Exploring epilepsy attendance at the emergency department and interventions which may reduce unnecessary attendances: a scoping review

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Abstract

Background: Repeat attendances to emergency departments for seizures, impacts on the individual and burdens health care systems. We conducted a review to identify implementable measures which improve the management of people with epilepsy reducing healthcare costs and their supportive evidence.

Methods: A scoping review design using suitable search strategy as outlined by PRISMA-ScR was used to examine seven databases: MEDLINE, EMBASE, CINAHL, AMED, PsychINFO, HMIC and BNI. A manual search of the COCHRANE database and citation searching was also conducted. A thematic analysis was conducted to explore the context and reasons of emergency department attendance for seizures, particularly repeat attendances and the strategies and measures deployed to reduce repeat attendances.

Results: Twenty-nine reports were included, comprising of a systematic review, a randomised control study, a multi-method study, quantitative studies (n=17), qualitative studies (n=6), an audit, a survey and a quality improvement project. Thematic analysis identified four broad areas for reducing repeat attendances. These were developing care pathways, conducting care and treatment reviews, providing educational interventions and role of ambulance staff.

Conclusion: The findings indicate varied reasons for attendance at ED following seizure, including mental health and knowledge of seizure management and lack of education. Implementations of care pathways in ED have been found to reduce admission related costs.
Introduction

Epilepsy is a common neurological conditions [1] with a prevalence of 4-10 cases per 1000 persons and an average yearly incidence of 80/100,000 persons [2,3]. Anti-seizure medications (ASMs) are the mainstay epilepsy treatment and there is evidence that they stop seizure in about 70% of people [4]. Across the globe, the World Health Organisation estimates that epilepsy causes 6.4million disability adjusted life years and 1.32 million years of life lost [1]. For people living with epilepsy, it can have significant impacts on daily living such as driving, employment, education, relationships and social participation. Whilst many of these aspects are individually and culturally dependent, they are important in enabling someone to live well with the condition [2]. One in 15 people with epilepsy are dependent on others to manage aspects of their daily living, and a fifth of adults with epilepsy have additional intellectual disabilities [2]. Ensuring people living with epilepsy have access to neurologists and epilepsy specialists; in addition to individualised and effective treatments, optimises health and social outcomes [3].

Seizure freedom rates in the UK are around 50% [5] leading to 40,000 hospital admissions and a further 60,000 attendances at ED within England (ED) [6]. A significant minority are repeat attendees: around one third of them account for 2/3 of the attendances [7,8]. Recommendations in the UK are that people with epilepsy are reviewed yearly by either a general physician or a specialist [3]; However in April 2014 epilepsy was no longer included in quality outcomes frameworks for primary care in the UK thus putting this recommendation at risk of compliance [9]. Significant concerns also exist of poor structure of care leading to epilepsy related pre-mature mortality (10, 11). There is no systematic approach across the UK to support this population to access alternative options to ED attendances.

We identified available reports of the characteristics of people with epilepsy attending EDs and preventative measures employed to reduce repeat attendances to place this problem into context.

Methods

A scoping review using the PRISMA-ScR guidance was conducted to look at evidence available on ED attendances (Supplemental file 1); Firstly, the context of
ED attendance for seizures was explored particularly reasons for repeat attendances. Secondly, current healthcare provision was examined, including measures deployed to reduce repeat attendances (Supplementary file 2).

The six-stage methodological framework was adopted alongside the PRISMA-ScR guidance. That is - Identify the research questions; Identify the relevant studies; Study selection; Charting the date; Collating, summarizing and reporting the results; consultation to inform and validate the study findings (Supplementary file 3). The initial long listing of the suitable reports was done by one of authors (LB). The list was then independently reviewed by two other authors (SL and RS).

Inclusion criteria

1. Reports focusing partly or fully on seizures and EDs
2. Reports focusing partly or fully on seizures and emergency care pathways, including Paramedic and Emergency Medical Services.
3. Reports focusing at least partly on mitigation plans or EDs attendance reduction

Although no formal quality appraisal process was followed, shortlisted studies were selected if broadly satisfying one of the three inclusion criteria. The thematic analysis framework was then applied to the selected reports, by manually grouping of papers under pre identified broad headings to be able to explore the following questions: (LB and SL).

