Best care for older people with epilepsy: a scoping review

Dr. Gabriella Wojewodka[1*], Dr. Alison McKinlay[1] and Professor Leone Ridsdale[1]

[11]King's College London, Institute of Psychiatry, Psychology and Neuroscience, Department of Basic and Clinical Neuroscience, London, UK

*corresponding author: gabriella.wojewodka@kcl.ac.uk, King's College London, Institute of Psychiatry, Psychology and Neuroscience, 16 de Crespigny Park, PO box 57, London, SE5 8AF, UK

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Abstract

There are two peaks of diagnosis of epilepsy: in childhood and in people over 65. Older people may have complex needs like co-morbidity, polypharmacy, frailty, and social isolation. This scoping review focusses on the care of older people with epilepsy beyond diagnosis and medical treatment. We sought to identify areas within the UK health service needing development either in clinical practice or through further research.

The search returned 4,864 papers with 33 papers included in the review. The papers were grouped into psychosocial, self-management and services themes. Only one randomised controlled trial was found. Research was mainly based on cohort and case-control studies.

Older people require more information to self-manage epilepsy and more psychological support to help with symptoms of anxiety and depression. People reported experiencing stigma and a reluctance to disclose their condition. This may increase the risk of isolation and difficulties in managing epilepsy. Studies reported that older people are referred less to neurologists, suggesting there may be a gap in care provision compared to younger people. Generalist health professionals may be better placed to provide holistic care, but they may need additional training to alleviate uncertainties in managing epilepsy. Care plans could help provide information, particularly for co-morbidity, but few had one.

Our findings highlight psychological and self-management needs for managing epilepsy in older people. Health service staff may require upskilling to shift epilepsy management from neurologists to generalists. More research is needed regarding psychological and self-management interventions, particularly in the form of randomised controlled trials.

Keywords: epilepsy, aged, elderly, psychosocial factors, self-management, health service

Introduction[i]

Approximately 600,000 people in the UK have epilepsy.[1] While epilepsy can occur at any age, there are two main peaks of diagnosis: in childhood and in people over 65. In the UK, there are nearly 12 million people aged 65 and above.[2] With increasing longevity, the number of people with epilepsy over 65 is likely to keep increasing.[3] The annual incidence of epilepsy in the UK is 86 per 100,000 for people aged 65–69 years and 135 per 100,000 for those aged over 80 years.[4] The prevalence of epilepsy for people over 65 is 1 in 67.[1] This means it is more common than Parkinson's disease, the prevalence of which is 1 in 98 for people aged 65 and over.[5] Older people with epilepsy are likely to have complex needs such as co-morbidity, with polypharmacy, frailty, and social isolation.[6] Epilepsy in the elderly should be considered as a special group.

The diagnosis of epilepsy in older people can be challenging. Seizures can present in different forms, not always convulsive.[7] With older people frequently living alone, seizures may not be witnessed. Loss of consciousness and confusion may be attributed to non-neurological reasons.[8] Diagnosis can involve multiple visits to a General Practitioner (GP) and different specialist referrals. Alternatively, diagnosis can come after a first seizure presentation in emergency departments.[9] Diagnosis can be a long process. Once an epilepsy is confirmed, treatment is often reported to be effective at controlling seizures in older people, although it is unclear why.[7,10-12] The types of epilepsy and/or different pharmacokinetics of drugs observed in older people may result in seizures coming under control more easily. However, seizure frequency is often self-reported in studies and may be under-estimated due to memory issues and lack of witnesses. There have been excellent reviews on the challenges in diagnosis and treatment of epilepsy in older people.[7,8,10,13,14]

This review focusses on the care of older people with epilepsy beyond diagnosis and medical treatment to assess what other needs would improve quality of life and help maintain autonomy. We conducted a scoping review of research with a narrative synthesis of the results. We sought to highlight what is best practice, with a view to identifying areas within the UK health service needing development either in clinical practice or with further research.

Methods

Scoping reviews follow a similar process to systematic reviews with a few exceptions. They aim to describe the breath of available research, using broad research questions, and allow for the inclusion of all study designs, without limiting the search to RCTs, for example.[15] Besides, diagnosis and medical treatment of epilepsy in older people, less is known about other aspects of care. By conducting a scoping review, we planned to identify key concepts within the literature, highlight the types of study designs used for research in epilepsy in older people, and identify the gaps in research.[16] We followed the Arksey and O'Malley framework for scoping reviews[15] with the addition of a quality appraisal as has been more recently proposed.[17] As scoping reviews aim to inform policy and practice,[17] we contextualised the findings within the UK's National Health Service (NHS).

Objectives of the review

We sought to answer the following questions:

[i] List of abbreviations. AED: antiepileptic drug; CBT: cognitive behavioural therapy; ESN: Epilepsy Specialist Nurse; GP: General Practitioner; GPwER: GP with Extended Role; NASH: National Audit of Seizure management in Hospitals; NICE: National Institute for Health and Care Excellence; NHS: National Health Service; QOL: quality of life; RCT: randomised controlled trial; SIGN: Scottish Intercollegiate Guidelines Network; UK: United Kingdom.

1. After diagnosis and treatment, what are the needs of older people with epilepsy which could improve quality of life and help maintain autonomy?
2. Are the needs different for people with a diagnosis of epilepsy in older age compared to people with long-term epilepsy?
3. What are the gaps in quality of care for older people with epilepsy in the UK National Health Service?

Search strategy

The literature search was conducted in November 2019 in Ovid (which searches Medline, Embase, PsycINFO, Global Health), PubMed, CINAHL, Web of Science and the Cochrane Database. With the following search terms: epilepsy AND (geriatric OR elderly OR 65+ OR 50+ or senior OR ageing OR aging OR older) AND adult. For example, the search strategy for Ovid was: adult*.ab,ti.// (epilepsy).ab,sh,ti.// (geriatric or elderly or senior or 65+ or 50+ or ageing or aging or older).ab,sh,ti.// 1 and 2 and 3//

Inclusion criteria were defined as: older people as defined 50 years and older, in English, published since 2000. We excluded systematic reviews, conference abstracts, studies including children, adolescents, and adults under 50 only, and grey literature. As we were most interested in highlighting gaps in the current UK National Health System (NHS), we restricted the scope to similar settings and population as the UK.

Papers were selected for relevance by checking titles and abstracts. Manual searches from reference sections were done for additional relevant papers. Reasons for inclusion or exclusion were recorded in a flow diagram (Figure 1).

Data charting

Data was extracted from papers and summarised in Table 2. Due to the varied study designs and outcome measures, we opted for a narrative review of the data. Data charting was performed by two researchers (GW and AMcK).

Quality appraisal

Quantitative studies were appraised by two reviewers using a modified version of the Downs & Black checklist.[18] Items from the modified checklist can be found in Appendix 1. Qualitative studies were appraised using the CASP qualitative appraisal tool, assigning numerical values to the ratings[19] (Appendix 1).

Two raters (GW & AMcK) completed an initial rating of six papers (4 quantitative and 2 qualitative). Raters then discussed the scoring and how questions would be interpreted in the future. To not penalise studies if an item was not applicable due to the study design, it was scored as 1. All papers were scored by both raters and initial scores were compared for agreement using Cohen's kappa and percentage agreement. Raters then discussed and came to a consensus about the scoring. Any disagreement on quality appraisal was resolved by the Principal Investigator (LR). Scores were grouped into quality categories as described in Table 1 (adapted from Hooper, 2008[20]).

Table 1. Quality rating attributed to appraisal scores depending on study type

	Quantitative	**RCT**	**Qualitative**
Max	*20*	*28*	*9*
Excellent	18 to 20	26 to 28	8 to 9
Good	14 to 17	20 to 25	6 to 7

Fair	11 to 13	15 to 19	5
Poor	10 or less	14 or less	4 or less

RCT: randomised controlled trial

Advisory panel

At the outset, a panel of clinical and community stakeholders advised on the review. The panel (named in the Acknowledgements) included geriatricians, neurologists, GPs, stroke physicians, a psychiatrist with special interest in epilepsy, epilepsy nurse specialists from hospital and community settings, a pharmacist, patient and public involvement (PPI) representatives, and representatives from Epilepsy Action. The panel met three times. The panel advised on the scope of the review, the thematic grouping of findings, and the interpretation of results.

