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**Highlights**

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Five self-management interventions for epilepsy were identified

A randomised controlled trial of a self-management intervention is currently underway

Findings suggest that self-management interventions targeted at people with ID are acceptable to this population

Pilot findings show improved epilepsy-related knowledge, improve seizure frequency, potential to improve quality of life

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Self-management interventions for epilepsy in people with intellectual disabilities: A scoping review

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## ABSTRACT

Purpose: People with intellectual disabilities (ID) experience higher incidences of chronic health conditions, poorer health outcomes, and increased risk of premature death. Epilepsy is 20 times more common in people with ID than in the general population. It tends to be more difficult to diagnose, more severe, and more difficult to treat. Improving epilepsy self-management in this group is advocated in guidelines for best practice. However, few self-management interventions exist, and a robust examination of their effectiveness is missing. Our aim was to identify existing self-management interventions for epilepsy in people with ID and to analyze their impact.

Methods: A scoping review using Arksey and O'Malley's framework was conducted. Medline, EMBASE, CINAHL, PsycInfo, OpenSIGLE, the Cochrane Database of Systematic Reviews, and Web of Science were searched from inception until June 2015. Using a piloted charting tool, selected articles were thematically analyzed.

Results: An initial search identified 570 articles, of which five met the inclusion criteria. Pilot and randomized controlled feasibility study findings suggest that self-management interventions targeted at people with ID are acceptable to this population, improve epilepsy-related knowledge, improve seizure frequency, and show potential to improve quality of life. A randomised controlled trial of a self-management intervention is currently underway.

Conclusion: Studies evaluating self-management interventions for people with epilepsy and ID are sparse. Our findings demonstrate the potential for self-management interventions to improve outcomes in this population. Controlled studies with comparable measures and longer follow-ups are needed to rigorously assess the impact of self-management interventions on this patient population.

Word count: 250/250

Keywords: Scoping review, Epilepsy, Intellectual disabilities, Self-management, Intervention

## INTRODUCTION

Compared to the general population, people with intellectual disabilities (ID) experience a disproportionate burden of illness, and are affected by twice the number of health issues [1–4]. Epilepsy is the most common neurological disorder in people with ID, with a reported prevalence of 22.2%, compared to 0.4% to 1% in the general population [2,5–10]. Epilepsy in people with ID can be more difficult to diagnose, more severe, and more difficult to treat than in the general population of people with epilepsy [11].

The clinical management of epilepsy in people with ID is complex [12]. Seizures are unpredictable, atypical and more frequent than in the general population, often refractory to treatments, and potentially life-threatening [13–15]. Seizures may also be accompanied by co-morbid mental health, sensory-motor, and communication issues [14–16]. Poorly controlled epilepsy can severely affect social relationships, work, daily activities, quality of life and mortality [17–20]. Recognising the particular needs of this population, clinical guidelines from the National Institute for Health and Care Excellence (NICE) in England, the Scottish Intercollegiate Guidelines Network (SIGN), and the International Association for Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) now emphasize the need for people with epilepsy and ID to receive appropriate information and education about all aspects of epilepsy, and to be empowered to manage their condition [21–24].

However, appropriate training and support for people with ID and their carers is rare [21,22]. Few interventions have been specifically developed to promote epilepsy management for people with ID. It is unclear how many interventions exist, what the features of those interventions are, what their impact may be, and whether these interventions are being implemented in routine clinical settings.

A systematic review of service responses to epilepsy in people with ID identified 35 studies [24]. Service responses were defined very broadly and included epilepsy reviews, epilepsy care plans, investigations, seizure diaries, medication adherence, management by proxy, risk assessment, managing prolonged or serial seizures and education for epilepsy in people with ID. Only one self-management intervention for epilepsy was included and no randomised controlled trials (RCTs) were identified [24]. As RCTs are the gold standard for evaluating interventions, this finding demonstrates a critical gap in the literature. Broader inclusion criteria, namely the inclusion of unpublished material, and a different review methodology (adapted to the state of research in this area) have been adopted in this review. The inclusion criteria and review approach allow for a comprehensive examination of completed research, research that is currently being conducted, as well as a consultation exercise, in order to accurately describe the current state of research. The overall aim of this scoping review is to identify existing self-management interventions for epilepsy targeted at people with ID, to outline their key features, and to analyze their impact.

## METHODS

### Scoping Review

The scoping review methodology is ideal for rapidly mapping relevant literature. This approach is recommended when the field of interest is complex and has not been comprehensively reviewed [25]. Scoping studies are typically used for one of four reasons; to examine the extent and nature of research activity, to determine the value of undertaking a full systematic review, to summarise and disseminate research findings, or to identify gaps in existing literature [25]. This approach was chosen to fully examine the extent and nature of research activity, beyond the published RCTs that would be included in a systematic review.

This review adopted Arksey and O'Malley's [25] rigorous framework for conducting scoping studies, comprising the following stages: (1) Identifying the research questions; (2a) Identifying relevant studies; (2b) Consultation exercise undertaken in parallel to the literature search; (3) Study selection; (4) Charting the data; (5) Collating, summarising and reporting the results [25]. The stages of this framework are similar to those of a systematic review, but all relevant literature, regardless of study design, is identified.

### Stage 1: Identifying the Research Question(s) and Operationalizing Terms

Three research questions guided this review to address current gaps in the literature:

1. What self-management interventions for epilepsy in people with ID have been developed in English?
2. What is the impact of those interventions on people with ID and epilepsy?
3. What interventions are implemented and available in routine clinical settings?

### Self-Management

For the purpose of this scoping review, we adopted Barlow et al.'s definition of self-management: 'Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life' [26].

