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Brief Communication

SUDEP and seizure safety communication: Assessing if people hear and act

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ABSTRACT

Background: Sudden unexpected death in epilepsy (SUDEP) is a leading cause of death among people with chronic epilepsy. People with intellectual disability (ID) are overrepresented in this population. The SUDEP and Seizure Safety Checklist (“Checklist”) is a tool to discuss risk factors influencing seizures and the risk of SUDEP. It includes questions about the availability of nocturnal monitoring. In Cornwall UK, people with epilepsy and ID and their relatives and carers are routinely advised to consider nocturnal surveillance to reduce harm from potential nocturnal seizures. We assessed the retention of advice provided on nocturnal monitoring and if there were differences between those in residential care and those living with their families.

Methods: A postal questionnaire was sent to carers of all people with epilepsy and ID in Cornwall followed by the adult specialist ID epilepsy service. All those who were contacted had received the same advice on SUDEP and nocturnal monitoring at least once in the past year. Each person was categorized into living in a residential setting or with their family group. Intergroup differences were compared using Fisher’s exact test.

Results: Carers for 170 people were contacted and 121 responded (71%). The family group had statistically more nocturnal seizures than the residential group. While there was no difference in the awareness of SUDEP, the groups differed in their recollection of the person-centered discussion of risk with carers in residential setting being less aware. Where nocturnal monitoring advice was given, it was followed, and previously unknown seizures were identified in 75%.

Conclusions: Carers in residential settings are less likely to recall specific person-centered discussion of risks to the individual they support as compared with those living with families although general awareness of SUDEP and implementing advice such as nocturnal monitoring is present equally in both groups. In improving detection of nocturnal seizures, audio monitoring may be a useful strategy to reduce risk of harm for people with ID.

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1. Introduction

Sudden unexpected death in epilepsy (SUDEP) is the leading cause of death among people with chronic epilepsy [1], and discussing the risk of SUDEP is now strongly recommended as good practice [2, 3]. A structured and validated tool for risk communication, i.e., the SUDEP and Seizure safety Checklist (“Checklist”) [4, 5] (Appendix 1), could be used to facilitate a person-centered discussion on SUDEP and its risk factors.

In the UK, people with epilepsy and intellectual disability (ID) tend to live either in family settings or in supported residential arrangements.

They may live with their biological families or in “Shared Lives” arrangements (i.e., with other host families). Those who do not live within a family setting may be supported by private sector care providers, funded by the state. Arrangements range from being in their own home with a professional care team, to living in multioccupancy residential units. Direct care providers are generally not trained clinicians though some larger establishments may have a trained nurse to administer medication. Medical provision for community residential care is provided by the usual local primary care team.

There is an overrepresentation of people with ID among people with chronic epilepsy. About half of these people with ID have nocturnal seizures [6]. The presence of night supervision seems protective; “supervision” could range from the presence of an individual in the same room to the deployment of devices such as listening devices [7]. There is evidence suggesting that seizures could be identified using audio detection

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devices in at least 50% of individuals [8]. A survey suggested that most parents found it useful to have some device, especially an audio monitor, to reduce stress and provide reassurance [9]. There is no evidence to suggest that sophisticated monitoring systems are more sensitive to identify seizures than a simple audio device [10].

Cornwall a county in the UK (population 538,000) is implementing national guidance [3] of advising about SUDEP risk, focusing on modifiable risks [4]. The county has a dedicated epilepsy service for people with ID. Since introducing a Checklist in 2011, all clinicians in the service use it at least annually to advise individuals, their families, and support workers of risk of SUDEP and inform of changes from previous checks. This includes applying the Checklist, feeding back information (orally and in writing), storing the Checklist results on e-health records and conducting regular updates. When people are supported by professional carers, advice is passed on to management, with a request to discuss the details of the person-centered risk with all relevant care staff. Regular advice is given to all service attenders to use an audio monitor to screen for nocturnal events as this is potentially a modifiable risk.

We attempted to assess whether people with epilepsy and their families or support workers were SUDEP aware and could recall discussion about SUDEP risk and the role of nocturnal surveillance. We also attempted to determine if advice on nighttime surveillance was adopted, and if this led to the identification of previously unknown nocturnal events. Lastly, we attempted to identify differences between responses provided by carers in family settings as opposed to those in residential settings.