Results of the literature search

Paper inclusion

The search identified 4,864 papers. The flowchart in Figure 1 describes why papers were excluded. A final 31 papers remained, and two papers were added after a manual search of reference lists for a total of 33.

The studies had varied designs. The majority were observational with 15 cohort studies, six case-control and three surveys. There were only two studies with interventions: one randomised controlled trial (RCT) and one cohort study nested within a larger clinical trial. Seven qualitative studies were included.

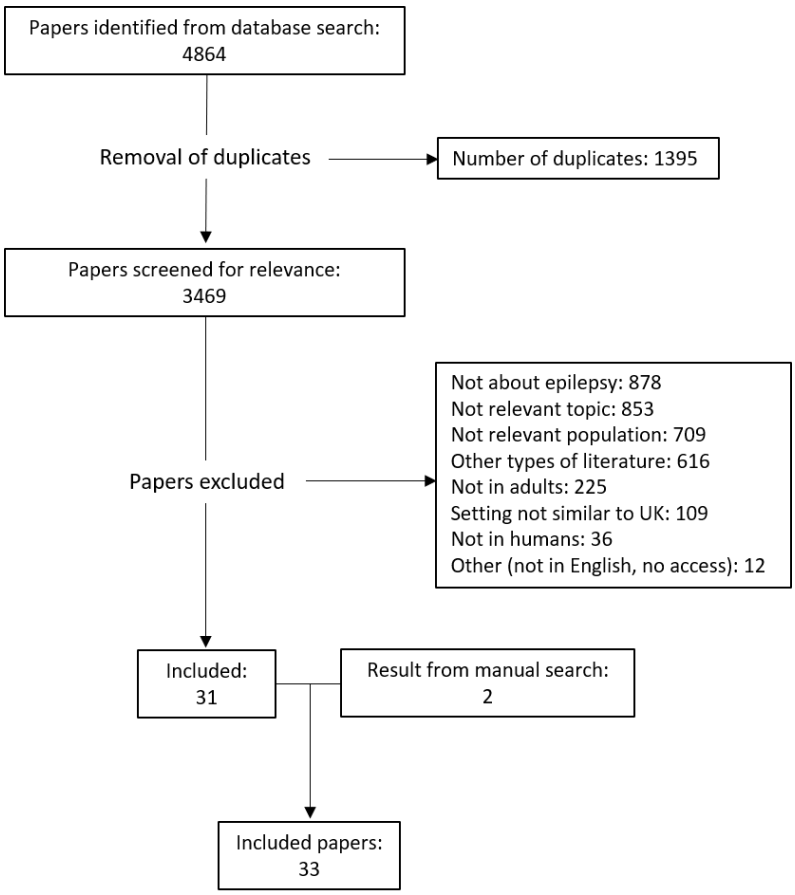

Figure 1. Selection of papers for the scoping review

Quality appraisal results

The inter-rater reliability was found to be "moderate" with a Cohen's Kappa of 0.53[21,22] and a good percentage agreement with 81%. Raters came to a consensus following discussion with the PI acting as third rater to resolve disagreements.

Quality of papers are described in Appendix 1 (Tables S1, S2 and S3) with specific scores for each item. To note, four groups published more than one paper using the same group of participants: Manacheril, 2015[23]and Sleeth, 2016[24]; Miller 2014[25] and 2014[26]; McLaughlin 2008[27], 2008[28] and 2010[29]; Moran[30] and Poole[31].

The majority of papers included cohort studies which offered the highest quality. Case-control and surveys were of lower quality. However, our quality appraisal checklist was not validated for use with surveys and thus may not have been the most appropriate. We found only one RCT which was assessed as "fair". Qualitative studies, in the majority, were of excellent quality.

Narrative review of the evidence

The papers were grouped into psychosocial (19 papers), self-management (7 papers) and services (7 papers) themes (Table 2).

1. Description of older people with epilepsy

Older people with epilepsy can be grouped into two categories: those receiving a new diagnosis and those with ongoing epilepsy diagnosed at a younger age. These groups may have different needs in older age. Throughout the review, those with a new diagnosis are referred to as having "new onset epilepsy" and with long-term epilepsy as "chronic epilepsy".

Compared to their peers, older people with epilepsy were generally more likely to be single, had fewer years in education and were less likely to be employed.[28]

Individuals with chronic epilepsy were more likely to be single or never have married[23,32] but less likely to live alone than people with new onset.[32] Older people with new onset epilepsy were more likely to have seizure control with 80% in one study being seizure free compared to under 50% of people with chronic epilepsy.[23] Study participants self-reported different seizure types. Chronic epilepsy was likely to be characterised by generalised, and focal seizures with impaired awareness.[33] New onset seizures tended to be mainly focal seizures with impaired awareness, with few reporting experiencing tonic-clonic seizures.[27] Some studies found people with new onset had higher antidepressant use,[23,27] and reported less anti-epileptic drug (AED) side-effects.[23] New onset epilepsy tended to be more manageable with one AED while chronic epilepsy was more likely to require polytherapy.[27,32] One study reported that 94% of their older participants with new onset were on monotherapy compared to 66% of those with chronic epilepsy.[32]

2. Psychosocial theme

The psychosocial theme grouped together papers related to mental health and social ramifications of epilepsy. We found studies exploring quality of life (QOL), anxiety and depression, stigma, and suicide.

2.1. Quality of life

Quality of life (QOL) is a term that is loosely defined as well-being, looking at an individual's satisfaction with life, and includes physical functioning, mental health, and social roles.[34,35] Some studies used

validated questionnaires to measure QOL[36-38] while others adapted measures for their studies,[32,33] making comparisons difficult.

Using a general QOL scale, older people with epilepsy scored lower than people of the same age without epilepsy.[39] Using an epilepsy-related scale, scores observed in older people were similar to those from a group of participants under 60,[40] and either comparable[36] or lower [28] than epilepsy population norms. Specific items relating to physical health, emotional wellbeing and social roles had the lowest scores.[36,37] It is unclear whether older people with new onset or chronic epilepsy have worse QOL as studies had conflicting results.[32,33,39] Developing epilepsy after stroke was found to be associated with worse QOL scores.[38] Depression, more frequent seizures and stigma were found to be associated with lower QOL scores in older people with epilepsy.[28,29,40]

Although studies have produced unclear and conflicting results relating to QOL of older people when compared to younger people, or chronic vs new onset epilepsy, it was clear that older people with epilepsy rate their QOL lower than people without epilepsy. There are limitations in QOL studies using non-validated measures as they cannot be compared. Although using validated questionnaires is more appropriate, they have not been explicitly designed for older populations where other issues such as co-morbidity, frailty, falls and cognitive impairment may be factors.[35]

2.2. Anxiety and depression

It is known that epilepsy affects mental health particularly resulting in anxiety and depression. A meta-analysis found that up to 27% may have an anxiety disorder.[41] Older people with epilepsy generally report more symptoms of anxiety[42] and depression than peers without epilepsy.[42-44] This was also true when excluding participants already undergoing treatment for depression.[45] Forty percent of older people reported symptoms of depression and dysthymia compared to peers without epilepsy (20% of controls reported depression, 6% dysthymia).[27] People with active seizures reported more symptoms of depression while seizure freedom conferred similar rates compared to peers without epilepsy,[42] A history of epilepsy was found to be a risk factor for developing a generalised anxiety disorder post-stroke.[46]

A similar proportion of younger and older people with epilepsy reported symptoms of anxiety and depression in one study.[32] Older people with new onset epilepsy reported more symptoms of anxiety and depression than those with chronic epilepsy.[32] The opposite was found in a qualitative study where more people with chronic epilepsy described symptoms and received psychological treatment.[23] Finally, one study reported a history of depression in 50% of older people of both chronic and new onset groups.[27]

Differences in outcomes may be due to some groups reporting a higher anti-depressant use with new onset epilepsy.[23,27] Mood can also be affected by type of AED, as a lamotrigine trial showed improved symptoms of depression in older participants.[47] Seizure frequency and monotherapy vs. polytherapy are also likely to affect mood.[47] Taken together, studies do not conclude whether mental health is affected more by chronic or new onset epilepsy. Would knowing this matter? Clinicians may want to be able to determine which patients are more at risk. However, as described above, mood can be affected by a number of factors (timing of diagnosis, seizure frequency and AED type). A better approach might be to offer psychological screening for all older people with epilepsy.