The following questions were explored:

1. How many people attend EDs yearly due to epileptic seizures?
2. How many are repeat attendances?
3. What are the demographics of the attendees?
4. What are the risk characteristics of the attendees?
5. How many are receiving epilepsy specialist care?
6. How many had a specialist review in the previous year?
7. What measures are implementable to reduce repeat attendance and improve care?
A secondary screening search was also undertaken specifically of the Cochrane database with the term ‘epilepsy’ to identify if there were any similar or other significant reviews of interest.

**Results**

The included reports comprised of quantitative (n=17), systematic review (n=1), qualitative (n=6), audit (n=1), survey (n=1), randomised control trial (n=1), multi-method (n=1), quality improvement (n=1). A bespoke document was created to record the full citation details of the reports, study design, data collection methods and results (Table 1).

The Cochrane database search highlighted 163 results of which one were directly relevant to the current study topic.

The thematic analysis provides four broad areas: educational interventions, ambulance staff training, care pathways and care and treatment reviews, with reports originating from the UK, Australia, USA, France and Italy (Figure One).

*The current context of ED attendance for seizures*

Ten reports included information on the context of seizures in the ED; including reasons for repeated attendance and the views of people with epilepsy [6-8, 12-18].

Hospital Episode Statistics (HES) were used in a study which looked to quantify various characteristics involved in the care for a suspected seizure within EDs in England, between 2007 and 2013. It found that 1.5% of all emergency admissions were for neurological conditions of which 47% were for suspected seizure. The average cost of attendance following a suspected seizure was £123, 22% of individuals had more than one admission per year, with a 34% chance of readmission within 6 years [12]. *The National Audit of Seizure management (NASH)[6] report* also examined seizure related attendances in 154 ED’s in the UK: 61% had a prior diagnosis of epilepsy, 12% had other neurological problems and 22% were people with their first seizure. Of the group with epilepsy, 18% were not on therapy and 48% were on monotherapy [6]. An audit similar to NASH conducted in France in 2011-2012 found that 1.6% (n=990) of admissions had a diagnosis of seizure and 59% were people with known epilepsy, of these 13% were admitted twice over the study period, and half were not admitted. It suggested that
emergency services, relatives and patients require educational programs to reduce the attendances at ED’s [13].

Two UK studies prospectively identified characteristics and factors associated with ED attendance using the same design, methodology and questionnaires [7,8]. Both studies found a third of the study population attending ED three or more times and accounting for over two third of the total yearly ED visits many unnecessary. Attendance reasons varied around demographic and clinical factors [14] such as depression [15], anxiety [7] quality of life [8,15-16], seizure frequency [7], lower social deprivation [5,9], stigma [8,15], low levels of medication self-management [8], high seizure frequency [8,16], polytherapy and co-morbidities [7]. Some reports had contrasting findings, with one finding that epilepsy knowledge, medication management and stigma were not concerns in rural areas [7] as suggested by a study in an urban area [8] raising the possibility of possible demographic differences in perceived needs between rural and urban populations.

Reasons for attendance from the perspective of people with epilepsy were assessed in three reports [16-18]. Quality of life in epilepsy-10 inventory as well as direct questions relating to seizure frequency, clinical and cost data were also gathered following an admission to an US hospital. It concluded that seizure frequency and poorer quality of life influences the higher use of health care services [16]. Interviews with people with epilepsy found that reasons for ED attendance were multifactorial including fear, ignorance and misinformation, and isolation. These findings were supported by a recent report of people with epilepsy feeling a sense of disempowerment and loss of autonomy by attending ED [17]. Participants acknowledged that ED use was not necessary but attendance was sometimes out of their control [18]. Quality of life is not only a possible indicator for repeat attendances but also can be impacted by poor seizure control [6]. One report was that attendance was not a sign of substandard epilepsy care but suggested that additional support may be required for this group of people [8]. Another study found that there is considerable geographical variation in admission rates, suggesting possible differences in clinical practice [9].
Care and treatment review