2. Methods

A simple, one page questionnaire was designed and approved by the department clinicians. It was then modified based on constructive feedback from families and carers (Appendix 2). All adults with epilepsy and ID who were under active follow-up during July 2017 in Cornwall were identified, and their carers sent the questionnaire with a return envelope. Documented person-centered counselling of SUDEP using the Checklist was documented for all service attendees. The data was stored on an Excel spreadsheet using only an identifier number. The project was registered as service evaluation with the local NHS Trust. The questionnaire enquired into the following:

Individuals were categorized into living in “residential” or “family” care. “Family” was defined as being in the family home, shared or supported living where family or friends had regular input to care. Those

who did not respond to the questionnaire were contacted once by telephone. The questionnaire, to ensure consistency, was completed by support workers or family members. Replies stated as “not sure” were considered as a “no”.

Standard inferential statistics was performed. Differences in questionnaire responses between the residential and family groups were compared using Fisher's exact test. The level of statistical significance was set at $\alpha = 0.05$.

3. Results

There were 170 people under active follow-up in July 2017, 55% ($n = 94$) with families and the remaining in residential settings. Of the 121 (71%) returned questionnaires, 75% ($n = 56$) were from the residential group and 69% ($n = 65$) from the family group.

Table 1 provides demographic details. Around two-thirds indicated having nocturnal seizures (69%). People living with their family were more likely to have nocturnal seizures than those within residential care ($p < 0.05$). No difference was noted in affirmative response between the residential and family population around presence of nighttime monitoring. Over 80% of both groups were aware of SUDEP. There was, however, a significant difference in the recollection between the two groups about the person-centered SUDEP discussion with two-third (65%) of the families recalling compared to two-fifth (39%) of the professional carers ($p = 0.006$). No statistical significance was seen between the two groups on their recollection of nighttime monitoring discussions. Of the total survey sample ($n = 121$), 35% ($n = 42$) had no previous nocturnal monitoring system in place and did so post-SUDEP advice. Of the 42, nocturnal seizures were found in 32. None of these 32 had previously been known to have nocturnal seizures. In 76% (95% CI: 63% to 89%), the monitor helped identify previously unknown nocturnal seizures.

4. Discussion

We assessed how structured risk advice given in a routine clinic is assimilated and used to mitigate SUDEP risk in a population with epilepsy and ID. Everyone in the target population had received the same advice, in a structured way through the SUDEP checklist. Our findings suggest that structured communication helps reduce risk.

The response rates of over two-thirds are a major strength of the exercise. The main limitation is the small size of the population affecting

Table 1
Results of the questionnaire including demographics.

	Grand total n =	Residential (R) n =	Nonresidential (NR) n =	Comparing R versus NR p-Value for test of difference ^a
Total caseload	170	76 (45%)	94 (55%)	
Postal replies	121	56 (74%)	65 (69%)	
Question				
Do they have generalized seizures?	97/121 (80%)	46/56 (82%)	51/65 (78%)	0.66
Do they have nocturnal seizures?	83/121 (69%)	33/56 (59%)	50/65 (77%)	0.049
Do they have night monitoring?	104 (86%)	51/56 (91%)	53/65 (82%)	0.19
Audio	60 (58%)	29 (57%)	31 (58%)	
AV	12 (11.5%)	4 (7.8%)	8 (15%)	
Intermittent checks	55 (53%)	31 (61%)	24 (45%)	
Alarm	6 (5.7%)	4 (7.8%)	2 (3.7%)	
Saturation monitor	2 (1.9%)	0	2 (3.7%)	
Same room	6 (5.7%)	0	6 (11%)	
(More than 1 method)	32 (31%)	12 (23.5%)	20 (37%)	
Are you aware of SUDEP?	98 (81%)	45/56 (80%)	53/65 (82%)	>0.999
Can you remember a person-centered discussion about SUDEP?	64 (53%)	22/56 (39%)	42/65 (65%)	0.006
Can you remember a discussion around Nocturnal Monitoring?	74 (61%)	33/56 (59%)	41/65 (63%)	0.71
Did the discussion change practice for Nocturnal Monitoring?	42/74 (57%)	17/33 (52%)	25/41 (61%)	0.48
Did the use of Nocturnal Monitoring following advice given, identify previously unknown nocturnal seizures?	32/42 (76%)	14/17 (82%)	18/25 (72%)	0.49

^a Fisher's exact test.

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