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The current clinical practice and experiences in buccal midazolam prescribing in community for status epilepticus termination in the United Kingdom: The Rescue Epilepsy Medication and Training (REMIT) study

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ABSTRACT

Background: Epilepsy is one of the commonest neurological conditions worldwide and confers a significant mortality risk, partly driven by status epilepticus (SE). Terminating SE is the goal of pharmaceutical rescue therapies. This survey evaluates UK-based healthcare professionals' clinical practice and experience in community-based rescue therapy prescribing.

Methods: A cross-sectional, 21 item questionnaire composed of Likert-style and free-text based questions was administered online. It was distributed through a non-discriminative snow-balling methodology to members of the Epilepsy Specialist Nurses' Association (ESNA) and the British International League Against Epilepsy (ILAE). Quantitative analysis used Chi-squared, Fishers' exact and Mann-Whitney tests. Qualitative data were analysed through NVivo 14 software, following Braun and Clarke methodology.

Results: 86 participants comprising of nurses ($n = 64$) and doctors ($n = 21$) responded. Participants' responses reflected guideline-concordant use of emergency management plans and buccal midazolam (BM) as a first-choice therapy for terminating tonic-clonic seizures in SE. However, significant variation ($P < 0.05$) was found between doctors and nurses in prescribing practices of BM including maximum dose prescribed/day, withdrawal plans and the use in multimorbid patients. Eight themes were identified with some suggestive of concerns of overuse, misuse and abuse of BM by patients/carers.

Conclusion: This is the first study to give insights to community management of SE using rescue therapies particularly BM. Further evidence-based guidelines are needed for BM use in multimorbid patients and for its deprescribing. Robust safeguarding protocols and vigilance is needed to regulate BM's misuse and abuse potential. Oncoming community-based technology could provide objective assurance for evidencing utility of rescue medications.

1. Introduction

Epilepsy is one of the commonest neurological conditions worldwide, with an estimated prevalence of 309/100,000 people globally (age-standardised, 2021) [1]. Epilepsy significantly compromises the quality of life and functioning of those affected, resulting in a global

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loss of 14,400,000 disability-adjusted life years [2]. In the UK around 1 % of the population have epilepsy [3]. It also confers a risk of death of approximately 1.6/1000 per year for people with epilepsy in the UK [4].

Contributing to this mortality rate is status epilepticus (SE) defined as a seizure that lasts for an abnormal amount of time identified as five minutes for a tonic-clonic seizure) [5]. If SE persists to a second time point i.e. 30 min for tonic-clonic seizures, the seizure can induce long term neuronal injury, neuronal death and functional deficits that may not be survivable [5].

Preventing the progression of SE through timely seizure termination is critical to minimising its consequent morbidity and mortality [6]. This may be achieved through the administration of an emergency pharmacological treatment, also known as a *rescue therapy* [6]. In the UK, the National Institute of Clinical Excellence (NICE) guidelines detail the optimal treatments and timings of rescue therapies [6]. To prevent SE related harm rescue medication can be used by non-medical people with suitable training [7]. The best evidenced first-line drug for termination of generalised seizures in community settings is buccal midazolam (BM), due to its efficacy and the relative ease and dignity of its administration (compared to therapies administered via the rectal route) [6–10].

Since the disbandment of the UK's Joint Epilepsy Council in 2015, significant quality improvement work has focused on increasing the availability and appropriate use of BM in community practice [7–10]. Generally, the need for community-based access to BM is indicated in individuals with a high risk or history of SE [6–10]. Such individuals are given an emergency management plan or seizure management plan [6–10]. These plans are formulated by specialist nurses or doctors and are based on an individual's characteristic semiology, seizure duration, dose requirements and typical reaction to rescue therapies [10]. They may be delivered by clinical or non-clinical carers trained in the administration of rescue therapies (usually BM) [10]. It is advocated that training should be regular (at least every two years) and delivered by epilepsy experts [10]. It is regulated through best practice guidelines co-produced by the Epilepsy Specialist Nurses Association, Royal College of Psychiatrists and International League Against Epilepsy [10]. The geographic variability of epilepsy services and heterogeneity of clinical need makes the standardisation of these services challenging [11].

Despite the progress that has been made in promoting and regulating the use of rescue therapies in the community, outstanding gaps in understanding and clinical guidance persist [7]. These include: drug selection for different seizure types; the maximum dosage of BM; its relative and absolute contraindications; use in multi-morbidity; abuse potential and indications for withdrawal [7].

There is limited insight into current prescribing practices and clinicians' and patients' experiences of community-based BM use. The REMiT (**R**escue **E**pilepsy **M**edi**c**ation and **T**raining) study aimed to understand the views, prescribing patterns and strategies of UK-based healthcare professionals delivering community-based seizure management.

2. Methods

The survey methodology is reported according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) checklist [12]. (supplementary information 1). The survey was open for 12 weeks, between 13/10/2023 and 29/12/2023. It was designed for completion by any registered healthcare professionals working with people with epilepsy.

2.1. Survey development

The survey items were developed iteratively, through informal interviews of specialists in epilepsy management and reviews of key documents regulating rescue therapies in the UK [6–10]. An initial draft (AM) was collaboratively revised in five rounds of revision (AM, LW, RS) between July and September 2023. The survey was then hosted online and completed by executive leads of the Epilepsy Specialist Nurse's Association (ESNA) to test its content and usability and finalised after their feedback.

2.2. Survey distribution, administration and design

A non-discriminative snow-balling methodology leading to non-probability sampling was used to disseminate the survey [13]. The survey was distributed through regular newsletter emails to members of ESNA and the ILAE and concurrently through snowball sampling of intellectual disability psychiatrists and neurologists.

The survey comprised 21 question items in total, 14 of which were presented to all participants and seven of which were adaptive. They covered participant demographics, experience with epilepsy, prescribing practices in terms of drug, route and dose preferences, use of emergency management plans, and concerns about drug abuse. A copy of the questionnaire is available in supplementary information 2.

2.3. Ethics and governance

The survey was reviewed by professional bodies i.e. the International League against Epilepsy (British branch) and ESNA prior dissemination to their members. All participants were advised at the start of the study that participation was voluntary and informed consent would be presumed if the survey was submitted. If they chose to participate, data would be pooled, anonymised and analysed. No participant identifier data was collected. Further, it was to a professional participant group where consent was implicit by participation.

2.4. Quantitative measure analysis

Survey responses were analysed in several sets, using the Stata software package (version 15.1). The first set of analyses summarised the survey responses for all participants. All questions were categorical in nature, and the questions were summarised by the number and percentage in each category.

