Seizure: European Journal of Epilepsy 132 (2025) 20–29

Contents lists available at ScienceDirect

Seizure: European Journal of Epilepsy

journal homepage: www.elsevier.com/locate/seizure

The epilepsy deaths register: Third-party reports of SUDEP in adults and older adolescents

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ARTICLE INFO

Keywords:
All Epilepsy/Seizures
All epidemiology
Risk factors in epidemiology
SUDEP
Mortality

ABSTRACT

Objective: The major source for sudden unexpected death in epilepsy (SUDEP) case series has been medical case record review, however most deaths occur at home, with no clinical witness. We set out to describe SUDEP characteristics using reports of deaths from third-parties and explore the effectiveness of this reporting as a sampling technique.

Methods: We collected characteristics of the deceased and narratives surrounding death via the SUDEP Action UK Epilepsy Deaths Register (EDR). We included adults and older adolescents with a certified cause of death, and narrative in keeping with definite or probable SUDEP. We collected demographics, details of follow-up, events leading to death, and attitudes towards condition and treatment in life from third-party reporters between 2013 and 2024.

Results: 407 SUDEP cases were identified, 268 definite, 16 definite plus, 112 probable and 11 near SUDEP. Ages ranged from 15–85 years, with the majority (76 % of cases) occurring between the ages of 19 – 49 years; 59 % were male. Most cases were found in the prone position (63 %), and death most frequently occurred during sleep (69 %). Inconsistencies were identified between death certification and reporter accounts in 24.8 % of cases, where SUDEP was consistent with the reporter account but not reflected in official death records. Increased frequency of SUDEP was observed with lengthening duration of epilepsy, with 41 % diagnosed more than 10 years prior to death. 24 % were reported as sometimes forgetting to take their medications. 16 % of cases lived alone and 16 % of deaths were witnessed.

Significance: Third-party death reports are an effective, under-utilised tool to sample SUDEP deaths which may currently be missed by conventional mortality records. SUDEP in the EDR was seen more frequently in young adults, those with longstanding epilepsy and during sleep and were most often found in a prone position. Heterogeneity across the spectrum of SUDEP deaths should prompt clinicians to warn all those with epilepsy of their SUDEP risk.

KEY POINTS

We describe a case-series of 407 sudden unexpected deaths in epilepsy (SUDEP) where details are reported by bereaved relatives, friends and healthcare professionals.

Cases were varied in age, living arrangements and occupations, most deaths occurred nocturnally.

Formal death certification did not clearly state SUDEP in a significant number of cases

A wide range of case characteristics highlight the importance of universally discussing SUDEP risk, and of signposting families to specialist support.

Third party reporting in the Epilepsy Deaths Register is a valuable

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https://doi.org/10.1016/j.seizure.2025.08.031
Received 11 June 2025; Received in revised form 27 August 2025; Accepted 28 August 2025
Available online 28 August 2025

tool to inform future SUDEP research including mortality trends relying on other big data sources.

1. Introduction

Epilepsy is a common neurological disorder with global importance [1,2]. Patients living with epilepsy experience premature death up to 11 times the rate of the general population [3], with sudden unexpected death in epilepsy (SUDEP) being the most common cause of epilepsy related death [4]. Seizure induced respiratory, cardiac, cerebral or brainstem dysfunction are all hypothesised pathophysiological mechanisms of SUDEP, however the environmental and social circumstances of a patient are thought to play a pivotal role in its precipitation [5–7]. SUDEP risk is not purely driven by witnessed convulsive seizure frequency, and has been documented in patients who have never had a convulsive seizure [8].

Studying SUDEP was the most important research priority in the 2025 UK's epilepsy priority setting partnership [9]. SUDEP is a devastating event to the family, friends or care-givers of the affected person [10], and many bereaved individuals are first-hand witnesses to the nature, circumstances, and consequences of a patient's death [11]. Concerns about exacerbating grief has led to the bereaved being overlooked from contributing to SUDEP research, despite their potential to offer detailed information on the circumstances of death [12]. Although engagement of bereaved persons in determining research priorities is increasing [13,14], data derived from 'snapshot' clinical encounters has traditionally been the major source for research [15,16].

Identification of common features in SUDEP—including circumstantial factors (nocturnal occurrence, prone positioning), patient characteristics (young adults with epilepsy, subtherapeutic AED levels), and temporal patterns, is vital in the development of preventative strategies.

Patients' attitudes towards their condition and treatments, risk factor behaviour, or living circumstances, are all typically best known by their closest acquaintances [12]. We analysed the Epilepsy Deaths Register to provide descriptive data on SUDEP deaths amongst adults and older adolescents. We aimed to describe demographic characteristics of SUDEP victims, and examine associations with time of day, sleep status, patient positioning, seasonality, and socioeconomic deprivation. We also aimed to assess the effectiveness of third-party reporting as a tool to sample SUDEP deaths and demonstrate the knowledge and experiences of the bereaved.

2. Methods

2.1. The epilepsy deaths register

The Epilepsy Deaths Register (EDR) is a voluntary register owned and managed by the UK charity SUDEP Action [12]. Anyone affected by the death of a person with epilepsy may register the death via an online reporting form, postal survey or phone report. Full methodologies from the EDR have been published previously [17], and further detail can be seen in the supplementary information.

