Trends in epilepsy admissions in children, 1981–2013: population-based observational study using the Scottish national hospital discharge database

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ABSTRACT

Objective To examine trends in epilepsy admissions in children from 1981 to 2013.

Design Repeated cross-sectional, population-based study.

Setting Scotland.

Patients We identified admissions among children between 1981 and 2013 inclusive. Epilepsy admissions were identified from the Scottish national hospital discharge database by using relevant diagnostic codes. Primary epilepsy admissions (PEAs) were those with epilepsy as the primary discharge diagnosis, or convulsions as the primary diagnosis but with epilepsy as secondary diagnosis. All other epilepsy admissions were secondary epilepsy admissions (SEAs).

Main outcome measures Trends in annual epilepsy and non-epilepsy admission rates, as well as sociodemographic, clinical characteristics, length of stay and readmissions of epilepsy admissions.

Results 57 031 epilepsy and 3 863 809 non-epilepsy admissions were available for analysis. Overall, epilepsy and non-epilepsy admissions increased, with a greater increase in epilepsy admissions (interaction \( X^2 \) test statistic 252, \( p<0.0001 \)). Elective epilepsy admissions, unlike elective non-epilepsy admissions, continually increased, but emergency epilepsy admissions increased until 2000 and showed only minor fluctuations thereafter. Increase in SEAs was more marked than PEAs (interaction \( X^2 \) test statistic 627, \( p<0.0001 \)). 48% of epilepsy admissions were to children’s hospitals. No substantial trends were apparent in age, gender or deprivation distribution of epilepsy admissions. There was a clear trend towards shorter length of stay.

Conclusions Childhood epilepsy admissions are increasing, at a faster rate than non-epilepsy admissions, and have changed towards shorter, more elective admissions. Many will not be to children’s hospitals, and the primary reason will often not be because of epilepsy/convulsions. More, not less, epilepsy resources are needed.

INTRODUCTION

The care of children with chronic illness in the UK requires improvement. Outcomes, while improving over time, are relatively poor compared with those achieved in other countries, with timely access to specialist care a particular challenge.1–3 Within this context, the management of children with epilepsy (CWE) warrants attention. CWE require coordinated inpatient, outpatient and community-based care.4 Admissions may be required for planned diagnostic or therapeutic interventions, or for urgent management of their epilepsy or comorbid conditions present in up to 80%.5 Understanding trends and characteristics of hospital admissions for CWE would facilitate resource allocation and service planning. Published studies on admissions for CWE are uncommon.6 7

What is already known on this topic?

► The epilepsy admission rate in England for adults and children combined declined between 2004 and 2010.
► Published studies on trends in epilepsy admissions in children alone are uncommon.
► There is no previous UK study on epilepsy admissions in children.

What this study adds?

► Despite decreasing incidence of childhood epilepsy, epilepsy admission rates in children have increased; the increase is greater than the increase in admissions for any cause.
► Elective epilepsy admissions in children, unlike elective non-epilepsy admissions, have continually increased, but emergency admissions increased until 2000 and showed only minor fluctuations since.
► Increase in epilepsy admission rates has been particularly marked where a comorbid health condition, rather than epilepsy, is the primary admission cause.
2. Sociodemographic and clinical characteristics of epilepsy admissions.
3. Length of stay and readmission of epilepsy admissions.
   Each was considered separately for emergency and elective admissions to identify divergent trends.

**METHODS**

Admissions of children (0–17 years inclusive) from 1981 to 2013 were identified using Scotland’s national hospital discharge database (Scottish Morbidity Record 01 (SMR01)).

SMR01 records episodes of day-case or inpatient care in Scottish National Health Service (NHS) hospitals except if they were provided in neonatal, maternity or psychiatric settings. An ‘episode’ of care ends when a patient is transferred between consultants, specialties or hospitals, is discharged home, or dies. Episodes relating to the same continuous hospital stay are linked together to provide complete admission records. SMR01 data were obtained from the NHS National Services Scotland Information Services Division (ISD). Non-Scottish residents were excluded. Scottish National Forensic Mental Health Facility residents were excluded due to disclosure sensitivities.

SMR01 includes demographics, care details, and coded information on patients’ diagnoses and any procedures. Primary and up to five secondary diagnoses are recorded using the International Classification of Diseases and Related Health Problems (ICD) codes (ICD9 to 1996, ICD10 thereafter). Primary diagnosis is ‘the condition, diagnosed at the end of the episode of health care, primarily responsible for the patient’s need for treatment or investigation’. Secondary diagnoses are ‘those conditions that co-exist or develop during the episode of healthcare and affect the management of the patient’.

