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Journal Pre-proof

Who cares? A scoping review on intellectual disability, epilepsy and social care

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Highlights

- Social care impacts on health outcome of people with intellectual disabilities (PWID)
- A significant minority of PWID have drug resistant lifelong epilepsy & social needs
- We explore key areas of social provision required in meeting needs in PWID & epilepsy
- This scoping review identifies four themes which require social care involvement
- Themes include holistic care, staff education, basic & emergency epilepsy training

Journal Pre-proof

Review

Who cares? A scoping review on intellectual disability, epilepsy and social care

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Statements and Declarations including competing interests

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Ethics Statement

We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Author Contributions

All authors satisfy the ICMJE guidance by substantially contributing to the design, analysis and interpretation of the work, drafting of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work is appropriately investigated and resolved.

Data statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Abstract

Purpose: Nearly a quarter of people with Intellectual disability (PwID) have epilepsy. Many have seizures across their lifetime. In the UK supporting their epilepsy linked risks and needs, particularly in professional care settings and in the community, requires significant social care input. Therefore, the interface between social and health care services is important. This study aim is to identify key intersectional areas of social provision for PWID and epilepsy.

Methods: A scoping review of the literature was performed in accordance with PRISMA guidance with suitable search terms. The search was completed in CINAHL, Embase, Psych INFO, SCIE, and Cochrane electronic databases by an information specialist. A quality

assessment was completed for the included studies where appropriate. The included studies were analysed qualitatively to identify key themes and provide a narrative description of the evidence by two reviewers.

Results: Of 748 papers screened, 94 were retrieved. Thirteen articles met the inclusion criteria with a range of methodologies. A thematic analysis generated four key categories for significant social care involvement i.e., staff training and education; emergency seizure management; holistic approach to care; and nocturnal monitoring and supervision.

Conclusions: PwID with epilepsy have support needs that require fulfilling by various aspects of special care provision, many within the social ambit. In spite of evidence of these needs and recurrent calls to work jointly with social care providers this has not happened. There is limited research into social care role in epilepsy management in PwID which needs addressing.

Keywords: Social care, SUDEP, basic epilepsy training, emergency seizure management, staff training, nocturnal monitoring

1. Background

Epilepsy is one of the more common neurological disorders in the general population, affecting around 50 million people worldwide (1). It affects 22.2% of people with intellectual disabilities (PwID) (2). PwID and epilepsy often have seizures that are less well-controlled, of multiple types and are more likely to be resistant to single-drug treatments (3). This population has increased levels of physical and psychological comorbidity (4-6). Polypharmacy is common, including psychotropic and anti-seizure medications (4-6). Their health risks also increase with ageing. PwID and epilepsy who are over 40 years old have higher levels of risk factors associated with comorbidities, polypharmacy and iatrogenic harm (7).

Premature mortality is increased in PwID and is particularly higher in people with both epilepsy and ID (8). The risk of Sudden Unexpected Death in Epilepsy (SUDEP) is increased in PwID, and epilepsy compared to epilepsy alone (9). Epilepsy is also one of the most common reasons for avoidable hospital admissions in PwID (10). There are additional care needs for those with co-existing epilepsy, including managing epilepsy risk factors, ensuring good seizure reporting, and having a good governance framework to ensure medications are given safely.

PwID are entitled to the support they need to enable them to attain a good quality of life. Social care professionals in the UK work according to the principles of the Care Act to support the complex needs of PwID in the community (11) using a person-centred approach which promotes independence, autonomy and social inclusion and aims to reduce health inequalities (12) by working as a conduit between PwID and proactive healthcare.

The social care role also includes offering assessments, care planning and information relating to finances, housing and other areas essential to everyday life (12).

This scoping review aims to identify the key intersectional areas of social care provision for PwID and epilepsy.

2. Methods

A scoping review of the literature was performed and reported in accordance with PRISMA guidance. The search method details are provided in supplementary information 1.