2.2. Case selection & data extraction

We assessed all cases reported since the creation of the EDR in 2013. Cases were screened to exclude children under the age of 15; paediatric cases of SUDEP are published in a separate report [18]. We included older adolescents aged 15 to 18 years to capture the transition period from paediatric to adult care, a high-risk period for deterioration of chronic health conditions [19]. We rejected duplicate submissions of the same case from different reporters and cases where the circumstances clearly indicated a non-SUDEP cause (e.g. such as status epilepticus, trauma or self-poisoning). All cases had a diagnosis of epilepsy, either reported as a known diagnosis or by inclusion of SUDEP or epilepsy on death certification. To improve comparability with previously published work, we excluded cases where no post-mortem results or certified cause of death were provided by the reporting individual [20,21]. We included all cases meeting the Nashef definitions of probable, near or definite SUDEP, and SUDEP plus [20]. Cases of near-SUDEP were those with survival beyond one hour without a structural cause of death identified at post-mortem.

Free text reports were scrutinised to code categorical variables. We determined sleep status based on the description of the scene provided by the respondent. Cases were presumed asleep if stated by respondent, or if description of the death scene indicated the case was in or around bed with no evidence of other activity. Cases were presumed not to be asleep if activities in the hours leading up to death or the death scene were not supportive of a presumption of sleep. SUDEP was presumed to have occurred at night if clearly stated by the respondent, described to occur after 10pm, or if description of the scene indicated an early morning discovery. Ethnicity was determined by third-party report.

For seasonality analysis, we calculated the proportion of UK SUDEP deaths in the EDR occurring per calendar month. This was compared to average all-cause mortality per calendar month for England between 2010–2020, openly available from the UK Office of National Statistics (ONS)[22]. Lower layer super output areas (LSOA), derived geographical areas with population sizes of between 1000–3000 people, were matched to reported UK postcode data, these cases were then matched to the English, Scottish and Welsh Indices of Deprivation 2019 [23]. Distribution of deprivation scores across the Epilepsy Deaths Register was compared to population wide data.

2.3. Statistics, consent, ethical approval

Proportions of SUDEP cases were calculated for each predefined variable. Variables with missing data were expressed as proportions of cases with available data, with numbers clearly stated. Where appropriate, chi squared, chi squared test for trend or Fisher's exact test examined associations between demographic characteristics and circumstances of death. Deprivation and monthly SUDEP death were compared to general population distributions using the chi-squared goodness-of-fit-test. Results were considered statistically significant at a p value <0.05. Data analysis and generation of figures was performed using R version R.4.4.1 [24].

Included EDR registrants consented to interrogation of anonymised data for the purposes of research. Ethical approval was provided by the Newcastle University ethics committee (52,890/2023). Original anonymised data are available by request to study team, subject to approval from SUDEP Action UK. This study was performed in line with STROBE guidelines [25] (Supp Table 1).

3. Results

3.1. Demographics

1056 case registrations were submitted to the EDR between March 2013 and data extraction in October 2024. Case screening defined a case-series of 407 cases matching the inclusion criteria, 12 duplicate submissions were removed, and 637 cases were excluded. Consistent with the EDR's being run by a British charity 67.6 % ($n = 275$) of cases were from the UK, with the rest being international (a comparison of these groups can be seen in Supplementary Table 1). Average age was 31.4 (SD 12.9), the oldest case was 85.1 years and the youngest 15. Most cases, 93.2 % ($n = 316$) were reported by a family member and 59.7 % of cases were male ($n = 243$). Most reported SUDEP deaths occurred between the ages of 19 – 49 years (76.3 %; $n = 310$). 11.3 % ($n = 46$) of our case-series were aged over 50. The majority of cases with a reported place of residence ($n = 338$) lived with family or friends 71.6 % ($n =$

243), with only 18.9 % ($n = 64$) of the case-series living alone. A large proportion were employed, or self-employed 40 %, ($n = 133$); 24 % ($n = 80$) with a reported occupation were at college, school or university; 82.1 % ($n = 334$) of cases occurred at home. Full Demographic information on cases is displayed in Table 1.

3.2. SUDEP classification

Of the 407 total cases 66 % ($n = 269$) were classified as definite SUDEP, 28 % ($n = 112$) as probable SUDEP, 4 % ($n = 15$) as definite SUDEP plus and 3 % ($n = 11$) as near-SUDEP. All cases of near-SUDEP had prompt initiation of resuscitation and survived over one hour before death. Demographic characteristics and clinical epilepsy variables did not significantly differ amongst groups.

3.3. Circumstances of sudep

16.3 % ($n = 55$) of deaths were reported as witnessed. Sufficient information to determine time of day was available in 293 cases (72 %) of which most ($n = 223$, 76.1 %) of deaths occurred at night. Data were available on sleep or wakefulness at time of SUDEP in 311 of cases (76.4 %). Amongst these cases 68.5 % ($n = 213$) of SUDEP occurred during sleep. There was no statistical association between age, sex or living arrangements and SUDEP during sleep. 9.1 % ($n = 37$) of deaths were witnessed, deaths among individuals living alone were significantly less likely to be witnessed compared to those living with others 4.8 % vs 19.4 % (OR 0.21, 95 % CI 0.05–0.59; $p = 0.004$) there was no significant association between time of day and likelihood of death being witnessed.

Where information on positioning was available, cases were most frequently discovered in the face down position after death 63 % ($n = 186$, X-squared = 228.08, p-value < 2.2e-16) (Fig. 1). A chi-square test of independence did not show any association between wakefulness and the position found in (X-squared = 2.1778, df = 3, p-value = 0.54). Only 5.5 % ($n = 18$) of cases were reported to be using a seizure alert device.

Table 1
Summary demographic data.