SMR01 records are subject to validation at submission to the ISD. The ISD also undertakes periodic data quality assurance. The accuracy of primary diagnosis ICD coding of a random sample of 3345 records in 2014/2015 was 89% at a three-digit ICD10 level. The diagnostic accuracy at a three-digit level for ICD10 code in a ‘booster’ sample of 135 epilepsy/convulsions records was 94% and 97% for records with an epilepsy code as primary and secondary diagnoses, respectively.

Definitions of admission characteristics derived from SMR01 are provided in table 1.

**Statistics**

Throughout, the magnitudes of effect were also considered since the very large sample size means statistical significance alone is insufficient to indicate a clinically important effect. There was no imputation of missing data because given the data source, these were expected to be rare.

**Aim 1**

We used midyear population estimates to calculate crude annual admission rates for epilepsy admissions, those with epilepsy as a primary (primary epilepsy admission, PEA) or, separately, a secondary (secondary epilepsy admission, SEA) diagnosis, and non-epilepsy admissions. Emergency and elective admissions were examined separately for each type.

Trends in admission rates were examined using crude and adjusted admission rate ratios (aARRs). The reference year was 2000, as the national guidance on recording of comorbidities in SMR01 (likely to influence the number of SEAs) was issued in mid-1999; it reinforced that chronic comorbidities should be recorded on inpatient and day-case records. This was strengthened in 2007. aARRs were derived using negative binomial regression incorporating an offset term for midyear population and adjusting for age, sex and socioeconomic deprivation. Linear trends in admission rates were also examined with pairwise interactions between year, admission type (emergency/elective) and diagnosis position (primary/secondary) to assess differential trends.

**Aim 2**

The characteristics of epilepsy versus non-epilepsy admissions were compared using χ² test. We examined the age, sex,
Table 2  Characteristics of primary, secondary or any epilepsy admissions, and those with non-epilepsy admissions over all years, 1981–2013