2.1. Search strategy

The search strategy was designed by the project team and implemented by a health information specialist using CINAHL (EBSCO), Embase (Ovid), PsycINFO (ProQuest), SCIE, Cochrane, and Google Scholar. A further search of SocINDEX did not identify any further relevant papers. Text terms and subject headings were combined with Boolean operators, with subject headings adjusted for each database. No limits were applied. The terms were developed around the health conditions of interest, i.e., epilepsy and Intellectual

disabilities (e.g., epilepsy, seizure, learning disabilities, intellectual disabilities, developmental disorder) and terms relating to social care (e.g., social care, social support, (epilepsy) care plan / rescue plan / awareness training / risk assessment).

The full search strategy can be found in supplementary information 2.

2.2. Article selection

Following the removal of duplicates, the remaining articles were screened for relevance, i.e., that they discussed the following topics: 1) intellectual disability, 2) epilepsy/seizures, and 3) social care. This first screen was performed by one reviewer. The second and third screens were performed by two reviewers. Articles were excluded where the aforementioned topics were not a primary focus (Reason 1). There was no limit for language at the search stage. However, during article selection it was not possible for the reviewers to read two articles for which the full text was only available in a different language (German and Norwegian), which were thus excluded from the review (Reason 2). Conference abstracts and presentations were also excluded, where there was no accompanying paper (Reason 3). Where there was discrepancy, this was discussed between the two reviewers and the senior author consulted for any conflicts. The reference lists for the included articles were then screened by the first reviewer and those felt to be relevant screened again by both reviewers. FLOWCHART (supplementary information 1)

2.3. Quality assessment

The articles included non-empirical articles, mixed methods studies, and quantitative descriptive studies. The quality of the data of the empirical articles was assessed using the Mixed Methods Appraisal Tool, which was the most appropriate scoring system given the heterogeneous nature of the articles. This was visualised as a star system, from one star (lowest quality) to five stars (highest). The non-empirical articles, as identified by the screening questions of the tool were not assessable, because there was not a clear research question.

3. Results (Table 1)

The search identified 895 articles, which were reduced to 815 following removal of duplicates using Endnote, and again to 748 following manual removal of the remaining 67 duplicates. The first screen reduced this number to 94. One article (a case report) could not be found by the first reviewer nor their institutional library, and thus could not be included in the further screening process. The second and third screens identified 10 articles to be included. Three further articles were identified through screening of the reference lists.

The 13 articles identified comprised of a literature review, four educational articles each summarising a report or guidance, three service evaluations/audits and five empirical studies. The designs of the five empirical studies were a case-control study, a cross-sectional analytic study, two cross-sectional surveys, and a cohort study. Nine of the articles were from the United Kingdom, two articles were from the Netherlands, and one was from Germany. Table 1 provides details of the article, article type, study population and the assessed quality of the publication.

Post content analysis, coding and agreement between reviewers, four themes emerged from the articles relevant to the topic of social care i.e., staff training and education, emergency seizure management in the community, holistic care and nocturnal supervision and monitoring. Where multiple themes have been identified, papers are discussed under their dominant theme.

It was agreed that the term “social care professional” is used for those who are specifically employed by the State to co-ordinate and deliver on statutory social need. Anyone else in a non-clinical paid care role are referred to as “care staff or paid professionals”.

3.1. Staff training and education

Five articles primarily discussed the need for training and education on epilepsy for social care staff: a literature review(13), a summary of the guidance developed by an epilepsy specialist group to support carers of PwID and epilepsy (14), an opinion piece positing the role of epilepsy specialist nurses in such education(15), a report on the recommendations made following an international online survey of professionals and family members by the International League Against Epilepsy (ILAE) and International Bureau for Epilepsy (IBE) (16), and a summary of recent advances in epilepsy and their implications on health and social care for PwID (17). The articles suggest that the training include general epilepsy education, education on the risk factors posed by epilepsy in PwID and how to manage them and seizure management protocols.