Characteristic	N	Overall $N = 407$	Male $N = 243$
Reporter	339		
Parent		269 (79 %)	157 (80 %)
Sibling		47 (14 %)	26 (13 %)
Healthcare Professional		21 (6.2 %)	12 (6.1 %)
Friend		2 (0.6 %)	1 (0.5 %)
Age	407		
15–18		51 (13 %)	25 (10 %)
19–30		186 (46 %)	115 (47 %)
31–49		124 (30 %)	80 (33 %)
50–74		43 (11 %)	22 (9.1 %)
75+		3 (0.7 %)	1 (0.4 %)
Place of Death	407		
Home		334 (82 %)	204 (84 %)
Hospital		26 (6.4 %)	13 (5.3 %)
Care		12 (2.9 %)	6 (2.5 %)
Other		35 (8.6 %)	20 (8.2 %)
Ethnicity	335		
Asian		1 (0.3 %)	1 (0.5 %)
Black/African		6 (1.8 %)	5 (2.6 %)
Mixed/Multiple Ethnic Groups		6 (1.8 %)	2 (1.0 %)
Other		1 (0.3 %)	0 (0 %)
Prefer not to say		6 (1.8 %)	4 (2.1 %)
White		315 (94 %)	182 (94 %)
Occupation	333		
At School		26 (7.8 %)	15 (7.9 %)
College Student		35 (11 %)	20 (10 %)
Employee or Self-employed		133 (40 %)	91 (48 %)
Other		110 (33 %)	59 (31 %)
Parent/Carer		10 (3.0 %)	0 (0 %)
University Student		19 (5.7 %)	6 (3.1 %)
Living Arrangement	338		
Living Alone		64 (19 %)	42 (22 %)
Living in Care		13 (3.8 %)	9 (4.7 %)
Living with Partner/Friends		242 (72 %)	133 (69 %)
Other		19 (5.6 %)	8 (4.2 %)
Specialist Care	332		
Yes		273 (82 %)	153 (81 %)
No		47 (14 %)	30 (16 %)
Unsure		12 (3.6 %)	5 (2.7 %)
Prescribed Epilepsy Medications	331		
Yes		300 (91 %)	173 (92 %)
No		28 (8.5 %)	15 (7.9 %)
Unsure		3 (0.9 %)	1 (0.5 %)

[a]Other living arrangements including sheltered housing and shared halls of residence.

3.4. Treatment

At least 90.6 % ($n = 300$) of the case-series were prescribed antiepileptic medication, with 17 % ($n = 69$) having a named medication (Fig 2A). 29.6 % ($n = 94$) had a reported medication change within the last month while 60.1 % ($n = 191$) reported no change, 31.4 % ($n = 99$) were reported to "sometimes forget to take medications". No statistically significant associations were demonstrated between age, sex and reported medication concordance. A significantly higher number of medication concerns were noted in patients living alone 44.2 % compared to those in care 7.7 % or with a friend/partner 29.2 %, Fisher's exact test revealed a significant association between living arrangements and medication concerns ($p = 0.01$). Recent medication changes were reported in 29.5 % ($n = 94$).

In 8.2 % ($n = 27$) of cases, non-pharmacological adjunctive epilepsy treatment was reported: 14 had a vagus nerve stimulator implanted; 5 had undergone epilepsy surgery; and 8 were on other treatments such as a ketogenic diet. 28 people were reportedly not taking anti-seizure medications. These cases were more frequently aged 15–30 ($n = 22$) and more often living with a partner or family and friends ($n = 25$).

3.5. Specialist follow-up & duration of illness

At least 96.7 % ($n = 266$) were under specialist follow-up at time of SUDEP, of these cases 84.2 % ($n = 224$) had attended specialist follow-up in the 12 months preceding SUDEP. 50.9 % ($n = 170$) of all cases were diagnosed with epilepsy more than 10 years prior to death, 6.6 % ($n = 22$) of these cases were reported to be undiagnosed or misdiagnosed however all of these cases had death certification with either SUDEP or epilepsy listed as a cause of death. Association with comorbidities are shown in Fig. 2.

3.6. Seasonality

Although we noted a slight increase in SUDEP frequency during the winter months (28 % of total mortality) and reduction in spring (22.8 % of total mortality) there was no statistically significant relationship when compared to monthly trends in English-wide all-cause mortality (chi-square test: $\chi^2 = 4.33$, df = 11, $p = 0.959$).

3.7. Deprivation analysis

EDR cases were relatively evenly distributed across the deciles of multiple deprivation, and the difference between the distribution of EDR cases across IMD deciles and that of the general population of England was not statistically significant. Cases from the most deprived three deciles were 13.2 % more likely to have medication concerns reported and 12.4 % more likely to have SUDEP documented in either post-mortem of death certificate compared to those from the least deprived three deciles. Both these values trended towards but did not meet statistical significance.