|                        | Primary epilepsy admissions | Secondary epilepsy admissions | Any epilepsy admissions | Non-epilepsy admissions | Epilepsy vs non-epilepsy admissions |
|------------------------|-----------------------------|-------------------------------|------------------------|-------------------------|-------------------------------------|
|                        | n (%)                       | n (%)                         | n (%)                  | n (%)                   | χ² | P values |
| Admissions             | 33 079 (100)                | 23 952 (100)                  | 57 031 (100)           | 3 863 809 (100)        |    |          |
| Sex                    |                             |                               |                        |                         |    |          |
| Male                   | 17 672 (53.4)               | 12 876 (53.8)                 | 30 548 (53.6)          | 2 177 775 (56.4)       | 179.1 | <0.0001  |
| Female                 | 15 407 (46.6)               | 11 076 (46.2)                 | 26 483 (46.4)          | 1 686 028 (43.6)       |    |          |
| Unknown                | 0 (0.0)                     | 0 (0.0)                       | 0 (0.0)                | 6 (0.0)                |    |          |
| Age group              |                             |                               |                        |                         |    |          |
| <1 year                | 2218 (6.7)                  | 1011 (4.2)                    | 3229 (5.7)             | 500 626 (12.9)         | 3867.8 | <0.0001  |
| 1–4 years              | 8633 (26.1)                 | 5928 (24.7)                   | 14 561 (25.5)          | 1 087 078 (28.1)       |    |          |
| 5–9 years              | 9109 (27.5)                 | 6730 (28.1)                   | 15 839 (27.8)          | 938 379 (24.3)         |    |          |
| 10–14 years            | 8165 (24.7)                 | 6654 (27.8)                   | 14 819 (25.9)          | 760 958 (19.7)         |    |          |
| 15+ years              | 4954 (14.9)                 | 3629 (15.1)                   | 8583 (15.0)            | 576 768 (14.9)         |    |          |
| Carstairs              |                             |                               |                        |                         |    |          |
| Least deprived Q1      | 5526 (16.7)                 | 3741 (15.6)                   | 9267 (16.2)            | 638 334 (16.5)         | 74.1 | <0.0001  |
| Q2                    | 5687 (17.2)                 | 4132 (17.2)                   | 9819 (17.2)            | 659 844 (17.1)         |    |          |
| Q3                    | 6401 (19.3)                 | 4725 (19.7)                   | 11 126 (19.5)          | 733 946 (19.0)         |    |          |
| Q4                    | 7285 (22.0)                 | 5315 (22.2)                   | 12 600 (22.1)          | 802 365 (20.8)         |    |          |
| Most deprived Q5       | 7607 (23.0)                 | 5871 (24.5)                   | 13 478 (23.6)          | 948 893 (24.6)         |    |          |
| Unknown                | 573 (1.7)                   | 168 (0.7)                     | 741 (1.3)              | 80 427 (2.1)           |    |          |
| Children's hospital    |                             |                               |                        |                         |    |          |
| No                     | 18 685 (56.5)               | 11 217 (46.8)                 | 29 902 (52.4)          | 2 571 735 (66.6)       | 5025.0 | <0.0001  |
| Yes                    | 14 394 (43.5)               | 12 735 (53.2)                 | 27 129 (47.6)          | 1 292 074 (33.4)       |    |          |
| Admission              |                             |                               |                        |                         |    |          |
| Emergency              | 25 715 (77.7)               | 13 397 (55.9)                 | 39 112 (68.6)          | 2 094 007 (54.2)       | 7043.6 | <0.0001  |
| Elective               | 5580 (16.9)                 | 6359 (26.5)                   | 11 947 (20.9)          | 794 287 (20.6)         |    |          |
| Day case               | 1776 (5.4)                  | 4196 (17.5)                   | 5972 (10.5)            | 975 515 (25.2)         |    |          |
| Length of stay (days)  |                             |                               |                        |                         |    |          |
| 0                      | 6223 (18.8)                 | 6227 (26.0)                   | 12 450 (21.8)          | 1 422 965 (36.8)       | 9300.0 | <0.0001  |
| 1                      | 10 575 (31.9)               | 5213 (21.8)                   | 15 788 (27.7)          | 924 998 (23.9)         |    |          |
| 2–6                    | 11 736 (35.5)               | 8361 (34.9)                   | 20 097 (35.2)          | 1 240 170 (32.1)       |    |          |
| 7–10                   | 2131 (6.4)                  | 1797 (7.5)                    | 3928 (6.9)             | 141 550 (3.7)          |    |          |
| ≥11                    | 2414 (7.3)                  | 2354 (9.8)                    | 4768 (8.4)             | 134 126 (3.5)          |    |          |
| Median (Q1–Q3)         | 1 (1–4) days                | 2 (0–4) days                  | 2 (1–4) days           | 1 (0–2) days           |    |          |
| 1st, 99th percentile   | 0, 39 days                  | 0, 50 days                    | 0, 44 days             | 0, 23 days             |    |          |
| Death during admission |                             |                               |                        |                         |    |          |
| Yes                    | 55 (0.2)                    | 184 (0.8)                     | 239 (0.4)              | 6116 (0.2)             | 236.2 | <0.0001  |

deprivation and hospital type distribution of emergency and elective epilepsy admissions using stacked bar charts. We also calculated the proportion of epilepsy admissions from 2000 onwards with a comorbidity recorded (online supplementary table S1). Trends in these characteristics were formally examined using logistic or robust linear regression models with interaction terms as above.

**Aim 3**

We examined the length of stay distribution of epilepsy admissions using stacked bar charts. We calculated the proportion of epilepsy admissions from 2000 onwards readmitted in the same or subsequent month. Trends were examined using regression models as above.

**RESULTS**

Among 3 920 840 admissions, 57 031 (1.5%) were epilepsy admissions; 0.8% were PEAs and 0.6% SEAs. Epilepsy were more likely than non-epilepsy admissions to be older, to a children’s hospital, to be an emergency admission and have longer length of stay (table 2).

Crude epilepsy admission rate was 93/100 000 (95% CI 88 to 98) in 1981 and 216/100 000 (95% CI 207 to 225) in 2013. Crude non-epilepsy admission rate was 8001/100 000 (95% CI 7954 to 8049) in 1981 and 10 990/100 000 (95% CI 10927 to 11054) in 2013 (online supplementary figure S1). aARRs are shown in figure 1. Overall, both emergency and elective epilepsy and non-epilepsy admissions increased over time, with a greater increase in epilepsy compared with non-epilepsy admissions (interaction Χ² test statistic 252, p<0.0001). The overall increase in emergency admissions for both epilepsy and non-epilepsy admissions was due to increase pre-2000, with minor fluctuations after (figure 1). By contrast, elective epilepsy admissions showed a continual increase while non-epilepsy admissions showed modest increase pre-2000, then no change.

Considering epilepsy admissions specifically, the increase in emergency and elective admission rates was more marked for
Sociodemographic and clinical characteristics of epilepsy admissions

There were no substantial trends in age (mean reduction of 0.04 years per annum, 95% CI 0.03 to 0.05), socioeconomic deprivation (mean reduction in quintile of 0.008 per annum, 95% CI 0.006 to 0.009) or sex (OR 0.998 per annum for female admissions, 95% CI 0.996 to 1.000) distribution (online supplementary figure S2).