Additional analyses divided the respondents into medics and nurses and compared both groups. Categorical variables with no ordering to the categories were compared between groups using the Chi-square test or Fisher's exact test. Categorical variables with a natural ordering to the categories were compared between staff groups using the Mann-Whitney test. Significance was taken at $P < 0.05$.

2.5. Qualitative measure analysis

Two items, related to participants' rationale for deprescribing BM after a specific time period and their experience regarding inappropriate use of BM, invited free text responses. These responses were uploaded to NVivo 14 and thematically analysed (AM, PT) following Braun and Clarke's methodology [14].

3. Results

3.1. Demographics (Table 1)

A total of 86 participants responded to the survey. By job role, the largest group of respondents were epilepsy specialist nurses at 60 % ($n = 52$), followed by doctors at 24 % ($n = 21$). The largest group of doctors were psychiatrists (12 %, $n = 10$), followed by neurologists (10 %, $n = 9$). Nurses of unspecified roles made up 14 % ($n = 12$) of participants. Just under half (49 %; $n = 42$) of respondents had over 10 years of experience in an epilepsy related role.

The uniqueness of site viewers and participants was not evaluated. The completion rate was 98 %. The completeness rate was ≥96 % for 78 % of participants (full completeness rate in supplementary information 3). All questionnaires were analysed.

A total of 225 comments were received for individual free text responses and were analysed for themes. Supplementary information 4 proves all comments.

3.2. Use of emergency management plans (Supplementary Information 5)

Participants were asked when they would suggest/formulate an emergency management plan for a patient. The majority of participants (68 %, $n = 58$) would suggest/formulate one after any of the following scenarios: one episode of SE, one episode of repeated or cluster seizures (defined as three or more self-terminating seizures in 24 h) or after a prolonged non-convulsive seizure. Over three-quarters suggested that the plan should be reviewed annually (77 %, $n = 64$).

3.3. Prescribing rescue therapies for community use (Supplementary Information 6)

Less than half of respondents stated that they prescribed rescue therapies (43 %, $n = 30$), however, only 28 % ($n = 6/21$) of doctor respondents completed this item. Of nurse respondents 40 % ($n = 25$) prescribed rescue therapies, of which just under two thirds (60 %, $n = 15$) prescribed rescue therapies directly and 88 % ($n = 22$) of 'prescribing nurses' requested GPs to prescribe.

3.4. First choice rescue therapies (Table 2)

Participants were asked about their first-choice therapies for different seizure types: tonic-clonic (prolonged), tonic-clonic (cluster), focal seizures (prolonged) and focal seizures (cluster). All participants responded to these items. For all seizure types, the most common first choice therapy was BM. For prolonged tonic-clonic seizures, 93 % ($n = 80$) of respondents chose BM as their first-choice therapy. Other responses were mixed, particularly for cluster focal seizures, where 40 % ($n = 34$) of participants selected oral clobazam as their first-choice therapy.

Generally, nurses and doctors responded similarly to these items. However, in the case of cluster tonic-clonic seizures, nurses were significantly more likely ($p = 0.05$) to choose BM plus one other drug (20 %, $n = 13$), whilst doctors were more likely to choose another drug (19 %, $n = 4$)

Furthermore, 6 % ($n = 4$) of nurses responded that they wouldn't use any drugs for prolonged focal seizures, whilst all medics selected a drug therapy.

3.5. Buccal midazolam (Table 3)

3.5.1. Dosage

Most respondents (57 %; $n = 46$) indicated that they would give allowance to prescribe up to 20 mgs dose of BM in 24 h. However, 32 % ($n = 26$) would give half that dose and 7 % ($n = 6$) would give more than 20 mg/day. There were no statistically significant differences between medics and nurses in maximum dose selection.

3.5.2. Withdrawal from plan

Opinions varied on the period of non-use after which BM should be withdrawn from an emergency management plan. The most common response was two years, but 20 % ($n = 17$) of participants thought that three years of non-use should elapse before BM was withdrawn. Amongst 'other' responses, seven participants indicated a specific time period for withdrawal and six of these were over two years. There was a significant difference ($p = 0.02$) between doctors and nurses regarding the time period of non-use to withdraw BM from the emergency plan. While 77 % ($n = 42$) of nurses indicated that they would withdraw BM within two years of non-use, only 33 % ($n = 7$) of doctors had the same view.

A free text response for participants to explain their rationale for withdrawing BM after their selected time period. Specific responses to this question (see Supplementary Information 3) were thematically analysed resulting in four themes are described below.Table 4 presents the themes with illustrative quotes.

Theme 1. Care and support

Participants frequently described using their clinical judgement, collaborative discussions with patients and carers and contextual factors (personalised care) in deciding when to deprescribe BM.

Respondents' clinical judgements largely depended on: features of patients' previous episodes of SE (1a.1.4,1a.1.5), resultant complications (1a.1.9) and features of patients' seizures including triggers, frequency, duration and seizure-free intervals (1a.1.1, 1a.1.11, 1a.1.13, 1a.1.14). Also, key was patients' proximity to hospital care (1a.3.4).

> *"Individual patient risk factors are taken into consideration, incidents of status and hospital admissions, rural locality, I always consider patient / carers views" (1a.1.15)*

Responses further emphasised the integrity of patient, family and carer views and anxieties to the decision to withdraw BM (1a.2.1,1a.2.3, 1a.2.9). Holistic considerations included the prescriptions' implications for patient's living opportunities:

> *"Can complicate care situations - restrict opportunities"* (1a.3.1.)

Theme 2. Seizure control and safety risks: a fine balance

Seizure freedom was amongst the most prominent of respondents' reasons for withdrawing BM, however participants varied significantly in how long they thought an individual should be seizure-free before deprescribing, ranging from one to five years (2a.1.9., 2a.1.14). Respondents noted exemptions to this rationale:

> *"Some patients can have a year or more between seizures then have a cluster or prolonged GTCS, it is risky to remove a rescue medication in these situations." (2a.1.20)*

Compliance with anti-seizure medications was a key feature of deprescribing rationale (2a.1.23, 2a.1.24). Respondents reported a

Table 1
Characteristics of study participants.