The NASH audit [6] analysed 4544 ED attendances for seizures and found that less than 30% of people were given advice on seizure management and just over half were seen by or referred to a neurology or epilepsy specialist. They also found that just over 1/3 of emergency attendees had seen a specialist in the previous year. It acknowledged that even with under-recording there are a significant proportion of people with established epilepsy who are not under specialist care and suggested that improved access to specialist services would enable individuals to have their management reviewed.

Two recent reports looked specifically at the management in English ED’s [19-20]. Both of these local studies reflect the results in the NASH study [6]. The first report analysed medical records of individuals attending the ED due to a seizure and 74% had an epileptic seizure. Only 61% of them were given follow up advice or a referral [19]. Similarly, the second report, found that only half of those admitted for a seizure were offered a specialist appointment. Of the 65% who had not been under specialist review, including first seizure, only 11% were offered a review within three months and only % offered a review within two weeks [3].

Referral was less likely if the individual was over 75 [20]; data from NASH assessing people admitted by age groups found a downward trend in referral to specialist services group, with 42% in the 60-69 age range being referred compared to less than a quarter in the 80-89 age range. For first seizures there was also a downward trend, with 52% in the 60-69 age range being referred and 25% in the 80-89 age range. A further indication of lack of structured escalation is that NASH found sodium valproate was the most commonly prescribed ASMs which likely reflects outdated practice and recommend the need for improved working between primary care and specialists [21].

A challenge has been nebulous primary care engagement. An example of this was the withdrawal of the quality and Outcome Framework (QOF) in UK primary care without a suitable evaluation. The QOF was an outcome measure to inform payment by results to primary care clinicians to enable management of refractory epilepsy in primary care. This would have possibly supported better collaboration between primary and secondary services [9].
Six reports looked at educational programmes for people living with epilepsy attending EDs [22-27]. One in the USA looked at the delivery of self-management intervention for people with epilepsy and a history of negative health events (SMART) using wide ranging assessment tools. It found that participants who had better SMART attendance had a reduction in negative health events counts (NHE), and seizure frequency, from base line to six month when compared to controls, however, seizure severity was not reduced, and no significance was found when specifically looking at ED attendance [22]. A US quality improvement project looked at the use of educational materials focusing on self-management and seizure first aid, such as educational handouts and a DVD, to see whether they reduced ED attendances. Visits were significantly less frequent following the provision of educational materials but the additional DVD viewing did not affect the outcome [23].

In contrast an UK study looked at the clinical and cost effectiveness of a self-management intervention led by an epilepsy nurse and found it did not lead to a reduction in ED attendance. While no significant effect of the intervention was found at the 12 month follow up on ED attendances an association with reduced inpatient time leading to reduced costs overall was identified by a health economic evaluation. It found that the cost of caring for a participant in the intervention group was £558 less per visit which was attributed to the reduced stay in hospital following ED attendance. This however was not recognised to be statistically significant [24]. An adjunct report also looked at the intervention from the perspective of people with epilepsy finding that the intervention was viewed as acceptable and those reporting the greatest benefit were those who had used the ED the most [25].

A small scale trial (n=32) using an adapted group based seizure managements course involved people with epilepsy, health professional and carers to reduce attendance. It found that there was ‘momentum for such an intervention’ following positive feedback form the participants. This training programme is now being developed further by means of an external pilot randomised controlled trial [26]. A recent systematic review concluded that currently there is limited evidence for the effectiveness of interventions to improve health and quality of life but the specialist epilepsy nurse and self-management education show some evidence of benefit [27].
Ambulance staff

Three of the included reports assessed the role of ambulance staff, within the UK, in managing seizures were qualitative [28-30] with two further quantitative reports [31,32]. Whilst two of the studies included staff across five NHS organizations, the total number of participants for each was small. Paramedics are not expected to transport all people they attend to hospital but to assess, treat and consider non-emergency alternatives where suitable [28]. The most common seizure presentation attended by ambulance is in a person with epilepsy, experiencing an uncomplicated seizure, resulting in ED attendance [29]. Clinical need is not, therefore, the only driver for transportation [30].

