

Circumstances of SUDEP: A nationwide population-based case series

Olafur Sveinsson^{1,2} | Tomas Andersson^{3,4} | Sofia Carlsson³ | Torbjörn Tomson^{1,2}

¹Department of Neurology, Karolinska University Hospital, Stockholm, Sweden

²Department of Clinical Neuroscience, Karolinska Institute, Stockholm, Sweden

³Institute of Environmental Medicine, Karolinska Institute, Stockholm, Sweden

⁴Center for Occupational and Environmental Medicine, Stockholm County Council, Stockholm, Sweden

Correspondence

Olafur Sveinsson, Department of Neurology, Karolinska University Hospital, Stockholm, Sweden.
Email: olafur.sveinsson@sll.se

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Summary

Objective: Given the increasing attention being paid to potential strategies for sudden unexpected death in epilepsy (SUDEP) prevention, we analyzed the circumstances of SUDEP and its incidence in relation to time of year, week, and day.

Methods: Prospective case-series based on persons with an International Classification of Diseases (ICD-10) code for epilepsy in the Swedish Patient Registry 1998-2005, who were alive on June 30, 2006 (n = 60 952). Linkage to the National Cause-of-Death Registry identified all deaths from July 2006 through December 2011, with epilepsy mentioned on death certificate, together with all deaths during 2008 (n = 3166). Death certificates, medical charts, autopsy, and police reports were reviewed to identify SUDEP cases and related circumstances. Autopsied non-SUDEP deaths (n = 60) from the study population served as a reference.

Results: There were 329 SUDEPs (63% men) of which 167 were definite, 89 probable, and 73 possible. SUDEP cases were younger at death (50.8 years) than non-SUDEP deaths (73.3 years) ($P < .001$) and more likely to be male (63% vs 55%, $P = .0079$). Most SUDEP cases died at night (58%), at home (91%), and 65% were found dead in bed. When documented, 70% were found in prone position. In 17%, death was witnessed and in 88% of these, a seizure was observed. Of the 329 SUDEP cases, 71% were living alone and 14% shared a bedroom. Compared to an autopsied non-SUDEP reference group, definite SUDEPs were more likely to die at home, during the night, unwitnessed, in the prone position, to live alone, and more often with a preceding seizure.

Significance: SUDEP cases live alone, die unwitnessed at home at night, with indication of a preceding seizure, supporting the critical role of lack of supervision. These facts need to be considered in the development of preventive strategies.

KEYWORDS

epilepsy, incidence, intervention, mortality, supervision

1 | INTRODUCTION

Sudden unexpected death in epilepsy (SUDEP) is a major contributor to excess mortality in people with epilepsy.^{1,2} The incidence of SUDEP has been estimated to approximately 1.2 per 1000 patient-years in population-based

studies,^{1,2} but varies markedly depending on the type of epilepsy population.^{3,4} Case-control studies from the last decades have identified risk-factors, for example, high frequency of tonic-clonic seizures, nocturnal seizures, and lack of nighttime supervision,^{5,6} but SUDEP mechanisms remain unclear although in most cases it appears to be

triggered by a seizure.⁷ Given the importance of SUDEP, increasing attention is being paid to potential strategies for its prevention.^{4,8,9} Suggestions include improvement of seizure control, seizure and apnea detection devices, nighttime supervision, antisuffocation pillows, change in sleeping position, correction of body position, and stimulation after a seizure, as well as different pharmacological interventions.^{6,8–11} The rationale for many proposed interventions is based on observations of circumstances surrounding SUDEP deaths,^{12–17} but our current understanding of circumstances relies on a relatively small and selected case series with uncertain representativeness.^{12–14}

Given the importance of the issue for identification of high-risk situations, as well as for the development of effective preventions, we analyzed for the first time SUDEP circumstances in a nationwide population-based case series including 329 SUDEPs in Sweden over a 6-year period. In addition, we also analyzed the incidence in relation to time of year, week, and day to compare seasonality with what has been reported for sudden infant death syndrome (SIDS) and sudden cardiac death.

2 | METHODS

2.1 | Standard protocol approvals

The study was approved by the Ethics Committee of Karolinska Institutet.