Variable	N	Category	*n*	%
Clinical role	86	Neurologist – epileptologist	5	6
		Neurologist – general	1	1
		Paediatrician – general	2	2
		Paediatrician – neurologist	3	3
		Psychiatrist	10	12
		Nurse – epilepsy specialist	52	60
		Nurse – other	12	14
		Other	1	1
Job category (combined)	86	Medic	21	24
		Nurse	64	74
		Other	1	1
Experience in epilepsy-related role	86	0–3 years	16	19
		3–5 years	17	20
		5–10 years	11	13
		10+ years	42	49
Epilepsy-specific Work	86	< 25 %	7	8
		25 %–50 %	15	17
		50 %–75 %	11	13
		> 75 %	53	62
Provide training in Epilepsy	86	No	15	17
		Yes	71	83
How training delivered (*)	71	Face-to-face + Virtual	30	42
		Face-to-face only	41	58
Frequency of training (*)	67	More than annually	14	21
		Annually	21	31
		Every 2 years	15	22
		Less than every 2 years	4	6
		As required	13	19

Table 2
All participant responses to the question: What is your opinion on the first-choice rescue therapy for each of the seizure types below, assuming intervention is required? (Only for use in an individual's emergency seizure management plan).

Seizure type	First choice therapy	All Staff (+) N	All Staff (+) *n* (%)	Medics N	Medics *n* (%)	Nurses N	Nurses *n* (%)	*P*
Generalised tonic-clonic (prolonged)	None	86	0 (0)	21	0 (0)	64	0 (0)	0.63
	Midazolam only		80 (93)		19 (90)		60 (94)	
	Midazolam+		6 (7)		2 (10)		11 (6)	
	Other		0 (0)		0 (0)		0 (6)	
(Cluster) Focal seizures	None	86	1 (1)	21	0 (0)	64	1 (2)	0.82
	Midazolam only		42 (49)		9 (43)		33 (51)	
	Midazolam+		8 (9)		2 (10)		6 (9)	
	Other		35 (41)		10 (48)		24 (38)	
(Cluster) Generalised tonic-clonic	None	86	0 (0)	21	0 (0)	64	0 (0)	0.05
	Midazolam only		65 (76)		16 (76)		48 (75)	
	Midazolam+		14 (16)		1 (5)		13 (20)	
	Other		7 (8)		4 (19)		3 (5)	
Focal seizures (prolonged)	None	85	4 (5)	21	0 (14)	63	4 (6)	0.77
	Midazolam only		61 (72)		16 (76)		45 (71)	
	Midazolam+		6 (7)		1 (5)		5 (8)	
	Other		14 (16)		4 (19)		9 (14)	

Table 3
Participant responses to items regarding buccal midazolam.

Variable	Category	All staff (+) N	All staff (+) *n* (%)	Medics N	Medics *n* (%)	Nurses N	Nurses *n* (%)	*P* (*)
Caseload on buccal midazolam	< 25 %	85	41 (48)	21	15 (71)	63	26 (41)	0.05
	25 %–50 %		30 (35)		3 (14)		26 (41)	
	50 %–75 %		12 (14)		2 (10)		10 (16)	
	> 75 %		2 (2)		1 (5)		1 (2)	
Maximum dose in 24 h	10 mg	81	26 (32)	21	5 (24)	59	20 (34)	0.32
	20 mg		46 (57)		12 (57)		34 (58)	
	30/40 mg		6 (7)		2 (10)		4 (7)	
	Other		3 (4)		2 (10)		1 (2)	
Concern of inappropriate use	No	81	23 (28)	20	7 (35)	61	16 (26)	0.45
	Yes		58 (72)		13 (65)		45 (74)	
Period of non-use to withdraw from emergency plan	1 year	84	12 (14)	21	3 (14)	62	9 (15)	**0.02**
	2 years		37 (44)		4 (19)		33 (52)	
	3 years/ Never		18 (21)		6 (29)		12 (19)	
	Other		17 (20)		8 (38)		8 (13)	

series of risks associated with long-term BM prescribing, highlighting that seizure control must be balanced against these risks. Such risks included the competence of carers to administer BM (2a.2.3), the risk of an adverse reaction to BM (2a.2.1.) and the risk of a reduced response to BM (2a.2.4), as well as unspecified risks (2a.2.6).

Theme 3. Trigger reviews

A critical motive for deprescribing was respondents' preference that patients having a seizure after an extended period of seizure freedom were reviewed by emergency care services (3a.7, 3a.13) rather than receiving rescue therapy administration (3a.1). This was due to the increased risk that a standalone seizure was triggered by underlying illness or infection that may require hospital treatment (3a.6, 3a.13)

"If an individual has not required midazolam for 2 years if they have an event that requires it I recommend calling an ambulance as it could a different medical emergency and it may be over shadowed." (3a.6)

Some respondents noted that they would expect subsequent review by an epilepsy specialist (3a.24, 3a.25).

Theme 4. Protocol and guidelines

Whilst there are not existing national guidelines on BM withdrawal in the UK, several respondents referred to guidelines, including 'ESNA' (4a.1), 'NICE' (4a.8) and unspecified guidance (4a.7).

Respondents also referred to a range of local standardised practices ranging from withdrawal of BM at two years (4a.5) to three years (4a.6) and to the role of consultant reviews in determining when BM should be deprescribed (4a.1., 4a.2).

"2years has been standard practice" (4a.5)

"I understand that's the guidance" (4a.7)

A number of participants also cited reasons of medication cost, wastage and ongoing prescribing and training costs as reasons for BM withdrawal (4a.1.3, 4a.1.4, 4a.1.7).

3.6. Prescribing practices (Table 5)

Participants were asked about the likelihood of them prescribing BM for people with epilepsy in a range of common co-morbid medical and social conditions. The majority of respondents were "unlikely or very unlikely" to prescribe BM in people with a history of alcohol related seizures (54 %, $n = 37$), adverse reactions to BM (78 %, $n = 54$) or respiratory compromise (66 %, $n = 46$). Most respondents were also "unlikely or very unlikely" to prescribe if they lacked confidence in the BM administrator (62 %, $n = 43$), if there was a risk of drug abuse (63 %, $n = 43$) or if there was a lack of carer support (62 %, $n = 43$).

There were several statistically significant differences between doctors and nurses in the above prescribing practices. Nearly 50 % ($n = 10$) of doctors were "neutral or likely" to prescribe to patients with a history of respiratory compromise, compared to 26 % ($n = 13$) of nurses ($p = 0.02$). Amongst doctors, 65 % ($n = 13$) were "likely or very likely" to prescribe to patients with cardiovascular co-morbidities, compared to 21 % ($n = 10$) of nurses ($p \leq 0.001$). Only 5 % ($n = 1$) of doctors would be "unlikely" to prescribe to people with T1DM compared to 33 % ($n = 16$) of nurses ($p \leq 0.001$). Only 21 % ($n = 4$) of doctors would be "unlikely" to prescribe to pregnant women compared to 45 % ($n = 21$) of nurses ($p \leq 0.009$). Almost twice as many nurses as doctors would be "unlikely

Table 4
Participants' themes/subthemes emerging from analysis and example free-text responses to the open question: "Please give your rationale for deprescribing after your selected time period".

