

Can an epilepsy nurse specialist-led self-management intervention reduce attendance at emergency departments and promote well-being for people with severe epilepsy? A non-randomised trial with a nested qualitative phase

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Scientific summary

An epilepsy nurse specialist-led self-management intervention to reduce ED use

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Introduction

Epilepsy is the most common serious neurological condition, with 0.6–1.0% of adults being affected at any point in time. The seizures of over one-third of people with epilepsy (PWE) remain uncontrolled with available treatments. As well as facing restrictions in activity and being at high risk of psychological distress and perceived stigma, poor epilepsy control is associated with unnecessary hospital admissions, which NHS policy aims to prevent. Epilepsy ranks highest of all chronic neurological conditions for emergency readmission within a year.

One UK study found that 18% of people with established epilepsy had attended an emergency department (ED) and 9% had been admitted to hospital for epilepsy in the previous year. A different study found that 13% of PWE had attended an ED for epilepsy, with a mean number of visits of 0.3. There is a gap in the evidence with regard to the frequency of ED use by PWE. If some people do attend EDs more frequently it is also not clear what their characteristics are, whether some characteristics predict more or less ED use and whether ED use was appropriate or preventable and, if so, by what means.

Epilepsy is costly. In the EU, the total cost of epilepsy was £15.5B in 2004. Six out of seven admissions for epilepsy are on an emergency basis. Accordingly, some studies have found that the largest element of health-care cost is associated with hospitalisation. However, there is a gap in the evidence with regard to the actual costs of ED use by PWE, particularly in deprived areas where use is likely to be high. Western economies are undergoing a period of recession, leading to restrictions in public spending. This means that information on the costs of emergency visits by PWE is important for health service planners as they scrutinise expenditure to reduce waste and optimise resource use.

The 2012 UK National Audit of Seizure Management in Hospitals (NASH) found that only a minority of PWE who had attended an ED received a basic neurological examination, that advice was not typically given to patients or carers on seizure management and that patients were not referred at the time for assessment by the neurology team, or for follow-up by a relevant specialist. This suggests that there has been little change in the service since a survey of usual ED care for PWE was carried out in the 1990s.

The needs of patients and the skills of care providers require careful matching, with the addition of an overarching strategy. There is evidence from a US study that a nurse-led self-management intervention can help patients manage their epilepsy and reduce hospital admissions. In this context we aimed to provide:

1. a description of people attending the ED for epilepsy, their use of the ED and their psychological state, knowledge of epilepsy, perception of stigma, quality of life (QoL) and needs
2. an economic evaluation of people attending the ED for epilepsy to determine the cost both for PWE and for society
3. quantitative evidence from a comparison of two groups, one receiving treatment as usual (TAU) and the other receiving TAU and an epilepsy nurse specialist (ENS)-led self-management intervention
4. qualitative evidence of PWE's experiences of emergency services and the way in which services meet/do not meet their needs, and their explanations of the process and rationale for attendance
5. qualitative evidence from a group receiving the ENS-led self-management intervention
6. an economic evaluation of the cost-effectiveness of services both for an ENS-led self-management intervention and comparison groups before and after the nurse-led self-management intervention.

Methods

Design

To achieve the aims we carried out a non-randomised trial, with a nested qualitative study, with PWE recruited from EDs. The trial compared the effect of an ENS-led self-management intervention plus TAU with the effect of TAU alone on subsequent ED use and psychosocial outcomes.

Setting

Patients attending the EDs of three inner London hospitals for epilepsy [King's College Hospital (KCH), St. Thomas' Hospital (STH) and University Hospital Lewisham (UHL)] were prospectively (from May 2009 to March 2011) recruited. These similar EDs serve residents in the London boroughs of Southwark, Lambeth and Lewisham respectively. Each borough has high levels of social deprivation and ethnic diversity, comparable rates of emergency epilepsy admissions and a worse level of epilepsy control than the national average.

Participants

Inclusion criteria were age ≥ 18 years, epilepsy diagnosed for ≥ 1 year and, to maximise the similarity of patients composing the treatment groups, residing in Lambeth, Southwark or Lewisham. Exclusion criteria were the inability to independently complete questionnaires, serious comorbidity, having seen an ENS in the previous year or having been referred to neurology for outpatient care by the ED.

Interventions

Those recruited from STH and UHL formed the TAU comparison group, whereas those recruited from KCH were each offered two one-to-one intervention sessions delivered on an outpatient basis at KCH by either one of the two ENSs based at the hospital. The intervention aimed to optimise patients' self-management skills and knowledge of appropriate emergency services use. The first session lasted for 45–60 minutes and took place 4 weeks following recruitment. The second session lasted for 30 minutes and took place 24 weeks later.