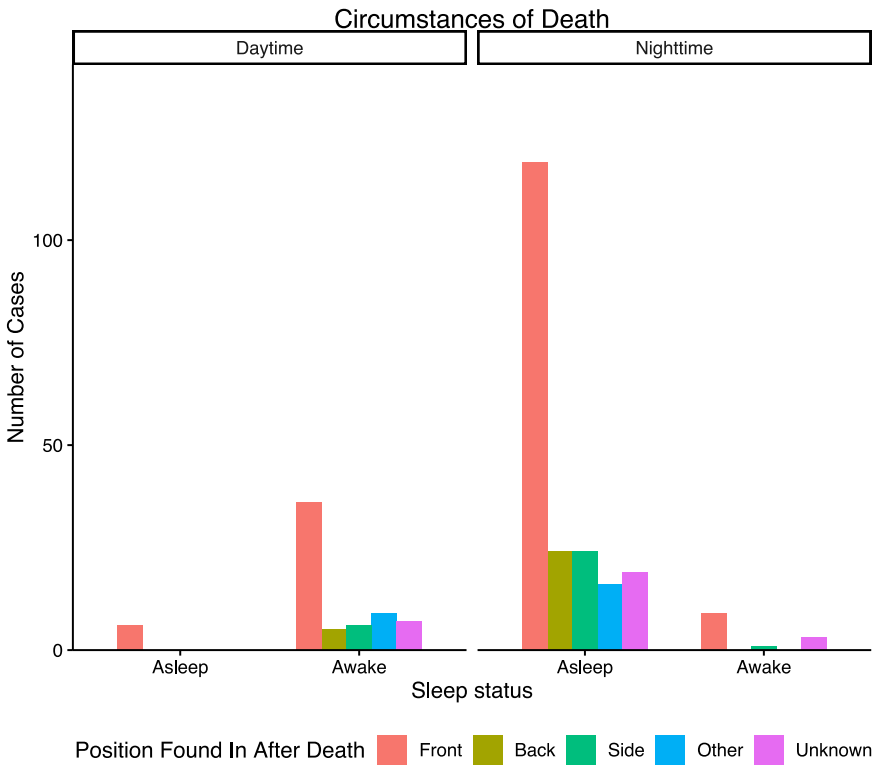

Fig. 1. Circumstances of death showing the time of day, position found in and wakefulness.

3.8. Distribution of cases

Where UK postcode data was available cases could be compared to a map of the UK (Fig. 3). This showed a broad distribution of cases centred over known major cities.

3.9. Death certification & communication

Discrepancies between official death certification and a reporter account consistent with SUDEP were present in 24.8 % (n = 101) of cases. In these instances, death certificates most commonly listed epilepsy/seizure disorders 70.3 % (n = 71), sudden death 6.9 % (n = 7) or cardiorespiratory failure 5.9 % (n = 6). Of the 86.1 % (n = 285) of cases with post -mortem examinations 23.5 % (n = 67) did not result in SUDEP being recorded as the cause of death. There were no significant demographic differences between populations with SUDEP reported in death certification or not.

Cases where SUDEP was not recorded were more likely to be witnessed 26.1 % vs 12.5 % (p = 0.008), had a higher proportion of epilepsy diagnosed over 10 years prior 55.4 % vs 37.4 % (p = 0.003) and were less likely to have a post-mortem examination 70.3 % vs 93 % (p < 0.001). We have shown two illustrative cases where SUDEP was not mentioned after post-mortem examination in Fig. 4.

Dissatisfaction at a lack of discussion regarding SUDEP risk was a common theme amongst free text comments (Table 2), further to this 51.4 % of reporters (n = 171) did not know that people could die of epilepsy. Reporters aware that people could die from epilepsy wrote significantly longer impact descriptions (mean 103 vs 76 words, p = 0.019), with no differences in negative sentiment (p = 0.131) or expressions of shock (p = 0.906).

4. Discussion

We describe one of the largest published case-series of SUDEP to date, provided predominantly by friends and relatives to the deceased. We show that SUDEP affects a wide spectrum of patients including those not typically recognised. Our cohort spans a wide range of ages, and were predominantly under specialist care, living with family or friends, and regularly took anti-seizure medications. These patient demographics support universal discussion of SUDEP amongst patients diagnosed with epilepsy and further highlight the importance of transition from paediatric to adult care [26–28]. The high proportion in full time education suggests this represents a higher risk period and may indicate a need for targeted epilepsy care provision at places of learning.

Seeking reports of death from third-parties offers rich data for researchers, and a conduit to specialised support for the bereaved Although these reports offer unique insights, their accounts have limitations. Firstly, a lack of supportive clinical information meaning details cannot be verified; secondly, socially isolated and homeless individuals will be underrepresented; thirdly, selective reporting may underestimate stigmatising characteristics such as alcohol or substance misuse, and over-estimate positive characteristics such as medication concordance [5]. Clinically phenotyping patients is also not possible within the EDR at present, as there are no links to formal medical records or information on seizure type. A further limitation is that 14 % of total EDR deaths had interim death certificates pending further investigation at data extraction, this is likely lower in our SUDEP cohort given higher post-mortem rates compared to the EDR as a whole. Finally recall bias increases with time between death and report. We recognise that without a control group of other epilepsy specific deaths, we cannot report on the effect sizes that identified characteristics have on SUDEP risk. Nevertheless, third-party reporters offer rich information on the circumstances of death and provide a sampling method to detect SUDEP deaths overlooked due to non-specific post-mortem reports, or poor engagement with healthcare. The reports also offer details and cases unavailable through current clinical records or big data approaches and are a valuable tool to inform and augment future SUDEP research and epilepsy mortality trends.