There are various factors highlighted across reports which may be useful in reducing people being taken to hospital unnecessarily. Experience rather than training and guidelines seem to guide paramedics’ decisions. They have to balance individual safety and individual choice, such as wanting or not to go to hospital. Other factors such as time pressure also have an impact [30]. The broad themes identified were access to relevant information to guide care and conveyance decisions, perverse incentives to transfer to ED due to time pressure/performance requirements, knowledge gaps and uncertainty about person-centred postictal care and limitations in care pathways. The reports also highlighted that confidence may be an issue due to the limited training on seizure management, particularly for the postictal phase. A further recommendation is that an emergency care plans is always carried by the individual, for example on their smart phone. These interventions have not been tested to see if they have an impact [28]. Paramedics felt there was limited formal training on seizure management pre and post registration with E-learning felt as the most appropriate method of learning [29]. In agreement with this paper was a conclusion from the service evaluation of a new care pathway made available to paramedics within an urban area of the UK. The results found that despite the positive outcome for 55% of referrals to epilepsy nurse specialist, paramedics only referred 9.8% of an eligible 22.5% people, citing that support tools are needed to be developed to enable paramedics to confidently identify people that are suitable for other referrals rather than ED. Results showed that each referral equated to 20 minutes of work for the epilepsy nurse specialist [31].
The audit study (EPIC1) conducted over one selected month analysed 132 calls to an urban 999 services for seizures. This pertained to 124 people with eight having two calls during this time. Details of clinical examinations were assessed with 74% of people being transported to hospital despite a low prevalence of true medical emergencies. Despite this being a small study it was able to give a snapshot. These results further demonstrate the potential for improved and more cost-effective emergency management of suspected seizures [32].

**Care pathways**

Four reports addressed the application of seizure care pathways in the ED. [33-36]. The element of care pathway was included to search for evidence available for alternatives to ED, such as rapid access to specialist services, care pathways to reduce any subsequent hospital admission. The papers were included as it was felt they added to the overall picture.

A care pathway was defined as to improve care and coordination of a service [33] however; expected gains were not apparent [34]. An Irish pathway assessed seizure management incorporating rapid access to a follow-up clinic via the epilepsy nurse specialist. The Hospital In-patient Enquiry data was compared between 2004 and 2009 following the implementation of the seizure care pathway. Overall ED attendance increased by 7.56% (2004 – 2009). However, hospital admissions declined (2.9% to 2.2%) with associated reduction in the length of hospital stay from 4 to 2 days. A seizure care pathway can possibly reduce unnecessary admissions and length of stay, due to early follow-up care and presumably also reduce hospital costs [34]. The sustainability of this pathway, within the Irish ED was investigated four years later and found user rates were low [35]. It was acknowledged the difficulty of implementing a care pathway in a dynamic and pressured environment and the need to identify potential barriers, to enable them to be mitigated. The pathway improved documentation of neurological examinations, witness accounts and the information provided about driving. It also acted as an educational tool for trainee physicians who may not have had much exposure to peoples with epilepsy. Those on the pathway were more likely to be referred for a specialist review in a timelier manner [36].
Pathways have also been implemented in North West England in collaboration with a specialist neurology hospital. An exploration of the care pathway from the point of view of individuals found five main themes. These include decision to seek care, responsiveness of services, waiting and efficiency, information and support, and care continuity. Particular issues were around waiting to be seen in the emergency department, feelings of self-perceived burden, poor coordination, lack of follow-up and the perception that care provided by primary care physicians were not sufficient to meet individual needs. These cumulatively resulted in participants reporting a sense of abandonment, feeling anxious and helpless [33].