Theme	Illustrative quotes
1a. Care and support	• 1a.1.4. "if serious status + ITU probably not." • 1a.1.5. "Depends on history how often status how severe complications" • 1a.1.9. "Depends on history how often status how severe complications and if they are still having seizures" • 1a.1.10. "Depends on the severity of previous stats - depends on frequency and duration of current seizures" • 1a.1.13. "Depends on other comorbidities too" • 1a.1.14. "Depends on their situation, living remotely, prone to triggers that could trigger prolonged seizures at other times. People with complex epilepsy and underlying symptom/ cause" • 1a.1.15. "Individual patient risk factors are taken into consideration, incidents of status and hospital admissions, rural locality, I always consider patient / carers views"
1a.2 Collaborative care	• 1a.2.1. "Expert assessment taking account of patient's / carer's views" • 1a.2.3. "Difficult - often individual/family/ carers are very anxious to withdraw rescue even after a few years. I don't pressure individuals to withdraw but may withdraw if the person has remained seizure-free for a considerable time." • 1a.2.9. "While it can be considered after 2 or 3 years it also depends on the confidence of the carers to let the midazolam go. Some prefer to keep it a just in case measure."
1a.3. Personalised care	• 1a.3.1. "Can complicate care situations - restrict opportunites" • 1a.3.4. "There are instances where midazolam is prescribed for people living in rurual areas where paramedic assistance may not get to patient in timely manner."
2a. Seizure control and safety risks: a fine balance	• 2a.1.9. "Suggests better control/not as likely required." • 2a.1.14. "If no seizures at all, then I feel there is a case for removing around 5 years from last seizure" • 2a.1.20. "Some patients can have a year or more between seizures then have a cluster or prolonged gtcs, it is risky to remove a rescue medication in these situations." • 2a.1.23. "A period of 2 or 3 years of seizure freedom can indicate stability of epilepsy and concordance with medication increasing the confidence to remove the prescription." • 2a.1.24 "I would think that if they have good seizure control on aed then the need for an emergency med is no longer vital. Can call 999 if happens again and contact cns for review"
2a.2. Risks of long-term buccal midazolam prescription	• 2a.2.1. "I would be concerned that a reaction may happen after a prolonged period of non use. and 999 would need to be called" • 2a.2.3. "Family/carer may be out of practice/ competence." • 2a.2.4. "beyond 2y of non-use cannot guarantee response" • 2a.2.6. "With Buccal remaining there are risks"
3a. Trigger reviews	• 3a.1. "second opinion - If Midazolam hasn't been used for over a year the assumption is that they haven't had a prolonged convulsive seizure in that time. So it would be unusual and I would want a paramedic to check their physical health/triggers" • 3a.6. "If an individual has not required Buccolam for 2 years if they have an event that requires it I recommend calling an ambulance as it could a different medical emergency and it may be over shadowed." • 3a.7. "If patient has status epilepticus after buccal midazolam is withdrawn then family/ carers advised to dial 999 for ambulance as there maybe an underlying issue why status is happening." • 3a.13. "Person should attend ED for review if status prolonged or cluster seizures to review other possible complications or co-morbidities" • 3a.24. "Can call 999 if happens again and contact cns for review" • 3a.25. "If someone had prolonged seizure after several years without, then they would need a specialist review as there may be new changes"
4a. Protocol and guidelines	• 4a.1. "ESNA guidelines and consultant" • 4a.2. "For me I have asked the neurologist to make this decision - unless it has never been used" • 4a.5. "2years has been standard practice" • 4a.7. "I understand that's the guidance" • 4a.8. "If an individual has not required Buccolam for 2 years if they have an event that requires it I recommend calling an ambulance as it could a different medical emergency and it may
4a.1 Cost and wastage	• be over shadowed. NICE guidelines" • 4a.1.3 "Cost of medicine" • 4a.1.4 "To avoid wastage of medication" • 4a.1.7 "Cost of prescribing and training"

or very unlikely" to prescribe where there was a risk of drug abuse (73 %, $n = 35$ vs 40 %, $n = 8$, $p \leq 0.001$).

3.7. Buccal midazolam misuse

Most respondents (72 %, $n = 58$) were concerned about inappropriate use of BM. A free text response describing participants' experiences of inappropriate use, was completed by 68 % ($n = 56$) of participants (Table 6 and supplementary information 3). Four themes emerged from these responses and are detailed below.

Theme 1. Is it misuse or abuse?

This theme arose from responses that described the misuse of BM. Descriptions of misuse most commonly referred to overuse of BM and related to three key issues: confirmed over-administration, frequent prescription requests and caregiver anxiety. Over-administration was either in the form of over frequent administration (1b.1.1., 1b.1.4.) or excessive dosing (1b.1.6., 1b.1.10) and was carried out by parents, relatives and carers. Respondents described frequent prescription requesting that did not correspond to seizure reporting (1b.2.2, 1b.2.5., 1b.2.7.) Some BM overuse was attributed to caregiver anxiety such as "fear/anxiety at the time and a wish to protect the person from harm" (1b.3.3)

> *"Overly attentive carers might use it for indications outside the agreed protocol predominantly out of fear/worry rather than with ill intentions." (1b.3.2)*

Participants also shared accounts of BM abuse. This was predominantly related to addiction, where BM was used by patients with a known or unknown addiction to benzodiazepines (1b.4.1.1., 1b.4.1.2., 1b.4.1.3). Recreational usage by patients' families was also reported (1b.4.1.6), however, it was not always apparent whether this usage was related to addiction (1b.4.1.8.).

Participants reported the use of BM for behavioural control, either by parents (1.4.2.1, 1.4.2.3.) or unspecified persons (1.4.2.2.). The sedation of children and a person with an intellectual disability was reported

Table 5
Participant responses to items asking about the likelihood of prescribing buccal midazolam in different scenarios.