2.2 | Study population

The Swedish National Patient Register (SNPR) contains all patients who were hospitalized (starting 1968, with total national coverage from 1987) or managed in hospital-based ambulatory care (since 2001) in Sweden.¹⁸ Each individual's outpatient visit or hospital discharge diagnosis (International Classification of Diseases [ICD] code) is linked with their unique personal identification number. We identified all persons that at some point during 1998–2005 were registered in the SNPR with an ICD-10 code for epilepsy (G 40) ($n = 78\,424$) and who were alive on June 30, 2006 ($n = 60\,952$). This constituted our study population. During follow-up from July 1, 2006 to December 31, 2011, 9605 deaths were identified by linkage to the National Cause-of-Death Registry (ICD-10 classified since 1994).¹⁹ Eligible SUDEP cases were all deaths with epilepsy mentioned on the death certificate ($n = 1562$), together with all individuals who died during 2008 ($n = 1890$), irrespective of whether epilepsy was mentioned on the death certificate. The rationale for the extended review of 2008 was our recent study of the incidence SUDEP during that specific year.¹ In all, 3166 deaths were reviewed (Figure 1).

Key Points

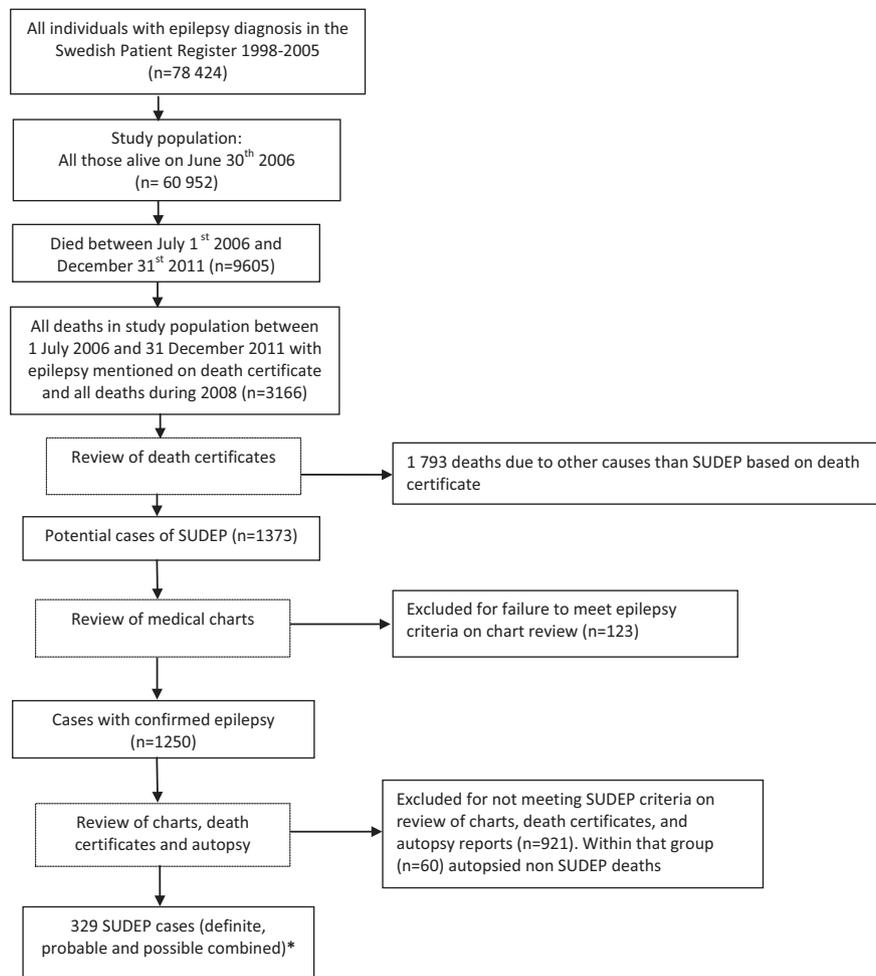
- Increased knowledge on circumstances of SUDEP enables physicians and family members to identify high-risk situations
- SUDEP cases largely live alone, die unwitnessed at home at night in bed, in the prone position, and with indication of a preceding seizure
- To be feasible, SUDEP prevention strategies should not rely on the presence of another person at the time of the event
- SUDEP seasonality is different from sudden infant death syndrome, and week-day and diurnal patterns differ from sudden cardiac death