One small RCT showed that group cognitive behavioural therapy (CBT) is effective for older people for seizure management, regardless of whether participants experienced depression at the start.[48] The study randomised 18 participants to a CBT intervention and offered 19 people a relaxation intervention as a control. The results three months post-intervention showed a decrease in

symptoms of depression in both groups. Interestingly, there was a significant decrease in seizure frequency in the CBT group (6.3/month to 1.4/month) which was not found in the control group (5.0/month to 4.4/month). The authors concluded both interventions were beneficial in terms of mental health and coping with seizures, but the CBT treatment also improved seizure control.[48] The authors speculated that group CBT improved coping skills and the peer interaction helped with self-confidence. Goal setting with CBT could improve self-efficacy which in turn could reduce seizure frequency. Other potential mechanisms of CBT could involve stress reduction and lifestyle changes by addressing psychological distress.

2.3. Stigma

Stigma is the experience of rejection or discrimination based on a certain characteristic. It can be *felt stigma*, where an individual perceives others have reacted negatively, or will react negatively, when they disclose epilepsy. It can be *enacted stigma*, where others overtly discriminate against the individual with epilepsy.[24] Stigma was measured quantitively using scales created for other purposes like stroke and adapted for epilepsy.[49,50] The evidence for whether older people experience stigma is conflicting. Using the same scale,[51] one Australian study reported that older people experienced extreme stigma,[37] while a UK study found no stigma at all.[32] Others found older people felt less stigmatized than younger people[52] or when diagnosed later in life.[23,52]

Qualitative studies highlighted the experience stigma, which may not be quantifiable. Study participants believed epilepsy was still not properly understood by the public in the UK and USA,[24,53] who perceived it as being linked to mental health and intelligence.[24] Some struggled to describe their condition to others as most people expect seizures to be convulsive.[24] This sense of stigma hindered the disclosure of epilepsy to others for participants in UK and American studies.[24,53] In one study from the USA, 40-50% of older participants reported experiencing a lack of support from friends,[23] indicating a risk of isolation and lack of support for older people with epilepsy.

Older people may have their own misconceptions about epilepsy which can hinder their acceptance of the diagnosis. Some refused to use terms related to epilepsy and continued to call it a “seizure disorder” as they were not experiencing tonic-clonic seizures.[23,24] Only one American study specifically examined enacted stigma reporting that it was experienced by only a small proportion of older people.[24]

Older age itself can lead to stigma and discrimination.[54,55] Older people may thus experience a double stigma due to epilepsy and getting older.[53] It may be challenging to differentiate between the two.

Study participants proposed solutions to reduce stigma which included greater education of the public about epilepsy. People teaching other people with epilepsy about their experience, or being more open about their diagnosis may help to reduce stigma over time.[24]

2.4. Suicide

Individuals aged 60 and over had a 1.6-fold risk of suicide compared to those without epilepsy.[56] An increased risk of suicide was found in older people with epilepsy, with 1.7-increased risk in men within three years of diagnosis.[57] When a psychiatric condition was documented at the time of suicide, the risk was the same in people with and without epilepsy, about 10-fold higher compared to people without a mental health condition.[56] In the general population, men were found to have higher suicide rates than women, with highest rates in the oldest old (80+) compared to men aged 65-79.[57] While specific rates according to older age groups have not been reported for epilepsy, these studies

emphasise that suicide is an important factor to consider for all ages, but also for those in later life especially with a psychiatric disorder.

3. Self-Management

Better self-management of a chronic condition is linked to better clinical outcomes.[58-60] For example, seizure freedom in older people was found to be associated with maintaining independence over a three-year study period.[61] For epilepsy, self-managment encompasses the activities that lead to a reduction of seizures or improvement of QOL.[62] This can include adherence to treatment, management of side-effects, seizure monitoring, good sleep hygiene, a healthy diet and injury prevention.[63] How well people self-manage is dependent on knowledge of the condition itself,[64] but is also linked to psychosocial factors such as depression,[65,66] self-confidence and self-efficacy,[52,67] and stigma.[68]

3.1. Self-management needs

A common theme was that epilepsy brings a loss of control.[53] Following a diagnosis of epilepsy, older people wanted to preserve their normal lives.[25] Roles were affected, such as looking after grandchildren or partners,[25] and being more dependent on others,[26,53] particularly for transportation[53,69] and medication management.[26,53] A common concern was that being too dependent on others could negatively impact relationships.[26] There was a sense of not having anyone to speak with about epilepsy.[53] The negative aspects of epilepsy may be compounded with the restrictions imposed due to normal aging.[53]

Self-management was a way to regain control and become more confident with epilepsy.[25,53] A qualitative study with 57 participants (15 with chronic epilepsy and 42 with new onset) showed that about 50% of both groups made adjustments to their lives to manage the condition.[23] Changes in physical and emotional health, with fatigue and memory issues, were managed by sharing their feelings with others, relaxation techniques, naps, using non-prescribed medication, diet and regular sleep.[26,53] Managing epilepsy with co-morbidities could be challenging and some felt other conditions were more important.[23] One quantitative study looked at self-management in relation to osteoporosis, due to the increased risk when taking AEDs. Results showed that older people with epilepsy did not take specific measures to reduce the risk compared to the older general population.[70]

3.2. Medication challenges

Medication management was seen as complex for some in terms of side-effects and polypharmacy for treatment of other conditions.[26] Dosing regimens were confusing and people often had to rely on others to help.[26] Memory problems were a big concern and were mostly mitigated by relying on others or using aids (calendars, alarms).[26] A small study found that some older people with epilepsy may have impaired medical decision-making compared to a control group of the same age.[71] Participants with epilepsy scored lower on assessments where new information on treatments needed to be retained and where the consequence of a treatment needed to be understood. Due to epilepsy, people may need to have medical information conveyed differently, such as repeated more often or given in writing. Clinicians should be made aware that more help may be needed in understanding medical treatments.[71] Medication costs were problematic for some older people in health systems with fees for prescriptions.[26] This is worsened when medication is required for other conditions, as some people may need to choose which one is more important.[26] In the UK, medication is free for anyone over 60, an important aspect when comparing studies from different countries.

3.3. Information for self-management

Older people reported not being provided with enough information which made them feel not involved in their own care, adding to the sense of loss of control.[25,53] In one qualitative study, almost

half of the new onset and almost 100% of the chronic group said they had not received enough information about their condition despite being seen by a neurologist.[23] There were no clear plans in place to help with management. Some were able to find information online, but others admitted to not having the proper skills or being more confused by what they found.[26] One study found a difference in information seeking with more of the new onset group (58%) researching epilepsy on their own compared to only a fifth of the chronic group.[23]

Some older people were not used to questioning doctors due to generational beliefs about respecting authority.[25] Some were also embarrassed to admit when they did not understand. The authors recommended a checklist be made available to healthcare providers to address the needs of older people. This may help the communication between clinicians and their patients, and help people voice their concerns, improving confidence in self-management.[25,26]

4. Services

In 2000, older people were surveyed about their experiences with NHS services for epilepsy.[30,31] About 30% had a consultation for epilepsy in the previous year, either with a GP or hospital doctor (unspecified speciality), compared to 54% of those aged 17 to 65.[30] More people over 65 preferred care in a primary care setting. However, this depended on epilepsy severity as those with more severe presentations preferred to be seen in hospital. Older people recalled receiving less information about epilepsy after a first seizure.[31] Seeing a neurologist was found to reduce the risk of losing independence, or having to rely on care, in an American study.[61]

The consensus from studies is that older people were referred less frequently to neurology specialists.[9,72,73] In a UK study looking at care received after admission to emergency departments for a seizure, people over 75 years old were 3 to 6 times less likely to be referred to neurology services than people under 55.[72]

The analysis of data for people over 60 from the National Audit of Seizure Management in Hospital (NASH) study showed that, of all emergency admissions for seizures, only 34% had a referral for an epilepsy outpatient review, compared to 68% of younger attendees, and 22% were given advice after a first seizure. However, CT scans were done in 71% of older people with a first seizure, compared to 43% of patients under 60.[9]