Variable	Category	All staff		Medics		Nurses		*P*
		N	*n* (%)	N	*n* (%)	N	*n* (%)	
People with intellectual difficulties	Very unlikely	86	6 (8)	21	0 (0)	51	6 (12)	0.17
	Unlikely		1 (1)		1 (5)		0 (0)	
	Neutral		12 (16)		3 (14)		8 (16)	
	Likely		25 (34)		6 (29)		19 (37)	
	Very likely		29 (40)		11 (52)		18 (35)	
Alcohol related seizures	Very unlikely	68	20 (29)	19	2 (11)	48	18 (38)	0.11
	Unlikely		17 (25)		7 (37)		10 (21)	
	Neutral		19 (28)		5 (26)		13 (27)	
	Likely		9 (13)		5 (26)		4 (8)	
	Very likely		3 (4)		0 (0)		3 (6)	
Person prone to falls	Very unlikely	69	12 (17)	20	0 (0)	48	12 (25)	0.05
	Unlikely		8 (11)		4 (20)		4 (8)	
	Neutral		9 (42)		7 (35)		21 (44)	
	Likely		10 (14)		5 (25)		5 (10)	
	Very likely		10 (14)		4 (20)		6 (13)	
History of adverse reactions	Very unlikely	69	39 (56)	20	10 (50)	48	29 (60)	0.20
	Unlikely		15 (22)		3 (15)		12 (25)	
	Neutral		10 (14)		4 (20)		5 (10)	
	Likely		5 (7)		3 (15)		2 (4)	
	Very likely		0 (0)		0 (0)		0 (0)	
Neurological comorbidities	Very unlikely	70	8 (11)	20	0 (0)	49	8 (16)	0.08
	Unlikely		4 (6)		1 (5)		3 (6)	
	Neutral		17 (24)		5 (25)		11 (22)	
	Likely		22 (31)		6 (30)		16 (33)	
	Very likely		19 (27)		8 (40)		11 (22)	
History of respiratory compromise	Very unlikely	70	27 (39)	20	4 (20)	49	23 (47)	**0.02**
	Unlikely		19 (27)		6 (30)		13 (27)	
	Neutral		15 (21)		5 (25)		9 (18)	
	Likely		9 (13)		5 (25)		4 (8)	
	Very likely		0 (0)		0 (0)		0 (0)	
Cardiovascular comorbidities	Very unlikely	69	12 (17)	20	0 (0)	48	12 (25)	**<0.001**
	Unlikely		8 (12)		1 (5)		7 (14)	
	Neutral		26 (38)		6 (30)		19 (40)	
	Likely		19 (28)		10 (50)		9 (19)	
	Very likely		4 (6)		3 (15)		1 (2)	
Lack of confidence in administrator	Very unlikely	70	23 (33)	21	7 (33)	48	16 (33)	0.28
	Unlikely		20 (29)		9 (43)		11 (29)	
	Neutral		17 (24)		4 (19)		12 (23)	
	Likely		7 (10)		1 (5)		6 (13)	
	Very likely		3 (4)		0 (0)		3 (6)	
People with Type 1 diabetes	Very unlikely	69	12 (17)	20	0 (0)	48	12 (25)	**<0.001**
	Unlikely		5 (7)		1 (5)		4 (8)	
	Neutral		23 (33)		3 (15)		19 (40)	
	Likely		18 (26)		9 (45)		9 (19)	
	Very likely		11 (16)		7 (35)		4 (8)	
Pregnant women	Very unlikely	67	16 (24)	19	1 (5)	47	15 (32)	**0.009**
	Unlikely		9 (13)		3 (16)		6 (13)	
	Neutral		23 (34)		6 (32)		16 (34)	
	Likely		15 (22)		6 (32)		9 (19)	
	Very likely		4 (6)		3 (16)		1 (2)	
Risk of drug abuse	Very unlikely	69	19 (28)	20	1 (5)	48	18 (38)	**0.001**
	Unlikely		24 (35)		7 (35)		17 (35)	
	Neutral		21 (30)		8 (40)		12 (25)	
	Likely		4 (6)		4 (20)		0 (0)	
	Very likely		1 (1)		0 (0)		1 (2)	
Known compliance issues	Very unlikely	70	21 (30)	21	4 (19)	48	17 (35)	0.18
	Unlikely		10 (14)		3 (14)		7 (15)	
	Neutral		19 (27)		6 (29)		12 (25)	
	Likely		13 (19)		6 (29)		7 (15)	
	Very likely		7 (10)		2 (10)		5 (10)	
Social issues (lack of carer support)	Very unlikely	69	20 (29)	20	4 (20)	48	16 (33)	0.30
	Unlikely		23 (33)		8 (40)		15 (31)	
	Neutral		21 (30)		5 (25)		15 (31)	
	Likely		5 (7)		3 (15)		2 (4)	
	Very likely		0 (0)		0 (0)		0 (0)	

Table 6
Participants' themes/subthemes emerging from analysis and example free-text responses to the open question: "Please give your rationale for deprescribing after your selected time period".