### Stage 2a: Identifying Relevant Literature

#### Search Strategy

The following electronic databases were searched from their respective inceptions until June 2015: MEDLINE, EMBASE, CINAHL, PsycInfo, OpenSIGLE, the Cochrane Database of Systematic Reviews, and the Web of Science using the terms epilepsy, learning disability and self-management. Additional details regarding the search terms are provided in Table 1. The following key journals were searched: *Epilepsia*, *Seizure*, *American Journal of Mental Retardation*, *Epilepsy & Behavior*, *Journal of Intellectual Disability Research*. Reference lists of all included primary and review articles were manually searched for additional articles. In addition, we reviewed grey literature and searched Google, Google scholar, conference proceedings, MEDLINE In-Process and Other Non-Indexed Citations.

<Insert Table 1 Here>

## Stage 2b: Consultation Exercise

In addition to the search strategies outlined above, experts in the field were consulted to identify other unpublished research that would have evaluated, or is currently evaluating, the impact of self-management interventions for people with epilepsy and ID. Key informants were identified through discussion amongst the research team (M-AD, SM and BG) and included prominent researchers in this field, as well as representatives from Epilepsy Action, and The British Institute for Learning Disabilities.

## Stage 3: Study Selection

All articles and abstracts identified via electronic and manual searches were screened by two researchers for eligibility. Articles were included if the intervention: (1) aimed to improve epilepsy self-management in adults with ID, (2) met Barlow's definition of self-management outlined above, (3) has been or is currently being evaluated, (4) is targeted primarily at patients, and (5) is available in English. Foreign language studies and interventions were excluded because of the cost and time involved in translating them into English. Educational packages were also included if they met all inclusion criteria.

## Stage 4: Charting the Data

Prior to beginning the review process, a standard protocol with research questions, inclusion and exclusion criteria, outcomes and search strategy was developed, reviewed and approved by all authors (Supplemental File 1). The research team developed a data-charting form for the purpose of this review. Two researchers (M-AD and MD) piloted this form by independently extracting data on one study and comparing their results. Using the piloted data extraction form (Supplemental File 2), the researchers (M-AD and MD) independently extracted data on the remaining four studies, including the study's country, location, type, purpose and methodological approach. Data collected on the study methodology included sample size, inclusion and exclusion criteria, type of intervention and duration, outcome measures and results, and reported use in clinical settings. If there were missing data, the authors of the study were contacted. Differences in extraction were resolved by discussion amongst M-AD and MD to reach consensus. If consensus could not be reached, a third member of the research team (SM) was consulted.

## Stage 5. Collating, Summarizing and Reporting the Results

Extracted data was tabulated and summarized by one member of the research team (MD) to help ensure consistency in interpretation and validity of the final results. A descriptive narrative is used to present the findings according to the following themes: features of existing self-management interventions, impact, and availability.

## RESULTS

### Included Studies

An overview of the study selection process is provided in Figure 1. The initial electronic search identified 562 records. The consultation exercise yielded eight additional articles for a total of 570 records. After removing duplicates, 359 articles remained and were independently screened for relevance by two researchers (M-AD, HD). 348 articles were excluded based on title and abstract screening. Eleven full-text articles were retrieved and reviewed for inclusion by the researchers (M-AD and HD). All disagreements were resolved with the help of a third reviewer (SM). Six articles were excluded. Of these, one study did not include an intervention and five studies included interventions that did not meet the inclusion criteria. A total of five studies met all inclusion criteria, and were subsequently included in the review.

<Insert Figure 1 Here>

### Study Characteristics

Five studies concerning self-management interventions for people with ID and epilepsy were identified. A summary of included study characteristics is presented in Table 2.

<Insert Table 2 Here>

Study designs included: a feasibility RCT [27], a cluster RCT currently underway [28], a deferred entry to treatment design [29], a repeated measure design [30], and user testing with the specific study design not indicated [31]. Two studies randomized patients to a control or intervention arm [27,28]. All five studies were conducted between 2001 and 2016 in the United Kingdom. Three of the five studies have been completed and have published their results [29–31]. The feasibility RCT has been completed and unpublished results (currently under review) have been made available for inclusion in this review [32]. Results, published or unpublished, are not yet available for the cluster RCT, which is still currently underway [28].

### Participants

All studies included participants with epilepsy and ID [sample size range of 18-408]. Durand et al. evaluated an intervention among 40 adults with ID and epilepsy as part of a randomised controlled feasibility study [27,32]. Ring et al. are currently investigating the efficacy of a nurse-led management intervention among 312 adults with ID and epilepsy [28][personal communication]. Clark et al. investigated the impact of a video-assisted educational package on knowledge among 18 adults with mild ID and refractory epilepsy [29]. Codling engaged 20 people with ID and epilepsy to learn about their condition and empower them to have a voice in their care [30]. Kushinga developed and tested an English language version of the PEPE intervention with 23 National Society for Epilepsy (NSE) service users with ID [31].

### Outcome Measures

All five studies assessed outcomes through questionnaires and two studies also conducted semi-structured interviews [27,28]. All studies administered questionnaires pre and post intervention, with three studies conducting follow-up assessments [27–29]. Three studies



assessed epilepsy knowledge [29,30,31]. Three studies assessed intervention acceptability [27,29,31]. Three studies assessed seizure frequency [27,28,30]. Both RCTs [27,28] also assessed seizure severity, quality of life and conducted an economic analysis. In addition, Durand et al. assessed health-related quality of life [27]. Ring et al. also assessed carer strain; carer preferences; intervention's impact on epilepsy-nurses, family-carers, and paid-carers relationships, carer and clinician perceptions of treatment, and descriptive and contextual accounts of epilepsy services [28].

Overall, we found a lack of robust methodology and study design, small sample sizes, lack of statistical power, and a tendency for studies to present findings and draw conclusions without providing data to support these assertions. It is worth noting that four out of five studies appeared underpowered [27,29,30,31].