People who had not been seen by neurology services in the previous year, either due to first seizure presentation or not actively being followed up, were given fewer referrals than active neurology outpatients.[9,72] Referrals to neurology decreased further with age, with those aged over 75 having half the referral rate than those aged 55 to 74.[9,72,73]

Two qualitative studies from the same research group looked into possible reasons for the lower referral rate: one from the point of view of health care providers and their perceptions of older people with epilepsy,[74] and the second with older people and their view of the services they receive.[75] Some professionals believed that mobility and frailty issues meant older people should be seen in primary care. Indeed, in one study, older people preferred to be managed locally by their GP.[31] However, some professionals assumed hospital referrals would not be attended due to travel difficulties, stigma and being overwhelmed with appointments for other conditions, and thus they may not be offering this option to patients.[74] In contrast, older patients stated they would attend appointments if needed and would prefer a specialist to advise on their case. They did not perceive a reluctance to attend appointments and stated they would find a way to travel.[75] Some professionals thought that health care providers are less pressured by older people and thus may “get away” with not having to refer to specialists.[74]

Low referral rates to neurology services may not necessarily mean older people are not receiving proper care. One important omission in these studies was the referral rate to geriatricians or other generalists. The NASH study highlighted this limitation and future studies may need to be designed to capture this information.[9]

Contextualising the findings

Consistently throughout the literature, older people did not receive enough information about epilepsy.[9,25,30,53] As older people score lower on cognitive tests than peers without epilepsy,[42-44,76-79] information should be provided in writing, and repeated periodically.

Checklists may help health care professionals ensure that all necessary information is provided and that patients' needs are discussed.[25] Care plans help with providing accurate information helpful for self-management. Only 30% of people over 60 from the NASH study had a documented care plan.[9] These need to be tailored for co-morbidity and polypharmacy.[26] Care plans are part of the NICE Clinical Guidelines for epilepsy[80] and the NHS Quality Outcomes for Epilepsy.[81] The Scottish Intercollegiate Guidelines Network (SIGN) for epilepsy management suggest that care plans be used for older people with cognitive difficulties.[82] In a recent survey about patient satisfaction, only 10% of older participants reported having a care plan compared to 35% of patients under 18.[83] Considering these are the two peaks in epilepsy diagnoses, epilepsy care in paediatrics could offer models to improve implementation.

Stigma continues to affect older people. Study participants suggested that more could be done to educate the public about epilepsy.[24] A large UK survey on attitudes towards epilepsy found that stigma towards epilepsy is generally low. However, respondents aged over 65 held more negative stereotypes about epilepsy and were more prone to avoid people with the diagnosis.[84] This supports the feeling older people had about disclosing epilepsy and risking less support from their peers.

None of the studies included in this review addressed potential cultural differences in the perception of epilepsy as the participants mostly self-identified as white. The impact on stigma, mental health and self-management might be different according to participants' ethnicities.[85-87] For example, people from African and Caribbean backgrounds living in London, UK, held different beliefs about the cause of epilepsy, which lead to differences in disclosure to others.[85] Researchers should be encouraged to include more older people from Black, Asian and Minority Ethnic backgrounds as their needs have been under-represented in research.

More information, confidence and access to services are likely to improve self-management, which is especially important when health services are stretched. Self-management programmes have been developed for children, adolescents, and adults with epilepsy, none have been developed specifically for older adults.[88,89] Current interventions may need to be adapted. Professionals within the health system, such as GPs, nurses and pharmacists could be involved to help with self-management, particularly for co-morbidities. The impact of co-morbidity has not been clear in the studies included in the review which would be another area needing further research.

The Royal College of Physicians and the Association of British Neurologists have highlighted inadequate neurology services in the UK with subspecialist epileptology available mainly in large tertiary centres.[90,91] Particularly in the UK, there is a capacity issue with only 958 neurologists, equivalent to 721 in full time employment.[92] As highlighted in the review, older people are referred less to neurologists, despite the NICE guidelines specifying the same level of care should be offered to them.[80] Suggestions have been made that resources may be increased by reorganising care pathways to achieve better cohesiveness between primary, secondary and tertiary care systems, in particular

having more specialised nurses and GPs manage care of neurological conditions.[90,93-95] Geriatric neurology is an emerging field in some countries, such as the USA, and could offer holistic care with epilepsy included in the training.[96] More research is needed on the role of neurologists in managing co-morbidity to determine whether it is feasible.

Generalists such as GPs or geriatricians, can offer more personalised care, managing other co-morbidities. Transitioning the management of epilepsy in older people from neurology to others would require workforce development. There was a perception held by health care professionals and patients that GPs may not have enough knowledge about epilepsy.[74,75,93] GPs reported feeling less confident in managing neurological conditions, even common ones like epilepsy.[97] However, they may also be the best placed to provide local and holistic care, with many older patients preferring this.[31] In the UK, GPs can specialise to become GPs with Extended Roles (GPwER, formerly called GP with Special Interest, GPwSI). Currently, GPwERs for epilepsy have no national formal training or accreditation process which may limit the number of new GPs taking up the specialisation.[98]

Less intensive training could be offered to GPs by GPwERs or Epilepsy Specialist Nurses (ESNs) to improve their confidence and skills. Such programmes have been in place for headache and migraine, with the aim of reducing referrals to specialist services.[99] Training packages have been tested for headache management in primary care to help combat *neurophobia*. GPs who took part in the training said they felt more equipped with managing headache.[100] The same process could be evaluated for epilepsy.

Apart from neurologists, older people with epilepsy may be referred to geriatricians. They may diagnose and start patients on AED treatment. In addition, they may be best trained to manage multimorbidity, impaired cognition and be more aware of services for older people. Epilepsy is not featured in the training curriculum for geriatrics in the UK.[101] As stroke is the most common reason for developing epilepsy in older age, epilepsy might at least be included in the curriculum of stroke specialisation. Geriatricians may also benefit from continuing development sessions so that current recommendations are followed, and outdated practices with older AEDs are avoided.

There is scope to involve community pharmacists to help older people with AEDs, highlighting compliance issues, and managing polypharmacy to minimise side-effects. Pharmacists see patients more often than GPs and specialists, thus are well placed to be a source of information for them and identify early onset of new conditions. Interventions in community pharmacies for other conditions tend to have a positive outcome on patients' QOL and can be cost-effective if based on appropriate models of care.[102] One self-management education trial for adults with epilepsy involved pharmacists reviewing medication and teaching about medication management. The intervention resulted in increased QOL scores.[103]

The evidence shows older people have more symptoms of anxiety and depression than peers without epilepsy. Some receive anti-depressant medication[23,27] but few studies have described psychological interventions. A survey of older people receiving home care in Canada reported only 2% received psychological help.[104] In England, it was reported that only 19% of adults with epilepsy said their mental health needs are met with "good" or "excellent" services.[105] Over 50% of older people were not asked about their mental health by health care providers and about 20% would want to be signposted to services.[83] Often ESNs are relied upon for psychological help.[53,106] Offering mental health assessments for all older people with epilepsy may help identify who could benefit from interventions. CBT was found to be effective for older people with depression[107,108] and reduced seizure frequency in older people.[48] These positive outcomes would benefit from more research to evaluate the need for mental health support for older people and the interventions best suited to address this.

ESNs are assets to epilepsy care and often undertake many roles.[106] They can help with holistic care plans and are often supporting patients psychologically.[53] Access to ESNs has been shown to reduce the length of admissions in hospitals.[109] More community-based ESNs could help maintain consistency of care, liaising with other services and offer local support which would reduce the impact of travel difficulties. Those with the ability to prescribe might, by better drug management, reduce hospital admissions particularly for older people in care homes or living alone. With capacity issues, the number of ESNs available is insufficient to support all people with epilepsy. There may be opportunities to provide additional training for community nurses about epilepsy in older people, to help recognise issues and be able to refer to appropriate services.

Limitations

We chose to conduct a scoping review to enable a broad search of the literature. This is however also its limitation. Some topics may warrant a more in-depth analysis in the future, particularly if more research will be available. The scoping review did not include abstracts, theses or trial registrations which fall under grey literature thus we may have missed data.