Theme	Illustrative quotes
1b. Is it misuse or abuse?	
1b.1. Over-administration	• 1b.1.1." Using more often than recommended dose." • 1b.1.4. "Overuse by the patient's relatives or carers, not following the agreed emergency medication administration plan" • 1b.1.6. "carers not following plan and administering extra doses" • 1b.1.10. "A parent using move than the prescribed dose"
1b.2. Frequent requests	• 1b.2.2. "also mother of a patient with ID who was requesting too frequently and not attending follow up appointments" • 1b.2.5. "Patient requesting lots of prescriptions from GP and not reporting increased seizure frequency" • 1b.2.7. "A patient requesting multiple prescriptions from the GP, not reporting frequent seizures to Neurology."
1b.3. Caregiver anxiety	• 1b.3.2. "Overly attentive carers might use it for indications outside the agreed protocol predominantly out of fear/worry rather than with ill intentions." • 1b.3.3. "Can occur if carer doesn't understand indications for use or due to their fear/anxiety at the time and wish to protect the person from harm."
1b.4 Abuse	
1b.4.1 Addiction	• 1b.4.1.1 "Staff Using for Dissociative seizures in a person with a benzodiazepine addiction." • 1b.4.1.2 "pt addicted but managed by GP - reported to GP, removed from her care!!" • 1b.4.1.3 "Individual requesting repeat prescription too frequently and not corresponding to seizure record/frequency. Getting angry when questioned about use." • 1b.4.1.6. "Family using the medications for themselves" • 1b.4.1.8. "Concerns that Buccal midazolam was being self-administered by a parent due to excessive ordering from the GP which did not correlate with the child's seizure history. Parent was recognised as having a history of medication abuse."
1b.4.2. Safeguarding issue	• 1b.4.2.1.. "also used inappropriately for behaviours not convulsive seizures in PWID by family members" • 1b.4.2.2. "Given for events that are behavioural rather than seizures" • 1b.4.2.3. "Prescribed for prolonged seizures but given after to calm behaviour by parents" • 1b.4.2.4.. "used by a family member of person with ID as a way of sedating them," • 1b.4.2.5.. "used to sedate children in safeguarding cases." • 1b.4.2.6. "Used by abusive carer to rape patient"
2b. Protocol breakdown	
2b.1. By patients	• 2b.1.1. "Frequent requests of repeat prescription when no ambulance or A&E notifications for seizure reported" • 2b.1.3. "Patient requesting lots of prescriptions from GP and not reporting increased seizure frequency" • 2b.1.4. "Individual requesting repeat prescription too frequently and not corresponding to seizure record/frequency. Getting angry when questioned about use." • 2b.1.6. "A patient requesting multiple prescriptions from the GP, not reporting frequent seizures to Neurology."
2b.2. By families	• 2b.1.1. "Overuse by the patient's relatives or carers, not following the agreed emergency medication administration plan" • 2b.2.2. "carers not following plan and administering extra doses" • 2b.2.3. "Carers not administering it as per guidelines in care plan - either giving it too early or not giving it at all • 2b.2.5. "not following plans and giving for inappropriate seizure types." • 2b.2.6. "In stressful situation when parents become very nervous and do not time the duration of the convulsion. Do not follow the guide line and are nervous and do not time the duration of the convulsion are anxious and do not wait"
2b.3. By professionals	
2b.3.1. Professional competence	• 2b.3.1.1. "Lack of understanding of seizures in staff teams, being too quick to administer, or even too slow when a person has recovered. Staff Using for Dissociative seizures in a person with a benzodiazepine addiction." • 2b.3.1.2. "School staff administering too early. Not following plan." • 2b.3.1.3 "carers not familiar with JEC plans in supported living settings i.e. the timing of when to give midazolam; 999 being called because 'no-one on site is buccal trained' (again in the same home" • 2b.3.1.4. "pt addicted but managed by GP - reported to GP, removed from her care!!"
2b.3.2. Prescribing	• 2b.3.2.1. "Patient prescribed by Gp to self administer," • 2b.3.2.2. "Sometimes prescribed inappropriately in the first place (e.g. A&E attendance) with poor training provided" • 2b.3.2.3. "GP had highlighted excessive use of oramorph post surgery and buccolam was then found to have also been requested more frequently than required." • 2b.3.2.5. "prescribed without appropriate supports at home to administer on occasions, prescribed before baseline medications are considered effective" • 2b.3.2.6. "I had a patient whose brother was advised to administer if he had a prolonged convulsion over 5 min. I found out his brother didn't live with him and he was using a box of 4 a month just for what he believed to be seizure warnings. I later found out that Pt had a hex of medication misuse" • 2b.3.2.7. "Not updated doses for age," • 2b.3.2.8. "out of date rescue plans"
2b.4 Medication control	• 2b.4.1. "Poor storage - loose in footwell of car" • 2b.4.2. "Also when not used in past 2 years" • 2b.4.3. "Midaz going missing in the community"
3b. Seizure knowledge	
3b.1. Misidentification of seizures	• 3b.1.1 "Misinterpretation of presenting events," • 3b.1.2 "School staff administering too early. Not following plan. Or not recognising that not Al events are epileptic" • 3b.1.3. "Misdiagnosis of seizure" • 3b.1.4. "Given for events that are behavioural rather than seizures" • 3b.1.5. "Have had some cases where discerning seizures from behaviours in patients with more severe learning disabilities can be difficult, so there is potential for midazolam To be given inappropriately"
3b.2 Wrong seizure type	• 3b.2.1. "Case of NEAD" • 3b.2.2. "carers administering for non epileptic seizures" • 3b.2.5. "over use in pseudo seizures due to incorrect identification as GTCS" • 3b.2.6. "Family and staff administering it for non epileptic attacks" • 3b.2.8. "School staff administering too early. Not following plan. Or not recognising that not Al events are epileptic" • 3b.2.10. "Wrong type of Sz eg absence" • 3b.2.12. "given for myoclonus not as prescribed"

(*continued on next page*)

Table 6 (*continued*)

Theme	Illustrative quotes
	• 3b.2.13. "Inability of carers to differentiate between seizure types plus NEAD comorbidity" • 3b.2.14. "Used inappropriately for wrong seizure type e.g. focal seizure."
3b.3. Timing	• 3b.3.3. "failure to use for example 30 min convulsion is not unusual so they won't give it to prevent status" • 3b.3.4. "Lack of understanding of seizures in staff teams, being too quick to administer, or even too slow when a person has recovered" • 3b.3.8. "May be used too early" • 3b.3.10. "Used for post ictal phase" • 3b.3.11. "used immediately seizure starts," • 3b.3.12. "Related to carer's misinterpretation/lack of understanding of what constitutes 'prolonged seizures'." • 3b.3.13. "In stressful situation when parents become very nervous and do not time the duration of the convulsion. Do not follow the guide line and are nervous and do not time the duration of the convulsion are anxious and do not wait"
4b. Mistrust and Relationships	
4b.1 Mistrust of patients	• 4b.1.2. "Individual requesting repeat prescription too frequently and not corresponding to seizure record/frequency. Getting angry when questioned about use."
4b.2 Mistrust of patients' families	• 4b.2.1. "Patient with very poor compliance who's partner was giving midazolam several times per week. He claimed to be helping her take her regular ASM as well, but levels in the community often unrecordable, but normal following in-patient admissions when ASM given by nursing staff." • 4b.2.3. "used by a family member of person with ID as a way of sedating them," • 4b.2.6. "This was before I was an epilepsy nurse but worked with a child with epilepsy. The GP had highlighted excessive use of oramorph post surgery and buccolam was then found to have also been requested more frequently than required." • 4b.2.7. "Fir seizures that have never been witnessed but reported by family members." • 4b.2.8. "Concerns that Buccal midazolam was being self-administered by a parent due to excessive ordering from the GP which did not correlate with the child's seizure history. Parent was recognised as having a history of medication abuse." • 4b.2.10. "Prescribed for prolonged seizures but given after to calm behaviour by parents,"
4b.3. Trust in healthcare professionals	• 4b.3.1. "Using more often than recommended dose. Has now been stopped by the Neurologist" • 4b.3.3. "This was before I was an epilepsy nurse but worked with a child with epilepsy. The GP had highlighted excessive use of oramorph post surgery and buccolam was then found to have also been requested more frequently than required."

(1b.4.2.5, 1b.4.2.1) and one case of "rape" was reported:

"Used by abusive carer to rape patient" (1b.4.2.6)

Theme 2. Protocol breakdown

This theme emerged from responses which referred to a breakdown of protocol in any aspect of an individual's care, from the prescribing of BM by healthcare professionals to its subsequent use. Protocol breakdowns varied according to stakeholder group of patients, families and professionals. Protocol breakdowns by patients typically related to increases prescription requests without commensurate increases in seizure reporting (2b.1.1., 2b.1.3., 2b.1.4., 2b.1.6.). Two responses implied that this was enabled by a separation between patients' general practitioners and patients' epilepsy specialists (2b.1.3, 2b.1.6).