Our findings align with established SUDEP demographics [15,29]: male predominance, peak incidence in young adulthood, and longer epilepsy

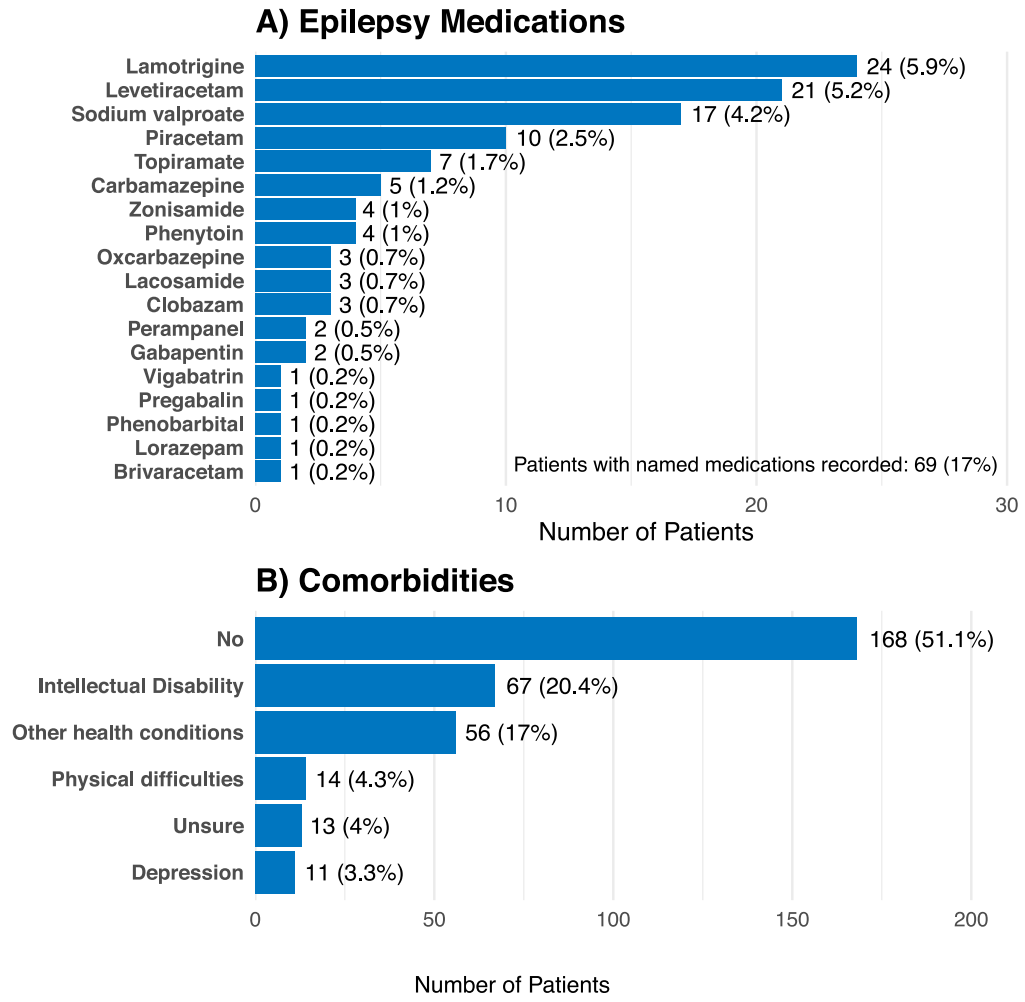

Fig. 2. A. Prescribed medications as mentioned in free text responses detailing current anti-epileptic medications. B. Associated comorbidities as reported by third parties.

duration. A longer duration is significant as each seizure represents a repeated risk exposure [30], increasing the likelihood of the peri-ictal cardiorespiratory abnormalities observed in directly monitored SUDEP cases [31,32],in keeping with previously published work [16,31].

Most deaths (68.5 %) occurred during sleep, with 63 % discovered in a prone position, consistent with the increased risk of SUDEP in sleep [33,34]. Surprisingly, we found no significant relationship between wakefulness and position after death, contrasting with previous work showing a six-fold increase in prone position during sleep [35]. Charities and clinicians have advocated back sleeping as a possible method to reduce epilepsy mortality [35], and a recent case series of directly observed seizures found that prone positioning at the start of a seizure carried a 26.9 times higher risk of post-ictal prone positioning than non-prone starting positions [36]. However, without baseline sleep position data for people with epilepsy we cannot determine if sleep position represents a modifiable risk factor or simply correlates with other risks.

19 % of our cases were living alone at the time of their death, exceeding the UK population level of 11.5 % [37,38]. This observation parallels other studies, Tomson et al. report 68.2 % of cases living alone in comparison to 31.3 % of controls with epilepsy [15]. People who live alone must be considered at greater risk of SUDEP, and if people are at short-term increased risk, they could be encouraged to temporarily co-habit. Yet most cases in the EDR lived with family or friends, suggesting domestic support alone is not protective against SUDEP. SUDEP is rare amongst patients in epilepsy monitoring units [30], hence automated seizure detection devices may offer an opportunity for family members to intervene [39],reposition patients, or in cases who live alone, automatically contact medical support. Only 18 of our cases reported use of a seizure alert device, but the frequency of use and nature of these devices overall is unknown, making it difficult to comment on any effect. There is some supportive data for nocturnal monitoring to reduce SUDEP incidence [40], however further evaluation of the efficacy of seizure alert devices in the prevention of SUDEP is vital.

Another aspect related to prevention is the 11 cases of near-SUDEP. These all had prompt resuscitation and survived past one hour, as detailed in previous cohorts of near-SUDEP [41], however subsequently died without a structural cause found. It is not yet clear if these cases of near-SUDEP represent a phenotype that is more amenable to resuscitation and prolonged survival or instead show the potential benefit of prompt and effective resuscitation. Data from the MORTEMUS trial [30] suggested that resuscitation initiated within 3 min of cardiorespiratory arrest can be successful, but these cases all occurred in a different clinical and environmental setting to the majority of SUDEP cases. There is a clear need for high quality data from successful cases of SUDEP resuscitation to guide potential preventative strategies.