Papers with similar settings to the UK were included so findings could highlight gaps in the UK National Health Service. This limits the generalisability to other settings. The findings from the literature review component can be applied to services in similar settings and we hope this study provides a model to do so. As we only found UK papers for the Services theme, we could not compare health care services for older people in other countries. More research could help highlight what is being done well in other countries.

Diagnosis and treatment of epilepsy in older adults can be challenging but were not featured in this report as they have been extensively covered in other reviews.[7,8,13,14,110] Aspects relating to medical treatments were only briefly mentioned when relating to self-management. Cognitive impairments, particularly affecting memory, are important factors for older people in general and may be exacerbated with AEDs or frequent seizures. This may warrant further analysis. Co-morbidity is also common in older age, which we did not examine in depth. Dementia would be an important topic to explore as there may be biological links with epilepsy and the management of both together can be difficult.[111] We also did not include research on older people with learning disabilities as the needs would be different and would benefit from a more focussed review. Stroke is the most common reason for epilepsy in older age. Some studies specifically excluded people with a history of stroke, while others included them. Only two studies focussed on post-stoke epilepsy,[38,46] which highlights the need for more stroke focussed research.

The older old, aged 75 and over, are underrepresented in research and thus we could not highlight difference between age groups, or with varying levels of frailty. Thus, more research is needed to determine their needs. Cognitive impairment and frailty issues may impede participation, and so health care professionals and carers could be involved in addition.

Conclusion

This review of care for older people with epilepsy highlighted the need for more information to self-manage and for more psychological support to help with maintaining independence. There are professionals best placed to provide holistic care, such as GPs, geriatricians and pharmacists, who may need additional training to alleviate uncertainties in managing epilepsy in older people. More research is needed to find how neurology can contribute to managing co-morbidity in older patients. The UK is well placed to offer good care so older people can maintain independent living with ESN support, having a health system with the goal of providing personalised care, and excellent research in health

services. More research is needed regarding psychological and self-management interventions, inclusive of people over 75 years of age and from diverse ethnic and cultural backgrounds.

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Table 2. List of papers included in the scoping review

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Baker[32]	2001	The quality of life of older people with epilepsy: Findings from a UK community study	psychosocial	Observational cohort	UK	Primary care	Older PWE: age of retirement (≥65 for men, ≥60 for women), Younger PWE	Group 1: younger PWE n = 514; Group 2: older PWE n = 155 (subgroups - Group 2a: older PWE diagnosed before retirement, n = 114, Group 2b: older PWE with diagnosis after retirement, n =32)	Group 1: 38; Group 2: 70; Group 2a: 69, Group 2b: 74	Health-related QOL based on Liverpool QOL Battery; The Impact of Epilepsy scale; Adverse Drug Events Profile; Hospital Anxiety and Depression Scale (HADS); The Stigma Scale adapted for epilepsy; The Terrible-Delighted Faces	Older PWE have less symptoms of anxiety and depression, especially when diagnosed after retirement. Older PWE experience less stigma and feel less impacted by epilepsy than younger PWE. Although when diagnosed post-retirement, more reported being impacted and have a worse QOL.
Bambara[71]	2007	Medical decision-making abilities in older adults with chronic partial epilepsy.	self-management	Observational case-control	USA	Neurology clinic (PWE) and research centre (controls)	PWE ≥ 60 and controls	PWE: n = 21; controls: n = 21	PWE: 67.1 (SD 3.9); controls: 70.1 (SD 5.4)	Capacity to Consent to Treatment Instrument, DRS	Older PWE exhibited worse medical decision-making capacity than controls, specifically in the areas of appreciating the consequences of treatment choice, reasoning about treatment and understanding a treatment choice. DRS scores, number of AEDs, duration of epilepsy and age of onset were correlated to medical decision-making capacity.
Baran[61]	2007	Epilepsy in a rural elderly population	self-management	Observational cohort	USA	Hospital inpatient and outpatient	Adults > 70 with epilepsy, seizures or syncope	n = 531 (PWE: n = 449)	PWE: 79.6, Seizures not epilepsy: 79.0, syncope: 80.5	Clinical information and change from independent living to care home after a 1-year follow-up.	There was a smaller proportion of PWE (14%) with depression than in the seizure (24%) and syncope groups (25%). 20% of the epilepsy group experienced falls, compared to 5% of the seizure and 0% of the syncope groups. 66% of the PWE group was taking phenytoin. Being seen by a neurologist was associated with maintaining independence. Transition to dependent living was associated with dementia, acute symptomatic seizures, not being seizure free, and age.

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Blank[74]	2013	Understanding referral patterns to an epilepsy clinic: professional perceptions of factors influencing the referral of older adults.	services	Qualitative	UK	Professionals	Health care professionals	n = 19	Not provided	Face to face interviews	Professionals gave reasons why older PWE may be referred less to specialists. Themes that were highlighted: access difficulties, reluctance to attend, complex differential diagnosis, characteristics of older patients, time since onset, referrer knowledge, unclear referral pathways.
Blank[75]	2014	Patient perceptions of the referral of older adults to an epilepsy clinic: do patients and professionals agree who should be referred to a specialist?	services	Qualitative	UK	Community and primary care	PWE ≥ 50 (although one participant was 49)	n = 15	No mean provided. Median 67 (range 49 - 84)	Face to face interviews	PWE were asked their views on the referrals to specialists. Themes that were highlighted: referrer knowledge, complex differential diagnosis, unclear referral pathways, time since onset, access difficulties, reluctance to attend, characteristics of older patients. Participants acknowledged difficulties in diagnosing epilepsy but would attend all referrals, regardless of transport difficulties.
Canuet[40]	2008	Factors associated with impaired quality of life in younger and older adults with epilepsy.	psychosocial	Observational cohort	Japan	Neuropsychiatry clinic	PWE aged 18 and over. Older PWE: age ≥60.	Younger PWE: n=69; Older PWE: n = 45	Younger PWE: 34.2 (SD 9.3); Older PWE: 66.5 (SD 5.7)	Quality of Life in Epilepsy (QOLIE-31), Beck Depression Inventory-II (BDI-II), Wecjsler Adult Intelligence Scale-Revised (WAIS-R), Mini-Mental State Examination (MMSE), seizure related variables	Older and younger PWE had similar QOLIE-31 scores except for the medication effects where older PWE were less impacted by this. For BDI-II assessments, 37.7% of older PWE and 49.4% of the younger group has scores indicating depression. QOLIE-31 scores were correlated with BDI-II scores and seizure frequency.
Christensen[112]	2007	Epilepsy and risk of suicide: a population-based case-control study.	psychosocial	Observational case-control	Denmark	National and hospital databases	Cases: people with recorded suicide; controls: sex and age matched from database	cases: 21,169; controls: 423,128	Not provided	Diagnosis of epilepsy, psychiatric disease, age at diagnosis and age at suicide	Epilepsy increased the risk of suicide 3-fold; this is further increased with diagnosis of psychiatric condition. Risk of suicide decreases with age and age at diagnosis. Risk of suicide in older PWE 60+ is the same in peers without epilepsy when a psychiatric condition is present.