Of 57,031 epilepsy admissions over the study period, 27,129 (48%) were to children’s hospitals (table 2). There was an increasing odds of admission to a children’s hospital (OR 1.08 per annum, 95% CI 1.08 to 1.09), with greater effect for elective admissions (interaction OR 0.94 per annum, 95% CI 0.93 to 0.94) (figure 2 and online supplementary figure S2).

53% of emergency and 69% of elective epilepsy admissions from 2000 to 2013 had comorbidity (table 3). The proportion of epilepsy admissions with comorbidity increased moderately (OR 1.026 per annum for any comorbidity, 95% CI 1.019 to 1.032; online supplementary figure S3).
TABLE 3  Number of admissions with comorbidity, a readmission (within 1 month), with any, primary or secondary diagnosis of epilepsy by admission type for years 2000–2013

| Comorbidities                      | Emergency | Proportion (95% CI) | Elective | Proportion (95% CI) |
|------------------------------------|-----------|--------------------|----------|--------------------|
| **Any epilepsy admission**         |           |                    |          |                    |
| Comorbidities                      |           |                    |          |                    |
| Neurological                       | 8200/18564| 44.2 (43.5 to 44.9) | 5793/9700| 59.7 (58.7 to 60.7) |
| Respiratory/gastrointestinal/cancer| 4013/18564| 21.6 (21.0 to 22.2) | 2509/9700| 25.9 (25.0 to 26.8) |
| Any                                | 9883/18564| 53.2 (52.5 to 54.0) | 6669/9700| 69.1 (68.1 to 70.0) |
| Readmissions                       | 7305/18334| 39.8 (39.1 to 40.6) | 3051/9635| 31.7 (30.7 to 32.6) |
| **Primary epilepsy admission**     |           |                    |          |                    |
| Comorbidities                      |           |                    |          |                    |
| Neurological                       | 3428/10814| 31.7 (30.8 to 32.6) | 1067/3046| 35.0 (33.4 to 36.7) |
| Respiratory/gastrointestinal/cancer| 1328/10814| 12.3 (11.7 to 12.9) | 351/3046 | 11.5 (10.4 to 12.7) |
| Any                                | 4095/10814| 37.9 (36.9 to 38.8) | 1236/3046| 40.6 (38.9 to 42.3) |
| Readmissions                       | 3967/10733| 37.0 (36.1 to 37.9) | 826/3020 | 27.4 (25.8 to 29.0) |
| **Secondary epilepsy admission**   |           |                    |          |                    |
| Comorbidities                      |           |                    |          |                    |
| Neurological                       | 4772/7750 | 61.7 (60.5 to 62.7) | 4726/6654| 71.0 (69.9 to 72.1) |
| Respiratory/gastrointestinal/cancer| 2685/7750 | 34.7 (33.5 to 35.7) | 2158/6654| 32.4 (31.3 to 33.6) |
| Any                                | 5788/7750 | 74.7 (73.7 to 75.6) | 5462/6654| 82.1 (81.2 to 83.0) |
| Readmissions                       | 3338/7601 | 43.9 (42.8 to 45.0) | 2225/6615| 33.6 (32.5 to 34.8) |

Length of stay and readmissions of epilepsy admissions

Over the 33-year study period, there was a 2.3-day (95% CI 2.2 to 2.4) reduction in mean length of stay, with no substantial difference between emergency and elective admissions (interaction 0.5, 95% CI 0.4 to 0.6).

Between 2000 and 2013, there were 27 969 epilepsy admissions of which 37% had readmissions (table 3). Readmission rates were higher for emergency compared with elective admissions (OR 1.56, 95% CI 1.48 to 1.65), and for SEAs compared with PEsas (OR 1.34, 95% CI 1.27 to 1.41) (online supplementary figure S4). Overall there was a small increase in readmission rates over the period (OR 1.02 per annum, 95% CI 1.01 to 1.03).

**DISCUSSION**

In this novel study of trends in epilepsy admissions in children, the following are our principal findings: (1) Despite a decreasing incidence of childhood epilepsy, epilepsy admissions are increasing. (2) This is driven by continual increase in elective but not emergency epilepsy admissions; the increase is not due to an overall systematic shift in elective admissions for any cause. (3) Increase in epilepsy admission rates has been particularly marked where a comorbid health condition, rather than epilepsy, is the primary admission cause. (4) An increasing number of elective epilepsy admissions are to children’s hospitals, but a substantial proportion of emergency and elective epilepsy admissions remains to general hospitals.