2.3 | SUDEP definition and classification

SUDEP is defined as a sudden, unexpected, witnessed or unwitnessed, nontraumatic, and nondrowning death of patients with epilepsy with or without evidence of a seizure, excluding documented status epilepticus, and in whom postmortem examination does not reveal a structural or toxicological cause for death.²⁰ We classified our SUDEP cases according to Annegers' criteria.²¹ This classification was selected to facilitate comparison since it has been used in most previous studies. SUDEP cases were divided into 3 subgroups on the basis of the certainty of the diagnosis: (1) definite SUDEP when all clinical criteria are met, and an autopsy is performed that revealed no alternative cause of death; (2) probable SUDEP when all clinical criteria are met, but no autopsy is performed; and (3) possible SUDEP, when SUDEP could not be ruled out, but there is insufficient evidence regarding the circumstances of the death and no autopsy is performed.²¹

2.4 | SUDEP identification of and information from patient records

All 3166 death certificates were reviewed by 1 neurologist (OS). Obvious non-SUDEP deaths such as cancer, terminal illness, postmortem confirmed pneumonia, stroke, or myocardial infarction were excluded from further analysis based on the information in the death certificates (Figure 1). This process considered all information on the death certificate, postmortem results, and whether the patient died in hospital. When SUDEP could possibly be the cause of death ($n = 1373$), patient records from family physicians, hospital records, nursing homes or other institutions, police records, and autopsy records were reviewed (OS) and all information was extracted by a standardized protocol. Emphasis was on attaining the doctor's and/or police report



*167 definite, 89 probable and 73 possible according to the Annegers' classification

FIGURE 1 Flow chart describing the selection process

regarding circumstances surrounding the death, including documented interviews with eyewitnesses, caregivers, and relatives. All obvious non-SUDEP cases were discarded. Remaining potential SUDEP cases were reviewed by 2 neurologists (OS and TT), and classification of the cases was made through consensus. A forensic pathologist was consulted in 29 cases where autopsy reports were difficult to interpret in relation to SUDEP criteria.

Information from all 329 SUDEP cases regarding circumstances (witnessed or not, seizure in conjunction with death, or indirect signs indicating seizure), time of day, time of week, time of year, location (at home and where, outside of home or in hospital), living conditions (living alone, with others, sharing a bedroom), and body position when found dead was extracted from patient records from family physicians, hospital records, nursing homes or other institutions, police records, and autopsy records. We classified the time of death into the following 3 diurnal

categories: Night (00.00-08.00), Day (08.00-16.00), Evening (16.00-00.00). In a few cases ($n = 17$) only the day of death, but not time, could be determined.

We classified deaths during June, July, and August as occurring in summer and during all other months as the rest of the year. Nonworking days were all weekend days, plus all public holidays. Working days were all other. Cases that were observed from a healthy state until dead were considered witnessed. Body position was defined as: prone, supine, sitting, lateral (on the side), or unknown.

2.5 | Autopsied non-SUDEP group

Obvious non-SUDEP deaths ($n = 1793$) such as cancer, terminal illness, postmortem confirmed pneumonia, stroke, or myocardial infarction were excluded from further analysis based on the information in the death certificates. Thereafter we excluded 921 deceased patients after

reviewing death certificates, patient, and autopsy records (Figure 1). During this selection process, there were 60 cases with an initial suspicion of SUDEP, but for which autopsy records revealed another definite cause of death. These autopsied non-SUDEP cases served as references for comparison with our 167 definite SUDEP cases who also had undergone an autopsy.

2.6 | Statistics

P-values for mean differences were calculated from the 2-sided *t* distribution. The chi-square distribution was used to calculate *P*-values for comparison of proportions and incidences. Incidence was calculated as number of SUDEP cases per calendar month, weekday, and working day, respectively, divided by the number of person-years. Person-years were calculated as the sum of all days for each individual during the follow-up period in the respective calendar month, weekday, and working day divided by 365. Confidence intervals were constructed by the exact method according to Garwood.²² SAS software (SAS software, Version [9.4] of the SAS System for [MS Windows]; SAS Institute Inc., Cary, NC, USA) was used for all statistical calculations.