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
DiIorio[52]	2003	The association of stigma with self-management and perceptions of health care among adults with epilepsy	self-management	Observational cohort	USA	Neurology and epilepsy clinic	Adults between 18 and 75	n = 314 (PWE 60+: n = 26)	43.3 (SD 11.7)	Parent Stigma Scale, Epilepsy Self-Efficacy Scale (ESES), a scale measuring outcome expectancy related to treatment, Epilepsy Self-Management Scale (ESMS), Self-Reported Medication-Taking Scale (for adherence), Patient Satisfaction Questionnaire -III, Multidimensional Desire for Control scale	PWE who had their first seizure aged 50 or over reported less stigma. Stigma was associated with age at first seizure, seizures in the past year, patient satisfaction, self-efficacy and outcome expectancies of treatment (negative expectancies with more stigma).
Erlangsen[57]	2015	Physical diseases as predictors of suicide in older adults: a nationwide, register-based cohort study.	psychosocial	Observational cohort	Denmark	National databases	Adults ≥65	n= 1,849,110	Not provided	Demographic characteristics and physical diseases	Epilepsy, amongst other conditions, was associated with a higher risk (approx 1.5-fold) of suicide within 3 years of diagnosis. This increased risk was more pronounced in men than women.
Fakhoury[47]	2008	Effects of lamotrigine on mood in older adults with epilepsy and co-morbid depressive symptoms: an open-label, multicentre, prospective study.	psychosocial	Interventional cohort	USA	Hospital outpatients	PWE aged ≥50	n= 40	56.6 (SD 6.8)	BDI-II, Neurological Disorders Depression Inventory in Epilepsy (NDDI-E), Centre for Epidemiological Studies-Depression Scale (CES-D), Profile of Mood State (POMS), QOLIE-31, Adverse event profile	All scores for depression improved with lamotrigine treatment, particularly with transitioning to monotherapy. QOLIE-31 scores improved similarly. BDI-II scores were correlated with Adverse Events Profile scores, but not with seizure frequency, suggesting that the improvement in depression score was related to treatment rather than the impact on seizures.
Fernandez[70]	2019	Epilepsy and lifestyle behaviors related to bone health.	self-management	Observational cohort	Canada	Community	Adults ≥ 50	n = 30, 965 (PWE: n = 161)	PWE: 59.3 (CI 56.4 - 62.2), Controls: 63.4 (CI 63.3 - 63.6)	Ambulatory status, physical activity, food choices, sun exposure and fractures	There were no differences for diet and sun exposure between older PWE and controls. PWE participated in less weight-bearing exercises in terms of frequency and duration. There were no differences in motivation between the groups to exercise more, or in the number of fractures

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Grainger[72]	2016	Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data	services	Observational cohort	UK	Emergency departments	Adults presenting with seizure	n = 12,369	55 (SD 20)	Referrals to specialist and other quality care targets	Half of admissions due to seizure were given referral. Only 11% who were not current under specialist review were given a referral within 3 months. Compared to people 75 and older, people aged 55 to 74 were 2.7 times more likely to be given a referral and those aged 35 to 54 were 3.5 times more likely.
Haut[42]	2009	Seizures in the elderly: Impact on mental status, mood, and sleep	psychosocial	Observational case-control	USA	Epilepsy clinic (PWE) and research centre (controls)	PWE aged ≥65; controls: sex and age matched within 5 years	PWE: n = 31, controls: n = 31	74.6 (SD 6.4)	Blessed Information Memory and Concentration (BIMC), Anxiety and Depression modules from the Patient Health Questionnaire (PHQ), Medical Outcomes Study (MOS) Sleep Scale, epilepsy variables	Older PWE had more cognitive impairment, more symptoms of depression and anxiety, and reported some sleep disturbances compared to controls.
Kehyayan[104]	2018	Profile of Persons With Epilepsy Receiving Home Care Services	psychosocial	Observational cohort	Canada	Community, with home care help	PWE aged ≥60; controls PWE under 60, all PWE were receiving home care help	Older PWE: n = 3,429; Younger PWE: n = 2,236	64.2 (SD 18.6)	Cognitive Performance Scale (CPS), Depression Rating Scale (DRS), Activities of Daily Living Hierarchy (ADLH), Aggressive Behaviour Scale (ABS), Pain Scale, Instrumental Activities of Daily Living Scale, Changes in Health, End Stage Disease and Signs and Symptoms (CHESS), and other patient characteristics	Most older PWE had mild to no cognitive impairment, could function independently, felt little to no pain, mild or no instability. The younger group had more impairments across all assessments. 43.1% of the older group experienced falls, and 68.7% had unsteady gait. 28% were on anti-depressants, however this was similar to the younger group.
Laccheo[36]	2008	Assessment of quality of life among the elderly with epilepsy	psychosocial	Observational cohort	USA	Epilepsy clinic	PWE aged ≥60	n = 23	66 (SD: 6)	QOLIE-31 and Short Form 36 Health Survey (SF-36)	Older PWE have similar overall QOL scores to population norms for QOLIE-31 and but were significantly lower using the SF-36. Comparing to population norms, some subscales were significantly lower in older PWE: physical function, role - physical, general health, social functioning and role - emotional.

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Leppavuori[46]	2003	Generalized anxiety disorders three to four months after ischemic stroke	psychosocial	Observational cohort	Finland	Research centre	Adults 3 - 4 months post-stroke	n = 277	70.7 (SD: 7.5)	Mini-Mental State Examination (MMSE), Barthel Index, Schedules for Clinical Assessment in Neuropsychiatry (SCAN), Zung Self-Rating Scale (for anxiety), Montgomery-Asberg Rating Scale (MADRS) (for depression), Global Assessment of Functioning (GAF)	More people with generalised anxiety disorder had a history of epilepsy than in the anxiety post-stroke group, compared to the post-stroke group without anxiety
Manacheril[23]	2015	Psychosocial Impact of Epilepsy in Older Adults	psychosocial	Qualitative	USA	Outpatient and community	PWE aged ≥65; focus group with partners/carers	Chronic epilepsy: n = 15; New diagnosis (after age 65): n = 42	Chronic epilepsy: 70.7 (SD 3.8); New onset: 76.2 (SD 6.7)	Demographic and clinical information, face to face interviews with PWE	Chronic epilepsy group: 47% on depression or anxiety medication, 47% are seizure free; New onset: 62% on depression or anxiety medication, 81% seizure free. Over 60% in both groups reported symptoms of anxiety and/or depression, about 50% reported physical symptoms such as fatigue and memory problems. Half of both groups made lifestyle changes to manage epilepsy. Participants reported lack of information despite being seen by neurologists, lack of awareness of public. Stigma felt more in the chronic epilepsy group. Relationships were affected with a lack of support from friends and about 25% of new onset rejected the diagnosis initially. Some refer to their condition as "seizure disorder".
Martin[69]	2005	What are the concerns of older adults living with epilepsy?	self-management	Survey	USA	Neurology clinic	PWE ≥ 50	n = 33	65.6 (range 60 - 80)	Concerns of PWE	Most common concerns were (with at least 20% of the participants reporting): driving, AED side effects, safety issues, AED costs, job loss, fear of embarrassment and memory loss

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
May[33]	2015	Epilepsy in the elderly: restrictions, fears, and quality of life	psychosocial	Observational case-control	Germany	Epilepsy clinics	PWE aged ≥ 65, controls PWE aged 18 - 50. (Group A1: Older PWE with onset of epilepsy after the age of 65; group A2: older PWE epilepsy onset before the age of 50 years; group B: PWE aged between 18 and 50)	n = 147 (Group A1: n = 47, Group A2: n = 56, Group B: n = 44)	Group A1: 74.9 (SD 4.9), Group A2: 69.6 (SD: 4.2), Group B: 33.2 (SD 7.9)	PErformance, Sociodemographic aspects, and Subjective Estimation (PESOS) for QoL, QOLIE-31 items, Social and leisure activities, seizure information	The older group with chronic epilepsy felt more fear in relation to the condition, specifically fear about seizures in public, rejection, disclosure, avoidance from others. The new onset group had a greater fear of fractures, but felt less fear of stigmatisation. The younger PWE group felt epilepsy inhibited work/education and social/leisure activities than the older groups.
McLaughlin[27]	2008	Depression in a community-dwelling sample of older adults with late-onset or lifetime epilepsy.	psychosocial	Observational case-control	Australia	Neurology and epilepsy clinics, and community (PWE and controls)	PWE aged ≥60; control group aged ≥60 without epilepsy	PWE: n = 64; Control: n = 60	PWE: 67.6 (SD 7.4); Control: 66.5 (SD 7.7)	Composite International Diagnostic Interview (CIDI) - Auto, Geriatric Depression Scale (GDS), clinical history	Older PWE group had 53% with history of depression compared to 25% of control group. GDS scores showed 55% of the PWE group with mild to severe depression, compared to 23% of controls. The CIDI depression scores were similar between groups, but CIDI Dysthymia scores were higher in the PWE group, with 41% meeting diagnostic criteria compared to 7% of the control group. Clinical assessment may be more accurate to study depression in epilepsy rather than self-report questionnaires.
McLaughlin[28]	2008	Stigma, seizure frequency and quality of life: the impact of epilepsy in late adulthood.	psychosocial	Observational case-control	Australia	Neurology and epilepsy clinics, and community (PWE and controls)	PWE aged ≥60; control group aged ≥60 without epilepsy	PWE: n = 64; Control: n = 60	PWE: 67.6 (SD 7.4); Control: 66.5 (SD 7.7)	MMSE, Washington Psychosocial Seizure Inventory (WPSI), QOLIE-31, Stigma Scale, seizure frequency,	QOLIE-31 scores were lower in the epilepsy group, suggesting a worse QOL. The WPSI scores were higher in PWE indicating worse adjustments to different roles. Overall QOLIE-31 and WPSI scores were worse compared to population norms. Two thirds of PWE felt stigma, with 29.7% reporting severe stigma. Stigma and seizure frequency were associated with QOLIE-31 scores.