Outcome measures

Each participant was followed up for 12 months. Using validated questionnaires, participants were assessed on recruitment (assessment 1), at 6 months (assessment 2) and at 12 months (assessment 3). Questionnaires assessed their use of different health services (including the ED) for epilepsy (modified Client Services Receipt Inventory, CSRI), seizures, health-related QoL (10-item Quality of Life in Epilepsy Inventory, QOLIE-10), medication skills (medication subscale of the Epilepsy Self-Management Scale), psychological distress (Hospital and Anxiety Depression Scale, HADS), felt stigma (Jacoby Stigma of Epilepsy Scale), epilepsy knowledge (Epilepsy Knowledge Profile – General, EKP-G), confidence in managing epilepsy (Epilepsy Mastery Scale), satisfaction with information received about medicines [Satisfaction with Information about Medicines Scale (SIMS)] and, for the calculation of quality-adjusted-life years (QALYs), health status (European Quality of Life-5 Dimensions, EQ-5D)

The primary outcome measure was the number of epilepsy-related ED visits that participants reported having made at assessment 3 over the preceding 6 months. Secondary measures were the number of ED visits that participants reported having made at assessment 2 over the preceding 6 months and scores on the psychosocial questionnaires at assessments 2 and 3.

To obtain qualitative evidence on patients' reasons for attendance and their views of the intervention, the first 24 participants completing the final questionnaire were invited to take part in semistructured interviews.

Analysis

To evaluate the characteristics and needs of PWE attending the ED and their pattern of ED use (aim 1), participants' responses to the questionnaires at the baseline assessment, which took place before allocation to the different treatment groups, are described and compared with previous findings from the

wider epilepsy population. The cost of the group's service use reported on the baseline CSRI for the year before recruitment (aim 2) was calculated using national unit costs.

To compare the outcomes of the two treatment groups (aim 3), negative binomial regression examined whether treatment allocation predicted ED visits made over follow-up. To account for imbalances between the groups in baseline characteristics, baseline predictors of subsequent ED visits were identified and adjusted for. Analyses were performed using an intention-to-treat approach with double-sided significance tests.

The cost-effectiveness of the intervention (aim 6) was determined by first comparing the cost of the service use reported by those in the two treatment groups following recruitment, after adjusting for baseline costs. The National Institute for Health and Care Excellence (NICE) recommends integrating the level of global health improvement perceived by patients from the different treatment groups into cost-effectiveness analyses. As such, the service use costs for each of the groups were combined with respective QALY gains.

Audio-recorded interviews from the qualitative study were transcribed verbatim and thematically analysed (aim 5).

Results

In total, 85 of 315 eligible patients agreed to participate. Forty-four were recruited from KCH and formed the intervention group and 41 were recruited from STH and UHL and formed the comparison group. Participants' and non-participants' characteristics were similar. The follow-up rate at 6 and 12 months was 81%, and 35 (80%) participants offered the intervention attended.

Compared with the wider epilepsy population, participants' scores on the baseline measures indicated that attendees experienced more seizures, had greater levels of anxiety, had lower epilepsy knowledge and experienced greater perceived epilepsy-related stigma. Most of the participants' epilepsy outpatient care was, however, consistent with standard criteria for quality.

In the 12 months preceding recruitment, the 85 participants had together made a total of 270 epilepsy-related ED visits [mean 3.1, standard deviation (SD) 3.6; median 2, interquartile range (IQR) 1–4]. The frequency of their visits was positively skewed. Over 60% were found to have made multiple visits to the ED in the same year. Thirty-three (39%) had attended only once, 21 (25%) on two occasions and 31 (36%) on three or more occasions. The last group accounted for 72% of all visits and reported the worst quality of life. Approximately one-quarter of participants had spent time as an inpatient, for which the mean time in hospital was 5 days and the median 3 days. A high number of participants had also spent time in an ED short-stay ward ('clinical decision unit').

The service costs for patients in the year before recruitment were skewed. The mean cost per patient was £2355 (SD £2455). Inpatient stays and time spent in ED clinical decision units accounted for most (43%) of the costs.

The outcome analyses found no significant effect of the intervention compared with TAU alone on ED use at either assessment 2 [adjusted incidence rate ratio (IRR) 1.75, 95% confidence interval (CI) 0.93 to 3.28] or assessment 3 (adjusted IRR 1.92, 95% CI 0.68 to 5.41) or on the measures of patient well-being.