#### Available Self-Management Interventions

Five self-management interventions for epilepsy in people with ID were identified; a video-assisted educational package, a multi-media psycho-educative programme (PEPE), an interactive group intervention, a picture booklet, and a nurse-led management intervention (Table 3). The video-assisted package, PEPE, and the interactive group intervention (which also used PEPE) were all delivered in a group format during weekly 1 or 2-hour sessions (range 3-10 weeks). The picture booklet was used once with a research nurse for up to one hour and participants were encouraged to use the booklet twice more at home after the intervention session. The nurse-led intervention was a one-to-one session with an Epilepsy Nurse over the course of six months. Three interventions used characters (animated or paper-based) to deliver epilepsy-related information [27,30,31]. The interventions all differed in the level of ID targeted; people with mild ID [29], mild to moderate [31], mild to severe [27], and mild to profound [28]. One study did not provide detailed information about its target population [30].

<Insert Table 3 Here>

#### Interventions' Impact on People with Intellectual Disabilities and Epilepsy

##### Epilepsy Knowledge

Epilepsy knowledge was measured in three studies [29–31]. Clark et al. investigated participants' knowledge regarding seizure presentations, assessment and treatment issues and epilepsy-related precautions using the Epilepsy Knowledge Questionnaire-Learning Disabilities (EKQ-LD). The authors also created an additional measure to assess knowledge; the Epilepsy and You-Checklist (EY-C), an epilepsy knowledge checklist of 24 items based on information presented in the Epilepsy and You video. This questionnaire was not validated. Both questionnaires were self-reported [29]. The treatment group gained significantly more knowledge on the EY-C after the intervention, as compared to immediately before ( $z = -2.02$ ,  $P = 0.04$ , two tailed). No significant difference was found on the EKQ-LD ( $P > 0.10$ ) but the trend suggested an increase in knowledge for the treatment group. Epilepsy and You had a significant effect on subjects' epilepsy knowledge ( $n = 18$ ) on the EY-C across all three study time periods ( $\chi^2 = 18.75$ ,  $df = 2$ ,  $P < 0.001$ ) but not on the EKQ-LD. Participants demonstrated the largest increase in knowledge on the EY-C about what an electroencephalogram (EEG) is (72.2% of

participants answered correctly post-intervention vs. 33.3% pre intervention), and about the importance of seizure diaries (55.6% of participants post vs. 22.2% pre-intervention). Participants demonstrated a significant increase in knowledge at follow-up as compared to knowledge pre-intervention ( $z=-3.62$ ,  $P<0.001$ ), and there was no significant decline in scores between post-intervention and follow-up. Based on evaluation questionnaires, 88.9% of participants ( $n=16$ ) felt they knew more about epilepsy after completing the program, and 83.3% of participants ( $n=15$ ) thought they knew more about other people's epilepsy [29].

Kushinga measured epilepsy knowledge of PEPE project's participants ( $n=23$ ) with the Epilepsy and Your Life questionnaire, a questionnaire the authors developed for this project (but not validated) based on Epilepsy Knowledge Profile questionnaire developed by Jarvie et al. [31]. The questionnaire was self-reported. However, many individuals needed assistance completing it, which changed the evaluation method to a structured interview. Results from the paired questionnaires were rated according to change in response as showing less knowledge or giving less detail, neutral, or showing more detailed knowledge or more accuracy. The authors reported that three factual questions about epilepsy knowledge showed the most changes with more detailed information being offered by participants. This was interpreted to indicate more personal knowledge about medication, seizure type and seizure frequency [31]. No data, including the number of participants upon which this interpretation was based on, were provided.

Codling compared participants' ( $n=20$ ) knowledge before and after the intervention using the knowledge questionnaire included in the PEPE programme (not validated). In addition, the authors described using flip charts to compare changes in knowledge and understanding pre- and post-intervention. However, information about how change in knowledge was precisely assessed is not provided. The results from these measures were not reported. It is therefore impossible to scientifically infer the effect of this intervention on knowledge [30].

In summary, out of three studies that measured knowledge, only one study [29] provided a statistically significant finding that confirms the effect of the intervention on epilepsy knowledge. It is worth noting that knowledge significantly increased on the intervention-specific questionnaire but not on the validated instrument.

### Seizure Frequency

Seizure frequency was assessed by three of the five studies [27,28,30]. Participants in the My Epilepsy Group were asked to keep a diary of their seizures and record any epilepsy-related information pertinent to them [30]. Codling reported that seizure diaries showed improved seizure frequency, but did not provide any data to support this interpretation [30]. The two RCTs [27,28] also assessed seizure frequency using seizure diaries, but entries were recorded by the participant's carer (with the patient's involvement when possible). Mengoni et al. found that the intervention group had fewer seizures over the course of the study than did the control group. In the My Epilepsy Project [30] and WIELD study [32], participants were asked to record seizure occurrence during the entire study period, while participants in the EpAid study [28] recorded seizures experienced over the baseline month and over month seven (after six months in the trial).

### Epilepsy Concerns

Codling used the Epilepsy Rating Scale to compare concerns about epilepsy pre and post intervention [30]. The scale consists of a set of questions around epilepsy management, epilepsy-related injury and effects on daily living, rated on a three-point Likert scale [30]. The author states that findings from the Epilepsy Rating Scale comparison showed that people with ID sustained fewer falls and injuries on completion of the intervention, interpreting this to 'further provide evidence that people had put their learning into practice' [30]. No data were provided to support this claim.

### Intervention Acceptability

Three studies assessed intervention acceptability [27,29,31]. Clark et al. assessed participant's views of Epilepsy and You by administering an evaluation questionnaire post intervention [29]. All participants completed the questionnaire and stated that they enjoyed the program [29]. The authors did not provide further details on questionnaire results regarding acceptability.