"A patient requesting multiple prescriptions from the GP, not reporting frequent seizures to Neurology." 2b.1.6.

Protocol breakdown by patients' families was characterised by deviations from emergency management plans. These included BM overuse (2b.2.1, 2b.2.2), mistimed administration (2b.2.3), administration for inappropriate seizure types (2b.2.5) and failures to time seizures (2b.2.6).

Protocol breakdown by professionals involved school staff, professional carers and healthcare professionals. Participants highlighted issues around the competence of professional care staff and school staff to implement emergency management plans in schools (2b.3.1.2) and supported living settings (2b.3.1.1, 2b.3.1.3.)

"carers not familiar with JEC plans in supported living settings i.e. *the timing of when to give midazolam; 999 being called because 'no-one on site is buccal trained' (again in the same home" 2b.3.1.3*

Reports of protocol breakdown by healthcare professionals were overwhelmingly concerned with prescribing practices, including outdated emergency management plans (2b.3.2.8.), outdated doses (2b.3.2.7.) and the prescription of BM without proper identification of an appropriate administrator (2b.3.2.5., 2b.3.2.6) Notably, this issue was specifically described as occurring in non-specialist settings (GPs and A&E) (2b.3.2.2., 2b.3.2.1). Relatedly, respondents described examples of GPs' both overlooking (2b.3.1.4.) and identifying (2b.3.2.3.) patients with addictions to BM, demonstrating their pivotal role in BM regulation.

*"Sometimes prescribed inappropriately in the first place (*e.g. *A&E attendance) with poor training provided" (2b.3.2.2)*

"GP had highlighted excessive use of oramorph post-surgery and midazolam was then found to have also been requested more frequently than required." 2b.3.2.3.

Issues with medication control included unsafe storage in a car footwell (2b.4.1.), outdated medication (2b.4.2.) and missing medication (2b.4.3.).

Theme 3. Seizure knowledge

The most commonly reported factor in inappropriate BM use was insufficient knowledge of seizures across stakeholder groups. This contributed to the misidentification of behavioural or other events as seizure activity (3b.1.1., 3b.1.2., 3b.1.3., 3b.1.4.), especially in PWID (3b.1.5.). Participants frequently described the administration of BM for inappropriate seizure types, either for non-epileptic seizures (3b.2.1., 3b.2.2., 3b.2.5., 3b.2.6.) or for seizure types where BM may not be indicated, such as absence and focal seizures (3b.2.10., 3b.2.12., 3b.2.14.). Psychogenic non-epileptic seizures were repeatedly highlighted as a complicating issue in seizure identification by both carers and professionals (3b.2.6., 3b.2.5., 3b.2.8., 3b.2.13.).

"Inability of carers to differentiate between seizure types plus NEAD comorbidity" (3b.2.13)

Participants also described how lacking seizure knowledge contributed to the premature administration of BM (3b.3.11., 3b.3.4., 3b.3.8.,3b.3.13), delayed administration (3b.3.10) or lack of administration (3b.3.12).

Theme 4. Mistrust and relationships

Issues of trust and mistrust in relationships between patients, patients' families, care professionals and healthcare professionals were highlighted by participants. Three key subthemes emerged from these: mistrust of patients, mistrust of patients' families and, less prominently, trust in healthcare professionals.

Respondents highlighted the reliance of healthcare professionals on patients to accurately report their seizure frequency and to comply with emergency management plans. Responses implied their suspicions that

patients were not being truthful in their reporting:

4b.1.2. *"Individual requesting repeat prescription too frequently and not corresponding to seizure record/frequency. Getting angry when questioned about use."*

The mistrust of patients' families by respondents emerged as a significant issue, either as the result of BM abuse by families (4b.2.3, 4b.2.6, 4v.2.7, 4b.2.8, 4b.2.10) or from uncertainties about the truthfulness of families' reports.

"For seizures that have never been witnessed but reported by family members." (4b.2.7.)

This contrasted with participants' trust in professionals, such as nursing staff in the quote below, GPs (4b.3.3) and neurologists (4b.3.1).

"Patient with very poor compliance who's partner was giving midazolam several times per week. He claimed to be helping her take her regular ASM as well, but levels in the community often unrecordable, but normal following in-patient admissions when ASM given by nursing staff." (4b.2.1.)

"Using more often than recommended dose. Has now been stopped by the Neurologist" (4b.3.1)

4. Discussion

4.1. Use of emergency management plans – initiation, review and deprescribing

Participants indicated that their initiation of emergency management plans after episodes of SE or prolonged seizures is in line with current guidance as outlined by NICE and ESNA [6]. There is currently no specific guidance on how frequently plans should be reviewed, but most participants (87 %) aim to review emergency management plans annually or six-monthly, suggesting an experience-based consensus, though NICE or ESNA do not provide any expert guidance on this. Contrastingly, survey responses indicated that participants varied widely in their practice of withdrawing BM from emergency management plans with a range of one to five years of non-use being reported as standard threshold timeframe for deprescribing. Practice also varied by profession, with doctors expressing a preference for longer periods of non-use compared to nurses. Free text responses communicated that some respondents describing locally standardised practices for BM withdrawal whilst others described the decision to withdraw BM as a complex and highly personalised one, comprising clinical judgements of individuals' epilepsy history, considerations of home and social contexts and the wishes of patients and carers. It is unclear what the impacts of this arbitrary practice are for patients and carers. Research is needed to evaluate how and when BM deprescribing is best implemented.

4.2. Prescribing practices

Participants' prescribing practices were largely concordant with NICE guidance and the majority of participants (93 %) chose BM as their first-choice therapy for prolonged tonic-clonic seizures (GTCS) [6]. For cluster focal seizures, participants expressed a preference for oral clobazam. A small minority of respondents (7 %) indicated that they would give more than the maximum recommended NICE dose of BM in 24 h (20mg).

Guidance on contraindications to BM is available from the British National Formulary (BNF) [15].

However, there is currently limited guidance on specific contraindications for BM as a rescue therapy and its use in multi-morbidity. Respondents indicated aversions to prescribing BM for individuals with alcohol related seizures, adverse reactions to BM, histories of respiratory compromise, a risk of drug abuse or lack of support to administer BM. This aligns with the BNF's guidance that BM is contraindicated in central nervous system depression and respiratory compromise and should be used cautiously in patients with respiratory disease, alcohol and drug dependency or abuse [15].