3 | RESULTS

3.1 | Demographics

Demographic data for the deaths in the study population, including SUDEP cases and the 60 autopsied non-SUDEP deaths, are summarized in Table 1. There were 329 SUDEPs (63% men) of which 167 were definite, 89 probable, and 73 possible. Probable (59.6 years) and possible (63.6 years) cases were significantly older than the definite cases (40.6 years) ($P < .001$). SUDEP cases were younger at death (50.8 years) compared to the non-SUDEP deaths (73.3 years, $n = 8947$) in the study population ($P < .001$) and consisted of significantly more men (63% vs 55%, $P = .0079$). The definite SUDEP cases were younger (40.6 years) than the autopsied non-SUDEP reference-group (58.9 years) ($P < .001$). The causes of death in the autopsied non-SUDEP reference group, where myocardial infarction was the most common cause ($n = 21$, 35%) are presented in Table S1.

3.2 | Time of death

In 58% of cases, SUDEPs occurred at night (Table 2). Incidence of SUDEP over weekdays and months is presented in Figure 2. For definite and probable SUDEP cases, there was a nonsignificant trend for higher incidence during the summer months compared with rest of the year; 0.96 vs

TABLE 1 Demographic data for all non-SUDEP deaths in the study population, the SUDEP cohort, and autopsied non-SUDEP reference cases

	Sex		Age at death	
	Men (%)	Women (%)	Average (years)	Median (years)
Non-SUDEP deaths ($n = 9276$)	5150 (55)	4126 (45)	73.3	77.5
SUDEP ($n = 329$)	207 (63)	122 (37)	50.8	53.6
Definite ($n = 167$)	103 (62)	64 (38)	40.6	43.3
Probable ($n = 89$)	52 (58)	37 (42)	59.6	60.7
Possible ($n = 73$)	52 (71)	21 (29)	63.6	69.1
Non-SUDEP deaths with autopsy ($n = 60$)	41 (68)	19 (32)	58.0	60.9

0.79 per 1000 person-years ($P = .86$) and on nonworking days, compared with working days, 0.94 vs 0.79 per 1000 person-years ($P = .19$) (Figure 2). The definite SUDEP cases died more often during the night (59%) than the autopsied non-SUDEP reference-group (22%).

3.3 | Place of death

Ninety-one percent of SUDEP cases died at home (Table 2) and among these, 65% were found dead in bed. No SUDEP death occurred at a workplace. Among the autopsied non-SUDEP patients, 43% died at home, while 53% died in hospital (with the majority admitted acutely to the hospital from home). The definite SUDEP cases died more often at home (89%) than the autopsied non-SUDEP reference patients (43%).

3.4 | Witnessed

In 17% of all 329 SUDEP cases, the death was witnessed and in 88% of these cases, a seizure was observed before death (Table 2). All witnessed seizures before death were generalized tonic-clonic seizures. In 7%, no seizure was observed and in 3 cases (5%) this was uncertain. In 67% there was either a witnessed seizure ($n = 49$) or indirect indications of seizures ($n = 171$), which were bitten tongue ($n = 89$), incontinence ($n = 57$), posturing consistent with a seizure ($n = 35$), secretions/blood/froth ($n = 76$), documented interpretation of the doctor at the death scene ($n = 67$), or of the coroner ($n = 103$). Most often it was a combination of the above-mentioned factors. Living with someone made it more likely that the SUDEP was witnessed ($P = .032$) (Table S2). SUDEP occurring during the night was associated with not being witnessed ($P = .013$)

TABLE 2 Circumstances of death and living conditions among SUDEP cases and autopsied non-SUDEP reference cases