Following each of the PEPE sessions, evaluation sheets were distributed to participants to find out what was enjoyable, difficult, or boring [31]. The author noted that participants required help completing the evaluation sheets (details on the number of participants requiring help were not provided). There was strong approval of PEPE from 20 out of the 23 respondents in Kushinga's evaluation of the intervention [31]. Themes that emerged from the questionnaires were that participants particularly liked the animated characters and found them helpful. Some respondents had positive reactions to the information provided during the course. Others found some of the information difficult, specifically "session 5 was harder this week" and "session 4 had too much writing on the text slides" [31]. Respondents also provided additional comments on social aspects related to the intervention, commenting that they had made friends and found the facilitator funny. Based on the majority of responses to all questions, participants liked the sessions overall [31]. Details regarding the type of response provided or what is meant by 'majority' are not available.

Mengoni et al. assessed intervention acceptability through qualitative interviews with a subset of patients and carers (15 sets of patient and/or carers). Thematic analysis showed high levels of acceptability of the booklet in the intervention group. Patterns of use of the booklet were also assessed at 4, 12 and 20 weeks. Results showed that 86% of participants used the booklet at least once after the intervention session, a majority of participants used it twice, and three participants never used the booklet at home. At home, use of the booklet, frequency, and time spent using it decreased over time. Interviews also revealed that participants minimally used other education and information resources.

### Quality of Life

Mengoni et al. found that the intervention group reported poorer quality of life at baseline as compared to the control group on the majority of the four Epilepsy and Learning Disabilities Quality of Life scale (ELDQOL) subscales. Adjusted means for the follow-up time-points were calculated controlling for baseline differences. Examination of effect sizes and confidence intervals indicated a positive effect from the intervention on the behaviour and mood

subscales of the ELDQOL at 4 and 20-weeks follow-up. The findings indicate a potential positive effect of the intervention on quality of life. Ring et al. are also assessing quality of life using several ELDQOL subscales and semi-structured interviews.

#### Seizure Severity

Both Mengoni et al. and Ring et al. measured seizure severity using the seizure severity scale from the Epilepsy in Learning Disabilities Quality of Life (ELDQOL-SSS). Mengoni et al. did not find that the intervention impacted seizure severity [32], but noted that the feasibility RCT was not powered to detect significant differences. The authors noted that the seizure subscale was completed only by carers of participants who experienced a seizure in the previous four weeks of assessment and that this sample was often very low: 8-11 people in the intervention group (n=21) and 10-13 people in the control condition (n=19).

#### Feasibility Outcomes: Recruitment Procedure Feasibility and Discontinuation Rates

Mengoni et al. met their target recruitment (n=40). Of the eligible screened participants, 34% were recruited into the study. The data indicate that the recruitment procedure used in the trial was feasible. Additionally, there were no discontinuations, with the exception of one death that was not related to the study [27,32].

#### Health Economic Analysis

Mengoni et al. undertook a health economic analysis, in which the cost of the intervention was estimated to be £122. Paired cost and EQ-5D-5L data were available for 29 of the 40 participants at T3, demonstrating that it was feasible to collect the economic data. Over the 20-week follow-up period, NHS costs were £87 (95% CI -376 to +550) higher for the intervention group compared to the control group. When personal social services and informal care costs were included, total costs increased substantially in both arms; however, the cost difference was not significant (-£2663, 95% CI -8480 to +3151). The mean QALY difference was 0.006 (95% CI -0.050 to + 0.038). There was no significant group difference between either the mean costs or QALY score. The authors were unable to draw conclusions as to the cost-effectiveness of the intervention until a definitive trial has been undertaken. Ring et al. are also conducting a health economic analysis using EQ-5D.

#### Additional Outcomes (Results Not Yet Available)

Additional outcomes assessed by Ring et al. include carer strain; carer preferences; intervention's impact on epilepsy nurses and family carers, and paid carers relationships; carer and clinician perceptions of treatment; and descriptive and contextual account of epilepsy services (see Table 2) [28].

#### Interventions' Availability in Routine Clinical Settings

Three self-management interventions were reported to be currently available for use in clinical settings; The Books Beyond Words booklet Getting on with Epilepsy, PEPE, and the My Epilepsy Group intervention (which includes PEPE as one of the intervention components). As of December 2015, over 4,200 Getting on with Epilepsy picture booklets have been sold [personal communication]. The National Society for Epilepsy, based in the UK, offers one-day workshops to health facilitators, learning disability nurses, supporters of self-advocacy groups,

day service workers and epilepsy specialist nurses to train them in the delivery of the PEPE package, which suggests that PEPE is being used in practice. However, details on the number of sites that use the program or the total number of PEPE facilitators trained to date could not be obtained. Codling confirmed that the My Epilepsy Group intervention is currently being used in practice [Personal communication]. Information regarding the implementation and current use of Epilepsy and You could not be found or obtained from the authors. The RCT of the EpAid intervention is still currently underway and the intervention is not yet available for routine use.

## DISCUSSION

### Main Findings

Out of 570 records identified, five articles met the inclusion criteria and were included in this review. Five studies of self-management interventions for people with epilepsy and ID were identified, three of which are currently available for use in clinical practice. The most frequently measured outcomes were epilepsy knowledge, intervention acceptability, and seizure frequency. Studies tended to be underpowered. Results were presented in a descriptive fashion, often without data available to justify the authors' conclusions, and mostly without the application of statistical tests. Reporting of outcomes varied across studies, and included self-reported (n=3) and proxy-reported methods (n=2).

Epilepsy and You is the only intervention that showed a statistically significant increase in epilepsy-related knowledge. PEPE was reported to improve participant's epilepsy-related knowledge, but no actual data were provided. According to the author, My Epilepsy Group participants showed improved seizure frequency, although no data were provided to confirm the authors' claim. Three studies [27,29,31] confirmed intervention acceptability, with two providing data [27,31]. Two studies conducted in a controlled context sought to assess the intervention's impact on seizure frequency, seizure control and quality of life. The feasibility RCT found an improvement in behaviour and mood subscales at two follow-up points, demonstrating a partially positive impact of the intervention on quality of life. Although results from the cluster RCT are not yet available, the trial is adequately powered to show statistical significance once it is completed.