However, there were differences in practice between doctors and nurses with nurses being unlikely to prescribe BM to pregnant patients, patients with a history of cardiovascular disease or T1DM. Neither diabetes nor pregnancy are contraindications for BM or benzodiazepine use, if used for seizure control [15]. If representative, these discrepancies illustrate significant variations in practice that are not all driven by an existing evidence base and may indicate a need for more detailed guidelines on prescribing BM for clinicians.

4.3. Inappropriate use of BM

Nearly three-quarters participants (72 %) were concerned about inappropriate BM use and participants' free text responses expanded on these concerns.

Most strikingly, respondents described the use of BM to sedate vulnerable patients (children/intellectual disability). The particular comment of its use in a case of rape is extremely concerning.

Participants also expressed suspicions about BM recreational use and overuse by patients or carers, as might be expected of a drug with well-recognised abuse potential [15,16]. While many of the participants' examples could not be straightforwardly labelled as drug abuse, they did conform to certain behaviours recognisable in drug abuse, such as the collection of multiple prescriptions [16]. The separation of emergency departments, specialist epilepsy services and general practice was recognised amongst participants as an exacerbating factor in preventing or delaying the timely identification of BM abuse. It should also be noted that non-abusive overuse must be addressed, due to the harmful psychological, neurological, respiratory and gastrointestinal effects of BM overuse [15].

The identification of seizures and the differentiation of tonic-clonic seizures from other seizure types or non-epileptic seizures presents a significant challenge to appropriate BM use, especially in patients experiencing multiple seizure types. Many of those who are on BM are likely to have pharmaco-resistant epilepsy [17]. Furthermore, vulnerable groups such as people with intellectual disability are likely to be over-represented in receiving BM as many have ongoing seizures across their lifetime [18]. It is well recognised that there is significant lack of awareness in epilepsy management for this group especially for those in professional care settings [19,20]. Similarly, the emerging evidence suggests the influence of the pandemic on people with intellectual disabilities and epilepsy and their carers has been a stressful one [21,22]. In such situations, it would not be unusual as described in some of the comments for drugs like BM to be used for behavioural management and not for it's indicated purpose.

While the issue of BM misuse especially given its UK status as a scheduled drug unlicensed in adults being used by non-medically trained people is a significant concern, it needs to be balanced against the fact that BM undoubtedly saves lives. It can keep people safe in community as prolonged seizures and SE are recognised direct and indirect risk factor to Sudden Death in Epilepsy (SUDEP) [23,24].

BM also enhances pre-hospital care to prevent unnecessary use of emergency care and admissions, improving patient experience, reducing economic and environmental costs [25,26]. Better integration of and communication between ambulance, emergency, primary and secondary care services would also meet patients' desires of care configuration while developing feasible person-centered care.

Further training of patients and carers in seizure differentiation may reduce BM misuse along with ongoing vigilance. These might include a shared prescribing mechanism between specialist epilepsy services, emergency departments and general practices, to promote the early identification of inappropriate BM use, interagency education on BM abuse potential and the application of a misuse screening tool, such as

those used in long-term opioid use [27].

However, this requires intensive manpower in a resource deprived health care setting. It could be that recent emergence of new technologies such as predictive seizure modelling, long-term home-based EEG capture and artificial intelligence (AI) video monitoring could be harnessed to improve prescribing practices of BM by ensuring suitable and appropriate patient compliance particularly in vulnerable populations like those in intellectual disabilites [28–33].

Another linked conundrum is the identified non-prescribing by the respondents for those with alcohol related seizures. While the logic of this is understandable, it is worth noting that they remain one of the highest risk groups for unplanned emergency department admissions, seizure related harm and pre-mature mortality [34–36].

Finally, a thought needs to be given to the positive economic impact and reduction of carbon footprint the use of BM in community settings is having especially in causing a channel shift in reducing emergency care and unplanned addmissions [37,38].

4.4. Strengths and limitations

This survey represents the first attempt in existing literature to characterise the current clinical practice and experiences of UK-based healthcare professionals delivering community-based rescue medication seizure management. The survey was largely answered by epilepsy specialist nurses. A larger sample, including a greater representation of different specialists (neurologists, epileptologists) and more doctors would increase the strength of confidence of these findings. Furthermore, capturing geographic demographic data could help to map and quantify variations in clinical practice. The survey did not include the perspectives of patients or their families, so does not represent their experiences in BM misuse or withdrawal. In addition, the survey would bring all biases associated with a cross-sectional study.

5. Conclusion

The study findings suggest that quality improvement work around the implementation of BM as a first-choice rescue therapy for GTCS has been taken up consistently [6–10]. However, an expansion of evidence-based guidelines around rescue therapies for other seizure types, the use of BM in multi-morbid patients and the indications for its deprescribing is needed. Respondents described instances of collaborative and personalised care in BM prescribing and emergency management plan use. However, they also described concerning instances of BM abuse and misuse that warrant further investigation, development of robust safeguarding protocols and further research.

Statements and declarations including competing interests

LW has received honoraria from UCB and Veriton Pharma as an invited speaker outside of this work. PT has received honoraria and support for educational projects from UCB Pharma outside this work. RS is the chief Investigator of the NIHR adopted national Ep-ID register (which is described in the paper and evidence from it used). The Register is supported and monitored by the National Institute of Health Research UK. The funding for each molecule examined by the Register is via an Investigator Initiated Support grant from each of the molecule's parent company. The funding is to RS's NHS institution and goes towards the salary of the research co-ordinator and the institution's project oversight costs. The contributing companies till date include Eisai, UCB, Bial, Jazz pharma (previously GW pharma) and Angelini. In addition to the above RS has received institutional research, travel support and/or honorarium for talks and expert advisory boards from LivaNova, UCB, Eisai, Neuraxpharm, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds or has held competitive grants from various national grant bodies including Innovate, Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (ESPRC), National Institute of Health Research (NIHR), NHS Small Business Research Initiative (SBRI) and other funding bodies including charities all outside this work. No other author has any declared conflict of interest related to this paper.

Ethics statement

We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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None.

Data statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

CRediT authorship contribution statement

Audrey McBride: Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Lance Watkins:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Samuel Tromans:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Paraskevi Triantafyllopoulou:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Paul Basset:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Phil Tittensor:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Caryn Jory:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation. **Rohit Shankar:** Visualization, Formal analysis, Data curation, Writing – original draft, Writing – review & editing, Investigation.

Declaration of competing interest

No direct conflict of interest exists for any author.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.seizure.2024.12.022.

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