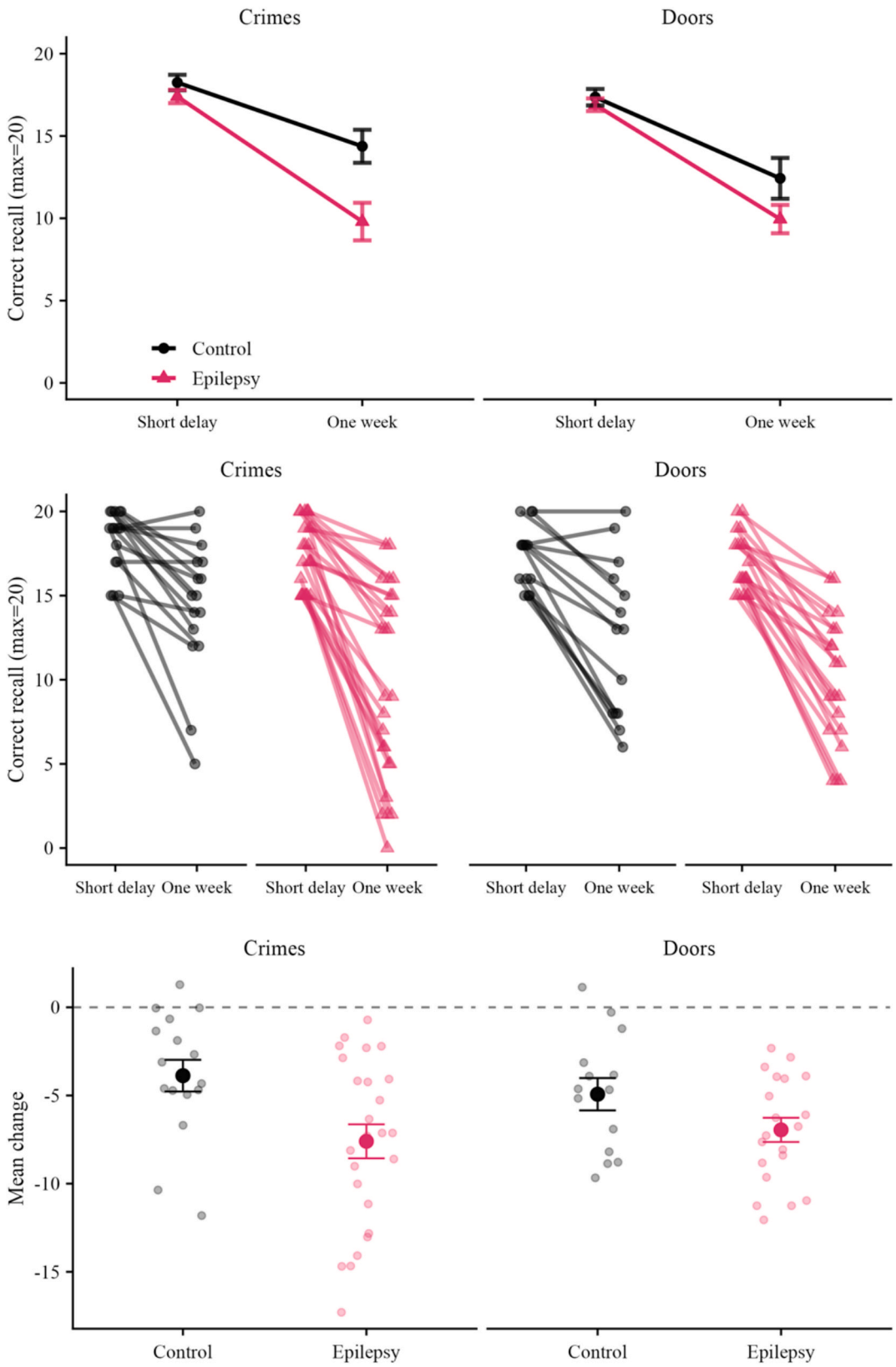

Fig. 3. The upper panel shows the mean number correct (and SE) on the Crimes and Four Doors tests, as a function of delay point and population group. The middle panel shows individual participants' performance. The lower panel shows change in the mean number correct (error bars show SE) between the short delay and one-week tests (with smaller, lighter points showing change for individual participant. A change score of 0 represents no forgetting, and values below 0 indicate forgetting between the short delay and one-week tests.