The heterogeneity of the studies, small sample sizes, poor study quality and reporting of findings without providing data impede a more in-depth comparison of individual interventions and assessment of the interventions' impact.

### Strengths and Limitations

One of the main strengths of this review was the use of a five-stage framework that allows for transparency and reproducibility. Another strength is the use of two researchers to independently screen, select and extract data, as well as the inclusion of a consultation exercise. A limitation of this study is the exclusion of articles not published in English. A potential limitation is that M-AD, BG and SM are part of the WIELD study team. In order to control for potential biases or intellectual conflict of interest, data extraction and data charting

were undertaken by another researcher (MD) not involved in the WIELD study. MD also undertook the collation and synthesis of all data.

### Results in Context

Self-management interventions for people with epilepsy and ID are not the only type of intervention with paucity of effectiveness information. A recent systematic review of the broader service responses to people with ID and epilepsy found very similar results to those found in this review. Although initiatives to improve service responses to people with intellectual disabilities and epilepsy exist, their evaluation is lacking [24]. The authors of this review identified 35 studies that met their inclusion criteria, mainly of small-scale surveys, qualitative studies, and audits with no RCTs or intervention study designs of similar robustness [24]. No articles were suitable for meta-analysis [24]. The authors of this review presented findings on a very broad range of topics related to service responses, including service provision; impact of service setting; epilepsy reviews; epilepsy care plans; investigations; seizure diaries; medication adherence; management by proxy; risk assessment; managing prolonged or serial seizures; educating people with intellectual disabilities about their epilepsy; evaluations of initiatives in services; prescribing practices; and views of families, carers, or professionals regarding services. Primary findings of the review suggested that access to specialists is inconsistent and that no methodologically robust studies on service-related interventions for people with ID and epilepsy exist [24]. The research into service responses to epilepsy in people with intellectual disabilities is described as being at an 'embryonic stage' [24].

This finding is consistent with the present scoping review findings, and not surprising given that studies of interventions for people with epilepsy in the general population (who do not suffer from cognitive impairments) have also experienced challenges in determining the intervention's effectiveness. In a Cochrane review of care delivery and self-management strategies for adults with epilepsy, that included 18 different studies of 16 separate interventions, authors commented on the methodological weaknesses of included studies [33]. Another Cochrane review, of psychological treatments for epilepsy, also determined that the methodological quality of many included studies was poor [34]. However, the present scoping review also indicates that this area of research is slowly evolving. Since Robertson's review, two randomised controlled trials have been undertaken, one of which is still underway and is adequately powered to demonstrate statistical significance.

The state of research in this area demonstrates that efforts are being made to improve epilepsy care, but overall there are difficulties with conducting rigorously designed studies. Study recruitment of people with epilepsy and ID is particularly difficult, given the ethical challenges around obtaining consent from participants who may not have the capacity to consent or the ability to properly communicate their wishes, depending on the participant's level of disability.

The level of ID also poses challenges in comparing outcomes, as there is variability of ID across studies and people with less severe ID are likely to have less severe epilepsy, which is more amenable to treatment and more likely to achieve better outcomes [19]. Defining how self-management may be achieved is also difficult, as people have different capabilities based on

their level of ID. A lack of validated questionnaires on self-management and knowledge provide additional barriers to assessing and comparing outcomes amongst this patient population [24].

#### Implications for future work

Additional controlled and adequately powered research is needed to confirm findings of the evaluations of self-management interventions presented in this review. One study [29] demonstrated an increase in epilepsy knowledge over a short follow-up (one month). Future studies should consider including longer follow-up periods to measure self-management interventions' effectiveness. The feasibility RCT, with a follow-up period of 20 weeks, demonstrates that longer follow-ups are indeed possible in this patient population and that a potential positive effect on quality of life was found at 20 weeks. Also needed are studies to investigate the efficacy of interventions with different severity of ID, given that three of the studies reviewed here only included people with mild ID.

#### CONCLUSIONS

Research regarding self-management interventions for epilepsy and their impact is sparse, but progressing, with an effort to adequately power studies and use control groups. Robertson's review of service responses for epilepsy in people with ID identified one self-management intervention. The present study found five, two of which are being or have been conducted in controlled contexts. Despite small sample sizes and heterogeneous designs and measures used, included studies showed improvement in epilepsy knowledge, seizure frequency and a potential positive effect on quality of life. Based on evaluation questionnaires and semi-structured interviews, three interventions demonstrated good acceptability.

Health policy and clinical guidelines emphasize the need to equip and empower patients with epilepsy and ID to self-manage their condition. To guide future research and intervention development that can respond to this need, larger and more carefully designed studies are required to assess the effect of self-management interventions on this patient population.

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#### Author contributions

M-AD planned and designed the study, protocol, and data extraction chart. MA-D conducted the search and selection process with a Research Assistant. MD and M-AD extracted all data. M-AD provided advice and guidance on the analysis and interpretation of results. MD and MA-D drafted the manuscript. All authors contributed to writing and approved the final draft of the manuscript.

#### Conflicts of interest

MA-D, BG and SM are part of the WIELD study team.