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
McLaughlin[29]	2010	The impact of depression, seizure variables and locus of control on health related quality of life in a community dwelling sample of older adults.	psychosocial	Observational cohort	Australia	Neurology and epilepsy clinics, and community (PWE and controls)	Older PWE	PWE: n = 64	PWE: 67.6 (SD 7.4)	QOLIE-31, CIDI-Auto, Internal/External Control of Reinforcement Scale (for locus of control), seizure information	QOLIE-31 scores were negatively correlated with CIDI-depression and CIDI-dysthymia scores, and seizure frequency.
McLaughlin[48]	2011	A randomized trial of a group based cognitive behavior therapy program for older adults with epilepsy: the impact on seizure frequency, depression and psychosocial well-being	psychosocial	Randomised controlled trial	Australia	Neurology and epilepsy clinics, and community	PWE aged ≥60	PWE: n = 37 split into CBT group (n = 18) and control (n = 19)	CBT group: 67.6 (SD 7.3), Control group: 67.4 (SD 7.5)	CIDI- Auto, GDS, WPSI,	Both CBT and control interventions improved mood (CIDI and GDS scores), and subscales of the WPSI (emotional adjustment, seizure adjustment, overall psychosocial score). Seizure frequency improved in both groups however there was a greater reduction in the CBT group (6.3 seizures a month to 1.4).
Miller[25]	2014	Patient-centered outcomes in older adults with epilepsy.	self-management	Qualitative	USA	Neurology clinic	PWE ≥ 60	n = 20	70 (range 60 - 80)	Face to face interviews	Main themes from interviews: maintaining normalcy (in roles, health, and life satisfaction), wanting to be involved, to be well-equipped, to be seizure free, managing of other conditions and incongruence with health provider goals.
Miller[26]	2014	Problems, needs, and useful strategies in older adults self-managing epilepsy: implications for patient education and future intervention programs.	self-management	Qualitative	USA	Neurology clinic	PWE ≥ 60	n = 20	70 (range 60 - 80)	Face to face interviews	Main themes: information, physical and emotional symptoms, memory and concentration, medication, commitments. The study reported the problems PWE face and how they cope and self-manage.

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Moran[30]	2000	NHS services for epilepsy from the patient's perspective: a survey of primary, secondary and tertiary care access throughout the UK.	services	Survey	UK	Primary care	PWE all ages	n = 1,652 (PWE over 65: n = 251)	Not provided	Seizure information, health care services received	PWE with controlled epilepsy, 75% had no consultations in the previous year (primary or hospital setting). 30% of older PWE had a consultation for epilepsy in the previous year compared to 54% of the 17-65 years group. Most had been seen in primary care, rather than hospital for epilepsy. People with new onset (regardless of age) were referred to a hospital doctor 80% of the time, with a mean waiting time of 6.5 weeks.
Poole[31]	2000	Patients' perspectives on services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy.	services	Survey	UK	Primary care and hospital clinics	PWE all ages	n = 2,394 (Primary care sample: n = 1,652; Specialist care sample: n = 742)	No mean provided. Primary care sample: median age = 43; Specialist care sample: median age = 28	Seizure information, health care services received, satisfaction with services	PWE aged ≥65 were satisfied with their care overall (88 to 94%). Seizure severity influenced the type of care older PWE would prefer. In general, older PWE preferred the service they were already receiving, e.g. those recruited from the primary care setting would prefer to be seen in this setting, rather than also having specialist consultations. The benefits of primary care were: being more personalised with the doctor knowing more about their personal medical history, able to see the same doctor, and easier access to clinic. Reasons for hospital care preference were: consultants being more knowledgeable about epilepsy, longer consultation times and ability to get specialised tests. Provision of information was found to be lowest for PWE 65 and over, with those in the primary care setting receiving the least.
Pugh[39]	2005	The impact of epilepsy on health status among younger and older adults.	psychosocial	Observational cohort	USA	Outpatient, inpatient and community veteran services	Adults over 18	n = 509,301	No provided. Sample grouped into: young (aged 18 - 40), middle-aged (aged 41-65) and older veterans (aged ≥65)	SF-36 adapted for the veteran population (VR-36), clinical characteristics	Veterans with epilepsy have lower VR-36 scores than peers without. Veterans with chronic epilepsy have better QOL scores than new onset across all age groups. The lowest scores for older PWE compared to peers were for role - emotional, social functioning and physical functioning subscales

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Reuber[73]	2010	Do older adults have equitable access to specialist epilepsy services?	services	Observational cohort	UK	Primary care and specialised epilepsy clinic	Adult PWE	n = 3,878	No mean provided. Median 67 (range 49 - 84)	Access to specialised epilepsy service	PWE under 20 were almost 20x more likely to be referred to specialised clinic than PWE aged 85+. Of PWE aged 65 to 69, 15% were referred to specialist, which declined in increasing age groups.
Sleeth[24]	2016	Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach.	psychosocial	Qualitative	USA	Community	PWE ≥65	n = 57	74.1 (SD 6.6)	Demographic information and face to face interviews	Stigma is felt by older PWE and can inhibit disclosing of epilepsy to friends and family. Feeling that public is misinformed about epilepsy. Solutions proposed: more education of public, PWE teaching other PWE about epilepsy, PWE being more open about condition may reduce stigma.
Winter[38]	2018	Health-related quality of life in patients with poststroke epilepsy	psychosocial	Observational cohort	Germany	Outpatients	Post-stroke patients	n = 374, with post-stroke epilepsy n = 23), without epilepsy n = 351	Post-stroke epilepsy: 67 (SD 8.4); without epilepsy: 69 (SD 4.9)	GDS, NIH Stroke-Scale, Barthel-index, health related QOL with European Quality of life (EuroQOL 5 dimension, EQ-5D and EQ visual analog scale-VAS)	People developing epilepsy after stroke showed more impairment at admission (NIH Stroke-Scale) and later at discharge (Barthel-Index). In half, seizures developed by 6 months after stroke. Most remained on monotherapy however 30% were on 2 AEDs at 12- and 24-months post-stroke. QOL at admission was the same in both groups. At 6 months post-stroke, the QOL improves in both groups however began to decline in the epilepsy group, with lower scores at 12 and 24 months, compared to scores at 6 months, and compared to the same time points in the group without epilepsy. QOL scores were associated with seizure frequency, depression and impairment measured by the Barthel index.
Yennadiou[53]	2017	The experience of epilepsy in later life: A qualitative exploration of illness representations	psychosocial	Qualitative	UK	Neurology clinic	PWE ≥65	n = 10	71.8 (SD 4.2)	Demographics and clinical information, face to face interviews	Epilepsy was seen as a powerful condition which was terrible, unpredictable and incurable. There is a sense of loss of control and dependence. Participants reported feeling impacted by society's negative views of epilepsy. Participants made adjustments to cope, had a desire for acceptance and understanding. Self-managing was a way to regain control and building support systems.

Authors - short	Year	Title	Topic	Study type	Country	Setting	Population	Sample size	Mean age	Outcome Measures	Summary of Relevant Findings
Ziso[9]	2017	Epilepsy management in older people: Lessons from National Audit of Seizure management in Hospitals (NASH)	Services	Observational cohort	UK	Emergency departments	PWE ≥ 60	n = 1,256	No mean provided. Median 74 (IQR range 66 - 82)	Clinical care received	80% of patients with first seizure aged 60 and over were admitted to hospital, compared to 65% under 60. Older patients received CT scans more than younger patients. Older patients received less referrals to specialists than younger patients, and this was true for people with known epilepsy, with previous seizures and first seizure presentation. Although information provision increased with age, except for the PWE group, referrals to specialists decreased with age.