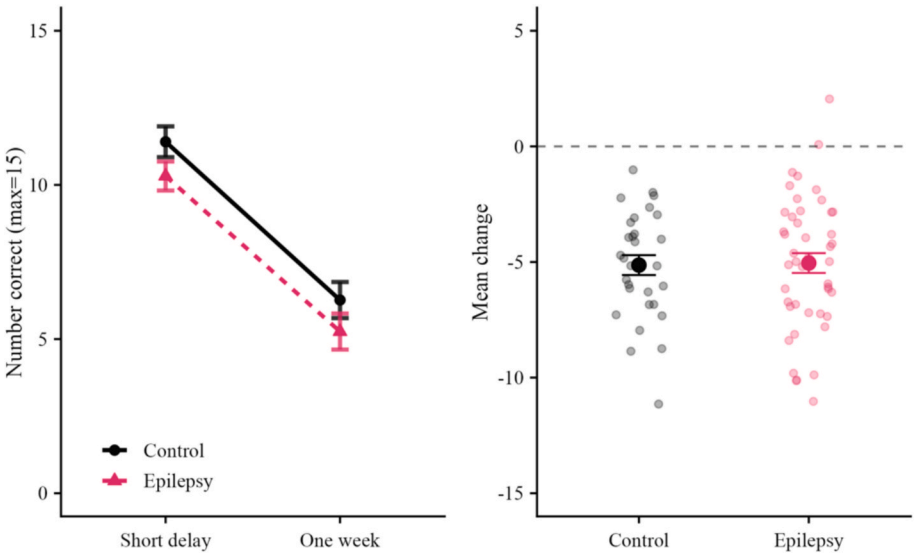

Fig. 4. The left panel shows mean number correct (and SE) on the BMIPB list Learning and recall test, after a short delay (the A6 test) and one-week. The right panel shows change in the mean number correct (and SE) between the short delay and one-week tests (with smaller, lighter points showing change for individual participant. A change score of 0 represents no forgetting, and values below 0 indicate forgetting between the short delay and one-week tests.

Table 3
Spearman's Rho correlations between subjective (Items 1–4: MMQ and ratings for STM, LTM, and forgetting) and objective outcomes (Items 5–8: Crimes/Doors (C/D) and BMIPB List long delay (at one-week) and change between short delay and long delay tests on these measures), for a). All participants ($n = 75$), b). The epilepsy group ($n = 45$), and c). Controls ($n = 30$).

a)	1	2	3	4	5	6	7
1. MMQ	–						
2. STM	0.56***	–					
3. LTM	0.59***	0.63***	–				
4. Forgetting	0.80***	0.48***	0.66***	–			
5. C/D one week	0.37***	0.19	0.23*	0.30**	–		
6. C/D change	0.31**	0.20	0.20	0.29*	0.92***	–	
7. List one week	0.14	0.10	0.15	0.09	0.36**	0.35**	–
8. List change	0.07	−0.03	0.04	0.00	0.24*	0.30**	0.57***

b)	1	2	3	4	5	6	7
1. MMQ	–						
2. STM	0.43**	–					
3. LTM	0.50***	0.50***	–				
4. Forgetting	0.62***	0.25	0.56***	–			
5. C/D one week	0.29	0.21	0.16	0.32*	–		
6. C/D change	0.21	0.21	0.04	0.27	0.91***	–	
7. List one week	0.18	0.14	0.10	0.05	0.45**	0.37*	–
8. List change	0.11	−0.06	0.03	−0.07	0.32*	0.32*	0.58***

c)	1	2	3	4	5	6	7
1. MMQ	–						
2. STM	0.28	–					
3. LTM	0.27	0.64***	–				
4. Forgetting	0.66***	0.36	0.43*	–			
5. C/D one week	0.14	−0.13	−0.16	−0.14	–		
6. C/D change	0.11	−0.05	0.03	−0.02	0.59***	–	
7. List one week	0.00	0.00	0.11	−0.01	−0.18	0.15	–
8. List change	0.13	0.06	0.09	0.16	−0.20	0.20	0.55***

*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$.