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Figure 1. Flowchart of studies from identification to inclusion

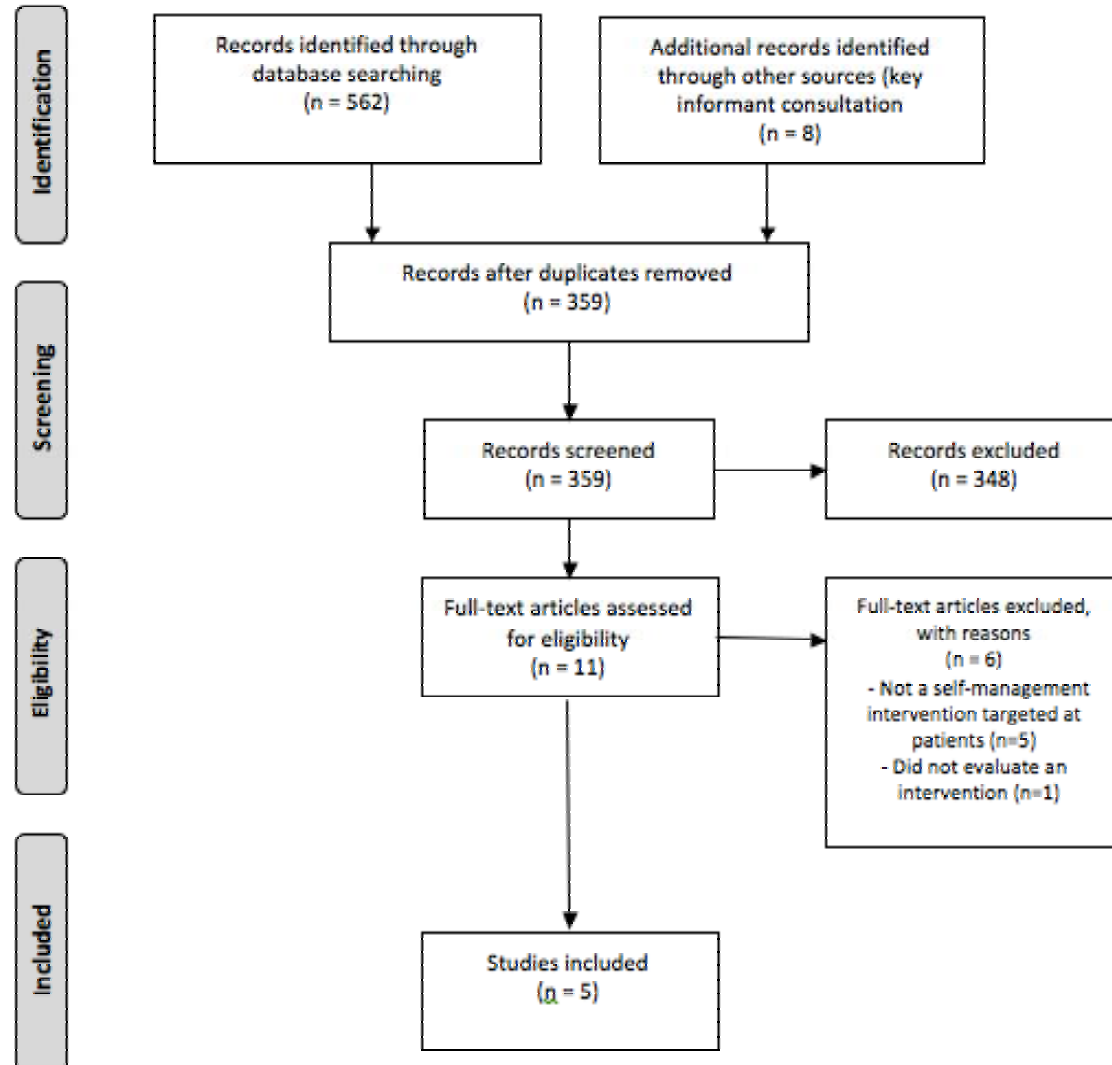


Table 1. Search terms

| Condition 1         | Condition 2             | Intervention         |
|---------------------|-------------------------|----------------------|
| Search operator     | AND                     | AND                  |
| Epilepsy            | Learning disability     | Health education     |
| Epilepsy/psychology | Intellectual disability | Education            |
| Epilepsy/nursing    | Learning disorders      | Knowledge            |
|                     | Cognitive impairment    | Risk evaluation      |
|                     |                         | Self-management      |
|                     |                         | Caregivers/education |
|                     |                         | Intervention         |
|                     |                         | Self Care/methods    |
|                     |                         | Disease management   |
|                     |                         | Training             |

Table 2. Characteristics of included studies

| Author, year [Ref]  | Intervention                   | Study design and aim  | Participants  | Outcome and measurement  | Follow-up | Findings   |
|---------------------|--------------------------------|---|---|--|-----------|--|
| Clark, 2001 [29]    | Epilepsy and You               | Quasi experimental: Deferred entry to treatment design to evaluate a video-assisted brief educational package for adults with mild ID and epilepsy                                  | N=18; Mixed sex, predominantly mildly learning disabled adults, of which a majority had refractory epilepsy and were being treated with anti-epileptic drug poly-therapy. | <p>Epilepsy knowledge</p> <ul style="list-style-type: none"> <li>• Measure: EKQ-LD + EY-C</li> <li>• Assessment: Pre and post intervention</li> </ul> <p>Intervention acceptability</p> <ul style="list-style-type: none"> <li>• Measure: Evaluation Questionnaire</li> <li>• Assessment: Post intervention</li> </ul>   | 4 weeks   | <ul style="list-style-type: none"> <li>• The TG gained significantly more knowledge on the EY-C (<math>z = -2.02</math>, <math>P = 0.04</math>, two tailed). No significant difference using the EKQLD (<math>P &gt; 0.10</math>). Trend suggested an increase in knowledge for the TG knowledge increased on the majority of items post intervention. Knowledge about what an EEG is and about the importance of seizure diaries</li> <li>• All participants stated that they enjoyed Epilepsy and You</li> </ul> |
| Codling, 2010, [30] | My Epilepsy Group intervention | Quasi experimental: Repeated measure design to enable people with ID and epilepsy to engage in learning about their epilepsy and hence, empower them to have a voice in their care. | N=20; People with learning disabilities and epilepsy, all with capacity to consent  | <p>Seizure control</p> <ul style="list-style-type: none"> <li>• Measure: Seizure diary</li> <li>• Assessment: Pre and post intervention</li> </ul> <p>Epilepsy knowledge</p> <ul style="list-style-type: none"> <li>• Measure: PEPE knowledge questionnaire and flip charts</li> <li>• Assessment: Pre and post intervention</li> </ul> <p>Concerns about epilepsy</p> <ul style="list-style-type: none"> <li>• Measure: Epilepsy rating scale</li> <li>• Assessment: Pre and post intervention</li> </ul> | NA        | <ul style="list-style-type: none"> <li>• Improved seizure frequency</li> <li>• Increased awareness about risk, demonstrated by participant's account of strategies devised to minimize risk</li> <li>• People with epilepsy sustained less falls and injuries on completion of the group</li> </ul>  |