Circumstances	SUDEP			Autopsied		P-value ^a
	All (n = 329)	Possible (n = 73)	Probable (n = 89)	Definite SUDEP (n = 167)	Non-SUDEP deaths with autopsy (n = 60)	
Time of death, n (%) ^b						
Night	190 (58)	39 (53)	53 (60)	98 (59)	13 (22)	<.001
Day	67 (20)	17 (23)	16 (18)	34 (20)	27 (45)	
Evening	55 (17)	14 (19)	18 (20)	23 (14)	20 (33)	
Undefined ^c	17 (5)	3 (4)	2 (2)	12 (7)	0 (0)	
Location at time of death, n (%)						
Home ^d	299 (91)	64 (88)	87 (98)	148 (89)	26 (43)	<0.001
Elsewhere ^e	19 (6)	1 (1)	1 (1)	17 (10)	2 (3)	
Hospital ^f	11 (3)	8 (11)	1 (1)	2 (1)	32 (53)	
Specific location at home, n (%)						
In bed ^g	195 (65)	41 (64)	51 (57)	103 (70)	16 (62)	.020
Bathroom	29 (10)	2 (3)	10 (11)	19 (13)	0 (0)	
Elsewhere inside home	75 (25)	21 (33)	28 (31)	26 (18)	10 (38)	
Witnessed, n (%)						
Yes	56 (17)	9 (12)	26 (29)	21 (13)	40 (67)	<.001
No	273 (83)	64 (88)	63 (71)	146 (87)	20 (33)	
Seizure in witnessed cases, n (%)						
Yes	49 (88)	6 (67)	23 (88)	20 (95)	8 (21)	<.001
No	4 (7)	2 (22)	2 (8)	0 (0)	31 (80)	
Unknown	3 (5)	1 (11)	1 (4)	1 (5)	0 (0)	
Documented body position, n (%)						
Prone	100 (70)	6 (33)	14 (52)	80 (82)	6 (16)	<.001
Supine	18 (13)	4 (22)	4 (15)	10 (10)	28 (76)	
Sitting	13 (9)	4 (22)	6 (22)	3 (3)	1 (3)	
Lateral	12 (8)	4 (22)	3 (11)	5 (5)	2 (5)	
Living conditions, n (%)						
Alone	233 (71)	58 (80)	66 (74)	109 (65)	31 (52)	<.001
Not alone	96 (29)	15 (20)	23 (26)	58 (35)	29 (48)	
With partner	43 (13)	9 (12)	17 (19)	17 (10)	24 (40)	
With parents/child/siblings	53 (16)	6 (8)	6 (7)	41 (25)	5 (8)	
Sharing a bedroom, n (%) ^h						
Yes	47 (14)	9 (12)	21 (24)	16 (10)	27 (45)	<.001
No	280 (85)	63 (86)	67 (75)	149 (89)	33 (55)	

^aComparison between definite SUDEP cases and non-SUDEP deaths with autopsy.

^bNight (00.00-08.00), day (08.00-16.00), evening (16.00-00.00).

^cDay of death known, but not time of day.

^dCould also include people living permanently in their own apartment in group homes.

^eNot at home or in hospital. There were 11 individuals who died elsewhere inside and 8 that died elsewhere outside. Nobody died at their workplace.

^fThe 11 patients were admitted to hospital for the following reasons: (4 seizures, 2 infections, 2 rehabilitations after fractures, 1 psychiatric worsening, 1 abdominal pain, 1 plastic surgery).

^gCould also be found lying next to the bed.

^hUnknown in 2 cases (1 probable and 1 possible).

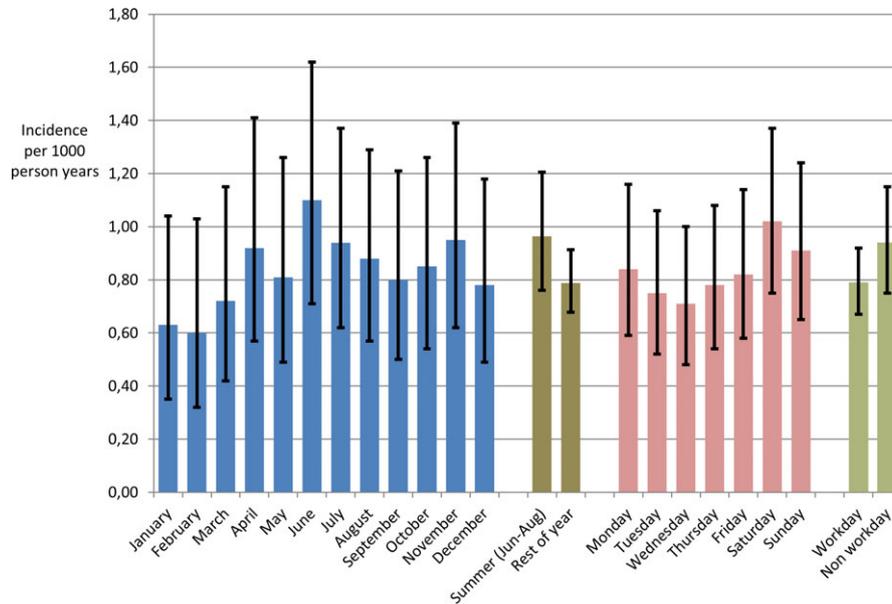


FIGURE 2 Incidence and 95% confidence interval (CI) of SUDEP across weekdays and time of year in definite and probable cases