**Limitations**

This is a scoping review which aimed to synthesise the evidence available. It is recognised that some notable papers might not have been captured. But, the data collected is informative enough to highlight the size of the problem, answer our aims and provide evidence based insights on how to help overcome it. Further the review process by experts helped identify notable exceptions which were included within the evidence [31,32]. It is recognised that there may be information available within unpublished data designed to reduce attendances at ED. Further, from the studies reviewed much of the evidence available is based on patient self-reporting; this is reliant on memory accuracy and no external influences when completing the assessments. As a critical appraisal of the studies was not undertaken this could have some bearing on the discussion and conclusion of our study.

**Conclusion**

The review set out questions to find evidence for at the beginning of the study. It is now possible to address these to some extent.

The influence of seizures on ED attendances has been found to be significant contributor to attendances at EDs, with increasing numbers being seen as repeated attendances.
The search for evidence for demographics and characteristics of ED attendees found associations with mental ill health (mood and, anxiety), poor quality of life, perceived stigma, social deprivation, lack of knowledge of seizure management and lack of education. Individuals with epilepsy that have attended the ED recognise that this is not always required but that sometimes the decision to take them to hospital is out of their control.

The evidence around standard and nature of care provided suggests that there is lack of coherent pathways for follow up reviews. A high number of people are not being reviewed by a specialist, as recommended in the NICE guidelines [3]. This may contribute to ED attendance and possible reasons for this have not yet been fully explored.

The evidence to reduce repeat attendance to ED and improve care suggests that an intervention incorporating; education, care pathways, specialist review and ambulance staff holistically (figure one) may systematically reduce the need to attend ED following a seizure. Ambulance staff while not a direct influence to ED needs to be considered given their role in shaping a significant number of attendances.

The impact and effect of care on large numbers of people attending EDs has been found to be costly on already stretched health care systems. Thus reducing unnecessary attendances is imperative.

Further research looking at any significance in the demographics, risk characteristics and how follow up procedures can be improved for yearly specialist review non-attendance is needed, together with improved training for ambulance service clinicians. The aim of further research should focus on measures that are implementable to reduce repeat attendances and improve patient care.
References


**Supplementary File 3**

**Flowchart of study selection**

- MEDLINE, (Life Sciences and Biomedical)
- EMBASE (Biomedical)
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- AMED (Allied and Complementary Medicine)
- PsychINFO (Behavioural science and mental health)
- HMIC (The Health Management Information Consortium)
- BNI (British Nursing Index)
- Cochrane database

**Total finds from the separate database searches N = 5170**

**Study selection**

- Title screen n=879
- Abstract screen n = 627
- Full text screen (n = 118)

**Exclusion Criteria**

- Abstract only, unable to obtain, not English, protocol, article related to insurance based health system

**Included (n = 26) and from additional searches (n = 3)**

- Excluded n = 4291
- Duplicates n = 252
- Excluded n = 507
- Excluded n = 94

**The included studies selected comprised of:**

- Quantitative n=15
- Systematic review n=1
- Qualitative n=8
- Audit n=1
- Survey n=1
- RCT n=1
- Multi-method n=1
- Quality improvement n=1

**Collating, summarizing and reporting the results**

- A bespoke word document was created to record the full citation details of the papers, study design, data collection methods and results

- The thematic-analysis provides four broad areas: educational interventions, training of ambulance staff, care pathways and care and treatment reviews.