The high levels of employment and full-time education in our cases likely reflect selection bias, this is supported by the low incidence of intellectual disability (ID) compared to other cohorts, 20.5 % vs 59.9 % [15]. Although our cohort's deprivation scores aligned with the general population, this suggests underrepresentation of socially isolated and socioeconomically deprived populations, where epilepsy prevalence is

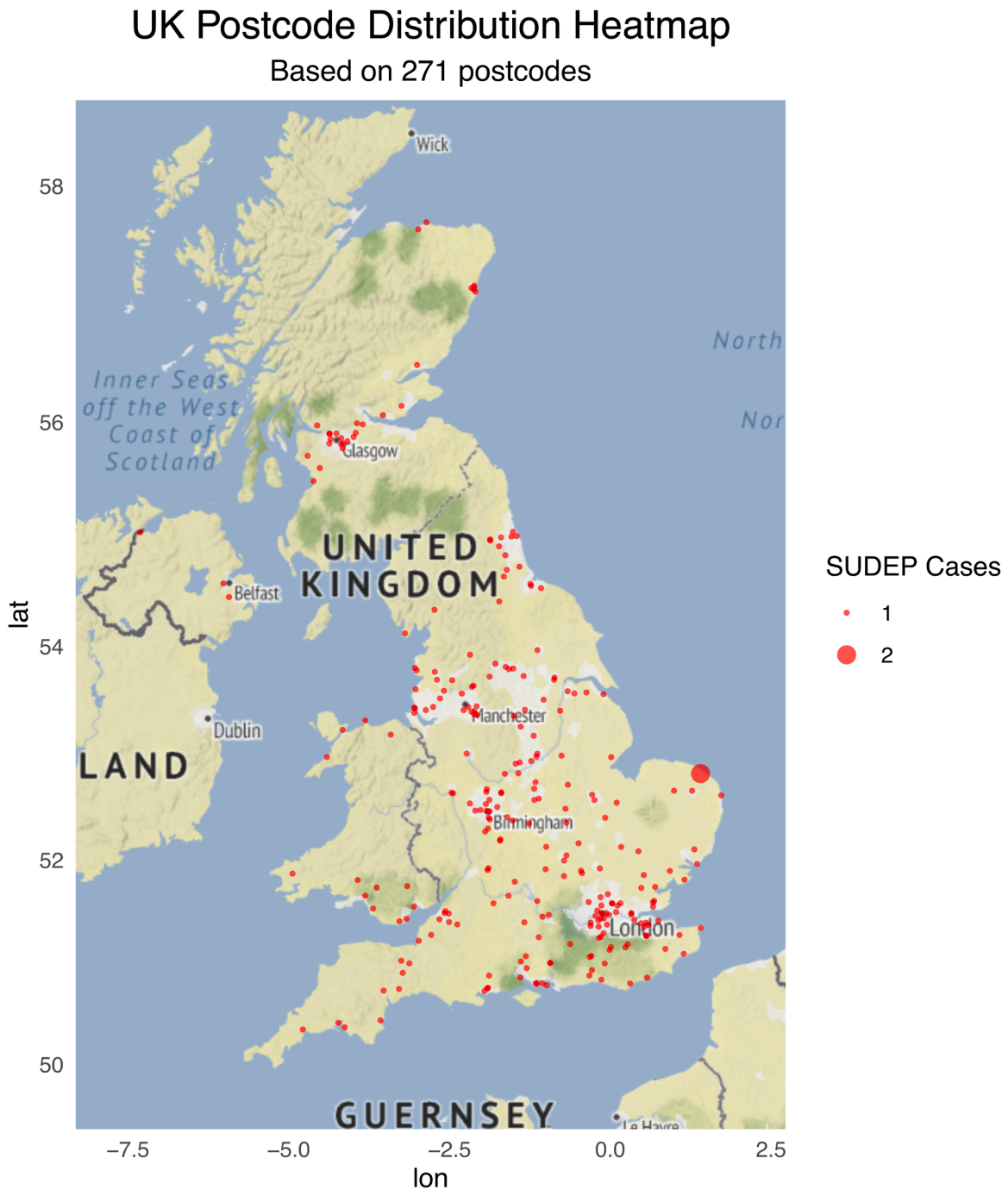

Fig. 3. Map of the United Kingdom showing the distribution of cases from the EDR cohort based on reported postcodes.

double that of the least deprived areas [42,43], and SUDEP rates are also increased [44]. Such biases are not unique to our cohort and potentially affect all SUDEP analyses relying on retrospective third-party reports. Additionally, socially isolated and socioeconomically deprived groups may also be underrepresented in healthcare record-based samples due to reduced healthcare engagement or access [45]. The high rate of students in our cohort may reflect the increased risks conferred by the transition from paediatric to adult services and often moving away from home.

Despite the underrepresentation of ID in our cohort a substantial proportion of cases reported to the EDR had ID, reflecting the markedly elevated risks of epilepsy related mortality in this group. SUDEP has consistently been found to be the second most common cause of death in adults with ID and epilepsy with standardised mortality ratios for SUDEP of up to 52 [46]. The clinical complexity of this cohort of patients who are often subject to multimorbidity and polypharmacy on complex social backgrounds highlights the need for comprehensive multidisciplinary risk management and care for this cohort of patients. The EDR also highlights the limited representation of individuals from ethnic minority backgrounds, a critical gap in outreach and research inclusivity. Epilepsy mortality is higher in ethnic minority populations [47], and their significant underrepresentation in the EDR further highlights the need for focussed research to identify incidence of and risk factors for SUDEP in these populations.