3.2. Emergency seizure management in the community

Three papers focussed on the need for training in emergency seizure management in the community. Two papers utilised cross-sectional surveys to evaluate their training programmes for social care staff on epilepsy awareness and the use of rectal diazepam (18, 19). These articles mainly described their service improvement programmes rather than providing empirical data. Further, these studies are pre-2005. Since then, buccal midazolam is now the primary medication for community emergency seizure management. The Care Quality Commission UK currently states that care home staff where PwID and epilepsy live should be trained to administer both (20).

The third article utilised a telephone survey of the managers of care homes for PwID to assess whether their staff were trained in the emergency administration of seizure rescue medication (21).

3.3. Holistic care

A cohort study assessed the effectiveness of a residential rehabilitation programme in Germany for young adults with epilepsy and mild ID (22). This study utilised rating scales to operationalise subjective concepts, such as quality of life, and undertook statistical significance testing. The scales used were based on the Performance, SOciodemographic aspects, Subjective evaluation questionnaire (previously developed in the Bethel Institute), the D-S' (Depressivitäts-Skala) depression scale and the German version of the Symptom Checklist 90-R (SCL-90-R). However, there was no control group, and it is difficult to know if the results would be generalisable. Intelligence quotients (IQ) were only available for 13 of the clients and the average was 74.6. This is above the usual IQ scores (55 -70) usually used to consider mild ID (23). There were no subgroup data reported for PwID with IQ less than 70.

The ILAE (2018) undertook a survey of healthcare professionals working with PwID and epilepsy to gain insights to the provision of care for this population (24). This sample did not include social care professionals. This survey had a wide scope and highlighted the impact of epilepsy on the quality of life of PwID, the need for collaboration with epilepsy specialist nurses to provide training and for up to date and easily accessible resources for carers.

3.4. Nocturnal supervision and monitoring

A service evaluation survey of family and residential carers for PwID and epilepsy under a specialist adult ID and epilepsy service in Cornwall UK investigated the retention of SUDEP risk advice and the use of nocturnal monitoring (25). The authors were concerned that their findings could reflect a lack of awareness of SUDEP risk factors among care home staff and that, as a result, PwID and epilepsy in residential care may be more likely to be failed than those living with their families. This survey relied on carer reporting for consistency. However, this could particularly influence the residential group due to the likelihood of multiple care staff looking after one person.

Two studies by a Dutch group looked at nocturnal supervision in residential care settings for PwID and epilepsy (26, 27). The nested case-control study in two residential units (27)

selected 198 controls for the 60 cases of SUDEP found that were matched for age and residential unit, with a view to increasing the statistical confidence and for reducing bias. The retrospective technique had limitations in that there could be gaps in records. There was a significant difference between the supervision levels in the two centres ($p = 0.001$) and the centre with the lower level of supervision had the higher number of SUDEP cases (35 compared to 25). However, there did not seem to be an analysis to determine if the difference in the number of SUDEP cases between the centres was statistically significant.

The second paper assessed the value of overnight video monitoring in detecting nocturnal seizures in a unit that provides care for people with refractory epilepsy and severe ID (26). The sample was representative of their target population i.e., all 46 residents who had been recommended by the Dutch Health and Care Inspectorate for use of video monitoring were asked to participate (of the overall 340 residents in the unit) and 41 participated. The authors concluded that while video monitoring facilitated nocturnal surveillance, the cost of providing it (compared to acoustic detection systems and bed motion sensors already in use) outweighed its clinical value. Further, the authors speculated that human error may be inherent when multitasking to monitor several screens and performing any additional duties. It is not clear whether the video monitoring was used according to its recommendations – for example, the staff to monitor ratio.