4.2. Objective memory

There is clearly therefore a need for objective measures that can appropriately capture the apparent memory problems that people with epilepsy often claim to experience. On this note, the group-level differences in forgetting on the Crimes and Four Doors tests over a one-week period indicated that these measures can objectively detect long-term memory difficulties in a mixed group of epilepsy patients recruited through non-clinical routes (see also [18]). In addition, the findings demonstrate the potential of remote online assessment for the measurement of cognitive profiles and detection of difficulties in clinical contexts, a growing area of interest in neuropsychological assessment [25–32]. However, although significant differences were observed at a group level, it is also important to note the range in performance (for all

groups) and the relatively intact profile of memory and forgetting observed for many individuals in the epilepsy group. Atypical forgetting is an issue for some people with epilepsy but is clearly not a universal signature of the condition. No group differences were found on the list learning and recall task, at least in the present sample.

4.3. Links between subjective and objective measures

The current study therefore provides evidence for substantial subjectively experienced memory problems along with objective detection of deficits in long-term memory and forgetting over a one-week period, in the same group of community-derived individuals with epilepsy. Is it possible to observe direct links between these types of measure? Across the whole sample, objectively measured extended memory and forgetting correlated with memory satisfaction (measured by the MMQ), and with participants' sense of their long-term memory ability and whether they experienced relatively more forgetting than other people. Thus, lower memory satisfaction and more subjectively experienced forgetting in everyday life was associated with lower recall at the long-delay test, and with more forgetting over one week. These patterns of correlations may at least partly reflect group differences between people with epilepsy and controls on subjective and objective outcomes. This relationship is useful to demonstrate in of itself, showing that objective delayed memory and forgetting relates to subjective experience when considering people with epilepsy as a subgroup within the broader population. However, even within the epilepsy group, an individual's subjective sense of their own vulnerability to forgetting correlated with objective recall performance at the one-week test. This indicates such measures have potential sensitivity to the variability in subjective experience of heightened forgetting within a sample of people with epilepsy, as well as in comparison with controls. We would note that some other subjective–objective correlations within the epilepsy group did not reach statistical significance, and we fully acknowledge that these analyses were based on small sample sizes. The findings should serve as motivation for larger and more systematic examination of links between subjective and objective memory and long-term forgetting in this population, possibly in conjunction with comparisons of the same relationships in neurotypical controls.

4.4. Limitations and directions for further research

The current study is the first to examine subjective and objective memory and forgetting using the Crimes and Four Doors tests in a diverse group of people with epilepsy, derived from the community. Our sample was adequate for current purposes and was larger and more diverse than the only previous published study to administer Crimes and Four Doors with an epilepsy group [17]. Moving beyond clinically derived samples is an important step given that problems with memory and cognition are often reported by people living with chronic epilepsy [1]. It is also useful to implement measures with a diverse sample that is not limited to one form of epilepsy. Problems with accelerated forgetting over longer time periods may be more prevalent in temporal lobe epilepsy [33,34], particularly in bilateral cases [35], but it has also been reported in other forms of epilepsy [33,36–38]. Therefore, as noted by Hall et al. [3], generalizability of findings is aided by exploring these questions in community-derived samples of patients that show variability in type and severity of epilepsy, and where their condition is being managed. However, a more comprehensive and systematic examination of performance on such tasks, and possible connections with subjective memory difficulty, will require a much larger sample. This would also better enable examination of possible variability between different epilepsy subtypes, for which the present study was not sufficiently powered.

Our self-developed questions were intended to capture subjective experience of memory at different time scales, and speed of forgetting over time (thus mapping onto the concept of ALF). In designing these, we incorporated examples to try and make the items accessible and relatable to everyday memory experience. The questions were successful in capturing variability between individuals, in differentiating between epilepsy and control groups, and particularly in how forgetting relates to broader memory satisfaction and objective delayed memory performance. However, it could be suggested that the specific everyday examples embedded in each question may have influenced how some individuals responded, though we have no direct evidence that this occurred in the present study. While future research should develop and implement more detailed, multi-item measures along these lines, the current work shows the importance of capturing different aspects of memory and forgetting in subjective measures.