Medication non-adherence is reported as a risk factor for SUDEP. While there are limitations in reporting of medication adherence by a third party, our reported 31.4 % of cases ‘sometimes forgetting to take

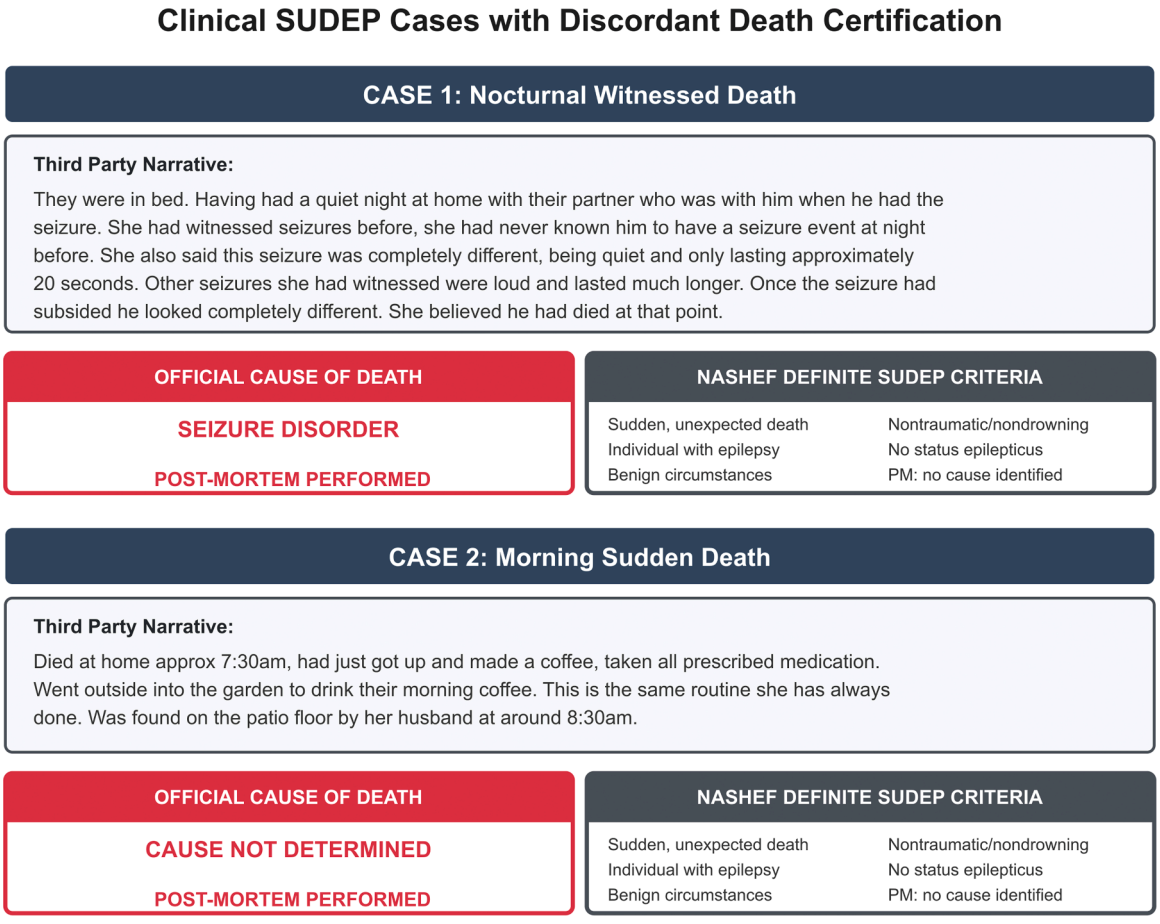

Fig. 4. Illustrative cases showing information provided to the EDR alongside the formal mortality reporting.

Table 2
Quotations regarding communication of SUDEP risk.

"We had no idea you could die from a seizure disorder. We had never heard of SUDEP"
"I loved him so much, but I never knew he could just die in his sleep for no Reason … Please inform people about it and save them my torment"
"People need to know that even after years of no seizures that something catastrophic can still happen"
"We all wish that we had known about the risk of SUDEP long ago"
"I have talked to a few people with family members who suffer from epilepsy and none of them have ever heard of SUDEP so I feel very disturbed they are not being told"
"All the years of Dr's appointments… no one ever mentioned the risk of death / SUDEP. This leaves me so very, very angry"

their medications', matches reported adherence in the general population with epilepsy [48] and other SUDEP cohorts [29]. It is notable that "medication concerns" were reported by 43 % of our respondents, with significant side effects reported in 23 % of cases. Weight gain, cognitive disturbance or mood issues were regarded as the most distressing side effects. The narrative reports in the ESR uniquely highlight these key medication issues that can influence adherence, seizure control and SUDEP. The increased medication concerns in those living alone potentially identifies a targetable intervention group. There is active research into strategies to improve medication adherence [49] and patients with epilepsy who live alone are likely to benefit from this.

The finding that SUDEP was not recorded as a cause of death in 24.8 % (n = 101) of cases despite consistent reporter accounts aligns with well-established patterns of systematic underreporting in the literature [50]. This discrepancy reflects persistent knowledge gaps among death certifiers rather than limitations in clinical assessment. A UK national audit [51] found that only 75 % of pathologists were aware of SUDEP, with deaths certified by doctors showing even greater misclassification. Of 39 deaths directly attributed to epilepsy, 15 were sudden with five meeting SUDEP criteria on expert review, yet only one was certified as SUDEP.