4. Discussion

During the screening process, it became evident that there were papers on one or two of the key areas of social provisions, community care, PwID and epilepsy, but few on all together. The articles were generally of a lower quality of evidence due to the inherent limitations of their study designs and the majority were non-empirical. The empirical studies were of small samples, usually confined to one geographical area or institution, and it is therefore difficult to know if their results are generalisable. Noticeably, the papers included originated from the UK and countries in Western Europe. There were no papers from countries with other healthcare systems including United States of America or Australia. The study of international professionals (24) and the article reporting on a similar survey (16) acknowledged that their respondents were mainly from the UK. Additionally, the response rates were low, increasing the risk of bias in the sample towards those with a greater interest in the subject.

These articles draw attention to the social care needs of PwID and epilepsy and the lack of research in this area. There has been seemingly little progress in the last 20 years, with articles at the start of this period and till more recently calling for more attention in the same areas such as, adequate training for care staff, which remains a prevalent theme. This was established in this review as part of a larger theme of the importance of communication and collaboration between health and social care services in delivering effective holistic care. A lack of competence and training in administering emergency antiseizure medications by non-clinical care staff caring for PwID and epilepsy was highlighted. It is recommended that residential care homes who care for people with epilepsy have staff trained in the administration of both buccal midazolam and rectal diazepam (20). This was shown to often not be the case in the papers discussed. The lack of research on care providers and training involving buccal midazolam, which is preferred and effective is glaring (28).

The two papers written in collaboration with epilepsy and ID groups such as the ILAE cover several themes including education, training and holistic care (16, 24). They recommend that professional groups take responsibility for developing and administering such training and information. Delivering and maintaining training would require active involvement of social care professionals. Increasing awareness of the greater risks faced by those with PwID and epilepsy may help promote engagement. A collaborative approach and information sharing between specialist healthcare and social care teams would be helpful, both for the individuals

in their care and to enable effective education. It is worth mentioning the lack of social care professional input into the ILAE survey (24). Perhaps this is representative of the more widespread problem of omitting social care from discussion around physical health and epilepsy-related issues in PwID.

A systematic and comprehensive approach is required to standardise training. Utilising technology could help to achieve this (29). Previous guidance on the delivery of such training by the Joint Epilepsy Council, which was disbanded in 2016, was not robust enough to allow for consistency in quality of the training received (29). A UK-wide consensus process of expert groups developed national guidelines on basic epilepsy awareness and seizure medication to address this gap (30). This could also be applied to the training of staff who care for PwID.

Nocturnal monitoring is an important modifiable risk factor for SUDEP (31). The National Institute for Health and Care Excellence recommends that clinicians discuss the risk of SUDEP with all people with epilepsy. It is recommended to discuss introducing or increasing night-time supervision for those at a higher risk of epilepsy-related death or have nocturnal seizures (32). This is of even greater importance in PwID and epilepsy due to their higher risk of SUDEP (9).

Awareness of SUDEP and its association with nocturnal seizures and mitigation via nocturnal surveillance are potentially modifiable risk factors. It is therefore of vital importance for PwID and epilepsy in residential care settings that this risk be communicated and mitigated. A recent study in a London Borough looking at 137 PwID and epilepsy identified that of the 103 contacted none (patient and/or carer) was SUDEP aware. The study also showed that 45% ($n = 46$) had nocturnal seizures and over a fifth (22%) did not have any nocturnal surveillance of any kind. (5). Another multicentre study across England and Wales found that only 61% of 904 PwID and epilepsy had a documented discussion regarding SUDEP, and this was less likely in those with mild ID or with their care stakeholders (4).

As was acknowledged by the Dutch study monitoring does have financial implications (26), and the type of monitoring and the implementation of this should be on an individual basis after a thorough risk assessment.

Recommendations for future research following this scoping review are summarised in Table 2.

4.1. Limitations

Limitations to this scoping review included the language barrier, which meant that two articles were not able to be screened further and potentially included in the review. Given that the search terms were also in English, relevant articles in other languages that did not include an English abstract or keywords would not have been identified. However, it is unlikely any substantial index linked work would have been missed.