**Consultation to inform and validate the study findings carried out by SL and RS**
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<tr>
<th>Reference</th>
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<th>Methodology</th>
<th>Population Studied</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Dickson et al (2018)</td>
<td>Cross-sectional study of emergency hospital care for adults with suspected seizures</td>
<td>Cross sectional study using hospital episodes statistics which looked at frequency, characteristics, geographical variation and costs.</td>
<td>Adults who attended an emergency department or who were admitted to hospital</td>
<td>Suspected seizures are the most common neurological cause of admissions and readmissions are common</td>
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<td>Allard et al (2017)[7]</td>
<td>Frequency and factors associated with emergency department attendance for people with epilepsy in a rural UK area</td>
<td>Quantitative questionnaires</td>
<td>46 people with epilepsy</td>
<td>Approximately 1/3 attended the emergency department on three or more occasions and accounted for 65% of total emergency department attendances reported</td>
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<td>Noble et al (2012a)[8]</td>
<td>Characteristics of people with epilepsy who attend emergency departments</td>
<td>Prospective study. Questionnaires</td>
<td>85 people with epilepsy</td>
<td>Compared to the wider epilepsy population, emergency department attendees experienced more seizures, anxiety, had lower knowledge of epilepsy and its management and greater perceived epilepsy related stigma</td>
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<td>Girot et al (2015) [13]</td>
<td>Use of emergency departments by people with epilepsy</td>
<td>Descriptive case series report of cases with epilepsy</td>
<td>448 people with epilepsy</td>
<td>People with known epilepsy are major consumers of pre and intra hospital emergency services</td>
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<tr>
<td>Balestrini et al (2013) [14]</td>
<td>Emergency room access for recurring seizures</td>
<td>Prospective comparative analysis of the clinical and social characteristics of two groups of participants</td>
<td>Participants were divided into two groups depending on whether they went to the emergency department after seizures. (n=209)</td>
<td>Factors related to emergency department use may be demographic and clinical</td>
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<td>Kumar et al (2018)</td>
<td>Clinical correlates of negative health events (NHE) in a research sample of people with epilepsy.</td>
<td>Analysis of baseline data from a larger randomised epilepsy self-management clinical trial</td>
<td>120 people with epilepsy, who had experienced a NHE within the previous 6 months. These were defined as seizures, accidents or traumatic injury, self harm attempt, ED visit and hospitalizations.</td>
<td>More frequent seizures were associated with worse depression severity and quality of life. Higher seizure frequency was also associated with worse epilepsy related stigma.</td>
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<td>Bautista et al (2008)</td>
<td>Factors associated with utilisation of healthcare resources among people with epilepsy</td>
<td>Interviews. Quantitative data</td>
<td>256 people with epilepsy</td>
<td>Seizure frequency and quality of life are major factors associated with health care use. Participants were interviewed following an admission to a hospital in the USA following a suspected seizure. Questions were used to examine the association between the use of health care resources, demographics and clinical variables.</td>
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<td>Peterson et al (2019)</td>
<td>Experiences of emergency department admissions of Australian people with epilepsy</td>
<td>Survey. Mixed methods analysis.</td>
<td>393 respondents completed the survey</td>
<td>The emergency department is not always the most appropriate place following a seizure. Misunderstanding around appropriate treatment continues.</td>
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<td>Ridsdale et al (2012)</td>
<td>Explanations given by people with epilepsy for using the emergency department</td>
<td>Qualitative. Semi-structured interviews</td>
<td>19 people with epilepsy</td>
<td>Use of emergency medical services was considered appropriate by participants when they were away from home or when someone nearby lacks knowledge of seizure management.</td>
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<td>Sajatovic et al (2018)</td>
<td>6 month randomised control trial on a remotely delivered group format self-management intervention for people with epilepsy (SMART)</td>
<td>RCT. The study involved 60 participants in the intervention arm and 60 participants in the control arm,</td>
<td>Assessments at screening, baseline, 10 weeks and 24 weeks. Comprised of 60-90 minute taught session and then seven group sessions delivered via telephone/computer, versus standard epilepsy care.</td>