Baseline variables were identified as predictive of a greater number of ED visits following recruitment, and they were adjusted for. They were, in descending order of importance, lower confidence in managing epilepsy (less mastery), higher number of prescribed antiepileptic drugs (AEDs), more felt stigma, higher

number of baseline ED visits, greater seizure frequency and higher levels of depression and anxiety. In multivariate analyses, felt stigma and mastery remained significantly predictive.

The cost-effectiveness results showed that over the entire follow-up period the average service cost for intervention group participants was lower than that for TAU participants (adjusted difference £558, 95% CI –£2409 to £648). This was accounted for by the intervention participants having spent less time as inpatients. The improvement in global health status reported by intervention participants (0.786 QALYs) was, however, less than that reported by the comparison group (0.807 QALYs). Therefore, according to NICE criteria, TAU was marginally more cost-effective.

Of the trial participants invited to interview, 19 (79%) agreed. Analysis of patients' reasons for attending the ED for epilepsy revealed that seizures alone were not the main reason; knowledge, experience and confidence of those nearby of what to do, as well as seizure context, were also important. The fear of sudden death held by the patient and others was also a trigger for ED use.

When asked about the intervention, most receiving it valued the additional support. Those who reported at baseline having used an ED the most perceived the most benefit. Participants said that the intervention redressed limitations in their usual care, such as providing information about managing their epilepsy and providing an opportunity to talk about their feelings. Benefits that participants reported included improved emotional well-being, confidence in managing seizures and medication adherence.

Discussion

This study revealed the economic costs associated with visits to EDs by PWE and showed that PWE who attend EDs frequently have complex needs. It provided needed information on the rate of return to EDs by PWE and found that > 60% of PWE who attend an ED reattend in the same year. This rate of return is higher than that reported for both the general ED population and for those with other chronic elapsing conditions.

Developing interventions to reduce repeated ED use by PWE has been challenging as policy-makers have lacked clear information about which factors influence visits to the ED by PWE. Evidence from our study brings greater clarity to the issue. As well as confirming that use of EDs by PWE is not satisfactorily explained by epilepsy duration or severity alone, our study has provided evidence on the independent, long-term predictive effects of other key variables on subsequent ED use. In multivariate analyses, felt stigma and confidence managing epilepsy (mastery) were found to be the best predictors of repeated use. This indicates that these factors should be targets for future interventions aiming to reduce ED use by PWE.

The interviews with participants also indicated that seizures were not always the main reason for an ED attendance. Instead, what was important from the patients' perspective was whether or not they had a family member, friend or colleague nearby who had the necessary skills to manage a seizure.

At interview, participants who received the ENS-led self-management intervention reported it to be acceptable. It was described by participants as improving on usual epilepsy care. Some reported benefits in emotional well-being, confidence managing seizures and medication adherence – domains possibly causally related to ED use. The level of benefit perceived by participants was, however, not universal. Those who reported at baseline having used EDs the most perceived the most benefit. For participants who had used an ED on only one occasion, the benefit was more negligible.

In line with this, the quantitative outcome analyses found no significant overall effect of treatment group on ED use or on the epilepsy-specific measures of patient well-being. However, costs were reduced

after the intervention. The average service cost for intervention participants was £558 less than that for TAU participants, with intervention participants spending less time as inpatients over follow-up.

Although there was no significant difference between the intervention and TAU groups on the epilepsy-specific quality of life outcome measure, the TAU group did report more improvement in health status over the follow-up period. According to NICE's formulae, the intervention did not therefore prove cost-effective.

Our study makes an important contribution to a small body of research. However, the results should be interpreted in light of its limitations. For example, we recruited from an urban, ethnically diverse population with high social deprivation. Our results may therefore not generalise to rural, less deprived populations. Treatment was also not randomised, which may have served to reduce the accuracy of our treatment effect estimate. Finally, although usual for such studies, the acceptance rate for the trial was low. One implication of this was that we recruited fewer participants than planned and so CIs are wide for key estimates.

In conclusion, we have described the high cost and complex challenges faced by PWE who attend the ED frequently. Two sessions with a nurse lasting for 90 minutes were valued by frequent ED users, but were not associated with significant changes using quantitative measures. From what we learned in our qualitative work, it may be helpful for PWE who attend the ED to test workshops for their family and friends to learn about seizure management. The low confidence in self-management skills, perception of stigma and death anxiety voiced by some interviewees may also require the development and testing of a more intensive intervention. From the economic evidence, an intervention that improves patient outcomes and reduces hospital use, which accounts for 43% of patient costs, would benefit PWE and the health service.

Study registration

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