The search terms were compiled to be as inclusive and broad as possible, and this generated a large number of articles. However, it is possible that other terms were not selected that may have cast a wider net. Using broad terms resulted in many articles in the field of healthcare rather than social care, which were not directly relevant to this review, however this increased the likelihood of picking some relevant articles as well. Articles that only discussed the caregiver burden were not included; however, this is another important area to consider. Four additional papers not selected for the review but of supportive interest focus on the development of nocturnal monitoring devices and their accuracy (33-36). The populations for these studies were PwID and epilepsy in residential care. These papers were not included in this review because they were focussed on the technology itself and not sufficiently focussed on its application in social care to meet our review criteria. However, they are important and linked to this topic. Also, no papers which investigated core social matters such as housing and finance were identified specific to PwID and epilepsy.

5. Conclusion

This scoping review highlights the small number of voices calling for greater attention to the social care needs of PwID and epilepsy, who are at high risk of multi-morbidity, polypharmacy and premature mortality. There needs to be more high-quality research into reducing the community-based risks for this vulnerable population. Greater awareness of their risks and engagement in community and mitigating them is required by the social care sector. Social care professionals are well placed to advocate for their clients' needs and alert specialist healthcare teams to changes in their status. Consistent training of social care professionals and collaboration between health and social care would help to allow these risks to be mitigated. Good social care provision could ultimately reduce unnecessary hospitalisations, healthcare costs and premature mortality, as well as improve quality of life in this vulnerable group.

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Table 1: Selected studies results and quality marking

Article	Article type	Study P population	Themes	Findings	Key messages relevant to this review	Quality Assessment
Bowley & Kerr, 2000 (Wales) (13)	Review (Non-empirical)	Not applicable	1. Staff training and education 2. Emergency seizure management in the community	<ul style="list-style-type: none"> There is a lack of research on care provision for PwID and epilepsy 	<ul style="list-style-type: none"> Epilepsy can be a barrier to accessing healthcare Important areas for research include staff training needs and acute seizure management protocols 	Not assessable
Codling et al, 2019 (UK) (14)	Professional communication (non-empirical)	Not applicable	1. Staff training and education	<ul style="list-style-type: none"> Not applicable 	<ul style="list-style-type: none"> Summarised guidance for carers, including on risk factors It is important to try to include service users in 	Not assessable

					risk assessments	
Deepak et al., 2012 (England) (21)	Cross-sectional survey (quantitative descriptive)	Managers of care homes for people with ID ($n = 21$) in one UK region (High Wycombe)	1. Emergency seizure management in the community 2. Staff training and education	<ul style="list-style-type: none"> Of the 11 care homes had residents with epilepsy, only five had staff trained in the emergency administration of seizure rescue medication Two had staff who were trained to administer both buccal midazolam and rectal diazepam Ten homes did not have a person with epilepsy and did not have any 	<ul style="list-style-type: none"> Care home staff require better awareness and training on epilepsy, particularly on the administration of emergency seizure medication 	****

				staff trained to administer emergency seizure medications		
Endermann, 2015 (Germany) (22)	Cohort study (quantitative descriptive)	Young adults with epilepsy & mild ID ($n = 97$) attending a rehabilitation programme in Germany between 1999 and 2011	1. Holistic care	<ul style="list-style-type: none"> After completing the programme, clients reported improvement in their activities of daily living ($p = 0.001$), aspects of their quality of life (e.g., epilepsy-specific fear, $p = 0.002$), and significantly reduced seizure frequency ($p = 0.003$) These persisted at two years in the 51 	<ul style="list-style-type: none"> Rehabilitation programmes such as this can improve the quality of life of people with epilepsy and mild ID, including more independent living and better seizure control 	***