Epilepsy admissions in England among adults and children combined showed a lower and decreasing annual admission rate compared with our findings. This may reflect differences in study population ages since higher incidence may result in higher admission rates; epilepsy incidence is a U-shaped curve, with the highest incidence in childhood and the elderly. Alternatively, they may reflect differences in admission practice due to greater challenges in the diagnosis of epilepsy in children. Epilepsy admissions in children in England and Wales in the 1990s showed similar trends to our data, suggesting external validation of our observations. It would be useful to see in future studies whether trends from 2000 onwards are similar to our findings.

Shorter stays of epilepsy admissions, continual increase in elective admissions and increasingly elective admissions being to children’s hospitals may reflect a greater use of short, planned admissions for specialist investigations or procedures. This would reflect what is often seen in our practice with videotelemetry and/or neuroimaging among the more common elective admissions. The levelling off of emergency admission rates for epilepsy from 2000 onwards may be related to improvement in epilepsy services, such as implementation of national epilepsy guidelines, increased availability of epilepsy training for clinicians, appointment of epilepsy specialist nurses (ESNs) and better treatments.

The greater increase over time in secondary rather than primary epilepsy admissions may reflect both improved recording of epilepsy as a secondary diagnosis (when CWE are admitted for intercurrent issues such as injuries or infections, or for management of chronic coexisting conditions/comorbidities). Alternatively, it could be related to increasing clinical complexity/comorbidity of epilepsy admissions.

This study shows paediatricians are likely to be regularly required to be involved in caring for children admitted with or for epilepsy. Despite the shift towards admission to specialist hospitals, many admissions will still be to general hospitals. Thus, more widespread expertise and competency in the management and diagnosis of childhood epilepsy among clinicians, rather than restricted solely to a limited number and/or within children’s hospitals, is needed. This would facilitate adherence to national guidelines and improvement in quality of care of CWE.

**Limitations**

High accuracy and quality of epilepsy coding in SMR01 has been evidenced earlier. Despite this, we may have missed epilepsy admissions where the discharge diagnosis was not ascribed an epilepsy code. Misclassification variation over time may have impacted on results. However, since the accuracy of...
main condition coding within SMR01 has been consistently high (88%) since at least 1992,11 the magnitude of trends indicates they are not entirely due to misclassification. Information on seizure phenotypes, type, number of antiepileptic medication, procedure/operation codes for elective admissions and out-of-hospital deaths was not available to allow us to put our findings in further context. ESNs were appointed over a wide range of dates, with some posts intermittently filled, so we were not able to directly examine their impact.

CONCLUSION

Epilepsy admissions are increasing, at a faster rate than non-epilepsy admissions, and have changed towards shorter, more elective admissions. Many will be of CWE with additional comorbid health conditions, will not be to children’s hospitals and will not be primarily because of epilepsy/convulsions. Clinicians and policy makers should consider these data in the design, commissioning and delivery of childhood epilepsy services; despite the decreasing incidence of childhood epilepsy, arguably more resources rather than less are needed for epilepsy admissions.

Acknowledgements We thank Omotomilola Ajetunmobi for assistance with data collection and preliminary analyses.

Contributors RFMC conceptualised the study, RFMC, CJW and RW designed the study, RFMC, CJW and RW obtained regulatory approvals. JS extracted the data. All authors had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. All authors contributed to the writing of the manuscript and have approved the final version submitted for publication.

Funding The study was funded by the Muir Maxwell Trust. CJW was supported in this work by NHS Lothian via the Edinburgh Clinical Trials Unit. The funders had no role in the study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication.

Competing interests The study was funded by the Muir Maxwell Trust, which has provided financial support to help establish the Muir Maxwell Epilepsy Centre at the University of Edinburgh.

Patient consent Not required.

Ethics approval We obtained governance approval in April 2014 from the Privacy Advisory Committee (PAC 35/13, now the Public Benefit and Privacy Panel)19 (http://www.informationgovernance.scot.nhs.uk/pbbphsc). The East of Scotland Research Ethics Service confirmed in April 2014 ethical approval was not required (C1A/AG/14/0/0047). Analyses were undertaken within the NHS Scotland Safe Haven.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement The data used in this project are controlled by NHS National Services Scotland. Other researchers wishing to access anonymised, patient-level data for research purposes should contact NSS’s research support team, eDRIS (see http://www.isdscotland.org/Products-and-Services/eDRIS/).

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