|                   |   |   |   |  |   |  |
|-------------------|---|---|---|--|---|--|
| Durand, 2014 [27] | The Books Beyond Words Getting on with Epilepsy | Feasibility RCT to explore key methodological, design and acceptability issues, in order to subsequently undertake a large-scale randomized controlled trial of the Books Beyond Words booklet for epilepsy in adults with learning disabilities. | N=40; Male and female adult patients with confirmed clinical diagnoses of epilepsy (at least one seizure over the past 12 months) and learning disability (significantly below-average general intellectual functioning, and an IQ below or equal to 70). | <p>Quality of life</p> <ul style="list-style-type: none"> <li>• Measure: ELDQOL</li> <li>• Assessment: Baseline and follow-up assessments</li> </ul> <p>Seizure control</p> <ul style="list-style-type: none"> <li>• Measure: seizure diary</li> <li>• Assessment: follow-up assessment</li> </ul> <p>Seizure severity</p> <ul style="list-style-type: none"> <li>• Measure: ELDQOL-SSS</li> <li>• Assessment: Baseline and follow-up assessments</li> </ul> | <p>4 weeks</p> <p>12 weeks</p> <p>20 weeks</p> <p>20 weeks</p> <p>4 weeks</p> <p>12 weeks</p> <p>20 weeks</p> | <ul style="list-style-type: none"> <li>• Intervention group had fewer seizures 13.78 (95% CI -0.36-35.61) compared to control group 17.63 (95% CI 1.73-25.83)</li> <li>• High levels of acceptability of the booklet in the intervention group</li> <li>• Intervention did not impact seizure severity</li> <li>• No significant difference between either the mean costs or QALY score for the intervention group compared to the control group.</li> </ul> |
|-------------------|---|---|---|--|---|--|

Table 2. Continued

| Author, year [Ref] | Intervention | Study design and aim | Participants | Outcome and measurement   | Follow-up  | Findings  |
|--------------------|--------------|----------------------|--------------|---|--|---|
| Durand Contd       |              |                      |              | <p>Economic analysis</p> <ul style="list-style-type: none"> <li>• Measure: Context specific resource use questionnaire and the EQ-5D-5L scale</li> <li>• Assessment: Baseline and follow-up assessments</li> </ul> <p>Intervention acceptability</p> <ul style="list-style-type: none"> <li>• Measure: Qualitative interviews</li> <li>• Assessment: Post intervention</li> </ul> <p>Recruitment procedure feasibility and acceptability</p> <ul style="list-style-type: none"> <li>• Measure: Semi-structured qualitative interviews</li> <li>• Assessment: Post intervention</li> </ul> <p>Use of other epilepsy-related information</p> <ul style="list-style-type: none"> <li>• Measure: Semi-structured qualitative interviews</li> <li>• Assessment: Post intervention</li> </ul> <p>Discontinuation rates</p> <ul style="list-style-type: none"> <li>• Measure: # participants that opt-out of study</li> <li>• Assessment: Over course of study</li> </ul> <p>Patterns of use of booklet</p> <ul style="list-style-type: none"> <li>• Measure: Questionnaire</li> </ul> | <p>4 weeks</p> <p>12 weeks</p> <p>20 weeks</p> <p>20 weeks</p> <p>20 weeks</p> <p>20 weeks</p> <p>4 weeks</p> <p>12 weeks</p> <p>20 weeks</p> <p>4 weeks</p> <p>12 weeks</p> | <ul style="list-style-type: none"> <li>• Recruitment procedure was feasible with no discontinuations</li> </ul> |

|                     |  |   |  | • Assessment: Post intervention   | 20 weeks |  |
|---------------------|--|---|--|---|----------|--|
| Kushinga, 2007 [31] | Psycho-Educative Programme about Epilepsy (PEPE) | Development and testing an English language version of PEPE | N=23; Service users with ID, including those who had epilepsy - people with good verbal understanding and expressive skills were most likely to volunteer. | <ul style="list-style-type: none"> <li>• Assessment: Pre and post intervention</li> </ul>         | NA       | <ul style="list-style-type: none"> <li>• Increased personal knowledge about medication, seizure type and seizure frequency</li> <li>• Strong approval (n=20/23)</li> </ul> |
|                     |  |   |  | <ul style="list-style-type: none"> <li>• Measure: Epilepsy and Your Life questionnaire</li> </ul> |          |  |
|                     |  |   |  | <ul style="list-style-type: none"> <li>• Intervention acceptability</li> </ul>                    |          |  |
|                     |  |   |  | <ul style="list-style-type: none"> <li>• Measure: Evaluation sheets</li> </ul>                    |          |  |
|                     |  |   |  | <ul style="list-style-type: none"> <li>• Assessment: Post individual sessions</li> </ul>          |          |  |