				<p>who were available for follow-up</p> <ul style="list-style-type: none"> • Of these, 56.8% ($n = 29$) moved to supported housing and 43.1% ($n = 22$) moved to further residential care 		
Graydon, 2000 (England) (15)	Review (non-empirical)	Not applicable	1. Staff training and education	<ul style="list-style-type: none"> • Not applicable 	<ul style="list-style-type: none"> • The majority of PwID now live in the community rather than large institutions • There is a need for epilepsy education for carers and professionals in the community • Epilepsy specialist nurses are well-placed to support 	Not assessable

					this education	
Kerr et al., 2014 (UK) (16)	Review (non-empirical) of international survey	Paid caregivers, professionals and family members of PwID and epilepsy	1. Staff training and education 2. Holistic care	<ul style="list-style-type: none"> • A key concern of participants was the lack of support for family and paid caregivers from epilepsy services • Another key concern was a lack of communication between epilepsy services and family or paid carers 	<ul style="list-style-type: none"> • Greater interagency collaboration is needed • A Working Group should be formed to provide guidance on minimising epilepsy-related risks • Training manuals should be developed for non-specialist community services by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy 	Not assessable
Kerr & Linehan, 2015 (UK) (17)	Review (non-empirical)	Not applicable	1. Staff training and education 2. Emergency seizure	<ul style="list-style-type: none"> • Not applicable 	<ul style="list-style-type: none"> • Presented recent advances in epilepsy and their implications on the 	Not assessable

			management in the community 3. Holistic care		optimisation of health and social care for PwID <ul style="list-style-type: none">• Care providers should ensure that a risk assessment is performed when perceived risks exclude and individual from an activity• Carers and families require education on epilepsy and its impact on social inclusion• Emergency seizure medications need to be made available in the community to reduce unnecessary hospitalisations• Health and social care	
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					professionals need to work together	
Kerr et al., 2018 (UK) (24)	Cross-sectional survey (mixed methods – qualitative and quantitative descriptive)	International healthcare professionals working with PwID and epilepsy ($n = 54$): neurologists, ID psychiatrists, epilepsy specialist nurses, ID specialist nurses, and ‘other’ professionals	1. Holistic care 2. Staff training and education	<ul style="list-style-type: none"> Two of the four emergent themes particularly relevant to social care were ‘risk’ and ‘broader impact upon quality of life’. 	<ul style="list-style-type: none"> Easily accessible standardised risk assessments for PwID and epilepsy need to be developed There is a need for research into the use of monitoring devices There is a need for education and training by the ILAE, in collaboration with epilepsy nurses, for healthcare providers who support the delivery of rescue medication and accurate seizure recording The ILAE should keep their 	***

					website up to date with user-friendly information, including for carers	
Pointu et al., 2005 (England) (18)	Cross-sectional survey / Audit (non-empirical)	Social care staff who care for PwID and epilepsy in one UK region	1. Emergency seizure management in the community 2. Staff training and education	<ul style="list-style-type: none"> Nearly all the staff members found the training appropriate or relevant to their practice (99% of 97 participants) Nearly all felt confident to administer rectal diazepam after the training (98% of 97 participants) 	<ul style="list-style-type: none"> This educational programme developed the skills of the local social care workforce to be able to support PwID and epilepsy 	Not assessable
		1996 audit: <i>n</i> = 173				
		2002 audit: <i>n</i> = 97				

Sterrick et al., 1999 (Scotland) (19)	Cross-sectional survey / Audit (non-empirical)	Care staff for PwID (private social organisations, respite units, day centres and care homes)	1. Emergency seizure management in the community 2. Staff training and education	<ul style="list-style-type: none"> Nearly all the staff members found the training appropriate or relevant to their practice (96% of 161 participants) 	<ul style="list-style-type: none"> There is a need for healthcare personnel to be prepared to respond to requests from lay carers for teaching in epilepsy and rectal diazepam administration This course was received positively and could be adapted and implemented by other services 	Not assessable
		<i>n</i> = 500				