(Table S3). Definite SUDEP cases were less often witnessed (13%) than the autopsied non-SUDEP deaths (67%). When witnessed, the definite SUDEP patients (95%) more often had a seizure before death than the autopsied non-SUDEP group (21%) (Table 2).

3.5 | Body position

Body position was documented in 43% of SUDEPs and among those, 70% were found prone (Table 2). The body position was documented in 59% of the definite cases but only in 30% and 25% of the probable and possible groups, respectively. In the definite SUDEP group, 82% were found prone. Among those who died during the night, 80% were found prone vs 55% among those who died at other times ($P < .001$) (Figure 3). Among the autopsied non-SUDEPs, body position was known in 62%. Definite SUDEP cases were more often found in a prone position (82%) than the autopsied non-SUDEP reference group (16%) (Table 2).

3.6 | Living conditions

Over two-thirds (71%) of SUDEP cases were living alone (Table 2). Among adults (>16 years), 75% were living alone. Under 16 years, 6 (23%) SUDEP cases (aged 11-15 years) were classified as living alone since they were living in their own apartment within a group home. Only 14% of all SUDEP cases shared a bedroom (Table 2). Definite SUDEP patients lived alone more often (65%) than the autopsied non-SUDEP patients (52%) and shared a bedroom less often (10% vs 45%) (Table 2).

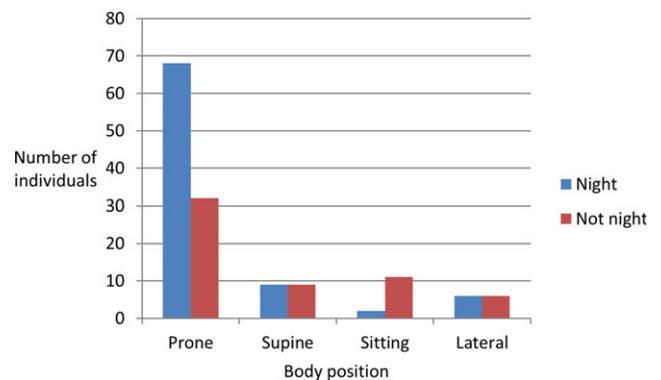


FIGURE 3 Documented body position in SUDEP cases by time of death

4 | DISCUSSION

This population-based nationwide study shows that SUDEP victims largely live alone, die at home unobserved in bed at night, and are found in the prone position and in most cases with indication of a preceding seizure. These circumstances were all more prevalent among our SUDEP cases compared with the non-SUDEP death reference-group and indicate a key role of unwitnessed seizures in the occurrence of SUDEP. This fits well with a previous case-control study reporting lack of nighttime supervision as an important risk factor.²³

In search of better understanding of SUDEP pathophysiology and preventive interventions, similarities between SUDEP and SIDS and sudden cardiac deaths have been discussed.⁴ In this context, our findings on the seasonality of SUDEP are of value. Although SIDS and sudden cardiac

death have a higher incidence in winter,^{24–26} this was not the case for SUDEP. A previous UK study, relying on death certificates for SUDEP diagnosis, also found no increase in winter.²⁷ Furthermore, we did not find a preponderance for Mondays and morning hours as reported for sudden cardiac death.²⁴ On the other hand, we found a clear diurnal variation, with the majority dying during night hours, as has been reported before.¹⁴ Taken together, the observed seasonality supports the view that underlying mechanisms in SUDEP are different from those of SIDS and sudden cardiac death.