The current work primarily focused on objective memory performance at two time points, firstly after a short (filled) delay to minimize storage and retrieval from working memory, and then one week later to measure delayed memory and forgetting. It would be valuable to systematically explore performance across different timescales. Firstly, people in our epilepsy sample often reported short-term memory problems, in their qualitative descriptions of how they felt epilepsy affected their memory, and in response to the specific question on this dimension. This maps onto evidence of objectively observed difficulties with working memory and executive function in epilepsy [39]. Thus, these apparent subjective difficulties likely relate to cognitive functions not directly indexed by our forgetting measures, as well as the adverse effects of other non-cognitive, clinical factors [2]. This highlights the issue of task specificity [9,40,41], and that no single test can capture all memory processes of possible interest [2]. Comprehensive clinical assessment should aim to include measures of memory and forgetting at very short timescales as well as over extended delays. However, we would also note a common tendency for non-experts to view 'short-term memory' as extending over several hours [e.g. 42], and so caution should be exercised when interpreting use of such terminology in self-report measures.

Secondly, because our primary focus in the objective memory tasks was to measure memory retention at the one-week test, we aimed to minimize possible effects of retrieval practice on later retention that might arise from the insertion of additional test points after the short delay test [15,16,18]. As a result, we did not assess memory at around a 30-minute delay as is commonly implemented in neuropsychological test batteries and so cannot claim to be directly and specifically testing patterns of ALF that only emerge beyond this point and that may be missed by such tests. Incorporating tests at such intervals while minimizing or allowing for any impacts of retrieval practice, with the aim of being able to identify more precisely when atypical forgetting starts to emerge, would be a challenging but useful future direction.

A further useful question to consider is the possible effect of domain-specific interference between different measures. The current study ran Crimes (i.e., a verbal task) or Four Doors (a visual task) alongside an additional verbal task, BMIPB list learning. Although Crimes and BMIPB list learning are quite different in materials (structured vignettes vs. unstructured word lists) and test format (cued recall vs. free recall), this may nevertheless have led to mutual interference between these verbal memory tasks. There is little direct and convincing evidence within the current data for this possibility, given we found no significant interaction with test group in analysis of objective performance. However, the possibility of intra-test interference should be considered in future work, as should the interesting question of whether people with epilepsy show greater vulnerability to such interference effects.

Research and neuropsychological practice remain in flux regarding the possible prevalence of ALF in different forms of epilepsy, the rates of typical or atypical forgetting that might be experienced across individuals, and the optimal methods that should be used to capture these. The current work suggests promise in these forms of delayed measures of objective memory, and in their remote implementation. However, they are not yet sufficiently developed and validated for widespread clinical implementation. Future work should prioritise development of such

appropriate tests of extended memory and forgetting for broader use across clinical contexts. Ideally, these should form part of a battery of measures assessing memory across different types of material and timescales, along with subjective self-report measures of memory difficulty.

5. Conclusions

Overall, people living with epilepsy in the community report substantial and varied problems with their memory function. Subjective experience of problems with memory are relatively common in epilepsy, and our findings from a community-derived and heterogenous epilepsy sample confirm and extend this observation from prior research. The difficulties that are reported in our sample are quite varied, and include immediate, delayed, and remote memory, and problems with forgetting over time. We also show that subjectively experienced issues with delayed memory and forgetting can be captured by objective measures. This has implications for how we might understand and measure possible memory problems in epilepsy.

CRediT authorship contribution statement

Richard J. Allen: Writing – review & editing, Writing – original draft, Visualization, Supervision, Software, Resources, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Steven Kemp:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Amy L. Atkinson:** Writing – review & editing, Software, Methodology, Funding acquisition, Conceptualization. **Sarah Martin:** Project administration, Investigation, Data curation. **Kata Pauly-Takacs:** Writing – review & editing, Supervision, Methodology. **Courtney M. Goodridge:** Project administration, Investigation, Data curation. **Ami Gilliland:** Project administration, Investigation, Data curation. **Alan D. Baddeley:** Writing – review & editing, Supervision, Resources, Methodology, Funding acquisition, Conceptualization.

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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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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2025.110519.

Data availability

The data is available here on the Open Science Framework.

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