PWE: people with epilepsy

Appendix 1. Quality appraisal scores

Table S1. Quality appraisal scores for quantitative studies

		Baker[32]	Bambara[71]	Baran[61]	Canuet[40]	Christensen[56]	Dilorio[52]	Erlangsen[57]	Fakhoury[47]	Fernandez[70]	Grainger[72]	Haut[42]	Kehyayan[104]	Laccheo[36]
Reporting quality	1. Is the hypothesis/aim/objective of the study clearly described?	1	1	1	1	1	1	1	1	1	1	1	1	1
	2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?	1	1	1	1	1	1	1	1	1	1	1	1	1
	3. Are the characteristics of the patients included in the study clearly described?	1	1	1	1	0	1	1	1	0	1	1	1	0
	5. Are the distributions of principal confounders in each group of subjects to be compared clearly described? (yes = 2, partially = 1, no = 0)	1	1	1	2	1	2	2	2	1	2	2	2	0
	6. Are the main findings of the study clearly described?	1	1	1	1	1	1	1	1	1	1	1	1	1
	7. Does the study provide estimates of the random variability in the data for the main outcomes?	1	1	1	1	1	1	1	1	0	1	0	1	0
	9. Have the characteristics of patients lost to follow-up been described?	1	1	1	1	1	1	1	0	1	1	1	0	1
External Validity	10. Have actual probability values been reported(e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	0	1	1	0	1	1	0	0	1	1	1	1	1
	11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	1	0	1	0	1	0	1	0	1	1	0	1	0
	12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	0	0	1	0	1	0	1	0	1	1	0	1	0
Internal Validity - bias	16. If any of the results of the study were based on "data dredging", was this made clear?	1	1	1	1	1	1	1	1	1	1	1	1	1
	17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	1	0	1	1	1	1	1	1	1	1	1	1	1
	18. Were the statistical tests used to assess the main outcomes appropriate?	1	1	1	0	1	1	1	1	1	1	1	1	1
	20. Were the main outcome measures used accurate (valid and reliable)?	1	1	1	1	1	1	1	1	1	1	1	1	1
Internal validity - confounding	21. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	1	0	1	1	1	1	1	1	1	1	1	1	0
	23. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	1	0	1	1	1	0	1	1	0	1	1	1	1
	25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	1	1	1	1	1	1	1	0	0	1	1	0	0
	26. Were losses of patients to follow-up taken into account?	1	1	1	1	1	1	1	0	1	1	1	1	1
Power	27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? (power calculation done?)	0	0	0	0	0	0	0	0	0	0	0	0	0
Total		**16**	**13**	**18**	**15**	**17**	**16**	**18**	**13**	**14**	**19**	**16**	**17**	**11**
Quality		**Good**	**Fair**	**Excellent**	**Good**	**Good**	**Good**	**Excellent**	**Fair**	**Good**	**Excellent**	**Good**	**Good**	**Fair**

Table S1 (continued). Quality appraisal scores for quantitative studies

		Leppavuori[46]	Martin[69]	May[33] 2015	McLaughlin[27]	McLaughlin[28]	McLaughlin[29]	Moran[30]	Poole[31]	Pugh[39]	Reuber[73]*	Winter[38]	Ziso[9]
Reporting quality	1. Is the hypothesis/aim/objective of the study clearly described?	1	1	1	1	1	1	1	1	1	1	1	1
	2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?	1	1	1	1	1	1	1	1	1	1	1	1
	3. Are the characteristics of the patients included in the study clearly described?	1	1	1	1	1	1	0	1	1	0	1	1
	5. Are the distributions of principal confounders in each group of subjects to be compared clearly described? (yes = 2, partially = 1, no = 0)	2	1	2	2	2	2	0	1	2	0	2	2
	6. Are the main findings of the study clearly described?	1	1	1	1	1	1	1	1	1	1	1	1
	7. Does the study provide estimates of the random variability in the data for the main outcomes?	1	0	1	1	1	1	0	0	1	0	1	1
	9. Have the characteristics of patients lost to follow-up been described?	1	0	1	1	1	1	1	1	1	1	1	1
External Validity	10. Have actual probability values been reported(e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	1	0	1	0	0	0	0	0	0	0	1	0
	11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	1	0	0	0	0	0	1	1	1	1	1	1
	12. Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	1	0	1	0	0	0	1	0	1	1	1	1
Internal Validity - bias	16. If any of the results of the study were based on "data dredging", was this made clear?	1	1	1	1	1	1	1	1	1	1	1	1
	17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	1	1	1	1	1	1	1	1	1	1	1	1
	18. Were the statistical tests used to assess the main outcomes appropriate?	1	1	1	1	1	1	0	0	1	0	1	1
	20. Were the main outcome measures used accurate (valid and reliable)?	1	1	1	1	1	1	1	1	1	1	1	1
Internal validity - confounding	21. Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	1	1	1	0	0	1	1	1	1	1	1	1
	23. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	1	0	0	0	0	1	1	1	1	1	1	1
	25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	1	0	1	0	0	1	0	1	1	0	1	0
	26. Were losses of patients to follow-up taken into account?	1	1	1	1	1	1	1	1	1	1	1	1
Power	27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? (power calculation done?)	0	0	0	0	0	0	0	0	0	0	0	0
Total		**19**	**11**	**17**	**13**	**13**	**16**	**12**	**14**	**18**	**12**	**19**	**17**
Quality		**Excellent**	**Fair**	**Excellent**	**Fair**	**Fair**	**Good**	**Fair**	**Good**	**Excellent**	**Fair**	**Excellent**	**Good**

Table S2. Quality appraisal scores for interventional quantitative studies

		McLaughlin[48]
Reporting	Is the hypothesis/aim/objective of the study clearly described?	1
	Are the main outcomes to be measured clearly described in the Introduction or Methods section?	1
	Are the characteristics of the patients included in the study clearly described?	1
	Are the interventions of interest clearly described?	1
	Are the distributions of principal confounders in each group of subjects to be compared clearly described?	1
	Are the main findings of the study clearly described?	1
	Does the study provide estimates of the random variability in the data for the main outcomes?	1
	Have all important adverse events that may be a consequence of the intervention been reported?	0
	Have the characteristics of patients lost to follow-up been described?	1
	Have actual probability values been reported(e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	0
External validity	Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	1
	Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	0
	Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	0
Internal validity - bias	Was an attempt made to blind study subjects to the intervention they have received?	0
	Was an attempt made to blind those measuring the main outcomes of the intervention?	0
	If any of the results of the study were based on "data dredging", was this made clear?	1
	In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?	1
	Were the statistical tests used to assess the main outcomes appropriate?	1
	Was compliance with the intervention/s reliable?	0
	Were the main outcome measures used accurate (valid and reliable)?	1
Internal validity - confounding (selection bias)	Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	1
	Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	1
	Were study subjects randomised to intervention groups?	1
	Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	0
	Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	0
	Were losses of patients to follow-up taken into account?	1
Power	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	0
Total		**17**
Quality		**Fair**

Table S3. Quality appraisal scores for qualitative studies

	Blank[74]	Blank[75]	Manacheril[23]	Miller[25]	Miller[26]	Sleeth[24]	Yennadiou[53]
Section A: Are the results valid?							
1.Was there a clear statement of the aims of the research?	1	1	1	1	1	1	1
2. Is a qualitative methodology appropriate?	1	1	1	1	1	1	1
3. Was the research design appropriate to address the aims of the research?	1	1	0	1	1	1	1
4. Was the recruitment strategy appropriate to the aims of the research?	1	1	0	1	0	0	1
5. Was the data collected in a way that addressed the research issue?	1	1	1	1	1	1	1
6. Has the relationship between researcher and participants been adequately considered?	0	0	0	0	0	0	1
Section B: What are the results?							
7. Have ethical issues been taken into consideration?	1	1	0	1	0	1	1
8. Was the data analysis sufficiently rigorous?	1	1	0	1	0	0	1
9. Is there a clear statement of findings?	1	1	0	1	1	1	1
Total	**8**	**8**	**3**	**8**	**5**	**6**	**9**
Quality Appraisal	**Excellent**	**Excellent**	**Poor**	**Excellent**	**Fair**	**Good**	**Excellent**

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