Table 2. Continued

| Author, year [Ref] | Intervention | Study design and aim  | Participants   | Outcome and measurement  | Follow-up                              | Findings  |
|--------------------|--------------|---|--|--|--|---|
| Ring, 2014 [28]    | EpAID        | Cluster RCT<br><br>To establish whether nurses with expertise in epilepsy and intellectual disabilities (ID), working to a defined clinical role, can improve clinical and quality of life outcomes in the management of epilepsy in adults with (ID) compared to treatment as usual. | N=312; Adults (male and female), aged 18 – 65 years. All participants will have a developmental intellectual disability associated with an IQ of 70 or less and a diagnosis of epilepsy with a history of at least one seizure in the six months preceding recruitment into the study. | <p>Seizure severity</p> <ul style="list-style-type: none"> <li>• Measure: ELDQOL-SSS</li> <li>• Assessment: Collected for one month baseline period and again for one month after six months</li> </ul> <p>Seizure frequency</p> <ul style="list-style-type: none"> <li>• Measure: Number of seizures per month</li> <li>• Assessment: baseline and after six months</li> </ul> <p>Quality of life</p> <ul style="list-style-type: none"> <li>• Measure: ELDQOL subscales</li> <li>• Assessment: baseline and after six months</li> </ul> <p>Carer strain</p> <ul style="list-style-type: none"> <li>• Measure: Carer Index Strain</li> <li>• Assessment: baseline and after six months</li> </ul> <p>Carer preferences</p> <ul style="list-style-type: none"> <li>• Measure: Mean willingness to pay values</li> <li>• Assessment: baseline and after six months</li> </ul> <p>Mood and behavior side effects</p> <ul style="list-style-type: none"> <li>• Measure: ELDQOL subscales</li> </ul> | 4 weeks post intervention (at month 7) | <ul style="list-style-type: none"> <li>• Results not yet available</li> </ul> |



for side-effects

- Assessment: Collected for one month pre randomization and for one month six months post randomization
- Intervention impact on EN and family/paid carers relationships
- Measure: Series of qualitative semi-structured interviews
  - Assessment: not specified

Table 2. Continued

| Author, year [Ref] | Intervention | Study design and aim | Participants | Outcome and measurement   | Follow-up | Findings |
|--------------------|--------------|----------------------|--------------|---|-----------|----------|
| Ring<br>Contd      |              |                      |              | Cost-utility analysis <ul style="list-style-type: none"> <li>• Measure: Client Service Receipt Inventory, EQ-5D</li> <li>• Assessment: Collected for one month pre randomization and for one month six months post randomization</li> </ul> Carer and clinician perceptions of treatment <ul style="list-style-type: none"> <li>• Measure: Client Service Receipt Inventory</li> <li>• Assessment: Collected for one month pre randomization and for one month six months post randomization</li> </ul> Intervention impact on relationships between EN and family/paid carers <ul style="list-style-type: none"> <li>• Measure: Series of qualitative semi-</li> </ul> |           |          |

structured interviews

- not specified
- Descriptive and contextual account of epilepsy services

- measure: (1) the EN role questionnaire (2) Community ID team epilepsy service questionnaire (3) EN self-completion diary
- assessment of all: during baseline period
- assessment of EN diary: collected during trial

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FU: Follow-up, TG: Treatment group, EN: epilepsy nurse, ID: Intellectual disability, RCT: Randomised controlled trial, PEPE: Psycho-Educative Programme about Epilepsy. EY-C: 'Epilepsy and You' Checklist, EKQ-LD: Epilepsy Knowledge Questionnaire-Learning Disabilities. ELDQOL: The Epilepsy and Learning Disabilities Quality of Life scale, ELDQOL-SSS: seizure severity subscale from the Epilepsy in Learning Disabilities Quality of Life

Table 3. Overview of self-management interventions for epilepsy in people with ID

| Name, Intervention producer, year   | Description  | Components   | Content  | Format   | Frequency & Length   | Type of ID       |
|---|--|--|--|--|--|------------------|
| Epilepsy and You Paul, 1996   | Video assisted educational package designed for, and by adults with a learning disability and epilepsy.  | 10 minute video + discussion   | Information about epilepsy and how it presents, medication and safety issues, and the importance of seizure diaries  | Group  | 3 one-hour sessions  | Mild             |
| PEPE – English language version, NSE, 2007  | PEPE is designed for people with learning disabilities, empowering them to have more control over their epilepsy through greater knowledge and understanding.      | Multi-media course that includes real and animated film clips, text, mini quizzes and photographs.                     | About epilepsy, from seizure types to medication, risks associated with epilepsy, employment, leisure, housing, feelings about epilepsy and relationships.   | Group<br>Delivered by a trained facilitator                        | 8 two-hour sessions  | Mild to moderate |
| The My Epilepsy Group intervention, Codling, 2011                                       | My Epilepsy Group approach is an active learning approach for people with epilepsy and ID  | PEPE programme (described above) + group discussions, role play, videos and pictures                                   | How to take medication, compliance and side effects.   | Group  | 10-weekly meetings   | Unclear          |
| The Books Beyond Words booklet Getting on with Epilepsy [Beyond Words Publishing, 1999] | Picture booklet designed to support epilepsy self-management in adults with mild to severe ID.   | Picture booklet  | Uses pictures to tell the story of a young man with learning disabilities and epilepsy who progressively learns to better manage his condition and recurrent seizures  | Participant uses it with a research nurse and their carer in study | 1 session with research nurse (up to one hour) + encouraged to use twice at home | Mild to severe   |
| EpAID, Ring, 2014   | Epilepsy Nurses (ENs) work to a defined competency-based role, based on the Learning Disability Epilepsy Specialist Nurse Competency Framework for adults with ID. | ENs will engage in the following:<br>1. Relationship with patients and carers<br>2. Relationship with other clinicians | Engage with patient and carers through regular collection of clinical information including seizure frequency, side effects, behavioral symptoms and effects of seizures on daily lives of patient and their carers. ENs will also facilitate communication participant's primary care health service, local community ID health team and/or local | Trained ENs  | 6 months   | Mild to profound |

neurology service as required

EN: Epilepsy nurse, ID: Intellectual disabilities, WIELD: Wordless Intervention for Epilepsy and Learning Disability

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