<p>Van der Lende et al., 2016 (The Netherlands) (26)</p>	<p>Cross-sectional analytic study</p>	<p>People with severe ID and refractory epilepsy in residential care who were recommended for video monitoring by the Dutch Health and Care Inspectorate</p>	<p>1. Nocturnal supervision and monitoring</p>	<ul style="list-style-type: none"> • Seizures detected only on video and not via the other monitoring methods were less likely to require intervention. Only 10% (39 out of 393) of seizures detected only by video required intervention, versus 16% (128 out of 687, $p = 0.006$) of those also detected by other means. • The cost per video monitoring-identified seizure that required 	<ul style="list-style-type: none"> • The monitoring required the employment of extra care staff • Human error may be inherent when multitasking to monitor several screens and performing any additional duties • Video monitoring facilitated nocturnal surveillance, but the cost of providing it (compared to acoustic detection systems and bed motion sensors already in use) outweighed its clinical value • Reliable seizure 	<p>*****</p>
		<p>$n = 41$</p>				

				an intervention was 7035 euros	detection devices need to be developed	
Van der Lende et al., 2018 (The Netherlands) (27)	Case-control study	PwID and epilepsy in two residential care settings, retrospectively over a 25-year period	1. Nocturnal supervision and monitoring	<ul style="list-style-type: none"> • There were 60 cases of SUDEP • Cases were more likely to have nocturnal convulsive seizures ($p = 0.001$) • There was no significant difference in the level of nocturnal supervision between the cases and controls 	<ul style="list-style-type: none"> • Different levels of nocturnal supervision may account for some of the difference in incidence found in SUDEP between the two centres studied • Reliable nocturnal seizure detection systems for different populations are important 	****

				<ul style="list-style-type: none"> • There was a significant difference in supervision level between the two centres ($p = 0.001$). The centre with the lower level of supervision had the higher number of SUDEP cases (35 compared to 25) 		
Young et al., 2018 (England) (25)	Cross-sectional survey / service evaluation (non-empirical)	Family and residential carers of PwID and epilepsy in Cornwall, UK	1. Nocturnal supervision and monitoring	<ul style="list-style-type: none"> • Advice given on nocturnal monitoring had been implemented in those 	<ul style="list-style-type: none"> • There may be a lack of awareness of SUDEP risk factors • PwID and epilepsy in 	Not assessable

		$n = 121$		<p>who had not previously had such equipment in place ($n = 42$, 35%)</p> <ul style="list-style-type: none"> • This had identified previously unknown nocturnal seizures in 76% ($n = 32$) of these individuals • Awareness of SUDEP risk was generally good • Carers in residential settings were less likely to recall person-centred risk discussions than family carers (59% $n = 22/56$) 	<p>residential care may be more likely to be failed than those living with their families</p> <ul style="list-style-type: none"> • Audio monitoring may be a useful strategy to improve detection of nocturnal seizures and reduce risk of harm for PwID. 	
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				versus 63% <i>n</i> =42/65, <i>p</i> = 0.006),		
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Table 2: Future research priorities

Area of research	Recommendations for future research
Risks in PwID and epilepsy living in the community	<ul style="list-style-type: none"> • Studies on the risks faced by PwID and epilepsy living in the community and strategies for the mitigation of these risks • Ideally multiregional, high quality and involving experts by experience
Training of social care professionals who care for PwID and epilepsy	<ul style="list-style-type: none"> • The development of and assessment of training and education programmes across different regions and

	<p>community settings</p> <ul style="list-style-type: none">• Key educational areas are general epilepsy awareness and acute seizure management protocols, especially the administration of buccal midazolam• The opinions of social care professionals should be included in this research
Seizure detection / nocturnal monitoring devices	<ul style="list-style-type: none">• The development of effective seizure detection and nocturnal monitoring devices• Multicentre and multiregional studies of their effectiveness and practical use in the community

Conflict of interest

No known conflict of interest exists for any of the authors involved in this manuscript.

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