Review

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

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A B S T R A C T

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.

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1. 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 0.4–1% 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].

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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.

2. Methods

2.1. 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.

2.2. 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?

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].

2.3. Stage 2a: Identifying relevant literature

2.3.1. 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.

2.4. 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.

2.5. 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.

2.6. 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

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