<td>Intervention is associated with reduced health complications and improved mood, quality of life and health functioning. The taught session was facilitated by a nurse educator-peer educator dyad, which also provided an online element of the intervention with phone calls to participants, using a semi-scripted structure find out about participant welfare and to reinforce the content of the online materials. The study was limited as it was carried out in a single site, short duration and reliance on self-reported measures.</td>
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<td>Pascual et al (2015) [23]</td>
<td>Outpatient education for people with epilepsy that use the emergency department</td>
<td>Quality improvement. Questionnaire</td>
<td>In total 90 participants were willing to receive one to one education by a physician and a nurse but not all watched the DVD (n=50).</td>
<td>Decline in the number of emergency department visits in the four months after receiving the educational materials</td>
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<td>Noble et al (2014) [25]</td>
<td>Clinical and cost-effectiveness of a nurse led self-management intervention to reduce visits to the emergency department for people with epilepsy</td>
<td>Quantitative (participants completed questionnaires on health service use and psychosocial well-being at baseline, 6 month and 12 month)</td>
<td>One emergency department provided the intervention plus treatment as usual and two emergency departments provided treatment as usual. 44 participants received the intervention and 41 received treatment as usual (treatment allocation not randomised)</td>
<td>This was a longer intervention and involved two, one-to-one sessions with a nurse, plus treatment as usual. Participants were also followed for 12 months after the intervention. There was no randomisation and only about a third of those invited to participate, agreed. Intervention did not result in a reduction of emergency department use but it did not cost more due to the reduction in hospital stay</td>
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<td>Noble et al (2012b) [24]</td>
<td>The view of people with epilepsy on a self-management intervention</td>
<td>Nested qualitative study. Interviews.</td>
<td>20 people living with epilepsy that had received the self-management intervention</td>
<td>Intervention was acceptable and participants felt it addressed limitations to usual care. People with epilepsy that are using the ED more are having increased difficulties with the management of their epilepsy and the emotional aspects linked to this. Limited education provided in general around seizure safety, physical and psychological well-being and their relationship and how this impacted on their self-management and confidence.</td>
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<tr>
<td>Snape et al (2017)[26]</td>
<td>Developing and assessing the acceptability of epilepsy first aid training intervention for patients</td>
<td>Multi-method.</td>
<td>Baseline document review, semi-structured interviews and focus groups</td>
<td>People with epilepsy who visit ED reported a positive view of the intervention. Their feedback was used to develop the intervention which will be evaluated. Study incorporates a presentation with videos, and first aid training, where people with epilepsy and their carers can talk with each other.</td>
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<tr>
<td>Bradley et al (2016) [27]</td>
<td>Care delivery and self management strategies for adults with epilepsy</td>
<td>Systematic review</td>
<td>18 studies of 16 separate interventions</td>
<td>Limited evidence for the effectiveness of interventions to improve the health and quality of life for people with epilepsy. Specialist epilepsy nurse and self-management education have some benefit.</td>
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<td>Noble et al (2016) [28]</td>
<td>Qualitative study of paramedics’ experiences of managing seizures</td>
<td>Semi-structured interviews</td>
<td>19 professionals from 5 different NHS trusts</td>
<td>Organisational, structural, professional and educational factors impact on decisions. Ambulance staff could play a key role in helping to reduce the conveyancing of people experiencing a seizure or those in the postictal phase but that current systems influence taking people to the emergency department as the default option</td>
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<tr>
<td>Sherratt et al (2017) [29]</td>
<td>Paramedics’ views on their learning needs of seizure management</td>
<td>Semi-structured interviews</td>
<td>19 professionals from 5 different NHS trusts</td>
<td>More training on the different types of seizures and guidance on which presentations should be conveyed to the emergency department, E-learning recommended. Little impact on the individual ambulance trusts directly but that it did impact on the emergency department and wider health</td>
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<tr>
<td>Burrell et al (2013) [30]</td>
<td>Decision-making by ambulance staff in managing people with epilepsy</td>
<td>Interviews</td>
<td>15 ambulance clinicians</td>
<td>Experience rather than training and guidelines impacted whether a case was transported to the emergency department</td>
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<td>Dickson et al (2017) [31]</td>
<td>Service Evaluation of new care pathway to epilepsy nurse specialists referral from Paramedics</td>
<td>11 months evaluation of adults with known epilepsy,</td>