Internationally similar trends are observed. One study showed forensic committees identified only 24 % (6/25) of sudden epilepsy deaths as definite/probable SUDEP, retrospective adjudication by epileptologists with seizure-mortality expertise identified 72 % (18/25) [52]. A separate study showed only 75 % of cases meeting definite/definite plus SUDEP criteria according to neurologists were reported as SUDEP, epilepsy, or seizure disorder in autopsy reports [53].

The proportion of cases identified in the EDR without mention of SUDEP align with established research showing that administrative classifications often fail to capture SUDEP cases when competing pathologies are present. While we recognize the importance of coroner determinations for legal purposes, the well-documented educational gaps and classification inconsistencies necessitate clinical expertise-based adjudication for accurate epidemiological research.

The EDR third-party based reporting complements existing SUDEP registries, the North American SUDEP Registry (NASR) and New Zealand's EpiNet based registry. NASR has operated since 2011 with detailed phenotyping protocol requiring dual-epileptologist adjudication on cases alongside a biobanking infrastructure including tissue

samples and digital neurophysiological and cardiac data. EpiNet uses population level ascertainment through systematic coronial notification and employs a prospective case-control design targeting 200 SUDEP cases with 600 matched controls. This national level surveillance yielded a SUDEP incidence of 1.93 per 1000 person years [54], exceeding previous estimates for high-income countries.

NASR's more restrictive inclusion criteria enable focussed mechanistic studies but may exclude more community based cases or those with competing pathologies. EpiNet's prospective design and predefined cohorts elimites the recall bias inherent to retrospective studies and its multiple controls for familial and epilepsy related factors strengthen its ability to assess causal factors. The EDR has the most inclusive criteria, looking at all epilepsy deaths and offers significant detail on the personal circumstances of each SUDEP case. Its broader inclusion allows for cases that might not be captured by the NASR or EpiNet.

Our work offers a valuable addition to the current literature on SUDEP. Although susceptible to selection bias we have gathered a series of SUDEP cases traditionally unrecognised by other case finding methodologies. We demonstrate SUDEP occurring in groups not commonly thought of as high risk; 11 % of our cohort are aged 50 or over at time of death, 68 % have attended specialist care in the past year and 59 % of the cohort were reported to be compliant with prescribed medication. In contrast to these groups with high engagement with healthcare, 7 % of cases were reported to be undiagnosed or misdiagnosed (though all had SUDEP or epilepsy listed on their death certificate), and 9 % were not prescribed anti-epileptic medication representing targets to focus improvements in access to preventative services.

International guidelines recommend discussion regarding SUDEP alongside general risk advice given to young people and adults with epilepsy [7]. Yet it is clear from our narrative accounts that families often felt underinformed on SUDEP, specifically expressing shock at the diagnosis of SUDEP and a desire for more information on SUDEP during the deceased person's life and in the immediate aftermath of a person's death. Evidence based tools can help to structure discussions with patients and families and identify areas for risk reduction. Decreased communication of epilepsy related risks has occurred during the COVID19 pandemic [55], and adoption of digitalised tools may empower patients, and their families, to understand SUDEP, reduce risk and access care. Predicting the risk of SUDEP is difficult based on clinical or demographic factors alone, as a result, all patients should be offered advice on this tragic consequence of epilepsy.

Contributorship

Name	Location	Contribution
Alexander Grundmann BMBCh MRCP	Royal Victoria Infirmary, Newcastle-upon-Tyne, NE1 4LP, UK	Data analysis and interpretation, writing and editing of manuscript
Jacob Brolly MBChB, MRCP (UK)	Royal Victoria Infirmary, Newcastle-upon-Tyne, NE1 4LP, UK	Data interpretation, Writing of manuscript
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Ethical publication 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

Declaration of competing interest

Jacob Brolly has received honoraria from UCB pharma

Donald P Craig has received a consultancy fee from Eisai

Karen Osland was project lead for the Epilepsy Deaths Register for the UK charity SUDEP action until April 2020.

Ben Donovan is the project lead for the Epilepsy Deaths Register for the UK charity SUDEP Action

Jane Hanna OBE was chief executive of the UK charity SUDEP action

Elaine Hughes, participated in multi-centre commercial trials of fenfluramine in treatment of epilepsy in Dravet syndrome and is a member of the GW Pharmaceuticals supported LGS Advisory Board.

Mike P Kerr is Vice Chair of SUDEP Action, the charity that supports the Epilepsy Deaths Register

Rhys H Thomas has received honoraria from Angelini, Bial, Eisai, GW Pharma, Paladin, NeuraxPharm, Sanofi, Takeda, UCB Pharma, UNEEG, Zogenix, and unrestricted research funding from Angelini and UCB Pharma, independent of this project.

Alexander Grundmann has no interests to declare

This study was not industry sponsored. Data collection was supported through the UK registered charity SUDEP Action.

Acknowledgements

We would like to offer our gratitude to the families and friends who offered information regarding the death of a loved one who lived with epilepsy.

We thank Tracy Cowdry, the Support Manager for the UK charity SUDEP Action, and all staff at SUDEP Action whom have provided support for the bereaved in the aftermath of an epilepsy death and have diligently collected data through the Epilepsy Deaths Register.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.seizure.2025.08.031.

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