Given that most cases of SUDEP occurred at home and during nighttime, it is not surprising that only a small fraction were witnessed, well in line with previous observations.²⁸ When witnessed there was a preceding seizure in most of our cases and all were tonic–clonic seizures. Among the witnessed definite SUDEP patients, a tonic–clonic seizure was present in 95% of cases compared to 21% in the autopsied non-SUDEP reference group, strengthening the notion that SUDEP in most cases is a seizure-related event. Even though most of witnessed deaths involved a preceding tonic–clonic seizure, there were 5 cases where this did not occur. This has been reported before in a few cases, suggesting a heterogeneous pathophysiology of SUDEP.²⁹ Living with someone made it more likely that SUDEP was witnessed and nighttime SUDEP made it less likely. The autopsied non-SUDEP reference cases more often lived with someone else and their deaths were more often witnessed than definite SUDEP cases were. Other studies^{14,30–32} have also reported that a large proportion of SUDEP cases occur at home in bed, but these studies are often lacking in information regarding whether the victims lived alone or shared a bedroom.

As in previous studies,^{12,13,15,33} the deceased was found in the prone position in most of cases. The prone position was also more prevalent among SUDEP cases that died at night compared to other times of the day (Figure 3). Definite SUDEP cases were more often found prone than the autopsied non-SUDEP reference group. It has been suggested that prone position may facilitate SUDEP by compromising postictal ventilation.³³ Referring to the public campaigns promoting supine sleeping position of infants and their success in reducing the incidence of SIDS,³⁴ similar actions have been proposed to prevent SUDEP.^{33,35} Video recordings of SUDEP cases in the MORTality in Epilepsy Monitoring Units Study (MORTEMUS) study indicate, however, that many of the SUDEP victims shifted position to prone as a manifestation of the fatal seizure.³⁶ The high prevalence of terminal prone position in SUDEP may thus be a consequence of the seizure rather than a reflection of sleeping patterns. The final body position may nevertheless contribute to the fatal outcome. It has been suggested that simple interventions such as shifting the patient position and stimulation after the seizure could

reduce the SUDEP risk,^{23,37} and that this can be a mechanism explaining the protective effect of supervision.

4.1 | Strengths and limitations

The strengths of our study rest in the size of the case-series, the population-based, nationwide design, and the standardized validation of SUDEP cases with a comparatively high proportion of definite cases. It is therefore likely that the results are representative for other countries with similar socioeconomic standards and healthcare systems. In addition, we have a small selected reference group of epilepsy patients from our study population with other confirmed causes of death for comparison, which showed clearly that the definite SUDEP cases died under circumstances other than those in the non-SUDEP reference group. Although the observed circumstances of SUDEP in our current study are intriguing, our results should not be considered as evidence that these circumstances constitute risk factors for SUDEP. We cannot exclude that the described living conditions reflect the general situation for people with refractory epilepsy, an established SUDEP risk factor.^{4,5} This can be clarified in a case-control study where seizure control as well as living conditions are compared between SUDEP cases and living epilepsy controls. We are in the process of conducting such a study.

5 | CONCLUSIONS

Our results demonstrating that the general SUDEP victim lives alone and dies at home in bed unwitnessed during night hours, highlight the difficulties in implementing preventive efforts that require immediate availability of another person to identify a seizure, to interact and correct body position, or to give pharmacological emergency treatment. These obstacles need to be considered when strategies for SUDEP prevention are being developed.

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The study was supported by Stockholm County Council. There was no industry sponsorship for this study. All authors contributed to study design, analysis, and interpretation of data. OS was responsible for collecting data and OS and TT for review of SUDEP case data. TA was responsible for the statistical analysis. All authors contributed to the writing of the manuscript.

DISCLOSURE OF CONFLICT OF INTEREST

SC and TA have no conflicts of interest to report. OS has received grants from GlaxoSmithKline, personal fees from

Biogen, honoraria to his institution from Biogen and UCB for lectures and advisory board, outside the submitted work. TT is associate editor of *Epileptic Disorders*; he has received speaker's honoraria to his institution from Liva-nova, Eisai, UCB, and BMJ India; honoraria to his institu-tion for advisory boards from UCB and Eisai; and received research support from Stockholm County Council, CURE, GSK, Bial, UCB, Novartis, and Eisai. We confirm that we have read the Journal's position on issues involved in ethi-cal publication and affirm that this report is consistent with those guidelines.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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