<td>Eligible people who had called 999 for seizure. Urban setting.</td>
<td>Potential to safely reduce rates of transport to hospital. Paramedics only utilised the service in a small amount of eligible cases. Suggestive of the need for support tools to safety manage patients in the community.</td>
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<td>Dickson et al (2016) [32]</td>
<td>Quantify the number of emergency telephone calls for suspected seizures in adults, the associated costs, and to describe the patients' characteristics, their</td>
<td>Quantitative cross-sectional study using routinely collected data and a detailed review of the clinical records of a consecutive series of adult patients, 1 months data</td>
<td>999 responses to adults following seizure within a predominantly urban area</td>
<td>The need for improved and more cost-effective emergency management of suspected seizures.</td>
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<td>Study</td>
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<td>Male et al (2018) [33]</td>
<td>Exploring whether cases found the seizure care pathway of benefit or not</td>
<td>Semi-structured interviews</td>
<td>27 participants (individuals attending the emergency department for a seizure)</td>
<td>Has the potential to enhance care in the emergency department and at follow-up</td>
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<tr>
<td>Iyer et al (2012) [34]</td>
<td>Evaluation of a seizure care pathway in the emergency department</td>
<td>2 baseline audits (prospective and retrospective) and 12 month intervention study. Study looked at rapid access follow up clinic, educational sessions, phone and email support from an epilepsy nurse and information card provided.</td>
<td>In the intervention study, 350 people with seizures and other forms of collapse followed the seizure care pathway</td>
<td>A seizure care pathway can improve the burden of seizure related admissions. A caution is that the use of retrospective data is not without problems due to potential recording errors but the use of prospective audit helped to validate some of retrospective data.</td>
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<td>Williams et al (2017) [35]</td>
<td>Identifying barriers to implementing an evidence based integrated care pathway for seizure management</td>
<td>Questionnaires</td>
<td>42 staff working in the emergency department (Nurses and Doctors)</td>
<td>10 barriers that were categorised into three main dependent categories; environmental, pathway design/operational and user related. All levels of clinical emergency department staff recognised the benefits of the care pathway but issues such as double documentation, being available in hard copy only, location of where they were stored, and clinician knowledge and behaviour impaired its smooth administration.</td>
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<td>Dickson et al (2017) [19]</td>
<td>Cross-sectional study of the hospital management of adults with a suspected seizure</td>
<td>Quantitative analysis of medical data</td>
<td>82 medical records were analysed – 30/82 were epilepsy; 5/82 were documented as psychogenic nonepileptic seizures (PNES) and 1/82 was epilepsy plus PNES</td>
<td>52/82 was not admitted following ED assessment, of which only 32 had documented referral or follow-up. 18/52 referred to epilepsy clinic, 13/52 referred to GP and 1/52 being referred to nurse specialist, and 19/52 with no referral documented. Of those admitted (n=26), 7 were admitted for a different medical problem (e.g. chest infection; 3 were for social reason. Relationship between the Sheffield Early Warning Score (SHEWS) and Glasgow Coma Scale (GCS) for those on arrival with the discharge, with patients with an abnormal SHEWS or a reduced GCS are arrival were more likely to be admitted</td>
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<td>Grainger et al (2016) [20]</td>
<td>Referral patterns following admission for a seizure</td>
<td>Observational study of routine hospital data</td>
<td>7 years of data</td>
<td>Most people admitted due to a seizure are not being referred to specialist services</td>
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<td>Ziso et al (2017) [21]</td>
<td>Epilepsy management in older people</td>
<td>Quantitative – data analysed from 154 emergency departments across the UK.</td>
<td>Data of 1256 patients over 60 analysed</td>
<td>Older people presenting with seizures are more likely to be admitted and have imaging but less likely to be referred to specialist services</td>
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<td>Minshall and Neligan (2014) [9]</td>
<td>Have the new GP contract and NICE guidelines improved clinical care of people with epilepsy</td>
<td>Quantitative analysis of 540 case notes</td>
<td>540 people on ASMs across 13 GP practices. Investigations into the case notes of 450 people on ASMs across 13 GP practices from April 2004 to April 2009,</td>
<td>Improvements were noted in review rates following the introduction of the GP contract but still significant unmet needs for people with epilepsy. Deficits also found in medication and treatment options, concordance issues, mental health oversight, bone density checks and advice to women of childbearing age.</td>
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